



SOUTHERN NETWORK
OF SPECIALIZED CARE

Dual Diagnosis Resource Manual for Direct Support Professionals



December 2011

FOREWORD AND ACKNOWLEDGEMENTS

Direct support professionals may be working with someone who has been identified or suspected to have a Dual Diagnosis. A person with a Dual Diagnosis is someone who has a developmental disability and a mental health issue and/or challenging behaviour. A person with a suspected or confirmed Dual Diagnosis is much more than a label and must be viewed in a holistic way considering all aspects of a person's traits, capabilities and circumstances.

The direct support professional role is often more complex when the person has a Dual Diagnosis. Each person counts on the direct support professional to support them well so ongoing education is imperative. This education needs to include issues related to Dual Diagnosis in general, strategies to support people, and understanding how to effectively work with the multi-disciplinary specialists. Being aware of these key elements will help a direct support professional and a person who has a dual diagnosis to succeed and have an improved quality of life.

When supporting someone who has a dual diagnosis including all of the specialized providers in planning supports is important. Each offers different perspective and contributions that enrich the process for the person.

Based on requests of community service agencies, the Southern Network of Specialized Care in cooperation with Community Partners and Specialized Providers in Southern Ontario has compiled this manual to provide some basic information, education material and resources that will help direct support professionals become informed about dual diagnosis. The resources shared here are established as best/promising practice. This manual provides information on how to access additional information on specific topics as it is intended to offer an overview of relevant information.

Gratefully,
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FOREWORD AND ACKNOWLEDGEMENTS

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Part 1: Dual Diagnosis

What is a Dual Diagnosis?

In Ontario, the term dual diagnosis is a term applied to a person who has a developmental disability and mental health need and/or challenging behaviours.

The term “challenging behaviour” is used to describe behaviour that interferes with a person’s daily life.

Reference: Joint Policy Guidelines for the Provision of community Mental Health and Developmental Services for Adults with a Dual Diagnosis December 2008).^{*} Dual Diagnosis Implementation Committee of Toronto (2006) *Building the Path to Home: Links to Sustainable Housing for People with Dual Diagnosis*. Toronto: Centre for Addiction and Mental Health

These guidelines are available in full in the Appendix section.

“Adults with a Dual Diagnosis are those persons 18 years of age and older with both a developmental disability and mental health needs.”

How is a Dual Diagnosis Confirmed?

Determination of a dual diagnosis must be done through formalized assessment of a person’s developmental level and their mental health. This process involves:

- Consultation with and assessment by a Psychologist or Psychological Associate qualified to complete psychometric or psychological assessments to determine development level.
- Consultation and assessment by a Psychiatrist or Psychologist/Psychological Associate who is qualified to assess and diagnose mental health issues.

Common Indicators of a Dual Diagnosis

If a person has a confirmed developmental disability, some common signs that they **MAY** also have a mental health issue/behavioural issue and, therefore, a dual diagnosis are:

- Family history of mental illness
- Hyper-vigilance: extreme worry, nervousness, may be compelled to complete repetitive behaviours, anxiety, panic or fright
- Psychosis: loss of contact with reality, hallucinations such as hearing voices. (Staff must be cautious not to confuse self-talk with psychosis).
- Hyper-arousal: increased muscle tension, emotional tension, periods of excitable behaviour with insomnia (rapid speech, pacing, repeating phrases or words), irritability, for prolonged periods.
- Rapid mood swings.
- Noteworthy changes in sleep patterns (sleeping during the day and up in the evening)
- Unexplained decrease in skills of daily living: hygiene, self-care, or communication skills
- Frequent complaints of not feeling well with no medical reason (pains and aches).
- Substance abuse or inappropriate self-medication.
- Lack of appearance of regret related to behaviour.

Part 1: Dual Diagnosis

- Increase in self-injurious or harmful behaviour.
- Changes in appetite (not eating as much as or eating more than normal for the person).
- Notable changes in ability to complete tasks that they could previously complete.
- Periods of sadness longer than normal for that person.
- Memory problems/changes in ability to remember.
- Need for instant fulfillment/gratification
- False beliefs (delusional thinking or paranoia)
- Lack of interest in previously enjoyed objects, people or events
- Lingering sadness
- Self-isolation

Common Indicators of a Developmental Disability

If a person has a confirmed mental illness:

- Challenges with communication
- Impulsive behaviour
- Poor judgement or ability to make effective decisions
- Lack of socially acceptable hygiene and life skills
- Limitations in understanding differences in social relationships or/and common slang
- Poor understanding of social and personal boundaries
- Difficulty when problem solving in different situations – difficulty generalising - i.e., believing the same response will solve all problems
- Easily influenced and lead by others, eager to please
- Concrete and absolute thinking

Learn the Signs.



Act Early.

Prevalence

The prevalence rate for developmental disability is between 1 and 3% of the population. With a low estimate of 1%, 125,400 people have a developmental disability in Ontario.

It is estimated that 30 - 38 % of persons with a developmental disability also have a mental health issue. Again with a low estimate of 30%, there are 37,620 people estimated to have a Dual Diagnosis.

NOTE: prevalence rate from Joint Policy Guidelines for the Provision of community Mental Health and Developmental Services for Adults with a Dual Diagnosis December 2008).

Part 1: Dual Diagnosis

Direct support professionals must be aware of high potential of people who have a developmental disability to also experience mental illness at some point in their lives and, therefore, alert to the signs that one may exist or is developing.

If any of the signs or indicators are present, direct support professionals need to communicate with the person and/or family, and/or substitute decision maker regarding the benefits of:

- Keeping the doctor informed – the family doctor is the hub of all clinical care for the person and must be kept informed about their welfare with the person's consent.
- Requesting a mental health assessment
- Requesting specialized clinical services

Differentiating between whether or not symptoms/signs are due to the presence of a mental illness or developmental disability can be difficult. Some of the main differences are detailed below.

Comparing the Differences between Developmental Disability and Mental Illness

Developmental Disability	Mental Illness
<ul style="list-style-type: none">• Below-average ability to learn and to use information	<ul style="list-style-type: none">• Inappropriate thought processes &/or emotions
<ul style="list-style-type: none">• Before adulthood	<ul style="list-style-type: none">• Can occur anytime in a person's life
<ul style="list-style-type: none">• Refers to IQ (below 70)	<ul style="list-style-type: none">• Has nothing to do with IQ
<ul style="list-style-type: none">• Lifelong. There is no cure.	<ul style="list-style-type: none">• May be temporary, cyclic, or episodic. May be curable
<ul style="list-style-type: none">• Services involve training and education not medication	<ul style="list-style-type: none">• Services involve therapy and medication
<ul style="list-style-type: none">• Is not psychiatric in nature	<ul style="list-style-type: none">• Diagnosed illnesses such as Depression, Schizophrenia, Bi-Polar Disorder
<ul style="list-style-type: none">• Impairments in social skills and adaptations	<ul style="list-style-type: none">• Does not necessarily impact social competence
<ul style="list-style-type: none">• Behaviour is usually rational	<ul style="list-style-type: none">• Behaviour may vacillate between normal and irrational



Part 2: Developmental Disability

What is a Developmental Disability?

On July 1, 2010 “*The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*” became law.

The Act identifies a person with a developmental disability as a person with “significant limitations in cognitive functioning and adaptive functioning and those limitations,

- a) originated before the person reached 18 years of age;
 - b) are likely to be life-long in nature; and
 - c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity. 2008, c. 14, s. 3 (1)”.
- “Adaptive functioning” means a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills in his or her everyday life;
 - “Cognitive functioning” means a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences. 2008, c. 14, s. 3 (2).

Reference: Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2010
http://www.e-laws.gov.on.ca/html/source/regs/english/2010/elaws_src_regs_r10299_e.htm (accessed Oct 31, 2011)

Causes of Developmental Disabilities

Several hundred causes of developmental disability have been discovered, however, many causes are still unknown. The most common ones determined to date are:

Biomedical causes - resulting from:

- Abnormal genes inherited from parents e.g. Fragile X Syndrome
- Errors when genes combine (e.g. Down syndrome, Prader Willi Syndrome)
- Nutritional deficiencies
- Metabolic conditions (e.g. phenylketonuria (PKU), and congenital hypothyroidism)

Behavioural issues during pregnancy:

- Smoking
- Use of alcohol and other drugs that affect the developing foetus (FASD)
- Malnourishment
- Contraction of certain illnesses/infections while pregnant

Problems at birth:

- Premature delivery or low birth weight
- Oxygen deprivation during birth
- Injury during birthing

Factors during childhood:

Part 2: Developmental Disability

- Illnesses (such as chickenpox, whooping cough, and measles)
- Exposure to lead, mercury, and other toxins
- Head injury
- Oxygen deprivation
- Social factors such as child stimulation and adult responsiveness



Reference: Youth In Transition Toolkit – Southern Network of Specialized Care

<http://www.community->

[networks.ca/uploads/Common/YITTool%20Kit%20CONTENTS%20FINAL%20%20March%201%202011.pdf](http://www.community-networks.ca/uploads/Common/YITTool%20Kit%20CONTENTS%20FINAL%20%20March%201%202011.pdf)

(accessed Oct 31, 2011)

Common Labels Used to Refer to a Person with a Developmental Disability

Many different terms and labels are used to refer to a developmental disability depending on region, country, culture, and organizational philosophy. Some of these labels are:

- Mental retardation – DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, edition IV, 1994). In Canada, this term is used almost exclusively by the medical community;
- Learning disability – United Kingdom;
- Intellectual disability - Community Living Ontario, Australia, Japan, Canada;
- Developmentally disabled - United States and Canada and other developed nations;

Reference: Dual Diagnosis Factsheet Prepared by National Coalition on Dual Diagnosis (2008) <http://care-id.com/wp-content/uploads/2011/09/factsheet.pdf> (accessed Oct 31st, 2011)



Part 2: Developmental Disability

Four Categories of Developmental Disability

The following categories are often used to describe the level of developmental disability determined through assessment:

Mild: 80 – 85% of people with dd <ul style="list-style-type: none">• IQ 50-70• Slower than normal development in all areas• Unusual physiology rare• Can learn practical skills• Ability to learn literacy skills• Can conform socially• Can learn daily tasks	Moderate: 10 – 12 % of people with dd <ul style="list-style-type: none">• IQ 35-49• Noticeable delays, particularly speech• May have unusual physiology• Can learn simple communication• Can learn simple health and safety skills• Can participate in some self-care• Can perform supervised tasks• Can travel alone to familiar places
Severe: 3-4% of people with dd <ul style="list-style-type: none">• IQ 20-34• Significant delays in some areas• May walk late• Limited expressive communication skills• Can learn daily routines and repetitive activities• May learn simple self-care• Need direction and supervision socially	Profound: 1-2% of people with dd <ul style="list-style-type: none">• IQ <20• Significant delays in all areas• Congenital abnormalities present• Need close supervision• Requires attendant care• May respond to regular physical and social activity• Not able to do self-care

Reference: Youth In Transition Toolkit – Southern Network of Specialized Care

<http://www.community->

[networks.ca/uploads/Common/YITTool%20Kit%20CONTENTS%20FINAL%20%20March%201%202011.pdf](http://www.community-networks.ca/uploads/Common/YITTool%20Kit%20CONTENTS%20FINAL%20%20March%201%202011.pdf)

Based on the above information, 80 to 85% of people who have a developmental disability are categorized as function in the mild range. This can make identification of the disability very difficult unless time is spent getting to know the person and the difficulties they face.

Adaptive Functioning

Adaptive skills are the skills necessary for daily living. Standardized tests can also determine limitations in **adaptive functioning**, which consists of three skill types:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
- Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Part 2: Developmental Disability

Not every person will have the same strengths or difficulties, but some of the challenges people who have developmental disabilities often experience are with:

- **Home living:** ability to cook or clean, shop for food, or complete general maintenance
- **Self care:** able to complete daily living activities like grooming, toileting, personal hygiene
- **Communication:** both expressive (spoken language) and receptive (ability to comprehend and apply what is said) language and difficulty interpreting body language of others
- **Self-Direction:** able to make decisions about their lives
- **Social skills:** difficulty making and keeping friends and understanding and applying social rules
- **Functional academic skills:** basic education learned in school for work in the world
- **Work:** ability to maintain a job
- **Leisure:** difficulty scheduling and attending activities that are fun like games, sports and going out for coffee with friends.
- **Health and safety skills:** making healthy food choices, making doctor's appointments with or without support, keeping doors locked, asking who is at the door before opening it, leaving home when fire alarm is sounded
- **Community integration:** difficulty using community resources like the bus, restaurants, places of worship, shopping centres – difficulty learning and maintaining skills to care for themselves and live independently

Reference: Youth In Transition Toolkit – Southern Network of Specialized Care

[http://www.community-](http://www.community-networks.ca/uploads/Common/YITTool%20Kit%20CONTENTS%20FINAL%20%20March%201%202011.pdf)

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(accessed Oct 31st, 2011)

With appropriate support, opportunity and safeguards, people who have a dual diagnosis can lead satisfying lives, participate and contribute within their community.

Recognizing a Developmental Disability

A formal diagnosis of developmental disability is made by a psychologist or psychological associate who will administer standardized tests. Diagnosis can be difficult if the person's family / friends / support circle aren't available to provide additional information about the person's level of functioning before the age of 18. If a person is suspected to need an assessment to determine if they have a developmental disability the referral can be made for psychometric testing.

Part 2: Developmental Disability

Eligibility Assessments

The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 identifies a person with a developmental disability as a person with “significant limitations in cognitive functioning and adaptive functioning and those limitations,

- (a) originated before the person reached 18 years of age;
 - (b) are likely to be life-long in nature; and
 - (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.
- 2008, c. 14, s. 3 (1).”

Programs and services are available to people who have a developmental disability. If a developmental disability is suspected, but not confirmed, an individual would qualify for a psychological assessment in order to determine eligibility. An eligibility assessment is completed by a psychologist or psychological associate registered with the College of Psychologists of Ontario (or equivalent body in another province) that states the individual has a developmental disability in accordance with the Act and Regulation.

The following questions are intended to assist direct support professionals/clinicians understand the person’s functional level and the challenges he or she faces. The person’s answers will also help start to figure out if the person who has a mental health problem may also have a developmental disability.

Questions that may provide more information to bring for a formal assessment;

- What grade did the person last complete in high school? How old were they when they left school? (If the person was 21 years old when he or she left school, then the person may be developmentally delayed. People who have a developmental disability can continue in the school system until they are 21; many have dropped out early).
- Did the person attend special education classes, behavioural classes, a special school? (This is another clue that there may have been a developmental issue). What was the name of the school?
- Did the person have an assessment (special tests) as a child at school? At a hospital? What was the name of the hospital? What did they tell the person about the results? (This information is not likely to come directly from the person. The family / friends / support circle may need to fill in the gaps).

Questions to Ask About Current Functioning

- Can the person tell time on an analogue watch (a watch with an hour hand and a minute hand)? Show the person a watch and ask what time it says. A person who has a developmental disability may find this difficult.
- Does the person travel alone on buses or the subway? Did they travel by themselves? What route did they take? (Get the person to describe it).

Part 2: Developmental Disability

- If the person is going to a new place, do they need someone to show them how to get there? (People who have developmental disabilities tend to learn routes by rote – with help at first, but would find it challenging to explain the route in detail).
- Do they read the newspaper? What sections do they like the best? (Often, the person can read only some parts of the paper and will say the comics are his or her favourite part).
- What is their favourite TV show? (Often, the person may choose children's or young teen's programming because of the high visual / low verbal content.)
- Does the person look after their own money? Do they pay the bills? Which bills do they pay?
- How do they pay them? (The person may pay by cheque, at a bank machine or over the phone).
- Ask how much familiar items cost. Then less familiar, more expensive items, "How much does a car cost?" "How much does a house cost?" (Often, the person will not be able to estimate well). The person may not be able to distinguish between the cost of familiar items and larger, significantly more expensive items.
- Does the person have a job? Did they ever have a job? What did they do? (e.g. competitive employment, sheltered workshop, co-op program through school)?

Cognitive Indicators

- Does the person communicate in short sentences?
Does the person seem, on the surface, able to do things you later discover he or she really can't do?
- Does the person have trouble generalizing (applying general information to more than one specific context)?
- Does the person seem to learn slowly?
- Does the person have trouble with abstract thinking (e.g. understanding how two things are similar)?
- Does the person do better on concrete and structured tasks (e.g. when directions are very specific and broken into steps)?
- Does the person have memory problems?
- Does the person have trouble solving problems?
- Does the person show poor judgment?
- Does the person have trouble understanding "why" questions?
- Is the person good at picking up non-verbal social cues?
- Is it difficult to get a true idea of what the person is capable of, what he or she understands in a conversation?

Reference: Dual Diagnosis Implementation Committee of Toronto (2006.) Building the Path to Home: Links to Sustainable Housing for People who have Dual Diagnosis. Toronto: Centre for Addiction and Mental Health.

Part 3: Mental Health



What is Mental Illness?

Mental illness can cause disturbance in thoughts, feelings and perceptions that may impact day-to-day functioning. It can happen any time in a person's life.

Symptoms of mental illness can impact a person's daily routine and ability to perform at their usual level. Mental health issues are common. Studies indicate that in any given year, one in every five Canadian adults under age 65 will have a mental health problem¹.



Reference: Offord, D.R. Boyle, M.H. Campbell, D. Goering, P. Lin, E. Wong, M., Racine, Y.A. (1996). "One-Year Prevalence of Psychiatric Disorder in Ontarians 15 to 64 Years of Age," Canadian Journal of Psychiatry 41 (9): 559-63.

Medication and counselling can aid in symptom control of mental illness.

Most experts and people living with mental health issues agree that "it is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing or recurring symptoms or problems."

Recovery refers to both a model and a process within mental health services. It is often characterised by peaks and valleys of wellness. There is much debate about what recovery really means.

Reference: "Making Recovery a Reality" Shepherd, Boardman and Slade, Sainsbury Centre for Mental Health, March, 2008.

http://www.centreformentalhealth.org.uk/pdfs/Making_recovery_a_reality_policy_paper.pdf

(accessed Oct 31, 2011)

Another way to look at recovery is by viewing consumers "not as passive objects of treatment, but as active participants –along with their families and caregivers – in creating and maintaining their own mental health. Recovery focuses on wellness rather than illness, Recovery is not a cure. There is no timeline. It is living life to the fullest despite challenges."

While there is significant advancement in diagnosis of and understanding of people who experience mental illness, stigma and discrimination can still contribute to people with mental health issues keeping them a secret or avoiding diagnosis.

Reference: "Working together towards recovery: Consumers, families, caregivers, and service providers.

A publication of the Canadian Collaborative Mental Health Initiative" p. 5-6 and p. 79

<http://www.ccmhi.ca/en/consumers.html> (accessed Oct 31, 2011)

Part 3: Mental Health

The Serious Mental Illnesses (SMIs) are:

- Schizophrenia
- Bi-polar disorder
- Depression

Other Mental Illnesses:

- Mood disorders, including “serious” mood disorders
- Anxiety disorders
- Situational Depression
- Personality disorders
- Obsessive Compulsive disorders

Mental illness is not always classified as serious. A serious mental illness (SMI) is diagnosed on the basis of three criteria:

1. Duration (length)
2. Distress (misery, upset, stress)
3. Diagnosis (identification)

In mental health services, it is more challenging to get services and supports if you have a mild to moderate mental illness. Services prioritize supports for people who have serious mental illness.

Signs a Person May Have a Mental Illness:

- | | |
|---|--|
| • Increased anxiety, panic or fright | • Excessive reactivity / moodiness |
| • Hearing, seeing, feeling imaginary things (hearing voices is not the same as talking to oneself for company or to reduce anxiety) | • Heightened emotional sensitivity |
| • Need for instant fulfillment / gratification | • Accelerated speech patterns |
| • Unusual sleep patterns (insomnia or lengthy periods of sleep) | • Lingering sadness |
| • False beliefs (delusional thinking or paranoia) | • Self-isolation |
| • Decline in personal hygiene | • Memory problems (worsening memory or change in memory) |
| • Inappropriate expressive reactions | • Changes in appetite (loss of weight or increase in weight) |
| • Family history of mental illness | • Self-injurious behaviour |
| • A functional or behavioural change | |

Part 3: Mental Health

Barriers to Assessment

Mental illness in people who have developmental disabilities may not be diagnosed successfully. A few of the factors that make diagnosis more difficult:

- Baseline Exaggeration: Describes how pre-existing behavioural challenges of a less significant level or difficulty coping may increase during periods of increased stress or psychiatric distress, and may be dismissed as possible symptoms of a psychiatric disorder because they have occurred before.
 - A person who engages in sensory stimulation by tapping their ears for auditory stimulation may start hitting their ears. This could be interpreted as an increase in the intensity of self-stimulation when it could be a new behaviour indicating a change in mental wellness.
- Behavioural Overshadowing: Occurs when an increase in the intensity or frequency of the maladaptive behaviour is attributed to “learned behaviour” rather than a function and behavioural expression of an underlying medical or psychiatric disorder.
 - “She cries to get attention from staff”.
- Medical Overshadowing: Present research indicates that physicians are less likely to order diagnostic tests to determine cause of symptoms for individuals with intellectual disabilities.
 - “I don’t feel right...” (Meaning: I have persistent feelings of vertigo and nausea), and being prescribed an antacid instead of completing a full diagnostic to determine exact nature of the issue.

Reference: *Dual Diagnosis: Concepts for Generalists and Advanced Generalists* – found in powerpoint presentation (Jan 27, 2010) given by Christine W. Grant, York Central Hospital
<http://www.community-networks.ca/uploads/DDx%20A%20Primer%20-%20February%2004%202010%20-%20Handouts.pdf> (accessed Oct 31, 2011)

*****People who have developmental disabilities have the same potential to develop a full range of psychiatric disorders as the general population. Therefore, it is important to understand how signs and symptoms of mental illnesses may look different in people who have a developmental disability to be able to support them in getting accurate diagnosis and proper treatment. *****

Family Physician Guide / Appendix 1: Developmental Disabilities p. 6.20.

Part 3: Mental Health

Recognizing Mental Health Problems

Indicators that someone with a developmental disability might be experiencing mental health problems:

- Person is overly dependent given his or her abilities
- Person is overly independent given his or her abilities
- Change is really hard for the person
- Person lacks peers and friends
- Person is impulsive
- Person is withdrawn
- Person is aggressive physically or verbally
- The person has trouble with anger
- Is the person irritable?
- Has the person been in trouble with the law?
- Has the person been socially or sexually inappropriate?
- Does the person feel that he or she is not intellectually disabled?
- Does the person appear higher functioning than he or she really is?
- Has the person been diagnosed with a mental illness?
- Does the person hurt himself or herself?
- Has the person been sleeping more or less than usual?
- Has there been a change in the person's appetite?
- Does the person seem overactive?
- Is the person overly fearful?
- Is the person extremely confused or disoriented?
- Does the person hear voices even when no one is there? (This is not the same as talking to oneself for company or to reduce anxiety).
- Do family problems interfere with the person's functioning?
- Is there a parent with a disability or mental health problem?

Other Resources:

- www.psychiatry.med.uwo.ca/bulletins.html
- www.thenadd.org
- www.camh.net/path_home/
- www.oadd.org
- www.mindyourmind.ca
- www.communitynetworksofspecializedcare.ca

Reference: * Dual Diagnosis Implementation Committee of Toronto (2006). Building the Path to Home: Links to Sustainable Housing for People who have Dual Diagnosis. Toronto: Centre for Addiction and Mental Health

Part 3: Mental Health

The impact of Trauma on People who have Developmental Disabilities

People who have developmental disabilities have been subject to high rates different types of abuse in childhood and adulthood; neglect, physical, emotional and sexual abuse.

People who have developmental disabilities have higher rates of sexual abuse than the general population (Furey, 1994). Sobsey (2001) reports that people with disabilities are twice as likely to experience abuse. Women with developmental disabilities within the mild range experience the highest levels of sexual abuse.

When a person who has a development disability experiences a traumatic event, they may have fewer internal and external resources to be able to process what has happened and to move forward. Support must be accessed to assist the person understand what happened to them. This will help to minimize the traumatic effect and the likelihood that PTSD will develop.

Reference: Doyle C. and Mitchell D. (2003) Post-traumatic stress disorder and people with learning disabilities. Journal of Learning Disabilities 7, 1, 23-33. The Mental Health Needs of Persons with Developmental Disabilities, and Abuse-Related Trauma: Defining the Issues, Identifying the Challenges, Dr. Lori Haskell 2010

Some of the signs of abuse-related trauma are

- anxiety
- sleeplessness
- depression
- eating disorders
- self-harming behaviour
- agitation

It is important for direct support professionals to recognise the signs of trauma a person may experience and seek the appropriate support. Clinical support should be accessed for the appropriate interventions for each person.

For more information on providing effective supports for a person who has experienced trauma can be found in the Trauma Informed: The Trauma Toolkit which is a resource for service providers to deliver services that are trauma informed.

<http://www.trauma-informed.ca>

“Front-line workers and service providers must also help these individuals, and their families and caretakers, to understand that seemingly unrelated mental health problems are often actually responses to — and attempts to cope with — the psychological and physiological disruptions caused by abuse-related trauma.”

Lori Haskell

Part 4: Types of Developmental Disabilities



Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a range of disabilities caused in infants who had pre-natal exposure to alcohol.

Forms of Fetal Alcohol Spectrum Disorders include Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), and Alcohol Related Neurodevelopmental Disability (ARND).

There is no known safe amount or safe time to consume alcohol during pregnancy.¹ FASD occurs in at least 1 to 3 in every 1000 live births. Of these, 10% will likely have an IQ of 70 or below. Increased knowledge and understanding of FASD has led to the realisation that it is the leading cause of developmental disabilities with a higher prevalence than autism spectrum disorders.

References: Fetal Alcohol Syndrome/Fetal Alcohol Effects: <http://www.hc-sc.gc.ca/fniah-spnia/famil/preg-gros/intro-eng.php> (accessed Oct 31, 2011) and, Fetal Alcohol Spectrum Disorder/Canadian Guidelines for Diagnosis: <http://www.faslink.org/CanadianFASDdiagnosisGuidelines.pdf> (accessed Oct 31, 2011)

The signs and symptoms of FASD are highly variable but commonly, people who have FASD will experience;

- Low birth weight and below average growth rate
- Problems with central nervous system or brain damage
- Vision or hearing problems
- Behaviour problems
- Difficulty learning or remembering

Slide and photo made available (2011) with permission from Dr. Susan Astley, Professor, Epidemiology, Adjunct Professor, Paediatrics, University of Washington, Seattle, Washington.



FAS and pFAS represent approximately 15% of people who have FASD. Most children with FASD have brain damage but generally lack any visible signs or symptoms of the condition. Only this small percentage experience abnormal facial features. They often present to parents and professionals as more capable than they actually are. As a result, these children are largely misdiagnosed or go unrecognized altogether, receiving inappropriate, ineffective support and intervention.

Part 4: Types of Developmental Disabilities

Common Health Challenges

- Failure to thrive
- Low birth weight and below average growth rate
- Problems with central nervous system
- Epilepsy
- Vision or hearing problems
- Abnormalities related to: the heart, the skeleton, the kidneys, the eyes or the ears

Common Behaviour Characteristics

While each person impacted by FASD is unique, brain damage from pre-natal alcohol exposure typically results in various dysfunctional behavioural symptoms. They include:

- Impulsivity
- Attention problems
- Delayed development
- Speech and hearing deficits
- Irritability and mood swings
- Difficulty sleeping
- Difficulty adapting to change
- Easily over-stimulated
- Sexual promiscuity, inappropriate sexual behaviour
- Trouble learning or remembering
- Problems making good decisions
- Memory lapses
- Repeatedly make the same mistakes
- Act too young for his or her age
- Hyperactivity
- Lack of remorse
- Impulsive / acts without thinking

Lack of identification creates even larger difficulties or secondary disabilities for the person and has a lifelong impact on all sectors of community service provision. These issues include:

- Over 90% will have mental health problems – many will have multiple diagnosis
- 68% will have trouble with the law
- 55% will be confined in prison or treatment centres
- 52% will have sexually inappropriate behaviour
- 35% of the females and 30% of the males will become drug and alcohol dependent
- 80% will be unable to live independently and account for much of the homeless population
- 70% will never be able to maintain employment

Part 4: Types of Developmental Disabilities

Support Strategies

Once FASD is identified or even suspected, it is important to provide appropriate supports for successful intervention and a positive long-term prognosis. Due to the effects of brain damage, typical behavioural modification approaches such as differential reinforcement or punishment are usually unsuccessful.

Before supports and intervention strategies are implemented, service providers need to first focus on developing a good understanding of FASD and its impact on the brain. This allows for a shift to a positive strength-based approach to service delivery.

Service providers must then provide and maintain structure (routine and consistency), supervision (intensity level varies depending on the functioning level of the person) and support. Modified approaches to communication are necessary, at all times, for optimal understanding. This includes the absence of abstract language, an increase in visual cues and a reduction in verbal interaction.

It is important to assess and support for the presence of sensory integration disorders (SID). SIDs are very common in people with FASD and often account for the presence of some problematic behaviours.

People affected by FASD are complex and can need the support of a variety of service providers. It is critical that all service providers involved have a good understanding of FASD and collaborate in the delivery of services for consistency and effectiveness. Lastly, FASD is a permanent disability and requires life-long inter-dependent supports for success.

For more information on FASD, visit www.fasdontario.ca or <http://report.nih.gov/NIHfactsheets>

Part 4: Types of Developmental Disabilities

Autism Spectrum Disorders

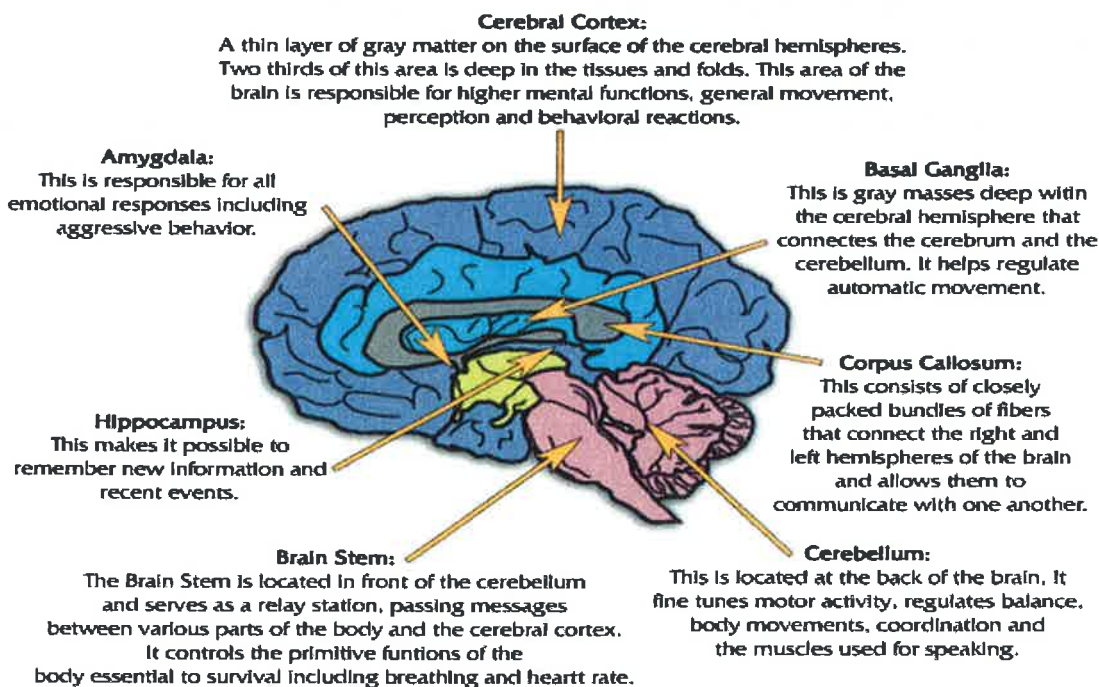
Autism Spectrum Disorder (ASD) is a complex condition that impacts normal brain development and affect a person's social relationships, communication, interests and behaviour. When most people talk about the autism spectrum disorders (ASDs), they are referring to the most common ones on the spectrum:

- Autism
- Asperger's Syndrome
- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)

The term spectrum is used to describe the vast differences in severity and symptoms. The actual diagnosis within the spectrum of disorders is based on:

- Number and particular kinds of symptoms
- Severity – mild to severe
- Age of onset
- Levels of functioning
- Challenges with social interactions

Parts of the Brain Affected by Autism



Part 4: Types of Developmental Disabilities

People who have an autism spectrum disorder often have difficulties with:

- Social relationships
- Transitions
- Communication / language
- Perseveration on interests and activities
- Dependence on routine
- Abnormal responses to sensory stimulation
- Behaviour problems
- Variability of intellectual functioning
- Uneven development profile
- Difficulties in sleeping, toileting and eating
- Immune irregularities
- Nutritional deficiencies
- Gastrointestinal problems

The primary symptoms of autism include problems with communication and social interaction as well as repetitive interests and activities.

Common Strengths

Although some areas of development in a person who has autism are delayed, people who have an Autism Spectrum Disorder (ASD) often exhibit skills in other areas. These intellectual strengths may overshadow the developmental problems experienced. These strengths may include one or more of the following:

- Non-verbal reasoning skills
- Reading skills
- Perceptual motor skills
- Drawing skills
- Computer interest and skills
- Exceptional memory
- Visual spatial abilities
- Music skills

Common Health Challenges

- Immune irregularities – may be related to food intolerance or limiting diets to certain foods
- Nutritional deficiencies
- Gastrointestinal problems – many people have problems with toileting, often related to sensory issues or actual gastrointestinal problems. A great many have diarrhea or constipation, abdominal pain, gaseousness and bloating and in many cases foul smelling, light coloured stools. This discomfort could be the cause of poor sleep habits as many individuals suffer from reflux esophagitis.

Part 4: Types of Developmental Disabilities

Common Behavioural Characteristics

People on the autism spectrum often experience one or more of the following problems:

- Impairment in social relationships – Autism is characterized by an impaired ability to engage in social relationships and can result in serious deficits in the ability to make friendships. Some of the different ways people who have autism may respond to social interaction include:
 - Failure to respond to their names when called;
 - Appearing not to listen when spoken to;
 - An inability to display/interpret situation appropriate facial expressions;
 - Avoidance of eye contact;
 - A failure to respond to affection and sometimes treating people as if they were inanimate objects
 - Difficulty identifying boundaries of others.
- Deficits in communication / language – difficulties using and understanding verbal and non-verbal language are exceedingly common in people who have autism. Deficits can be found in these areas:
 - The development of spoken language – no speech
 - Responses to the communications of others (e.g. won't look)
 - Failure to initiate or sustain conversations (e.g. turn taking)
 - Pronoun confusion (e.g. I vs. You)
 - Stereotypical and repetitive use of language (e.g. using lines from a favourite movie to communicate)
 - Idiosyncratic use of words and phrases (e.g. always salutes and says "Yes sir" when given a direction)
 - Abnormalities in pitch, stress, rate, rhythm and intonation of speech
- Perseveration of interests and activities – people who have ASD typically have a narrow range of interests. They may also engage in repetitive, stereotyped body movements such as hand flicking, spinning or rocking. Perseverations might extend to food.
- Dependence on routine
- Difficulties in sleeping, toileting and eating
- Abnormal responses to sensory stimulation – many people who have ASDs have unexpected reactions to stimuli. People may have hypersensitivity (cannot tolerate touch, can hear the sound of a light buzzing, can be fascinated with an object spinning, etc.) or hyposensitivity (can appear deaf, extremely high pain tolerance to different sensory stimuli).

"I can remember the frustration of not being able to talk. I knew what I wanted to say, but I could not get the words out, so I would just scream."

Temple Grandin

Reference: Autism Society of Canada: <http://www.autismcanada.org/aboutautism/characteristics.html>
(accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Support Strategies

Rule out a medical problem that could be related to behaviour:

- ASD can have many different associated communication challenges. A thorough assessment by a Speech/Language Clinician will assist in determining specific challenges and support strategies in this area.
- When getting to know a person and how they learn, establishing a rapport and finding out as many interests/reinforcers as possible is extremely pertinent. This may be done by interviewing or observing the person or soliciting input from a support team, agency, family or friends. At the same time, try to figure out what learning style may be the best support for teaching, i.e., are they visual learners, verbal learners, tactile learners, or a combination of styles. Take into consideration that a combination of styles might provide too much input for the person and make learning more challenging for them.
- Find out what the person does, what they do best, and how often they can engage in their preferred activities. Are there ways to increase reinforcement and choice on a daily basis?
- Work with a clinician to review existing support strategies and determine effectiveness.
- Work with the person to develop a predictable environment and daily routine. Ensure the person has as much choice and input into the routine as possible. If visual stimulation is helpful for the person, visual schedules will be effective in assisting them to understand and predict the routine and any necessary transitions.
- If visual strategies are most effective for the person, ensure that visual strategies and cues are used to support them through any changes in the routine.
- Once a skill has been acquired, assist the person generalize the skill across different situations and tasks with different stimuli.
- Access all environments the person experiences. Determine how to set up introductions to new environments or frequent environments by planning short visits that are set up for success. For example, if the person has to go to the grocery store, the trip will likely be more successful if they go in the evening on a weekday to purchase a few items as opposed to a busy weekend to get a full list of items.
- When the person experiences behavioural challenges, direct support staff should complete a functional assessment of behaviour to assist in understanding the motivators behind the behaviour. All direct support professionals supporting the person must be aware of typical antecedents to behaviour and ensure that consistent support strategies are in place to help the person learn/cope.
- People who have an Autism Spectrum Disorder can have many different associated communication challenges. As assessment by a Speech and Language clinician may help to determine what specific challenges the person faces and possible treatment options to increase communication.
-

Part 4: Types of Developmental Disabilities

Down Syndrome

Down syndrome is a set of mental and physical symptoms that result from having an extra copy of chromosome 21. In most people who have Down syndrome, there is an extra copy of chromosome 21 (also called trisomy 21 because there are three copies of this chromosome instead of two). This changes the body's and brain's normal development (www.nichd.gov).

Common Physical Characteristics

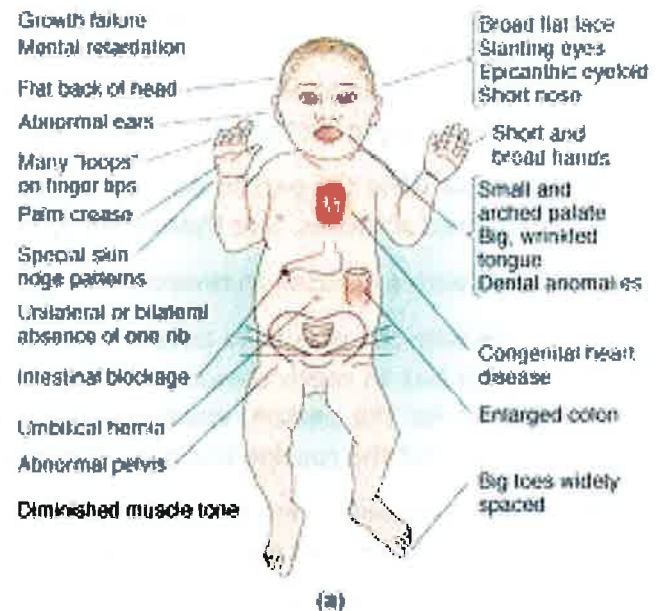
People who have Down syndrome may have very similar physical features, which include:

- Flat face with an upward slant to the eye, short neck and abnormally shaped ears
- Deep crease in the palm of the hand
- White spots on the iris of the eye
- Poor muscle tone, loose ligaments
- Small hands and feet

Common Health Challenges

Down syndrome is associated with several health challenges resulting from the chromosomal abnormality. People who have Down syndrome often experience the following challenges with their health:

- Abnormal brain development
- Congenital heart defects
- Thyroid problems
- Hearing and vision problems
- Celiac disease – inability to properly digest gluten products
- Gastro esophageal reflux disease (GERD)
- Sleep apnea
- Instability in the cervical column
- Cancer of the testes and ovaries
- Cataracts
- Early on-set dementia/Alzheimer's Disease



Common Behavioural Challenges

People who have Down syndrome also tend to share similar behavioural characteristics which may be viewed as strengths or roadblocks for them:

- Unique memory skills with very concrete interpretation
- Very strong social skills
- Strong ability to read the feelings and attitudes of those around them – very empathic and sensitive to emotions of others
- Tendency to absorb conflict that occurs around them
- Wandering / running off

Part 4: Types of Developmental Disabilities

- Stubborn / oppositional behaviour – can be resistant to change or prone to get “stuck” in rituals or routines
- Attention problems – individuals with Down syndrome can have ADHD
- Routines and rituals that can lead to obsessive / compulsive behaviours. These can be viewed like ruts in a road that trap a tire. Sometimes a person who has Down syndrome may need a little assistance getting “unstuck”
- Rich fantasy lives and strong imagination
- Self-talk

Support Strategies

The first step in trying to understand a person who has Down syndrome who presents with a behavioural concern is to rule out any acute or chronic medical problems that may be expressed through behaviour.

People who have Down syndrome have a wider range of abilities and skills. One of the most notable skills is an exceptional visual memory and a high capacity to understand and recall information that is presented visually. To help support a person who has Down syndrome, direct support professionals can ensure that they:

- Make use of visual cues
- Use visual story boards and calendars to provide information – particularly related to abstract concepts such as time. Visual calendars and checklists can really assist a person understand abstract concepts related to time
- Consider emotional stresses in the social environment that may impact behaviour
- Consider communication challenges that could impact on behaviour
- Build in movement breaks as needed
- Teach coping skills and strategies
- Work with a professional (psychologist, behavioural consultant, counsellor), to develop a behaviour treatment plan using the ABC's of behaviour (Antecedent, Behaviour, Consequence of the behaviour)
- Medication may be indicated in particular cases such as ADHD, OCD and autism

Reference: Dr. Dennis McGuire, Ph D, Mental Wellness in Adults with Down Syndrome, (2006). Dennis McGuire and Brian Chicoine, M.D., Woodbine House, inc. Publish date: 1997.

Preferred citation: Eunice Kennedy Shriver National Institute of Child Health and Human Development, NIH, DHHS, (1997). Facts about Down Syndrome 97-3402). Washington, DC: U.S. Government Printing Office. NIH Publication No. 97-3402

Part 4: Types of Developmental Disabilities

Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) is a genetic disorder that is complex in origin but results from an abnormality of the 15th chromosome. The abnormality creates challenges with the following:

- Hunger and satiety
- Temperature and pain regulation
- Fluid balance
- Puberty
- Emotions
- Fertility
- Speech and language development and function

Prader-Willi syndrome also causes developmental disabilities that can range from mild to severe.

There are two generally recognized stages of the symptoms associated with PWS:

- Stage one occurs in early infancy and is typified by “failure to thrive”. Infants will usually experience poor muscle tone, a weak cry and poor sucking reflex. These issues will generally improve over time but milestones are delayed
- Stage two generally develops between the ages of 2 and 6 and primarily involves an inability to satisfy appetite. People who have PWS lack the normal hunger and satiety cues
- Food seeking behaviours are very common. To further complicate PWS, the metabolic rate of persons with PWS is lower than normal. These two factors together often lead to obesity and its associated medical issues.

Common Physical Characteristics:

- Hypopigmentation – fair skin and hair compared with family
- Short stature for genetic background by age 15
- Small hands and/or feet for height / age
- Narrow hands with straight ulnar border
- Distinctive facial features – dolichocephaly (longer head than would be expected in infants)
- Narrow face / bifrontal diameter
- Almond-shaped eyes
- Small-appearing mouth with thin upper lip and down-turned corners of mouth



Part 4: Types of Developmental Disabilities

Common Health Challenges

People who have PWS may also experience these related symptoms:

- Insatiable hunger
- Short stature and small hands and feet
- Scoliosis
- Sleep disturbances with excessive daytime sleepiness
- Low sex hormones – undescended testicles in males
- Delayed motor skills and speech due to low muscle tone
- High pain threshold
- Infertility
- Diabetes Type II
- Other obesity-related problems
- Dental problems

Reference: Prader-Willi Syndrome Association USA – www.pwsausa.org/syndrome/basicfac.htm (accessed Oct 31, 2011); Ontario Prader Willi Syndrome Association: www.opwsa.com (accessed Oct 31, 2011).

Common Behavioural Presentation

- Food seeking behaviour can lead to property damage, aggression and serious risk to the personal health and safety of the individual.
- Picking skin, typically on forearms, face/neck and legs. Rectal picking in about 8% of cases.
- Nocturnal enuresis/encopresis resistant to change
- Challenging behaviour typically begins around the age of puberty. Presents as a compulsive need to manipulate others in the environment.
- There is often a high level of interest/skill with puzzles and or “Lego” type toys.

Support Strategies

Ensure thorough and regular health checks with the primary care physician to monitor any potential or existing health conditions.

When supporting a person who has Prader-Willi Syndrome, it is critically important to rule out a medical problem that could be related to the behaviour. Direct support professionals must be aware of what behaviours and health challenges can be expected because the person has Prader-Willi Syndrome. For example, individuals with PWS should be seen by a doctor should they vomit as this is typically a sign of potentially serious/significant health issues.

Direct support professionals must:

- Understand the frustration associated with insatiable hunger and provide a diet rich in variety and “free” snacks
- Develop strategies for support around obsessive compulsive tendencies and anxiety
- Assist in developing alternative communication systems to help people express themselves and ensure that their receptive communication needs are met
- Provide visual cues, calendars and checklists to help with understanding abstract concepts

Part 4: Types of Developmental Disabilities

Angelman Syndrome

Angelman syndrome (AS) is a neuro-genetic disorder usually caused by deletion or inactivation of genes on the maternally inherited chromosome 15 while the paternal copy, which may be of normal sequence, is imprinted and therefore silenced. The sister syndrome, Prader Willi syndrome, is caused by a similar loss of paternally inherited genes and maternal printing.

Angelman Syndrome is characterized by:

- Developmental delay and functional impairment
- Problems with planning and initiating motor acts
- Frequent laughter or smiling
- Usually a happy demeanour
- Disparity between understanding language and speaking; speaks few or no words; may be able to use nonverbal gestures
- In addition, individuals with Angelman syndrome may have:
 - Wide mouth
 - Some people who have Angelman syndrome have widely-spaced teeth, protruding tongue, drooling, feeding problems and frequently put things in the mouth during infancy



Common Health Challenges

- Sleep disturbance
- Seizures
- Vision problems – particularly strabismus (eyes not lining up in the same direction)
- Jerky movements (especially hand-flapping)
- Delayed, disproportionate growth of head in childhood
- Hypo-pigmented skin and eyes (decreased pigment production causing loss of skin colour)
- Difficulty with movement or balance, including difficulty walking and/or tremors of limbs
- Hearing difficulties caused by ear infections
- Reflux and gastrointestinal difficulties
- Increased weight gain possible
- Musculoskeletal problems

Common Behavioural Challenges

- Short attention span
- Temper outbursts and non-compliance
- Aggression – grabbing at people and things
- Chewing or mouthing hands and objects including non-food items
- Hyperactivity
- Fascination with water/excessive water play
- Repetitive or stereotyped behaviour
- Easily excitable
- Appears happy, frequently smiling and/or laughing

Part 4: Types of Developmental Disabilities

Support Strategies

Rule out a medical problem that could be related to behaviour.

- Specific medical treatment may be needed for problems such as seizures, feeding problems or sleep disturbance
- Physical therapy is helpful for improving walking
- Occupational therapy can help the person develop everyday living skills
- Speech and communication therapy can help the person, if able, to develop nonverbal means of communication and use communication aids such as pictures to express needs
- People who have Angelman Syndrome generally have good health and can be expected to live a normal life span
- Constant and close supervision along with hazard-proofing the environment are required to maintain safety due to a tendency to engage in particular behaviours. (e.g. mouthing or swallowing non-food items or involvement in water-related activities)

References: <http://rarediseases.about.com/od/rarediseases/a/angelman05.htm> and, <http://www.angelmancanada.org/about-as/diagnosis-treatments> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Klinefelter Syndrome

Klinefelter syndrome, also known as the XXY condition, is a term used to describe males who have an extra X chromosome in most of their cells. Instead of having the usual XY chromosome pattern that most males have, these men have an XXY pattern. Even though all men with Klinefelter syndrome have the extra X chromosome, not every XXY male will exhibit the common symptoms.

Scientists believe the XXY condition is one of the most common chromosome abnormalities in humans. About one of every 500 males has an extra X chromosome, but many don't have any symptoms. Klinefelter Syndrome can cause developmental delays.

Common Features

The XXY condition can affect three main areas of development:

Physical development:

- weak muscles and reduced strength as babies
- delayed reaching markers
- less muscle control and coordination than other boys after age four
- produce less testosterone during puberty
- less muscular than average in puberty
- less facial and body hair than average in puberty
- as teens, males may have larger breasts, weaker bones, and a lower energy level than other boys

Language development:

- learn to talk late
- trouble using language to express thoughts and needs
- problems reading
- trouble processing what they hear
- As adults - harder time doing work that involves reading and writing

Social development:

- As babies, XXY males tend to be quiet and undemanding.
- quieter, less self-confident, less active, and more helpful and obedient than other boys as they get older
- As teens - tend to be quiet and shy.

Common Health Challenges

By adulthood, XXY males look similar to males without the condition, although they are often taller. They are also more likely than other men to have certain health problems;

- Developmental Delay
- Autoimmune disorders
- Breast cancer
- Vein diseases

Part 4: Types of Developmental Disabilities

- Osteoporosis
- Infertility
- Delayed onset of puberty
- ADD/ADHD
- Dental issues
- Lung disease and respiratory difficulties

Common Behavioural Challenges

- Behavioural outbursts
- Frustration
- Difficulty focusing/paying attention
- Impulsiveness
- Anxiety

Support Strategies

Thorough and regular medical screening should be done to monitor for any health challenges and to address any health issues that may present through behavioural challenges. Testosterone therapy is a common for men who have Klinefelter Syndrome. Working with clinicians in speech, language and physical therapy will be helpful for the person.

Reference: www.nichd.nih.gov/health/topics/klinefelter_syndrome.cfm and, www.klinefeltersyndrome.org (accessed Oct 31, 2011).

Part 4: Types of Developmental Disabilities

Lesch-Nyhan Syndrome

Lesch-Nyhan syndrome is an X-linked inheritable trait that affects how the body builds and breaks down purines. Purines are a normal part of human tissue and help make up the body's genetic blueprint. It leads to a build-up of uric acid in the body. The condition affects about 1 in 380,000 people and causes developmental delay.

Lesch-Nyhan disease is only suspected when developmental delay is combined with evidence for overproduction of uric acid or self-injurious behaviour.

There are no common physical features associated with Lesch-Nyhan Syndrome.



Common Health Challenges

Many of the common health challenges result from the build-up of uric acid in the body.

- Developmental delay in the mild to moderate ranges
- Gout like swelling in joints
- Kidney stones
- Bladder stones
- Males with Lesch-Nyhan have delayed motor development followed by bizarre, sinuous movements and increased deep tendon reflexes.
- Continued reduction in mobility over time

Common Behavioural Challenges

Severe self-injury is a significant characteristic of Lesch-Nyhan Syndrome. People who are affected by the syndrome are inclined to chew/bite their fingertips, tongue and lips. Self-injury can be so severe that people may chew off or bite off their fingertips, lips, tongue or other appendages.

Other challenges include:

- Impulse control problems
- Poor attention spans
- Difficulty with complex planning and predicting the consequences of future events

Support Strategies

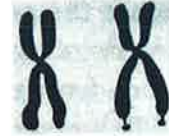
People who have Lesch-Nyhan Syndrome need regular medical support to monitor and treat physical symptoms of the syndrome. They will also benefit from clinical involvement by occupational therapists, physiotherapists, behavior therapists to address other physical and behavioural issues appropriately.

References: <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002620/> and, www.lesch-nyhan.org (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Fragile X Syndrome

Fragile X syndrome is a genetically inherited syndrome that causes an error with the manufacture of a protein the brain requires for normal development and function. It is the most common inherited form of mental retardation. It results from a change, or mutation, in a single gene, which can be passed from one generation to the next.



Common Physical Characteristics

- Very soft, velvety skin
- Broad forehead or a slightly larger head
- In puberty, they often may begin to develop certain features that are typical of teens and adults with Fragile X, such as a longer face or jaw and larger, more noticeable ears.
- Shorter than average height for their age.
- Many males develop enlarged testicles, a condition called macro-orchidism

Common Health Challenges

- Have poor fine and gross motor coordination
- Social anxiety
- Distressed by unexpected change in routine
- Many people who have Fragile X have loose, flexible joints
- May have flat feet and be able to extend joints like the thumb, knee and elbow further than normal
- Weak connective tissue which causes predisposition to certain medical conditions such as hernia, frequent middle ear infections, heart valve and vessel function with blood flow (creating a heart murmur)



Common Behavioural Characteristics

- Repeat words and phrases, or the last words in a sentence
- Fail to respond to direct questions
- Speak in rapid bursts
- Find large, noisy, unstructured group times distressing
- Stressed by pressures of time
- Oversensitivity to relatively minor upsets and/or have disruptive outbursts
- Emotional outbursts in stressful situations.
- Language difficulties
- Great need to please/be loved
- Great need to have mutually satisfying relationships
- Sensory issues

Part 4: Types of Developmental Disabilities

Support Strategies

Rule out a medical problem that could be related to behaviour

- Develop a consistent daily schedule or routine
- Use visual signs (pictures, [sign language](#), logos, and words) and concrete examples or materials to present ideas, concepts, steps, etc.
- Prepare the person for any changes in routine by explaining them ahead of time, possibly using visual signs
- Include functional goals with academic goals; for instance, teaching the person the names of different pieces of clothing as well as how to dress him/herself
- Provide opportunities for the person to be active and move around
- Provide a quiet place where the person can retreat and regroup
- Have sensory needs assessed and provide a sensory “diet” including preferred and needed sensory stimulation

Reference: Fragile X Research Foundation of Canada www.fragilexcanada.ca (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Turner Syndrome

Turner Syndrome is a genetically based condition affecting only females. A portion of the second X chromosome is missing. The absence of all or part of one X chromosome is associated with a range of health, developmental, social and learning challenges which affect girls and women who have Turner Syndrome to different extents. Turner Syndrome is not an inherited genetic condition.

Common Physical Characteristics

- Short stature; average height is 4' 9" (144 cm)
- Puffy hands and feet, edema may persist into adulthood
- Pigmented moles on skin
- Overweight
- Broad chest

Common Health Challenges

- Infertility
- Heart abnormalities
- Hearing problems including chronic or recurrent middle ear infections and hearing loss
- Feeding problems in infancy & childhood
- Kidney and urinary tract differences
- Diabetes
- Eye problems (drooping eyelids, "lazy" eye)
- Cataracts
- Wide and short neck with excess skin that joins the neck with collar bone ("neck webbing")
- High arched palate with associated dental problems
- Curvature of the spine (scoliosis)
- Brittle bones (osteoporosis)
- High blood pressure

Common Behavioural Characteristics

There is no true set of common behavioural challenges among people who have Turner Syndrome. Most commonly the areas affected are:

- Visual spatial learning challenges
- Difficulty with social skills

Support Strategies

Rule out a medical problem that could be related to behaviour.

When supporting a person who has Turner Syndrome, focusing on strengths and abilities will help build self-esteem and confidence. Clinical support to assist in building esteem, social skills and assess spatial learning challenges is beneficial for people who have Turner Syndrome to reach their full potential.

Reference: Turner Syndrome Society of Canada – www.turnersyndrome.ca (accessed Oct 31, 2011).

Part 4: Types of Developmental Disabilities

Cornelia de Lange Syndrome

Cornelia de Lange Syndrome is a genetic disorder found equally in males and females affecting 1 in 10,000 to 30,000 newborns. It affects brain development and functioning and causes a number of physical abnormalities as well.

Although three separate gene mutations have been identified as causing Cornelia de Lange Syndrome, not every person tests positive for one of these gene changes.

Common Physical Characteristics

People who have Cornelia De Lange Syndrome may typically have some of the following common physical features:

- thin eyebrows that meet in the middle
- long eyelashes,
- a short upturned nose
- thin downturned lips
- low birth weight with delayed growth
- microcephaly – smaller than average head size
- excessive body hair
- small hands and feet
- small widely spaced teeth
- low-set ears
- skeletal abnormalities, including scoliosis
- limb differences (missing limbs or portions of the limbs)
- partial joining of the second and third toes
- incurved 5th fingers
- [heart](#) defects
- cleft palate
- long philtrum (the midline groove in the upper lip that runs from the top of the lip to the nose)
- bowel abnormalities



Common Health Challenges

- Developmental delays/learning disabilities
- Heart abnormalities
- [Seizures](#)
- Vision and hearing problems
- Gastro-oesophageal reflux disease
- Bowel problems
- Feeding/eating difficulties
- Problems with digestion
- Chronic sinusitis/nasal polyps

Part 4: Types of Developmental Disabilities

- Delay of onset of puberty
- Lack of sensitivity to pain and/or heightened sensitivity to touch – indicating neurological impairment

Common Behavioural Characteristics

Although many people who have Cornelia de Lange have no significant behavioural problems, there are some conditions that make self-injurious behaviour more likely to occur. They may also have:

- Strong reactions to ordinary stimuli that continue long after the stimulus is gone
- Disturbances in patterns of behaviour in the areas of eating, sleeping and emotional response
- Difficulty with facial expression of emotion
- Language delay
- Behavioural problems such as:
 - hyperactivity
 - short attention span
 - oppositional or repetitive behaviour

Support Strategies

Rule out a medical problem that could be related to behaviour.

Persistent behavioural difficulties, including hyperactivity that does not respond to medication, severe impulsive behaviour, oppositional behaviour, aggression, or self injury, may require treatment by a specialist in behavioural psychology or a psychiatrist (clinician).

There is ongoing research by the National Institutes of Health to identify the genes responsible for Cornelia de Lange Syndrome, which will assist in early diagnosis and intervention.

References: www.cdlsCanada.ca (accessed Oct 31, 2011), and <http://ghr.nlm.nih.gov/condition/cornelia-de-lange-syndrome> (accessed Oct 31, 2011) and <http://www.cdlsusa.org/what-is-cdls/treatment-protocols.htm> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Smith-Magenis Syndrome

Most people who have Smith-Magenis Syndrome have a deletion of genetic material from a specific region of chromosome 17. Smith-Magenis syndrome is a developmental disorder that affects many parts of the body. The major features of this condition include:

- mild to moderate intellectual disability
- delayed speech and language skills
- distinctive facial features
- sleep disturbances
- behavioural problems

Common Physical Characteristics

People who have Smith-Magenis Syndrome often have similar physical features, particularly facial features, which become more distinctive in later childhood and adolescence. These features include:

- broad, square-shaped face
- deep-set eyes
- full cheeks
- prominent lower jaw
- dental abnormalities
- the bridge of the nose often appears flattened
- downward turning mouth with a full, outward-curving upper lip
- short stature
- abnormal curvature of the spine (scoliosis)
- reduced sensitivity to pain and temperature
- hoarse voice
- although less common, heart and kidney defects also have been reported



Common Health Challenges

- hearing loss following recurrent ear infections
- decreased or absent deep tendon reflexes
- decreased sensitivity to pain
- feeding difficulties in children with the syndrome are common especially when chewing solid foods

Common Behavioural Characteristics

People who have Smith-Magenis Syndrome are frequently described as eager to please with a good sense of humour, friendly and outgoing.

Part 4: Types of Developmental Disabilities

At the same time, the following challenges can be quite common:

- aggression
- tantrums
- repetitive behaviours
- attention deficits
- attention seeking behaviours
- self-injurious behaviours can be extreme in some cases and may include head banging, hand biting and skin picking, orifice stuffing
- sleep problems
- anxiety
- impulsiveness
- repetitive self-hugging is a behavioural trait that may be unique to Smith-Magenis syndrome – other hugging possibly with little understanding of the intensity
- compulsive licking of fingers and flip pages of books and magazines (a behaviour known as "lick and flip")

Support Strategies

Rule out a medical problem that could be related to behaviour.

Consult a qualified clinician to assist in understanding and developing strategies around persistent challenging behaviour. A Speech and Language Therapists can assist with swallowing and eating problems. Frequent hearing checks are recommended. A Behaviour Therapist can assist develop support strategies to address the syndrome driven behaviours.

Reference: <http://ghr.nlm.nih.gov/condition/smith-magenis-syndrome> (accessed Oct 31, 2011)

Reference: Smith-Magenis Syndrome Foundation UK <http://www.smith-magenis.co.uk/> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

PKU (Phenylketonuria)

PKU is an inherited genetic disorder that affects the body's ability to process phenylalanine, an amino acid commonly found in most foods. If not treated within the first week of life, it will cause a build up of phenylalanine in body cells and can lead to nervous system and brain damage causing developmental delays. In Canada, all babies are tested for PKU within days after birth. If PKU is diagnosed, treatment by low protein diet is implemented immediately. Early diagnosis is critical to help minimize the effect of high phenylalanine levels on the body.

PKU is characterized by;

- Delayed mental and social skills
- Head size significantly below normal
- Jerking movements of the arms or legs
- Unusual positioning of hands
- Hyperactivity
- Behavioural or social problems
- A musty odour in the breath, skin or urine caused by too much phenylalanine in the body
- Mood problems

Common Health Challenges

Because people who have PKU cannot process food, treatment focuses on diet and eliminating those foods that have particularly high protein content.

In addition, people who have PKU often have:

- Developmental delays
- Seizures
- Skin rashes
- Tremors
- Heart defects



Common Behavioural Characteristics

Hyperactivity is the primary behavioural challenge experienced by a person who has PKU.

Support Strategies

Regular medical checks are recommended for a person who has PKU. A strict diet with very limited intake of phenylalanine, which is mostly found in protein rich food, is required.

Reference: <http://ghr.nlm.nih.gov/condition/phenylketonuria> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Cri du Chat Syndrome

Cri du chat syndrome is a group of symptoms that result from missing a piece of **chromosome** number 5 and is characterized by developmental disability. Infants with Cri du Chat syndrome have high-pitched cries similar to a cat, which is how the syndrome was named. Most cases of Cri-du-Chat syndrome are not inherited.

Common Physical Characteristics

People who have Cri du Chat Syndrome may have similar physical characteristics including:

- small head size (microcephaly)
- low birth weight
- failure to thrive in infancy – poor sucking and swallowing reflexes
- weak muscle tone (hypotonia) in infancy
- widely set eyes (hypertelorism)
- low-set ears
- small jaw
- rounded face
- prematurely greying hair



Common Health Challenges

- Heart defects
- Recurrent upper respiratory infections
- Recurrent ear infections
- Severe constipation
- Poor muscle tone
- Eye problems, such as a squint (strabismus).
- Hearing loss
- Deformities of the skeleton, such as curvature of the spine (scoliosis)
- Hernias
- Heart and kidney problems

Common Behavioural Characteristics

People who have Cri du Chat Syndrome will often have challenges with:

- hyperactivity
- aggressive behaviour
- temper outbursts
- repetitive and self-injurious behaviours
- hypersensitivity to sound
- clumsiness
- obsessive attachments to objects

Part 4: Types of Developmental Disabilities

Support Strategies

Rule out a medical problem that could be related to behaviour.

There is no cure for Cri du Chat Syndrome. Treatment aims help people address some of the challenges they face. For example,

- Physiotherapy to improve poor muscle tone
- Speech therapy
- Communication alternatives such as sign language, since speech is usually delayed, often severely
- Occupational therapy to teach coping strategies and new skills

References: <http://ghr.nlm.nih.gov/condition/cri-du-chat-syndrome> (accessed Oct 31, 2011)

http://www.madisonsfoundation.org/index.php/component/option,com_mpower/diseaseID,186/ (accessed Oct 31, 2011)

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Cri_du_chat_syndrome?open (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Williams Syndrome

Williams Syndrome is a rare genetic disorder caused by the deletion of a group of genes on chromosome 7. The deletion of this gene interferes with the production of a protein responsible for providing strength and elasticity to blood vessel walls. Williams Syndrome is characterised by mild to moderate developmental delays.

Common Physical Characteristics

There are several physical characteristics common among people who have Williams Syndrome.

- puffiness around the eyes
- short nose with a broad nasal tip and low nasal bridge
- wide mouth with irregularly spaced teeth
- full cheeks
- full lips
- a small chin
- long neck
- sloping shoulders
- short stature
- a star-like pattern in the iris of their eyes



Common Health Challenges

- Some type of heart or blood vessel problem. Usually, this is because part of the aorta or the pulmonary arteries has narrowed, causing a heart murmur
- Blood pressure problems
- Limited mobility in their joints
- Curvature of the spine
- Cardiovascular disease caused by narrowed arteries
- Feeding problems in infancy
- Gastrointestinal problems, such as severe or prolonged [colic](#)
- Abdominal pain and [diverticulitis](#)
- [Nocturnal enuresis](#) (bed wetting) and urinary difficulties
- Dental irregularities and defective [tooth enamel](#)
- Hormone problems, the most common being [hypercalcemia](#) (elevated calcium levels in the blood)
- [Hypothyroidism](#) has been reported to occur in children
- Diabetes

Common Behavioural Characteristics

While infants who have Williams Syndrome are often colicky and irritable, most people who have Williams Syndrome often exhibit the following characteristics:

- are over-friendly
- high levels of empathy
- childhood hyperactivity

Part 4: Types of Developmental Disabilities

- extreme uninhibited behaviour
- excessive talking, in an inappropriate and "adult" manner as children
- over-friendliness with strangers
- high verbal ability leading to artificial expectations of matching functional ability
- "obsessive" interest in certain things: e.g. cars, ambulances, vacuums, wheels etc.
- fear of heights, open stairs, uneven surfaces
- very short concentration span adding to learning difficulties, high distractibility
- emotional immaturity exhibited by over-reaction to events and exaggerated displays of fear, excitement, sadness, happiness etc.
- hypersensitivity to noise
- anxiety

Support Strategies

Rule out a medical problem that could be related to behaviour.

People who have Williams Syndrome can develop health problems as a result of the syndrome and also ordinary health problems unrelated to the syndrome. It is important to make good use of local resources (e.g. general practitioners, health visitors, clinicians and consultants) to help the person reach their full potential.

A qualified clinician can assist in assessing the function of behavioural challenges and developing a support strategy to assist the person.

References: <http://www.ninds.nih.gov/disorders/williams/williams.htm> (accessed Oct 31, 2011), <http://www.caws-can.org/> (accessed Oct 31, 2011), and, <http://caws.sasktelwebhosting.com/about.html> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Rett Syndrome

Rett Syndrome is a disorder of the nervous system that leads to developmental reversals, especially in the areas of expressive language and hand use. An infant with Rett syndrome usually has normal development for the first 6 - 18 months. Symptoms range from mild to severe.

Genetic testing is not consistently effective in diagnosing Rett Syndrome since the genetic defect associated is not identified in everyone with the disease. Diagnosis is usually based on the presence of symptoms. It occurs almost exclusively in females.

Signs and symptoms include:

- normal development in infants up to 18 months although in rare cases symptoms can be apparent at birth or after 18 months
- occurs almost exclusively in females
- apraxia - disorder of the brain and nervous system in which a person is unable to perform tasks or movements when asked
- change in development
- excessive saliva and drooling
- floppy arms and legs -- frequently the first sign
- intellectual disabilities and learning difficulties



Common Health Challenges

- cardiac irregularities, particularly problems with the rhythm of their hearts
- seizures
- ongoing, severe constipation and **gastro oesophageal reflux (GERD)**
- poor circulation that can lead to cold and bluish arms and legs
- breathing problems -- problems tend to get worse with stress; breathing is usually normal during sleep and abnormal while awake
- irregular sleep patterns

Common Behavioural Characteristics

People who have Rett Syndrome often will have the following behavioural characteristics:

- anxiety in response to external situations
- brief and consistent screaming
- self-injurious behaviour – particularly biting fingers and hands
- frightened expressions and general distress
- depressed moods
- loss of social engagement

Resources: <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002503/> (accessed Oct 31, 2011) and Dual Diagnosis – An introduction to the mental health needs of persons with developmental disabilities – Griffiths Stavrakaki and Summers – Appendix A

Part 4: Types of Developmental Disabilities

Support Strategies

Rule out a medical problem that could be related behaviour.

- Physical therapy to help improve or maintain mobility and balance, address diminished motor skills, maintain flexibility, and strengthen muscle
- Speech-language therapy to assist with communication skills
- Occupational therapy
- Physiotherapy (like massage and exercise) to relieve pain
- Consultation with a clinician for assessment and support strategies for any behavioural challenge

Reference: <http://www.mychildwithoutlimits.org/?page=rett-syndrome-treatment> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

22q11.2 Deletion Syndrome

The 22q11.2 deletion syndrome is a recognizable pattern of physical and developmental features associated with a missing piece of genetic material from chromosome 22. The condition is sometimes referred to as velo-cardio-facial or DiGeorge syndrome. Many people who have 22q11.2 deletion syndrome show a spectrum of developmental issues including learning, social, and emotional difficulties.

Common Physical Characteristics

The effects of the deletion can include a set of common physical characteristics:

- Droopy eyelids
- Small ears with squared upper ear
- Prominent bridge of the nose and narrow eyes
- Extra ribs, extra fingers and toes
- Cleft lip and/or palate
- Asymmetric facial appearance when crying
- Small mouth, chin, and side areas of the nose tip
- Genital abnormalities
- Short stature



Common Health Challenges

- Cardiac defects
- Developmental delays
- Differences in soft and hard palates
- Endocrine imbalances
- Low calcium levels in childhood
- Thyroid problems
- Hearing loss - ear infections are common
- Problems with airway due to structural differences
- Gastrointestinal and feeding difficulties - gastro-esophageal reflux (GERD)
- Dysmotility leading to constipation
- Hernias
- Immune system problems – chronic infections
- Seizures
- Bone troubles
- Differences in the way kidneys are formed and function

Common Behavioural Challenges

- Hyperactivity
- Obsessive compulsive disorder
- Anxiety
- Perseverations

Part 4: Types of Developmental Disabilities

- Psychosis - a symptom or feature of mental illness typically characterized by significant changes in personality, impaired functioning, and a distorted or nonexistent sense of objective reality

Support Strategies

Rule out a medical problem that could be related behaviour.

People who have 22q11.2 deletion should receive coordinated care from a multi-disciplinary team that includes;

- Medical professionals
- Clinicians
- Speech and Language Specialists
- Occupational Therapists
- Psychiatrists

References: <http://www.22q.org> (accessed Oct 31, 2011)

<http://www.migeneticsconnection.org> (accessed Oct 31, 2011)

<http://www.yalemedicalgroup.org/stw/Page.asp?PageID=STW036144> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Rubenstein-Taybi Syndrome

Rubinstein-Taybi syndrome is a genetic disease characterized by broad thumbs and toes, short stature, distinctive facial features, and varying degrees of mental retardation. Most cases are sporadic (not inherited) and likely due to a new mutation occurring during fetal development, which was not passed on by either parent. However, in some cases, it is inherited in an autosomal dominant fashion, which means that if just one parent passes on the defective gene, the child will be affected.

Rubenstein-Taybi Syndrome is characterized by developmental delay.

Common Physical Characteristics

- Broadening of the thumbs and big toes
- Excess hair on body (hirsutism)
- Short stature that is noticeable after birth
- Slow development of cognitive skills
- Narrow palate
- Crowded teeth
- Unsteady or stiff walking gait
- Downward-slanted eyes
- Low-set ears or malformed ears
- Drooping eyelid (ptosis)
- Narrow, small, or recessed mouth with crowded teeth
- Prominent or "beaked" nose
- Skeletal (limb) abnormalities including the last segment of the other fingers and toes, appearing broad on x-rays or physical examination
- Thick and arched eyebrows with long eyelashes



Common Health Challenges

- Constipation
- Heart defects possibly requiring surgery (about 30% of patients)
- Seizures
- Slow development of motor skills accompanied by low muscle tone
- Absent or extra kidney, and other problems with kidney or bladder
- An underdeveloped bone in the mid-face
- **Cataracts**
- Eye defects
- **Macrocephaly** (excessively large head) or **microcephaly** (excessively small head)
- Undescended testicle or other testicular problems
- Gastro esophageal reflux and vomiting
- Orthopaedic problems
- Often difficulty with administration of general anaesthetics

Part 4: Types of Developmental Disabilities

Common Behavioural Challenges

There are no recognized common behavioural challenges associated with Rubenstein-Taybi Syndrome.

Support Strategies

Rule out a medical problem that could be related behaviour.

There is no specific treatment of Rubenstein-Taybi Syndrome. However, as with many other syndromes, specific treatments can assist in lessening or addressing some of the symptoms.

Suggestions for treatments include:

- Speech and language therapy
- Physical therapy
- Occupational therapy

References: <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002229/> (accessed Oct 31, 2011) and <http://www.rubinstein-taybi.org/> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Hunter Syndrome

Hunter syndrome is an inherited condition. Boys are most often affected. Hunter Syndrome may have early on-set or late on-set in life. The stage of on-set determines the level of developmental delay involved. Early on-set typically results in severe to profound developmental delay. Late on-set can result in mild or no developmental delay. Early on-set of Hunter Syndrome is usually apparent by age two and can severely limit the person's life span.

Common Physical Features

- large head ([macrocephaly](#))
- increased hair ([hypertrichosis](#))
- coarse features of the face
- short stature
- pebbly, ivory-colour skin lesions on upper arms, legs, and upper back

Common Health Challenges

- abnormal [retina](#) (back of the eye)
- enlarged liver
- enlarged spleen
- inguinal [hernia](#)
- spasticity
- frequent ear infections
- hearing loss that gets worse over time
- limited lung capacity
- respiratory infections
- cardiac/valvular heart disease
- breathing problems while sleeping
- joint stiffness and limited range of motion
- carpal tunnel syndrome



Common Behaviour Challenges

- Aggressive behaviour
- [Hyperactivity](#)
- Mental function gets worse over time
- Loss of ability to complete daily living activities

Support Strategies

Rule out a medical problem that could be related behaviour.

The primary supports needed for people who have Hunter Syndrome relate to management of symptoms and medical issues. It is critical to have involvement of clinicians and specialists who specialize in patients with complex needs.

References: <http://www.nlm.nih.gov/medlineplus/ency/article/001203.htm> (accessed Oct 31, 2011) and <http://www.hunterpatients.com/> (accessed Oct 31, 2011).

Part 4: Types of Developmental Disabilities

Acquired Brain Injury

According to the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, traumatic brain injury can now be classified as a developmental disability and people who have acquired brain injury can now qualify for services through Developmental Services.

Acquired brain injury (ABI) is a complex injury with a broad spectrum of symptoms and disabilities. Brain injuries do not heal like other injuries. Recovery is a functional recovery, based on mechanisms that remain uncertain.

“The deficits resulting from an (acquired) brain injury can range from impairment of higher level cognitive functions to comatose states. Survivors may have limited function of arms or legs, abnormal speech or language, loss of thinking ability or emotional problems. The range of injuries and degree of recovery is very variable and varies on an individual basis.”*

Acquired brain injury can cause a wide range of functional changes, both short and long-term and can affect the following:

- **Thinking** (i.e., memory and reasoning);
- **Sensation** (i.e., touch, taste, and smell);
- **Language** (i.e., communication, expression, and understanding); and
- **Emotion** (i.e., depression, anxiety, personality changes, aggression, acting out, and social inappropriateness).¹

Acquired brain injury can also:

- Cause epilepsy
- Increase the risk for conditions such as Alzheimer’s disease, Parkinson’s disease, and other brain disorders that become more prevalent with age

Emotional effects vary as well as the person with a brain injury will see changes in emotional control; either related to the brain injury or to the frustrations resulting from learning to adapt. Depression can be common as a result of increased dependence on others.

Support Strategies

Rule out a medical problem that could be related behaviour.

Strategies for supporting a person who has an acquired brain injury are dependent on the specific brain injury and resulting needs of the person. Detailed assessment of the person’s health needs and functional abilities will help inform any needed support strategies.

References: <http://www.traumaticbraininjury.com> (accessed Oct 31, 2011) and, <http://www.cdc.gov/traumaticbraininjury> (accessed Oct 31, 2011) and, <http://biac-aclc.ca/en/what-is-it/> (accessed Oct 31, 2011)

Part 4: Types of Developmental Disabilities

Genetic Testing

Many developmental disabilities are caused by genetic abnormalities. When the specific abnormality the person carries is identified, the specific health and social challenges a person has may be able to be identified and plans made for early intervention. Genetic testing can assist in determining needed preventative care, assessments, diagnosis of associated medical conditions and treatment.



Since each is genetically based developmental disability is associated with different health, mental health and behavioural pre-dispositions. Identification of genetic syndromes allows direct support professionals the opportunity to prepare and plan supports with the person specific to their needs much more effectively.

Examples:

- A person who has Cri du Chat Syndrome is prone to severe constipation as a result of their genetic make-up. Knowing this, direct support professionals can help plan diet and exercise regime specific to preventing constipation and promoting good bowel health. They will also be aware of the need for close monitoring of bowel movements and for signs of constipation.
- A person who has Williams Syndrome is more likely to be negatively affected by loud noises. When planning activities with a person with Williams Syndrome, direct support professionals can be sensitive to this challenge and help the person plan activities that avoid loud noises or help the person plan for and support them through situations where loud noises cannot be avoided.
- A person who has Down Syndrome typically has strong visual memory. Direct support professionals can help the person create visual schedules and calendars to learn new tasks and activities.

The companion Toolkit for the Primary Care Guidelines contains a section on Genetic Assessment: Frequently Asked Questions. The Appendix – Health Section contains a copy of this chart. It also contains several useful website resources to assist in locating a centre to complete genetic testing and syndrome specific reviews.

***Please note that the list of developmental disabilities above is not exhaustive but is meant to be a summary of several of the more common syndromes/conditions that cause developmental delays.

Health watch tables for several of the syndromes listed in this chapter can be located in the Appendix. They are also available the Surrey Place Centre Website at:

<http://www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx>

Part 5: Mental Illness



The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Mental health is included in this definition.

Mental Wellness is a state of being in which a person is able to deal with the demands of everyday life and thinks, feels and behaves in ways which are appropriate for his or her age, relationships and responsibilities.

Mental illnesses (also called mental disorders) can be defined as a variety of psychiatric conditions which typically shows thought, behavioural or emotional impairments as a result of:

- Genetic
- Environmental
- Biological
- Psychosocial factors

Mental disorders cause distress and can interfere with a person’s ability to cope with daily life and may disrupt their work, social, and family life. Individuals experiencing a mental illness may have problems with behavioural and emotional control, communication and their sense of reality may become distorted.

Reference: Canadian Mental Health Association <http://www.cmhniagara.ca/mental-illness.html> (accessed October 2011)

Mental Health Disorders are classified within the American Psychiatric Association’s DSM IV (Diagnostic and Statistical Manual of Mental Disorders Fourth Edition) to facilitate diagnosis and treatment.

The DSM-IV classifies mental illness as follows:

A) Axis I: Clinical disorders, including major mental disorders, and learning disorders, substance use disorders.

Common Axis I Disorders are:

I. Depression: a period of at least two weeks during which there is either depressed mood or the loss of interest or pleasure in nearly all activities. In people who have a developmental disability, the mood may present as irritable, not sad.

The person must also experience at least four of the following as well:

- Decreased energy
- Feelings of worthlessness or guilt
- Changes in appetite or weight, sleep and psychomotor activity
- Difficulty concentrating, thinking, or making decisions
- Or recurrent thoughts of death or suicidal ideation, plans or attempts

Part 5: Mental Illness

Causes:

There is no one specific cause of depression. The following factors may make some people more prone than others to react to a loss or failure with a clinical depression:

- Specific, distressing life events
- A biochemical imbalance in the brain
- Psychological factors, like a negative or pessimistic view of life
- There may also be a genetic link since people with a family history of depression are more likely to experience it

Treatment:

Depression is the most treatable of mental illnesses. Most people who suffer from depression are helped by the treatment they get, which usually includes medication and/or psychological counselling.

II. Anxiety Disorders:

Anxiety disorders are a group of disorders which affect behaviour, thoughts, emotions and physical health. Research into their origins continues, but it is believed they are caused by a combination of biological factors and an individual's personal circumstances, much like other health problems.

Types of anxiety disorders include:

- Panic attacks
- Agoraphobia
- Social phobia
- Acute stress disorders
- Generalized stress disorders
- Anxiety due to medical conditions or substance abuse

Treatment:

There are two main medical approaches to treating an anxiety disorder:

1. Drug therapy and;
2. Cognitive-behavioural therapy (CBT)

Combining the two types of treatment can be effective.

III. Bipolar Disorders:

Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in mood, energy, activity levels and the ability to carry out day-to-day tasks.



Symptoms:

People with bipolar disorder experience unusually intense emotional states that occur in distinct periods called "mood episodes". An overly joyful or overexcited state is called a manic episode, and an extremely sad or hopeless state is called a depressive episode.

Part 5: Mental Illness

Sometimes, a mood episode includes symptoms of both mania and depression, i.e., a mixed state. People with bipolar disorder also may be explosive and irritable during a mood episode. Extreme changes in energy, activity, sleep, and behaviour go along with these changes in mood. It is possible for someone with bipolar disorder to experience a long-lasting period of unstable moods rather than discrete episodes of depression or mania.

Treatment:

Bipolar disorder tends to worsen if it is not treated. Because bipolar disorder is a lifelong and recurrent illness, people with the disorder need long-term treatment to maintain control of bipolar symptoms. An effective maintenance treatment plan includes medication and psychotherapy for preventing relapse and reducing symptom severity.



Reference: Miklowitz, DJ. (2006). A review of evidence-based psychosocial interventions for bipolar disorder. *J Consult Clin Psychol* 67, (suppl 11):28-33.

IV. ADHD (Attention Deficit Hyperactivity Disorder):

Symptoms include difficulty staying focused and paying attention, difficulty controlling behaviour, and hyperactivity (over-activity).

ADHD has three subtypes:

- predominantly hyperactive-impulsive,
- predominantly inattentive,
- combined hyperactive-impulsive and inattentive.

Causes:

The main causes of ADHD are unclear, although many studies suggest that genes play a large role. In actuality, many factors will play a role in contributing to the cause.

Treatment:

Currently, available treatments focus on reducing the symptoms of ADHD and improving functioning. Treatments can include medication, various types of psychotherapy, education or training, or a combination of treatments.

V. Autism Spectrum Disorders:

See description in Part 4: Different Types of Developmental Disabilities.

VI. Eating Disorders:

Eating disorders are a way of coping with deeper problems that a person finds too painful or difficult to deal with directly. They are complex conditions that signal difficulties with identity, self-concept and self-esteem. Eating disorders are cross-cultural, have no racial and socio-economic boundaries and affect men and women. Eating disorders have the highest mortality rate of all mental illnesses, with 10% to 20% eventually dying from complications.



Part 5: Mental Illness

Three chronic eating disorders have been identified:

- **Anorexia nervosa:**
Characterized by severe weight loss due to extreme food reduction.
- **Bulimia nervosa:**
Results in frequent fluctuations in weight due to periods of uncontrollable binge eating, followed by purging.
- **Binge-eating disorder:**
Also known as compulsive eating, it is often triggered by chronic dieting and involves periods of overeating, often in secret and often carried out as a means of deriving comfort.

Causes:

There is no single cause but is usually the result of a combination of factors including:

- Psychological factors: include low self esteem, feelings of inadequacy or lack of control, depression, anger or loneliness
- Interpersonal factors: include troubled family and personal relationships, difficulty expressing emotions and feelings, history of physical or sexual abuse

Treatment:

A multi-disciplinary approach is the most effective treatment route. This involves a thorough medical assessment, nutritional guidance, support, medical follow-up, individual, group and family therapy. Because eating disorders have a profound negative impact on all family members, the entire family may need counselling.

Reference: Canadian Mental Health Association, Understanding Mental Illness – Eating Disorders
http://www.cmha.ca/bins/content_page.asp?cid=3-98&lang=1 (accessed Oct 31, 2011).

VII. Schizophrenia:

Schizophrenia and psychosis are characterized by delusions, hallucinations, disturbances in thinking and withdrawal from social activity. Is a complex mental disorder that makes it difficult to:

- Tell the difference between real and unreal experiences
- Think logically
- Have typical emotional responses to situations and events
- Behave normally in social situations
- Schizophrenia affects both men and women equally



Causes:

The causes of schizophrenia are still not clear. However, researchers have determined there is a strong association with a chemical imbalance in the brain. Although they are serious mental illnesses, schizophrenia and psychosis are treatable and most people do go on to live lives of recovery.

Part 5: Mental Illness

Treatment:

Antipsychotic medications are the most effective treatment for schizophrenia. They change the balance of chemicals in the brain and can help control symptoms.

References: Schizophrenia Society of Canada; <http://www.schizophrenia.ca/heimEnglish1.htm> (accessed Oct 31, 2011) and, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001925/> (accessed Oct 31, 2011)

B) Axis II: Personality disorders and intellectual disabilities:

Common Axis II Disorders Include:

I. Personality Disorders: Personality disorders exist in several forms. Their influence on interpersonal functioning varies from mild to serious. Personality disorders cause enduring patterns of inner experience and behaviour that deviate from the expectations of society, are pervasive, inflexible and stable over time, and lead to distress or impairment.

Reference: American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4th edition. Washington, DC: American Psychiatric Association, 1994.

There are currently 10 classified personality disorders:

- Borderline personality disorder
- Antisocial personality disorder
- Histrionic personality disorder
- Narcissistic personality disorder
- Avoidant personality disorder
- Dependent personality disorder
- Schizoid personality disorder
- Paranoid personality disorder
- Obsessive compulsive personality disorder
- Schizotypal personality disorder

Causes:

Personality disorders likely result from the complex interplay of early life experience, genetic and environmental factors.

Treatment:

Intensive individual therapy along with a combination of mood stabilizing medication and group therapy can be effective in treatment of personality disorders. However, most are particularly difficult to treat due to self-denial about the presence of a problem.

Reference: Public Health Agency of Canada – Report on Mental Illness in Canada, Chapter 5

II. Intellectual Disabilities

The DSM IV identifies an intellectual disability existing when intellectual functioning is between 71 and 84 on the 1Q scale. This is termed Borderline Intellectual Functioning and classifies as a mental illness on Axis II.

Part 5: Mental Illness

C) Axis III: Acute medical conditions and physical disorders:

Common Axis III Disorders include acute medical conditions and physical disorders. These include diseases that may have a direct impact on the development of or worsening of the person's mental illness symptoms such as:

- Hypothyroidism
- Arrhythmia
- Epilepsy
- Headaches
- Bronchitis
- Brain Injuries



D) Axis IV: Psychosocial and environmental factors contributing to the disorder such as:

- Negative life events
- Environmental difficulties or deficiencies
- Familial or other interpersonal stressors
- Inadequate social support or personal resources
- Problems relating to the context in which a person's difficulties have developed

E) Axis V: Global Assessment of Functioning or Global Assessment Scale (for children and teens under the age of 18):

This process allows for an assessment of the person's general functioning in their current life situation. This assessment can be used as a guideline for treatment and whether or not hospitalization is necessary.

Reference: Lundbeck Institute, Diagnosis of Mental Disorders: How doctors diagnose: signs and symptoms, www.brainexplorer.org/facesheets/psychiatry%20diagnosis.pdf (accessed Oct 31, 2011)

Part 6: Introduction to Interactions and Relationships



Attitudes are understood as being composed of a set of values or core beliefs, which can form a framework for providing supports for people. The attitude direct support professionals bring to their work will influence their interactions and relationships with the people for whom they provide support.

Most service agencies will have a clearly articulated mission statement about the service they provide and how they value the people for whom they provide support. Direct support professionals must also adhere to a set of principles that will guide their interactions and supports with people who have a dual diagnosis.

Community Living Owen Sound and District has developed the following example of specific list of values as a guide for direct support professionals when supporting people:

Dignity and Worth of Every Person

We need to get to know the person first and then discover their needs. This value reminds us of the wholeness (mind body and spirit) of the people we support.

Mutual Respect and Healthy Relationships

We will treat others as we would want to be treated. We recognize that everyone has their own path in life. Our interactions will be based upon an understanding of differences and respecting of choices.

Family and Friends

Our Primary concern is for the person we support and we will encourage and honour the participation of family and friends within a circle of support.

Privacy and Confidentiality

We will respect privacy and treat all personal information with the utmost confidentiality and we will abide by "our organization's" confidentiality policy.

Informed Choice

We will act as a resource and assist in gathering information to assist the people we support in the process of making life choices.

Part 6: Introduction to Interactions and Relationships

Risk, Opportunity and Lifelong Learning

We will ensure that the integrity of the persons we support is protected without compromising basic safety and security.

Community Inclusion

We will assist the people we support in building relationships and encourage a sense of belonging. Inclusion will be based on the concepts of:

- preferences, i.e. what people like and want to do;
- opportunities, i.e. what is available; and
- choices, i.e. the ability to make use of opportunities to satisfy one's own preferences.

Reference: Adapted from Mission Statement: Community Living Owen Sound and District, Owen Sound, Ontario.

In May 2008 December 2008, the United Nations General Assembly ratified the Convention on the Rights of Persons with Disabilities. The Convention is an instrument to protect the rights and dignity of persons who have disabilities.

There are eight guiding principles that underlie the Convention:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

As of October 2011, the Convention has 153 signatories and 106 parties, which indicates their agreement to adhere to the Convention's expectations around dignity and preservation of rights for people who have disabilities. Adherence to the Convention is monitored by a special committee, The Committee on the Rights of Persons with Disabilities. The Committee meets twice a year in Geneva.

Link to UN Convention:

http://www.un.org/disabilities/documents/gadocs/a_66_121.pdf

Part 6: Introduction to Interactions and Relationships

Professional and paraprofessional disciplines, such as psychologists, psychological associates, will have a clearly articulated code of ethics and/or values framework upon which practice is built. The following is an example of a code of ethics for professionals working with people who have a dual diagnosis.

1. Value for the citizen and their rights

- Belief that people who have a dual diagnosis have the same rights as other citizens, including the right to access to services and supports, regardless of their needs and disabilities.

2. Value for the person-centered approach

- Belief that people who have a dual diagnosis are diverse, with a wide range of strengths, abilities, and complexities.

3. Value for gaining understanding before taking action/making judgment

- Belief in the importance of exploration as a basis for understanding the person.

4. Value for collaboration towards gaining understanding; solution finding at all stages of assessment, formulation, planning, intervention and evaluation

- Belief in the importance of many perspectives, the need to share both expertise and responsibility in responding to people's needs.

5. Value for the biopsychosocial approach to assessment, planning, intervention and evaluation

- Belief that effective practice integrates the psychological and sociological effects on mental health and behaviour as well as the biological causes of behaviour and the biological response to medication treatment.

6. Value for continuous learning and system improvement

- Belief that learning is an ongoing process, that planned change and quality improvement come from application of new knowledge.

7. Value for Responsible and Ethical Practice

- Belief that the person's practitioners are required to practice within the bounds of governing legislation (e.g. Regulated Health Professionals), their discipline-based commitment (e.g. Code of Ethics for practice), within the practice standards and structures of the organization in which, they work as well as from a personal commitment to ethical practice.

Regardless of the specific set of values or ethics a service provider adopts, each direct support professional must view the person, for whom they provide support, with respect and dignity, understanding that they are a person first and foremost.

Part 6: Introduction to Interactions and Relationships

8. Value for Accountable practice

- Willingness to take responsibility for ensuring that one's own action is effective.

Reference: Attitude, Knowledge & Skill Requirements for: The

Generalist, Advanced Generalist, the Specialist. Training and Education Workgroup; Dual Diagnosis Implementation Committee of Toronto P. 6 (2003)

Building Rapport

A person receiving support may have a variety of labels used to describe them as a service recipient. These may include:

- Consumer
- Participant
- Client
- Person
- Individual
- Self advocate



The label used depends on the agency and its philosophy of service. This document has used the label “person” as is recommended by the People First Movement, an international self-advocacy group run by and for people who have disabilities to raise awareness of and campaign for their rights.

References: Developmental Disabilities in Ontario 2nd Edition (2003). Ontario Association on Developmental Disabilities Printed in Canada. Brown & Percy (eds)

www.motivationalinterviewing.org

Gilles Brideau - Point from Tay Tool Kit

Building rapport with people can be complex anytime. When a person has a dual diagnosis, the relationship building process can be even more complicated. The person may have complex past history, altered perceptions of reality, a tendency to self-isolate, or other issues with which they are dealing. All of these will impact the person's ability to build and maintain relationships. These situations challenge the direct support professional to find different ways to build relationships with the person.

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However, having knowledge of the following considerations may assist in the relationship-building process:

- The relationship between a direct support professional and a person involves a power imbalance. Power can easily be, and often is, accidentally misused by direct support professionals when this type of relationship is not understood. Direct support professionals must understand that their role is to eliminate power differences; that they are with the person to guide and support, not lead and control.
- Building trust with a person may take a long time but is critical in developing a healthy connection.
- Direct support professionals' duty is to help people feel safe and consistently demonstrate their role as supportive.
- The use of insight and patience is necessary in relationship building; direct support professionals should not expect people to share all of their history and/or thoughts without building a relationship first.
- Direct support professionals should help people understand their role by simply and clearly letting people know what it is.
- Direct support professionals must be clear about what they can do to support a person and what the boundaries are – both for their own awareness and the person's.
- It is necessary to realize that people may wish to make staff "happy" by complying with requests or saying what they believe staff may want to hear.
- For some people, having choices has not been a common experience in their lives. Ensuring people have choices and respecting the choices they make based on their ability to make those informed choices help direct support professionals establish relationships built on trust and respect.
- Direct support professionals can learn as much from the person as they can teach and is important for a healthy relationship. They will share the roles of "teacher" and "learner" throughout their time together.
- All direct support professionals are required to respect the goals people have for their own lives. They must look for the moments that occur, where they can provide support for a person working toward achieving their goals.

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Further Suggestions on How to Build Rapport:

- 1) Find a Common Ground
- 2) Establish support people as generalized reinforcers
 - a. First establishing rapport with an individual you are supporting, keep demands to a minimum. Remember – no one likes to be told what to do by someone they do not know or do not like.
 - b. Use non-contingent reinforcement. Non-contingent reinforcement is the presentation of reinforcement (or good things) not contingent on desired or challenging behaviour.
 - c. Re-establish yourself as a generalized reinforcer. Do not take incidents personally and re-establish yourself as a generalized reinforcer after such incidents occur.
 - d. Pair delivery of tangible reinforcement with social praise.
- 3) Demonstrate Greater Responsivity to Communicative Attempts. With all communicative attempts it is important to acknowledge, assess, and address.
 - *i.e., a staff member Alex says a joke and the individual he is supporting, Joe, laughs. Alex says, "Joe, you're laughing (acknowledgement)! Do you like my joke?" Joe replies, "Yes" with a smile. Alex says another joke (address need/request based on Joe's communicative attempt).*
 - *i.e., Alex is talking to Joe and Joe starts to walk away. Alex says "Joe you're walking away (acknowledgement). I guess we've done enough talking (assessed need/request for a break from talking). Maybe we can talk again later (addressed need for break).*
- 4) Increase Turn-Taking
- 5) Be Respectful
- 6) Provide Choices

Reference: Brooke Myers, MA, BCBA, Community Behaviour Consultant, Regional Support Associates, unpublished paper

McLaughlin, D. M., & Carr, E. G. (2005). Quality of rapport as a setting event for problem behaviour: Assessment and intervention. *Journal of Positive Behaviour Interventions*, 7, 68-91.

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Power Struggles

Direct support professionals, have a critical role in supporting people to make informed choices in life. Many staff view their role as ensuring that the person makes the most informed choice, which can often lead to power struggles.

Power struggles occur when one person has a strong belief that their opinion is right and have a high investment in making sure the other person does what they believe is right. When direct support professionals engage in these types of power struggles, the person that they support most often ends holding the responsibility or blame for the power struggle.

Power and control situations invariably include some kind of threat to punish as they escalate; either by applying a consequence or by removing a positive, as part of the effort by direct support professionals to gain control.

“Recognize that your job isn’t to craft people who have disabilities into your own image. This will lead to frustration and to battles of will and power. You end up with the use of force. Simply recognizing that the only thing that’s important is that people who have disabilities discover their own way in the world, you can let go of a lot of frustration.”

Reference: Hingsburger, David. (2000). Power Tools, Diverse City Press, page 18

If direct support professionals can turn potential power struggles into learning opportunities by providing information and respecting choices, people have an opportunity to learn about the outcomes and how to make informed choices.

“...I don’t think we often think of people who have disabilities as our employers, we think of them as our raw ore, the skills we teach as our product and the behaviours we suppress as quality control. Their need gives us our power. Their vulnerability, our control. Their disability, our reason. ”

David Hingsburger

Reference: Hingsburger, David. (2000). Power Tools, Diverse City Press, page 18

Choices

Helping people understand their choices and learn to make effective ones is one of the most powerful tools that direct support professionals have to build trust and promote positive behaviour change with a person. It is also a teaching/learning opportunity on how to make good choices.

For more information on the importance of choices:

<http://learningcommunity.us/documents/RevisitingChoiceParts1and2.pdf>

[http://www.communitylivingbc.ca/what we do/innovation/pdf/The Role of Informal Community Safeguards.pdf](http://www.communitylivingbc.ca/what_we_do/innovation/pdf/The_Role_of_Informal_Community_Safeguards.pdf)

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Important facts to remember about setting limits:

Choices are about helping people be informed.

For example:

An informed choice:

If you take your diabetes medication your doctor prescribed, it will help you to feel well and you can do all the things you had planned. If you don't take your medication, you will feel tired and sick. Then you won't be able to do all the things you want, like going to the movies this afternoon.

The choice about taking it or not is in the person's hands, but with the information attached about the outcome of each option.

- To assist a person in making informed choices, direct support professionals should make sure that the choices the person have and the consequences (outcomes of those choices) are:
 - presented in a clear way for the person to understand
 - the choices and outcomes are reasonable for the person to obtain
 - the outcomes (consequences) are enforceable – this means both the desirable and undesirable outcomes of the choice a person makes.
- Consistency – direct support professionals must follow-through 100% of the time to provide effective learning opportunities for people.
- Listening is often more effective than talking.

References: www.crisisprevention.com

T.D. Frawley, M.A. Psych - Behaviour Consultant, Regional Support Associates, Unpublished paper

Providing effective support

- Continued education helps direct support professionals keep up to date recent "Best Practices".
- Shaping a setting to reduce outside and inside distractions helps reduce interference with making sure communication is shared effectively.
- Concentrate on the person and take time to explain things clearly and simply.
- Try not to use abstract terms for example, concepts such as time, can be, dates, days of the week can be difficult to understand. Placing activities in sequences of before and after can be useful in helping a person understand. "After you brush your teeth, we will leave for your appointment"
- Allow extra time for the person to listen, to process and to answer questions.
- Common slang should not be used because it may not be understood.
- Sarcasm is disrespectful and inappropriate. Often it is not understood by people because it is an abstract concept. People who have more severe developmental disabilities or neurological challenges are not able to process abstract information as well.

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- Avoid closed questions requiring only 'yes or no' answers. People will often answer questions based on what they believe the staff wants to hear. Open ended questions will provide an opportunity for answers with more information about what a person really wants, thinks or feels.
- Be aware of body language. People often have difficulty interpreting body language and may be confused if the verbal and physical messages are not compatible. According to research completed by Albert Mehrabian 1971; words account for 7% of the overall message,

- How we say what we say accounts for 38% of the overall message, and
- Body language accounts for 55%.

Only 7% of words we use contribute to how we understand communication.

When supporting a person with a challenging behaviour, direct support professionals must also consider the following:

- The safety of the person and the direct support professional is always a priority.
- People must not be defined by their challenges or disabilities – but recognized for their strengths and skills. Direct support professionals must recognize that the behaviour is something the person is doing, not who the person is.
- Respect is earned by direct support professionals. Direct support professionals earn respect by treating people who have respect.
- Direct support professionals must behave respectfully toward and about the people they support.



Effective Teamwork and the Impact on People

- How well the direct support team members work together and communicate with each other. These interactions and relationships directly affect the life experience of the person supported. Inconsistent teams who do not cooperate or communicate well together create difficult environments/conditions for the person.
- Direct support professionals must know a person's history to be able to understand who they are today and the experiences that have helped shape them.
- Direct support professionals must be aware of a person's medical and psychiatric diagnoses and the way they may impact mood and behaviour.
- Behaviour must be carefully observed, documented and reviewed for direct support professionals to effectively help a person make changes.

Since 2007, the Provincial Network on Developmental Services and the Ministry of Community and Social Services have been collaborating on identifying core competencies for direct support professionals.

Competencies identify the standards by which direct support professionals are expected to perform within their roles.

Part 6: Introduction to Interactions and Relationships

Collaboration with Others is the competency identified that relates to team work.

Collaboration is about communicating with others both within one's team as well as with individuals, agencies and organizations outside one's immediate work area or span of control (i.e., with community partners and stakeholders) to create alignment within and across groups. It is not only encouraging but expecting collaborative efforts and information sharing across agency/organizational lines toward shared outcomes.

The areas identified within Collaboration with Others as important for direct support professionals to demonstrate within their roles of supporting people who have developmental disabilities are:

- Collaborates, does own share of work
- Values others and solicits input
- Encourages others
- Works to build team commitment and spirit

Reference: Developmental Services Human Resources Strategy, A Collaborative Initiative Between the Provincial Network on Developmental Services and the Ministry of Community and Social Services

The core competencies project is currently being piloted at 16 developmental services agencies across Ontario. Provincial implementation will follow when the pilot has been evaluated.

A report on the provincial Human Resources Strategy is available through the following link:
[http://www.ontariodevelopmentalservices.ca/sites/default/files/ProgramStandards Committee eReport.pdf](http://www.ontariodevelopmentalservices.ca/sites/default/files/ProgramStandards_CommitteeReport.pdf)

Part 7: Introduction to Health and Medications



In 2009, a study by Dr. Yona Lunskey found that adults with a developmental disability are more likely to use the emergency department than those without a developmental disability. "The concern with this population is that their health needs are being met in the Emergency Department so they use it more frequently. And this is most unfortunate because the Emergency Department visits can end up being stressful for everyone. This indicates the need to improve primary care and social services in the community," says Paul Kurdyak, Adjunct Scientist at ICES and psychiatrist in the ED at CAMH. "People who have a developmental disability have complex health issues, some differing from those of the general population. Adequate primary health care is necessary to identify these issues and to prevent morbidity and premature death."

Reference: Sullivan, W.F., Berg, J.M., Bradley, E., Cheetham, T., Denton, R., Heng, J., Hennen, B., Joyce, D., Kelly, M., Korossy, M., Lunskey, Y. and McMillan, S. (2011). Primary Care of Adults with Developmental Disabilities, Canadian Family Physician (May, p 541).

People who have developmental disabilities have at least the same or increased vulnerability to many health conditions. Health care professionals may not be aware of or understand the increased risk and need for care for people who have disabilities.

Therefore, when a person has a dual diagnosis or suspected dual diagnosis, the first step in effective health supports is ensuring a thorough health screening. This first step supports a functional assessment of behaviour as recommended using a bio-psycho-social approach.

Additionally, many challenging or complex behaviours may be the result of an undiagnosed or untreated medical condition. A thorough health check must be completed to ensure appropriate diagnosis and treatment.

Developmental Disabilities and Health Screening

As noted in Part 4, different developmental disabilities may have different health challenges associated with them. In providing effective support for a person with a developmental disability to obtain optimal health direct support professionals must make themselves aware of any health challenges to which the person may be predisposed, any preventative measures that can be taken, early warning signs and treatment options.

Part 7: Introduction to Health and Medications

In 2006, Surrey Place Centre, an interdisciplinary, community based agency in Toronto, developed a five year project to develop best practice guidelines for primary care medical professionals treating people who have developmental disabilities. This plan is supported by Ontario's Ministry of Community and Social Services and Ministry of Health and Long Term Care and Surrey Place Centre Foundation. Revised guidelines and a companion toolkit to the Primary Care Guidelines were released in 2011.

The toolkit: Tools for the Primary Care of People who have Developmental Disabilities, includes resources for primary care providers, like direct support professionals. The resources include health watch tables for different developmental disabilities. The tables provide information on health issues commonly associated with different developmental disabilities and recommendations for health practitioners for screening and treatment. The health watch tables can also be valuable for direct support professionals to have a better understanding of potential health problems and increased awareness for monitoring.

The health watch tables for different developmental disabilities can be found in the Appendix for the Health and Medications Section.

These include:

- Down Syndrome Health Watch Table
- Fragile X Syndrome Health Watch Table
- Prader-Willi Syndrome Health Watch Table
- Smith-Magenis Syndrome Health Watch Table
- 22q11.2 Deletion Syndrome (DiGeorge Syndrome) Health Watch Table

While many primary care professionals are aware of the Primary Care guidelines and implementing them in their practices, it is still necessary for direct support professionals to be informed about health issues, prevention, and accessing the appropriate health care with people.

How to Prepare for a Doctor's Appointment :

When supporting a person with a doctor's appointment, direct support professionals must prepare in advance to make sure they are covering all important points that need to be reviewed.

When preparing consider the following:

- Current medical conditions and any effects the person experiences
- Any changes in the current conditions
- Review any health watch items associated with the person's disability and possible symptoms they may be experiencing or recommended preventative/diagnostic screenings
- Changes in:
 - behaviour
 - energy level
 - appetite
 - mood
 - sleep patterns
- How long the symptoms/changes have been occurring
- Anything that appears to help the person feel better when symptoms are present

Part 7: Introduction to Health and Medications

- A list of current medications, why they have been prescribed and any noted side effects
- Medical and medication history
- Family history
- Make sure the person brings their Health Card to the appointment.

What NOT to do:

- Forget to do data collection or forget to bring it with you
- Send an unfamiliar direct support professional member with the person
- Don't bring any historical information to the appointment
- Bring information from only one setting
- Don't follow through with recommendations
- Avoid precision – "Joe's not himself", "He seems worse than before", "He's having mood swings"
- Forget to bring lab slips and other investigations.

The appendix (section) contains examples of different types charts to monitor health, including sleepcharts, mood charts, bowel charts, etc. as well as a sample health review checklist

Finding a Family Physician:

Through the Ministry of Health and Long Term Care, there are resources available to assist in finding a family physician. Health Care Connect helps Ontarians who are without a family health care provider (family doctor or nurse practitioner) to find one. People who do not have a family health care provider are referred to a family doctor or a nurse practitioner who is accepting new patients in their community.

For more information

Call: 1-800-445-1822 or link to

<http://www.health.gov.on.ca/en/ms/healthcareconnect/public/>

Medications and Psychiatric Consultation:

Many people who have a dual diagnosis have been prescribed medication for various reasons and are taking medication to address behavioural concerns, psychiatric symptoms or for a medical condition. Many people who have developmental disabilities are taking psychotropic medication for behavioural concerns such as aggression and self-injurious behaviour (SIB). Most have not been informed about the medication and its possible risks and benefits. There is often no evidence for informed consent.

Administering medication is one of the most important duties that direct support professionals carry out in their daily work. It is critical that a person or decision maker has been informed of the reason medication has been prescribed, its possible risks and benefits, and given consent for its use.



Part 7: Introduction to Health and Medications

It is also critical that direct support professionals are knowledgeable about what medications they are supporting people to take. Having knowledge about medications will help direct support professionals to have the confidence they need to ensure the person is safe when taking a medication. Having knowledge of medications will also assist with helping the individuals that are supported to better understand their medications and the reasons for their use. The following section provides an overview of the use of psychotropic medications commonly prescribed for people who have a dual diagnosis.

How to Prepare for a Psychiatric Consultation:

When a person is scheduled for a psychiatric consultation, some key elements to prepare for the visit are important for helpful interaction and assessment.



Canadian Association
Psychiatric des psychiatres
Association du Canada

Psychiatric Consultation Checklist:

- If possible, forward any information that can be sent in advance of the appointment
- Past reports (the last psychiatric consult notes)
- Past diagnosis and assessments (last assessment report from a specialized service provider and/or psychologist)
- Important history such as developmental milestones and family history
- Important changes in characteristic behaviour such as mood, sleep and appetite
- Main reason for the referral
- Present and past medication – for medications that have been discontinued, provide date of discontinue and reason
- Medical history including allergies, past surgeries, medical problems, weight changes, cognition changes, hearing and vision assessments, dental screening, sleep and appetite history
- Copies of most recent blood work if possible
- Family doctor's name, office number and mailing address

During the consultation it is recommended that you write notes on:

- Recommended treatment
- Risks of treatment
- Possible side effects
- Length of treatment, re-assessment
- What data needs to be gathered or checklists need to be completed?
- Remember to ask questions such as, "How will the medication help the target symptom?", "What is the proposed treatment supposed to do?" "What are the side effects?" and "Are there diet restrictions?"
- Make sure you request information regarding the visit is sent to the family doctor.

Part 7: Introduction to Health and Medications

It may take a few visits for the psychiatrist to understand the history and to establish shared trust. Confirm the history with different family/direct support professionals involved in the life of the person. Detailed research may be necessary to present an inclusive but concise picture of the person you support.

Common misconceptions about psychiatric consultations:

- An accurate diagnosis will be made at the first visit
- Psychiatrist know everything and should be able to cure the behaviour
- Everything has been tried and the psychiatrist is the last resource
- Psychotropic medication should cure the person
- On-going conversation between the person and the psychiatrist happens naturally
- The amount of time the psychiatrist has to spend with the person is unlimited
- Psychiatrists are counsellors

The Facts:

- Psychiatrists need to work together with and have conversations with the person and the direct support professional to develop a picture of the complaint.
- The expectation that a psychiatrist will quickly understand complex situations and provide solutions is unrealistic.
- Information direct support professionals can provide in a referral regarding past treatment, specific diagnosis, sleep patterns, aggressive or passive behaviour, current medication and, living situation will assist the psychiatrist with developing a better understanding of why the person has been referred.
- Any other information that direct support professionals feel needs to be included can be added like an Antecedent Behaviour Consequence (ABC) chart(s), complete history from the past to present data and, any recent laboratory results is helping to have prepared prior to the appointment.

Psychotropic Medication:

Psychotropic medication is any medication capable of affecting the mind, emotions, and behaviours.

When assessing people who have a developmentally disability for mental illness, it is important to use a biopsychosocial perspective, i.e. are there health issues or environmental issues that are the root causes of the challenges the person is having?

Medical illnesses that can have symptoms similar to those of psychiatric disorders must be ruled out. Conditions such as bladder infection, GERD, headache, dental pain or constipation may cause people to present with behaviours which might be mistaken for psychiatric symptoms.

Similarly, consideration must be given to any triggers in a person's environment resulting in responses that may also appear psychiatric in nature. For example, a person who has autism may have difficulty with scents or lighting in environments, causing anxiety or acting out response. Medical, psychological, and social factors must be considered when completing a psychiatric assessment.



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Psychotropic medication can be classified in categories which include:

- Anti-depressants - used to treat depression, anxiety
- Anti-psychotics – treating hallucinations, uninhibited behaviour, loss of connection with reality
- Anti-anxiety medications – treating anxiety, obsessive compulsive disorder, panic
- Sedatives - hypnotics treating unsettled sleep patterns, general nervousness, irritability
- Mood stabilizers - to treat mood disorders or behavioural issues
- Stimulants - often prescribed to treat ADD or ADHD. The way in which stimulants work in the brain can be effective in creating a calming effect for people who have ADD or ADHD.
- Other medications that are traditionally used for other reasons

Side Effects:

Remember any medication can have side effects – both desired effects and adverse effects for a person.

For example:

- A side effect of a seizure medication can help some people who have mood disorders feel better and calmer.
- A side effect of a low dose aspirin can help keep the blood thin to help prevent heart attacks.
- A side effect of an anti-psychotic could be a tremor in a hand significant enough to make holding a cup very challenging.
- Many medications have the side effect of sensitivity to sun light causing severe sunburn if a person is in the sun for longer than five minutes.
- The use of anti psychotics in this population is associated with greater risk of developing movement disorders such as tardive dyskinesia, akathisia, dystonia, and metabolic disorders.

Tardive Dyskinesia: involuntary repetitive movements of the facial muscles and the tongue, usually resembling continued chewing motions, and involuntary movements of the muscles of the limbs. This is associated with long-term use of medication like such as antipsychotics.

Akathisia: is a pattern of involuntary movements induced by anti psychotic drugs. An affected person is driven to restless over activity that can be confused with agitation for which the drug was originally prescribed.

Dystonia: neurological movement disorder, in which sustained muscle contractions cause twisting and repetitive movements or abnormal postures.

Metabolic Disorders: occurs when abnormal chemical reactions disturb the body's normal metabolic processes.

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Every person is different and has different responses to medication. Some people can take a medication and not have a side effect, while others have severe side effects to the same medication.

Side effects can be described as problems that occur when treatment goes beyond the desired effect or problems that occur in addition to the desired therapeutic effect.

To effectively monitor the side effects of medication, direct support professionals should:

- Be aware of the effect of medication being used or other forms of treatment
- Explore the side effects and use medication review sheets
- Make a follow up appointment with a psychiatrist
- Have the psychiatrist prescribe treatment for the side effects of medication. Side effects can be hard to assess because some people can't describe how they are feeling with the medication in their system.
- Ensure regular check-ups to monitor complications caused by the extended use of medication (e.g. constipation)
- Track symptoms and signs associated with the side effects of any medication. Document any observations you make. Sample of side-effect check lists is provided in the appendix.

The appendix contains several medical check lists, including a medication review form and a side effects monitor scale.

Why is medication being prescribed?

The most common reason for a request for psychiatric assessment is aggression or self injury, but aggression or self-injury are often the outward symptoms of common mental health needs, a physical cause, or change in surroundings. Anti-depressants were developed to treat depression, but they also help people who have anxiety disorders.

Reference: Mental Health Services for People who have Developmental Disability: Planning Guidelines for Health Authorities in BC (2004). <http://www.health.gov.bc.ca/mhd/publications.html#Developmental> (accessed Oct 31, 2011)

Questions to ask the Psychiatrist if medication is prescribed:

- What are the names of the medication? (both the generic name and the brand name)
- What is the medication supposed to do?
- How and when should it be taken?
- What is the dosage?
- How will it interact with other medication(s) that the person is taking?
- Should any types of food or drink be avoided while taking this medication?
- Should the medication be taken with food?
- What are the side effects that may be seen?
- What should be done if a person is experiencing side effects? (direction about when a doctor should be contacted)
- When should a follow up appointment be scheduled?



Reference: National Institute of Mental Health (2009) P. 16 & 17

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New medications are always being created and marketed while some older medications are no longer approved for use. The following Health Canada site advises of health advisories, warnings and recalls related to medications and health products:

<http://www.hc-sc.gc.ca/dhp-mps/medeff/advisories-avis/index-eng.php>

Reference: Health Canada Health Advisory: <http://www.hc-sc.gc.ca/dhp-mps/medeff/advisories-avis/index-eng.php>
(accessed Oct 31, 2011)

This website can be used to check for medication that is taken off the market or when warnings are given. Most pharmacists will be aware when a medication is going to be discontinued for sale and use can be used as a resource to family doctors to recommend a different medication.

Please see appendix for more information.

Overuse and Misuse of Psychotropic Medications:

There has often been a tendency to over-medicate the dually diagnosed population because there was not a lot of information available regarding diagnosis or treatment. The opinion existed that if the medication is increased then the person will settle. There are many times when this is not the case. There may be some situations where the medication is responsible for unwanted behaviour.

Other reasons for overuse/misuse may include:

- The frequent presence of aggression and self-injury
- Lack of understanding of the function of the behaviour
- Hesitancy to withdraw someone from an anti-psychotic medication after they have been on it for many years. This process must be done very slowly to minimize possible serious withdrawal effects such as agitation, insomnia, confusion or, aggression.

PRN Medication:

PRN is an abbreviation of the Latin term "Pro Re Nata" which means as the circumstances arise.

PRN medication is therefore not given on a scheduled basis, but only when the need arises based on what the PRN medication is intended to address. For example, Tylenol could be a prescribed PRN for a headache so it is only taken when a person has a headache.

Direct support professionals, in consultation with the prescribing physician, are responsible to support and assist a person to communicate and record a protocol for the use of PRN medication.

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Medication Administration and Rights:

When administering any medication for a person, direct support professionals must ensure that they are that they have been attentive to the “rights” of medication administration.

These are:

- the right patient
- the right drug
- the right dose
- the right route
- the right time
- the right to know information about the drug
- the right to refuse the drug
- the right documentation

Reference: <http://www.nurses-neighborhood.com/5-rights.html> (accessed Oct 31, 2011)

Recommendations for Writing a PRN Protocol:

A **PRN protocol** is needed as a guideline when PRN orders are given because, unlike medications that are ordered on a regular daily basis, the person and direct support professionals have to make a decision about whether or not a PRN medication is needed.

PRN medication can be prescribed for a number of different reasons.

For medical issues like:

- pain
- insomnia or difficulty sleeping
- gastrointestinal issues like diarrhoea or vomiting
- constipation

PRN medication is also often prescribed for people who have a dual diagnosis to address psychiatric symptoms or a behaviour that is out of control.

These issues may include:

- severe self-injury
- episodes of extreme anxiety
- mood instability
- psychosis (loss of contact with reality and/or in contact with reality but experiencing hallucinations)

1. When writing a protocol for PRN administration for any type medication that is to address a behavioural or psychiatric symptom, direct support professionals must first understand clearly what the symptom is that the PRN is attempting to target. If a person is prescribed a medication, direct support professionals must ask the psychiatrist or doctor what they are prescribing the medication for and under what circumstances it is given e.g. for anxiety, for insomnia, etc. This reason must be clearly written in the PRN protocol.

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2. A PRN protocol must describe what the person says, looks like and behaviours they typically show when they are experiencing this problem. For example, "When Jane is anxious, she will repeat questions about when she will be visiting her parents. Her face will look flushed and will appear to be moving more quickly than usual. She will pace back and forth in front of the window." Describe in as much detail as possible what the situation really looks like. This helps everyone have a clear understanding of what signs to look for when a person is having difficulty.
3. The next step in the PRN protocol is making sure there are clear, consistent responses for direct support professionals to use to engage the person in conversation or activity that may be successful in preventing or redirecting a crisis situation. A series of non-intrusive preventative approaches should be in place. With a consistent approach and problem-solving, the person may learn more successful ways to problem solve for themselves and/or deal with issues without the use of PRN medication. If there is a clear behavioural support plan, the PRN protocol should be incorporated into this plan.

PRN medication is typically the last step in this process when the preventative approaches have been used but were unsuccessful.

4. After the preventative steps have been taken, the PRN protocol should describe how to administer the PRN medication as per the physician/psychiatrist orders.
5. PRN protocol should include a list of signs to look for to determine if the PRN is working for the person.
6. PRN protocol should also include a list of signs to look for to determine if the PRN is not working for the person or the person has a negative reaction or side effects from the medication and the next steps to follow e.g. a second administration if ordered by doctor/psychiatrist, seek immediate medical attention, etc.
7. The protocol must include what information or data is being collected for review at the next doctor/psychiatrist appointment; how and where to record this information.
8. The protocol should also include clear time frames for review for both the medication and the protocol, including dates and the person responsible to ensure the review happens.

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Key points to remember:

- Decisions around what signs to look for before giving PRN medication should be discussed and decided at team meetings. This allows for understanding and input to be given by all direct support professionals supporting the person. All direct support professionals must follow the established protocols for them to be successful.
- Discussions around events and their significance can help to identify patterns in behaviours, which are helpful in identifying the purpose or function of behaviour.
- Regularly review the current behavioural interventions in use for the person and determine any changes that need to take place for success.
- Remember that most PRN medication is prescribed including time intervals for a second or third administration if needed, such as a three or four hour interval between doses. This means a repeat can be given after that interval has passed, but only if needed.
- All direct support professionals must follow the protocol as written. Many people view the administration of PRN medication as harmful to the person or a punishment for “negative” behaviour and therefore wait to administer until it is too late for the medication to be helpful to the person. The doctor/psychiatrist gives direct support professionals the instructions for when to administer based on when it will be most helpful for the person. PRN medication is NOT meant to be harmful to the person nor a punishment. Its administration has been reviewed by the doctor/psychiatrist and the risk of administration has been weighed against the risk of doing nothing. PRN medication is intended to help a person settle who is not able to settle on their own.

*“Where there are
pills, there should
be a plan.”*

Al Fewster, R.N.

Part 8: Challenging Behaviour

Introduction to Challenging Behaviour and Support Strategies

Everything a person does that is observable is considered behaviour. Behaviour occurs for a reason and serves a purpose or has a function for all of us.

People are complex beings.

As an extension of this, behaviour can be quite complex and can have many layers to examine when attempting to understand why people behave the way they do.

Challenging Behaviour

“Challenging behaviour” is a term used to describe behaviour that interferes with a person’s daily life. It does not describe a person or define them. It describes the behaviour itself. Terminology and language are critical when supporting people who have challenging behaviours and developing relationships based on respect and understanding. For example, a person should not be called or referred to as behavioural. A person may be said to have a challenging behaviour.

Some common examples of challenging behaviour are:

- Aggression – physical or verbal
- Self-injurious behaviour
- Property destruction
- Behaviour that appears oppositional – e.g. appearing to refuse to do something that may be in their own best interest, like taking needed medication, complete basic personal hygiene
- Socially inappropriate behaviour – e.g. as extreme friendliness with strangers
- Withdrawal
- Impulse control problems

Functional Assessment of Behaviour

The success of a behavioural support strategy is dependent on understanding why a person responds in a certain way and teaching a more suitable way to get the same need met. The process of understanding why a person behaves the way they do is called functional assessment of behaviour.

One of the first steps in completing a functional assessment of behaviour is developing a hypothesis or theory about the function of the behaviour.

Once the hypothesis is developed, information that will help inform a behavioural support strategy is collected over time (generally the period of time depends on the frequency and intensity of the behaviour).

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The information gathered for the functional assessment generally includes but is not limited to:

- What health or medical factors may be influencing the behaviour of the person?
- Are there unmet sensory needs or a Sensory Integration Disorder (SID) present influencing the behaviour of the person?
- What is the effect, if any, of the physical environment? Is it noisy, crowded, over-stimulating, under-stimulating, too bright, too cold, too warm, etc.?
- What events occurred before the behaviour? (antecedents or setting events)
- What happens after the behaviour? (consequences)
- Where does the behaviour occur most often? Least often?
- What support strategies have been used before – what had an impact on the behaviour and what didn't?
- What communication skills does the person have?

A functional assessment of behaviour helps identify the possible reason(s) behind behaviour so that it may be shaped or a new skill taught in its place. The new behaviour or skill can then meet the same function without the interference in the person's daily life that the challenging behaviour had.

There are many different types of functional assessment checklists that gather different information depending on the hypothesis about the function of the behaviour.

The appendix contains several examples of checklists that can be useful in completing a functional assessment. Checklists can be useful in prompting direct support professionals to observe and record different details related to behaviour. Interpretation of the information gathered should be done with the support of a clinician.

The Bio-Psycho-Social Approach to Understanding the Function of Behaviour



Another way to understand the function of challenging behaviour is from a bio-psycho-social perspective. The bio-psycho-social model stresses an integrated approach to challenging behaviour. The challenging behaviour can be seen as a symptom of other conditions. Assessment of behaviour involves focus on the following factors:

- Bio (medical): pain, medical (illness), medication reactions, syndromes, neurological factors. Biological (medical) conditions that may be causing or contributing to the behaviour are examined first and any potential causes addressed, psychiatric diagnosis.
- Psycho (logical): personality, temperament and environmental experiences, skills, learning styles as identified in a psychometric/psychological assessment.

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- **Social:** environmental, interpersonal, program-related, physical. The person's current living, working and leisure environments are examined. Are there people in the environment that have an impact on the person? Is there enough activity or too much activity for their well-being? Is the noise level high? Is there an absence of natural light where they spend most of the day? Is there a consistent routine and structure in place? Is communication clear and concrete?

The model emphasizes that each of these conditions affects and is affected by each other. Approaching behaviour from the three perspectives allows us to understand what is contributing to the behaviour so that appropriate interventions can take place. Reduction or elimination of the challenging behaviour is not the goal of the intervention process. Identification of the various conditions that contribute to the behaviour and addressing these represent the focus of the approach.

Reference: Behavioural Supports: Individual Centred Interventions. A multi-modal Functional Approach, 1999).
Transitional Aged Youth

Dual Diagnosis: An Introduction to the mental health needs of persons with developmental disabilities – the biopsychosocial approach to challenging behaviour – Griffiths and Gardner

Common Functions of Challenging Behaviours

There are many functions of different behaviours – both behaviour that others perceive as “positive”, and behaviour others perceive as “negative”. One observable behaviour can also have many different functions for a person.

Some of the common functions of challenging behaviour are:

- The expression of a medical or psychiatric illness
- To get attention, a reaction or interaction with another person
- To get a desirable item or get access to a favourite activity
- For sensory stimulation – such as touching things, smelling or tasting things, avoiding unpleasant sensory input
- To escape/avoid unwanted attention
- To escape/avoid a non-preferred task or activity
- To express emotions
- Frustration with communication
- Etc.



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The ABC's of Behaviour

Direct observation of behaviour informs the functional behaviour assessment. A key component of this is ABC (Antecedent, Behaviour, Consequence) observation and charting.

- **The Antecedent:** What happened before the behaviour? Where was the person? Who was around? What was happening? What interactions were occurring? What happened that might have prompted the start of the behaviour? The antecedent is the phase of behaviour where staff have the most control over the outcome of the event. This is referred to as antecedent management.

For example: Direct support professionals make a request of the person to assist with completing his laundry since he has few clean clothes left.

- **The Behaviour:** The description of the behaviour in as much detail as possible. Direct support professionals have no control over this phase of the event. The person is in control of their own behaviour.

For example: Following the request above, the person throws the laundry basket across the room and runs out of the area.

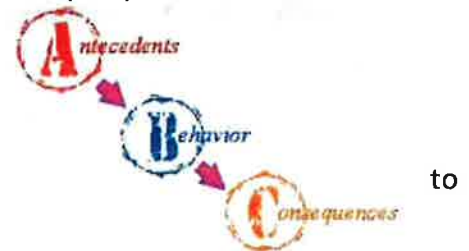
- **The Consequence:** What occurred as a result of the behaviour? Are there potential short-term/long-term outcomes of the behaviour? What was the end result? What did the person gain? What was the reinforcement for the behaviour? Direct support professionals affect this phase through imposing consequence to alter behaviour. Introducing different outcomes for consequences alter the behaviour in future. This is referred to as consequence management.

For example: the person has avoided the task and sits quietly in his room while staff completes the laundry.

Antecedent and consequence management are effective ways of creating conditions in which adaptive behaviour is more likely to be used and maladaptive less likely.

When reviewing the ABC data on behaviour, sometimes the function of the behaviour may appear clear. In the example, it appears that the function of the behaviour was avoidance of an unpleasant task. However, assumptions about the function of behaviour should be avoided until there is opportunity to review all information and the situation from different perspectives.

In this example, the assumption is acting out to avoid doing laundry. This could be the simple function of the behaviour. However, direct support professionals still need to determine why the person is avoiding doing the laundry. Are they allergic the soap and their skin itches when their clothes are newly cleaned? Do they have difficulty with the sounds of the washer and dryer or the lights in the laundry room?



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The ABC theory of behavioural intervention involves teaching a person effective adaptive behaviour through antecedent and consequence management.

Setting Events

Setting events are events that would possibly increase the likelihood of challenging behaviour. Setting events can also increase the likelihood of desired behaviour. Different setting events are often looked for to explain why a person, who would usually be expected to behave in a predictable way, changes their response. The change could be explained by considering what has recently occurred in their life.

For example:

A person who loves going out to eat but is sensitive to crowds and loud noises; having dinner in a busy restaurant. If the restaurant is not usually loud but there is a party there that night, the noise and crowd would increase the likelihood of the person experiencing anxiety and they would have difficulty staying in the restaurant. In this example, setting events are the noise and the number of people in the restaurant. Both of these events have increased the likelihood of the person having to leave the restaurant.

There are three types of setting events:

1. Physical state – illness, medication effects, thirst, etc.
2. Social state – interaction issues, responses to events
3. Environmental conditions – noise, activity, large groups of people in small spaces

Setting events checklists can be helpful in identifying any situation or event that contributed to the behaviour occurring. Examples of setting events checklists can be located in the appendix.

The strengths of creating a setting events checklist include:

- Comparison of checklists to direct observations of how often a behaviour occurs gives a picture of what is happening when the behaviour occurs
- They show events that may determine if the behaviour will occur or not
- Helps direct support professionals to shape the environment to better meet the person's needs
- Encourages collaboration among all support systems involved in the person's life

Differential Reinforcement

Reinforcement is a consequence that increases the chance of the target behaviour occurring again. **Punishment** is a consequence that decreases the chance that a target behaviour will be made again.

Rewards meant to strengthen a behaviour but do not, are not reinforcement. They are a form of indulgence.

Continued use of aversive treatments that are meant to weaken a behaviour but do not are not punishment and may/should be considered abusive.

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Reinforcement is used for eliminating unwanted behaviour by reinforcing its absence or reinforcing appropriate/incompatible replacement behaviours. Anything that increases the frequency of the behaviour that it is paired with is a reinforcer. It is important to emphasize that **anything** can be a reinforcer. It depends on the person and their responses.

Reinforcement and reward are often confused with each other. The **reinforcement** process involves giving a positive after the behaviour occurs and not in a contractual way. A reward is something given in exchange for “good” behaviour and offered as an incentive before the behaviour occurs.

All behaviours continue or are learned only because they are reinforced. Reinforcement is one of the most effective techniques available to assist in addressing challenging behaviour and helping the person to learn new, more effective behaviours. This teaching process is called Differential Reinforcement.

Differential reinforcement means that reinforcement is provided for behaviours when these behaviours occur at certain times and places, whereas reinforcement is not provided when the behaviours do not occur during other times and places.

Behaviour can be shaped by:

- Providing reinforcement contingent upon either the occurrence of a behaviour other than the problem behaviour
- Withholding reinforcement for problem behaviour

There are two processes for reinforcement, positive and negative:

- **Positive Reinforcement:**

Involves the addition of something after a behaviour occurs that increases the likelihood of it occurring in the future.

Example: Having some 1:1 time with a direct support professional after completing a task as independently as possible.

- **Negative Reinforcement:**

Involves the removal of something after a behaviour that increases the likelihood of it occurring in the future.

Example: Turning off a really bright light to help get rid of a headache. By removing the headache, turning off the light has been negatively reinforced.

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- **Punishment:**

Anything that decreases the frequency of the behaviour that it is paired with is a punisher. The intended outcome of the punishment is to decrease a behaviour. Punishment is an aversive treatment and not used without the specific consultation, review and approval of a qualified specialist. When used by direct support professionals without specific, written approval, protocol, and conscientious review, it is abuse.

The outcome or effect on the behaviour is what differentiates reinforcement and punishment. The intention of reinforcement is to increase a desired or appropriate behaviour. The intention of punishment is to reduce an undesired or inappropriate behaviour. For more information on how to implement differential reinforcement, see Appendix.

Reference: T.D. Frawley, M.A. Psych – Behaviour Consultant, Regional Support Associates, Nov 2011, unpublished paper
http://wps.prenhall.com/chet_cooper_appliedbeh_2/73/18707/4789152.cw/index.html (chapter summary accessed Oct 31, 2011) <http://oxforddictionaries.com/page/oxfordenglishdictionary/> (accessed Oct 31, 2011)

Guidelines for Using Reinforcement

- Establish appropriate criteria for reinforcement
- Choose the appropriate reinforcers
- Used generalized conditioned reinforcers
- Reinforce appropriate behaviour immediately
- Reinforce often
- Use reinforcement across settings, behaviours and time
- Use cues to prompt behaviour and create the opportunity

**** Please note: Punishment and all forms of reinforcement, with the exception of immediate reinforcement, are typically ineffective with individuals with neurological damage such as Fetal Alcohol Spectrum Disorder (FASD). Intervention must focus on the modification of external supports for positive change. This includes: increased environmental modifications for support (i.e.: softened colours, less clutter/organized, labelled environment, attention to sounds and smells), modified communication approaches (i.e.: use of concrete language, reduction of verbal interaction and increased visual aids and prompts), the provision of structure/routine and an assessment and support for Sensory Integration Disorders (SID).**

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The Importance of Data Collection

The importance of data collection, at first glance, may not be as obvious as the importance of interactive supports directly with the person. But for a person who is exhibiting challenging behaviour, data collection is a crucial process to provide objective evaluation and observation regarding the challenging behaviour that will inform the development of support strategies. It will also increase the effectiveness of evaluating the support strategies.

Data is used as the starting point for the development of any person-centered support plan. Appropriate assessment at the start of the planning process provides baseline data from which all future progress can be measured.

A common form of data collection is based on the ABC's of Behaviour.

Data is collected on the following:

- **Antecedent:** What happened directly before the behaviour occurred? What was going on in the environment?
- **Behaviour:** What are the details of the behaviour itself? Did the person hit someone? How often? Where? Etc.
- **Consequence:** What was the consequence of the behaviour? Did the person get injured and attention for injury (medical)? Did they break a favoured item? What was the staff response to the behaviour? Etc.

ABC charting can help set the stage for a clear picture of what is happening. It can help identify what may be contributing to the occurrence of the challenging behaviour and any conditions that may be reinforcing its continuation.

While there are many different processes for data collected and different types of data collected, information is often gathered about the behaviour itself based on the following descriptions of the targeted behaviour:

- **Topography:** A description of the behaviour – an operational definition which gives an outline for data to be collected. What does the behaviour look like? What is the person doing?
- **Frequency:** How often the behaviour happens
- **Latency:** How long after an event does the behaviour happen? (i.e. after supper, after getting up, after being denied something)
- **Duration:** How long does the behaviour last?
- **Intensity:** How severe was the behaviour?

Examining the details of the behaviour may also help in determining the function of the behaviour and an appropriate support plan.

Data informs sound clinical practice. By reviewing data collected regarding defined target behaviour, direct support professionals and clinicians can more effectively determine if a support strategy is working to help the person in the way in which it was intended.

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Data provides objective information regarding support needs and validates the experience and observation of direct support professionals. It gives concrete credibility to what direct support professionals report to managers, clinicians, doctors, psychiatrists, etc. It also helps direct support professionals know when what they are doing is working, to the extent that the data is accurate, complete and objective.

Reference: <http://news.developingmindssoftware.com/?p=243> (accessed Oct 31, 2011)

Positive Systems Approach

The Positive Systems approach was developed in the 1980's and has been strongly recommended for use to promote positive ways of supporting people who have challenging behaviours. It is a philosophy of support for direct support professionals and organizations as they provide respectful support for people.

Some of the cornerstones of Positive Systems Approaches are:

1. Identification of all factors that might cause a behaviour
2. Investigation of the amount of unconditional (non-contingent) positive reinforcement available to the person and finding ways to increase it
3. Finding ways to re-direct the person in positive ways at the earliest possible point.
4. Supporting the person to learn new skills to deal with many of the causes of behaviour – dealing with stress, anxiety, frustration
5. Determining the cause or function of the behaviour and what the person is trying to communicate
6. Developing strong relationships with issues of power imbalances addressed and an understanding of equality
7. Supporting the person to have a fulfilled life experience with activities and goals meeting their interests and needs
8. Person-centred supports developed based on the person's individual needs and interests.

Reference: Positive Systems Approach, Workshop, Regional Support Associates, Woodstock, Ontario; <http://www.regionalsupport.on.ca/rsa/index.php/resources> (accessed Oct 31, 2011)

Prevention

The most effective intervention staff can use in dealing with challenging behaviour is in the area of prevention. By addressing environmental, biological, psychological and social causes of behaviour, staff may be able to assist the person to cope, maintain control of their own behaviour, and learn positive, productive ways that address the the function of the behaviour. Antecedent management is the most significant component of behaviour over which staff can have direct input/control and can have a critical impact on preventing a challenging behaviour from occurring.

Effective prevention techniques are taught in many non-violent crisis intervention classes. Some of the considerations staff should be aware of when supporting people who have a dual diagnosis are:

- Maintaining an appropriate activity/interest level for the person's needs
- Respecting personal space – of the person and themselves

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- Appropriate tone of voice for the situation
- Clear and neutral body language
- Having knowledge of internal triggers related to past history, health, psychiatric conditions a person may experience, effects of medications, etc.
- Being aware of external environmental triggers – room temperature, noises, people, disorganization if they need things done in a certain way, disappointments, etc.
- Helping the person develop positive relationships and making sure staff build them as well
- Reducing the stress around transitions
- Redirection to a different activity or conversation

There is an extensive list of prevention techniques and specific interventions that can be effective for a person. Once a direct support professional and team have built relationships with a person and had the opportunity to get to know them, they can work with them to develop a list of strategies that can effectively help the person cope and maintain control over their own behaviour.

Challenging behaviour can be the most effective way a person knows to be able to meet their needs and may seem entirely reasonable from the person's perspective. Therefore an important focus for service providers and direct support professionals is trying to determine what is the **function** of the behaviour to assist the person to learn a more positive and effective ways to meet the same purpose.

Direct support professionals can also have an influence on prevention through consequence management. When the reinforcement for inappropriate behaviour is removed and reinforcement for appropriate behaviour is introduced, direct support professionals help people learn more effective ways to have their needs met in future.

Teaching Skills and Shaping Behaviour

The inventory of skills or behaviours a person has learned and is able to access is often quite limited. There are varied reasons for this but among them is the nature of cognitive development. Skill development and traditional learning is often provided at a more complex level than is effective for the person's ability. It is the responsibility of direct support professionals to identify the need for new skills and teach them to help the person shape a new behaviour. Moreover, some skills may already be within the persons repertoire but not applied to the right situation.

Behaviours and skills that people have are often long-standing. They have been learned and worked to help people cope with unpleasant situations or meet their needs. They have been maintained because they worked effectively for the person. There has generally been no need or opportunity for the person to acquire new skills or change their behaviour because what they were doing has met their needs.

The function of the behaviour direct support professionals attempt to shape will always exist. It is staff's responsibility to teach new skills or new, more appropriate ways of behaving that still serve the function and are more effective (at least as effective) at getting the need met.

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Direct support professionals can do this through teaching new skills, new ways of thinking, evaluating and new ways of behaving in small steps, reinforcing success along the way. Staff can also assist people to learn new ways of behaving through the effective use of setting limits/informed choices.

It is important to consider that behaviour change can be difficult, particularly if it is long standing. Patience and empathy are essential.

Concepts on Impulse Control and Self-Injurious Behaviour (SIB)

Problems with impulse control can be defined as *“the failure to resist an impulsive act or behaviour that may be harmful to self or others”*. By definition, impulsive behaviour is not premeditated nor is it considered in advance of acting. A person has little or no control over the impulsive behaviour, therefore does not predict the consequences or outcome of the behaviour.

Impulse control problems are often the result of frontal lobe damage, which causes problems with executive functioning. The term executive function describes a set of cognitive abilities that control and regulate other abilities and behaviours. Executive functions are necessary for goal-oriented behaviour. They include the ability to initiate and stop actions, to monitor and change behaviour as needed, and to plan future behaviour when faced with novel tasks and situations. Executive functions allow us to anticipate outcomes and adapt to changing situations. The ability to form concepts and think abstractly are often considered components of executive function.

Basically, this means that for people who have impairments in executive functioning and impulse control problems, there is no stop sign between impulse and action. There is no process to consider consequences of behaviour. Therefore, very little behaviour is pre-planned or the consequence thought through in advance.

Impulse control difficulties represent a major feature of a number of behavioural and mental health disorders in people who have developmental disabilities. The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) includes Impulse Control Disorders as a specific group of psychiatric disorders. They can occur frequently in people who have a developmental disability and may be inherent to the specific diagnosis (syndrome driven). The DSM IV lists the following as included under impulse control disorders:

- Trichotillomania
- Intermittent Explosive Disorder
- Pathological Gambling
- Kleptomania
- Pyromania
- Not Otherwise Specified
- The uncontrollable plucking of one's own hair
- Involves inability to control violent impulses
- Inability to resist impulses to gamble
- Inability to resist the impulse to steal
- Inability to resist the impulsive desire to set fires
- Residual category for those impulse control disorders that do not fulfill either the criteria for the specific disorders (i.e. repetitive self-mutilation, impulsive sexual disorders, compulsive shopping, etc).

Part 8: Challenging Behaviour

Impulse control disorders also include more commonly known disorders such as Tourette Syndrome and Obsessive Compulsive Disorder.

Treatment of impulse control problems is often complex. The most important point for direct support professionals to understand is that the person has little or no control over the impulsive behaviour.

References: NADD <http://www.thenadd.org/cgi-bin/checkmember.pl?page=pages/membership/bulletins/v8n3a1> (accessed Oct 31, 2011)

<http://www.forensicpsychiatry.ca/impulse/overview.htm> (accessed Oct 31, 2011)

<http://www.minddisorders.com/del-fi/executive-function.html#ixzz1IbX1kbD> (accessed Oct 31, 2011)

Self-Injurious Behaviour

Self-injurious behaviour was defined by Murphy and Wilson (1985), p. 15 as:

“Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm (includes) bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage”.

The most common forms of self-injurious behaviours are:

- Head-banging
- Skin-picking
- Self-biting
- Self-scratching and excessive self-rubbing

Some individual characteristics seem to be associated with an increased risk of having self-injurious behaviour:

- Sensory deficits
- Poor expressive language
- Autism
- Severe or profound disabilities
- Poor mobility
- Specific syndromes, such as Lesch-Nyhan syndrome, Smith-Magenis syndrome, Prader-Willi syndrome, Tourette’s syndrome, Cornelia De Lange syndrome, Borderline Personality Disorder

Self-injurious behaviour (SIB) is quite complex and can serve many different functions for a person. The causes of SIB include behavioural, psychiatric and medical concerns. There are many reasons why a person may engage in self-injurious behaviour and a functional assessment should always be completed (investigation to determine the function of the behaviour). A functional assessment should include:

- Who was present?
- What happened before, during and after the behaviour?
- When did it happen?
- Where did it happen?

Part 8: Challenging Behaviour

Some of the reasons people engage in self-injurious behaviour are:

- | | |
|--|--|
| • Biochemical | Some research suggests certain levels of neurotransmitters are associated with SIB |
| • Seizures | SIB can be associated with seizures in the frontal and temporal lobes. This behaviour is voluntary |
| • Genetic | SIB is a common behavioural phenotype of several genetic disorders (e.g. Fragile X, Prader-Willi, Cornelia de Lange, Smith Magenis) |
| • Arousal | Under and over-arousal can lead to SIB in some people |
| • Pain | To reduce pain such as from a middle ear infection, migraine headache, gastro-intestinal problems |
| • Sensory | Some forms of SIB may be a form of sensory stimulation in people who may not be able to perceive “normal” levels of physical stimulation |
| • Frustration | Such as with communication challenges |
| • Social attention | |
| • To obtain objects | |
| • Avoidance/escape | |
| • A response to coping with a traumatic event. | |

Regardless of the psychological/behavioural antecedents of SIB, medical, psychiatric and neurological problems must be examined as potential causes.

Best efforts should be made to not inadvertently reinforce the behaviour by attending to (or drawing attention to) the behaviour. Direct support professionals should put efforts into paying attention to the person.

Self-injurious behaviour can range from mild to severe in intensity. Direct support professionals should consult a clinician to develop support strategies when they observe that a person is engaging in self-injury.

References: <http://www.thecbf.org.uk/pdf/self-injurious.pdf>

Rene Fucilla Ristic (2005). Self-injurious Behaviour in People who have Developmental Disabilities, Journal of Safe Management, (Sept). <http://www.ddmed.org/pdfs/7.pdf> (accessed Oct 31, 2011)

Part 8: Challenging Behaviour

Suicidal Ideation

While people who have a dual diagnosis are at greater risk of experiencing mental health issues than the general population, suicidal ideation and gestures have been underreported and few studies have been conducted to identify the risk factors.

However, several conditions/circumstances are known to heighten the potential for the development of suicidal ideation. These include:

- Anxiety disorders
- Mood disorders
- Certain types of psychosis
- Oppositional defiant disorder
- Depression
- Bi-polar disorder
- Post-traumatic stress disorder
- Family history of mental illness
- Family history of suicidal ideation
- History of physical or sexual abuse
- Lack of social support

Symptoms

A few studies conducted in symptoms of suicidal ideation indication that symptoms are quite similar for people who have developmental disabilities and the general population.

These symptoms include;

- Talking about death, dying or killing oneself but without expressed intent to do so
- Verbal threats about intent to hurt or kill oneself without action ("Such as I am going to choke myself" without taking the action.)
- At risk behaviour without any verbalization – such as running toward a busy street
- Impulsivity
- Poor concentration
- Hyperactivity
- Sadness
- Aggressive behaviour
- Sleep disturbances
- Eating disturbances

Part 8: Challenging Behaviour

Intervention

Treatment and intervention should include addressing risk factors and underlying causes of suicidal ideation. Clinical intervention is necessary to help access the function of the behaviour and address risk factors. Research is on-going regarding the development of specific intervention strategies for people who have developmental disabilities and dual diagnosis.

Reference: <http://www.ncbi.nlm.nih.gov/pubmed/10425656>

http://www.psychiatry.org.il/upload/infocenter/info_images/1004200752829PM@Pages%20from%20JP-43-4-5.pdf

Accessed: November 3, 2011

Addictions and Dual Diagnosis

People who have developmental disabilities and/or dual diagnosis often have multiple risk factors for developing addictions. In fact, people who have a dual diagnosis are at greater risk of developing addictions to alcohol, tobacco, prescription medication, illegal drugs and gambling addictions.

These risk factors include:

- Medication use
- Health problems
- Societal enabling
- Lack of identification of potential problems
- Lack of accessible and appropriate prevention and treatment services

Identifying Addictions

- Symptoms of a dual diagnosis can themselves mask potential substance abuse problems, making identification difficult
- Frequent intoxication: Do recreational activities center around getting and using substances, as well as recovering from use?
- Atypical social settings: Does the person's immediate peer group suggest that substance abuse may be encouraged? Is the person reluctant to attend social events where substances will not be present?
- Intentional heavy use: Does the person in question use substances along with prescribed medication? Does the person seem to use more than is safe?
- Job problems: Has the person missed work or been late because of use of substances? Does the person blame his/her ID/D status for work problems?
- Health problems: Does this person have medical problems that are aggravated by repeated substance use? Has this person been victimized while under the influence?

Part 8: Challenging Behaviour

- Problems with significant others: Has a family member or friend expressed concern about this person's substance use? Have important relationships been impaired as a result of substance use?
- Problems with authority/the law: Has the person been visited by police and/or arrested as a result of alcohol or drug-related offenses?

Reference:

http://www.socialworker.com/home/Feature_Articles/Professional_Development_&_Advancement/Identifying_Substance_Abuse_Among_Clients_With_Intellectual_Disabilities/ accessed November 3, 2011

Treatment

People who have developmental disabilities or dual diagnosis need access to substance abuse education and prevention materials that are culturally sensitive, linguistically accessible, and inclusive in order to meet their needs.

Reference: CAMH - Mental Health and Addiction Statistics, Prevalence and Incidence

Sep 02, 2009 4:31 PM

Published: Aug 31, 2011 6:47 PM

ID#P2837

United States Office on Disability - Substance Abuse and Disability

A COMPANION TO CHAPTER 26 OF HEALTHY PEOPLE 2010

Part 9: Crisis Planning

Crisis



Due to the complex support needs of a person with a dual diagnosis, frequent medical/mental health support is often required. A Crisis is any serious deterioration of a person's ability to cope with everyday life. It does not necessarily involve danger of serious physical harm to self or others.

People with a Dual Diagnosis are at risk of crisis for many reasons including:

- Medication or medical complications
- Changing life circumstances
- Inappropriate or inadequate supports
- Flare up of their illness
- Substance abuse problems
- Genetics

When supporting someone who has a dual diagnosis, crisis planning should be completed long before any crisis occurs so there is clear direction for direct support professionals to follow when or if crisis occurs.

Most developmental services agencies and mental health services have templates for crisis plans. With the development of the Toolkit supporting the Primary Care Guidelines, a standardized crisis template was developed to assist direct support professionals collect and document the necessary information for physicians and health professionals will refer to in crisis situations. This Crisis Prevention and Management Plan is available in the Appendix.

The benefit of completing a crisis plan is to give direct support professionals clear information on what constitutes a crisis for the person, what steps to take to help the person stay out of crisis, and what to do if crisis does occur.

When the crisis plan has been followed and direct support professionals must accompany a person to the emergency department or emergency mental health services, a crisis plan provides clear documentation of what steps have been taken to support the person so far. This can give a level of accountability, credibility and professionalism to the interaction between direct support professionals and crisis supports, which will make the process much smoother and easier for the person. The intention of planning for crisis before it happens is to reduce the risk of it occurring and the risk to the person.

Part 9: Crisis Planning

Evaluating the Risks

Do we need a crisis plan?

Evaluating risk is a vital part of a good person-centred support to people who have a dual diagnosis. Ideally, issues of risk are discussed and a plan to address them is developed **before** a [crisis](#) occurs.

There are several primary areas to consider when evaluating risk of a person escalating and a crisis occurring such as the potential to damage or harm self, staff and/or others around, and to goods and/or property.



Some questions to consider asking:

- What danger exists?
- Is it possible that the person would
 - Yell at someone?
 - Threaten someone?
 - Harm themselves, someone else or damage property?
- How great is that danger?
- How likely is the behaviour to occur?
- If we provide more support, is the behaviour less likely to occur?
- How often has it occurred?
- When and where does it occur?
- What factors may be causing the situation?

Once risk has been assessed, a crisis plan is easier to determine. The Toolkit for the Primary Care of People with Developmental Disabilities contains a Risk Assessment Tool for Adults with DD in Behavioural Crisis, which is available in the Appendix.

Reference: * Dual Diagnosis Implementation Committee of Toronto (2006) *Building the Path to Home: Links to Sustainable Housing for People who have Dual Diagnosis*. Toronto: Centre for Addiction and Mental Health

Developing a Crisis Plan

Any information available regarding decisions made about how to manage a crisis and what direction to take as discussed with the person and their circle of care before a crisis happened. Specific things to do to manage a crisis may be individual to the person.

General recommendations for what to include in a crisis plan:

- Descriptions of the severity and nature of the crisis. There are different issues to consider regarding what constitutes a crisis for a person and action taken as a result may be different depending on the type and severity of the crisis. A crisis plan should clearly outline what will constitute a crisis for that person.
- The crisis plan should clearly outline the action a staff must take in the event of a crisis occurring for the person.
- Crisis plans should include contact information for resource/people/services staff need to access when a crisis occurs.

Part 9: Crisis Planning

Different crisis situations and issues needing immediate medical/psychiatric intervention:

- Is this person experiencing side effects from a medication that is causing sudden and noteworthy changes in mental states such as:
 - Confusion
 - Sluggishness/hyperactivity
 - Current medical condition such as sudden high fever
 - Is the person considered to be a danger to themselves, to others?
 - Are they in danger or at risk due to the inability/refusal to care for themselves in areas of:
 - Nourishment
 - Personal care
 - Medical safety with reasonable probability that death will result in a short period of time

Reference: Ministry of Health Form 2 Mental Health Act Order for Examination under section 16, Part A-subsection 16(1) <http://www.ocfp.on.ca/docs/collaborative-mental-health-care-network/a-blank-copy-of-a-form-2.pdf> (accessed Oct 31, 2011)

Where do you go in a crisis?

Outside of regular business hours the emergency department may be the most appropriate place to seek support for the person when:

- The crisis plan outlines that it is the appropriate place to seek help
- There is no clear direction provided in a crisis plan and the route to get support for the person is not clear
- The person's crisis is health related
- There is no appropriate mental health crisis service available
- The person is in danger of harming themselves or someone else

When trying to determine the best place to access care with the person, direct support professionals should be aware of the following:

- The policy for the agency for which they work. The policy may provide clear directions for what to do in an emergency.
- Online and phone line resources that can provide assistance and direction:
 - Telehealth Ontario, a free, confidential telephone service you can call to get health advice or general health information from a Registered Nurse. Call 1-866-797-0000 or TTY: 1-800-797-0007
 - Mental health crisis line for information and guidance i.e. http://www.ontario.cmha.ca/services_and_supports



Part 9: Crisis Planning

Some reasons to call 9-1-1:

Staff must be aware of the policy and procedure the agency has regarding what needs to happen when EMS is accessed.

- Person is experiencing chest pains or tightness in chest
- Person is in severe pain
- Person is experiencing shortness of breath
- Person is choking or having breathing difficulties
- Person experiences sudden, severe headaches, vision problems, sudden weakness, trouble speaking, dizziness, numbness and or tingling in the face, arm, or leg
- Person has diarrhoea and vomiting and won't eat or drink
- Person has sudden change in mental state
- Person is or has threatened, or attempted to harm themselves or others



Emergency Departments and Emergency Medicine

Emergency medicine is a medical specialty in which physicians care for patients with acute illnesses or injuries which require immediate medical attention. While not usually providing long-term or continuing care, emergency medicine physicians diagnose a variety of illnesses and undertake acute interventions to stabilize the patient.

Reference: http://en.wikipedia.org/wiki/Emergency_medicine (accessed Oct 31, 2011)

Emergency departments are intended to offer acute care for medical illnesses. While this does include mental illness for patients with dual diagnosis it is important to understand what the available resources are in the emergency department for patients who have a mental illness and what you may reasonably expect once there.

The **Canadian Triage Acuity Scale** for patient triage in the emergency department is a resource to help patients understand how they will be assessed and treated when they arrive at the emergency department.

What to expect when arriving at the emergency department: adapted from the Canadian Triage and Acuity Scale (CTAS) National Guidelines

A triage nurse will assess the person from head to toe, which is done using the **Canadian Triage Acuity Scale (CTAS)**. This scale helps the nurse with determining who needs to be seen immediately.

Part 9: Crisis Planning

The Canadian Triage Acuity Scale levels are designed to show that level 1 represents the sickest patients and level 5 represents the least ill group of patients.

Level 1: Is a condition that is a threat to life or limb (or imminent risk of deterioration) that needs urgent care.

Resuscitation - for example conditions like cardiac/respiratory arrest, major trauma.

Level 2: Is a condition that is a possible threat to life limb or function that needs fast medical treatment.

Emergent - for example conditions like altered mental states, head injury.

Level 3: Is a condition that could possibly lead to a serious problem requiring emergency treatment and may be associated with major discomfort or affecting ability to function at work or activities of daily living.

Urgent - for example is a condition such as pregnancy, acute psychosis/and or suicidal thoughts. **Acute psychosis and/or suicidal thoughts:** Psychiatric problems, not really agitated but some uncertainty as to whether they are a threat to themselves or others. Normal vital signs but the person may be very emotional but not violent and reasonably cooperative. Some “bipolar” (manic-depressive) require safe caring setting and some assessment of risk for overdose.

Level 4: Is a condition that is related to the patient’s age, distress, possibility for decline or, a complication that would benefit from treatment or support within 1-2 hours.

Less urgent - for example are conditions such as headache, chronic back pain, **Suicidal/Depressed:** Patients complaining of suicidal thoughts or have made gestures but do not seem agitated.

Level 5: Is a condition that may be acute but non-urgent as well as conditions which may be part of a chronic problem with or without signs of worsening.

Non-urgent - for example sore throat, vomiting alone, and diarrhea alone. **Psychiatric:** Constant or frequent depression, trouble coping, impulse control, normal mental state, without somatic/vegetative findings (appetite, weight, sleep pattern disruption, unexplained crying episodes) and normal vital signs. Some chronic but more serious psychiatric disturbances or behavior disorders for which there is no support of decline or change. This cannot usually be fully evaluated in triage.

For Level 4 and Level 5 of the Canadian Triage Acuity Scale people may choose to go to urgent response/walk in clinics in their communities if available.

To locate the nearest clinic in your community that you can access go to www.health.gov.on.ca/ms/healthcareoptions or call 1-866-330-6206

(Canadian Triage and Acuity Scale (CTAS) Guidelines Policy #1451 pg 4 Appendix 4)

Part 9: Crisis Planning

Emergency departments are intended to help stabilize acute illness. Treatment for the chronic conditions happens elsewhere within the medical system. So for a person who has a dual diagnosis, the emergency department may help stabilize acute symptoms of mental illness – generally with the use of medications. They may be able to set up access to services and resources for chronic care of mental illness by directing people to the appropriate community based mental health services once the crisis has been stabilized. Admission may also be recommended if the acute symptoms of the mental illness are not able to be stabilized and admission to a psychiatric ward or hospital is deemed appropriate.

What a person should bring with them when going to the emergency department:

- Family, caregivers, and direct support professionals, should stay with the person whenever possible because the person may need an advocate and be a useful link with hospital workers
- Ontario Health Card
- Bring important issues in writing - short, clear, documentation-just the facts
- All medication in original packaging including over the counter medication such as vitamins. Remember to also include dosages, why they are being taken, and documentation from specialists with instructions if needed
- List of allergies for example food, medication, seasonal etc.
- List of any past surgeries or hospitalizations for illness
- List of immunization history-especially current flu and pneumonia vaccinations
- Documentation of reason for going to the emergency department
- Something to keep the person occupied like a game.
- Snack - and let the triage nurse know that the person is eating
- A bottle of water (during wait time staff are still required to administer medication)
- Current list of any diagnoses.
- Any other special instructions that the nurse/doctor may need to know to provide services: For example the person being supported at the hospital may not like crowds, bright lights, lab coats, being touched, eye contact, etc. These are things that the nurse/doctor may need to know in order to provide the best possible care to the patient.

The companion Toolkit to the Primary Care Guidelines contains a list of items recommended for direct support professionals to bring to the emergency department. This list can be located in the Appendix – Crisis Section.

The Toolkit suggests the person bring these items as well; Comforters – items which seem to provide comfort to the person

- Favourite food/drink and snacks
- Communication strategies that work
- Someone who knows them well
- Ways to illustrate to the medical practitioners what the person is usually like
- Social story for the person to assist in helping them understand how hospitals work

Part 9: Crisis Planning

Debriefing after a Crisis

After any crisis situation occurs, debriefing with the person, the staff team and other involved parties, should occur to make sure everyone has had an opportunity to discuss what occurred, evaluate effectiveness of plans, and move forward with direction.

After any emergency situation - trip to the emergency room or inpatient stay - the crisis care plan (CPP) needs to be reviewed to see if any changes are necessary. The case manager/primary support person will be responsible to review and revise the CCP. The team supporting the person, including all clinical providers and other professionals involved, need to participate in the review. If someone does not have a Crisis Care Plan it may be helpful to have one developed.

The key is to develop rapport and relationship with all of the professionals involved so you can work together to provide critical information to inform decision-making and to develop the best treatment plan for the person.

Working together helps to ensure the person with Dual Diagnosis has a supportive living situation with a positive support plan, good medical care, meaningful relationships and activities, in order to reduce the chance of ER visits and hospital stays and for improved overall physical and mental health.

Crisis Protocols

In some communities crisis protocols have been developed between mental health, developmental services, health services and emergency services (police and EMS). These protocols predetermine each partner's responsibility in a crisis. They ensure valid up to date crisis plans are available and utilized as needed. This creates consistency and, over time, supports the circle of care around the person in crisis.

Crisis Protocols ensure that the specialized needs of a person with a dual diagnosis are taken into account when they are in unlawful situations. These protocols and relationships help increase the awareness of community services (police, justice, health) about the needs of people who have a dual diagnosis and help access the most appropriate supports in any given situation.

An example of a Crisis Protocol is also provided in the Appendix – Crisis Section.

Part 10: Useful Links and Resources

Dual Diagnosis,

An introduction to the mental health needs of persons with developmental disabilities

Editors: Dorothy M. Griffiths, Chrissoula Stavrakaki and Jane Summers, Habilitative Mental Health Resource Network, First Printing, June 2002

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Plaza 69 Postal Outlet, 1935 Paris Street, Box 21020, Sudbury, Ontario P3E 6G6 Canada

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2000 Continuum of Care Project

University of New Mexico

Health Sciences Centre School of Medicine

2350 Alamo Avenue SE Suite 155

Albuquerque, NM 87106

<http://hsc.unm.edu/som/coc/docs/doctor.pdf>

Fanlight Productions

Distributor of innovative film and video works on social issues relevant to our times – specializing in healthcare, mental health, professional ethics, aging and gerontology, disabilities, the workplace and gender and family issues.

<http://www.fanlight.com/>

The Family Village, Wiseman Centre

University of Wisconsin, Madison

<http://www.familyvillage.wisc.edu/>

Southern Network of Specialized Care

The Southern Network of Specialized Care links 11 Local Service Delivery Networks and Dual Diagnosis Committees in Grey/Bruce, Huron/Perth, London/Middlesex, Elgin/Oxford, Windsor/Essex, Chatham/Kent, Sarnia/Lambton, Brant, Haldimand/Norfolk, Hamilton and Niagara under one umbrella. www.community-networks.ca

National Association of Dual Diagnosis (NADD)

132 Fair Street, Kingston NY 12401

Ph: 845-331-4336 or 800-331-5362

Website: www.thenadd.org

Email: info@thenadd.org

Ontario Association on Developmental Disabilities (OADD)

2 Surrey Place, Toronto, ON M5S 2C2

Tel: 416-657-2267

www.oadd.org

email: oadd@oadd.org

Part 10: Useful Links and Resources

Joint Dual Diagnosis Guidelines 2008

Ontario Ministry of Health and Long Term Care

http://www.health.gov.on.ca/english/providers/pub/mental/joint_policy_guideline.pdf

www.learningdisabilities.org/uk/publications

Best Buddies:

www.bestbuddies.org

Our Kids:

www.our-kids.org

Educational Institutions:

International Certificate Programme in Dual Diagnosis – Intensive training courses in Habilitative Mental Health for persons with Developmental Disabilities.

A certificate programme offered by Brock University, St. Catharines, Ontario, Canada, in association with Niagara University, Lewiston, New York, USA, and the NADD

<http://www.brocku.ca/dualdiagnosis/index.html>

Developmental Disabilities Division

University of Western Ontario

850 Highbury Ave., Room E 126

London, ON N6A 4H1

<http://ddd.uwo.ca/>

email: ddd@uwo.ca

The Family Village

Waisman Center

University of Wisconsin-Madison

1500 Highland Ave

Madison, WI 537 05 2280

www.familyvillage.wisc.edu

Center on Human Policy

Syracuse University School of Education

805 South Crouse Ave

Syracuse, NY 13244-2280

Ph: 1-800-894-0826

Email: thehcp@syr.edu

Part 10: Useful Links and Resources

Institute on Disabilities / Temple University

1601 N. Broad Street
University Services Building Suite 610
Philadelphia, PA 19122
Ph : 215-204-1356

Training :

Therapeutic Guidelines Limited

Therapeutic Guidelines Limited is an independent not-for-profit organization dedicated to deriving guidelines for therapy from the latest world literature, interpreted and distilled by Australia's most eminent and respected experts.
West Melbourne, Australia

Therapeutic Guidelines Limited

Ground Floor, 473 Victoria Street
West Melbourne, Victoria 3003, Australia
Ph : 613-9329-1566
Email : sales@tg-org.au
<http://www.tg.org.au/>

Safeguards Training for Children and Adult Services

9011 Leslie St., Suite 312
Richmond Hill, ON L4B 3B6
Ph: 905-889-5030
www.safeguards-training.net

Legal Resources:

ARCH Disability Law Centre

Toronto, Ontario
ARCH provides a range of legal services to people with disabilities who live in Ontario, disability advocacy organizations, and the legal profession.
<http://www.archdisabilitylaw.ca>

Law Enforcement Awareness Network

L.E.A.N. On Us provides first responders with information and resources that will allow them to better serve individuals within their communities affected by the hidden disabilities and mental illness. This item is free to other law enforcement agencies.

Part 10: Useful Links and Resources

Crime Victims with Disabilities:

What the prosecutor needs to know about Autism, Cerebral Palsy, Mental Retardation and Traumatic Brain Injury (2006) 2.5 hour DVD program features experts from across the United States, in the fields of prosecution, law enforcement – present techniques for accommodating individuals, conducting interview and presenting cases in court. DVD is free to law enforcement agencies

Ph: 916-443-2017

Email: help@leanonus.org

www.leanonus.org

Other:

Joint Dual Diagnosis Guidelines 2008

Ontario Ministry of Health & Long Term Care

www.health.gov.on.ca/english/providers/pub/mental/joint_policy_guideline.pdf

Mental Health Aspects of Developmental Disabilities

www.mhaspectsofdd.com

U-First

Training for professional caregivers of people with Alzheimer's Disease and other dementias
Alzheimer's Society of Ontario

<http://u-first.ca>

Centre on Human Policy, Law and Disability Studies

The Center on Human Policy (CHP) is a Syracuse University based policy, research and advocacy organization involved in the national movement to insure the rights of people with disabilities.
Syracuse University, Syracuse, New York

<http://thechp.syr.edu>

Handbook of Mental Health Care for Persons with Developmental Disabilities

Ruth Ryan, M.D. Copyright 2001

DM-ID Dual Diagnosis Manual of Intellectual Disabilities

A textbook of diagnosis of mental disorders in persons with intellectual disabilities.

Edited by: Robert Fletcher, D.S.W., A.C.S.W., Chief Editor, Earl Loschen, M.D., Chrissoila Stavarakaki, M.D., Ph.D. Michael First, M.D.

Part 10: Useful Links and Resources

Life Space Crisis Intervention 2nd Edition

Talking with Students in Conflict

Authors Nicholas J. Long, Mary M. Wood, Frank A. Fecser

Copyright 2001, 1991 by Pro-ED, Inc.

HCH Clinician's Network publication

Healing Hands Volume 4, No. 5, October 2000

Synergy, Volume 11, No. 2 Summer 2007

Queen's University, Department of Psychiatry

Kingston, ON

<http://psychiatry.queensu.ca/page.asp?id=224&tab=education>

Continuing Medical Education

nzpf Volume 34, No. 5, October 2007

Mental Illness in people with Intellectual Disabilities

Author: Chris Perkins, M.D.

Brief overview of Common Psychotropic Medications: A Practical Guide from a Clinical Point View Point

Author: Paula Bank, M.D., Ph.D.

Department of Psychiatry, University of Michigan

CAMH – Center of Addiction and Mental Health Dual Diagnosis Program

Dual Diagnosis Fact Sheet Prepared by the National Coalition on Dual Diagnosis (I found this):

<http://care-id.com/wp-content/uploads/2011/09/factsheet.pdf>

National Institute of Mental Health – Bethesda, Maryland, U.S.A.

The mission of NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery, and cure.

<http://www.nimh.nih.gov/index.shtml>

A Guide to Psychotropic Drugs by Christine Culhane

Psychotropic Drug Advisory Service

http://www.bendigohealth.org.au/app/cmslib/media/lib/1008/m14938_v1_634165223159742865.pdf

Early Effects of Alcohol Exposure

by John W. Olney et al., Science, 11 February 2000.

Prenatal alcohol exposure and childhood behaviour at age 6 to 7 years: I. Dose-response effect. Beena Sood et al., Paediatrics 108, no.2 (August 2001), e34

Part 10: Useful Links and Resources

"Fetal Alcohol Spectrum Disorder (FASD) and the role of family court judges in improving outcomes for children and families"

by Diane V. Malbin (2004) *Juvenile and Family Court Journal*, 55 (Spring 2004); 53-63

Fetal Alcohol Spectrum Disorder

(FASD, Public Health Agency of Canada, p.5, 2005 <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php>

Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

University of Washington School of Medicine, Department of Psychiatry and Behavioral Sciences, 1996, p.30. found this:

<http://www.cdc.gov/ncbddd/fasd/facts.html>

<http://depts.washington.edu/fadu>

www.gutsense.org/constipation/normal_stools.html

Part 10: Useful Links and Resources

Genetic Resources:

Online Mendelian Inheritance in Man

www.ncbi.nlm.nih.gov

Genetics Education Center

University of Kansas Medical Center

<http://www.kumc.edu/gec/>

Angelman Syndrome

Angelman Syndrome Foundation Inc. (USA)

www.angelman.org

Canadian Angelman Syndrome Society

www.angelmancanada.org

Cornelia de Lange Syndrome

Cornelia de Lange Syndrome Foundation Inc. (USA)

www.cdlsusa.org

Cornelia de Lange Syndrome, Canada

www.cdlsCanada.ca

Cri-du-Chat Syndrome

UK Cri Du Chat Syndrome Support Group

www.criduchat.co.uk

5p Minus Society (USA)

www.fivepminus.org

Down Syndrome

Down Syndrome Research Foundation (Canada)

www.dsrf.org

National Down Syndrome Society (USA)

www.ndss.org

Fragile X Syndrome

The Fragile X Syndrome Foundation of Canada

www.fragile-x.ca

FRAXA Research Foundation (USA)

www.fragilex.org

PKU

National PKU News

www.pkunews.org

Part 10: Useful Links and Resources

Prader-Willi Syndrome

The Prader-Willi Syndrome Association (USA)

www.pwsausa.org

Prader-Willi Alliance of N.Y. (USA)

www.prader-willi.org

Rett Syndrome

International Rett Syndrome Association (USA)

www.rettsyndrome.org

Rett Syndrome Association (UK)

www.rettsyndrome.org.uk

Smith-Lemli-Opitz Syndrome

Smith-Lemli-Opitz/RSH Foundation

www.smithlemliopitz.org

Smith-Magenis Syndrome

Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) (USA)

www.smithmagenis.org

Tuberous Sclerosis

Tuberous Sclerosis Alliance (USA)

www.tsalliance.org

Williams Syndrome

Williams Syndrome Foundation (USA)

www.wsf.org

The Williams Syndrome Association (USA)

www.williams-syndrome.org

Other genetic websites:

Geneclinics

www.geneclinics.org

Your Genes, Your Health

www.ygyh.org

SOUTHERN NETWORK OF SPECIALIZED CARE RESOURCE LIBRARY

* New Additions – October 2011

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A Guide to Consent, Edited by Robert D. Dinerstein, Stanley S. Herr, Joan L. OSullivan, AAMR, 1999

Behaviour Modification for Persons with Developmental Disabilities: Treatment and Supports: volume 1, Edited by Johnny L. Matson, Rinita B. Laud, Michael L. Matson, NADD, 2004

Behaviour Modification for Persons with Developmental Disabilities: Treatment and Supports: volume 2, Edited by Johnny L. Matson, Rinita B. Laud, Michael L. Matson, NADD, 2004

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Clinical Judgment, Robert Schalock, Ruth Luckasson, AAMR 2005

Collaborative Leadership: How citizens and civic leaders can make a difference, David D. Chrislip and Carl E. Larson, Jossey-Bass Publishers, 1994 (one copy in SNSC London office, one copy in SNSC Hamilton office)

Collaborative Leadership Fieldbook: A guide for citizens and civic leaders, David D. Chrislip, Jossey-Bass Publishers, 2002.

Contemporary Dual Diagnosis: MH/MR: volume 1: Residential and Day Services, John W. Jacobson, James A. Mulick, Steve Holburn, NADD, 2002

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Contemporary Issues in Administration: Total Quality Management in Mental Health and Mental Retardation, Edited by Gary V. Sluyter, AAMR, 2000

Criminal Offenders with Mental Retardation: Risk Assessment and the Continuum of Community-Based Treatment Programs, Edwin J. Mikkelsen and Wayne J. Stelk, NADD, 1999 (First Printing)

Crisis: Prevention & Response in the Community, Edited by Ronald H. Hanson, Norman A Wieseler, K. Charlie Lakin, AAMR, 2002

Demystifying Syndromes: clinical and educational implications of common syndromes associated with persons with intellectual disabilities, Edited by Dorothy Griffiths and Robert King, NADD, 2004

Diagnostic Manual- Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability, Robert Fletcher, Earl Loschen, Chrissoula Stavrakaki, Michael First, NADD Press, 2007

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Do?Be?Do?: What to Teach and How to teach people with developmental disabilities: Dave Hingsburger, Diverse City Press, Inc, 1998 (one copy at SNSC London office and one copy at SNSC Hamilton office)

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Early Detection: Prevention and Amelioration of Mental Health Conditions in Young People, Ann R. Poindexter, NADD Press, 2008

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Handbook on Quality of Life for Human Services Practitioners, Robert Shalock and Miguel Angel Verdugo Alonso, AAMR, 2002

Health Management of Aging Adults with Mental Retardation: A Practice Guide, Ann R. Poindexter, NADD, 2002

Hidden Curriculum, The: Practical Solutions for Understanding Unstated Rules in Social Situations: Brenda Smith Myles, Melissa L. Trautman, Ronda L. Schelvan, Autism Asperger Publishing Co, 2004 (includes video) (one copy located at Bethesda Highlands Treatment Program)

Innovations: Assessing Problem Behaviours, MaryAnn Demchak and Karen W. Bossert, AAMR Research to Practice Series, 1996

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**Intellectual Disability and Problems in Sexual Behaviour: Assessment, Treatment and Promotion of Healthy Sexuality*, Robin J. Wilson and Michele Burns, Trillium Health Centre, Mississauga, ON, 2011 (Book and Quick Reference Resource Guide)

Leading at a Higher Level, Ken Blanchard, Pearson Prentice Hall, 2007

Mental Wellness in Adults with Down Syndrome: A guide to emotional and behavioural strengths and challenges, Dennis McGuire and Brian Chicoine, Woodbine House Inc, Bethesda, MD, 2006 (Hamilton office only)

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Motivational Interviewing: Preparing People for Change, Second Edition, William R. Miller, Stephen Rollnick, The Guildford Press, 2002

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Supports Intensity Scale, Users Manual, James R. Thompson, Brian R. Bryant, Edward M. Campbell, Ellis M. (Pat) Craig, Carolyn M. Hughes, David A. Rotholz, Robert L. Schalock, Wayne P. Sliverman, Marc J. Tasse, Michael L. Wehmeyer, AAMR, 2004

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Visual Recipes: A Cookbook for Non Readers : Tabitha Orth, Autism Aspergers Publishing Co, 2006 (one copy located at Bethesda Highlands Treatment Program)

Videos/DVD's:

*A Family Healing: Michael Connelly, Kinetic Video, Toronto (one copy in Hamilton office)

Fetal Alcohol and Other Drug Effects: A Four-Part Training Series for Parents and Professionals, Diane V. Malbin (one copy at Niagara SNSC office and one copy at London offices)

Who Do We Serve: A short film about supporting intellectually disabled sex offenders in community settings: Dave Hingsburger, Diverse City Press, Inc. (one copy at SNSC London office and one copy at SNSC Hamilton office)

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Journal on Developmental Disabilities: Down Syndrome – Supplement (2): O.A.D.D., Volume 12, No 1, Supplement (2), 2006

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Journal on Developmental Disabilities: Transitions, O.A.D.D., Volume 14, No. 1, 2008

Journal on Developmental Disabilities, Volume 14, No. 2, 2008

Journal on Developmental Disabilities, Volume 14, No. 3, 2008



**Ministry of Health and Long-Term Care and
Ministry of Community and Social Services**

**Joint Policy Guideline for the Provision of
Community Mental Health and Developmental
Services for Adults with a Dual Diagnosis**

December 2008

Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis

1. Purpose of the Guideline

To provide a framework for the planning, coordination and delivery of community mental health and developmental services and supports that will promote better access to both sectors for persons 18 years and older with a dual diagnosis.

2. Context

In 1997 the Ministries of Community and Social Services (MCSS) and Health and Long-Term Care (MOHLTC) released a joint Guideline on dual diagnosis that updated earlier documents. The Guideline provided a definition of dual diagnosis and expectations for how the funded community service sectors of both Ministries would work together to provide supports to this population.

Since 1997 there have been many changes in the ministries and sectors as well as a growing understanding of the needs and challenges of adults with a dual diagnosis. As a result there is a need to update the 1997 Dual Diagnosis Guideline to reflect current structures and to restate the expectations for cooperative supports to this population. It is also the intention of the two ministries to review the Guideline on a regular basis.

3. Vision

Community mental health and developmental services for persons with a dual diagnosis and their families will be integrated, coordinated and operate responsively and proactively both within and across sectors.

4. Principles

Persons with a developmental disability may have mental health needs that require different types and intensity of service response from both the community mental health and developmental services systems. Interventions should be appropriate to address the individual's circumstances and needs and should progress as required along the continuum from the least restrictive and least intrusive to the most specialized response.

Health, mental health and developmental services all have a role in the provision of services and supports to people with a dual diagnosis. The development of cross-sector linkages will serve to:

- Strengthen community capacity to address the needs of those with a dual diagnosis through the provision of a coordinated, integrated and flexible service response;
- Promote cross-sector planning to facilitate access to local services in the health, mental health and developmental services sectors;

- Engage consumers, families/natural supports¹ and service providers as partners in the planning and delivery of services.

Education and training initiatives will work to integrate and promote increased knowledge and skills regarding service provision for people with a dual diagnosis. These initiatives will be based on academic research where available and promote evidence-based practices.

5. Key Assumptions

- Dual diagnosis is a complex condition that often requires a multi-faceted service response from both the health and social services sectors. Effective cross-sector collaboration at all levels is essential to the provision of appropriate services.
- Services for adults (age 18 and older) with a dual diagnosis are a responsibility shared by both ministries. While some responsibilities such as policy direction and planning are shared by both ministries, other responsibilities are distinct. Community-based mental health services and supports include: counselling and treatment, 24-hour crisis response including short-term crisis residential beds, Assertive Community Treatment Teams (ACTTs) and consumer/survivor/family initiatives. Developmental services include: residential, community participation and respite supports, case management, and specialized community supports (refer to appendices 1 and 2 for lists of services).
- System planning for transitional age youth (ages 16 and 17) with a dual diagnosis is a responsibility shared by both ministries to work with the Ministry of Children and Youth Services (MCYS) which has responsibility for developmental and mental health services for children and youth under age 18. Local system planning will also occur to facilitate the transition of youth to adult services.
- Individuals should have access to a continuum of care that provides the most appropriate and least intrusive service possible, based on assessment of need. For some, this may mean support through general health care services such as primary care providers and general hospital services. For others with more complex needs, integrated cross-sector responses may be required. A segment of the population may require access to specialized services that integrate the expertise and knowledge of both the mental health and developmental services sectors.
- Mental health and developmental services funded by the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services are responsible for continuing to work collaboratively within and across sectors so that individuals who have a developmental disability and mental health needs receive the appropriate levels of service to respond to those needs and so that effective case resolution mechanisms are in place in communities.
- It is an expectation of the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services that this joint Guideline will be implemented across the province by the responsible parties.

¹ Natural supports refer to friends, volunteers, and other non-paid personal supports.

6. Demographic/Prevalence Rates for Dual Diagnosis

While the Statistics Canada Participation and Activity Limitation Survey (PALS) sets the prevalence rate of people who have a developmental disability in Ontario as 0.7 per cent other sources cite the rate as more appropriately expressed as being between 1 to 3 per cent of the population.² Using the prevalence rate of 1 per cent and the Ministry of Finance 2005 Ontario population figure of 12,540,000 there are 125,400 persons with a developmental disability estimated to reside in Ontario.

The National Association for the Dually Diagnosed (NADD) estimates that 30 per cent of the population with a developmental disability also has a mental health disorder. Other sources have suggested the prevalence of dual diagnosis may range as high as 38 per cent. Using the NADD figure of 30 per cent, it is estimated that there are approximately 37,620 individuals with a dual diagnosis in Ontario.

7. Defining the Population to be Served

7.1 Individuals with a Dual Diagnosis

The definition of the population for whom this Guideline applies remains the same as it was in the 1997 Guideline stated below:

“‘Adults with a Dual Diagnosis’ are those persons 18 years of age and older with both a developmental disability and mental health needs.”

This definition was acceptable in 1997 both to the developmental and mental health sectors as well as families and consumers because it was considered broader and more inclusive than previous definitions. It is unchanged in this Guideline.

7.2 Individuals with a Developmental Disability

The Ministry of Community and Social Services uses the definition of developmental disability described in the Developmental Services Act R.S.O. 1990, c. D.11 (DSA):

“‘Developmental Disability’ means a condition of mental impairment, present or occurring during a person’s formative years, that is associated with limitations in adaptive behaviour.”

The health system uses the definition of mental retardation contained in the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR) which is published by the American Psychiatric Association:

“‘Mental Retardation’ – this disorder is characterized by significantly sub-average intellectual functioning (an IQ of 70 or below) with onset before age 18 years and concurrent deficits or impairments in adaptive functioning.”

The DSM-IV-TR and DSA definitions are comparable in most aspects with the key distinction between the two being the explicit statement of required IQ level in the DSM-IV-TR definition.

² Bradley, Thompson, and Bryson 2002; Ouellette-Kuntz and Paquette 2001; Health and Welfare Canada 1988; Battaglia and Carey 2003; Massey and McDermott 1995; McLaren and Bryson 1987; Stevenson 1996.

7.3 Individuals with Mental Health Needs

For the purposes of this Dual Diagnosis Guideline, “mental health needs” are defined as diagnosed mental illness or symptoms consistent with mental illness.

7.3.1 Individuals with Serious Mental Illness

In 1999 the MOHLTC released *Making It Happen: Implementation Plan for Mental Health Reform* and *Making It Happen: Operational Framework for the Delivery of Mental Health Services and Supports*. These documents provided the framework to guide mental health reform in Ontario and stated that the priority population to be served by community mental health services and supports is people with a serious mental illness.

The documents describe three categories to identify individuals with a serious mental illness: disability, anticipated duration and/or current duration, and diagnosis. The critical dimension is the extent of disability and serious risk of harm to themselves or others, related to a diagnosable disorder.

- **Disability:** lack of ability to perform basic living skills that interferes with or severely limits an individual’s capacity to function in one or more major life activities;
- **Duration:** the acute and ongoing nature of the problems including intermittent episodes between which there are periods of full recovery, and
- **Diagnosis:** including schizophrenia, mood disorders, organic brain disorders, paranoid psychosis or other psychoses, severe personality disorder, concurrent disorder and dual diagnosis.

The two “*Making It Happen*” documents define populations to be served according to their need for services: first-line, intensive and specialized:

- **First-line:** prevention, assessment and treatment provided by front-line health care providers including general practitioners, mental health services, social services, hospital emergency services and hospital primary care clinics. Services include: information and referral, crisis telephone services, mobile crisis teams, safe beds, mental health counselling and emergency services in Schedule 1 hospitals;
- **Intensive:** mental health assessment, treatment and support services which are provided in community or hospital settings and are focused on people with serious mental illness. Services include: intensive case management and housing supports, skill development, psychosocial rehabilitation programs, medication clinics, Schedule 1 inpatient and outpatient services;

- **Specialized:** highly specialized mental health programs provided in community or hospital settings and which focus on serving people with serious mental illness who have complex, rare and unstable mental disorders. Services include: assertive community treatment teams, mobile outreach teams, residential treatment, specialized inpatient and outpatient services and forensic services.

Each level describes a flexible or variable combination of specific service functions that differ in terms of level of resource intensity, specialization, and/or service duration. For individuals with serious mental illness, “levels of need” serve as a guide to mental health resource utilization which must be applied in conjunction with sound clinical judgment. The services a client receives will usually be based on client choice and offered in accordance with the client’s functional needs.

Given that groups of clients share many common needs and will benefit from similar service approaches, people will receive most of their services from within a particular level but are not limited to accessing services from only within one level.

8. Provincial Roles and Functions

The Ministry of Health and Long-Term Care (MOHLTC) is responsible for stewardship of the provincial health system. It sets overall policy direction for health and mental health services. Until April 1, 2007, MOHLTC directly funded hospitals and other transfer payment agencies to provide adult mental health services. Effective April 1, 2007, the MOHLTC provides funding to Local Health Integration Network (LHINs). LHIN legislation enabled 14 LHINs across the province to become the planners and direct funders of community and inpatient mental health services. Most physicians are not included in the LHIN mandate.

The Ministry of Community and Social Services (MCSS) funds and has responsibility for setting the overall policy direction and planning guidelines for a broad range of social services for adults with a developmental disability and their families.

Together, through a coordinated interministerial approach and based on the knowledge, skills and expertise that currently exist in both sectors, MOHLTC and MCSS will:

- Provide policy direction and develop corporate linkages that strengthen the range and capacity for a continuum of mental health and developmental services;
- Coordinate planning and monitor the impact of changes on service access and availability at the provincial level;
- Monitor and evaluate mechanisms for inter/intra-ministerial planning and coordination at a provincial level;
- Encourage availability of appropriate training and education for service providers in both the developmental and mental health sectors.

9. Local Roles and Functions

Effective service responses at the local/regional level are the product of strong and meaningful linkages across the sectors. MOHLTC will continue to provide funding to Local Health Integration Networks (LHINs) and MCSS will continue to provide funding to Regional Offices for delivery of services at the community level by transfer payment agencies. Responsibility for planning, building capacity and linkages across both sectors will rest primarily with the following structures:

- The Ministry of Health and Long-Term Care funded Local Health Integration Networks (LHINs) for mental health services and,
- The Ministry of Community and Social Services Community Networks of Specialized Care (CNSCs) for developmental services with the support of the Ministry Regional Offices.

9.1 Local Health Integration Networks (LHINs)

Effective April 1, 2007 LHINs assumed planning and funding responsibilities for most community and hospital-based mental health services in their jurisdictions. LHIN Integrated Health Service Plans are consistent with the strategic planning directions for MOHLTC. The responsibilities of LHINs are to:

- Support and facilitate the development of cross LHIN boundary and cross-sector planning at a LHIN level;
- Facilitate integration of the local health system and develop strategies to integrate services;
- Facilitate case resolution linkages, consistent with reforms in both sectors;
- Develop a process with local communities to assess the mental health and other resources needed to serve persons with a dual diagnosis and establish cross-sector partnerships to implement effective solutions;
- Plan and consult with the MCSS Community Networks of Specialized Care (CNSCs) so that persons with a dual diagnosis have access to a range of mental health services, consistent with the ministry's mandate, that are responsive to individual needs, including clients who will be affected by institutional closures of either ministry.

9.2 Community Networks of Specialized Care (CNSC)

The Community Networks of Specialized Care funded by MCSS are partnerships of specialized Developmental Services and other community agencies, including LHIN funded mental health service providers and organizations, working together to improve and coordinate specialized services for people who have a developmental disability and mental health issues and/or challenging behaviour. The CNSCs were created with a mandate to build capacity and linkages across local planning groups in relation to serving persons with a dual diagnosis.

In their leadership role on behalf of service provision for persons with a dual diagnosis the four Networks (East/North/Central/West) will coordinate a Specialized Service System to:

- Streamline access to specialized services:
 - break down barriers between the developmental services specialized and mental health service systems;
 - function at a local level and facilitate the development of protocols and agreements between service providers involved in serving people with a dual diagnosis;
 - expand partnerships and strengthen linkages with specialized mental health service providers such as LHIN funded Assertive Community Treatment Teams;
 - better coordinate scarce resources and improve the case resolution process for the most challenging individuals.
- Enhance service delivery:
 - improve capacity of Network members to develop a broader range and increase the volume of services that both specialized and developmental services service providers can offer;
 - assess community needs and opportunities and provide advice to MCSS and LHINs about the allocation of resources to meet priorities and support restructuring in their communities.
- Train and build capacity in the community:
 - develop relationships with the academic and research community;
 - improve access to research/best practices;
 - increase expertise in specialized services through professional development;
 - train general health and social service practitioners;
 - develop plans to recruit and retain more specialized professionals.

These actions will be undertaken in partnership with local dual diagnosis planning and/or advisory groups and LHINs with the support of the MCSS Regional Offices.

9.3 MCSS Regional Offices

In relation to the CNSCs, the Regional Offices will work with the Networks to:

- Develop cross-sector linkages that strengthen the capacity for the planning and coordination of services and supports for persons with a dual diagnosis;
- Help coordinate, support and build upon the existing continuum of services and supports in local communities, in partnership with institutional and community mental health and developmental service providers;
- Address unmet service needs and pressures in local communities by identifying and prioritizing the gaps and barriers to access throughout the developmental services system based on individual needs;

- Enable planning and coordination in local communities for persons with a dual diagnosis that is consistent with MCSS policy direction.

In addition, the Regional Offices will work with the LHINs with respect to initiatives in the mental health service sector related to:

- MCSS Schedule 1 Facility closures and downsizing (i.e., Rideau and Huronia Regional Centres);
- Development of appropriate community program strategies for inpatients of hospitals in order to support community living options for these individuals;
- Participation in education and training initiatives within and across mental health and developmental services.

10. Next Steps

Implementation of this Guideline at the local level will be the responsibility of the regional/local structures and service providers to work together to enhance the capacity across both sectors to serve this population. Specifically:

- It is the expectation of both ministries that the LHINs and the appropriate local developmental services planning forum (Networks or other forums as defined by the local community) will link to define how the local system will implement this Guideline;
- LHINs and Networks will take the appropriate steps to recognize and address the service needs for this population by building local cross-sectoral relationships and defining expectations for local service providers in both the health and social service sectors.

Ministry of Health and Long-Term Care, Mental Health and Addictions Unit
Ministry of Community and Social Services, Developmental Services Branch
December, 2008

Appendix 1: Community Mental Health Services for Adults with a Dual Diagnosis

Service	Description
Case Management	Includes outreach, comprehensive individualized assessment and planning, service coordination and support, monitoring and evaluation of services provided to recipients, systems advocacy/resource coordination and Community Treatment Order (CTO) coordination.
Counselling and Treatment	Counselling, psychotherapy and other treatment services to individuals with serious mental illness in the community including tele-psychiatry.
Assertive Community Treatment Team (ACTT)	Multi-disciplinary clinical teams provide treatment, rehabilitation and support services to clients with severe and persistent mental illness. They provide assertive outreach, individualized treatment, ongoing and continuous services, linkages to services and monitoring/evaluation.
Clubhouses	Multi-service psychosocial rehabilitation based on the psychosocial rehabilitation principles, which includes assistance to further vocational and educational goals, secure housing and engage in social and recreational programs.
Early Intervention	Specialized treatment and support services for individuals experiencing a first psychotic episode, and their families.
Diversion and Court Support	Court support is provided in the courts to assist individuals and their families with the legal process, link to services and to assist the judiciary. Diversion is provided pre- or post-charge to link individuals to community or institutional mental health services.
Social Rehabilitation/ Recreation	Provision and promotion of opportunities to develop interpersonal, social, and leadership skills, in order to interact fully in their communities as defined by themselves including assessment, counselling, planning, consultation with other service providers, coordination, advocacy, monitoring and evaluation.
Abuse Services	Provision of counselling, treatment services and support to women who have experienced an abusive act or who are in an abusive situation.
Crisis Intervention	Active treatment and support such as provision of safe beds, urgent psychological and/or medical attention offered as soon as possible after an individual has been identified as in acute distress. Includes: assessment and planning, crisis support/counselling, medical intervention, environmental interventions and crisis stabilization, review/follow-up referral.
Primary Day/ Night Care	Free-standing or attached units where treatment, counselling, rehabilitative/ social and recreational services are provided to recipients who attend for three to twelve hours on average.

Appendix 1: Community Mental Health Services for Adults with a Dual Diagnosis (cont'd)

Service	Description
Community Service Information and Referral	Information and referral services over the telephone or in person.
Consumer/ Survivor Initiatives	Provision of a range of consumer directed initiatives including self-help, peer support and drop-in centres based on the needs and interests of consumers/survivors in local areas.
Family Initiatives	Provision of support and training to strengthen and maximize natural supports and existing community networking systems that are relevant to the consumer/family. Family groups participate in planning and evaluation of care delivery, as well as provision of services such as self-help, peer support and education.
Alternative Businesses	Provision of consumer operated businesses that offer full- or part-time employment at market rate or higher. They offer a combination of job development, job placement and supported education within the self-help context. They may also offer self-employment opportunities for consumers to earn income through independent contract work. Support and accommodation are provided on site to consumer employees.

Appendix 2: Services Funded by the Ministry of Community and Social Services for Persons with a Developmental Disability

Service	Description
Case Management	Includes service coordination, planning and support, monitoring, advocacy and resource coordination.
Community Participation Supports	Community participation supports provide opportunities for individuals who have a developmental disability to find more ways to participate in their communities, such as through social and recreational activities, work and volunteer activities.
Specialized Community Supports	Specialized resources include services such as behavioural assessment and counselling services, speech and language therapy; specialized training for professionals who work with individuals who have a dual diagnosis (e.g., psychiatrists, psychologists, social workers and behaviour therapists); services that provide urgent support for individuals whose needs exceed the capacity of their caregivers; community outreach such as training, consultation and counselling for caregivers (e.g., agency staff, family, community health professionals); residential arrangements where individuals receive transitional or ongoing clinical supports from specialized professionals; research, professional development and training in best practice models of care, support and interventions.
Residential Supports	Provision of housing supports to assist individuals to live independently in the community. Programs offered are Supported Independent Living, Group Home living situations, Family Home arrangements, and Individual Residential Model options.
Special Services at Home (SSAH)	A directly operated MCSS respite program for children and adults who have a developmental disability and for children with a physical disability. The program provides annual funding directly to families so that they may purchase respite services and supports not already available in the community.

Appendix 2: Services Funded by the Ministry of Community and Social Services for Persons with a Developmental Disability (cont'd)

Ontario Disability Support Program (ODSP)	<p>People with a developmental disability can apply to the Ontario Disability Support Program (ODSP) which is designed to meet the unique needs of people with disabilities who are in financial need, or who want and are able to work and need support. It is directly operated by the Ministry and the program has two components: Income Support; and Employment Supports.</p> <p><u>Income Support</u></p> <p>Income Support provides financial assistance and other benefits to eligible people with disabilities and their families. This includes accommodation and basic living expenses, as well as prescription drugs and basic dental care.</p> <p><u>Employment Supports</u></p> <p>The ODSP Employment Supports program works with community service providers to help people with disabilities prepare for and find jobs, keep a job and advance their career. The program can also help people with disabilities become self-employed.</p> <p>Some examples of the supports that may be available include:</p> <ul style="list-style-type: none"> Job coaching On-the-job training Adaptive software and mobility devices Interpreter/intervenor services Transportation assistance Assistive devices and training to use them Tools and equipment Special clothing Specialized computer training Other items that may be needed for work.
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A Credo for Support

**Do Not see my disability as the problem.
Recognize that my disability is an attribute.**

**Do Not see my disability as a deficit.
It is you who see me as deviant and helpless.**

**Do Not try to fix me because I am not broken.
Support me. I can make my contribution to the community in my way.**

**Do Not see me as your client. I am your fellow citizen.
See me as your neighbor. Remember, none of us can be self-sufficient.**

**Do Not try to modify my behavior.
Be still & listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.**

**Do Not try to change me, you have no right.
Help me learn what I want to know.**

**Do Not hide your uncertainty behind "professional" distance.
Be a person who listens, and does not take my struggle away from me by trying to
make it all better.**

**Do Not use theories and strategies on me.
Be with me. And when we struggle with each other, let that give rise to self-
reflection.**

**Do Not try to control me. I have a right to my power as a person.
What you call non-compliance or manipulation may
actually be the only way I can exert some control over my life.**

**Do Not teach me to be obedient, submissive, and polite.
I need to feel entitled to say No if I am to protect myself.**

**Do Not be charitable towards me.
The last thing the world needs is another Jerry Lewis.
Be my ally against those who exploit me for their own gratification.**

**Do Not try to be my friend. I deserve more than that.
Get to know me. We may become friends.**

**Do Not help me, even if it does make you feel good.
Ask me if I need your help. Let me show you how you can best assist me.**

**Do Not admire me. A desire to live a full life does not warrant adoration.
Respect me, for respect presumes equity.**

**Do Not tell, correct and lead.
Listen, Support, and Follow.**

**Do Not work on me.
Work with me."**

Dedicated to the memory of Tracy Latimer

**--Norman Kunc and Emma Van der Kliff
Copyright 1995**

Community Living Owen Sound & District

CLARIFYING OUR VALUES

The Core Values represent the shared perspectives of the people within Community Living Owen Sound & District, self advocates, families, leadership and staff. To further our understanding of how the Core Values shape our work, we have included the interpretation of the Core Values by representatives of the self advocates group (in italics).

Dignity and Worth of Every Person

We need to get to know the person first and then discover their needs. This value reminds us of the wholeness (mind body and spirit) of the people we support.

*"I am appreciated for who I am.
My situation is unique and never like a text book."*

Mutual Respect and Healthy Relationships

We will treat others as we would want to be treated. We recognize that everyone has their own path in life. Our interactions will be based upon an understanding of differences and respecting of choices.

*"Respect goes both ways in healthy relationships.
I want to be respected and I will respect others."*

Family and Friends

Our primary concern is for the person we support and we will encourage and honour the participation of family and friends within a circle of support.

*"I am part of a circle of family and friends
and that is important to me."*

Privacy and Confidentiality

We will respect privacy and treat all personal information with the utmost confidentiality and we will abide by Community Living Owen Sound and District's confidentiality policy.

"Respect everyone's privacy and property."

Informed Choice

We will act as a resource and assist in gathering information to assist the people we support in the process of making life choices.

*"Support me in making informed choices,
so that I can fulfill my dreams."*

Risk, Opportunity and Lifelong Learning

We will ensure that the integrity of the persons we support is protected without compromising basic safety and security.

*"There is good risk and bad risk. I want the
Opportunity to learn and try new things. If I mess up, nobody
says I told you so, but I can learn from that experience."*

Community Inclusion

We will assist the people we support in building relationships and encourage a sense of belonging. Inclusion will be based on the concepts of:

- preferences, i.e. what people like and want to do;
- opportunities, i.e. what is available; and
- choices, i.e. the ability to make use of opportunities to satisfy one's own preferences.

*"Being included and participating in things I
enjoy is important to me."*

Communicating Effectively with Persons with Developmental Disability¹

- Patients are likely to have communication difficulties; become familiar with their means of communication, including any device they may employ.
- While they may have trouble speaking, they may be able to understand what is said to them. Differences in muscle tone may make it hard to read facial expressions.
- Patients with poor language understanding rely on routines and cues from their environments to understand or anticipate what will happen
- It will generally take more time to communicate. Non-verbal communication techniques may be required.

ISSUE	SUGGESTED COMMUNICATION TECHNIQUES
ESTABLISH COMMUNICATION Try to speak directly with the person, rather than a family member or support worker. Avoid treating them as a child or in patronizing tones	<ul style="list-style-type: none"> ➤ Do you want the support worker to stay in the room for this visit? ➤ If possible involve someone familiar with communication technique. ➤ Ask simple introductory questions (e.g., name, DOB, reason for visit). ➤ Gain their attention and eye contact if possible by using their name or with touch before speaking. ➤ Determine how they communicate: How do you say, 'Yes'? 'No'? ➤ Do you use a device? Can you show me how to use this machine? ➤ Use open-ended questions. Slow down rate of speech.
EXPLAIN CLEARLY Explain what is happening before you start. Use brief, simple sentences. Tell or show what you are going to do and why.	<ul style="list-style-type: none"> ➤ Avoid jargon. ➤ Rephrase questions, if necessary. ➤ Use concrete language, such as: "Show me"; "Tell me"; "Do this" (with gesture); "Now"; "Is it easy ...?"; "Is it hard ...?"; "Come with me"; "It's time to go when ..."; "I'm going to" ➤ Do you understand? Do you agree?
CHOOSE LANGUAGE CAREFULLY Do not shout Avoid abstract language	<ul style="list-style-type: none"> ➤ The concept of time may be difficult. Use examples from their daily routines (e.g. breakfast, lunch, dinner) and familiar routines in their life. ➤ Avoid phrases such as: "Why?"; "Wait!"; "Later"; "What are you feeling?"; "Let's get started!"; "Get ready!"; "Ask for help".
LISTEN Listen to what they try to say Let them know you understand Allow enough time; may take time to answer questions	<ul style="list-style-type: none"> ➤ Tell them when you do not understand them. ➤ If you have trouble ask them to repeat; "Can you repeat what I said in your own words?" ➤ Wait at least 10 seconds for a response. Allow time. ➤ Visit will likely take more time than usual; may take several consultations to complete a full assessment and examination.
SUPPLEMENT VERBAL COMMUNICATION Visual Acting	<ul style="list-style-type: none"> ➤ Use pictures or simple diagrams and gestures. ➤ Allow them to handle and explore equipment. ➤ Act out actions or procedures. ➤ Use picture language when explaining: find sign in their communication book. "It looks like " (objects familiar to client).

References: The Bridging Project 2006; McTear 2006; Therapeutic Guidelines 2005

Communicating Effectively with People with Developmental Disabilities (DD)

- People with developmental disabilities (DD) are likely to have communication difficulties.
- It will generally take more time to communicate.
- An assessment of language skills helps to choose the level of language to use. Talking with someone with a mild DD is very different than talking with a person with a moderate or severe DD.
- Many people with DD have stronger receptive (understanding) communication skills than expressive skills. Assume that the person with DD can understand more than he/she can communicate.
- Conversely, the person's expressive speech may sometimes give an impression of better comprehension than is actually the case, so check the person's understanding.
- People with DD have a variable, and sometimes limited, ability to interpret their internal cues (e.g., need to urinate, anxiety). They may not be able to give you an accurate picture of their feelings and symptoms. Involving caregivers who know the person well may help you to better understand his/her subjective experiences. However, continue to focus your communication efforts on the person rather than his/her caregiver.
- If you are in a busy area with many distractions, consider moving to a quieter location to minimize environmental distraction.

GOAL	SUGGESTED COMMUNICATION TIPS
ESTABLISHING RAPPORT	<ul style="list-style-type: none"> • Speak directly to the person with DD, not to his/her caregiver(s). • Ask the person: "Do you want your support worker to stay here for this visit?" • Explain at the outset the purpose and process of the meeting in simple terms.
SPEAK DIRECTLY WITH THE PERSON	<ul style="list-style-type: none"> • Ask simple introductory questions (e.g., name, reason for visit). • Gain the person's attention and eye contact if possible by using his/her name or by touching his/her arm prior to speaking.
AVOID TALKING TO AN ADULT AS IF HE/SHE WERE A CHILD	<ul style="list-style-type: none"> • Determine how they communicate: "How do you say Yes? No?" "Do you use a device? Can you show me how to use this book/machine?" • If the person uses a communication technique or device, involve a caregiver who is familiar with it. • Show warmth and a positive regard. • Encourage the use of "comforters" (e.g., favourite item the person likes to carry, or a preference for standing and pacing rather than sitting). • Show interest in a precious object the person is holding on to. • Some people (e.g., with autism spectrum disorders [ASD]) prefer to avoid eye contact. This should be respected. • Use positive reinforcement and focus on the person's abilities rather than disabilities.

GOAL	SUGGESTED COMMUNICATION TIPS
CHOOSING APPROPRIATE LANGUAGE	<ul style="list-style-type: none"> • Use plain language. Avoid jargon. • Use short, simple sentences. • Use concrete as opposed to abstract language, for example: "Show me"; "Tell me"; "Do this" (with gesture); "Now." "Come with me"; "I'm going to..." • Use "Put your coat on" instead of "get ready." • Use "Are you upset? Are you sad? Are you happy?" instead of "What are you feeling?" • The concept of time is abstract and may be difficult to comprehend. Use examples from daily and familiar routines (e.g., breakfast, lunch, dinner, bedtime). • Ask or test whether the person wants you to refer to him or her in the third person (e.g., he, she, or name) rather than the second person (e.g., you).
USE CONCRETE LANGUAGE	
AVOID SHOUTING	
LISTENING	
LISTEN TO WHAT THE PERSON SAYS	<ul style="list-style-type: none"> • Let the person know when you have understood. • Tell him or her when you do not understand. • Be sensitive to cues and tone of voice. • It may be difficult to read facial expressions or body language because of differences in muscle tone. You may need to check/validate your perceptions.
ALLOW ENOUGH TIME	<ul style="list-style-type: none"> • Tell the person when you do not understand him/her. • Be aware that the visit will likely take more time than usual and that several consultations may be required to complete a full assessment.
EXPLAINING CLEARLY	
EXPLAIN WHAT WILL HAPPEN BEFORE YOU BEGIN	<ul style="list-style-type: none"> • Speak slowly. Do not shout. • Pause frequently, so as not to overload the person with words. • Give the person with DD enough time to understand what you have said and to respond.
TELL AND SHOW WHAT YOU ARE GOING TO DO AND WHY	<ul style="list-style-type: none"> • Rephrase and repeat questions, if necessary, or write them out. • Check understanding. Ask the person: "Can you explain what I just said?" "Can you explain what I am going to do and why?" • If you are unsure whether the person has understood, ask, "Can you repeat what I said in your own words?"
COMMUNICATING WITHOUT WORDS	
USE VISUAL AIDS	<ul style="list-style-type: none"> • People with poor language understanding rely on routines and cues from their environments to understand or anticipate what will happen. • Use pictures or simple diagrams and gestures (e.g., basic sign language). • Some people with DD may express themselves only in writing. • Allow them to handle and explore equipment.
ACT OR DEMONSTRATE	<ul style="list-style-type: none"> • Act out actions or procedures. • Use picture language when explaining; find signs in their communication book: "It looks like ..." (point to objects familiar to the person with DD). • Point to a body part or mime a procedure (e.g., checking ears).

Resources

The Easy Health Organization in the U.K. has developed downloadable leaflets to help physicians talk with patients in plain language about common conditions: www.easyhealth.org.uk.

The hospital communication book (2008). Developed with the Surrey Learning Disability Partnership Board (U.K.), this is a practical guide to help people who have difficulty communicating due to impairments with learning, sight, hearing, or speech, to get equitable service in hospital. It contains clear pictures that can aid communication with health professionals: www.mencap.org.uk/document.asp?id=1480.

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Revisiting Choice - Part 1

by Michael W. Smull
AAMR's News and Notes

Choice is the most powerful word and the most abused word in the current lexicon of the disabilities services system. For some people choice means that how they want to live has been discovered and carefully supported. For others choice is an excuse or the basis of a bizarre rationalization. Perhaps because choice is the word de jour, it has been used to argue that congregate facilities are needed in order to ensure residential "choice". An even more egregious example is justifying the use of pain to control behavior to allow "choice among a full range of treatment options". (The same argument could be made to retain "bleeding" as a treatment option for the flu.) Other abuses are more subtle. When you look behind the rhetoric of agencies which say "we offer and teach choice", you find places that ask people what they want to wear but not who they want to live with. What appears to be absent is depth of understanding and a sense of balance. A single word is being used for complex concepts. Too often, there is no recognition of the need for an individual balance between honoring choice and ensuring safety.

Preferences, opportunities, and control Choice, as it is being used in current disability discussions, appears to have 3 related concepts embedded in it - preferences, opportunities, and control.

Preferences include not only what someone likes but also their desires and dreams. Preferences includes: who people want to spend time with; what to do during that time; and where to spend their time.

Opportunities are the available array of: people to spend time with; things to do during that time; and places to spend that time. Opportunities should also include being able to spend time by yourself. Preferences reflect what people want while opportunities reflect what is available.

Control is the authority to make use of an opportunity to satisfy a preference.

Looking at preferences, desires, and dreams Any effort to support choice should start with discovering what is important to the people who are being supported. What do people want in their relationships with others? How do people want to spend their time? What do people want to do (and not do)? What kinds of environments in general and what specific places do people want to spend time in or avoid? Do people have dreams about how they would like to live and do they have nightmares about what they are afraid will happen to them? While answers to these questions are sought (with varying degrees of emphasis) in all of the formal processes for person centered planning, careful efforts are required.

Many people lack the life experiences necessary to know what they like and dislike Will something that sounds desirable to a person feel that way when it is experienced? Some people want to try things or live in ways that put their safety or health (or both) at risk Many people need to have a life of their own before they can have a dream of their own. As people try things (and as they age) their preferences change. In a system that offers real choice, people continuously have opportunities and are continuously supported in expressing their preferences. Supporting choice requires that there be recognition that everyone has preferences and desires regardless of the severity of disability. Supporting choice also requires that we recognize that what we need to know is taught by the people that we support. Some of what my colleagues and I have learned about preferences from the people that we have listened to follows.

We have taught learned helplessness, now we need to teach trust Many people have experienced systematic ignoring of their preferences. This is an unintended consequence of current "individual" planning and professional practice within the disability system. We cope with the poverty of opportunities for the people we support by suppressing their preferences for what is absent. "Learned helplessness" has been taught and many of those we support have learned this lesson well. For these people, what needs to be taught is that we can be trusted.

Trust is "taught" by having those with control listen to all expressions of preference and, where possible (and sensible), to help people get what they want. "Teaching choice" is a poor label. Those who teach must remember that they are not "offering choices" but soliciting preferences and then demonstrating that staff can be trusted to honor the preference expressed. Staff must learn to acknowledge the preferences that people are expressing with their behavior while not asking what people want until there is a commitment to honor their requests.

Shouting (with behavior) has been the only way to be heard Most of us have had the experience of raising our voices in the belief that it will increase understanding. We shout so that we will be heard. A number of people with disabilities have learned to "shout" with their behavior because it is the only way that they are heard. If you do not like your current job, complaining about it does not produce change. Acting in unacceptable ways does produce change. Complaining about who you live with is unlikely to get you a new roommate, but aggression often works. "Shouting" gets our attention, but rarely gets people what they really want. We need to listen for the preference that is underneath the shouting. Once real preferences are understood (and acted on), the need for "shouting" with behavior is eliminated (although the person may always be someone who has a loud "voice").

Most of what people want is modest What people want is usually modest. When critics say that we cannot afford choice they have typically confounded what is important to people with what might be nice to have. There is also a difference between learning what is important to people and taking someone on a guided fantasy. Careful planning discovers preferences such as: having a say in who helps me; having privacy in the

bathroom; being asked not ordered; going for a walk when I want; and (for one person who uses a wheelchair) to be able control the direction in which I face.

A few people's desires are not modest. While the vast majority of people have modest desires, there are a few people who sincerely want frequent trips to the tropics, a car continuously at their disposal, and support staff who take on the role of servants. They may see these as essential to a reasonable quality of life. They are "virtual yuppies", without the income needed to support their desired lifestyle. They are also unusual, as careful planning identifies very few people with these expensive tastes. Where rational decisions are being made about allocation of resources, these people are disappointed with the outcome.

Some people have reasonable requests that are difficult to afford. The fact that someone wants something, even if they see it as very important, does not mean that it has to be delivered. However, we do have an obligation to respond to sincere requests as we can. For example, there are many people who would like to try living by themselves. The cost of support (in staff and housing) presents a real challenge to those attempting to create a system of support. The demand for living alone is somewhat reduced when there is more careful listening. For example, some people really do not want to live alone but simply do not want to live with other people with disability labels. Other people have always had to share lives (e.g. it is Tuesday so we all go bowling) and have not learned that you can also live with someone where you only share space.

After these situations have been clarified there are still many people who simply want to have the experience of living by themselves. Where people have been able to live by themselves for a year or two many would like to have a roommate for company (but not to share lives with). Some people, however, find that living alone is the only way they wish to live. The support costs for most of these people decline dramatically as behaviors change, skills are learned, and connections to the community are built. However, the cost of support for some people remains high. From the perspective of a system, a small percentage of people can always be supported in relatively expensive lives. The challenge is to not have that percent exceed the resources available.

What people don't want is as important as what they do want. In learning people's preferences, it is important to discover what they dislike. Simple lists are not adequate, we must go beyond a statement that George likes barbecues and dislikes broccoli. We have a significant degree of control over who we spend time with and what we do. We use that control to avoid people and activities that we strongly dislike. People with disabilities have not had that control. In the absence of being able to "vote with your feet" we need to insure that those things that people hate or strongly dislike are absent.

Choice making is not a solitary activity Figuring out what we want is usually not a solitary activity. To tell people that yesterday we made the choices and that today they are in charge is to ignore that few of us make significant choices without discussion. Before we make major decisions, such as changing jobs or changing partners, we have typically discussed the "pros and cons" at some length. We seek advice, support, and

people who just listen. We strive to determine what is right for us. We frequently get conflicting advice and pick the advice that agrees with what we want. We reserve the right to make "bad" choices after we have heard the "good" advice. People with disabilities need the same opportunities.

What people ask for may not be what they want People will ask for those things that they know about. One woman who was being assisted in leaving an institution said that she wanted to move to a "group home". One man said that he wanted to live alone. The woman who said that she wanted to live in a group home spoke very little English. She knew that she wanted to leave the institution and the only place away from the institution that she knew of was a "group home". The man who said he wanted to live by himself thought that the only choices that existed were to live by himself or with other people with disabilities. The woman is living happily in supported living and the man is living in a house that he wanted where he rents rooms to 5 people who have no formal disability labels.

When people express a desire for a job (or anything else) where their disability or circumstances preclude obtaining what is asked for, we need to listen to what lies beneath the surface. One man said he wanted to be a pilot. After a lot of discussion we discovered that while he did want to be a pilot he also just loved airplanes. We could not help him become a pilot but we could help him get a job at an airport.

Some years ago I worked with another man said that he wanted to have a job just like his father's. His father is a well known research scientist with the federal government who determined what projects got funded. Many conversations later we found that the characteristics that mattered to him were that he be treated with the same respect that his father received and that he wear a tie to work. We helped him find a job where he wore a tie and ran a large copying machine at a facility that did scientific research. If you were a scientist who wanted your latest journal article copied you went to his copy center. If you just filled out the form your article would get copied in turn, if you treated him with "respect" he would do your copying while you waited.

Sometimes what people want is not possible A woman I met in the Midwest, Susie, wants to live with her mother. It is so important to her that she sees it as the only acceptable place for her to live. Unfortunately this is not possible. Susie had lived with her mother for several decades and mother had been the person who provided care and support. After a sudden loss of capacity Susie left her home and entered a hospital and then a nursing home. The supports necessary to support Susie in her mother's house are available and affordable. However, Susie's mother would not agree to her return regardless of the supports that could be provided. This is not to disparage Susie's mother. She continues to be deeply caring and intimately involved in Susie's support, but she is "burnt out" as a caregiver.

In these circumstances our obligation is to acknowledge and honor the positions of both Susie and her mother. Honoring her mother's position requires that we not use guilt or otherwise coerce her to support Susie's return to her home. It requires that we support

her in developing her new relationship with her daughter. Honoring Susie's position requires that we acknowledge what is important to her and help her get on with her life. We have to avoid the temptation to deny the presence of a preference that cannot be realized. We also have to help Susie deal with a very real loss and to help her begin to develop new relationships. She needs support in her changing relationship with her mother and in developing new relationships.

Helping people be safe and happy requires thought and effort. One of the traps of the current system of planning is that we determine how people can be safe before we look at what they require to be happy. We forget that there is no such thing as a risk free life, that risk is relative and has a context. What we need is to begin with an understanding of what is required for the "pursuit of happiness" and then seek to reduce or avoid risk within that context. What is not acceptable is to simply say it was his choice, that is why I stood by while he hurt himself. Helping people be happy and safe requires thought and creativity. The following stories give some examples of the efforts needed.

A story that I enjoy telling (and writing about) is that of a man who wants to go for walks whenever he wants and who also thinks that, when he crosses a street, traffic should stop for him. The initial thinking was that he needed one to one staffing across all waking hours. The cost of the staffing necessary for a couple of walks each day was an expense that was disproportionate to the result. On the other hand not being able to go for walks on his schedule significantly reduced the quality of his life. Further discussion lead us to realize that this man would be happy to live in a rural setting. He moved to a house on a five acre Christmas tree farm where he goes for walks whenever he wants without having to cross a street.

One man that we did planning with liked to use "found objects" in his art projects. The challenge was that he would "find" objects in stores and leave without paying for them. He understood the concept of money but was remarkably uninterested in it. The people who supported him could have said that it was his "choice" and let him be arrested. Instead they would go to stores with him, with his money in their pocket. (He would give his money away if it was in his pocket.) As they left each store the support staff would ask if he had "found" something in that store and, if yes, the staff would pay for it.

We got a phone call several years ago from a service provider asking for help with someone who was severely injuring himself. This man is now described as a tall, charming, ladies man who does not use words to talk. At the time, his brother said that he looked like a hockey goalie with the helmet and all of the padding that he wore to keep from injuring himself. There were people who said that he needed a "more restrictive" setting and there were people who said that pain should be used to control his behavior. The service provider could have argued that an institution would be the "safe place" for him to be. Instead we were asked to help the provider "listen" to what this man was asking for.

After listening to what he was saying with his behavior and after listening to what those who loved him knew, we found that there was no single answer. However, there were a

host of simple things that we could do. There were many ways in which we were not listening to how he wanted to live. Some examples include that he: needs to close all doors (except for his bedroom door at night) and to line up all shoes; must be able to make and eat his own snacks when he wants them (including raw onions with salt); must not be ignored (even if it is planned); and he must always have a non-glossy magazine to hold onto. His life is not perfect and he still gets upset occasionally. On these infrequent occasions he still needs people who keep him from hurting himself. However, because we have been listening carefully to what he is asking for he is living in his community. He lives (and goes to concerts with his brother) without pads, splints, or a helmet.

Choice requires opportunities and sharing control A preference is something that people want. Unless they have already experienced it they will not know whether or not they like it or not. Many people with disabilities have never had the life experiences necessary to determine how they really want to live. Honoring choice for these people requires opportunities and taking advantage of the opportunities may require encouragement. As people begin to find that their choices are honored they want control over those choices. Honoring choice requires that control is shared. This is the subject of part 2 of revisiting choice.

Revisiting choice - part 2

Choice, as we are using it, is a simple word that contains 3 concepts - preferences opportunities, and control. Learning people's preferences is a complex and on-going activity. What people want (and the values that underlie their desires) provide a picture of how people want to live. This was the subject of part 1 of "revisiting choice". However, learning how people want to live is only the beginning. It is the necessary foundation but just the foundation. In order to get the life that you want and to maintain it you need opportunities and control.

For people with disabilities the absence of control and opportunities is a devastating combination. Flooding people with opportunities or simply handing over control can be equally devastating. Everyone needs opportunities and everyone needs control but they need them on their own terms. People who have never had opportunities need to sample life in their own way. Some people need to dive in. They do not want and cannot tolerate transitions. Others are most comfortable with first putting a toe in. They want lengthy and careful transitions. Both need the control necessary to change their minds. Some people have been demanding control over significant aspects of their lives and we have seen them as having challenging behaviors. Some have given up hope and we see them as withdrawn or even as compliant. However, regardless of the severity of disability, people want control over parts of their lives.

Providing opportunities, sharing control. Having control is how we maintain a balance in our own lives. Each of us needs control sufficient to keep (or secure) what we value in our lives and to reject (or leave) situations that we cannot stand. One definition of emotional health is that we recognize what a balance is and that we recognize opportunities that enable us to maintain or enhance that balance. That is, we are able to use opportunities to get more of what we value or less of what we dislike. Control is what allows us to try new things and discard them when they do not fit. Control is what we require when we find our lives out of balance and we look for the opportunities that will bring a positive balance. The situations we find the most frustrating are those where we lack control and/or where the opportunities that we need are absent.

Control is a complex concept. Having control means that we have to make decisions and all of us create a set of positive rituals or routines that allow us to get through much of our day without treating each situation as if it were new. Most of us do not want absolute control. We may joke that if we were in charge of the world we could fix things, but most of us want (and welcome) limits to the areas where we have to make decisions. We conform to large sets of societal rules without much thought and only remark on those few areas where we disagree. Those of us who live with others find that we have to share control. Each of us has our own rules that we insist that our partner honor and our partners expect the same of us. Where expectations regarding behavior are not met, or are mutually exclusive, conflict arises. The outcome of a resolved conflict is a mutual agreement on the behaviors expected. Our vision of the best outcome is that our

partners will see the error of their ways and the wisdom of our words. A more rational outcome is that each of us will better understand the other and make the compromise that works for the relationship. In reciprocal relationships control is shared.

If we apply what works for everyone to people with disabilities, then we should be helping people with disabilities to have sufficient control to maintain a balance in their lives and to create their own rituals and routines. We should help them develop relationships (both paid and unpaid) where control is shared. A brief description of what the disability system should be doing is: to discover how people want to live; provide them with the opportunities necessary to get the lives they want; and help them have the control needed to maintain it. Many of the challenges in doing this arise from the disabling environments in which people have lived. We have created these environments with a binary view of control. Either I have control or you have control. The idea that control can and should be shared seems to be an alien concept.

Control, opportunities, and preferences as developmental triplets. Parents support the development of their children by asking the child to choose from alternatives and then honoring the choice the child makes. As children grow in capacity and experience the span of control gets broader. Children may move from what they will wear, to when they will go to bed, to how they spend most of their waking hours. They move from nearly constant supervision to doing what they want within defined (and often disputed) boundaries. Parents transfer control slowly. All parents worry about whether their children are "ready". When a child breaks a rule about the boundaries of behavior the child loses control for a time (smaller children may go to their rooms, older children may be "grounded"). Parents share control with their children while they are transferring it. Typical children go through phases where they rely on their parents control for most things, go through a period where they both want and do not want parental control (teenagers can simultaneously tell their parents that they are ruining their lives while wanting limits to push against), and end up, as adults, with control regardless of their parents desires.

For people with disabilities the analogy with the developmental process that children pass through is both helpful and dangerous. It is helpful in that it provides some guidance as to where someone is and how we might help them move forward in a safe and rational way. The analogy breaks down as the inevitability of autonomy for typical children is not present for people with disabilities. It is dangerous in that we are talking of supporting adults who may have already been trapped by developmental concepts such as mental age.

Control and capacity. How much control we have and what we have control over should be a function of desire and capacity. However, our stereotypes of people with severe cognitive impairments cause us to over look the capacities that are present. I have met a number of people who do not use words to talk but who are good at training staff in listening to their behaviors with regard to what they want. They demonstrate a much greater capacity for (and interest in) controlling their lives than they are given credit for. At the same time we need to recognize that positive control is learned and

control should be coupled with a knowledge of consequences.

We need to ask what are people asking for and how can we help them get it without putting them at unnecessary risk. It can be as simple as supporting Rhonda, who uses a wheel chair, in being where she wants to be. Any sunny warm day she will want to go outside and enjoy the sun. Unfortunately she is also very allergic to pollen and needs to be told, on days with a high pollen count, that she would not enjoy the consequences of going outside.

Timing and opportunities. Timing is important in how people respond to opportunities. We tell our friends that we are not ready or that we will do it when we are ready. Opportunities have a developmental sequence, people need to be offered what they are ready to try. What people are ready for and when they will be ready requires judgment. Given the uneven, but generally impoverished, life experiences that people have had they need to be encouraged to try new things. They may need to have an opportunity presented again and again. Judgment is required to determine where encouragement stops and coercion starts. At the same time a lack of experience coupled with uneven deficits in skills and capacities makes people more vulnerable. Opportunities can lead to injury and judgment is again required. There is little growth that comes without risk. People need to be able to fail and to feel hurt. Supporting people in having opportunities so that we will know what they will want tomorrow is as important as it is to learn what people want now.

What opportunities we provide, hold back, encourage people to find, or protect people from, depends as much on our values as they do on the preferences and capacities of the people we support. We need to listen to ourselves when we say that someone is not ready or that they should be able to do something simply because it is their choice. Our values influence and often control what we support. We need to talk about what our values are so that we understand the basis on which we are making decisions. We need to remember that the opportunities that are made available depend on the values of those with control.

Looking for control. Most of us seek, and to a large degree achieve, the amount and kind of control that we want over major aspects of our lives. Control is part of what gives us the predictability that we value. One of the more devastating feelings that people report is being out of control or experiencing a loss of control. When we have less control than we desire, increased emphasis is placed on the control that remains. For people with disabilities who live in very controlled settings control is sought where ever it can be found. Some of the behaviors that we want to change around food, aggression, self-injury, and sexuality are a reflection of a lack of desired control over other aspects of life. When people gain positive control over their lives the behaviors that have caused us concern may diminish and with some people vanish.

The difference between sharing control and giving control. Control is not a fixed quantity. It ebbs and flows in our relationships and it can ebb and flow with the people we support. An agency in North Carolina that is supporting people with severe and

persistent mental illnesses as well as cognitive impairments sees control as moving toward the person supported whenever possible but also returning to staff when the person supported has an acute episode. Someone with a severe seizure disorder maybe able to do some things when the seizures are under control and should not have the same opportunities when the seizures are not under control.

Rethinking choice. Our recent history is filled with stories of people whose lives were totally controlled who now live in happy interdependence. People who were seen as not competent to select what to wear are now living in their own homes. We are also hearing of the people who have been injured when some one used choice as an excuse to not think. We need to recognize that the people we support are the experts on what they want while we are their partners in helping them get it. We need to have relationships where we share control and continuously support people in gaining as much control as is possible. Many people, especially those with severe disabilities are only asking for modest control. They want to be able to: control the pace of life (to not be rushed); to be listened to (to only got to bed when they are sleepy); and to have a say in who their staff are (to only be supported by people that they trust).

In our relationships we should help people grow and remember that there is a dignity to risk. At the same time there is no dignity in serious injury. We need to see the key to growth as starting with understanding what people want today and then helping people find opportunities so that they will know what they want tomorrow. We need to recognize that everyone wants and needs control over some aspects of their lives. Our jobs include supporting people in gaining that control.

Baltimore August, 1995

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Genetic Assessment: Frequently Asked Questions

Etiologic assessment is often helpful in planning preventive care, treatment, and management strategies. Many adults whose developmental disabilities (DD) are of unknown origin may benefit from etiologic assessment or reassessment.

Contact a local Genetics Centre for help in deciding whether to refer, and for the referral criteria and protocol.

How do I find the nearest Genetic Centre for my patient?

Contact information for Genetic Centres in Canada is available at <https://cagc-accg.ca/>.

Are there ways of determining the likelihood of a patient's having a genetic etiology for his/her DD, so as to prioritize whom I should consider referring?

The chances of individuals having a genetic etiology for their DD generally range from greater to lesser likelihood in the following order:

- Family history of DD.
- Congenital malformations.
- Dual diagnosis (DD and co-occurring mental illness). If possible, patients should be seen by a knowledgeable psychiatrist and/or clinical geneticist who can identify those more likely to have a genetic etiology, including those with a specific pattern of behaviours or with a specific psychiatric diagnosis.
- Severe to profound DD, congenital malformation(s).
- Mild to moderate DD, congenital malformation(s).

Why might a genetic assessment be helpful?

Optimal medical management

- A tailored medical and psychosocial management approach to address physical and mental health issues can be developed once the etiology is established. For example, people with Down syndrome have an increased probability of developing thyroid disease throughout their lifespan and will benefit from earlier and more regular screening than guidelines for the general population recommend.
- Identifying a genetic etiology can have health management consequences for other family members. For example, in the fragile X syndrome, pre-mutation carrier males and females have the potential to develop fragile X-associated tremor/ataxia syndrome and females have an increased risk of premature ovarian failure.

Family reasons

- The patient and other family members may want information about the cause of the DD and the risk of recurrence within the family.
- There can be substantial guilt about having a child with a DD. Knowing the cause can relieve parental guilt and provide reassurance. As well, with this knowledge, family members will be aware of and be able to address issues related to specific syndromes, such as by connecting with syndrome-specific organizations.

Is there a special referral form? What information is needed on the referral?

Contact or check the website of your nearest genetic centre.

- Helpful information to include in a referral:
 - Detailed reason(s) for referral.
 - Any previous genetic test results and the date of the test(s).
 - Copies of other pertinent investigations (e.g., MRI, echocardiogram).
 - Name and contact information of the Substitute Decision Maker, if needed, to provide consent for genetic testing.

Are there some tests I should do, as a family physician, prior to sending a patient with DD to a genetic centre?

- Currently some genetic centres request that fragile X molecular testing and karyotype (chromosome analysis) be done before the patient is seen for genetic assessment. Microarray analysis is a much more sensitive test that is replacing the karyotype. Call the genetics centre closest to you, or visit its website, for further information as to which tests are appropriate to do prior to referral, and for access to requisitions.
- The reasons for these tests and for a genetics referral should be discussed with the individual, his/her family, and/or the Substitute Decision Maker in order to obtain appropriate consent for undertaking them.
- Salient clinical information should be included on the requisition form.
- If you order a test and the results are abnormal (including any type of variant found on microarray or chromosome analysis and pre-mutation carrier status for fragile X), consult a clinical geneticist regarding implications and for patient and family feedback and counseling. Referral to a genetics centre is highly recommended. In some cases, parental studies may be undertaken through the genetics centre to assist in interpretation of results.

Is genetic testing covered by health insurance?

- In Canada, genetic assessment and some medical tests are covered by the provincial health care plan. The clinical geneticist may request some tests that are performed only outside Canada and may seek prior approval for payment for them from the provincial authorities.
- Private labs may charge a fee to take and transport a blood sample for some tests (e.g., molecular testing). Check with the service providers in your area.

Which diagnoses can be detected through genetic testing?

- Over 900 diagnoses are currently possible through genetic testing, a number that increases annually.
- Genetic testing diagnoses include single gene mutations, whole or partial chromosome duplications and deletions (including micro-duplications and micro-deletions), imprinting defects, and mitochondrial disorders.
- Relevant to the population with DD, examples of diagnoses from genetic testing include Down syndrome, fragile X syndrome, Prader-Willi syndrome, Williams syndrome, Smith-Magenis syndrome and 22q11.2 deletion syndrome. Some syndrome-specific reviews are available at www.ncbi.nlm.nih.gov/sites/genetests.

Which diagnoses are not primarily genetically determined?

- DD can be caused by factors other than genetic conditions, including infections, exposure to toxins/teratogens, and perinatal hypoxemia or trauma. Cerebral palsy and fetal alcohol spectrum disorders are examples.
- Such a diagnosis does not preclude the person from also having a genetic syndrome.

What happens when the patient and family members go for genetic testing and counseling?

- The patient and family members will meet with a genetic counselor and/or geneticist who will obtain a detailed patient and family medical history, as well as explain the reason for the genetic assessment.
- A physical exam is usually done by the geneticist. This may include measurement of salient physical features (e.g., facial ones), and photography of such features (with appropriate consent) for the individual's medical record.
- Possible genetic diagnoses may be reviewed and appropriate tests to help determine a diagnosis will be discussed. Consent to retrieve records may be requested.
- Information will be given so that the patient and family can provide informed consent with respect to the proposed genetic testing.
- Lab tests will usually be done, including blood or urine tests. In some circumstances it may be helpful to obtain other investigations such as a skin punch biopsy, X-rays, ultrasound, CT or MRI scans. Referral to other specialists may also be recommended.

How are test results communicated?

- Results are normally reported to the referring physician and communicated to the patient, family and/or Substitute Decision Maker by the geneticist. This may include providing a genetic diagnosis and offering further counseling.
- Genetic changes causing DD can occur sporadically or may be hereditary. Potential consequences of a hereditary disorder, the likelihood of developing it or transmitting it to one's children, and whether there are means to prevent it or lessen any of these effects would be discussed.
- Reproductive options should also be discussed at the request of the patient and/or family members.

How does management of the patient proceed?

- Management may be through the geneticist, family physician or other specialist, depending on the condition, the needs of the patient, and available resources.
- If no etiology is determined, periodic reassessment is recommended.

Resources

www.geneticresourcesontario.ca This online guide for health care providers and the public includes a list of genetic centres and specific genetic services in Ontario.

www.mountsinai.on.ca/care/family-medicine-genetics-program/family-medicine-genetics-program
This Canadian website gives primary health care providers current practical information regarding screening and prevention of hereditary disorders.

www.ncbi.nlm.nih.gov/sites/genetests Provides "Gene Reviews," expert-authored peer-reviewed disease descriptions.

www.askthegen.org This website of the Department of Human Genetics at Emory University, "Ask the Geneticist," answers questions about genetic concepts, and the etiology, treatment, research, testing and predisposition to genetic disorders.

"Genetics through a Primary Care Lens" at

www.genetests.org/servlet/access?id=8888892&key=VVeQo6NaqTUT8&fcn=y&fw=W5jm&filename=/tools/index.html US National Institutes of Health Genetic Tools website provides background information, teaching cases, and links to other resources for primary care providers, including a section on Developmental Delay and Genetics at a Glance.

Developed by: *Cynthia Forster-Gibson, GP Practising in Clinical Genetics*

Informed Consent in Adults with Developmental Disabilities (DD)

Primary care providers initiate the consent process for a person with DD when:

- (1) A new treatment or a change in treatment is proposed, unless it had been accepted through a previously agreed-to 'plan of care.' Consent should be obtained not only for treatment/management but also for assessment/investigation, especially if invasive. The health care provider who proposes a treatment/investigation has the obligation to obtain consent to administer it from the patient, if capable, or from his/her legally authorized Substitute Decision-Maker (SDM).
- (2) There is a change in the patient's ability to understand the nature and effect of the treatment. This change can be positive as well as negative (e.g., the patient may develop new skills that facilitate their giving consent, or his/her function may deteriorate and thus require a SDM.)

STEPS INVOLVED IN THE CONSENT PROCESS

A. Determine Capacity (see Checklist C)

- **Capacity** refers to the mental ability to make a *particular* decision at a *particular* time; it is question- and decision-specific and should be documented relative to each decision. Assess capacity to consent for each treatment or plan of treatment. Even when a Power of Attorney (POA) for Personal Care exists, capacity for consent to the particular treatment at this time should be assessed.
- **Capacity is not static** but can change over time or require distinct abilities depending on the nature and complexity of the specific treatment decision. Specific capabilities may be lost or gained at different times during the life of a patient with DD. Situations may arise where consent to a treatment has been given or refused on a patient's behalf. However, if that patient then becomes capable of consenting to the treatment in the opinion of the health care practitioner, the patient's own decision would take precedence over that of the SDM.
- **Assessed capacity can vary according to the supports provided.** Involve the patient wherever possible by adapting the level and means of communicating to him/her; patients require functionally appropriate means of communication and support to realize their capacity for informed consent to, or refusal of, treatment. Offer information in a form you believe the patient will understand (e.g., pictures, symbols, gestures, vignettes). (See also *Communicating Effectively with People with Developmental Disabilities*.)
- **Involve others who know the patient best**, such as family members or paid care givers, to obtain information or to facilitate the patient's understanding and communication. Note that although paid care givers may provide valuable support for decision making, *they are not legally permitted to consent to or refuse treatment on behalf of a patient* in Ontario and in various other jurisdictions.
- **If the patient is incapable of giving consent**, or if there is uncertainty in this regard, follow appropriate legal procedures and ethical guidelines for assessing capacity. If incapable, delegate authority for decision making, which should be based on the patient's best interests in the circumstances. Generally, only patients with mild to moderate DD will be capable of consenting, whereas those with severe to profound DD will not have that capability but may be able to assent to a proposed treatment. Whenever possible, even when consent is obtained from a SDM, assent should be sought from the patient and be documented.

B. Obtain and Document Consent

- **Consent must be given voluntarily:** Allow sufficient time for the patient to understand, consider the information, and ask questions. If the patient requests additional information, provide a timely response.
- **Consent must be related to a proposed investigation or treatment and be informed by adequate disclosure:** The person obtaining consent should be knowledgeable and well-informed about the condition and proposed intervention.
- **Consent must not be obtained through fraud, coercion or misrepresentation:** The patient should not be under any duress or pain. It is important to be familiar with how the individual with DD usually exhibits pain (e.g., normal or unique pain responses), which may unduly affect decisions.

Name: _____

DOB: _____

C. Informed, Voluntary Consent Checklist and Sample Questions *

Inform the patient that you will be doing a capacity assessment with him/her. Do not assume that the patient will understand the connection between the illness and some consequent intervention.

Use the categories below to guide your assessment, and the examples below them if helpful.

- For each category of question, check Yes, No or Unsure.
- If the answer is No to any of these questions, the patient is not capable.

1. Does the patient understand that you are offering an intervention for a health problem?

e.g., What problems are you having right now?
What problem is bothering you most?
Do you know why you are in the hospital/clinic?

☐ Yes ☐ No ☐ Unsure

2. Does the patient understand the nature of the proposed investigation or treatment and the expected benefits, burdens, and risks?

e.g., What could be done to help you with your (specify health problem)?
Do you think you are able to have this treatment?
Do you know what might happen to you if you have this treatment?
Do you know if this treatment can cause problems? Can it help you live longer?

☐ Yes ☐ No ☐ Unsure

3. Does the patient understand possible alternative treatment options and their expected benefits, burdens, and risks?

e.g., Do you know different ways that might make you better?

☐ Yes ☐ No ☐ Unsure

4. Does the patient understand the likely effects of not having the proposed investigation or treatment?

e.g., Do you know what could happen to you if you don't have this (specify) done?
Could you get sicker or die if you don't have this (specify treatment)?
Do you know what could happen if you have this (specify treatment)?

☐ Yes ☐ No ☐ Unsure

5. Is the patient free from any duress (e.g., illness, family pressure) or pain or distress that might impair his/her capacity regarding the particular decision? (Note that a relatively minor illness can cause significant anxiety.)

e.g., Can you help me understand why you've decided to accept/refuse this treatment?
Do you feel that you're being punished? Do you think you're a bad person?
Is anyone telling you that you should or should not get this treatment?

☐ Yes ☐ No ☐ Unsure

6. Is the patient free from a mental health condition (e.g., mood disturbance or psychiatric illness) that may influence his/her capacity to give consent? (Note that having mental illness is not in itself an indicator of permanent incapacity. This factor may change once the mental health condition is treated.)

e.g., Are you hopeful about the future?
Do you think you deserve to be treated?
Do you think anyone is trying to hurt and/or harm you?
Do you trust your doctor and nurse?

☐ Yes ☐ No ☐ Unsure

Assessment:

DATE: _____ PRINT NAME: _____ SIGNATURE: _____

CAPABLE	NOT CAPABLE	UNSURE
<p>If "YES" to ALL of the above, and the patient can remember the information long enough to make a decision (verify by asking him/her to explain the information to you), then consider that capability exists to consent to or refuse the proposed treatment.</p>	<p>If "NO" to ANY of the above, then repeat the questions; you may need to repeat this process several times to ensure that the patient understands.</p> <p>If the patient still does not understand, he/she is incapable and a legal Substitute Decision Maker (SDM) should be assigned (see below).</p>	<p>Consult family, if not already done</p> <p>Consider seeking a second opinion from:</p> <ul style="list-style-type: none"> • Designated "capacity assessor" (e.g., for admission to long-term care and/or personal assistance services) www.ccboard.on.ca • Hospital ethicist/bioethics committee if available • Provincial regulatory College or Medical Association, especially if the decision is related to reproduction, genetic testing, chemical restraints, procedures, or end-of-life issues

D. Identify the Current Substitute Decision Maker (SDM)

If a patient is incapable of providing voluntary and informed consent, then consent must be obtained from the highest ranked eligible person identified in the hierarchy set out in the provincial regulations. That person is the Substitute Decision Maker (SDM).

The hierarchy in Ontario is as follows:

1. Guardian of the patient (under the Substitute Decision Act) with authority to provide consent to treatment
2. Power of Attorney (POA) for Personal Care (this individual may be a different person than POA for Property)
3. Representative appointed by the Consent and Capacity Board
4. Spouse/partner
5. Child older than 16 years of age/custodial parent or Children's Aid Society
6. Parent with right of access
7. Sibling
8. Any other relative (related by blood, marriage or adoption)

Note: In Ontario, a paid care provider cannot function as a SDM, although he/she can come to appointments and convey information.

E. Documentation

Document and Update Power of Attorney (POA) for Personal Care

- Even if a POA for Personal Care document exists, the physician should first assess present capacity of the patient before seeking the consent of the POA for Personal Care.
- Make sure to document and update the delegated POA for Personal Care, including specifying who (e.g., from social services) needs to initiate Power of Attorney delegation.
- If the parents have delegated SDM power to another caregiver, this should be documented.
- Document Plan of Care for Ongoing Treatment.
- Consent for treatment can apply over a period of time with a specified renewal period and may include items such as adjustment of medications. Having this consent and a documented plan of care is also useful for anticipated health problems, given the patient's current health status.

Document 'Circle of Care'^{b, c}

- Consists of all health care providers and support personnel who are permitted to rely on a patient's implied consent to collect, use or disclose his/her health care information for the purposes of providing health care. In a physician's office this includes physicians, nurses, specialists or other health care providers to whom the physician refers the patient, and health professionals selected by the patient (e.g., pharmacist, physiotherapist). In a hospital it includes the attending physician and members of the health care team who have direct health care responsibilities to the patient.

Advance Care Planning

- Discuss with patient and his/her caregivers and record (e.g., patient's preference for SDM, Advance Directives or a Living Will).

Cross-Cultural Sensitivity

- Be respectful of cross-cultural differences in communication styles.
- Seek consultation and input from members of the patient's cultural community, as necessary, to enhance communication.

^b www.mcmasterchildrenshospital.ca/body.cfm?id=209

^c www.ipc.on.ca/images/Resources/circle-care.pdf

F. Consent Required for Incapable Patients in Various Medical Situations in Ontario

(HCCA¹, CPSO²) Note: In Ontario, The Mental Health Care Act supersedes the Health Care Act.

EMERGENCY SITUATIONS

ACTION IF
CONSENT NOT
AVAILABLE

- Patient is experiencing severe suffering or is at risk of sustaining serious bodily harm if the treatment is not administered promptly.
- To save life or prevent serious damage to health.
- Treatment^d may be given **without consent** to an incapable patient if, in the opinion of a physician, there is an emergency and the delay required to obtain consent or refusal on the patient's behalf will prolong that patient's suffering or will put him/her at risk of sustaining serious bodily harm or death.
- Inquire if the patient has Advance Directives.

NON- EMERGENCY MAJOR

ACTION IF
CONSENT NOT
AVAILABLE

- Administering medications, or certain procedures (e.g., long-acting injectable hormonal substances for contraception, IUD insertion, draining an abscess).
- Testing for HIV.
- Providing treatment(s) for situations that pose substantial risk to the patient.
- Providing procedural sedation and analgesia in the Emergency Department.
- If there is no SDM or he/she cannot be contacted, only the Consent and Capacity Board can give consent.

NON- EMERGENCY MINOR

ACTION IF
CONSENT NOT
AVAILABLE

- Providing routine medical or dental treatments (e.g., check-up, ear syringe, nail cutting).
- Administering routine medications or adjusting doses.
- Providing topical anaesthetics or mild analgesia for minor procedures (e.g., laceration repair).
- If there is no SDM or he/she cannot be contacted then treat if patient assents or does not object, and treatment is necessary.
- Make a note in the patient record that he/she is assenting or not objecting and that treatment is necessary. Obtain consent from SDM as soon as possible.
- Defer or re-book.

^d**Treatment includes:** anything performed for a therapeutic, cosmetic or other health-related purpose, treatment plan, adjustments in the treatment, and continuation of the same treatment in a different setting.

Treatment does not include: assessing the patient's capacity to make decisions about treatment, admission to a care facility or personal assistance services, assessing the patient's capacity to manage property, taking a health history, assessing or examining a patient to determine the general nature of the patient's condition, communicating an assessment or a diagnosis, admitting a patient to a hospital or other facility, providing a personal assistance service, providing a treatment that in the circumstances poses little or no risk of harm or performing anything prescribed by the regulations.

References

1. Health Care Consent Act of Ontario, 1996. Chapter 2, Schedule A Ontario Regulation 856/93, as amended 2007 (made under the Medicine Act, 1991).
2. College of Physicians and Surgeons on Ontario Consent to Medical Treatment. Policy available at www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/Consent.pdf.

Resources

Consent: A Guide for Canadian Physicians, Third Edition, The Canadian Medical Protective Association, 1996.

The Mini Task Force on Capacity Issues, The Dementia Network of Ottawa (2007). Determining capacity to consent: Guiding physicians through capacity and consent to treatment law. *Dialogue*, 3(3) July 2007: 32-38.
www.cpso.on.ca/uploadedFiles/policies/policies/policyitems/capacity_consent_july07dialogue.pdf

U.K. Web Resource for determining capacity for persons with developmental disabilities:
www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics/

In Ontario: Consent and Capacity Board: www.ccboard.on.ca
 1 800 461-2036; 416 327-4142 Direct Line in Toronto
 Legal Aid Ontario: www.legalaid.on.ca
 Office of the Public Guardian and Trustee 1 800 366-0335
 Ontario Partnership on Aging and Developmental Disabilities: www.opadd.on.ca
 Psychiatric Patient Advocate Office (PPAO): www.ppao.gov.on.ca

Federal and Provincial Informed Consent Legislation Websites

Federal	Supreme Court of Canada Re Eve [1986] 2 S.C.R. 388 http://scc.lexum.org/en/1986/1986scr2-388/1986scr2-388.html
	Personal Directives Act, R.S.A. 2000, c. P-6 http://www.qp.gov.ab.ca/Documents/acts/P06.CFM
Alberta	Dependent Adults Act, R.S.A. 2000, c. D-11 www.qp.alberta.ca/570.cfm?frm_jsbn=9780779752935&search_by=link
British Columbia	Health Care (Consent) and Care Facility (Admission) Act [RSBC 1996] www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96181_01
Manitoba	The Health Care Directives Act, C.C.S.M. c. H27 web2.gov.mb.ca/laws/statutes/ccsm/h027e.php
New Brunswick	Infirm Persons Act, R.S. 1973, c. 1-8 www.gnb.ca/0062/pdf-acts/i-08.pdf
Newfoundland and Labrador	Advance Health Care Directives, S.N.L. 1995, c. 4-41 www.assembly.nl.ca/legislation/sr/annualstatutes/1995/A04-1.c95.htm
Nova Scotia	Personal Directives Act 2008, c.8,s.1. http://nslegislature.ca/legc/statutes/persdir.htm
Northwest Territories and Nunavut	Guardianship and Trusteeship Act, S.N.W.T. 1994, c. 29, as duplicated for Nunavut by s. 29 of the Nunavut Act. www.justice.gov.nt.ca/PDF/ACTS/Guardianship%20and%20Trusteeship.pdf
	Health Care Consent Act, 1996 www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm
Ontario	Substitute Decisions Act, 1992, S.O. 1992, c. 30 www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm Trillium Gift of Life Network Act, R.S.O. 1990, c. H.20 www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90h20_e.htm
Prince Edward Island	Consent Treatment and Health Care Directives Act, S.P.H.I. 1996, c. C-17.2 www.gov.pe.ca/law/statutes/pdf/c-17_2.pdf
Quebec	Civil Code of Québec (C.C.Q.), S.Q. 1991, c. 64 (Articles, 12, 15, 20 and 22) http://www.canlii.org/en/qc/laws/stat/sq-1991-c-64/latest/sq-1991-c-64.html
Saskatchewan	The Adult Guardianship and Co-decision-making Act, S.S. 2000, c. A-5.3 www.justice.gov.sk.ca/Adult-Guardianship-and-Co-decision-making-Act
Yukon	Decision Making, Support and Protection to Adults Act, SY 2003, c.21 www.gov.yk.ca/legislation/acts/dmspa.pdf#page=30

TODAY'S VISIT

**Main Reason for Today's Visit to the Physician or Nurse
(To be filled out by the Patient with DD and Caregiver)**

- Please bring an updated form for each visit to the physician/nurse.
- Bring an updated medication list, or all medications being taken.
- Bring any monitoring forms being used (i.e., sleep or behaviour charts).
- Keep a copy of this completed form for the patient's home medical files.

Name: _____ Gender: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit: _____

Up-to-date Medication List attached? ☐

What is the main health problem the patient with DD or caregivers are concerned about?

When did it start?

List any new symptoms.

List possible contributing factors.

Patient / Caregiver (see back of page)

Circle or list other needs – e.g., prescription renewals, test results, forms to be filled out, appointment for annual exam

Any Recent Changes or Stressors?

☐ No

☐ Yes:

(e.g., staff changes, family illness or stress, changes in living or social environment)

Any recent visit to the dentist or other doctor?

☐ No

☐ Yes:

Any recent medication changes or additions?

☐ No

☐ Yes:

(include antibiotics, creams or herbal medicines)

Caregiver Needs – Write down or tell doctor or nurse whether there are issues regarding caregiver fatigue or burnout

Name/Position:

Contact #:

Signature:

**PHYSICIAN / NURSE TO COMPLETE, KEEP COPY FOR CHART,
AND GIVE COPY TO THE PATIENT / CAREGIVER**

Assessment:

Physician / Nurses

Treatment Plan
including Medication
Changes:

Advice to Patient
and Caregivers:

Next Planned Visit / Follow-Up: _____ MD / RN Signature: _____

Recent Changes? If yes, check and briefly describe. Complete appropriate sections of monitoring chart below

- | | |
|--|--|
| <input type="checkbox"/> Activity level | <input type="checkbox"/> Mobility |
| <input type="checkbox"/> Sleeping habits | <input type="checkbox"/> Pain or distress |
| <input type="checkbox"/> Eating patterns/Weight change | <input type="checkbox"/> Swallowing |
| <input type="checkbox"/> Bowel routine | <input type="checkbox"/> Mood or behaviour |
| <input type="checkbox"/> Other: _____ | |

MONITORING OF DAILY FUNCTIONS DURING THE PAST WEEK

	MON.	TUES.	WED.	THURS.	FRI.	SAT.	SUN.
ACTIVITY LEVEL (N, ↓ or ↑)							
SLEEP Pattern and Hours required (daytime and night)							
EATING/WEIGHT (N, ↓ or ↑) Include total # of meals and # completed/day							
BOWEL ROUTINE (N, ↓, ↑, C)							
MOOD/BEHAVIOUR (N, ↓ or ↑) Describe if changed (e.g., agitated, withdrawn)							

Fill in chart using: N = Normal or usual for that person; ↓ = Decrease in amount, level or function; ↑ = Increase in amount, level or function
 C = Constipation – a stool is passed less often than every two days or stools are hard and/or difficult or painful to pass, even if the person has stools many times per week.

Community Resources in Ontario **for Adults with Developmental Disabilities (DD), including Mental Health**

Ministry of Community and Social Services (MCSS) – Developmental Services Branch: Developmental Services fall under the umbrella of MCSS

- Ontario is divided into nine regions with a Regional Director for each regional office
- Services and supports for adults with DD, 19 years and older, include:
 - transition for young adults leaving school
 - community, financial, employment, residential and family supports
 - case management

If the adult with DD does not have a case manager and appropriate services, contact the Regional MCSS Office at 1-866-340-8881 (toll-free main number) or go to www.mcss.gov.on.ca/en/mcss/regionalmap/regional.aspx.

Starting July 1, 2011, under the new umbrella of “Developmental Services Ontario”, a single agency will serve as the regional contact and service coordination point in each of the nine provincial regions. Go to www.mcss.gov.on.ca/en/mcss/programs/developmental/improving/new_application.aspx.

Community Networks of Specialized Care (CNSC) www.community-networks.ca

- Coordinate specialized services for adults with DD with behavioural or mental health issues (dual diagnosis).
- Each regional Network has a CNSC Coordinator who works with local community agencies and mental health service providers to coordinate access to appropriate services.
- They can be a very helpful starting point for accessing services for patients with DD and complex behavioural/mental health issues.

ConnexOntario – Mental Health Service Information Ontario (MHSIO) www.mhsio.on.ca

- This province-wide information and referral service provides Ontarians with round-the-clock access to information about mental health services and supports.
- Funded by the Ontario Ministry of Health and Long-Term Care (MOHLTC).
- Designed to link callers with suitable options tailored to their individual needs.
- MHSIO operates a confidential and anonymous Information Line (1-866-531-2600) which is available 24 hours a day, seven days a week.

Respite Services for Families in Ontario www.respiteservices.com

Lists respite programs and services for children and adults in Ontario, by location.

CAMH (Centre For Addiction And Mental Health) <http://knowledge.camh.net>

Effective July 2011, a new toolkit for primary care providers will be posted on the CAMH Knowledge Exchange website. It was developed by CAMH, Surrey Place Centre and the CNSCs, with input from primary care providers. This toolkit will list the resources needed to help primary care patients with DD and their caregivers, and will include resources for situations of behaviour concerns or crises.

Preventive Care Checklist Form for adult females with a developmental disability (DD)



Original developed by: Dr. V. Dubey, Dr. R. Mathew, Dr. K. Iglar.
Adapted with permission by the DD Primary Care Initiative 2011

Please note:

- Bold** = Good evidence
(Canadian Task Force on Preventive Health Care)
- Italics* = Fair evidence
(Canadian Task Force on Preventive Health Care)
- Plain text = Guidelines (other Canadian sources)
- Highlighted = Differences with respect to DD
— refer to Explanations sheet.

Etiology of DD, if known:

Capacity to consent:

- ☐ Capable ☐ Guardian ☐ Substitute Decision Maker
- ☐ Power of Attorney ☐ Public Guardian & Trustee

Advance Care Planning Needs:

Current Concerns

Name: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit: _____

Living Situation:

- ☐ Family ☐ Group home ☐ Foster home ☐ Independent
- ☐ Other: _____

Update Cumulative Patient Profile ☐ Medications

- ☐ Family History ☐ Communication
- ☐ Hospitalizations/Procedures ☐ Allergies

Lifestyle/Habits

- Diet: ☐ Fat /Cholesterol ☐ Smoking:
☐ Fibre ☐ Alcohol:
☐ Calcium ☐ Illicit Drugs:
☐ Sodium
- Exercise/Obesity: ☐ Sexual History:
Day Program/Work: ☐ Family Planning/ Contraception:
Family: ☐ Sleep:
Relationships (recent changes?): ☐

Functional Inquiry

	Normal	Remarks
HEENT:	<input type="checkbox"/>	
CVS:	<input type="checkbox"/>	
Resp:	<input type="checkbox"/>	
GI:	<input type="checkbox"/>	Screen: GERD, constipation, H.pylori
GU:	<input type="checkbox"/>	
Sexuality Issues:	<input type="checkbox"/>	
MSK/mobility:	<input type="checkbox"/>	
Fall assessment (if indicated):	<input type="checkbox"/>	
Derm:	<input type="checkbox"/>	
Neuro:	<input type="checkbox"/>	

Health Behaviours:

- ☐ folic acid (0.4-0.8 mg OD, for childbearing women)
- ☐ adverse nutritional habits
- ☐ dietary advice on fat/cholesterol (30-69 yrs)
- ☐ adequate calcium intake (1000-1500 mg/d) *
- ☐ adequate vitamin D (400-1000 IU/d; 800-1000 IU/d > 50 yrs)
- ☐ regular, moderate physical activity
- ☐ weight loss counselling if overweight
- ☐ avoid sun exposure, use protective clothing
- ☐ safe sex practices/STI counseling

Alcohol ☐ Yes ☐ No

- ☐ case finding for problem drinking
- ☐ counseling for problem drinking

Normal Remarks

- Cognitive Changes:** ☐
functional assessment (if indicated)
dementia screen (if indicated)
- Behavioural Changes:** ☐
difficult or challenging behaviours
possible pain or distress
possible abuse or neglect or exploitation (screen annually) ☐

Mental Health: ☐ Depression screen ☐ +ve ☐ -ve

Constitutional Symptoms: ☐

Smoking ☐ Yes ☐ No

- ☐ smoking cessation
- ☐ nicotine replacement therapy
- ☐ dietary advice on fruits and leafy green vegetables
- ☐ referral to validated smoking cessation program

Personal Safety

- ☐ noise control programs
- ☐ hearing protection
- ☐ seat belts
- ☐ bicycle helmets
- ☐ propensity to ingest noxious substances (pica)

Oral Hygiene (q6mths)

- ☐ regular dental care
- ☐ brushing/flossing teeth
- ☐ fluoride (toothpaste/supplement)
- ☐ tooth scaling and prophylaxis
- ☐ smoking cessation

Section II: Physical Health Tools

Please note:

Bold = Good evidence
(Canadian Task Force on Preventive Health Care)
Italics = Fair evidence
(Canadian Task Force on Preventive Health Care)

Plain text = Guidelines
(other Canadian sources)
Highlighted = Differences with respect to DD
- refer to explanation sheet which follows.



Name: _____

Physical Examination

HR: _____ BP: _____ RR: _____ HT(cm): _____ WT(kg): _____ BMI: _____ or Waist Circumference: _____ or Waist-hip ratio: _____
Hip Circumference: _____

Eyes: _____ Snellen sight card: R _____ **Breasts:** _____
L _____ Abdo: _____

Nose: _____

Ears: _____ whispered voice test: R _____ Ano-Rectum: _____
L _____

Mouth/Throat/Teeth: _____ Pelvic: ☐ Pap _____

Neck/Thyroid: _____ MSK/Joints/Scoliosis/Mobility aids: _____

CVS: _____ Extremities: _____

Resp: _____ Neuro: _____

Derm: _____

Age 21 and Older

Lab/Investigations

- ☐ **Mammography** (50 until 69 yrs, q1-2yrs; consider if 40-49 yrs)
- ☐ **Hemoccult multiphase q1-2 yrs** (age ≥ 50)
 - OR ☐ Sigmoidoscopy OR ☐ Colonoscopy
- ☐ Cervical Cytology q1-3 yrs (sexually active until age 69)
- ☐ **Gonorrhea/Chlamydia/Syphilis/HIV/HPV⁵** screen (high risk)
- ☐ Fasting Lipid Profile (≥ 50 yrs or postmenopausal or sooner if at risk)²
- ☐ Fasting Blood Glucose, at least q3 yrs (≥ 40 yrs or sooner if at risk)³
- ☐ Bone Mineral Density if at risk 21-64 yrs¹; ≥ 65 yrs q 2-3 yrs if normal and q1-2 yrs if abnormal¹
- ☐ Audiology assessment if indicated by screening, & q5 yrs after age 45
- ☐ Thyroid (TSH/T4) q 1-5 yrs if elevated risk or behaviour change

Immunization

- ☐ **Tetanus vaccine q10yrs**
- ☐ **Influenza vaccine q1yr**
- ☐ Rubella vaccine ☐ Rubella Immunity
- ☐ Varicella vaccine (2 doses) ☐ Varicella Immunity
- ☐ Pneumococcal vaccine (high risk or ≥ 65 yrs)⁴
- ☐ Acellular pertussis vaccine⁴
- ☐ Hepatitis B (screen/consider immunization if high risk)
- ☐ Hepatitis A (screen/consider immunization if high risk)
- ☐ Human papilloma virus vaccine (3 doses) (age 9-26)⁴

Assessment and Plans:

Date: _____

Signature: _____

References

- DD references: Sullivan WF et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can Fam Physician* 2011;57:541-53.
- Unless otherwise stated, recommendations come from the Canadian Task Force on Preventive Health Care: The Canadian Guide to Clinical Preventive Health Care. Ottawa: Minister of Supply and Services Canada and www.canadiantaskforce.ca.
1. Scientific Advisory Board, Osteoporosis Society of Canada. 2010 Clinical practice guidelines for the diagnosis and management of osteoporosis in Canada: summary. *CMAJ* 2010;DOI:10.1503/cmaj.100771
 2. Working Group on Hypercholesterolemia and Other Dyslipidemias. Recommendations for the management and treatment of dyslipidemia and the prevention of cardiovascular disease: 2006 update. *Can J Cardiol* 2006;22(11) 913-927.
 3. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. Canadian Diabetes Assn 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. *Can J Diabetes* 2003;27 (Suppl 2).
 4. National Advisory Committee on Immunization. Canadian Immunization Guide, 7th edition. Ottawa: Minister of Public Works and Government Services Canada; 2006.
 5. Expert Working Group on Canadian Guidelines for STIs. Canadian Guidelines on Sexually Transmitted Infections, 2006 edition. Ottawa: Public Health Agency of Canada.

Preventive Care Checklist Form for adult males with a developmental disability (DD)



Original developed by: Dr. V. Dubey, Dr. R. Mathew, Dr. K. Iglar.
Adapted with permission by the DD Primary Care Initiative 2011

Please note:

- Bold** = Good evidence
(Canadian Task Force on Preventive Health Care)
Italics = Fair evidence
(Canadian Task Force on Preventive Health Care)
Plain text = Guidelines (other Canadian sources)
Highlighted = Differences with respect to DD
— refer to Explanations sheet.

Etiology of DD, if known:

Capacity to consent:

- ☐ Capable ☐ Guardian ☐ Substitute Decision Maker
☐ Power of Attorney ☐ Public Guardian & Trustee

Advance Care Planning Needs:

Current Concerns

Functional Inquiry

	Normal	Remarks
HEENT:	<input type="checkbox"/>	
CVS:	<input type="checkbox"/>	
Resp:	<input type="checkbox"/>	
GI:	<input type="checkbox"/>	Screen: GERD, constipation, H.pylori
GU:	<input type="checkbox"/>	
Sexuality Issues:	<input type="checkbox"/>	
MSK/mobility:	<input type="checkbox"/>	
Fall assessment (if indicated):	<input type="checkbox"/>	
Derm:	<input type="checkbox"/>	
Neuro:	<input type="checkbox"/>	

Health behaviours:

- ☐ adverse nutritional habits
☐ dietary advice on fat/cholesterol (30-69 yrs)
☐ adequate calcium intake (1000-1500 mg/d)
☐ adequate vitamin D (400-1000 IU/d; 800-1000 IU/d > 50 yrs)
☐ regular, moderate physical activity
☐ weight loss counseling if overweight
☐ avoid sun exposure, use protective clothing
☐ safe sex practices/STI counselling

Alcohol ☐ Yes ☐ No

- ☐ case finding for problem drinking
☐ counseling for problem drinking

EDUCATION / COUNSELING

Name: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit:

Living Situation:

- ☐ Family ☐ Group home ☐ Foster home ☐ Independent
☐ Other: _____

Update Cumulative Patient Profile ☐ Medications

- ☐ Family History ☐ Communication
☐ Hospitalizations/Procedures ☐ Allergies

Lifestyle/Habits

- Diet: Fat /Cholesterol Smoking:
Fibre Alcohol:
Calcium Illicit Drugs:
Sodium Sexual History:
Exercise/Obesity: Family Planning/ Contraception:
Day Program/Work:
Family: Sleep:
Relationships (recent changes?):

	Normal	Remarks
Cognitive Changes:	<input type="checkbox"/>	
functional assessment (if indicated)		
dementia screen (if indicated)		

Behavioural Changes:	<input type="checkbox"/>
difficult or challenging behaviours	
possible pain or distress	
possible abuse or neglect or exploitation (screen annually)	<input type="checkbox"/>

Mental Health: ☐ Depression screen ☐ +ve ☐ -ve

Constitutional Symptoms: ☐

Smoking ☐ Yes ☐ No

- ☐ smoking cessation
☐ nicotine replacement therapy
☐ dietary advice on fruits and leafy green vegetables
☐ referral to validated smoking cessation program

Personal Safety

- ☐ noise control programs
☐ hearing protection
☐ seat belts
☐ bicycle helmets
☐ propensity to ingest noxious substances (pica)

Oral Hygiene (q6mths)

- ☐ regular dental care
☐ brushing/flossing teeth
☐ fluoride (toothpaste/supplement)
☐ tooth scaling and prophylaxis
☐ smoking cessation

Section II: Physical Health Tools

Please note:

Bold = Good evidence
(Canadian Task Force on Preventive Health Care)

Italics = Fair evidence
(Canadian Task Force on Preventive Health Care)

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(other Canadian sources)

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– refer to explanation sheet which follows.



Name: _____

Physical Examination

HR: _____ BP: _____ RR: _____ HT(cm): _____ WT(kg): _____ BMI: _____ or Waist Circumference: _____ or Waist-hip ratio: _____
Hip Circumference: _____

Eyes: _____ Snellen sight card: R

L Abdo: _____

Nose: _____

Ears: _____ whispered voice test: R Ano-Rectum/Prostate: _____

L

Mouth/Throat/Teeth: _____

Genitalia: _____

Neck/Thyroid: _____

Derm: _____

CVS: _____

MSK/Joints/Scoliosis/Mobility aids: _____

Extremities: _____

Resp: _____

Neuro: _____

Age 21 and Older

Lab/Investigations

- ☐ Hemoccult multiphase q 1-2 yrs (age ≥ 50)
OR ☐ Sigmoidoscopy OR ☐ Colonoscopy
- ☐ Gonorrhea/Chlamydia/Syphilis/HIV/HPV⁵ screen (high risk)
- ☐ Fasting Lipid Profile (≥ 40 yrs or sooner if at risk)²
- ☐ Fasting Blood Glucose, at least q 3 yrs (≥ 40 yrs or sooner if at risk)³
- ☐ Bone Mineral Density if at risk 21-64 yrs¹; ≥ 65 yrs q 2-3 yrs if normal
and q 1-2 yrs if abnormal¹
- ☐ Audiology assessment if indicated by screening, & q 5 yrs after age 45
- ☐ Thyroid (TSH/T4) q 1-5 yrs if elevated risk or behaviour change

Immunization

- ☐ Tetanus vaccine q10yrs
- ☐ Influenza vaccine q1yr
- ☐ Varicella vaccine (2 doses) ☐ Varicella Immunity
- ☐ Pneumococcal vaccine (high risk or ≥ 65 yrs)⁴
- ☐ Acellular pertussis vaccine⁴
- ☐ Hepatitis B (screen/consider immunization if high risk)
- ☐ Hepatitis A (screen/consider immunization if high risk)

Assessment and Plans:

Date: _____

Signature: _____

References

DD references: Sullivan WF et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. Can Fam Physician 2011;57:541-53.
Unless otherwise stated, recommendations come from the Canadian Task Force on Preventive Health Care: The Canadian Guide to Clinical Preventive Health Care. Ottawa: Minister of Supply and Services Canada and www.canadiantaskforce.ca.

1. Scientific Advisory Board, Osteoporosis Society of Canada. 2010 Clinical practice guidelines for the diagnosis and management of osteoporosis in Canada: summary. CMAJ 2010;DOI:10.1503/cmaj.100771

2. Working Group on Hypercholesterolemia and Other Dyslipidemias. Recommendations for the management and treatment of dyslipidemia and the prevention of cardiovascular disease: 2006 update. Can J Cardiol 2006;22(11) 913-927.

3. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. Canadian Diabetes Assn 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. Can J Diabetes. 2003;27 (Suppl 2).

4. National Advisory Committee on Immunization. Canadian Immunization Guide, 7th edition. Ottawa: Minister of Public Works and Government Services Canada; 2006.

5. Expert Working Group on Canadian Guidelines for STIs. Canadian Guidelines on Sexually Transmitted Infections, 2006 edition. Ottawa: Public Health Agency of Canada.

CUMULATIVE PATIENT PROFILE

For adults with developmental disabilities (DD)

Adapted from template originally developed by the Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, and Electronic Medical Record, DFCM, St. Michael's Hospital, Toronto

Initial Assessment Completed:

____/____/____
dd mm yyyy

Consider annual review, and update sooner when changes occur, e.g., decision-making capacity

Name: _____ Gender: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Prefers to be called: _____

Etiology of DD: _____ ☐ Definite ☐ Probable ☐ Possible ☐ Unknown

Genetic assessment: ☐ No ☐ Yes Date: ____/____/____
dd mm yyyy

Report on file? ☐ No ☐ Yes: _____

Psychological assessment: ☐ No ☐ Yes Date: ____/____/____ Report on file? ☐ No ☐ Yes
dd mm yyyy

Level of adaptive functioning: ☐ Mild ☐ Moderate ☐ Severe ☐ Profound ☐ Unknown

Decision-Making Capacity

Decision-Making Capacity: Capacity to consent may vary over time and with the type of decision. Assess when proposing interventions for which consent is required. [Guideline 7] See Informed Consent Tool

☐ Capable ☐ Not capable ☐ Unsure

Substitute Decision Maker (SDM):

Name: _____ Contact Information: _____

Next of Kin (if not SDM):

Name: _____ Contact Information: _____

Others who may be helpful in decision making (e.g., Guardian, Power of Attorney for Personal Care, Office of the Public Guardian and Trustee, helpful agencies/support persons):

SPECIAL NEEDS AND COMMUNICATION

Special Needs and Communication

Usual Clinic Visit Routines: ☐ Prefers early day ☐ Prefers end of day ☐ Limit time in waiting room

☐ Special positioning for exam ☐ Extra staffing needed ☐ May require sedation

Tolerates venipuncture? ☐ Yes ☐ No

☐ Other: _____

Expressive Communication (method, devices):

Receptive Communication – prefers:

☐ Pictures ☐ Simple explanations ☐ Written ☐ Sign language ☐ Other: _____

Triggers (e.g., trauma, noise, lighting, smells, colour, textures): _____

Response Behaviours:

How to help:

Usual Response to Medical Exam: ☐ Fully/partially cooperates ☐ Fearful ☐ Resistant ☐ Aggressive

Usual Response to Pain or Distress: ☐ Normal ☐ Unique (describe): _____

Cautions (e.g., aggression, pica, aspiration risk): – specify modifications, precautions

Date

Billing
Code

PROBLEM LIST – Current Problems
(description, date identified, associated diagnoses)

PROBLEM LIST

CURRENT MEDICATIONS

Start Date

Name of Medication and Directions
(dose, route, frequency, any specific instructions)
Asterisk(*) to indicate if repeatable

CURRENT MEDICATIONS

RECORD OF PAST MEDICATIONS

RECORD OF PAST MEDICATIONS

Start Date	Stop Date	Name of Medication and Directions (dose, route, frequency, specific instructions)	Comments Reason for discontinuation (e.g., ineffective, adverse effect, treatment complete)
---------------	--------------	--	---

ALLERGIES (include medications, food, stinging insect, pollen and dander, other)

ALLERGIES

Allergy	Medication Reaction Type (allergy, side effect, exaggerated, other effect)	Reaction Severity (life threatening, major reaction, minor reaction, no reaction)	Status (confirmed, suspected)	Brief Description of the Reaction	Treatment Details (optional)
---------	--	--	-------------------------------------	--------------------------------------	------------------------------------

IMMUNIZATION

Year

Year

Year

Year

IMMUNIZATIONS

Influenza Immunization

Pneumovax

Family History

Patient's Past History (including hospitalizations)

FAMILY and PAST HEALTH HISTORY

PERSONAL HISTORY

PERSONAL HISTORY

Living Situation: ☐ Family ☐ Group home ☐ Foster home ☐ Independent ☐ Other: _____

Most important relationships:

Caregivers and supports:

Employment or Day Program (indicate total hours/week):

Leisure Activities:

Nutrition, Dietary:

Exercise:

Sexually active:

Past ☐ No ☐ Yes ☐ Unknown

Current ☐ No ☐ Yes ☐ Unknown

RISKS

RISKS

Tobacco

Alcohol

Street Drugs

Behaviour

REMINDERS (include exams indicated, e.g., vision, hearing, dental, psychology/genetic reassessment, cancer screening)

Periodic Tests	Date	Date	Date	Date	Date	Comments or follow-up

REMINDERS

Advance Planning Needs:

☐ Transition ☐ Crisis ☐ Palliative ☐ End of Life ☐ DNR If yes, record on file?

☐ Other: _____

Health Watch Table — Down Syndrome

Forster-Gibson and Berg 2011

CONSIDERATIONS

RECOMMENDATIONS

1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)

Children and Adults: Vision:
~15% have cataracts;
~20%-70% have significant
refractive errors

5%-15% of adults have
keratoconus

Hearing: 50%-80% have a
hearing deficit

- ☐ Neonatally: refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus or poor vision is identified
- ☐ Arrange ophthalmological assessment: first by 6 months for all; then every 1-2 years, with special attention to cataracts, keratoconus, and refractive errors
- ☐ During childhood: screen vision annually with history and exam; refer as needed
- ☐ Arrange auditory brainstem response (ABR) measurement by 3 months if newborn screening has not been done or if results were suspicious
- ☐ During childhood: screen hearing annually with history and exam; review risks for frequently occurring serious otitis media
- ☐ Undertake auditory testing: first at 9 – 12 months, then every 6 months up to 3 years, annually until adulthood, then every two years

2. DENTAL

Children and Adults: tooth
anomalies are common

Increased risk of periodontal
disease in adults

- ☐ Undertake initial dental exam at 2 years, then every 6 months thereafter. Encourage proper dental hygiene. Refer to an orthodontist if needed
- ☐ Undertake clinical exams every six months with referral, as appropriate

3. CARDIOVASCULAR

Children: 30%-60% have
congenital heart defects (CHD)

Adults: ~50% have
cardiovascular concerns,
commonly acquired mitral valve
prolapse (MVP) and valvular
regurgitation

- ☐ Newborn screening: Obtain an echocardiogram and refer to a cardiologist, even in the absence of physical findings
- ☐ In children and adolescents: review cardiovascular history and assess for physical signs with specialist referral if indicated
 - Refer for an echocardiogram if not previously done
 - Undertake SBE prophylaxis as indicated by findings
- ☐ Ascertain a comprehensive cardiovascular history
- ☐ Undertake an annual cardiac exam, with echocardiogram to confirm new abnormal findings and follow-up depending on the type of cardiovascular problem present or refer to an Adult Congenital Heart specialist or Disease clinic
- ☐ Monitor regularly those that have had surgery in childhood
- ☐ An echocardiogram is indicated to assess new abnormal physical findings or if unable to assess adequately by physical exam. Consider echocardiogram to establish baseline cardiac anatomy and function if not previously done or records are unavailable ¹

4. RESPIRATORY

Children and Adults: 50%-80%
have obstructive sleep apnea
(OSA)

Adults: 50%-80% have
obstructive sleep apnea (OSA)

- ☐ Newborn: Refer to an ENT surgeon if recurring otitis media infections
- ☐ Treat infections promptly and aggressively
- ☐ Ascertain a detailed sleep history, with special attention to OSA symptoms. Refer to an ENT surgeon, including sleep study, if OSA is suspected
- ☐ If aspiration pneumonia is suspected, investigate for possible swallowing disorder and gastro-esophageal reflux disease

CONSIDERATIONS

5. GASTROINTESTINAL

Children: ~ 50% have gastrointestinal (GI) tract anomalies including duodenal atresia, celiac disease, Hirschsprung disease, and imperforate anus

Adults: ~ 95% are obese; ~ 7% have celiac disease

6. GENITOURINARY

Children: Cryptorchidism is common

Adults: Have increased risk of testicular cancer

7. SEXUAL FUNCTION

Adults: Fertility has been documented in women

Fertility in males rarely reported

8. MUSCULOSKELETAL (MSK)

Children: ~15% have atlanto-axial instability (AAI)

Adults: Continued risk for spinal cord compression secondary to AAI

Though data are limited, osteoporosis (associated with increased fractures risk) may be more common in older adults with Down syndrome than in similar aged individuals in the general population or with other developmental disabilities

RECOMMENDATIONS

- ☐ Newborn: with vomiting or absent stools, check for GI tract blockage and refer to a gastroenterologist
- ☐ Infants and children: anticipate constipation; treat with fluid/fibre/laxative/stool softener/exercise/dietary change
- ☐ From 2-3 years of age, screen for celiac disease
- ☐ Establish good dietary and exercise habits to prevent or manage obesity
- ☐ Monitor for obesity
- ☐ Screen for celiac disease, which may present in adulthood; screening tests used are the same as in the general population ²
- ☐ Test for *Helicobacter Pylori* and treat if positive, regardless of symptoms
- ☐ Manage constipation proactively

- ☐ Assess for hypogonadism, undescended testes, and possible testicular germ-cell tumors, or refer to a urologist, as appropriate
- ☐ Assess annually by clinical exam, and refer to a urologist as appropriate ³

- ☐ Counsel regarding fertility possibility and the 50% ⁴ risk of Down syndrome in offspring

- ☐ Arrange lateral cervical spine X-rays (flexed, neutral, and extended positions) between 3-5 years of age
- ☐ Screen, as needed, prior to high risk activities (e.g., tumbling) and if participating in Special Olympics
- ☐ Undertake an annual neurological exam for signs or symptoms of spinal cord compression. If present, refer urgently to a neurosurgeon and arrange an urgent MRI
- ☐ Obtain a detailed MSK history with particular attention to possible joint subluxations/dislocations, scoliosis, and hip abnormalities
- ☐ Undertake an annual neurological exam and assess for evidence of spinal cord compression
- ☐ Arrange lateral cervical spine X-rays if not previously done, if presenting with signs and symptoms of AAI or if participating in Special Olympics
- ☐ Take detailed history and attend to joint complaints, scoliosis, and hip abnormalities
- ☐ If suspected, undertake bone mineral density (BMD) screening and refer to an appropriate specialist if indicated
- ☐ Encourage ambulation/mobility and weight reduction if obesity is present to decrease the risk of osteoarthritis

CONSIDERATIONS

RECOMMENDATIONS

9. NEUROLOGICAL

Children: Epilepsy in up to 22%

Adults: Dementia is frequent and occurs earlier:

11%: 40 – 49 y,

77%: 60 – 69 y,

Up to 75% with dementia have seizures with frequency increasing with age

- ☐ Take careful neurological history with particular attention to seizures (infantile spasms or tonic-clonic-type)
- ☐ Arrange an EEG and refer to a neurologist
- ☐ Obtain a neuropsychiatric history at every visit with particular attention to change in behaviour, loss of function/activities of daily living, and new onset seizures
- ☐ If functional decline and/or signs/symptoms of dementia, use history, exam, and blood work to check for other conditions and treatable causes (e.g., hearing/vision deficits, obstructive sleep apnea, hypothyroidism, chronic pain, medication side effects, depression, menopause, low folic acid/vitamin B12)
- ☐ For possible seizures, arrange an EEG and refer to a neurologist

10. DERMATOLOGICAL

Children and Adults:

Dry skin, atopic dermatitis, seborrheic dermatitis, chelitis, impetigo, and alopecia areata are more common than in general population

- ☐ Examine skin as part of routine care
- ☐ Treat as per general population, with referral to dermatologist as needed

11. BEHAVIOURAL/MENTAL HEALTH

Children: Self-talk is very common; autism spectrum disorder occurs in 5%-10% of children with DS

Adults: ~ 30% have a psychiatric disorder, including depression

- ☐ Review regularly with respect to behavioural concerns
- ☐ Review for positive or negative signs suggestive of psychosis
- ☐ Review regularly with respect to behavioural concerns
- ☐ Ascertain neuropsychiatric history at every visit, with particular attention to changes in behaviour, loss of function/activities of daily living, and new onset seizures

12. ENDOCRINE

Children: ~ 1% have congenital hypothyroidism; ~ 20% develop hypothyroidism after birth

- ☐ Review neonatal screening
- ☐ Ascertain TSH and free T4 tests to confirm euthyroid status at 6 and 12 months, then annually
- ☐ If signs of hyperthyroidism in adolescence, check for autoimmune thyroiditis

CONSIDERATIONS

Adults: 15%-50% are hypothyroid
Subclinical hypothyroidism, hyperthyroidism, and autoimmune thyroiditis are more common than in the general population

13. HEMATOLOGICAL

Children and Adults: Increased frequency of transient myeloproliferative disorder and leukemia

No increased risk of leukemia in adults

RECOMMENDATIONS

- ☐ For adults who are euthyroid, check TSH and free T4 levels at least once every 5 years ⁵ (some recommend annually) ⁶
- ☐ If subclinical hypothyroidism (i.e., elevated TSH with normal free T4), follow free T4 every 6 months 4 to one year ⁷ (some recommend treatment if thyroid antibodies are positive)
- ☐ Consider checking thyroid function whenever there are changes in mental status, behaviour or functional abilities

- ☐ Neonates to 1 month olds: investigate for polycythemia and thrombocytopenia
- ☐ Assess history periodically for symptoms of leukemia, with close attention to those with a history of transient myeloproliferative disorder

Resources

22 published Down syndrome health care guidelines were reviewed and compared (For full list of references, see www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx)

Down syndrome websites that may be helpful for families and caregivers

Canadian Down Syndrome Society www.cdss.ca/

Down Syndrome Education International [DownsEd] www.downsed.org/

Down Syndrome: Health Issues by Dr. Len Leshin www.ds-health.com/

Down Syndrome Medical Interest Group [DSMIG-UK] www.dsmig.org.uk/

National Down Syndrome Society [USA] www.ndss.org/

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Health Watch Table — Fragile X Syndrome

Forster-Gibson and Berg 2011

CONSIDERATIONS

1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)

Children Vision: strabismus, refractive errors are common

Hearing: recurrent otitis media is common

Nose: sinusitis is common

Adults: strabismus and refractive errors are common

2. DENTAL

Children and Adults: High arched palate and dental malocclusion are common

3. CARDIOVASCULAR

Children: Mitral Valve Prolapse (MVP) is less common in children (~10%), but may develop during adolescence

Adults: MVP is common (~80%). Aortic root dilation usually is not progressive
Hypertension is common and exacerbated by anxiety

4. RESPIRATORY

Children & Adults: Obstructive sleep apnea (OSA) may be due to enlarged adenoids, hypotonia or connective tissue dysplasia

5. GASTROINTESTINAL

Children: In infants, feeding problems are common with recurrent emesis associated with Gastroesophageal Reflux Disease (GERD) in ~30% of infants

6. GENITOURINARY

Children and Adults: Inguinal hernias are relatively common in males
Macroorchidism generally develops in late childhood and early adolescence and persists

Ureteral reflux may persist into adulthood

7. SEXUAL FUNCTION

Adults: Males and females are fertile

RECOMMENDATIONS

- ☐ Undertake newborn vision and hearing screening and an auditory brainstem response (ABR)
- ☐ Refer for a comprehensive ophthalmologic examination by 4 years of age
- ☐ Visualize tympanic membranes at each visit
- ☐ Undertake hearing and vision screening at each visit with particular attention to myopia and hearing loss

- ☐ Refer to a dentist for an annual exam

- ☐ Auscultate for murmurs or clicks at each visit. If present, do an ECG and echocardiogram; refer to cardiologist, if indicated
- ☐ Undertake an annual clinical exam. Based on findings, obtain an ECG and echocardiogram. Refer to cardiologist, as appropriate
- ☐ Measure BP at each visit and at least annually
- ☐ Treat hypertension when present

- ☐ Ascertain a sleep history and assess for evidence of OSA
- ☐ Obtain a sleep study as appropriate

- ☐ Refer for assessment of GERD. Thickened liquids and upright positioning may be sufficient to manage GERD

- ☐ Assess for inguinal hernia annually beginning at age 1 year
- ☐ Macroorchidism can be measured with an orchidometer; reassure parents and patients that it does not require treatment
- ☐ Evaluate recurring urinary tract infections (UTI) with cystourethrogram and renal ultrasound. Refer to a nephrologist or urologist as needed
- ☐ Consider and assess for a renal etiology, such as scarring, as the basis for persistent hypertension

- ☐ Consider discussion of recurrence risk and reproductive options as a basis for referral to a geneticist. Make such a referral even if fragile X is only suspected so that molecular testing can be undertaken in the person concerned and relevant family members

CONSIDERATIONS

8. MUSCULOSKELETAL (MSK)

Children & Adults: Hyperextensible joints and pes planus are common. Scoliosis, clubfeet, joint dislocations (particularly congenital hip) may also occur

9. NEUROLOGY

Children & Adults: ~ 20% have epilepsy (may include generalized tonic-clonic seizures, staring spells, partial motor seizures, and temporal lobe seizures)

Hypotonia is common, in addition to fine and gross motor delays

Epilepsy occasionally persists into adulthood

10. BEHAVIOURAL/MENTAL HEALTH

Children: 70%-80% are hyperactive; ~ 30% have autism

Autistic-like features are common and may indicate concurrent Autism Spectrum Disorder

Anxiety and mood disorders can also be present

Some features of autism, tantrums and aggression as well as anxiety and mood disorders may be treated with specific pharmacological agents

Sensory defensiveness is common

Adults: Aggressive behaviour, sensory defensiveness, Attention Deficit Hyperactivity Disorder (ADHD), mood instability, and anxiety are common in adolescence and adulthood

11. ENDOCRINE

Children: Precocious puberty may occur

Adults: Premenstrual symptoms (PMS) may be severe

RECOMMENDATIONS

- ☐ Undertake an MSK exam at birth, then every 4 months to adulthood, then at least annually
- ☐ Elicit a history of possible dislocations
- ☐ Refer to an orthopedic surgeon as dictated by clinical findings
- ☐ Referral to an occupational therapist (OT) in childhood is essential
- ☐ Consider referring to a physiotherapist and podiatrist for orthotics

- ☐ Ascertain a history of seizures, which usually present in early childhood
- ☐ Assess for atypical seizures in adulthood if suspicious findings occur or if intellectual function decreases
- ☐ Arrange an EEG if epilepsy is suspected from the history
- ☐ Refer to a neurologist as dictated by clinical findings

- ☐ Make an early referral to a clinical psychologist for essential parental teaching of appropriate behaviour modification techniques following diagnosis
- ☐ Encourage use of antioxidants including Vitamin E, Vitamin C, folate and fruit juices
- ☐ Hyperactivity may be managed using stimulant medications after age 5 years
- ☐ Refer to an Intensive Behavioural Intervention (IBI) Autism treatment program if Autism Spectrum Disorder is present
- ☐ Consider a referral to a psychiatrist for possible mental health disorders
- ☐ Refer to a speech and language therapist following diagnosis
- ☐ Refer to an occupational therapist (OT) for a sensory diet and sensory integration program
- ☐ Consider referral to a psychiatrist or psychologist to assess and manage possible mental health disorders
- ☐ Violent outbursts are frequent, especially in males, and may respond to behavioural and/or pharmacological measures (as for children)

- ☐ Include attention in clinical examination to signs of precocious puberty in females. Refer to an endocrinologist for consideration of use of a gonadotropin agonist to manage precocious puberty
- ☐ Ascertain history of PMS with attention to menstruation, anxiety, depression, and mood lability. Consider an SSRI to stabilize mood if PMS symptoms are severe enough

CONSIDERATIONS

12. OTHER

Occasionally presents as Prader-Willi syndrome-like phenotype

PREMUTATION CARRIERS:

A late onset tremor/ataxia syndrome has been reported in ~ 40 – 50% of male and ~ 8% of female fragile X premutation carriers

Premature ovarian failure by age 45 has been reported in ~ 20 – 40% of female fragile X premutation carriers

Psychiatric problems (e.g., mood and anxiety disorders) seem likely to occur in both male and female fragile X premutation carriers ^{1,2}

RECOMMENDATIONS

- ☐ For management of obesity and hyperphagia, consider approaches recommended for persons with Prader-Willi syndrome
- ☐ Refer to appropriate specialists (e.g., neurologist, endocrinologist, psychiatrist) as indicated to assist in managing Prader-Willi syndrome-like symptoms
- ☐ If premutation is suspected but not yet identified, order fragile X DNA testing or refer to a genetics clinic
- ☐ To manage depression or anxiety in premutation carriers, SSRIs, regular exercise and counseling have been helpful

Resources

10 published fragile X syndrome health care guidelines reviewed and compared (For full list of references, see www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx)

Fragile X syndrome websites that may be helpful for families and caregivers

FRAXA Research Foundation www.fraxa.org

Fragile X Research Foundation of Canada www.fragile-x.ca/default2.htm

The National Fragile X Foundation www.fragilex.org/html/home.shtml

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Health Watch Table — Prader-Willi Syndrome (PWS)

Forster-Gibson and Berg 2011

CONSIDERATIONS

RECOMMENDATIONS

1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)

Children: Strabismus and myopia are common

Adults: Visual acuity is more commonly diminished than in the general population

- ☐ Arrange an auditory brainstem response (ABR) in newborns
- ☐ Undertake ophthalmology evaluation before 2 years of age, with particular attention to strabismus and visual acuity
- ☐ Screen vision (DD Guideline 11)¹

2. DENTAL

Children: Decreased and sticky saliva flow can predispose to dental caries

Delays in teeth eruption and dental overcrowding may occur

- ☐ Attend to oral hygiene in infants and children including use of soft foam toothbrushes, as well as dental products (toothpaste, sugarless gums, mouthwash) to stimulate saliva production
- ☐ Arrange regular dental visits with particular attention to crowding of teeth and dental caries
- ☐ Make orthodontic referral, as necessary

3. CARDIOVASCULAR

Adults: Cor pulmonale is a commonly reported cardiovascular complication in those who are obese or have significant obstructive sleep apnea (OSA)

Cardiopulmonary compromise related to obesity is a common cause of death

Hypertension is frequently reported but is uncommon in children

- ☐ Arrange cardiac evaluation (DD Guideline 13)¹ including cardiology consultation for severely obese patients
- ☐ Manage underlying obesity (see below)

4. RESPIRATORY

Children: At risk for sleep disordered breathing

Unexpected death may be caused by respiratory obstruction early in Growth Hormone therapy

Some tolerate upper respiratory infections poorly

Adults: At risk for sleep disordered breathing

Cardiopulmonary compromise is the most common cause of death

- ☐ Arrange routine sleep studies during infancy and childhood, and before starting growth hormone therapy and 3 months after initiating it
- ☐ Ascertain a sleep history and then arrange a sleep study before anesthesia, and if evidence of respiratory distress, sleep apnea, or obesity is present
- ☐ All children with PWS who have an upper respiratory tract infection should be assessed as soon as possible
- ☐ Ascertain a sleep history with attention to sleep disorders, obesity of any level, snoring, asthma, respiratory infections, and excessive daytime sleepiness
- ☐ Consider sleep study, respirology, and ENT referral as indicated

CONSIDERATIONS

RECOMMENDATIONS

5. GASTROINTESTINAL AND NUTRITION

Children: Early concerns include Gastroesophageal Reflux Disease (GERD) and reduced intake due to poor sucking

Failure to thrive is common in infancy followed by the development of hyperphagia and obesity in early childhood

~10% develop gall bladder stones

Gastric paresis is common

Adults: Obesity is common without a nutrition and food security program

Vomiting often reflects very serious illness (e.g., gastric necropsy)

Gastric paresis is common

Anal picking is common and may lead to colonic tears/bleeding

Constipation due to hypotonia is common

6. GENITOURINARY

Children: 80%-90% of males have cryptorchidism

Precocious adrenarche may occur

Delayed and incomplete pubertal development is common in both sexes

Adults: Incomplete pubertal development is common in both sexes

7. SEXUAL FUNCTION

Adults: Males and most females are infertile

Pregnancy, though unlikely, has been reported

- ☐ Ascertain a comprehensive GI and nutrition history
- ☐ Undertake video swallow in neonates based on clinical concerns
- ☐ Attend to feeding ability and need for assisted feeding
- ☐ Educate caregivers regarding the necessity of a lower calorie regime, and environmental controls to prevent ready access to food
- ☐ Attend to diet, nutrition, physical activity, and obesity including plotting weight on standard growth charts
- ☐ Refer to a dietitian/physician with experience in PWS, if possible, to develop an appropriate nutrition and food security regime
- ☐ Refer to a gastroenterologist, nutritionist, or dietician as appropriate. Behavioural management programs should be instituted

- ☐ Ascertain a comprehensive GI and nutrition history. Attend to diet, nutrition, and obesity. Refer to a gastroenterologist, dietitian/physician with experience in PWS. Implement the modified Red, Yellow, Green (RYG) ² diet based on energy requirements (ideally measured by indirect calorimetry) and food security programs
- ☐ Behavioural management should be maintained with the assistance of a behavioural specialist
- ☐ In the event of emesis history, the adult with PWS requires immediate evaluation and possibly medical imaging
- ☐ Provide daily multivitamins
- ☐ Provide usual interventions to prevent and manage constipation

- ☐ Verify testicular descent before 2 years of age
- ☐ Refer to a urologist for cryptorchidism (i.e., absence of one or both testes from the scrotum)
- ☐ Consider referral to an endocrinologist or gynecologist/urologist, as appropriate, regarding hormone replacement therapy (HRT)
- ☐ Refer to gynecologist/urologist, as indicated by clinical findings, and for guidance regarding HRT for both sexes

- ☐ Educate and, if sexually active, counsel
- ☐ Consider contraception in women who menstruate

CONSIDERATIONS

8. MUSCULOSKELETAL

Children: 30%-70% have scoliosis

~10% have hip dysplasia

Prevention of osteoporosis should start at an early age

Adults: Scoliosis and osteopenia/osteoporosis are common in both sexes.

Kyphosis may also occur

9. NEUROLOGY

Children: Hypotonia is common and leads to impaired or absent swallowing and sucking reflexes

Hypotonia gradually improves over time

Narcolepsy/cataplexy is more common than in general population

~10% have epilepsy

10. BEHAVIOURAL/MENTAL HEALTH

Children & Adults:

Severe skin picking is common and tends to increase with age

Severe maladaptive behaviours are common (including obsessive-compulsive disorders).

Psychosis may occur in adolescents and adults. Some features of PWS (e.g., tantrums, aggression, compulsivity, anxiety and mood disorder) may be treated with specific pharmacological agents

Risperidone, if indicated, does not usually lead to additional weight gain

RECOMMENDATIONS

- ☐ Assess for hip dysplasia in early infancy and before 2 years of age
- ☐ Evaluate for scoliosis from infancy
- ☐ Monitor with X-rays and refer to an orthopedic surgeon as necessary (Timing of surgical interventions are influenced by the severity of scoliosis and the degree of skeletal maturation)
- ☐ Ensure adequate intake of calcium and vitamin D from childhood
- ☐ Screen for scoliosis and kyphosis with spinal X-rays and refer to an orthopedic surgeon as necessary
- ☐ Assure adequate calcium and vitamin D intake
- ☐ Screen for osteoporosis with regular Bone Mineral Density tests
- ☐ Refer to an endocrinologist for consideration of sex-hormone therapy to promote bone health

- ☐ Undertake clinical evaluation with attention to reduced motor activity and psychomotor delay
- ☐ Consult relevant specialists as indicated by clinical findings
- ☐ Treat epilepsy as in general population

- ☐ Examine skin for evidence of severe skin picking, edema and skin breakdown
- ☐ Students require a behaviour management program to support their dietary requirements. Avoid food-related occupational and educational activities. Refer to a psychologist or psychiatrist familiar with PWS when necessary to assist in distinguishing between behaviour problems and psychiatric illness

CONSIDERATIONS

11. ENDOCRINE

Children: Hypothyroidism, diabetes mellitus (Type II), growth hormone (GH) and sex hormone deficiencies may occur

GH therapy and strict dietary modifications can normalize body habitus

~ 60% can develop central adrenal insufficiency³

Adults: As per children, growth and sex hormone deficiencies continue to be found

Growth hormone therapy in adults can help to prevent obesity and improve strength and endurance

12. OTHER

Molecular causes of PWS differ (e.g., in order of frequency: deletion, uniparental disomy, imprinting errors) each of which effect recurrence risks and possible clinical manifestations

RECOMMENDATIONS

- ☐ Arrange for a PWS pediatric endocrinologist to assess for GH therapy as soon as diagnosis is confirmed. An orthopedic surgery referral may also be indicated before GH treatment is started
- ☐ Make ENT referral to evaluate upper airway with regards to enlarged tonsils and adenoids prior to starting GH therapy
- ☐ Screen before and during GH replacement for hypothyroidism, diabetes, and scoliosis (See 4 above for other recommended assessments prior to GH replacement)
- ☐ Beginning at age 2, assess obese children for diabetes mellitus (Type II)
- ☐ Refer to an endocrinologist as appropriate for consideration of sex-hormone replacement therapy (See 6 above)
- ☐ Undertake cortisol evaluation for all children
- ☐ Undertake clinical assessment with attention to thyroid function, diabetes mellitus (Type II), and hypogonadism
- ☐ Refer to an endocrinologist, as appropriate, including for consideration of GH and sex-hormone therapy
- ☐ Refer to a genetics clinic for evaluation and counseling, where appropriate

Resources

11 published Prader-Willi syndrome health care guidelines reviewed and compared (For full list of references, see www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx)

Prader-Willi syndrome websites that may be helpful for families and caregivers

Prader-Willi Syndrome Association USA www.pwsausa.org/

Prader-Willi Syndrome Network (Ontario) www.pwsnetwork.ca/pws/index.shtml

Pittsburgh Partnership, Specialists in Prader-Willi Syndrome www.pittsburghpartnership.com

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Health Watch Table — Smith-Magenis Syndrome

Forster-Gibson and Berg 2011

CONSIDERATIONS

RECOMMENDATIONS

1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)

Children and Adults: Vision: ~ 85% have eye abnormalities, including strabismus, myopia, iris anomalies, and microcornea

Retinal detachment, which may be related to self-injurious behaviour in childhood, can occur
~ 25% of adults develop retinal detachment

Hearing: Chronic ear infections and hearing loss are common

Throat: Almost all have delayed speech
~ 65% have palatal abnormalities such as velopharyngeal insufficiency (VPI) and cleft palate
A deep, hoarse voice is common

- ☐ Refer to an ophthalmologist following initial diagnosis and annually thereafter
- ☐ Arrange an annual hearing assessment during childhood then as per DD Guideline 11 ¹
- ☐ Refer to an ENT surgeon regarding palatal abnormalities following initial diagnosis and annually thereafter
- ☐ Refer to a speech and language pathologist in early childhood
- ☐ Consider referring to an occupational therapist (OT) or physiotherapist (PT) regarding oral sensorimotor development

2. DENTAL

Children and Adults: ~ 75% have dental anomalies including tooth agenesis, premolars and taurodontism

- ☐ Arrange early and regular dental assessments
- ☐ Review brushing and flossing techniques with each dental cleaning

3. CARDIOVASCULAR

Children & Adults: ~ 50% have congenital cardiovascular abnormalities

- ☐ Obtain an echocardiogram
- ☐ Refer to a cardiologist at initial diagnosis with follow up arrangements with congenital heart disease clinics, depending on the abnormalities detected.
- ☐ Follow recommendations for adults as per DD Guideline 13 ¹

4. RESPIRATORY

Children & Adults: ~ 75% have sleep disturbances usually related to inverted circadian rhythm of melatonin release

Melatonin and acebutolol have been used with some success. Over-the-counter melatonin dosages may be inexact and acebutolol use has some contraindications ²

- ☐ Undertake a sleep assessment with attention to sleep disturbance, short sleep cycle, early rising, frequent night awakenings, and daytime napping
- ☐ Consider evening melatonin and morning acebutolol (presumed to counter daytime melatonin release)
- ☐ Consider strategies to address nighttime safety issues (e.g. enclosed bed)
- ☐ If there is evidence of obstructive sleep apnea (OSA), arrange a sleep study

5. GASTROINTESTINAL

Children and Adults: Feeding problems and gastro-esophageal reflux disease (GERD) are common

- ☐ Undertake a clinical assessment in infancy with attention to feeding problems and evidence of GERD
- ☐ Monitor regularly for constipation and manage proactively

6. GENITOURINARY

Children and Adults: Congenital renal or urinary tract abnormalities are common
Nocturnal enuresis is common in children

- ☐ Obtain a renal ultrasound at initial diagnosis
- ☐ Screen for urinary tract infections with an annual urinalysis or as indicated

CONSIDERATIONS

7. MUSCULOSKELETAL

Children & Adults: ~ 75% of children develop scoliosis, which tends to become more severe with age

8. NEUROLOGY

Children: ~ 90% have speech and motor delay as well as hypotonia (particularly in infancy) ~ 75% have peripheral neuropathy, often associated with decreased pain sensitivity

Hereditary neuropathy with liability to pressure-related palsies may occur in those with relatively large chromosomal deletions

~ 10%-30% have evident and subclinical epilepsy

9. BEHAVIOURAL/MENTAL HEALTH

Children & Adults: Self-injurious, maladaptive, and other behaviours (e.g., head banging, nail yanking, self-hugging, teeth grinding, and inserting objects into body orifices) are nearly always present

These may decrease with time

10. ENDOCRINE

Children and Adults: ~ 25% are mildly hypothyroid

Hypercholesterolemia is common
Hypoadrenalism, though rare, can occur, particularly in children

11. INFECTIOUS DISEASE / IMMUNIZATION

Children & Adults: IgA is reduced in some

12. OTHER

Children and Adults: Phenotype/genotype correlations are beginning to emerge for 17p11.2 deletions of different size and for RAI1 mutation carriers

Relatively rare condition, first described in the 1980s, may be under recognized

Limited data and recommendations are currently available for adults but more information is emerging as identified children age

RECOMMENDATIONS

- ☐ Obtain spine X-rays at diagnosis to assess for vertebral anomalies then annually to assess for scoliosis

- ☐ Undertake a neurological assessment at diagnosis and annually thereafter as clinically indicated
- ☐ Provide periodic neurodevelopmental assessments during infancy and childhood
- ☐ Arrange speech and language pathologist, PT and OT assessments in infancy and periodically thereafter as appropriate
- ☐ Consider subclinical seizures if behaviour change occurs
- ☐ To evaluate seizures, consider electroencephalography (EEG), and Computed Axial Tomography (CAT) scan and Magnetic Resonance Imaging (MRI) scan of head as indicated during infancy and childhood

- ☐ In children, arrange early intervention with specific preventative behavioural strategies and special education techniques that emphasize individualized instruction
- ☐ Use of computer-assisted technology and medication may be helpful
- ☐ An annual interdisciplinary team assessment of children is warranted and may also be helpful for adults
- ☐ Plan respite care, family psychological and social supports
- ☐ Facilitate contact with Parents and Researchers interested in Smith-Magenis Syndrome (PRISMS) to provide support and education (see website below)

- ☐ Undertake annual thyroid function and fasting lipid testing
- ☐ Start screening for hypercholesterolemia in childhood and consider dietary modification for hypercholesterolemia and the possible role of medication
- ☐ Assess for hypoadrenalism in the event of any serious illness

- ☐ Arrange qualitative immunoglobulin testing at diagnosis
- ☐ Undertake periodic review if recurrent infections

Resources

Six published Smith-Magenis syndrome health care guidelines reviewed and compared. (For full list of references see: www.surreyplace.on.ca/Clinical-Programs/Medical_Services/Pages/PrimaryCare.aspx.)

Smith Magenis syndrome website that may be helpful for families and caregivers

www.prisms.org is a website for Parents and Researchers interested in Smith-Magenis syndrome or google "PRISMS".

Developed by: *Forster-Gibson, Cynthia, MD, PhD; Berg, Joseph M, MB, BCh, MSc, FRCPSYCH, FCCMG*

Expert Clinician Reviewer

Thanks to the following clinician for her review and helpful suggestions:

Kerry Boyd, MD
McMaster Children's Hospital,
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Chief Clinical Officer, Bethesda Services, Thorold, Ontario

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2. De Leersnyder H, de Blois MC, Bresson JL, Sidi D, Claustat B, Munnich A. Inversion of the circadian melatonin rhythm in Smith-Magenis syndrome. *Rev Neurol (Paris)*. 2003 Nov;159(11 Suppl):6S21-6.

Health Watch Table — 22q11.2 Deletion Syndrome^a

Forster-Gibson and Berg 2011

CONSIDERATIONS

1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)

Children and Adults:

~ 15% have strabismus in addition to other ocular issues (e.g., cataracts, retinal problems)

Conductive and/or sensorineural hearing loss (often unilateral) occur in ~ 45% and ~ 10% respectively

Most have chronic otitis media

There is an increased frequency of velopharyngeal insufficiency (VPI) that is often associated with hyper-nasal speech, some of whom have submucosal cleft palate, and a small minority have overt cleft palate which can lead to nasal regurgitation

2. DENTAL

Children and Adults: Retrognathia (over-bite) is common and may cause dental malocclusion

Significant dental issues are a recognized part of the syndrome

3. CARDIOVASCULAR

Children and Adults: ~ 40% have congenital heart defects, most commonly of the conotruncal type (e.g., Tetralogy of Fallot, Interrupted Aortic Arch, Ventricular Septal Defect)

4. RESPIRATORY

Children: Congenital malformations may lead to upper and/or lower airway obstructions and obstructive sleep apnea (OSA)

Most airway concerns resolve spontaneously with time but some require surgical intervention (e.g., Robin sequence)

Adults: In order of prevalence, there is an increased frequency of recurrent pneumonia, atelectasis, asthma, and chronic obstructive pulmonary disease

Those with uncorrected congenital malformations remain at risk for OSA

RECOMMENDATIONS

- ☐ Refer to an ophthalmologist for assessment at diagnosis and during preschool years
- ☐ Refer to an audiologist for evaluation in infancy (or when diagnosed) and every 6 months up to 8 years of age, then annually until adulthood, then according to DD Guideline 11¹
- ☐ Examine the palate in infancy and evaluate for feeding problems and/or nasal regurgitation and, if warranted by clinical findings, refer to a cleft palate team
- ☐ Refer to a speech and language pathologist for assessment by 1 year of age, sooner if warranted or when diagnosis is made
- ☐ Evaluate nasal speech quality
- ☐ Often need regular ear cleaning to remove cerumen

- ☐ Refer to a dentist in early childhood
- ☐ Advocate and ensure for appropriate dental care

- ☐ At the time of diagnosis, complete a cardiovascular assessment, including EKG and echocardiogram
- ☐ Refer to a cardiologist as warranted by clinical findings

- ☐ Refer to an ENT surgeon for evaluation as warranted by clinical findings
- ☐ Undertake a sleep study in infancy and then as warranted by clinical findings after 3 years of age
- ☐ Consider a pre-op anesthesia consultation regarding narrow airways prior to the first surgery

- ☐ Consider periodic pulmonary function studies and referral to a respirologist as warranted by clinical findings
- ☐ Undertake sleep study as warranted by clinical findings

^a Includes: DiGeorge Syndrome (DGS), Velocardiofacial Syndrome (VCFS), Shprintzen Syndrome, Conotruncal Anomaly Face Syndrome (CTAF), Caylor Cardiofacial Syndrome, and Autosomal Dominant Opitz G/BBB Syndrome

CONSIDERATIONS**5. GASTROINTESTINAL**

Children and Adults: Feeding difficulties, related to pharyngeal and gastrointestinal tract hypotonia, commonly lead to failure to thrive

Dysphagia and constipation are common

~ 20% develop gallstones

6. GENITOURINARY

Children and Adults: Up to ~ 33% may have renal tract anomalies

~ 10% may develop renal failure in adulthood

7. SEXUAL FUNCTION

Children and Adults:

People with the 22q11.2 deletion syndrome are fertile and have a 50% chance of transmitting the 22q11.2 deletion to children

8. MUSCULOSKELETAL

Children and Adults: Many have skeletal abnormalities, most commonly vertebral or rib anomalies

A minority have short stature during childhood which improves by adulthood

9. NEUROLOGICAL

Children and Adults: Impairments due to reduced muscle tone and motor delay are common in children

Seizures are frequently associated with hypocalcemia

~ 40% of adults have recurrent (often hypocalcemic) seizures

Cord compression may occur related to skeletal anomalies

RECOMMENDATIONS

- ☐ Refer to a gastroenterologist and feeding specialist (e.g., speech-language-pathologist)
- ☐ Treat constipation
- ☐ If difficulty swallowing pills, adapt medication regime (e.g., provide with liquid medication, crush pills)
- ☐ Consider obtaining an abdominal ultrasound in adults to assess for gallstones
- ☐ Follow DD Guideline 15 ¹ for recommendations for managing constipation and Gastroesophageal reflux disease (GERD)

- ☐ Undertake a renal ultrasound at the time of diagnosis
- ☐ Maintain surveillance for urinary tract infections (UTIs)
- ☐ Determine creatinine levels at diagnosis and annually thereafter

- ☐ Referral for genetic counseling may be appropriate

- ☐ Undertake cervical spine X-rays after age 4 years to assess for vertebral anomalies and instability on flexion/extension (five views: flexion, extension, AP, lateral, and open mouth)
- ☐ Arrange chest X-ray to evaluate for thoracic vertebral anomalies
- ☐ Provide clinical evaluation for scoliosis at diagnosis, during preschool, and periodically thereafter

- ☐ Undertake a neuro-developmental assessment of infants with particular attention to reduced muscle tone and motor delay
- ☐ Refer to a physiotherapist (PT) and/or occupational therapist (OT), as needed
- ☐ Ascertain history with attention to seizures
- ☐ Following every seizure, check serum ionized calcium and magnesium
- ☐ Include EEG examination in evaluation if indicated
- ☐ Symptoms of cord compression are an indication for an emergent referral to a neurologist or neurosurgeon

CONSIDERATIONS

10. BEHAVIOURAL / MENTAL HEALTH

Children and Adults: Conditions such as Autism Spectrum Disorder (ASD), Attention Deficit Disorder (ADD), Attention Deficit Hyperactivity Disorder (ADHD), and Obsessive-Compulsive Disorder (OCD) are common

Treatable anxiety disorders are common

Many of the childhood psychiatric disorders do not necessarily persist, nor do they predict psychiatric illness during adulthood

Schizophrenia can become apparent in adolescence and ~ 25% develop schizophrenia or other psychotic disorders in adulthood

11. ENDOCRINE

Children & Adults: ~ 60% have episodic hypocalcemia (often missed when mild or transient)

Hypocalcemia is due to hypoparathyroidism in children and adults

Long-term calcium supplementation can lead to renal calculi

Hypo- and hyperthyroidism have been reported in children and adults

~ 4% have growth hormone deficiency

~ 35% of adults are obese

~ 20% of adults have hypothyroidism

~ 5% of adults have hyperthyroidism

12. HEMATOLOGY

Children and Adults: Autoimmune diseases (e.g., thrombocytopenia, juvenile rheumatoid arthritis [JRA], Grave's disease, vitiligo, neutropenia, hemolytic anemia) may be more common than in the general population

~ 10% develop splenomegaly

RECOMMENDATIONS

- ☐ Ascertain comprehensive behavioural and mental health history
- ☐ Refer to a psychiatrist if evidence of ASD, ADD, ADHD, or OCD occurs
- ☐ Assess for psychiatric illness with attention to changes in behaviour, emotional state and thinking, including hallucinations or delusions and at-risk behaviours (e.g., sexual activity, alcohol/drug use) in teens and adults
- ☐ Refer to a psychiatrist as warranted by clinical findings
- ☐ Consider psychiatric assessment at or near puberty with behavioural changes

- ☐ Measure serum ionized calcium concentration in neonates then annually to assess for hypoparathyroidism
- ☐ Assess calcium levels in infancy, every 3 to 6 months, every 5 years through childhood, and every 1 to 2 years thereafter
- ☐ Be vigilant regarding risk of hypocalcemia with acute illness and childbirth
- ☐ All patients should have Vitamin D supplementation; those with documented hypocalcemia and/or relative or absolute hypoparathyroidism may require prescribed hormonal forms supervised by endocrinologist
- ☐ Refer to an endocrinologist as warranted by clinical and laboratory findings and for initial management of hypocalcemia
- ☐ Consider densitometry to assess for osteopenia earlier than in general population
- ☐ Undertake T4 and TSH baseline screening ²
- ☐ Treat with standard thyroid replacement or antithyroid therapy where warranted ²
- ☐ Monitor growth and growth hormone levels annually and consider endocrinology assessment for poor growth

- ☐ Monitor with CBC; thyroid function annually or if concerns arise
- ☐ Investigate arthritis problems for JRA and refer to a rheumatologist as warranted

CONSIDERATIONS**RECOMMENDATIONS****13. INFECTIOUS DISEASE/IMMUNIZATION**

Children and Adults:

Congenital thymic aplasia is recognizable in infancy³

Immune function may be impaired (although thymic aplasia is rare, thymic hypoplasia is common); improvement in T-cell production occurs over time

~ 75% have chronic middle ear infections (otitis media) and frequent respiratory infections

Irradiated blood products have been used when blood replacement has been necessary

Recurrent upper and lower respiratory tract infections are common in adults

- ☐ In addition to obtaining a CBC with differential in newborns, consider undertaking flow cytometry. At age 9 to 12 months (prior to live vaccines), assess flow cytometry, immunoglobulins and T-cell function
- ☐ For infants, minimize exposure to infectious diseases and withhold live vaccines initially. Refer infants to an infectious disease specialist to assess regarding influenza vaccines, CMV-negative irradiated blood products and RSV prophylaxis
- ☐ Measure absolute lymphocyte count following initial diagnosis and refer to an immunologist if count is low
- ☐ Evaluate immune status before offering any live vaccines
- ☐ Treat respiratory and other infections aggressively in children and adults

14. OTHER

Incidence: 1/4000, but more likely higher and many without typical features

Huge variability in level of developmental disability and the number and severity of associated features

IQ: The majority of affected people with 22q11 deletion fall in the high mild to borderline range; moderate to severe rates and average levels of IQ are less common

A selection bias in reported studies may result in over-estimating some prevalence rates

Resources

11 published 22q11.2 deletion syndrome health care guidelines reviewed and compared. (For full list of references see www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx)

22q11.2 Deletion syndrome websites that may be helpful for families and caregivers

www.c22c.org

www.22q.org

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Expert Clinician Reviewer

Thanks to the following clinician for her review and helpful suggestions:

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Director, Clinical Genetics Research Program, Centre for Addiction and Mental Health, Toronto
Canada Research Chair, Schizophrenia Genetics

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2. Weinzimmer SA. Endocrine aspects of the 22q11.2 deletion syndrome. *Genet Med* 2001 Jan-Feb;3(1):19-22.
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The Non-Communicating Adult Pain Checklist—NCAPC

Name of individual _____ Observer: _____

Date _____ Sum score when individual is not in pain _____

The individual's behavior is being evaluated due to:

How often has the client been showing the down listed behaviors within a 10 minutes period?

Item #	Sub-category	Item description	Not at all	Just a little	Fairly often	Very often
1	Vocal reaction	Moaning, whining, whimpering (fairly soft)	0	1	2	3
2		Crying (moderately loud)	0	1	2	3
3		Screaming/yelling (very loud)	0	1	2	3
4		A specific sound or word for pain (e.g. a word, a cry, a type of laugh)	0	1	2	3
5	Emotional reaction	Not co-operating, cranky, irritable, unhappy				
6		Being difficult to distract, not able to satisfy or pacify				
7	Facial expression	Furrowed eyebrows, raising eyebrows	0	1	2	3
8		A change in eyes including (squinting of eyes, eyes opened wide, eye frowning)	0	1	2	3
9		Turning down of mouth	0	1	2	3
10		Movements of the lips and tongue (lips puckering up, tight, pouting, or quivering, teeth grinding, tongue pushing)	0	1	2	3
11	Body language	Moving more or less	0	1	2	3
12		Stiff/spastic, tense, rigid	0	1	2	3
13	Protective reaction	Gesturing to or touching part of the body that hurts	0	1	2	3
14		Protecting, favoring, or guarding part of the body that hurts	0	1	2	3
15		Flinching or moving the body part away, being sensitive to touch	0	1	2	3
16		Moving the body in a specific way to show pain (e.g. head back, arms down, curls up)	0	1	2	3
17	Physiological reaction	Change in facial color	0	1	2	3
18		Respiratory irregularities (breath holding or gasping)	0	1	2	3

Sum score _____

(Score of 8 or more indicates pain & the higher the score, the higher the amount of pain.)

"JUST NOT RIGHT"

Many individuals are not able to tell us with words how they feel or what exactly is bothering them. But they can and do frequently tell us by a change in the way they act or the sounds they make. Often, it is the direct service provider who knows the individuals the best and is able to pick up small changes that could be signs of illness. When such changes happen direct service providers often describe the individual as "not right", "something is wrong", "not themselves". How the change is described to a physician will make a difference in the physician's ability to understand the value of the observation, figure out what the problem is and treat it.

When you notice that someone is not right, it may be helpful to think about describing your observations by comparing them to how the individual usually behaves or appears. When you look at the person or think about what you are seeing, what is different from what you usually see?

- Does he /she have a different **look on their face**? Tired, afraid, in pain?
- Are they sitting or **moving differently**? Protecting a hand or foot, refusing to take a position that is normal for him/her?
- Is there a change in the type of **sounds** a person is making? Are they more highly pitched? Or perhaps they are not making any sounds at all.
- What is their **temperature**?
- What is their **breathing** like?
- What is their **color** like? Pale or red? Blue around the lips?
- Have you seen this before? When? What was going on?
- Has there been a recent **new medication**, adjustment to medication or diagnosis that might help explain the change?
- Sometimes a **significant change** in a person's life or relationships will cause behavioral or physical signs. Has there been a death or loss of a person or a change in a routine?
- Are they eating and drinking? If so, is this different than their usual pattern?
- Is there a change in their bowel or bladder habits?
- Has there been a change in their willingness or ability to participate in activities?
- When did you notice this change? Did it just start today, or has this been a gradual change?

IF YOU NOTICE CHANGES, WHAT SHOULD YOU DO?

Call 911 if this happens:

- The change is very sudden
- The person looks very sick
- The person won't wake up

In other situations:

- Call or talk to your supervisor or nurse about what you see or hear
- Write down what you see or hear and share the information with other staff.
- Talk about what you see and hear with other staff and write down what they report
- Make a physician appointment
- Keep notes of what you see and hear and bring them with you to the Dr.'s appointment to assist the physician in diagnosing the problem.

Name: _____

Instructions: Use 1-column for each event.

Check off all behaviors that apply.

During Seizure	Date/Time	Date/Time	Date/Time	Date/Time	Date/Time	Date/Time	Date/Time
Awareness							
Fully Aware							
Confused							
Responds to Voice							
Responds to Light Touch							
Not Responsive							
Facial Expressions							
Staring							
Twitching							
Eyes Rolling							
Eyes Blinking							
Head Movements							
Sudden Head Drop							
Turns to 1-Side							
Turns Side to Side							
Body Stiffens							
Whole Body							
Legs							
Arms							
Jerking Movements							
Whole Body							
Legs							
Arms							
Automatic Movements							
Hands clapping, rubbing							
Lip Smacking, Chewing							
Walking, Wandering							
Running							
Speech							
Able to Talk Normally							
Unable to Talk							
Incoherent/Nonsense Words							
Mixing Up Words							
Falls							
Yes/No							
Injury							
Yes/No							
Type of Injury							
Incontinent							
Yes/No							
After Seizure							
Fully Aware							
Responds Normally							
Confused							
Tired							
Asleep							
Agitated/Irritable							
Length of Seizure							
Before Return to Baseline							
Interventions							
Medicine Given							
Triggers							
Name of Observer							

DEMENTIA/ALZHEIMER DISEASE SCREENING TOOL

This assessment tool is designed to identify early changes that could signal the onset of dementia. This checklist should be completed at least twice a year and is especially important for individuals over the age of 35 with Down Syndrome. Any area that changes from the previous assessment should be marked in red or highlighted so a clear pattern can be identified.

CODE

A. Always Name of individual: _____
 B. Usually
 C. Rarely Name of Assessor: _____
 D. Never
 • Items = Y or N Review Dates: 1. _____ 2. _____ 3. _____ 4. _____

MENTAL STATUS

	1	2	3	4
1. Alert				
2. Naps during the day				
3. Awake at night				
4. Initiates activities and/or social contact				
5. Becomes easily discouraged				
6. Forgetful				
7. Combative				
8. Cries				
9. Fearful				
10. Oriented to time				
11. Oriented to place				
12. Recognizes familiar people				
13. Organizes leisure time				

DAY/WORK CHANGES

	1	2	3	4
1. Attends day/work program as scheduled				
2. Able to complete work/day routines				
3. Work/day outcomes are consistent				
4. Maintains energy for complete day				
5. Stays focused on tasks				

SEIZURES

	1	2	3	4
• 1. History of seizures				
• 2. Takes seizure medications				
• 3. Seizure activity noted (not seen before)				

COMMUNICATION

	1	2	3	4
1. Speaks in full sentences				
2. Speaks in phrases				
3. Difficulty in word finding				
4. Uses sign language				
5. Indicates needs and wants				
6. Follows simple directions				
7. Uses coherent speech				

DEMENTIA/ALZHEIMER DISEASE SCREENING TOOL

MOBILITY	1	2	3	4
1. Travels independently				
2. Walks up and down stairs alone				
3. Walks with assistance				
4. Gets up from chair independently				
5. Uses walker				
6. Uses wheelchair				
7. Gets disoriented or lost when traveling				
EATING				
1. Eats independently				
2. Uses utensils correctly				
3. Holds cup correctly				
4. Chews properly				
5. Swallows without problems				
TOILETING				
1. Independent				
2. Incontinent of urine				
3. Incontinent of feces				

HEALTH REVIEW CHECKLIST

To be used by clinical or support staff to record health-related information and to help communicate recent changes to a supervisor or health care provider (HCP). Must be completed prior to annual physical and any visit to primary care physician (PCP).

NAME: _____ DATE: _____ ALLERGIES: _____

FILLED OUT BY: _____ HCP: _____
Staff Name and Title *Health Care Provider*

Health Status Indicators <i>**Highlight or circle changes in health status. Any "Yes", "Don't know" or "Recent Change" may indicate a need for further exploration by the HCP.</i>	No	Yes	Don't know	Check if recent change
HABITS: Does this person:				
1. smoke or use tobacco products?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. drink alcohol?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. avoid regular exercise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. engage in sex?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SLEEP: Does this person:				
1. have problems sleeping at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. get up 2 or more times during the night to go to the bathroom?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. fall asleep during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EATING/WEIGHT: Has this person:				
1. gained or lost more than 10 pounds in the past year?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ever choked while eating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. had trouble chewing or swallowing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. cough or had a change in their breathing during or after eating or drinking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. ever been reluctant to eat or drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. needed to change the texture of their food or drink?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CARDIAC: Does this person:				
1. ever complain of chest, jaw or left arm pain?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have swollen feet or ankles?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ever have blue lips or nails?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
RESPIRATORY: Does this person:				
1. frequently cough or wheeze?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have shortness of breath when at rest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. have shortness of breath while exercising?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have frequent colds, pneumonia, sinus infections or bronchitis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GASTROINTESTINAL: Does this person:				
1. complain of or appear to have heartburn: rub chest, or burp frequently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. vomit 2 or more times per week?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. complain of or appear to have abdominal pain?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have a bowel movement less than 3 times per week?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. frequently have 3 or more bowel movements per day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. seem to have difficulty moving their bowels?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. ever have blood in their bowel movements?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NEUROLOGICAL: Does this person:				
1. have a seizure disorder?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. complain of headaches, loss of consciousness, or dizziness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. fall a lot or have difficulty with balance?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. walk differently lately?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. show a change in what their seizures look like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Health Status Indicators	No	Yes	Don't Know	Check if recent change
SKIN & NAILS: Does this person:				
1. have dry skin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have any rashes, redness or open sores on their skin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. have any unusual lumps or bumps on or under the skin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have any unusual marks or moles on the skin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. have problems with fingernails or toenails?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. have any blisters or calluses on their feet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MOUTH: Does this person:				
1. have gums that bleed while brushing their teeth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have any sores in their mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. grind their teeth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have bad breath?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. have swollen gums?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
VISION/ HEARING: Does this person:				
1. ever have redness or drainage from their eyes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. rub their eyes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. squint?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ever have drainage from their ears or earwax problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. respond to sound differently lately?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. wear a hearing aid or glasses?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MOBILITY: Does this person:				
1. have trouble using stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have trouble getting around the house?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. have difficulty standing, sitting, or bending?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MUSCULOSKELETAL: Does this person:				
1. complain of or appear to have joint or muscle pain or stiffness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. have a history of broken bones or osteoporosis (brittle bones)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. have any deformities of the feet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. wear special shoes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GENITOURINARY: Does this person:				
1. have trouble starting to urinate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. complain of pain or burning during or after urinating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. have urine that has an unusual color or bad odor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. have frequent bladder or kidney infections?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. menstruate (have a period)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. experience pain or other behavior changes during their period (menstruation)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. report a change in their menstrual cycle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. ever have any unusual vaginal bleeding or discharge?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. ever bleed or have unusual discharge from their penis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. have any lumps or report pain in their groin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BEHAVIOR: Currently, does this person ever:				
1. hurt himself/herself or others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. damage property?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. appear unusually sad or depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. withdraw from others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. display moodiness or irritability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. eat nonfood items?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. complain of pain?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. have any recent history of personal losses or major life stressors?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. display sexually inappropriate behavior?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. run or wander away?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. appear anxious (nervous, agitated, restless)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. appear forgetful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. repeat words and/or actions again and again?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Notes:

MEDICATION TREATMENT PLAN

Client: _____ DOB: _____ Date: _____

Address: _____

Primary Contact: _____ Phone: _____

Diagnosis and/or description of behaviour for which medication is prescribed:

Medication:

Dosage:

Length of treatment trial (considered sufficient to determine if medication is effective):

Dates for Review: _____

Behavioural criteria to evaluate effectiveness of medication (what changes in behaviour, mood, thought or functioning should be expected):

Behavioural criteria to use to monitor for adverse effects:

Prescriber should be contacted immediately when: _____

Prescriber name and contact information: _____

Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in items 1-24 in the last 5 minutes.
Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands),
then indicate "not applicable" for that item.

- 0 = Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
- 1 = Seen or heard rarely (hardly at all), but is present.
- 2 = Seen or heard a number of times, but not continuous (not all the time).
- 3 = Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
- NA = Not applicable. This person is not capable of performing this action.

0 = Not at all	1 = Just a little	2 = Fairly Often	3 = Very Often	NA = Not Applicable	
1. Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. A specific sound or word for pain (e.g. A word, cry or type of laugh)	0	1	2	3	NA
4. Not cooperating, irritable, unhappy	0	1	2	3	NA
5. Less interaction with others, withdrawn	0	1	2	3	NA
6. Seeking comfort or physical closeness	0	1	2	3	NA
7. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8. A furrowed brow	0	1	2	3	NA
9. A change in eyes, including: squinting of eyes, opened wide, eyes frowning	0	1	2	3	NA
10. Turning down of mouth, not smiling	0	2	2	3	NA
11. Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13. Not moving, less active, quiet	0	1	2	3	NA
14. Stiff, spastic, tense, rigid	0	1	2	3	NA
15. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16. Protecting, favouring or guarding part of body that hurts	0	1	2	3	NA
17. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19. Shivering	0	1	2	3	NA
20. Change in colour, pallor	0	1	2	3	NA
21. Sweating, perspiring	0	1	2	3	NA
22. Tears	0	1	2	3	NA
23. Sharp intake of breath, gasping	0	1	2	3	NA
24. Breath holding	0	1	2	3	NA

Subtotals:

1. For each subtotal write the number of times each value was chosen NA 1x____ 2x____ 3x____ NA
2. Multiply the value of each selection by how many times that value was chosen **Total:**
3. Add each subtotal to find the total score =____ =____ =____ =____

SCORING:

The Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID) is a 24-item scale designed to assess the frequency of pain-related behaviors in nonverbal adults with intellectual disabilities. The scale is scored by circling a number (0, 1, 2, 3, or NA) for each item. The total score is the sum of the scores for all 24 items. A score of 0 indicates no pain, a score of 1 indicates mild pain, a score of 2 indicates moderate pain, and a score of 3 indicates severe pain. A score of NA indicates that the behavior was not applicable to the person.

Factsheet – Constipation

Disclaimer: This fact sheet is for education purposes only. Please consult with your doctor or other health professional to make sure this information is right for your recipient.

Some people go to the toilet to pass a bowel motion two or three times a day. Others may go only twice a week, without problems. "Constipation" is when there is difficulty passing a bowel motion or stool because it is hard, painful and/or infrequent.

What's the Problem?

Your recipient may be constipated if he or she:

Says it hurts to pass stool (poo)

When this happens, will not want to go to the toilet as often. Pain makes it more difficult to poo/pass stool. Hard stool may tear the anus (back passage) causing pain and bleeding. This may also lead to a pattern of "holding on" and avoiding passing a stool.

Passes stool in his / her pants without meaning to

Sometimes people who are constipated have runny stools, which they can't control due to overflow of liquid stool around constipated older stool that is stuck there. This may soil their underwear. If this happens regularly, see your doctor who may prescribe medication.

Has tummy pains that may come and go

What causes constipation?

It is not always clear why people become constipated. Causes may include:

Holding onto stools. Sometimes people put off going to the toilet because they are too busy or avoid passing stool because it hurts. Others don't want to use other toilets due to smelly toilets, lack of privacy or teasing. Waiting too long to go to the toilet can cause the stool to build up in the bowel and it may also become very hard. The large amount of retained hard stool may stretch the lower bowel and it may not work normally.

Not enough fibre from food. Fibre helps our bowels to work properly and regularly. We all need to eat fibre-containing foods such as whole meal or grain bread, fresh fruit and vegetables every day. Having foods with fibre will help to keep bowels working regularly.

An illness, such as tonsillitis, where people eat and drink less.

Some underlying medical conditions may also cause constipation. Your doctor will be able to work out if any tests are necessary.

What to do

It is important to get rid of the hard stool and let the bowel recover from being stretched and to keep the stool soft enough to be passed without pain. Usually a stool that is as soft as toothpaste can be passed without pain. There are different ways of treating constipation. Whilst it is important that your recipient eats a high fibre diet, the best chance of fixing constipation is with special medications (laxatives) and correct toileting behaviour.

A stimulant laxative may sometimes be needed to clear a hard lump of stool. Movicol or Sennekot can be used in this way.

Liquid Paraffin (eg Parachoc) softens the stool and makes it easier to pass, but should not be given to children with Cerebral Palsy or other children with a tendency to gastro-oesophageal reflux.

Children may then need to continue other medications to keep the stool soft and easy to pass with no pain or straining. These medicines include liquid paraffin, Movicol, lactulose (Duphalac, Actilax) sorbitol (Sorbilax) and poly lax. Some people prefer benifibre. All of these are safe in children over 1 year of age, and they are safe when used for short or long times. Some other medicines that can be used in adults are not usually used in children. Your doctor will give you advice about the type of laxative or stool softener that is right for your child and how long your child will need this help. It is important to follow their instructions carefully. Your child needs to drink plenty of fluids when they are taking these medications.

Preventing further problems

Having enough fibre is a good lifelong habit for everybody. To prevent constipation, combine food containing enough fibre with lots of fluids and daily exercise. Increasing the fibre and having extra drinks will not usually treat constipation - but these can be important to prevent it coming back after things have improved with the above treatments. Encourage your child to go to the toilet regularly - at least once a day - after meal times is a good time. Teach them to go to the toilet when they feel the urge/need to go (and not to hold on!). It is very important that a child is encouraged in correct toileting behaviour and not criticised or punished.

Ways to increase fibre... you may like to try some of these ideas...

Try wholegrain breads and cereals

- For breakfast cereals include Weetbix™ / Vitabrits™, Shredded Wheat™, Puffed Wheat™, muesli, porridge, Mini Wheats™, Fruity Bix™.
- For breads, muffins, cereals and crackers, use wholemeal, wholegrain, high fibre white or rye.
- Try wholemeal pasta or brown rice.
- Try adding some wholemeal flour and fruit when cooking biscuits or cakes. (We recommend that you use ground nuts in cooking for people with difficulty swallowing so that there is no risk of them accidentally choking).

Eat plenty of fruit and vegetables

- Include fresh, frozen and canned varieties.
- Dried fruit can also be included, eg dried apricots, dried apple, prunes.
- Prunes and kiwifruit also contain a natural laxative (you can also try prune juice, start with about 50 ml per day and increase gradually if necessary).
- Legumes and pulses contain large amounts of fibre, eg baked beans, lentil soup, pea and ham soup, lentil burgers, chilli beans, chilli con carne and burritos.

Include nuts

For example, spread peanut butter or other nut pastes on bread or crackers, include nuts in cooking, eg, stir fries or in cakes and biscuits or as a snack (we recommend you use ground nuts in cooking for with swallowing difficulties so that there is no risk of choking).

Special note on bran

- Bran is another source of fibre, It is always better to eat high fibre foods than take supplements such as bran. This is because bran may interfere with the absorption of minerals, such as iron and zinc.
- Small amounts of bran can be used cautiously and remember to provide plenty of fluid at the same time.

Ways to include enough fluid

Include at least four to five glasses of fluid each day, especially water, or diluted juice. Some fruit juices for example prune, apple and pear juice contain a natural poo softener.

R E M E M B E R

- Make sure that your recipient eats a fibre-rich diet, drinks plenty of fluids and has regular exercise.
- Constipation can, and often does, happen again.
- Treatment of constipation often takes time.
- Plan a toileting program.
- Encourage your recipient to go to the toilet at least once a day.
- Avoid overusing laxatives.
- It is important that medicines are used as directed. Always follow the advice of your doctor*

Fact Sheet Urinary Tract Infections

Urinary tract infections are a serious health problem affecting millions of people each year. Infections of the urinary tract are the second most common type of infection in the body. One in five women will develop a urinary tract infection (UTI) during her lifetime (National Kidney and Urologic Diseases Information Clearinghouse).

What is a UTI?

A urinary tract infection occurs when bacteria from the digestive tract cling to the opening of the urethra and multiply.

Who can get a UTI?

Anyone can develop a UTI, but some people are more likely than others. Most UTIs occur in people with catheters, diabetics, infants with abnormal urinary tracts, and women.

Why do women get more UTIs than men?

- A woman's urethra is short, giving bacteria quick access to the bladder. A woman's urethral opening is close to sources of bacteria. Other factors that may increase a woman's risk for developing a UTI include:
- Frequent sexual intercourse
- Diaphragm use
- Using condoms with spermicidal foam

Symptoms of a UTI

- Frequent urge to urinate
- Burning during urination
- Fatigue
- Feeling pressure above pubic bone
- Only able to pass a small amount of urine
- Fever may indicate that infection has spread to the kidneys

SEE A HEALTH CARE PROVIDER IF YOU EXPERIENCE ANY OF THESE SYMPTOMS!

How to prevent UTIs

- Drink plenty of water
- Urinate when you feel the need
- Wipe from front to back to prevent bacteria from the anus from spreading
- Take showers instead of baths
- Wash the genital area (of both partners) before sexual intercourse
- Urinate after intercourse
- Avoid feminine hygiene products
- Decrease use of alcohol and caffeine
- Some doctors also recommend drinking cranberry juice, which can inhibit the growth of bacteria by acidifying the urine

When should I see a doctor?

If you experience heartburn more than twice a week, frequent chest pains after eating, trouble swallowing, persistent nausea, and cough or sore throat unrelated to illness, you may have GERD. For proper diagnosis and treatment, you should be evaluated by a physician.

How can my ENT help?

Otolaryngologists, or ear, nose, and throat doctors, and have extensive experience with the tools that diagnose GERD and they are specialists in the treatment of many of the complications of GERD, including: sinus and ear infections, throat and laryngeal inflammation, Barrett's esophagus, and ulcerations of the esophagus.

How is GERD diagnosed?

GERD can be diagnosed or evaluated by clinical observation and the patient's response to a trial of treatment with medication. In some cases other tests may be needed including: an endoscopic examination (a long tube with a camera inserted into the esophagus), biopsy, x-ray, examination of the throat and larynx, 24 hour esophageal acid testing, esophageal motility testing (manometry), emptying studies of the stomach, and esophageal acid perfusion (Bernstein test). Endoscopic examination, biopsy, and x-ray may be performed as an outpatient in a hospital setting. Light sedation may be used for endoscopic examinations.

While most people with GERD respond to a combination of lifestyle changes and medication. Occasionally, surgery is recommended. Lifestyle changes include: losing weight, quitting smoking, wearing loose clothing around the waist, raising the head of your bed (so gravity can help keep stomach acid in the stomach), eating your last meal of the day three hours before bed, and limiting certain foods such as spicy and high fat foods, caffeine, alcohol.

Medications your doctor may prescribe for GERD include: antacids (such as Tums, Rolaids, etc.), histamine antagonists (H2 blockers such as Tagamet), proton pump inhibitors (such as Prilosec, Prevacid, Aciphex, Protonix, and Nexium), pro-motility drugs (Reglan), and foam barriers (Gaviscon). Some of these products are now available over-the-counter and do not require a prescription.

Surgical treatment includes: fundoplication, a procedure where a part of the stomach is wrapped around the lower esophagus to tighten the LES, and endoscopy, where hand stitches or a laser is used to make the LES tighter.

Are there long-term health problems associated with GERD?

GERD may damage the lining of the esophagus, thereby causing inflammation (esophagitis), although usually it does not. Barrett's esophagus is a pre-cancerous condition that requires periodic endoscopic surveillance for the development of cancer.

Bowel Diary

Name: _____

Start Date: _____

Instructions: When you have a bowel movement, please fill in the letter(s) corresponding to what happened in the appropriate day and time box.

Key: N = Normal bowel movement

I = Incontinence/Bowel accident

P = Pad or pants change

S = Straining to pass stool

F = Fingers needed to push stool out
(splinting)

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Gas Meds
6am								
7am								
8am								
9am								
10am								
11am								
12pm								
1pm								
2pm								
3pm								
4pm								
5pm								
6pm								
7pm								
8pm								
9pm								
10pm								
11pm								
12am								
1am								
2am								
3am								
4am								
5am								

Notes: _____

Type 1	Type 2	Type 3	Type 4	Type 5	Type 6	Type 7
Separate hard lumps, like nuts	Sausage-shaped but lumpy	Like a sausage but with cracks on its surface	Like a sausage or snake, smooth and soft	Soft blobs with clear-cut edges	Fluffy pieces with ragged edges, a mushy stool	Watery, no solid pieces, entirely liquid

When you have a bowel movement, place the number that best characterizes your stool type in the appropriate place in the table

Sleep Charting _____

Name: _____

Date: From _____ TO: _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
2100-2200							
2200-2230							
2330- 2400							
2400-0030							
0030-0100							
0100-0130							
0130-0200							
0200-0230							
0230-0300							
0300-0330							
0330-0400							
0400-0430							
0430-0500							
0500-0530							
0530-0600							
0600-0630							
0630-0700							
0700-0730							
0730-0800							

Please record the sleep activity for the times listed according to the following code.

- 1 = Sleeping soundly
- 2 = Snoring loud
- 3 = Snoring softly
- 4 = Awake quiet in bed
- 5 = awake to bathroom back to bed
- 6 = awake talking to self
- 7 = restless sleeping
- 8 = awake for the day

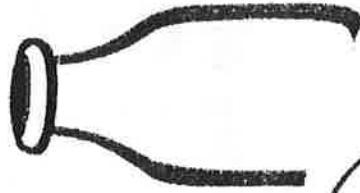
Directory of Genetics Centres in Ontario

City	Name	Address	Contact Information
Hamilton	Program in Human Genetics Hamilton Health Sciences Corporation	1200 Main Street W, Rm 3N19 Hamilton, ON L8S 4J9	T 905-521-5085 F 905-521-2651
	Familial Breast Cancer Clinic Familial Gastrointestinal Cancer Clinic Hamilton Regional Cancer Centre	699 Concession Street Hamilton, ON L8V 5C2	T 905-387-9495 x 65922 F 905-575-6310 www.hrcc.on.ca
Kingston	Adult Genetics Clinic Department of Family Medicine, Queen's University	P.O. Bag 8888, 220 Bagot Street Kingston, ON K7L 5E9	T 613-544-3400 x 3960 F 613-544-9899
	Genetics Clinic Kingston General Hospital	20 Barrie Street Kingston, ON K7L 3J6	T 613-533-6310 F 613-5481348
	Kingston Regional Cancer Centre Familial Oncology Program	25 King Street West Kingston, ON K7L 5P9	T 613-544-2631 x 2800 F 613-545-5722
London	Medical Genetics Program of Southwestern Ontario Children's Hospital of Western Ontario	800 Commissioners Road East London, ON N6C 2V5	T 519-685-8140 F 519-685-8214 www.lhsc.on.ca/programs/rmgc/
	London Regional Cancer Centre	790 Commissioners Road East London, ON N6A 4L6	T 519-685-8721 F 519-685-8664 www.lhsc.on.ca/Health_Professionals/L RCP/Professional_Disciplines/Genetics ts.htm
Mississauga	Clinical Genetics Credit Valley Hospital	2200 Eglinton Avenue West Mississauga, ON L5M 2N1	T 905-813-4104 F 905-813-4347
	Familial Cancer Credit Valley Hospital	2200 Eglinton Avenue West Mississauga, ON L5M 2N1	T 905-813-4104 F 905-813-4347
North Bay	Genetics Service North Bay and District Health Unit	681 Commercial Street North Bay, ON P1B 4E7	T 705-474-1400 x 305 F 705-474-0153 www.nbdhu.on.ca/en/index- direct.asp?DirectURL=clinics/clinics_in dex.htm
North York	Clinical Genetics Diagnostic Centre North York General Hospital IODE Children's Centre	4001 Leslie Street, Room 161 North York, ON M2K 1E1	T 416-756-6345 F 416-756-6727 www.nygh.on.ca/programs/genetics.htm l
	The Charlotte and Lewis Steinberg Familial Breast and Ovarian Cancer Clinic, North York General Hospital Genetics Program	4001 Leslie Street, Room 161 North York, ON M2K 1E1	T 416-756-6345 F 416-756-6727
Orillia	Genetic Service Orillia Soldiers' Memorial Hospital	170 Colborne Street West Orillia, ON L3V 2Z3	T 705-327-9154 F 705-325-3459
Oshawa	Genetic Service Lakeridge Health Oshawa	1 Hospital Court Oshawa, ON L1G 2B9	T 905-433-2733 F 905-721-4757
Ottawa	Division of Genetics Children's Hospital of Eastern Ontario	401 Smyth Road Ottawa, ON K1H 8L1	T 613-737-2275 F 613-738-4822 www.cheo.on.ca/english/8359.shtml www.cheo.on.ca/francais/8359.shtml
	Thrombosis Assessment and Treatment Unit, Ottawa Hospital, Civic Campus	737 Parkdale Ave., Room 460 Ottawa, ON K1Y 4E9	T 613-798-5555 x 19841 F 613-761-4840
Peterborough	Peterborough County-City Health Unit Genetics Program	10 Hospital Drive Peterborough, ON K9J 8M1	T 705-748-2021 F 705-748-3865
Richmond Hill	Genetic Clinic York Central Hospital	10 Trench Street Richmond Hill, ON L4C 4Z3	T 905-883-2007 F 905-883-2531
Sault Ste. Marie	Genetic Clinic Algoma Health Unit Genetics Program	63 East Street, Unit 1 Sault Ste. Marie, ON P6A 3C4	T 705-541-7057 F 705-759-5953 www.ahu.on.ca

City	Name	Address	Contact Information
Scarborough	Genetic Clinic Scarborough Centenary Health Centre	2867 Ellesmere Road Scarborough, ON M1E 4B9	T 416-281-7425 F 416-281-7306
Sudbury	Genetic Counseling Services Hopital Régional de Sudbury Regional Hospital	4 Boland Avenue Sudbury, ON P3E 1X7	T 705-675-4786 F 705-675-7911 www.hrsrh.on.ca/
Thunder Bay	Genetic Counseling Services Thunder Bay District Health Unit	999 Balmoral Street Thunder Bay, ON P7B 6E7	T 888-294-6630 F 807-623-2369 www.tbdhu.com/Clinics/Genetics/
	Northwestern Ontario Regional Cancer Centre	290 Munro Street Thunder Bay, ON P7A 7T1	T 807-625-5921
	<i>Manitoba: Clinical Genetics Health Sciences Centre, Children's Hospital</i>	<i>685 William Avenue Winnipeg, MB R3E 0Z2</i>	<i>T 204-787-2494 F 204-787-1419</i>
	<i>Manitoba: Hereditary Breast Cancer Clinic</i>	<i>608-400 Taché Avenue Winnipeg, MB R2G 2S1</i>	
Timmins	Genetic Services Procupine Health Unit	Postal Bag 2012 169 Pine Street South Timmins, ON P4N 8B7	T 705-267-1181 F 705-264-3980 www.porcupinehu.on.ca/Genetics/
Toronto	Adult Genetics Program Toronto General Hospital	ES - 3 401 B Toronto, ON M5G 2C4	T 416-340-4800 x 6632 F 416-340-3709 www.uhn.ca/Clinics_&_Services/services/adult_genetics/health_profes.asp
	Cancer Care Ontario	620 University Avenue Toronto, ON M5G 2L7	T 416-971-9800 F 416-971-6888 www.cancercare.on.ca/index_researchGenetics.hun
	Cancer Genetics Program Division of Hematology/Oncology Hospital for Sick Children	555 University Avenue Toronto, ON M5G 1X8	T 416-813-8597 F 416-813-5327 www.sickkids.ca/cancergeneticsprogram
	Clinical and Metabolic Genetics Clinic Hospital for Sick Children	555 University Avenue Toronto, ON M5G 1X8	T 416-813-6390 F 416-813-5345 www.sickkids.on.ca/cgenetics/
	Familial Breast Cancer Clinic The Centre for Research in Women's Health	790 Bay Street, 7 th floor Toronto, ON M5G 1N8	T 416-351-3800 F 416-351-3767
	Familial Breast Cancer Clinic Marvella Koffler Centre Mount Sinai Hospital	600 University Avenue Toronto, ON M5G 1X5	T 416-586-3244 F 416-586-8659 www.mtsinai.on.ca/FamMedGen
	Familial Gastrointestinal Cancer Registry Mount Sinai Hospital	600 University Avenue, Suite 1157 Toronto, ON M5G 1X5	T 416-586-8334 F 416-586-8644 www.mtsinai.on.ca/familialgicancer/
	Familial Ovarian Cancer Clinic Princess Margaret Hospital	610 University Avenue, Room M704 Toronto, ON M5G 2M9	T 416-946-2270 F 416-946-6528
	Prenatal Diagnosis and Medical Genetics Program. Mount Sinai Hospital	Ontario Power Generation Building 700 University Avenue Toronto, ON M5G 1Z5	T 416-586-4523 F 416-586-4723 www.mtsinai.on.ca/pdmg/
	Preventive Oncology Program Toronto-Sunnybrook Regional Cancer Centre	2075 Bayview Avenue Toronto, ON M4N 3M5	T 416-480-6944 F 416-217-1338
	Canada Research in Schizophrenia Genetics, Clinical Genetics Research Program, Centre for Addiction & Mental Health (CAMH)	1001 Queen Street West Toronto, ON M6E 1H1	T 416-535-8501 x 2732 F 416-535-7100
Windsor	Genetic Services Windsor-Essex County Health Unit	1005 Ouellette Avenue Windsor, ON N9A 4J8	T 519-258-2146 x 1220 F 519-258-8431

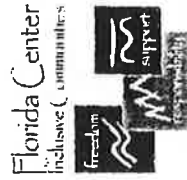
What Should I Do?

- ✓ Put less food on your plate.
- ✓ Eat lots of different fruits, vegetables, and whole grain foods.
- ✓ Eat 3 meals and healthy snacks everyday.
- ✓ Eat slower and enjoy every bite— you will feel more full!
- ✓ Stop eating when you feel full! You do not have to clean your plate!
- ✓ Restaurants usually give too much food!
- ✓ Ask to wrap half of your meal so you can eat it later or share with a friend.
- ✓ Choose steamed, grilled, or baked food instead of fried.
- ✓ Get the small sizes (never Biggie) at fast-food restaurants.
- ✓ Don't go to the all-you-can-eat buffet.
- ✓ Drink water, low-fat milk, or unsweetened tea instead of drinks with extra sugar.



Where Do I Go for More Help?

- ✓ Montana Disability & Health Program:
<http://mtdh.ruralinstitute.umd.edu/Directory/Nutrition.htm>
- ✓ Dietary Guidelines for Americans:
<http://www.healthier.us.gov/dietaryguidelines/>
- ✓ National Center for Physical Activity and Disability: <http://www.ncpad.org>
- ✓ My Pyramid: <http://www.mypyramid.gov>
- ✓ My Pyramid for Kids:
<http://www.mypyramid.gov/kids/index.html>



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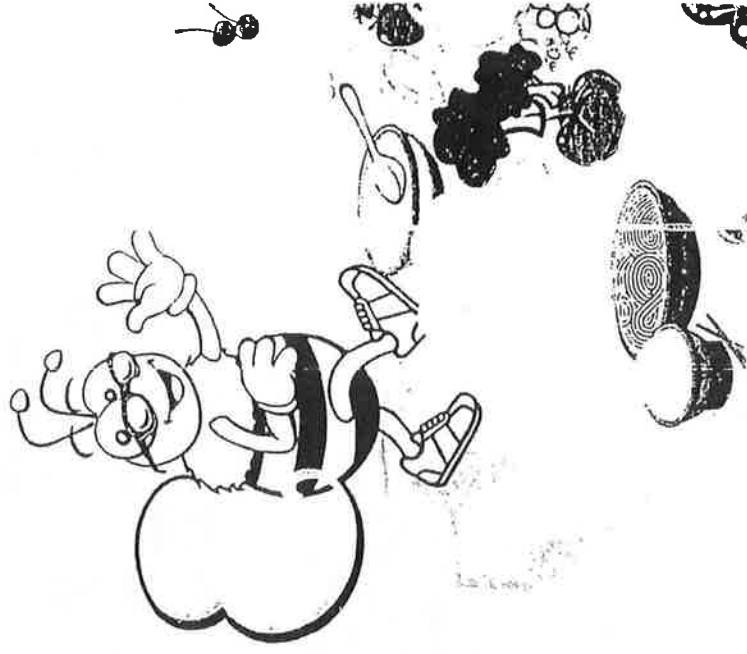
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A Behavioral-Health Information Program

Nutrition



Eating Healthy

The Importance of a *Healthy Diet?*

Research shows that a healthy diet will help you feel better and live longer.

Eating well can give you:

- ✓ More energy
- ✓ Better sleep
- ✓ Healthy weight

Poor diet is related to unhealthy weight and health problems like:

- ✓ Heart disease
- ✓ Cancer
- ✓ Diabetes
- ✓ High blood pressure

Poor diet can also cause:

- ✓ Sleep problems
- ✓ Feeling tired for no reason
- ✓ Extreme feelings of sadness

Eating right can help you feel better and stay healthy. Don't forget to include physical activity in your diet.

The New *Food Pyramid*

What is this pyramid?

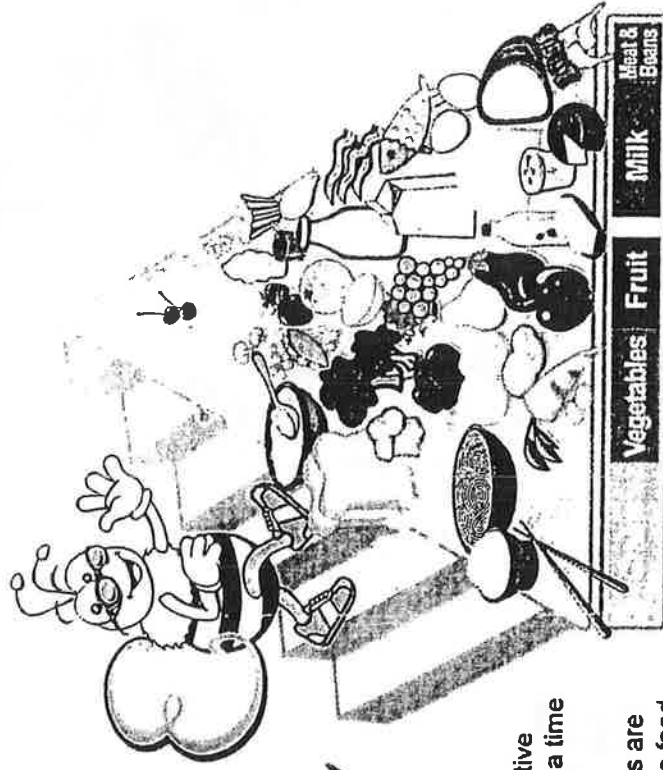
- ✓ Steps remind you to be physically active and that you should take one step at a time in making healthy choices.
- ✓ Did you notice that some color stripes are wider than others? Eat more from the food groups with the widest stripes.
- ✓ Eat less candy, chips, sodas, and desserts.
- ✓ Eat different kinds of foods from each group everyday.

More about My Pyramid

Any food made from whole wheat, brown rice, oats, cornmeal, barley or another cereal grain. Whole wheat bread or brown rice is better than white. Eat 3 servings per day.



Any vegetable or 100% vegetable juice. Vegetables are raw or cooked; fresh, frozen, canned, or dried and are OK whole, cut-up, or mashed. Examples are broccoli, spinach, carrots, sweet potatoes, and dark green leafy lettuce. Eat 3 servings per day.



Any fruit or 100% fruit juice counts as fruit. Fruits can be fresh, canned, frozen, or dried, and may be whole, cut-up, or pureed. Examples are apples, pears, bananas, melons, nectarines, peaches, plums, and berries. Eat 1 1/2 to 2 servings per day.



Examples are milk, yogurt, pudding, and cheese (cream cheese, cream, and butter ARE NOT HEALTHY). Fat-free or low-fat milk is a better choice. Eat 3 servings per day.



Meat, chicken, fish, dry beans (kidney, pinto, lentils, black-eyed peas), eggs, nuts, and seeds count. Meat and chicken should be lean or low-fat. Fish, nuts, and seeds have healthy oils, so they are healthier than meat or chicken. Eat 5 servings per day.

Physical Activity

Ideas

- ✓ Gardening or yard work
- ✓ Household chores like sweeping the floor
- ✓ Biking
- ✓ Walking or jogging (better with music!)
- ✓ Dancing
- ✓ Following an exercise video
- ✓ Hiking at a park
- ✓ Swimming
- ✓ Bowling
- ✓ Playing ball or Frisbee
- ✓ Jump rope
- ✓ Group games with Parachute
- ✓ Obstacle courses
- ✓ Take an exercise or dance class
- ✓ Join a recreational group like the Special Olympics::
- ✓ Join a bowling group
- ✓ Moving ribbon wands to music
- ✓ Martial arts
- ✓ Boating or Kayaking
- ✓ Walk in the mall



More Ideas

- ✓ Turn off the TV and plan fun activities to get you moving!
- ✓ Plan fun activities with a friend!
- ✓ Make a list of fun activities and put them in your weekly schedule.
- ✓ Ask support people for help with transportation and money for activities.
- ✓ Make physical activity a goal.
- ✓ Consult your doctor about the amount and types of physical activity that are right for you.
- ✓ Check out the National Center on Physical Activity website, www.nccpad.org, for a list of recreational programs by state, city or zip code.



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A Behavioral-Health Information Program

Physical Activity:

Getting Fit for Life



Physical Well-Being

Why is Physical Activity

Important?

People with disabilities need physical activity as much as anyone! But people with disabilities are usually less active than people without disabilities.

What Causes Unhealthy Weight & Obesity?

- ✓ Sitting around too much instead of being active and not eating a healthy diet causes unhealthy weight.
- ✓ Children and adults with disabilities can and should be physically active!

Did You Know?

- ✓ Keep your heart healthy
- ✓ Help control cholesterol and blood sugar levels
- ✓ Keep your bones strong as you get older
- ✓ Protect you from getting some kinds of cancer
- ✓ Be healthier and live longer
- ✓ Feel happier and have more energy
- ✓ Keep a healthy weight

What is

Physical Activity? Not Just Exercise!

- ✓ Exercise is one kind of physical activity that is planned and structured. It is also repetitive and done to improve your health and fitness, like going to the gym or taking an aerobics class.

There are three main kinds of physical activity:

1. Aerobic activity makes your heart beat faster and makes you breathe harder.
 - examples: walking, running, bicycling, dancing, swimming, vacuuming, walking the dog
 2. Muscle-Strengthening activity works all the muscle groups of your body (legs, hips, back, chest, stomach, shoulders, and arms).
 - examples: climbing, push-ups, sit-ups, lifting weights, yoga
 3. Bone-Strengthening activity is when your feet, legs, or arms carry your weight.
 - examples: basketball, tennis, hopscotch, dancing, jumping jacks, walking
- ✓ It is important to do ALL 3 kinds of physical activity to keep your body healthy.
 - ✓ You should do 1 hour or more of physical activity almost every day.
 - ✓ Even more physical activity may be needed to lose weight or to keep weight

How can I

Protect Myself?

- ✓ You have a right to be safe and to be treated with respect
- ✓ You have the right to decide who will touch your body, and how and when you will be touched.
- ✓ Remember that you have the right to say "no" to any unwanted touch, even from a boyfriend or girlfriend, caregiver, attendant, family member, health care provider or other person in your life.
- ✓ You have the right to say **STOP** the touching whenever you want, even if it felt good at first.
- ✓ If someone hurts you, makes you feel bad about yourself, or touches you in a way that you do not like, **tell someone you trust**. If the first person does not help, tell someone else!
- ✓ If someone you know takes your money or things, **they are not being a friend!** Tell someone you trust!
- ✓ Say **NO!** Then **GO TELL!**

Who Can Help?

- ✓ Someone at church
- ✓ Someone who helps you at work or at home
- ✓ Someone in your family
- ✓ Your doctor or therapist

Resources

- ✓ My Florida Zero Tolerance Initiative:
<http://apd.myflorida.com/zero-tolerance/index.htm>
- ✓ State of Oregon information website on disability and abuse:
<http://www.oregon.gov/DHS/spwpd/index.shtml>
- ✓ Important numbers to report abuse:
 - 911
 - 1-800-96ABUSE (7-800-962-2873)
 - TDD: 1-800-453-5145
 - Fax: 1-800-914-0004



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<http://ffccic.org>

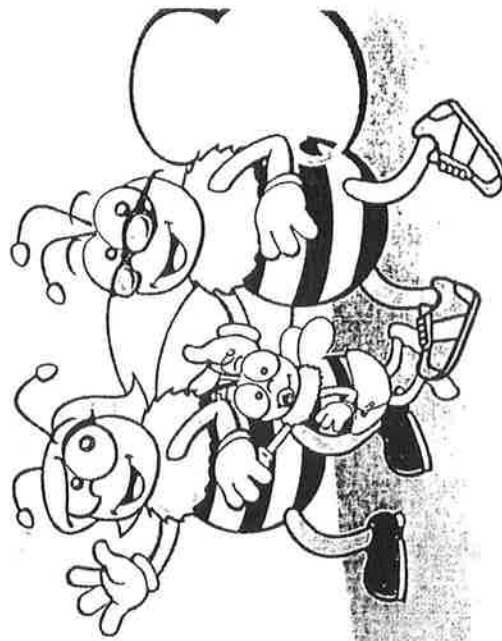
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A Behavioral-Health Information Program

Abuse, Neglect, & Exploitation:



Personal Safety

The Problem

People with disabilities, children, and the elderly are especially likely to be abused, neglected, and exploited.

Did you know that almost 90% of children and adults with developmental disabilities are abused or exploited sometime in their life?

People with disabilities are at risk because:

- ✓ They depend on others for basic needs
- ✓ They are taught to cooperate with "people in charge" like staff members
- ✓ They often live in group settings and can't choose roommates or caregivers

People with disabilities may not report abuse, neglect, or exploitation because they:

- ✓ Feel guilty, ashamed, and/or love for the person that hurt them (abuser)
- ✓ Do not want to make the abuser mad or get them in trouble
- ✓ Do not know *how* to get help
- ✓ Do not even know they are being abused!

The abuser can be anyone but is usually someone the victim knows well such as a caregiver, a friend, a family member, or a spouse!

Abuse can be physical, emotional, or sexual. Taking your money or things from you (financial exploitation) is abuse too!

What Should I Look For?

Signs of abuse:

- ✓ Bruises, cuts, burns, grip marks
- ✓ Any injury that is unusual, unexplained, or the explanation does not make sense
- ✓ Any injury that has not been properly treated (sometimes injuries are hidden on areas of the body normally covered by clothing)
- ✓ Genital pain or itching, or sexually transmitted diseases

Also, pay attention to changes in behavior!

- ✓ Suddenly scared of certain people, or a specific gender, or certain situations
- ✓ Sudden fear of bathing or toileting
- ✓ Changes in personal hygiene
- ✓ Sleep problems, nightmares
- ✓ Sudden use of rude, abusive, or threatening language
- ✓ Signs of helplessness, unwilling to talk openly, fear, depression, agitation, nervousness, or confusion
- ✓ Unusually disobedient or overly obedient behavior
- ✓ Sexually inappropriate behaviors, masturbation, or new interest in sex
- ✓ Hints about sexual activity and a new or detailed understanding of sexual behavior

What

Can I Do?

- ✓ If you have seen any of these signs and are concerned about someone, you know, do not wait—do something!
- ✓ Document everything; bruises, cuts, scratches, etc...as soon as you notice it. Write down where on the body the injury is located, whether it is an old or new injury, and a possible explanation of how it happened.
- ✓ Take notes on any new or unusual patterns.
- ✓ Talk with someone you trust (like a supervisor or case manager).
- ✓ Report your concern! You could end terrible suffering and even save a life!

Reporting Abuse & Exploitation

Note: If you know that a life is in immediate danger due to abuse, neglect, or exploitation, you should call 911 before calling anyone else.

- ✓ Call the Florida Abuse Hotline, which is a nationwide, toll-free telephone number, at 1(800)96-ABUSE or 1(800)962-2873 (TDD: 1-800-453-5145).
- ✓ Or send a faxed statement to the Abuse Hotline's statewide toll-free fax number, 24 hours a day, 7 days a week, at 1(800)914-0004, and
- ✓ Call the police

National Empowerment Center - Articles

Reclaiming your power during medication appointments with your psychiatrist

By Patricia Deegan, Ph.D.

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(PDF, 2 pages, 121KB)

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(PDF, 2 pages, 156KB)

Meeting with a psychiatrist during "medication appointments" is usually a very disempowering experience. The meetings usually last for 15 or 20 minutes. During the meeting we are expected to answer a few perfunctory questions and to leave with prescriptions for powerful drugs that can dramatically alter the quality of our lives. In these meetings the psychiatrist assumes a position of power and we usually fulfill the expected role of being a quiet, unquestioning, passive patient. Subsequently we will be praised for merely being compliant or scolded/punished if we fail to comply with prescribed medications. Over the years I have developed a number of strategies for changing the power imbalance during medication meetings with psychiatrists. I would like to share some of these strategies with you.

Strategy #1: Learn to think differently about medication

1. **There are no magic bullets.** Recovery is hard work. No pill can do the work of recovery for me. If I sit back and wait for a pill to make me better, I will not get better. If I patiently wait for a drug to cure me I may become a chronic, helpless patient who swallows pills on command, but I will not recover. Recovery means taking an active stance towards the problems and challenges I face.
2. **Medications are only a tool.** Psychiatric medications are one tool among many other tools that I can use to recover. Physical exercise, eating well, avoiding alcohol and street drugs, love, solitude, art, nature, prayer, work, and a myriad of coping strategies are equally important to my recovery.
3. **Using medications is not a moral issue.** There was a time when I thought using medications was a sign of weakness or that people who no longer used medications were better than I was. I no longer think this way. There is no right or wrong way to recover. What matters to me is taking care of myself in such a way that I have a chance to become the best person I can be. There are periods of time when I do not use medications and there are times when I do. It is a personal choice that I make.
4. **Learn to use medications.** Today I do not simply take medications. Taking medications implies a passive stance. Rather I have learned to use medications as part of my recovery process. Learning to use medications within the recovery process means thoughtfully planning and following through with medication trials, medication reductions and/or medication withdrawal.
5. **Always use medications and coping strategies.** There are many non-drug coping strategies that can help alleviate symptoms and distress. Take the time to learn strategies for coping with voices, delusions, paranoia, depression, obsessive thinking, self injury, flashbacks, and so forth. I have found that learning to use a variety of non-drug coping strategies helps to minimize the amount of medications I take or, with practice, can actually eliminate the need for medications.
6. **Learn about medications.** It is easy to feel intimidated by all the big words and technical jargon that get used about psychiatric medications. However, there are a number of ways that I have found helpful in getting reliable and accessible information about the medications I am considering using. I am careful to ask the psychiatrist I am working with about the medication he/she is prescribing. However, I often find this information insufficient. A great source of information is talking with other people who have used the drug. Perhaps the cheapest and easiest way to get more information is to ask a pharmacist who will give you a written fact sheet

describing what the drug is supposed to do, what the unwanted effects are, and precautions including drug interaction information. These drug fact sheets are written in nontechnical jargon, but unfortunately leave out a lot of detail that might be important to you. If this is the case you can always ask your pharmacist for drug-insert information. The drug-insert information is essentially the same information that is contained in the Physicians Desk Reference (PDR). It is printed on a small roll of paper and inserted in the box of medications that the pharmacist receives. There is a lot of technical jargon in the insert but the information is more thorough than the fact sheet. In addition you can go to the library and use the Taber's Cyclopedic Medical Dictionary to look up words you are not familiar with. There are also a number of good books that can help you get answers to your questions. These include Clinical Psychopharmacology Made Ridiculously Simple (John Preston and James Johnson, published by MedMaster, Inc.) or Instant Psychopharmacology (Ronald Diamond, published by W.W. Norton) or Toxic Psychiatry (Peter Breggin, published by St. Martin's Press) or Natural Healing for Schizophrenia (Eva Edelman, published by Borage Books, Eugene Oregon) or Living Without Depression & Manic Depression (Mary Ellen Copeland, published by New Harbinger). If you have access to the Internet there are lots of resources including these:

- Dr. Bob's Psychopharmacology Tips at <http://uhs.bsd.uchicago.edu/~bhsiung/tips/tips.html> (<http://uhs.bsd.uchicago.edu/~bhsiung/tips/tips.html>)
- Healthtouch, with an excellent data base of over 7,000 prescription and over the counter drugs at http://www.healthtouch.com/level1/p_dri.html (http://www.healthtouch.com/level1/p_dri.html)
- Medline at <http://www.ncbi.nlm.nih.gov/pubmed> (<http://www.ncbi.nlm.nih.gov/pubmed/>).

Strategy #2: Learn to think differently about yourself

1. **Trust yourself.** You know more about yourself than your psychiatrist will ever know. Begin to trust yourself and your perceptions. Sometimes I found it hard to trust my perceptions after being told that what I felt, thought, or perceived, was crazy. Part of recovery is learning to trust yourself again. Even during my craziest times there was a kernel of truth in all of my experience. If you are experiencing unwanted drug effects such as a feeling of apathy, constipation, loss of sex drive, double vision, or the like, trust your perception. Don't let others tell you that such side effects are "all in your head." Check with the pharmacist, or with friends who have used the drugs, and check the books or the Internet. Chances are that you are not the first person to have these drug effects.
2. **It's your recovery.** Too often I have heard people say that "the drug made me feel better." Don't give all the credit to the chemical! Even if you found a drug helpful, look at all the things you have done to get well and stay well. A drug can sometimes open a door, but it takes a courageous human being to step through that door and build a new life.
3. **Your questions are important.** Anyone who has been on psychiatric drugs for a period of time is probably going to ask these important questions:
 - What am I really like when I am off these medications?
 - What is the "real me" like now?
 - Is it worth taking these medications?
 - Are there non-drug methods I can learn to reduce my symptoms instead of using medications?
 - Have my needs for medications changed over time?
 - Do I have tardive dyskinesia that is being masked by the neuroleptics I am taking?
 - There are no long-term studies on the medication I use. Am I at risk? Do I want to take the risk of not knowing the long-term effects?
 - Am I addicted to these medications?
 - Has long-term use of these medications resulted in memory loss or decreased my cognitive functioning?

There is nothing crazy about having such questions. What is unfortunate is that most mental health professionals do not recognize that these questions are to be expected. A recovery oriented system would have detox centers and other supports available so that

people could plan a rational withdrawal from medications in order to explore these important questions.

Strategy #3: Think differently about psychiatrists

1. **Most psychiatrists are too busy for our own good.** We would be wrong to assume that most psychiatrists have a thorough knowledge of their clients' treatment history. In an age of managed care psychiatrists have less and less time to spend with more and more clients. Many psychiatrists have never read the full case record of the people they prescribe medications to. Even fewer could identify all of the various drugs and drug combinations that you have tried over the years and what the outcomes of those drug trials were. In light of this I have found it important to begin to keep my own record of what medications I have tried, for what symptoms, at what dosages, and for what period of time. Whenever a psychiatrist suggests a new drug or a new dose, I always check my record just to be sure it hasn't been tried before. I don't want to repeat ineffectual or even harmful drug trials.
2. **Psychiatrists often have conflicting interests.** It would be comforting to think that psychiatrists were serving our individual interests. But this assumption would be naive. Many psychiatrist complain of the competing interests that tear at the ethical fabric of their practice. Especially if I am working with a psychiatrist who is part of a managed care system, I feel it is important to ask what, if any, caps on services he/she is working under. In other words, some psychiatrists receive their paychecks from managed care corporations that require them to prescribe one type of drug rather than others that are expensive. If this is the case, we should have this information!
3. **Sometimes psychiatrists are wrong.** Most psychiatrists do not encourage us to seek second opinions regarding diagnosis, medications, or other somatic treatments such as ECT. However, at certain times I have found it important to seek out a second opinion. Even with a managed care plan or if you are on Medicaid or Medicare, it is possible to get a second opinion on an issue you deem important. It can take a lot of work, phone calls and even a friend to help advocate, but it can be done and you are worth it!
4. **Psychiatrists are not experts on everything.** Most psychiatrists believe in the primacy of biology. Most have a mechanized and materialist world-view. Thus, chances are that if you have a diagnosis of major mental illness and you talk to your psychiatrist about ecstatic spiritual experiences, mystical experiences, psychic abilities, or similar experiences, these will be perceived as crazy or symptomatic. One way of taking back your power is to recognize that you have control over what you share with a psychiatrist and what you choose to keep private.

A meeting with a psychiatrist need not be a confession! Talk with mystics about your mystical experiences. Talk with psychics about telepathy, etc.

Strategy #4: Prepare to meet with your psychiatrist

1. **Set your agenda for the meeting.** I have found it important to set my agenda for a meeting with a psychiatrist rather than simply reacting to what he/she does or does not do. In order to set an agenda it is important to define your immediate goals. Possible goals might include starting medication, discussing a medication change, planning for a medication reduction, planning for a medication withdrawal, checking for tardive dyskinesia, finding a solution for unwanted drug effects, or reporting on a medication trial. Try, if possible, to set one goal for each meeting.
2. **Organize your thoughts and concerns.** I have also found it important to prepare ahead of time for a meeting with a psychiatrist. I have developed a form that helps me organize my thoughts and to put things in writing. A copy of this meeting preparation guide is available through the National Empowerment Center.
3. **Be specific.** The more specific we can be about our concerns, the more control we can exercise during a meeting with a psychiatrist. For example, if a psychiatrist begins a meeting by asking, "How is that new medication working?" a vague answer would be "Oh, it's helping a little I think." Imagine how empowered you would feel if, instead, you were able to answer, "Well, before I began this medication trial I was so depressed that I missed seven days of work, spent 14 days in bed and lost 3 pounds. But during the last two months, since starting the drug and

using the new coping strategies, I have only missed 2 days of work, have regained the weight I lost and I have only spent 4 days cooped up in my apartment." Notice how this level of specificity puts you squarely in the driver's seat of your life and positions the psychiatrist as a co-investigator, as opposed to being the authority over your life. Getting this specific may sound difficult, but it is not. It simply requires that you learn how to record your medication and/or self help trial on a daily basis and that you summarize this information before seeing your psychiatrist. A guide to recording your medication and/or self-help trial is available through the National Empowerment Center.

4. **Write your questions down.** Write your questions down before seeing your psychiatrist. Bring the questions with you to the meeting. My experience is that these meetings can be stressful and that having my questions written down allows me to relax a bit. If you are considering trying a new medication, be sure to ask the following questions:
 - Exactly how will I know if this medication is working for me?
 - How long before I should start to notice an effect from this medication?
 - What are the unwanted effects or side effects associated with this drug?
 - If I should experience unwanted side effects, what should I do about it?
 - How can I contact you if, during this medication trial, I have questions of concerns I want to check out with you?
5. **Role-Play.** Sometimes it can be helpful to role-play with a friend or someone you trust before seeing your psychiatrist. Learning to talk to a psychiatrist from a position of personal power is a skill that can be learned and must be practiced. Be patient and give yourself time!

Strategy #5: Take charge of the meeting

1. **Bring a note pad and pen to the meeting.** Most of us have had the unnerving experience of talking to a psychiatrist while he/she busily jots notes that we never get to see. Bringing your own note pad and pen, and taking your own notes is a good way to break the habit of being a passive patient. It gives you something to concrete and active to do while in the meeting. Writing notes can also help you remember important points.
2. **Tape-record the meeting.** I can get very anxious when meeting with a psychiatrist and thus a lot of information passes by me. I have tape recorded meetings so that I can listen to them afterwards and pick up on the information I may have missed. I have always asked permission before recording. Although some psychiatrists don't feel totally comfortable with the idea (they fear lawsuits), all have agreed to it when I explain why I am taping the meeting.
3. **Announce your agenda at the beginning of the meeting.** If you have done your meeting preparation work, then you know what you want to get out of the meeting with your psychiatrist. There have been many times when I bring two copies of a one-page, written statement of my agenda, concerns, and observations to the meeting. I hand a copy to the psychiatrist and begin the meeting by reading my statement out loud. My experience has been that most psychiatrists initially object to my starting this way. They are accustomed to starting meetings with their own agenda, which is usually vague and centered on the notion that they will observe me for significant clinical signs and symptoms while I answer the questions. But if I insist on beginning the meeting with my statement and assure them they can talk later, I find they soon come to understand the value of my preparation. In fact, some of the psychiatrists I work with keep the copy of my agenda and statement and add it to the clinical record. For a sample copy of an opening statement, contact the National Empowerment Center.
4. **Bring a friend or advocate.** Many people bring a friend or support person when they see a dentist or have a physical exam. It makes sense to bring a friend to a meeting with a psychiatrist, especially when you are first breaking out of the role of passive patient and are learning to reclaim your power.

These strategies have worked for me. Together these strategies have helped shift the balance of power between me and the psychiatrist I am working with. Perhaps some of these strategies will make sense

to you. I am sure that you will come up with your own strategies as well. What is important is to realize that you can take your power back and become the director of your own recovery and healing.

Download a **free information packet** ([../downloads/MedicationMeetingPacket.pdf](#)) with a guide to meeting preparation, organizing your own medication/self-help trial, and a sample meeting agenda statement.

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599 Canal St., Lawrence, MA
800-power2u (800-769-3728), From outside the US: 978-685-1494
www.power2u.org - Site by [Tom Rogers Web Design](#) | [Internet Solutions](#)

Observation Record for Mania

(Adapted from the Dual Diagnosis Primer – Edward E. Hughes)

Name: _____ Date: _____

Baseline: _____ Week # _____ Rater: _____

0 = never 1 = occasional 2 = often 3 = frequently 4 = always

Euphoric, Elevated or Irritable Mood

___ Smiling, hugging, or being affectionate with people who previously were not favored by the individual.

___ Aggression towards previously favored person.

___ Boisterous.

___ Over-reactivity to small incidents

___ Extreme excitement.

___ Excessive laughing and giggling.

___ Self-injury associated with irritability.

___ Enthusiastic greeting of everyone.

Decreased Need for Sleep

___ Behavioural changes when prompted to go to bed.

___ Constantly getting up at night.

___ Seems rested after not sleeping (not irritable after lack of sleep)

☐ Works on activities at night in room.

Inflated Self-Esteem / Grandiosity

☐ Making improbable claims (claims to be c

☐ Wearing excessive makeup.

☐ Dressing provocatively.

☐ Demanding rewards.

Flight of Ideas

☐ Disorganized speech.

☐ Thoughts are not connected.

☐ Quickly changes subject.

More Talkative / Pressure of Speech

☐ Increased singing.

☐ Increased swearing.

☐ Perseverative speech.

☐ Screaming.

☐ Intruding in order to say something.

☐ Non-verbal communication increase.

☐ Increase in vocalizations.

Observation Record for Mania

(Adapted from the Dual Diagnosis Primer – Edward E. Hughes)

Name: _____ Date: _____

Baseline: _____ Week # _____ Rater: _____

0 = never 1 = occasional 2 = often 3 = frequently 4 = always

Euphoric, Elevated or Irritable Mood

___ Smiling, hugging, or being affectionate with people who previously were not favored by the individual.

___ Aggression towards previously favored person.

___ Boisterous.

___ Over-reactivity to small incidents

___ Extreme excitement.

___ Excessive laughing and giggling.

___ Self-injury associated with irritability.

___ Enthusiastic greeting of everyone.

Decreased Need for Sleep

___ Behavioural changes when prompted to go to bed.

___ Constantly getting up at night.

___ Seems rested after not sleeping (not irritable after lack of sleep)

☐ Works on activities at night in room.

Inflated Self-Esteem / Grandiosity

☐ Making improbable claims (claims to be a staff member, police officer)

☐ Wearing excessive makeup.

☐ Dressing provocatively.

☐ Demanding rewards.

Flight of Ideas

☐ Disorganized speech.

☐ Thoughts are not connected.

☐ Quickly changes subject.

More Talkative / Pressure of Speech

☐ Increased singing.

☐ Increased swearing.

☐ Perseverative speech.

☐ Screaming.

☐ Intruding in order to say something.

☐ Non-verbal communication increase.

☐ Increase in vocalizations.

Distractability

- ☐ Decrease in work / task performance.
- ☐ Leaving tasks uncompleted.
- ☐ Inability to sit through activities (favorite TV show)

Agitation / Increase in Goal Directed Behaviour

- ☐ Pacing
- ☐ Negativism
- ☐ Working on many activities at once.
- ☐ Fidgeting.
- ☐ Aggression.
- ☐ Rarely sits.

Excessive Pleasurable Activities

- ☐ Increase in masturbation.
- ☐ Sexualizing previously platonic relationships.
- ☐ Teasing others.
- ☐ Giving away, spending money excessively.

Observation Record for Depression

Name: _____ Date: _____

Baseline: ____ Week # : ____ Rater: _____

0 = never 1 = occasional 2 = often 3 = frequently 4 = always

Taking into consideration the persons behaviour in the last month please complete the record.

Depressed Mood

____ Frequent, unexplained crying.

____ Decrease in laughter and smiling.

____ General Irritability and subsequent aggression or self injury.

____ Sad facial expression.

Loss of Interest in Pleasure

____ No longer participates in favorite activities

____ Reinforcers no longer valued.

____ Increased time spent in room alone.

____ Refusals of most work/social activities.

Weight Change / Appetite Change

____ Measured weight change.

____ Increased refusals to come to the table to eat.

____ Unusually disruptive at meal times.

___ Constant food seeking behaviours.

Insomnia

___ Disruptive at bed time.

___ Repeatedly gets up at night.

___ Difficulty falling asleep.

___ No longer gets up for work / activities.

___ Early morning awakening.

Hypersomnia

___ Over 12 hours of sleep per day.

___ Naps frequently.

Psychomotor Agitation

___ Restless, fidgety, pacing.

___ Increased disruptive behaviour.

Psychomotor Retardation

___ Sits for extended periods.

___ Moves slowly.

___ Takes longer than usual to complete activities.

Fatigue, Loss of energy

- ___ Needs frequent breaks to complete simple activity.
- ___ Slumped / tired body posture.
- ___ Does not complete tasks with multiple steps.

Feelings of Worthlessness

- ___ Statements like “I’m dumb,” “I’m retarded”, etc.
- ___ Seeming to seek punishment.
- ___ Social isolation.

Lack of Concentration / Diminished ability to think

- ___ Decreased work output in vocational setting.
- ___ Does not stay with tasks until completion.
- ___ Decrease in IQ at testing.

Thoughts of Death

- ___ Preoccupation with family member’s death (e.g., increased interest in visiting grave, carrying photo’s of deceased relatives, etc.)
- ___ Talking about committing or attempting suicide.
- ___ Fascination with violent movies / television shows.

Adapted from The Dual Diagnosis Primer – Edward E. Hughes

BEHAVIOR MANAGEMENT AND ANTIPSYCHOTIC MEDICATION PRESCRIBING

August 18, 2003

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
ASSESSMENT/PROBLEM RECOGNITION		
1. Were behaviors characterized in enough detail (onset, trigger, nature, intensity, duration, frequency, consequences, and other relevant information)?	<p>-Staff should describe target behaviors, using specific written criteria. Examples of possibly problematic behaviors or symptoms could include wandering, disruptive behaviors, hallucinations, increased withdrawal or isolation, etc.</p> <p>-Once a target behavior has been identified, staff should describe the behavior's characteristics (when it began, whom it affected, the intensity or severity of the behavior, how often it occurred, how long it continued and what happened over time, its consequences (including impact on self and others); - the circumstances, events, physical, environmental, or interpersonal factors that may have brought on or contributed to the behavior; - and other relevant information). The behavior(s) should be described in some detail, instead of by a single word like "agitated" or "combative".</p> <p>The content of hallucinations and delusions should be specifically described, as well as how it is impairing the resident's functioning.</p> <p>-Staff should use a consistent behavior-monitoring tool to quantitatively and qualitatively document targeted behaviors.</p>	<p>-Like any symptoms, behavioral symptoms can reflect anything from normal variations to an indication of severe underlying illness. Details are needed to determine whether a behavior is a problem and to identify its possible causes.</p> <p>-Consistent vocabulary and documentation over time is important in order to effectively compare behaviors and the potential value of specific interventions.</p>
2. Was there documentation that justified why the behavior was considered problematic?	<p>-Staff should clarify why a behavior was problematic, instead of a variation of a normal or natural response to a situation.</p>	<p>-Behaviors are a natural biological survival tactic of all living things.</p> <p>-Many behaviors in residents are purposeful and little different than those of individuals who reside outside of long term care facilities; for example, agitation in the face of an unmet need.</p> <p>-Individual direct care staff should not arbitrarily decide what constitutes a problem and when a treatment should be instituted.</p>

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
3. Was there timely recognition of problematic behavior?	<p>-For a new resident, staff should identify factors that influence behavior, taking into consideration caregiver input regarding previous behaviors and supportive interventions. situational and environmental factors, PAS/ARR information, MDS lifelong and customary routine information, and resident input, adaptive behavior, and strengths.</p> <p>-Within 24 hours of admission of a resident who has been identified as having a behavior problem or who enters the facility receiving treatment for a behavior problem or a psychiatric disorder, staff should initiate an in-depth evaluation of behavior.</p> <p>-Upon identification of a significant change in usual behavior patterns, staff should a) describe the details of the behavior and b) identify urgent behaviors requiring prompt intervention.</p> <p>-The staff and practitioner should be able to recognize symptoms that could represent conditions such as delirium, dementia, and psychosis.</p> <p>- Staff should document a discussion of significant symptoms with the physician after identifying their presence. The situation might require a consultation with Community Mental Health staff. PAS/ARR and MDS documentation may be required.</p> <p>-Staff should also evaluate more gradual changes in behavior, including those behaviors that become more frequent or more intense. A significant increase in problematic behaviors that cannot be resolved readily may represent a decline in condition that would require MDS revision.</p>	<p>-A comprehensive, individualized, resident-focused assessment provides necessary information to correctly identify resident needs and problems. causes of behaviors, and appropriate interventions.</p> <p>-High-risk behaviors require prompt interventions. whereas other behaviors can be evaluated over a longer time before determining specific interventions.</p> <p>-Delirium is an urgent situation that presents as changes in function, behavior, attention, or level of consciousness. It requires prompt medical and nursing evaluation and intervention. It may not require transfer from the facility.</p> <p>-Residents with mental illness or mental retardation must be appropriately placed and be offered appropriate mental health treatment.</p>
4. Were specific behaviors identified for which a medication or other	<p>-When a resident is receiving any psychoactive medications or any other interventions related to</p>	<p>-Residents may be taking a medication for which there is no clear indication.</p>

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
intervention was provided?	<p>problematic behaviors or disturbed mood, staff should identify the specific behaviors that the interventions are intended to influence or prevent or determine the symptoms that led to the diagnosis.</p>	<ul style="list-style-type: none"> -It cannot be assumed without verification that because someone is receiving a medication, there must be a reason for it. -Some people are stable or improve despite, not because of, medications and treatments. In other words, there is not always a direct correlation between intervention and outcome. -Some illnesses, conditions or situations that result in problematic behavior, altered mood, or impaired cognition resolve, making prolonged interventions unnecessary.
DIAGNOSIS/CAUSE IDENTIFICATION		
5. Was the current medication regimen reviewed as a potential source of problematic behavior?	<ul style="list-style-type: none"> -Staff, including the physician, should review the current medication regimen for medications that may affect mental status or behavior. -If the consultant pharmacist or other staffs identify high-risk or problematic medications, staff should notify and discuss the situation with the physician. -The physician, or staff who have communicated with the physician, should document that a review has occurred. 	<ul style="list-style-type: none"> -Many categories of medications may cause changes in cognition, level of consciousness, and behavior. -Often these changes may be caused by the collective effect of several medications in different categories with central nervous system (CNS) effects.
6. If a plausible cause was not found readily in someone with an acute behavior change, were fluid and electrolyte imbalance, acute infection, pain, or other potential causes considered?	<ul style="list-style-type: none"> -Each case should be reviewed for possible evidence of an underlying medical problem. -If delirium is suspected, prompt action is required by the staff, with physician notification, and by the physician, with possible medical intervention. -If delirium is not present, staff and the physician should consider psychiatric illnesses that might be causing problematic behavior; for example, new or recurrent depression or worsening of schizophrenia. -If delirium or major psychiatric illnesses are not present, staff should review and identify environmental factors, functional (task 	<ul style="list-style-type: none"> -Delirium is an acute change in mental status and level of consciousness due to medical causes, and requires prompt assessment and intervention because it may be associated with significant complications, including an increased risk of death. -Delirium is common in the elderly, and has several common identified causes. -Adverse drug reactions (ADRs), infection, fluid and electrolyte imbalance, and pain are commonly identified causes of acute changes in behavior. -Other medical conditions with or without delirium can also affect behavior. -Situational-psychosocial factors (such as noise, type and amount of activities, conflicts with other

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
	performance) impairments, and other factors related to interactions with others that could be related to problematic behaviors.	residents/staff, caregiver responses, communication problems) and functional impairments (such as tasks that are too complicated, complex or unfamiliar, not modified for increasing impairment, or that the resident is able, but not allowed, to complete) are other causes of problematic behaviors. -Staff beliefs and behaviors also influence the behavior of the resident. Challenging behavior may be a staff problem, instead of a resident problem.
7. Was there an attempt to identify categories of cause(s) of any problematic behavior, OR explain why causes could or should not be sought?	<p>-Once an abnormal or target behavior has been identified, staff should attempt, with the physician, to recognize causes of the behavior or explain why identification of causes of behavior is not feasible or not indicated (for example, cannot cooperate with testing, knowing cause would not change management, resident is terminal, etc.).</p> <p>-The various categories of causes, such as medications, physical health, psychiatric illness, and situational-psychosocial factors should be evaluated as indicated.</p>	<p>-Problematic behavior has causes and root-cause analysis is a crucial step in cause identification.</p> <p>-Conditions need to be clearly and correctly identified for effective management. (For example, agitation could be due to delirium, pain, psychosis, depression, anxiety, frustration, environmental stress, or simply a typical response in a person who is not cognitively impaired but has reacted that way in annoyance throughout his lifetime).</p>
8. Was a plausible explanation offered as to how it was determined that certain causes were the most likely reason for the behavior?	-If problematic behavior worsens during the subsequent 48 hours or is not resolving within a week, staff or the physician should document a basis for conclusions about the cause(s) of a resident's behavior; for example, why current treatment is still warranted.	<p>-There are factors that can help differentiate categories of causes.</p> <p>-A systematic approach is crucial.</p> <p>-Expecting staff and physician to explain their conclusions enhances their ability to make better, more specific decisions and reduces the risk of recommending inappropriate or potentially harmful interventions.</p>
TREATMENT/PROBLEM MANAGEMENT		
9. Were specific goals and objectives identified for managing behaviors?	-Before or soon after initiating interventions, staff should identify and document resident-specific goals for managing behaviors. These goals should be relevant to that individual's condition, prognosis, wishes, causes, etc.; for example,	-Appropriate goals for managing problematic behavior depend on understanding the nature and causes of behavior and realistic potential treatments/interventions.

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
<p>10. Were appropriate individuals consulted in planning the management of problematic behavior?</p>	<p>reduce the frequency of aggressive behaviors, stabilize mood, correct underlying causes and consequences of the problematic behavior, reduce undesirable medication side effects, etc.</p> <ul style="list-style-type: none"> -Education and training that reflects standards of practice and current knowledge base regarding behavior management of the specific population at the facility should be provided. -For non-emergency or non-urgent situations, appropriate individuals such as family, resident, and interdisciplinary, multi-level staff should be included in setting goals and managing problematic behavior. -For urgent or emergency situations, the physician should be included and the appropriate family or other substitute decision maker should be informed of the situation. -A mental health consultant or Community Mental Health staff may be involved. As with integration of specialists/contracted for staff in any area, both the facility and consultant should clearly understand one another's roles, responsibilities and expectations, as well as the resident's needs. -If the staff and the physician have identified a relevant intervention, which the resident or a substitute decision maker refuses, staff should document the refusal, including evidence that the resident or substitute decision-maker was informed of the potential consequences associated with not rendering that treatment. If another valid alternative is available, staff should use it or identify why it is not feasible or appropriate for that resident. Staff, in conjunction with the physician, should document when they believe that refusal of a relevant alternative prevents them from managing a resident's target behavior 	<ul style="list-style-type: none"> -Long-term management of chronic behaviors is different from the acute management of high-risk behaviors due to delirium, psychosis, or other urgent situations. -Use of a specialist with expertise regarding the population may provide helpful options for planning and/or achieving treatment goals, monitoring the resident's progress, and educating/training staff. Often, problematic behavior can be managed effectively by properly identifying causes and then using non-pharmacologic interventions. -A resident/substitute decision maker has the right to consent to, as well as to refuse, treatment. Informed consent requires education about the benefits and risks associated with the treatment, and consequently, the risks and consequences of not providing said treatment. -The Alternative Treatment Order is included in the Mental Health Code. Upon petitioning the Court it allows for treatment to take place in a community setting and would prevent the resident from refusing treatment during the time of court commitment. -In the event that the treatment team believes that refusal of a relevant alternative prevents them from managing a resident's target behavior effectively and there is no other recourse, the facility may be unable to continue to provide care.

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
	<p>effectively. It may be necessary to obtain an Alternate Treatment Order.</p> <p>-In the event that the resident has no substitute decision maker, it may be necessary to obtain an Alternate Treatment Order.</p>	
11. Was cause-specific management used OR an explanation why it was not feasible or not provided?	<p>-Staff should implement a care plan that relates to the identified target behavior(s), identified causes of problematic behavior, and resident-specific goals and needs. As indicated, the plan should include specific non-pharmacologic, behavior management strategies.</p> <p>-When the cause of a problematic behavior is identified or suspected, staff should address the causes or indicate why they could not or should not have done so for that resident (for example, cause not treatable, previous adverse reaction to a medication, terminal condition, etc.).</p>	<p>-It is often possible to target particular treatments to specific causes, based on evidence of what is more or less likely to work.</p> <p>-Not all problematic behaviors require medication.</p> <p>-Cause-specific interventions are likely to be more effective and may pose lower risk than using non-specific psychoactive medications.</p> <p>-Even when causes are unclear, a systematic approach may provide additional important information to the Interdisciplinary Team.</p>
12. Was a rationale documented for the specific choice of interventions?	<p>-Staff should be able to show evidence as to why they chose specific interventions in specific situations, and how interventions are relevant to the needs, problems, strengths, limitations, and goals of the resident.</p>	<p>-Having a pertinent rationale demonstrates that the staff used a systematic, knowledge-based approach to analyze resident information and to create and implement a plan that is most relevant to those needs.</p>
13. Was there some documented explanation, in conjunction with a physician, for the dose, frequency, and duration of medication treatments?	<p>-If management of problematic behavior requires a medication, the physician (or the staff, based on discussion with the physician) should document rationale for the medication. For example, in the presence of hallucination or delusion, there must be an indication that the hallucination was associated with impaired functioning.</p> <p>-When causes of behavior are not readily identifiable or treatable, symptomatic interventions may be indicated. Therapeutic trials should be considered, documenting the target behavior, rationale, anticipated risks and benefits, and results of the trial.</p>	<p>-Because of their risk of causing ADRs, medications prescribed for problematic behaviors should be used for specific indications, at the lowest effective dose, and for the shortest possible period of time.</p>

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
<p>MONITORING</p> <p>14. Were the individual's behavior and related causes monitored and treatment adjusted accordingly?</p>	<p>-In conjunction with the physician, staff should monitor periodically the progress of a resident with problematic behavior, using the basic care process steps.</p> <p>-For chronic or intermittent problematic behaviors, staff should discuss the behaviors and treatment plans at least quarterly; or more often as indicated by the resident's response to interventions. For urgent or emergency problematic behavior, staff should monitor at least several times daily until the resident is stable or improving.</p> <p>-Staff should document descriptions of target behaviors (changes or stabilization) over time and use this information to determine whether/how to modify planned interventions.</p> <p>-If an unstable target behavior worsens during the subsequent 48 hours (or other appropriate time frame established by the care team) after initiating treatment, or is not resolving within a week (or other appropriate time frame established by the care team), then staff should review current interventions with the physician and discuss whether/how to modify the interventions. The discussion and resultant decisions should be documented.</p>	<p>-A systematic approach and descriptive documentation helps the staff see more clearly the outcomes of treatment, to measure the results more objectively, and determine if modifications are necessary or appropriate.</p> <p>-Underlying causes of problematic behavior may resolve, or the resident's condition may change over time. Periodic monitoring is part of a systematic approach to care.</p> <p>-Lack of anticipated response to treatment requires reevaluation of approaches.</p>
<p>15. Were the risks for significant complications and problems related to interventions identified and addressed?</p>	<p>-Staff should monitor all residents for the effects of nonpharmacological interventions.</p> <p>-When planning and implementing care, staff should understand how to adapt or adjust the environment to prevent problematic behaviors.</p>	<p>-Interventions, or lack of them, may precipitate problematic behaviors if they fail to adequately meet the resident's needs or are inappropriate to the condition or background of the resident.</p>
<p>16. Were possible significant adverse drug reactions (ADRs) or other complications of psychoactive medications considered?</p>	<p>-Staff should review each resident's medication regimen for medications that may be associated with increased risk of altered mental states or level of consciousness and other side effects such</p>	<p>-Medications sometimes may exacerbate instead of improve problematic behavior or may adversely affect level of consciousness or function, especially in combination with other medications in various</p>

CARE PROCESS STEP	EXPECTATIONS	RATIONALE
	<p>as tardive dyskinesia, postural hypotension, akathisia, and parkinsonism.</p> <p>-When a possible ADR is identified, staff should notify the physician who should address the possible complications.</p> <p>-If there is no change in medication in the presence of a possible ADR, the staff that communicated with the physician, or the physician, should document rationale for not tapering or discontinuing the medication.</p> <p>-The consultant pharmacist should participate in the evaluation on an ongoing basis and should help staff recognize medications that may be associated with changes in mental status or behavior.</p>	<p>categories that are known to affect the central nervous system (CNS).</p> <p>-More psychoactive medications should not be added to a regimen without considering possible problems caused by the existing ones.</p>

Antipsychotic Side-effects *Checklist* (ASC)

A Tool for Facilitating Dialogue Between Patients and Mental Healthcare Providers

To be completed in the clinic

ASC is a new screening tool designed to be a user-friendly "checklist" of common and distressing side-effects associated with antipsychotic medications. ASC is meant to be flexible. You may either have your patients complete ASC with their caseworker and review their responses during your next session or you can complete ASC with your patient during an appointment. Either way, ASC can help you maintain an open dialogue with your patients about side-effects.

Patient name: _____ Date seen: _____

Comments: _____

Next Steps: _____



Antipsychotic Side-effects Checklist (ASC)

Problem	Yes	No	Comments
1. Loss of energy and drive: Have you had trouble moving, getting going, or starting things? Do you feel slowed down?	<input type="checkbox"/>	<input type="checkbox"/>	
2. Feeling unmotivated or numb: Have you had trouble getting motivated or wanting to do the things you used to? (Sometimes people describe this as "feeling like a zombie.")	<input type="checkbox"/>	<input type="checkbox"/>	
3. Daytime sedation or drowsiness: Are you tired or sleepy during the day? Feelings of tiredness can happen throughout the day or only at certain times.	<input type="checkbox"/>	<input type="checkbox"/>	
4. Sleeping too much: Do you sleep too much? Do you feel you sleep for too long? Do you have a problem getting out of bed in the morning, or do you need to go back to sleep for a large part of the day?	<input type="checkbox"/>	<input type="checkbox"/>	
5. Muscles being too tense or stiff: Do your muscles feel stiff or rigid? Do you feel cramps or muscle pains in the arms, legs, or neck?	<input type="checkbox"/>	<input type="checkbox"/>	
6. Muscles trembling or shaking: Have you had any shaking or muscle-trembling?	<input type="checkbox"/>	<input type="checkbox"/>	
7. Feeling restless or jittery: Have you had any feelings of restlessness? Do you ever feel like you want to "jump out of your skin"?	<input type="checkbox"/>	<input type="checkbox"/>	
8. Need to move around and pace; can't sit still: Do you often need to get up and pace around? Do you have trouble sitting still? Do you rock from one leg to the other?	<input type="checkbox"/>	<input type="checkbox"/>	
9. Trouble getting to sleep or staying asleep (insomnia): Do you have trouble falling asleep or getting to sleep? Do you wake up too often during the night or wake up too early in the morning?	<input type="checkbox"/>	<input type="checkbox"/>	

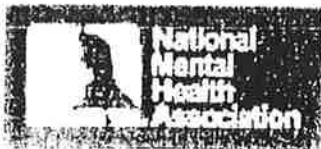
Antipsychotic Side-effects Checklist (ASC)


Problem	Yes	No	Comments
10. Blurry vision: Do you have blurry vision? Things may seem out of focus. People with blurred vision may have trouble with reading printed words in newspapers.	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
11. Dry mouth: Is your mouth too dry? Does it feel like you have cotton in your mouth? Does it seem like your tongue sticks to the top of your mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
12. Drooling: Do you have too much saliva (spit)? Is your pillow wet when you wake up?	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
13. Memory and concentration: Do you have any memory problems? Are you more forgetful? Is it hard to concentrate? Do you find it hard to follow conversations, watch programs on TV, or read?	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
14. Constipation: Do you have problems with constipation?	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
15. Weight change: Have you had any changes in weight? Do you feel that you are overweight? Do you gain weight quickly, or cannot seem to go on a diet? Are your clothes getting too big or too small for you?	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
16. Changes in sexual functioning: Do you have any sexual problems or difficulties? Sometimes people say they have problems with low sex drive. Some men say that they have difficulties with erections or ejaculation, and some women say that they have difficulty achieving orgasm.	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>
17. Menstrual or breast problems: If you should have regular menstrual periods, have you had any menstrual problems lately? Sometimes women stop having their normal periods, or have irregular periods. Have you had this problem recently? Sometimes there may be milk leakage from the breasts.	<input type="checkbox"/>	<input type="checkbox"/>	<hr/> <hr/> <hr/>

For more information or to obtain additional
Dialogue for Recovery materials, please contact your
local Mental Health Association, or

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314

1-800-969-NMHA (6642)
www.nmha.org



ASC and the National Mental Health Association *Dialogue for Recovery* program are supported by unrestricted educational grants from AstraZeneca 

BIPOLAR MOOD CHART

NAME: _____
MONTH: _____

Assess the supported person's mood by selecting a range from the mood scale. Shade in the range on the scale. Your rating should be based on observations for the entire day even if _____ is both manic and depressed during the day. When completing the log, please use the following anchor points in your mood ratings.

- | | |
|----|--|
| +5 | markedly manic (ie: aggression, resists any interaction) |
| +4 | |
| +3 | moderately manic (ie: constant pacing, restless re: conversation, grabbing food) |
| +2 | |
| +1 | milky manic (ie: does not comply, occasionally restless) |
| 0 | normal mood for the day (ie: able to sit, relax, eat, sleep, follow requests, appropriate affect of happy or sad) |
| -1 | milky depressed (ie: unusually tired, lethargic, not interested in activities, suggestions, looks/acts bored, refusing food) |
| -2 | |
| -3 | moderately depressed (ie: excessively tired, sits for long times without being engaged in activity, sleeps in, lack of interest in activities usually liked) |
| -4 | |
| -5 | markedly depressed (ie: sad, crying, lethargic for long periods of time, unable/unwilling to cooperate, refusal to get out of bed) |

[illegible]

MEDICATION MANAGEMENT AND REDUCTION OF ADVERSE DRUG REACTIONS

Revised February 2004

CARI: PROCESS STEP	EXPECTATION	RATIONALE
Assessment/Problem Recognition		
1. Was the problem or condition (onset, frequency, intensity, duration, etc.) for which a medication was being given clearly identified?	<p>-When medication is prescribed in response to an identified problem or condition, the staff and health care practitioner should ensure that the problem has been clearly identified, or that there is some rationale for empirical interventions.</p> <p>-Symptoms should be characterized in sufficient detail (onset, nature, location, duration, progression, intensity, frequency, etc.) to help identify whether a problem exists that requires an intervention and the potential causes of the problem.</p>	<p>- Medications are often helpful in addressing problems of elderly individuals.</p> <p>- However, many medications can cause significant adverse drug reactions (ADRs); the risk of having a significant ADR increases as the number of medications increase.</p> <p>-Frail elderly and chronically ill individuals often exhibit symptoms as side effects of treatment. These symptoms may be mistaken for a new illness, leading to additional treatment, which can lead to further complications.</p> <p>-By suspecting and responding to a possible adverse drug reaction (ADR), facility staff and the physician can potentially reverse the symptoms and head off subsequent complications by a change in medications.</p>
2. Was the rationale for the use of medication as treatment for the problem or condition clearly identified?	<p>- There should be a clear indication for the use of each medication given to a resident, based on considering the resident's age, conditions, risk factors, and health status.</p> <p>-The rationale should clearly indicate why the resident is receiving the prescribed medication (what the medication is supposed to do or prevent)</p> <p>-In the case of a newly admitted resident, it may take time to obtain a history that justifies the use of a particular medication, but in the clinical judgment of the medical provider, the benefits of continuing to use the medication outweigh the potential risks to the resident.</p> <p>- For any medication with a significant risk of ADRs, if the indication is unclear, documentation</p>	<p>-A clearly identified rationale for treating a problem/condition with a prescribed medication helps demonstrate that the information collected during the comprehensive assessment was used to determine the most appropriate treatment.</p> <p>-The rationale guides the development of the individualized medication plan for the resident.</p> <p>-A diagnosis by itself may not suffice; just because a condition exists does not necessarily mean that it has to be treated, or that a medication is necessary.</p>

CARE PROCESS STEP	EXPECTATION	RATIONALE
	<p>should reflect the rationale for continued use during this time.</p> <ul style="list-style-type: none"> -Medications prescribed without a clear rationale or on a PRN (as needed) basis should be carefully reviewed to make sure they are being given to treat a problematic condition or risk, instead of in response to a medication side effect mistaken for a new condition or a symptom of an untreated illness. 	
<p>3. Were risk factors identified for the use of prescribed medications, given the resident's condition and existing medication profile?</p>	<ul style="list-style-type: none"> - The MDS and other relevant information should be reviewed to identify risk factors that are likely to predispose a resident to adverse drug reactions. -Whenever there is a significant change in the resident's condition, a reassessment should be completed. -Suspected adverse drug reactions should be identified and pursued. -The consultant pharmacist should conduct a more focused medication review for individuals with significant condition changes; especially, repeat falling, anorexia, and changes in mental status or behavior. 	<ul style="list-style-type: none"> -Medications are often helpful to the elderly, but functional decline and serious adverse drug reactions can often be attributed to various medication combinations. -Identification of risk factors that are likely to predispose a resident to adverse drug reactions is a necessary part of medication management. Many ADRs are serious, even life-threatening. -Because the symptoms of an ADR often resemble those of an acute illness, the true cause of the problem may be overlooked unless doctors, nurses, and consultant pharmacists are aware of the possibility. -MDS data such as cognitive patterns, communication patterns, vision patterns, mood and behavior patterns, physical functioning and structural problems, continence, disease diagnosis, health conditions, nutritional status, oral/dental status, skin condition, activity pursuit patterns, medications, and special treatments and procedures is useful for identifying risk factors. - This information may help identify the need for closer monitoring, identify existing signs/symptoms that could be confused with ADRs, or identify the need to revise the current medication regimen to minimize medications that may exaggerate current symptoms. For example,

CARE PROCESS STEP	EXPECTATION	RATIONALE
		someone with a seizure disorder may be at risk from medications that lower the seizure threshold; a resident may be at increased risk for falls due to medication combinations that cause dizziness or postural hypotension.
<p>Diagnosis/Cause Identification</p> <p>4. For any new or recurrent loss of appetite/weight, fall, or change in mental status/behavior, was the drug regimen reviewed to determine the possibility that one or more medications may have contributed to the change in condition or functional decline?</p>	<p>-Once a change in condition has been identified, the staff and practitioner need to investigate the cause.</p> <p>-The consultant pharmacist must review the regimen monthly and may need to assist with interim reviews where a resident's symptoms or condition change suggest a possible ADR.</p> <p>-Ongoing discussions among the consultant pharmacist, nurses and physician about each medication regimen, including medications recently started or changed, are expected.</p> <p>-Over time, documentation should reflect ongoing review of the effects of medication administered and consideration of whether unresolved risks or recurrent symptoms warrant continued use of a medication, especially those with substantial risks for a particular resident.</p> <p>-The physician should document, or discuss with a nurse who documents, that a medication with significant risk potential in an individual resident has been considered as a potential cause of any a) significant condition change; b) new onset of a significant problem/condition or worsening of an existing one; or c) an otherwise unexplained decline in function or cognition.</p>	<p>-Medications are often the first "dominoes" in a chain reaction that may result in potentially preventable illness, functional decline, or even death. The geriatrics approach is to prevent the chain reaction or to intervene early enough to forestall serious complications.</p> <p>-Three common symptoms in those with chronic illnesses and disabilities that often reflect an ADR are: 1) loss of appetite (anorexia) or unplanned weight loss; 2) new or repeat falling, and 3) change in mental status or behavior. Long-term care residents may experience other equally or more significant side effects as well, depending upon that resident's conditions and medication profile.</p> <p>-The consultant pharmacist is in a key position to identify and alert the nursing staff and physician to potential medication causes of resident symptoms.</p> <p>-An adverse drug reaction can happen unexpectedly or repeatedly at any time in any resident. The nurses and physician should not simply rely on the consultant pharmacist to perform medication reviews, provide notification of risks/events, and/or make recommendations.</p> <p>-Often, medications are administered for months or years, despite the resolution of temporary problems. Residents may improve or remain stable despite, not because of, taking certain medications.</p>

CARE PROCESS STEP	EXPECTATION	RATIONALE
<p>5. When a new or recurrent loss of appetite/weight, fall, or change in mental status/behavior resulted in adding another medication to treat the symptom. was it explained why the additional medication was the most appropriate treatment?</p>	<p>-When a resident has new or recurrent weight loss/anorexia, falling, or change in mental status or behavior without a readily identifiable cause, the treatment team should consider the possibility that current medications may be causing or contributing to the symptom before deciding to prescribe additional medications to address the symptoms.</p> <p>-If additional medication is prescribed, the physician and nursing staff should document the reason why additional medication was warranted despite the possibility that the symptom could be related to the existing medication regimen.</p> <p>-When root causes of symptoms are not sought or addressed, documentation should reflect the rationale for a decision to treat the symptom instead of seeking or managing the cause.</p>	<p>-Symptoms of ADRs may mimic other conditions, resulting in overlooking the true cause of the problem.</p> <p>-As the number of medications increases, so does the risk for a serious ADR.</p> <p>-Although it may seem urgent to treat a reported symptom, it may be more judicious to consider the cause(s) of symptoms and whether another approach might be more prudent.</p> <p>-When someone is receiving hospice or palliative care for a terminal condition, relief of pain or other symptoms may outweigh the side effects of medications or the relevance of seeking causes.</p> <p>-Adequate documentation of the rationale for medication use shows why it was necessary for appropriate treatment of a particular resident.</p>
<p>6. When a recent change of condition has occurred, was an adverse drug reaction or a problem related to medication administration (transcription error, illegible handwriting, adequate fluid for swallowing, taken with/without food, the amount of medication taken at one time, right resident, right medication, right dose, right time, right route, etc.) considered as a contributing factor to the resident's change in condition?</p>	<p>-All aspects of medication orders and their execution must be accurate.</p> <p>-The orders or prescription, and the subsequent transcription, must be accurate, complete, understandable, and legible.</p> <p>-Facility routines should ensure that medications are passed at proper times, using proper procedures, and that the resident's routines are considered.</p> <p>-The correct medication must be given to the right resident, in the correct dose, by the correct route, and at the right time.</p> <p>-The facility should provide, and the staff should use, relevant resources and current reference materials regarding medications, including proper administration, and their associated effects and risks.</p>	<p>- Adverse drug reactions may result from mistakes in ordering or administering medications.</p> <p>-Professionals should use relevant evidence and follow pertinent standards of professional practice, to be aware of and address medication-related risks and symptoms.</p> <p>- The Physician's Desk Reference (PDR) and other standard references list most of the important side effects and risks associated with specific medications. Other resources such as various AMDA Clinical Practice Guidelines and the OBRA Resident Assessment Protocols (RAPs) list medication classes likely to cause or increase the risk of various symptoms.</p> <p>-Proper medication administration requires following relevant procedures for the drug and its use, knowledge of the resident, and coordinating facility routines.</p> <p>Examples include: Some medications are to be taken on</p>

CARE PROCESS STEP	EXPECTATION	RATIONALE
	<p>-Those providing the care should appropriately question situations that could represent an ADR and report their valid concerns.</p>	<p>an empty stomach; others must be taken with food; certain medications must be administered at certain times of the day to maintain adequate blood levels or to reduce the risk of an adverse event; oral medications require the ability to swallow the pill and adequate fluid intake to swallow properly.</p>
<p>Treatment/Problem Management</p> <p>7. Were significant risks related to individual medications or medication combinations identified and addressed for individual residents?</p>	<p>-It is expected that a rationale will be documented when the dose, duration, or frequency of a prescribed medication is greater than the manufacturer's recommendations or than recommended in a specific population, or the medication is considered high-risk compared to other available, relevant alternatives.</p> <p>-Unless otherwise indicated, the physician should start with the lowest dose possible or substitute lower risk for higher risk medications.</p> <p>-It is expected that the medication will be reevaluated periodically for continued necessity.</p> <p>-The consultant pharmacist should help identify high-risk medications for the population of the facility, as well as for individual residents.</p> <p>-When the consultant pharmacist reports findings and recommendations, the attending physician, Medical Director, and Director of Nursing should acknowledge them in a timely manner and take appropriate action based upon their knowledge of the individual resident's condition, prognosis, and wishes for treatment or treatment limitations.</p> <p>-The physician and staff are expected to identify the rationale, goals and objectives of a resident's medication plan.</p>	<p>-Although medication management is primarily a physician and nursing responsibility, effective use of the consultant pharmacist may help in planning and/or achieving treatment goals, monitoring the resident's progress, and educating/training staff.</p> <p>-Timely and appropriate responses to notification of potential problem situations can prevent an adverse event or lessen its consequences.</p> <p>-Prescribing medications is a medical function requiring prudent use of clinical judgment and demanding professional accountability.</p> <p>-Some medications are prescribed for temporary conditions or the resident's status may change, rendering a medication unnecessary or risky.</p> <p>-Determination of individual risks should also consider food-drug interactions, effects of medication combinations, and drug-disease/condition implications.</p>
<p>8. Was it explained why the benefit of a high-risk medication, dose, medication combination or</p>		<p>-Appropriate goals depend on understanding the nature and causes of an individual's condition/status and realistic potential treatments/interventions.</p>

CARE PROCESS STEP	EXPECTATION	RATIONALE
<p>other factors outweighed the potential risk?</p>	<p>-For high-risk medications, the physician or staff who have consulted with the physician should explain why treatment benefits were believed to outweigh the risks to the resident.</p> <p>-When a medication is prescribed to address problematic behavior, the facility must demonstrate that the medication is used to treat medical or neuropsychiatric symptoms, signs, or conditions. The goals and objectives must be clearly indicated. Response to treatment must be documented, including attempts to reduce the dosage and the response to this intervention. If dose reduction is not possible, or is clinically contraindicated, a relevant explanation must be provided.</p>	<p>-Having a pertinent rationale demonstrates that the staff used a systematic, evidence-based approach to analyze resident information and to create and implement a plan that is relevant to those needs.</p> <p>-Because of their risk of causing ADRs, medications prescribed for problematic behaviors should be used for specific indications, at the lowest effective dose, and for the shortest possible period of time.</p> <p>A process to monitor and document behavioral responses to medication interventions is required to support treatment decisions. When using psychoactive medications, staff must document monitoring for tardive dyskinesia, postural hypotension, akathisia, and parkinsonism.</p>
<p>9. Were likely adverse drug reactions of loss of appetite/weight, falls, or change in mental status/behavior managed in a timely manner by changing the medication or dose, or documenting why such changes could not or should not be made?</p>	<p>-Probable ADRs should be addressed in a timely manner.</p> <p>- When a medication has been identified that may be associated with a probable adverse drug reaction, the medical practitioner should try to discontinue or taper dosage for a trial period to determine the effects, unless adjustment would create an immediate risk to life and health.</p> <p>-The rationale for the treatment decision should be clearly documented.</p>	<p>-ADRs may represent urgent or emergent conditions that require a timely response because of a threat to an individual's life, health, or safety.</p> <p>- Often, the only way to know if an ADR exists is to observe the results of stopping or adjusting the potentially problematic medication.</p> <p>- Being able to explain why a medication regimen was maintained or adjusted in response to a probable ADR, helps demonstrate a systematic approach to care based upon knowing the resident and the risks that medications pose.</p>
<p>Monitoring</p> <p>10. Was the resident periodically monitored for significant effects, side effects, and complications (monitor target symptoms, perform appropriate laboratory tests, etc.)</p>	<p>-The facility must clearly demonstrate that it periodically reviews the indications and effects (desired and undesired) of each resident's medication regimen.</p> <p>-Utilizing current literature and recognized references, and relevant standards of professional</p>	<p>-A systematic approach including sufficiently detailed, relevant documentation helps the staff understand why medications are being given and how the resident is expected to benefit from them, what they are expected to do for the resident, so that they can identify the benefits and the complications of those interventions.</p>

CARI PROCESS STEP	EXPECTATION	RATIONALE
	<p>practice, staff should look for and report probable or suspected adverse drug reactions.</p> <ul style="list-style-type: none"> -It is expected that the facility will have a reliable system for interpreting the significance of and reporting periodic diagnostic tests associated with medication monitoring. -The consultant pharmacist must review the medication regimen monthly; or more frequently if warranted. -The physician should review the relevance and possible problems of high-risk medications at least with each visit, and the overall regimen in more depth at least annually. -Periodically, the staff and practitioner should document the absence of significant ADRs in individuals taking medications associated with significant risks such as falling, change in mental status or level of consciousness, and unplanned weight loss/anorexia. -Periodically, the physician should review a resident's medication regimen with the staff, including the consultant pharmacist, for opportunities to reduce dosages or discontinue possible unneeded medications. 	<ul style="list-style-type: none"> -Underlying causes of conditions may resolve, or the resident's status may change over time. Periodic monitoring is part of a systematic approach to care. -Diagnostic and laboratory tests may help identify effectiveness of treatment and may indicate untoward effects. -Because nursing staff provides daily care to the resident, they may be the first to observe symptoms and condition changes that could indicate a developing problem. -The consultant pharmacist reviews the medication regimen at least monthly, but may need to do a more frequent review related to the use of high-risk medications, including identification of factors such as comorbidities and medication combinations that could potentially affect the outcomes of drug treatment. -A safe, effective medication management system must contain accurate, current resident medication profiles at all times.
<p>11. Was there a timely response to identified or likely adverse drug reactions?</p>	<ul style="list-style-type: none"> -It is expected that the facility will use a reliable, consistent approach to identify and respond to ADRs in a timely manner. All direct care staff, physicians, and administrative staff should clearly understand their roles and responsibilities. -The medication management plan should contain criteria for determining the desired and undesired 	<ul style="list-style-type: none"> -An effective medication management system requires all staff to understand and uphold their roles and responsibilities in identifying and responding to ADRs. Staff must understand what to report, when, and to whom, as well as what kind of a response they should be expecting from a practitioner. -The rationale for deciding whether to continue or to

CARE PROCESS STEP	EXPECTATION	RATIONALE
	<p>effects of treatment, including significant or severe symptoms to be reported to the physician.</p> <p>-The physician should respond in a timely manner to reports of possible significant ADRs or other medication-related issues, relative to the urgency of the threat to an individual's life or health.</p> <p>-If the practitioner's response is to maintain the current medication regimen despite the probability of an ADR, documentation should explain why a change in treatment was not considered appropriate.</p>	<p>modify a current medication regimen in the presence of a probable ADR should show that the staff and practitioner systematically considered resident-specific information and other readily available information about potential medication complications, as is contained in the PDR and other references.</p>
<p>12. Was a possible adverse drug reaction monitored until the symptoms resolved or another cause for the symptoms was identified?</p>	<p>-When an adverse drug reaction is suspected, it is expected that the providers will follow up on the condition until the symptoms have resolved or another cause is identified.</p> <p>-Appropriate interventions should be made; for example, an individual experiencing delirium may need additional help with ADLs, or someone with medication-related anorexia may need additional support to get enough food and fluids.</p>	<p>-Sometimes symptoms will resolve spontaneously, but medications (either individually or in combination) may exacerbate symptoms or otherwise adversely affect resident status/function, especially in combination with other drugs.</p> <p>-It may not be prudent to prescribe another drug to treat a symptom, as this may add to the drug regimen without treating the root cause of the problem, and may increase the potential for additional ADRs.</p> <p>- ADRs often affect an individual's function and cognition, resulting in the need for additional support until the symptoms resolve.</p>

Psychological Assessment: Frequently Asked Questions

What are the indicators that an adolescent or adult with a developmental disability (DD) should be considered for psychological testing? When and why would a psychological assessment be important?

What types of psychological testing can be done?

Is psychological testing of people with DD a specialty area of psychology? Do I need to find a psychologist with special training or expertise in DD?

Reasons to consider referring an individual for psychological testing include:

- **The person is not well understood by his/her support system:** He/she is not learning well, having difficulties coping, and/or caregivers need information on how to better understand and support him/her.
- **Change from an earlier assessment:** A reassessment is recommended if there has been a long interval since the last testing, or no testing in adulthood, as early results may be less stable and factors influencing the earlier testing may have changed.
- **Future planning needs:** Includes vocational, education, and housing directions. For example: Can the person live independently? What are his/her current abilities and challenges? What are his/her support needs?
- **Before a psychiatric diagnosis:** It may be important to know the person's level of functioning in order to put presenting symptoms in context. Some aspects of DD (e.g., a low functioning person talking to him/herself may be developmentally appropriate for his/her level of function, but it may be interpreted as a symptom of psychosis to those who do not understand the effects of the functional level).
- **Significant, unexplained change in the individual's behaviour** (e.g., new onset withdrawal or aggression).
- **A specific diagnosis may be needed for income support services** (e.g., for Ontario Disability Support Program [ODSP] and disability tax credits).
- **Cognitive:** To identify level of intellectual ability, strengths, and vulnerabilities.
- **Adaptive behaviour:** To determine and describe how a person functions in day-to-day life.
- **Neuropsychological:** For issues such as dementia, stroke, head injury, and genetic disorders associated with cognitive decline (e.g., Down syndrome).
- **Personality and psychiatric type:** As an adjunct to psychiatric care (e.g., testing for depression, anxiety, or hyperactivity).
- For those who are *borderline to mildly impaired*, any qualified psychologist can provide testing.
- For those who are *moderately or severely impaired*, ideally, a psychologist should be experienced and skilled in testing such individuals.

How do I go about finding a psychologist to do testing on my patient with DD?

- For patients under the age of 21 who are still in school, the best route is through the school board.
- Local developmental services (through the Ministry of Community and Social Services, or Community Networks of Specialized Care) are generally the best resource. Consult professionals in this field in your area.
- In Toronto, consult the Developmental Services Toronto (DSTO) website www.dsto.ca.
- Elsewhere in Ontario, consult the College of Psychologists of Ontario website www.cpo.on.ca.

How long is the usual wait time, before my patient will be seen?

- Services provided through school boards vary, but the wait can be up to a few years.
- Surrey Place Centre, which provides testing for the Toronto catchment area, has a wait time of anywhere between one to two months up to about one year depending on the type of assessment and priority given to the case.
- Private testing can be arranged within a few weeks if the patient or their family has the financial resources to pay for it.

How much will this testing cost?

- **School Board:** No cost. It is important to consider obtaining an assessment while the individual is in school when the cost is covered. Records of past assessments can be requested from the school.
- **Developmental Centre** (e.g., Surrey Place Centre in Toronto): No cost.
- **Private:** The typical cost for a full developmental assessment is from \$1,500 - \$2,500. This can be paid for privately or through employer-extended health care benefits, if available.

Are there any other resources available that do not charge, or any government or other funds to help a patient pay for this testing?

- Rehabilitation, vocational placement or developmental services programs sometimes offer assessment services.
- Many extended health care insurance plans (e.g., some provided by one's employer) cover psychological testing under a co-pay or partial payment basis.
- A portion of payments for psychological assessment or treatment can be deducted in the individual's income tax return under health care expenses.

What information does the psychologist need in the referral?

- **Developmental history:** Especially early development – when he/she walked, talked, and toiletied.
- **Medical disorders:** Particularly those that can affect or interfere with cognition, including epilepsy, psychiatric diagnoses (e.g., depression, schizophrenia), and attention-deficit hyperactivity disorder (ADHD).
- **Medications:** Particularly those that may affect or interfere with cognition.
- **Relevant past assessments:** Psychological, psychiatric, previous brain scans (CT or MRI) or occupational therapy.
- **History of exposure or injury:** Includes history of alcohol exposure in utero or past traumatic brain injuries.

What can my patient and his/her caregiver(s) expect during the appointment for psychological testing?

- The individual and caregiver will be interviewed. This typically takes one to two hours.
- Testing will be done with the individual one-on-one. There may be one or more sessions of one-on-one testing that will last between one and four hours each, depending on the type of testing.
- Testing will be followed by a feedback session for the individual and caregiver where the results of the testing, an explanation of what they mean, and any recommendations will be provided. This generally takes about an hour.
- The patient can identify to whom he/she would like the report to be sent.

What information am I likely to receive back from the psychologist to help me in managing my patient?

- **Level of functioning:** Will include how the individual compares cognitively to others in his/her age group as well as his/her relative strengths and vulnerabilities. The information may be expressed in various ways, including standard scores (e.g., IQ range) and/or Age Equivalence (AE) scores.
- **Education/placement:** Recommendations regarding education and skill development abilities and capacities, and strategies to use to help the individual learn.
- **Emotional disorders, personality:** How the individual compares with others (e.g., those with a similar level of DD or with average intelligence) on various scales (e.g., depression or anxiety scales).
- **Behavioural management:** May include recommendations or strategies for dealing with challenging behaviours.
- **Other services:** May include recommendations regarding such services as counseling, occupational therapy, Adult Protective Services Worker and local programs.

Developed by: *Valerie Temple, Psychologist, Surrey Place Centre*

PRIMARY CARE PROVIDERS AND CAREGIVERS:

Name:

Psychiatric Symptoms and Behaviours Screen

DOB:

Can be filled out by primary care provider, or by caregiver, and reviewed by primary care provider.

Symptoms and behaviours

BASELINE ¹

Check if usually present

NEW

Check if recent onset

COMMENTS

If new onset or increased

Anxiety-related

Anxiety

Panic

Phobias

Obsessive thoughts

Compulsive behaviours

Rituals/routines

Other

Mood-related

Agitation

Irritability

Aggression

Self-harm behaviour

Depressed mood

Loss of interest

Unhappy/miserable

Under-activity

Sleep

Eating pattern

Appetite

Weight (provide details)

Elevated mood

Intrusiveness

Hypersexuality

Other

Psychotic-related ²

Psychotic and psychotic-like symptoms (e.g., self talk, delusions, hallucinations)

Movement-related

Catatonia ('stuck')

Tics

Stereotypies (repetitive movements or utterances)

ADHD-related or Mood Disorder

Inattention

Hyperactivity

Impulsivity

Dementia-related

Concentration

Memory

Other

Other

Alcohol misuse

Drug abuse

Sexual issues/problems

Psychosomatic complaints

¹ Establish usual baseline i.e., behaviours and daily functioning before onset of concerns.

² Use caution when interpreting psychotic-like symptoms and behaviours in patients with DD. These may be associated with anxiety (or other circumstances) rather than a psychotic disorder.

BIOPSYCHOSOCIAL MODEL

Understanding the Person and the Problem

EXAMPLES

	Biological (physical)	Psychological (cognitive/emotional)	Social (external world)
Predisposing factors (vulnerabilities or risk factors)	<ul style="list-style-type: none"> *older age * chronic health condition * genetics/syndrome * mental illness/psychiatric diagnosis * medications 	<ul style="list-style-type: none"> *low cognitive level * personal history (past trauma) * obsessive *anxious personality * lack of insight 	<ul style="list-style-type: none"> *environment is crowded *lack of resources, low staffing *lack of emotional support-family, friends * poor interpersonal skills * lack of stimulation in daytime hours
Protecting factors (keeping it from being worse, the person's strengths)	<ul style="list-style-type: none"> *younger age * physically healthy * no alcohol/drug usage * appropriate medications 	<ul style="list-style-type: none"> * higher cognitive level * happy temperament * no recent losses or changes in person's life *healthy coping skills *higher language/ communication skills 	<ul style="list-style-type: none"> * positive & close relationships with family/friends * appropriate housing *appropriate agency staff support * meaningful day activities
Precipitating factors (what seems to have triggered the problem)	<ul style="list-style-type: none"> *recent physical illness * pain *recent injury *recent change in medications *sleep loss 	<ul style="list-style-type: none"> *fear - identifiable source * recent loss * decreased cognition due to medication side effects *frustration 	<ul style="list-style-type: none"> *conflict with or among others * change in living situation * change in staffing *recent changes in family contact *loss of day program
Perpetuating factors (What makes the problem continue?)	<ul style="list-style-type: none"> *medication problems *pain/chronic effects of physical illness *communication deficits (hearing, speech) *psychiatric illness 	<ul style="list-style-type: none"> *ongoing sadness * poor impulse control *emotional issue such as embarrassment 	<ul style="list-style-type: none"> * noisy household *lack of social skills * inconsistent staffing * lack of day program *limited family contact

Psychiatric Appointment Review Sheet

Client Name : _____ Date: _____

Support staff attending: _____

Documentation REQUIRED at every appointment, if applicable:

- Medication record (MAR sheets)
- PRN medication records
- Behaviour tracking: ABC sheets or 5 W's
- Graphs (tracking behaviours, sleep, bowel movements, menstruation, etc)

Health Review:

Has there been any change in medication since the last consultation? If so, explain:

If yes, describe any behavioral changes since the medication changed:

Any changes/concerns in health status that may be impacting mental status/behaviour?
Check all that apply:

bowels	<input type="checkbox"/>	activity level	<input type="checkbox"/>	appetite	<input type="checkbox"/>
seizures	<input type="checkbox"/>	mood	<input type="checkbox"/>	fatigue	<input type="checkbox"/>
sleep	<input type="checkbox"/>	toileting	<input type="checkbox"/>	pain	<input type="checkbox"/>
sexuality	<input type="checkbox"/>	menses	<input type="checkbox"/>	weight	<input type="checkbox"/>
smoking	<input type="checkbox"/>	hearing	<input type="checkbox"/>	vision	<input type="checkbox"/>
caffeine use	<input type="checkbox"/>	gait, movement and physical mobility <input type="checkbox"/>			

Please describe:

Medical investigations or tests. or visits to a specialist since last consultation:

Target Behaviours:

Update on any issues that were to be monitored from last appointment

Data:

Include number of incidents (↑ or ↓ or *no change*) compared with last observation period.

- Note any patterns that staff members have observed, eg. time of day.
- Were any interventions tried? If so, please describe:

➤ What worked? _____

➤ What did not? _____

PRN Medication:

Summarize use over time since last appointment (or provide MAR sheet):

Is the PRN medication effective? **Yes** **No** (*Circle one and describe the effect.*)

Environment: Identify any changes since last consultation: social, routines, staffing, etc.
Home:

Day Program:

Other:

Signature of agency representative: _____

PSYCHIATRIC TREATMENT PLAN

Client: _____ DOB: _____ Date: _____
Address: _____
Referral Source: _____
Reason for Psychiatric Consultation: _____
Primary Contact: _____ Phone: _____
Family Physician: _____ Phone: _____
Pharmacy: _____ Fax: _____

Description of presenting behaviours and/or symptoms: _____

Historical Diagnoses: _____

Medications List: _____

Bloodwork Results: _____

Length of Treatment trial (considered sufficient to determine if medication is effective): _____

Behavioural criteria to evaluate effectiveness of medication (what changes in behaviour, mood, thought or functioning should be expected): _____

Methods to use to monitor for adverse effects: _____

See appendix of possible charts and tools such as the Beck scales, (for Hopelessness, depression, suicidal ideation); mood charting by self or staff/other or both (see samples); OCD severity scale; Safety plan in place?

Recommendations: _____ (this could include referrals for further testing such as additional bloodwork, MRI's, neurology, follow-up with family physician)

CLIENT/AGENCY INVOLVEMENT WITH THE PLAN:

The above psychiatric medication trial and Treatment Plan and the reasons for implementing it has been reviewed and agreed to by _____ and RSA.

The potential benefits and side effects have been reviewed and all involved agree with the implementation of this Psychiatric Treatment Plan. The use of this plan can be discontinued by any one of the signing parties, once consent has been revoked in writing.

This Psychiatric Treatment plan will be reviewed every ____ months. A new consent will be signed every ____ months. Next psychiatric review will be in ____ months.

Client signature: _____ Agency/Collateral: _____

RSA Consultant: _____ Psychiatrist: _____

PSYCHIATRIC CONSULTATION QUESTIONNAIRE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Date of Completion: _____

Client's Name: _____ Date: _____ Date of Birth: _____

Male _____ Female _____ Height: _____ Weight: _____

Date of admission to current residential setting: _____

Guardian: (Complete if client has a legal guardian) Name: _____

Address: _____

Telephone: _____ city _____ prov. _____ postal code _____

Legal Status: _____

Chief Complaint: (Briefly state why this person is being referred for a psychiatric evaluation)

Family History of Mental Illness, Developmental Disabilities, or Neurological Illness:

(List all biological relatives who have a history of mental illness, developmental disability or neurological illness. Include periods of overt symptoms, suicide attempts, severe substance abuse, psychiatric hospitalization, and/or treatment as evidence.)

_____ no information available _____ no family history of neuropsychiatric illness

(List diagnoses or associated behaviors for family members with mental illness, developmental disability and/or neurological illness.)

Name	Relationship to Client
_____	_____
_____	_____

Current Drug Therapy: (List all current medications)

Drug Name	Dosage	Times/Day	Result & Date of Most Recent Blood Level	Reason for Med

Past Reactions To Psychotropic Medications:

Medication with known positive effects:	Medication with known negative effects:	Other medications:

Other Treatments: (Medical, PT, OT, etc)

Drug Sensitivities: (List unusual or negative reactions to any type of drug therapy.)

History of Psychiatric Hospitalizations: (List all psychiatric hospitalization.)

Hospital	Dates of Stay	Diagnosis/Treatment

Current Diagnoses:

AXIS I:

AXIS II:

AXIS III:

Pregnancy and Delivery

1. Pregnancy: (___ no information available) Duration (in months) ___ complication: no ___ yes ___ if yes, describe:

2. Delivery: (___ no information available) Birth weight (if known): ___ lbs ___ oz Apgar score (if known): ___
Delivery: spontaneous ___ induced ___ cesarean ___ Complications: no ___ yes ___ if yes, describe:**Early Development**1. Milestones: (___ no information available) toilet trained spoke sat up walked talked urine feces 1" words
mos. mos. mos. mos. mos. mos. mos. mos.

2. Developmental disability diagnosis: (___ no information available)

Age when diagnosis first made: ___ Cause of developmental disability (if known): ___

Childhood Illnesses: ___

Developmental Disabilities Information1. Level of disabilities: (___ no information available) ___ borderline intellectual function ___ mild ___ moderate
___ severe ___ profound ___ unspecified

2. IQ testing: (___ no information available)

Test Name	Date	Examiner	Full Scale	Perform	Verbal

3. Adaptive behavior testing: (___ no information available)

Test Name	Date	Examiner	Results

Residential/Institutional Placements: *(Complete for clients who are currently living in or have lived in a provincial developmental center, provincial psychiatric hospital, or other residential facility for persons with developmental disabilities.)*

Admission to Facility	Date	Reason for Admission	Discharge Date

Ability Of Client To Participate In Interview/Others With Patient For Information:Method Of Communication: Speech ___ Signs (ASL) ___ Short Sentences ___
Gestures ___ Single Words ___ Complete Sentences ___

Current Living Arrangements And Any Difficulties Noted: ___

Current Occupational/Day Program And Any Difficulties Noted: ___

Current Behavioral problems Reported by Caregivers: (circle one)

Duration: A B C D
 1-3 months 3-6 months 6-12 months 12+months

Behavioral Patterns:

A = Chronic – person displays behavior on a daily basis, but severity may wax and wane.

B = Acute – behavior represents a dramatic change

C = Episodic – periods of disturbance and periods of normal functioning

BEHAVIOR:	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Is aggressive	1. _____	1. _____
2. Is self-injurious	2. _____	2. _____
3. Eats non-food items (pica)	3. _____	3. _____
4. Drinks excessive amounts of water	4. _____	4. _____
5. Is overactive	5. _____	5. _____
6. Is under active	6. _____	6. _____
7. Engages in ritualistic behavior, compulsions	7. _____	7. _____
8. Has self-stimulatory behavior – spins, rocks, hand flaps, etc.	8. _____	8. _____
9. Steals	9. _____	9. _____
10. Has tantrums	10. _____	10. _____
11. Is impulsive	11. _____	11. _____
12. Other:	12. _____	12. _____
SEXUALITY:	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Publicly masturbates	1. _____	1. _____
2. Inappropriately touches others	2. _____	2. _____
3. Has attempted to coerce others into having sex	3. _____	3. _____
4. Fetish/oddities	4. _____	4. _____
5. Other	5. _____	5. _____
MOOD CHANGES:	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Is excessively angry	1. _____	1. _____
2. Is overly anxious/fearful	2. _____	2. _____
3. Has periods of acute fearfulness	3. _____	3. _____
4. Is easily startled	4. _____	4. _____
5. Is withdrawn	5. _____	5. _____
6. Labile/frequent mood changes	6. _____	6. _____
7. Appears sad	7. _____	7. _____
8. Cries easily	8. _____	8. _____
9. Is unable to enjoy activities	9. _____	9. _____
10. Is excessively elated/excited	10. _____	10. _____
11. Is excessively irritable	11. _____	11. _____
12. Has periods of acute and precipitous anger	12. _____	12. _____
FORMS OF SPEECH:	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Increase in rate of verbalizations	1. _____	1. _____
2. Speech that is echolalic	2. _____	2. _____
3. Pressured speech (he/she is constantly verbalizing and cannot seem to stop)	3. _____	3. _____
4. Mute	4. _____	4. _____
5. Other:	5. _____	5. _____
SPEECH CONTENT:	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Has plans and goals that far exceed his/her abilities	1. _____	1. _____
2. Is preoccupied with death	2. _____	2. _____
3. Talks of suicide	3. _____	3. _____
4. Is preoccupied with returning to a previous residential program	4. _____	4. _____
5. Is preoccupied with sexual themes	5. _____	5. _____
6. Talks of being harmed or attacked	6. _____	6. _____
7. Engages in conversations with people from his/her past	7. _____	7. _____
8. Other	8. _____	8. _____

Current Behavioral problems Reported by Caregivers: (circle one)

Duration: **A** **B** **C** **D**
 1-3 months 3-6 months 6-12 months 12+months

Behavioral Pattern:

A = Chronic – person displays behavior on a daily basis, but severity may wax and wane

B = Acute – behavior represents a dramatic change

C = Episodic – periods of disturbance and periods of normal functioning

PSYCHOMOTOR ACTIVITIES:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Is unable to sit still for more than a few minutes at a time	1. _____	1. _____
2. Moves slowly or remains motionless for long periods of time	2. _____	2. _____
3. Tics	3. _____	3. _____

ATTENTION AND CONCENTRATION:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Cannot attend to daily tasks within their presumed level of MR/DD	1. _____	1. _____
2. Is preoccupied	2. _____	2. _____

MEMORY:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Forgets things he/she has just done	1. _____	1. _____
2. Forget verbal directions	2. _____	2. _____
3. Forgets routines that had been familiar	3. _____	3. _____

ORIENTATION:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Often appears confused in a familiar environment	1. _____	1. _____
2. Sometimes does not recognize people that he/she knows	2. _____	2. _____

SLEEP:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Has difficulty falling asleep	1. _____	1. _____
2. Repeatedly awakens in the middle of the night	2. _____	2. _____
3. Awakens one hour or more before his/her times to get up and remains up for the rest of day	3. _____	3. _____
4. Requires too little sleep	4. _____	4. _____
5. Requires an excessive amount of sleep	5. _____	5. _____
6. Naps during the day.	6. _____	6. _____

APPETITE:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Has a decrease in appetite	1. _____	1. _____
2. Had a weight loss of more than 5 lbs	2. _____	2. _____
3. Had an increase in appetite	3. _____	3. _____
4. Had a weight gain of more than 5 lbs	4. _____	4. _____

BOWEL/BLADDER:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Daytime urinary incontinence	1. _____	1. _____
2. Nighttime urinary incontinence	2. _____	2. _____
3. Daytime fecal incontinence	3. _____	3. _____
4. Nighttime fecal incontinence	4. _____	4. _____

If yes to any of above - note changes in medication around the time first occurred.

PSYCHOTIC/PSEUDO-PSYCHOTIC BEHAVIORS:

	DURATION (A, B, C OR D)	PATTERN (A, B, OR C)
1. Talks to self out loud	1. _____	1. _____
2. Appears to talk directly to people not there	2. _____	2. _____
3. Talks to self more out loud if upset	3. _____	3. _____
4. Says he/she sees things that are not there	4. _____	4. _____
5. Complains that he/she smells things not evident	5. _____	5. _____
6. Reports feeling sensations that are not explainable	6. _____	6. _____
7. Has beliefs that seem strange or untrue	7. _____	7. _____
8. Thinks people are controlling self, or are out to get self	8. _____	8. _____
9. Engages in fantasy thought or play	9. _____	9. _____
10. Has an imaginary friend	10. _____	10. _____

OTHER CONCERNS:

Medical History

1. Does client have neurological problems?

A seizure disorder? No ___ yes ___ Date of last neurological consult: _____

Seizure Type	Date of Last Seizure	Age of Onset

An abnormal EEG? No ___ yes ___ if yes, describe results or enclose report _____

Has client had a CAT/MRI/PET scan? No ___ yes ___ if yes, describe results or enclose report _____

2. Does client have any other type of neurological problem? (i.e. History of head injury, Tardive Dyskinesia, Tics, Cerebral Palsy)
No ___ yes ___ if yes, describe results or enclose report _____

3. Does client have a specific eye, ear, nose, throat problem? No ___ yes ___ if yes, describe results or enclose report _____

4. Does client have heart problems? (include abnormal EKG's) No ___ yes ___ if yes, describe results or enclose report _____

5. Does client have respiratory problems (shortness of breath, smoker)? No ___ yes ___ if yes, describe results or enclose report _____

6. Does client have gastrointestinal problems (nausea, vomiting, constipation, diarrhea)? No ___ yes ___ if yes, describe results or enclose report. _____

7. Does client have gynecological or urinary problems? No ___ yes ___ if yes, describe results or enclose report _____

8. Does client have skin problems (rashes, changes in color)? No ___ yes ___ if yes, describe results or enclose report _____

9. Does client have Musculoskeletal problems (scoliosis, kyphosis, CP)? No ___ yes ___ if yes, describe results or enclose report _____

10. Does client have allergies? No ___ yes ___ if yes, describe results or enclose report _____

11. Does client have endocrinological problems? (Diabetes, Hypothyroidism, etc)
No ___ yes ___ if yes, describe results or enclose report _____

12. Does client have impaired vision? No ___ yes ___ if yes, describe results or enclose report _____

13. Does client have hearing or ear problems (ear infections, hearing loss)?
No ___ yes ___ if yes, describe results or enclose report _____

14. Does client have a known genetic/MR syndrome? (Down's, PKU, Fragile X, etc)
No ___ yes ___ if yes, describe results or enclose report _____

15. Does client have feeding problems? (GERD, G-tube, dental status, history of aspiration, etc)
No ___ yes ___ if yes, describe results or enclose report _____

16. Past Surgeries: No ___ yes ___ if yes, describe results or enclose report _____

Towards a Provincial Strategy

Summary: Advancing Effective Service Provider Practices in Fetal Alcohol Spectrum Disorder

2016

FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

Intervention and Support Working Group

For a copy of the Full Report visit
<http://www.fasdontario.ca/groups/intervention.htm>

Laughter, friendship, love



***Towards a Provincial Strategy:
Advancing Effective Service Provider Practices in
Fetal Alcohol Spectrum Disorder (FASD)
(Summary)***

What we seek

A provincial strategy to address Fetal Alcohol Spectrum Disorder (FASD) developed in collaboration with FASD ONE, parents/caregivers, service providers, and other stakeholders. We invite the provincial government to become the leaders in Advancing Effective Practices, and to address the need for the life-long supports required by children, youth, and adults affected by FASD.

Why?

Ontario is one of the only provinces without a provincial strategy to address the disorder, yet FASD is considered to be the leading cause of developmental disability in Canada (Public Health Agency Canada, 2007). One percent or approximately 300,000 Canadians are currently FASD affected (Public Health Agency of Canada, 2007). In Ontario, that number translates into 30,439 children and youth under the age of 19 who would be affected by the disability.

In spite of this number, much remains unknown about FASD because it is most often an invisible disability. Most people with FASD do not have distinguishing facial characteristics, appear normal, and are of average to above-average intelligence. In addition, Ontario currently has limited diagnostic capabilities.

The result of this ignorance is costly in terms of the secondary disabilities that people with FASD develop without proper support. These may include: mental health issues, poor academic or employment outcomes, addictions, and involvement with the child welfare system and/or the law.

The question is whether to pay now to put the necessary systems and safety nets in place or to pay later, when the costs to society in all these areas will be much higher. It is extremely likely that the costs of paying later will be many times the cost to the system of paying now. It is a question of funded interdependence versus the "bottomless pit" of high-cost failure for both the system and the adult with FASD. (Public Health Agency of Canada, 2007).

What exactly is FASD?

FASD is an umbrella term describing a range of disabilities that may affect people whose mothers consumed alcohol while pregnant. While there are different diagnoses included in the FASD spectrum, all individuals with FASD have brain damage. This brain damage can cause a range of disabilities including mild to severe delays in cognitive, physical, emotional, social, and behavioural skills.

Who We Are

FASD ONE (Ontario Network of Expertise, formerly known as the FASD Stakeholders for Ontario) is a group of stakeholders working together to address issues related to FASD in Ontario. Our membership includes experts and specialists in the following areas:

health	child welfare
children's mental health	research
addictions	justice
early learning and development	Aboriginal services
developmental services	

It also includes family members, who have an intimate knowledge of the practical needs of individuals living with this disability.

FASD ONE is an unincorporated collaboration of diverse provincial and local stakeholder groups. We work to promote, plan, facilitate, and support the coordination, enhancement, and expansion of services and initiatives. Our aim is to better serve children, youth, parents, pregnant women, and families affected by FASD in communities across Ontario.

In order to better educate the public on issues facing people with this range of disabilities, the Intervention and Support Working Group of FASD ONE commissioned three research papers in areas of critical importance: effective practices, education, and respite.

About Effective Practices—Findings from the Research

The Intervention and Support Working Group of FASD ONE embarked on a project to explore standard practices that are effective in supporting people with FASD and to determine if any effective service providers can be found in the province of Ontario. The literature review and full findings of this project can be found in the report *Towards a Provincial Strategy: Advancing Effective Service Provider Practices in Fetal Alcohol Spectrum Disorder (FASD)* (Hall, Cunningham & Jones, 2010), of which this paper provides a summary.

There is a prevalent lack of knowledge among the general and professional population regarding the nature and treatment of FASD. This lack of knowledge extends to ministries of the Ontario provincial government.

Of seven ministries approached for this study, only the Ministry of Children and Youth had a designated provincial service addressing FASD: the Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program, geared to the Ontario Aboriginal population. On this finding, the researchers of this project conducted a survey of parents and caregivers asking them to identify effective service providers, of which a group of thirty service providers were identified from across the province—not an exhaustive list of FASD-related service providers in Ontario, but one that served the study.

The approaches these service providers used for success mirror and support the following eight main practices presented that are summarized under the following four headings.

Importance of early diagnosis and education

Overall, a number of general practices were identified that are essential for effective intervention with people affected by FASD, emphasis on early diagnosis being the most critical.

Given that many people with FASD do not have identifying facial features, early diagnosis prevents misunderstandings and unrealistic expectations and can prevent the onset of secondary disabilities. It also emphasizes the importance of professional care-providing agencies and services having a dedicated process for identifying clients with potential FASD: they should "Think FASD First."

Training and education in FASD—for caregivers, schools and service providers, the communities in which FASD affected people reside, and the general population—are also critical effective practices. Whether a diagnosis is confirmed or suspected, all individuals supporting the person affected by FASD *must* have a strong understanding of how alcohol affects the brain, its impacts on behaviours, and how to support effectively.

Lack of knowledge contributes to

- high frequency of misdiagnosis for clients affected by an FASD;
- failure to provide the best management strategies or alternative treatments through support services that address dysfunctional behaviours rather than understand or treat underlying brain damage;
- ineffective supports for parents/caregivers, which can result in family breakdown, the high cost of having individuals affected by FASD being put into permanent care, and the ongoing development of secondary disabilities.

FASD-oriented education and training for service providers, however, was often not part of any professional training or workplace mandate. Fifty-seven percent of identified individuals in the survey were self-taught on the subject of FASD. In some cases this was necessary due to lack of professional development opportunities within the agencies themselves.

Strength-based approach and collaborative services

Another effective practice is a paradigm shift to a positive, strength-based approach in the way that professionals and caregivers perceive and serve individuals affected by FASD. Once service providers and caregivers understand the neurological impairments of FASD and its effects on behaviours, feelings of frustration and anger evolve into understanding, increased patience and acceptance. Programs would do best to reflect this understanding and shift the underlying perception of the person affected by FASD from someone who "won't" to someone who "can't." Service providers with a "no-eject" policy for individuals with FASD are often the most successful in serving individuals with FASD.

Collaborative services are another effective practice. Individuals with FASD need to access many supports over their lifetimes; due to the nature of their condition, most of them are not able to coordinate all the services they need. An advocate—ideally an agency or service provider—can work to change the system in order to better accommodate the individual and coordinate the many services that are necessary to support the person affected by FASD. This is effective case management.

Interdependent supports, structure, and communication

Life-long interdependent supports are another effective practice for success in dealing with people affected by FASD. Service providers and caregivers should teach people with FASD from an early age not only how to be interdependent, but that interdependence is good for them and essential for their success as adults.

This means

- reinforcing this reality as early as possible; and
- service providers no longer expecting that people affected by FASD will become independent over time and, as a result, planning for life-long interdependence.

Structure, routine and supervision are additional effective practices. People with FASD must have external structure to organize their own time and to keep focused and/or busy. Without this structure they may react impulsively or prolong responses to random external stimuli. Structure includes altering the environment to support structure and routine. Routine and supervision are essential in preventing behaviours. Supervision sets up people with FASD for success; some level of supervision will always be required as the brain damage is permanent.

Effective communication approaches are another effective practice. Early language development is often delayed in individuals with FASD. Receptive language is more impaired than expressive language. An understanding of the emphasis on receptive language skills and a modified approach to communication with persons impacted by FASD are essential elements of effective practice. Effective communication includes using clear language that is simple with step-by-step instructions. In general, caregivers and programs should “think younger” when working with clients with FASD.

Awareness of and supports for Sensory Processing Disorders

The last effective practice identified by this research to successfully deal with people affected by FASD is awareness of and supports for Sensory Processing Disorders or SPDs (formerly Sensory Integration Disorders [SIDs]). Sensory Processing Disorders are neurological disabilities in which the brain is unable to accurately process the information coming in from the senses. Everyday environments may be overstimulating and overwhelming for people affected by FASD whose brains cannot prioritize or process stimuli. Many of these people seem to have sensory sensitivities to sight, sound, touch, smell, or taste. In order to provide effective services for individuals with FASD, caregivers and service providers *must* assess, understand, and address Sensory Processing Disorders.

Recommendations

Based on the results of the literature review in *Towards a Provincial Strategy: Advancing Effective Service Provider Practices in Fetal Alcohol Spectrum Disorder (FASD)* (Hall, Cunningham & Jones, 2010), the most effective practices to deal with people impacted by FASD must be founded on early diagnosis, education, and training, as well as life-long supports for those affected and their care providers. Currently, these services are neither promoted nor readily available.

To improve cost effectiveness and the provincial capacity to successfully support people with FASD, it is critical that

- the Ontario government assign a lead ministry to work with other ministries to create a provincial FASD strategy and ensure that effective practices are utilized.
- staff within the service sector be assigned to the FASD file and receive designated funding to propel their work using effective practices.
- a provincial inter-ministerial and cross-sectoral FASD committee be responsible for addressing the needs of individuals affected by FASD who are either currently receiving services or are in need of services. The existing operating group FIANO (FASD Intergovernmental Action Network of Ontario) provides a model for inter-ministerial cooperation of this type; however, the network needs to be supported by a lead ministry.
- the diagnostic capacity for FASD in the province of Ontario be increased.
- education, training and increased awareness of FASD throughout the province of Ontario be prioritized.
- policy makers, service providers, legislators, and funders utilize and build on the current effective practices in the development of services for people and families affected by FASD.

AUDITING PSYCHOTROPIC MEDICATION THERAPY

Name: _____

DOB: _____

	Yes	No	Not Sure
1. Has the patient been given a psychiatric diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is an interdisciplinary assessment indicated for the concerns for which the medication is being used, and has it been carried out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is medication treatment consistent with the diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. If patient does not have a psychiatric diagnosis and is being treated for "behaviour problems" are guidelines for problem behaviours being followed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the patient capable of consenting to medication treatment? If capable, has he/she given consent? If not capable, has consent been obtained from his/ substitute decision maker?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Has the patient and/or his/her substitute decision maker (SDM) been informed regarding anticipated therapeutic medication treatment effects and potential side effects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Has a proper medical assessment been carried out prior to initiating medication therapy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Have target behaviours against which to monitor medication effectiveness been defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is there a plan to measure these target behaviours objectively and systematically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Is the patient being regularly monitored for side effects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Is the patient receiving too many psychotropic agents?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Is the patient being under-medicated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Is the patient being over-medicated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Is medication therapy being changed too rapidly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Are PRN and stat doses of medications being used excessively?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Are patients treated with antipsychotic agents being regularly evaluated for tardive dyskinesia and metabolic syndrome?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Have the psychotropic medication therapy and psychiatric diagnosis or special behavioural pharmacological justification for the medication been reviewed in the past year?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Has a date been set for the next review?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments/Action Plan (for issues flagged): _____

Date (dd/mm/yyyy): _____ Signature: _____

This tool was developed in recognition of the complexities of psychotropic medication use in adults with developmental disabilities (DD). Research has demonstrated that such medications are often overprescribed or otherwise inappropriately prescribed. This tool is intended to help primary care providers to audit psychotropic medication use in their patients with DD, so that such medications are used following best practice guidelines in this population.

Underlying the use of this tool is the concept of partnership with patients and caregivers in use of psychotropic medications, monitoring effectiveness, and any side effects of these medications.

As recommended in the *Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines*¹:

- Medications should be reviewed **every three months, including indications, dosages, efficacy and side effects** [Guideline 5].
- Regularly audit the use of prescribed psychotropic medication, including those used PRN [Guideline 22].
- Review the psychiatric diagnosis and the appropriateness of prescribed medications for this diagnosis whenever there is a behaviour change [Guideline 27].
- Adults with DD may be unable to communicate side-effects and may also respond to psychotropic medications differently from those in the general population [Guideline 27].
- Reassess the need for ongoing use of antipsychotic medications at regular intervals and consider dose reduction or discontinuation when appropriate [Guideline 28].

Adapted from Sovner 1985 and Deb 2006 by the Behavioural and Mental Health Working Group, chaired by Dr. E. Bradley, Surrey Place Centre.

1. Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunskey Y, McMillan S. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can Fam Physician* 2011;57:541-53.

2. Sovner R, Hurley AD. Assessing the quality of psychotropic drug regimens prescribed for mentally retarded persons. *Psych Aspects Ment Retard* 1985 August/September; 4 (8/9):31-38.

3. Deb S, Clarke D, Unwin G. Using medication to manage behaviour problems among adults with a learning disability. 2006;36. www.ld-medication.bham.ac.uk/1qrg.pdf

BIOPSYCHOSOCIAL MODEL *Understanding the Person and the Problem*

	Biological (physical)	Psychological (cognitive/emotional)	Social (external world)
Predisposing factors (vulnerabilities or risk factors)			
Protecting factors (keeping it from being worse, the person's strengths)			
Precipitating factors (what seems to have triggered the problem)			
Perpetuating factors (What makes the problem continue?)			

Name: _____

SCATTER PLOT

Month/year: _____

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
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Legend: Highlighted yellow = time asleep, X = incidents of aggression, O = incidents of yelling, BM# = bowel movement & type, days of menstruation noted in red

ABC (Antecedent-Behaviour-Consequence) Chart

To record baseline information for incongruent, challenging or problematic behaviours*

Name:

DOB:

Occasion

Date
Time
Observer

Pre-existing conditions

Factors that increase vulnerability or sensitivity to triggers

Antecedent

What happened just before the behaviour occurred and might have triggered it?
Include SETTING & ACTIVITY

Behaviour

Describe the behaviour as accurately and specifically as possible. Include frequency, duration, and intensity on a scale of 1 to 5 (5 is most severe).

Consequence

Things that happened immediately after the behaviour occurs, and make it more or less likely to happen again

Example

Date
Feb 6/10

Time
6:30-7:10 pm

Observer
Rene – primary staff member

John's mother was in hospital with broken hip, and could not visit.
John had a toothache.
John's usual primary staff member was on holidays.

John was eating supper in kitchen when another resident bumped into him when passing food.

John started to yell and threw his plate across the table. He ran out of room, screamed for 10 minutes and threw cushions around living room. The intensity was 4/5.

Staff tried to direct John to his room for a time-out but he became more agitated. They also tried to distract him with ice cream but were unsuccessful. They directed other residents to leave the room.

John began to hit staff when they approached him. Staff observed him from a distance, gave him time and reduced stimuli, and he calmed down in about 30 min.

Date

Time

Observer

Date

Time

Observer

Date

Time

Observer

*Adapted from www.peatni.org/directory/resources/index.asp with input from Carol Drummond, Behaviour Therapist, Surrey Place Centre

Functional Analysis Observation Form:

Location: _____

Settings / Events /

DISABILITIES

Discriminative Stimuli

PERCEIVED FUNCTIONS

Date	Time	Staff	Location	On - Task Time	Off - Task Time	Aggression: Verbal	Aggression: Physical	Property Destruction	Non - Cooperation	Crine/Screaming	Throwing self on floor	Self - Harm	Stripping Clothing	Demand	Request	Transition: Task	Transitions: Setting	Interrupted in Activity	Alone-no attention	Rejection Response	Get attention	Get item/activity	Self-stimulation	Other: Record	To Escape request	To Escape activity	To Escape a person	PRN Time Given	Time to be Effective	Not Effective
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FUNCTIONAL ANALYSIS CHECKLIST

Client Name: _____

Age: _____

Date of Assessment: _____

Location: _____

Interviewer: _____

Guest: _____

BIOLOGICAL FACTORS

Discomfort and Medication Related Factors

- Does the behaviour occur more often just before the menstrual period? Yes / No
- Does the behaviour occur more when the individual is in the same position for an extended period of time? Yes / No

Specify: _____

- Could the individual have a disease or condition that is producing pain or discomfort? (ie. Tooth ache, earache, hemorrhoids, etc.) Yes / No

Specify: _____

- Does the behaviour occur more/less often after any medication is taken? Yes / No

Specify: _____

- Was the onset of the behaviour associated with the introduction of a new medication? Yes / No

If Yes, what medication was introduced, what is the dosage and how frequently is it administered?

Specify: _____

- How much time usually elapses between the intake of the suspected food and occurrence of the behaviour?

Minutes _____ Hours _____

- Does the behaviour occur more/less often after consumption of coffee, tea, soft drink, chocolate, or any other substance with a high caffeine content? Yes / No
- Is it more likely to see the behaviour occur before or after meals? No / Before / After

Seizure Related Factor

- Does the behaviour occur more often just prior, during or after a seizure activity? Yes / No
- If yes, what type of seizure is the individual having?

- How frequent are the seizures?

- What is the average duration of a typical seizure?

Alertness Related Factor

- Does the individual appear vague, puzzled, confused or baffled just prior, during or after a change (increase/decrease) in the behaviour? Yes / No

Specify: _____

PHYSICAL ENVIRONMENT RELATED FACTORS

- Does the behaviour occur more when the environment is noisy? Yes / No

Specify: _____

- Does the behaviour occur more often when a task is introduced that is associated with a higher ratio of incorrect to correct responses? Yes / No

ELICITED OR ADJUNCTIVE BEHAVIOUR RELATED FACTORS

- Does the behaviour occur more when the individual has to wait for an item or activity or is told he/she has to wait for an item or activity that you suspect he/she likes? Yes / No
Specify: (What Is the item or activity?) _____

- Is the behaviour often associated with the termination of specific activities? Yes / No
Specify: (Describe the activity) _____

- Does the behaviour reliably occur following the presentation of specific stimuli such as:
- Activities Yes / No
 - People Yes / No
 - Objects Yes / No
 - Other Yes / No

Specify:

- Does the behaviour occur following the presentation of a brief event? Yes / No
Specify: (Describe the event) _____

AGITATED BEHAVIOR SCALE

Patient _____

Period of Observation:

Observ. Environ. _____

From: _____ a.m. _____ / _____ / _____
p.m. _____

Rater/Disc. _____

To: _____ a.m. _____ / _____ / _____
p.m. _____

At the end of the observation period indicate whether the behavior described in each item was present and, if so, to what degree: slight, moderate or extreme. Use the following numerical values and criteria for your ratings.

- 1 = absent: the behavior is not present.
- 2 = present to a slight degree: the behavior is present but does not prevent the conduct of other, contextually appropriate behavior. (The individual may redirect spontaneously, or the continuation of the agitated behavior does not disrupt appropriate behavior.)
- 3 = present to a moderate degree: the individual needs to be redirected from an agitated to an appropriate behavior, but benefits from such cueing.
- 4 = present to an extreme degree: the individual is not able to engage in appropriate behavior due to the interference of the agitated behavior, even when external cueing or redirection is provided.

DO NOT LEAVE BLANKS.

- _____ 1. Short attention span, easy distractibility, inability to concentrate.
- _____ 2. Impulsive, impatient, low tolerance for pain or frustration.
- _____ 3. Uncooperative, resistant to care, demanding.
- _____ 4. Violent and or threatening violence toward people or property.
- _____ 5. Explosive and/or unpredictable anger.
- _____ 6. Rocking, rubbing, moaning or other self-stimulating behavior.
- _____ 7. Pulling at tubes, restraints, etc.
- _____ 8. Wandering from treatment areas.
- _____ 9. Restlessness, pacing, excessive movement.
- _____ 10. Repetitive behaviors, motor and/or verbal.
- _____ 11. Rapid, loud or excessive talking.
- _____ 12. Sudden changes of mood.
- _____ 13. Easily initiated or excessive crying and/or laughter.
- _____ 14. Self-abusiveness, physical and/or verbal.

_____ Total Score

BEHAVIOURAL DATA SHEET

Name: _____		Recorder: _____		Date: _____ <input type="checkbox"/> AM. <input type="checkbox"/> PM.	
Antecedent (What happened before) Transition Environmental change Someone in space Object taken away Requested to do something Change in routine Sitting in Circle _____ _____	Behaviour (Identify what they are) Behaviour Area Start Time _____ Time Stopped _____ Run _____ Hit _____ Throwing _____ Self-injury _____ Kick _____ Bite _____ Verbal Response _____ Crawl under table or mat _____ Slap table _____	Consequences (What did you do) Ignored _____ Redirected _____ Followed Protocol _____ _____ _____ _____ _____ Effective? Yes/No _____ _____	Communicative Intent What was the child trying to say? Protest _____ Request _____ Comment (greetings, etc.) _____ Escape _____ Attention Seeking _____ _____ _____		

Name: _____		Recorder: _____		Date: _____ <input type="checkbox"/> AM. <input type="checkbox"/> PM.	
Antecedent (What happened before) Transition Environmental change Someone in space Object taken away Requested to do something Change in routine Sitting in Circle _____ _____	Behaviour (Identify what they are) Behaviour Area Start Time _____ Time Stopped _____ Run _____ Hit _____ Throwing _____ Self-injury _____ Kick _____ Bite _____ Verbal Response _____ Crawl under table or mat _____ Slap table _____	Consequences (What did you do) Ignored _____ Redirected _____ Followed Protocol _____ _____ _____ _____ _____ Effective? Yes/No _____ _____	Communicative Intent What was the child trying to say? Protest _____ Request _____ Comment (greetings, etc.) _____ Escape _____ Attention Seeking _____ _____ _____		

Name: _____		Recorder: _____		Date: _____ <input type="checkbox"/> AM. <input type="checkbox"/> PM.	
Antecedent (What happened before) Transition Environmental change Someone in space Object taken away Requested to do something Change in routine Sitting in Circle _____ _____	Behaviour (Identify what they are) Behaviour Area Start Time _____ Time Stopped _____ Run _____ Hit _____ Throwing _____ Self-injury _____ Kick _____ Bite _____ Verbal Response _____ Crawl under table or mat _____ Slap table _____	Consequences (What did you do) Ignored _____ Redirected _____ Followed Protocol _____ _____ _____ _____ _____ Effective? Yes/No _____ _____	Communicative Intent What was the child trying to say? Protest _____ Request _____ Comment (greetings, etc.) _____ Escape _____ Attention Seeking _____ _____ _____		

Behaviour Data Sheet and PRN Recording Sheet

Target Behaviours	Intensity/Duration	PRN begin working	Duration of PRN
1. aaa	1. Mild intensity, Short duration < 5 minutes (1)	1. < 10 minutes	1. < 10 minutes
2. bbb	2. Moderate intensity, Long duration > 5 minutes (2)	2. 10–20 mins	2. 10–20 mins
3. ccc	3. Severe intensity, Short duration < 5 minutes (1)	3. 20–40 mins	3. 20–40 mins
	4. Severe intensity, Long duration > 5 minutes (2)	4. 40–60 mins	4. 40–60 mins
		5. Not effective	5. 60+ minutes

[illegible]

Completing the Target Behaviour/Intensity PRN Chart

It is very important that this chart be completed accurately so that we can assess the effectiveness of medications and to develop effective behavioural support strategies.

1. Complete Date
2. Time each of the different target behaviours occurs
3. Initial of the staff completing the chart
4. Circle the target behaviour (a separate line for each of the target behaviours)
5. Rate the intensity based on the highest level of occurrence during the outburst
6. Indicate if a PRN is given – what the PRN is
7. Indicate the time the PRN is actually taken
8. The effectiveness is the length of time for the PRN to begin working
9. Duration of effects of PRN – how long does the client remain calm without exhibiting the target behaviours

Setting Events Checklist

Student: _____ Respondent: _____

Behavior Interest: _____ Date: _____

Instructions: The list below includes events that could possibly increase the likelihood of problem behavior occurring. If an event contributes to the student's behavior, check the appropriate column to indicate when the event occurs in relation to when it contributes to the problem behavior. For longstanding influences, note only those that contribute to the current incident or behavior.

SETTING EVENT (by type)	Same Day	Day Before	Within Week	Long Standing
Physical				
Meal time change or meal missed				
Sleep pattern (including duration) atypical				
Medications changed or missed				
Appeared or complained of illness				
Appeared or complained of pain or discomfort				
Allergy Symptoms				
Seizure				
Chronic health condition				
Other (specify):				
Learning and self-regulation				
Specific disability (specify):				
Learning difficulties (specify):				
Low frustration tolerance/impulsive				
Short attention span				
Poor organizational or planning skills				
Anger management problems				
Atypical sensory needs				
Other (specify):				
Social-Emotional				
Anxious				
Irritable or agitated				
Depressed, sad, or blue				
Experienced disappointment (specify):				
Refused a desired object or activity				
Disciplined or reprimanded, especially if atypical				
Fought, argued, or had other negative interaction				
Difficulty with peer(s) (specify):				
Changes in living environment (specify):				
Other (specify):				

Setting Event Checklist

Check any of the following events that occurred last evening (PM) or this morning prior to work/school (AM). Briefly describe items that are checked.

	AM	PM
Was informed of something usually disappointing.	<input type="checkbox"/>	<input type="checkbox"/>
Was refused some requested object/activity	<input type="checkbox"/>	<input type="checkbox"/>
Fought, argued, or had other negative interactions	<input type="checkbox"/>	<input type="checkbox"/>
Was disciplined/reprimanded (behaviour or Disciplinary action was atypical)	<input type="checkbox"/>	<input type="checkbox"/>
Was hurried or rushed more than usual	<input type="checkbox"/>	<input type="checkbox"/>
Sleep pattern (including duration) was unusual	<input type="checkbox"/>	<input type="checkbox"/>
Was under the care of someone new/favourite caregiver was absent	<input type="checkbox"/>	<input type="checkbox"/>
Experienced other major changes in living environment	<input type="checkbox"/>	<input type="checkbox"/>
Learned about visit/visitation with friends/family (will or will not occur)	<input type="checkbox"/>	<input type="checkbox"/>
Visitors arrived/failed to arrive	<input type="checkbox"/>	<input type="checkbox"/>
Medications were changed/missed	<input type="checkbox"/>	<input type="checkbox"/>
Has menstrual period	<input type="checkbox"/>	<input type="checkbox"/>
Appeared excessively tired/lethargic	<input type="checkbox"/>	<input type="checkbox"/>
Appeared excessively agitated	<input type="checkbox"/>	<input type="checkbox"/>
Appeared in a negative mood	<input type="checkbox"/>	<input type="checkbox"/>
Appeared/complained of being ill	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	<input type="checkbox"/>	<input type="checkbox"/>

GUIDELINES FOR STAFF SAFETY WHEN PROVIDING SPECIALIZED SUPPORTS

As a staff member working within Enhanced Specialized Services, additional cautions should be in place in comparison to other support settings. In recognition of the increased challenges and complexities of those who require treatment, the following are guidelines intended to reduce risk to both yourself as well as to those you are providing support to.

Personal Attire

- ✗ Don't wear jewelry, specifically hoop or dangling earrings, necklaces or bracelets.
- ✗ Don't attach any items to your clothing, such as keys, pens ect.
- ✗ Don't wear open toe shoes or shoes with heels.
- ✓ Do wear flat, non-slid sole shoes.
- ✓ Do consider wearing long pants and long sleeve shirts to help in providing protection against the possibility of scratches and bites.

Personal Belongings

- ✓ Do keep your car secure, windows up and car locked.
- ✓ Do secure your personal items, car keys, wallets, and purses in a locked area in the office.
- ✗ Don't bring anything of value into work.
- ✗ Don't bring in personal medication, unless it's a necessity.

Environmental Awareness

- ✓ Always be aware of where the resident is, the area of the home, closeness to you and others
- ✓ Maintain appropriate distance, one arms length, from the resident
- ✓ Always perform environmental scans for potential hazards to your own and the resident's safety. Ensure furnishings are not blocking safe exits, secure or remove items which are potential weapons
- Don't allow yourself to be drawn into a corner, or any area where you do not have safe exit
- Never turn your back on the person you are supporting

Vehicle Safety

- ✓ A van is a preferable vehicle for transportation, as it allows for more room between passenger(s) and driver
- ✓ The person(s) being supported, should be seated in back passenger seats, so they are not directly behind or beside the driver
- ✓ A cellular phone should be with the driver in case of emergency and/or the need for back up assistance
- ✓ PRN medication and personal profile information of the person(s) being supported should always be available when the person(s) are being transported
- ✓ A vehicle safety protocol should be provided for each person being supported, specific to their needs and safety cautions

Interpersonal Awareness

- ✓ Be aware of activity level, mood of the individual.
- ✓ Be aware of the content and tone of remarks/conversation of the client so that any escalation can be identified.
- ✓ Model appropriate voice tone/volume
 - × Do not disclose personal information to the resident
 - × Do not become less vigilant if the person appears to be having good days

Additional information about these training opportunities can be found online at:

Crisis Prevention Intervention Program (CPI)-Non Violent Crisis Intervention Crisis Prevention Institute Inc

3315-H North 124th Street
Brockfield, WI 535005
USA
Toll Free US and Canada 1-800-558-8976
E-mail: info@crisisprevention.com



Safe Management Group Inc.

345 Lakeshore Rd. E. Suite: 506
Oakville, ON L6J 1J5
Canada
905-849-0967
E-mail: smg@safemanagement.org



Safe Management Group
Caring for your safety

Safeguard Training for Children and Adult Services

9011 Leslie Street, Suite 312
Richmond Hill, ON L4B 3B6
Canada
Telephone: 905-889-5030
Web Site: www.safeguards-training.net



DISABILITY SOLUTIONS

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"Self-Talk" in Adults with Down Syndrome

*by Dennis McGuire, Ph.D., Brian A. Chicoine, MD.,
and Elaine Greenbaum, Ph.D..*

Do you talk to yourself? We all do at different times and in various situations. In examining and evaluating over 500 patients at the Adult Down Syndrome Center of Lutheran General Hospital, we have heard repeatedly that adults with Down syndrome talk to themselves. Sometimes, the reports from parents and caregivers reflect deep concern that this behavior is "not normal" and symptomatic of severe psychological problems.

Preventing misinterpretation of self-talk as a sign of psychosis in adults with Down syndrome is a major motivation for this article. Too often, we believe, these conversations with self or imaginary companions have been equated with "hearing of voices" and treated with anti-psychotic medications (such as Haldol, Mellaril, or Risperdal). Since it is extremely difficult to evaluate the thought processes of adults with cognitive impairments and limited verbal skills, we urge a very cautious approach in interpreting and treating what seems to be a common and at times very helpful coping behavior for adults with Down syndrome.

The Adult Down Syndrome Center (the Center) was developed to address the health and psycho-social needs of adults with Down syndrome. The Center is a unique collaboration of the National Association for Down Syndrome, a parent advocacy group, Advocate Health Care, a private health care provider, and the Institute on Disability and Human Development at the University of Illinois at Chicago. Since its inception in 1992, over 500 individuals have been evaluated at the Center.

Our records at the Center indicate that 81 percent of adults seen engage in conversations with themselves or imaginary companions. Patients have ranged in age from 11 to 83 years of age. The median age in our data base is 34. This high prevalence of self-talk does not seem to be widely known. For some parents and caregivers, the fact is reassuring. But the content of these conversations, their frequency, tone, and context can be important in determining if treatment is warranted.

Helpful Self-talk

Families and caregivers should understand that self-talk is not only "normal" but also useful. Self-talk plays an essential role in the cognitive development of children. Self-talk helps children coordinate their actions and thoughts and seems to be an important tool for learning new skills and higher level thinking. Three-year-old Suzy says to herself: "This red piece goes in the round hole." Then Suzy puts the red piece into the round hole of the puzzle.

We suspect that self-talk serves the same useful purpose of directing behavior for adults with Down syndrome. Consider the case of twenty-two-year-old "Sam" (not his real name). His mother reported the following scene. She asks Sam to attend a family function on a Sunday afternoon. Sam's regular routine is to go to the movies on Sunday afternoons. Sam tells his mother he will not go with the family. Then the mother asks Sam to think it over. Sam storms off to his room and slams the door. His mother overhears this dialogue:

"You should go with your family, Sam."

"But I want to go to the movies."

"Listen to your Mom!"

"But Sunday is my movie day."

"You can go next Sunday."

Sam's mother said he went to the family function, with the proviso that he could go to the movies the next Sunday. Sam may have been talking to an imaginary person or arguing with himself, but Sam clearly managed to cope with a situation not to his liking.

In children without identified learning problems, the use of self-talk is progressively internalized with age. Moreover, children with higher intellectual abilities seem to internalize their self-talk earlier. As self-talk is transformed into higher level thinking, it becomes abbreviated and the child begins to *think rather than say* the directions for his or her behavior. Thus, the intellectual and speech difficulties of adults with Down syndrome may contribute to the high prevalence of audible self-talk reported to us at the Center.

In general, the functions of self-talk among adults are not as well researched or understood. Common experience suggests that adults continue to talk to themselves out loud when they are alone and confronting new or difficult tasks. Though the occurrence may be much less frequent, the uses of the adult's self-talk seem consistent with the findings about children. Adults talk to themselves to direct their behavior and learn new skills. Because adults are more sensitive to social context and may not want to overhear

these private conversations, their self-talk is observed less frequently.

Adults with Down Syndrome show some sensitivity about the private nature of their self-talk. Like Sam in the example above, parents and caregivers report that self-talk often occurs behind closed doors or in settings where the adults think they are alone. Having trouble judging what is supposed to be private and what is considered "socially appropriate" also may contribute to the high prevalence of easily observable self-talk among the patients visiting the Center.

In the general population, self-talk among older persons is frequently notable and, usually, easily accepted, just as it is with children. Among the elderly, social isolation and the increasing difficulty of most tasks of daily living may be important explanations for this greater frequency of self-talk. For adults with Down syndrome, these explanations also make sense. Adults with Down syndrome are at greater risk for social isolation and the challenges of daily living can be daunting.

Additionally, we have found that many adults with Down syndrome rely on self-talk to vent feelings such as sadness or frustration. They *think out loud* in order to process daily life events. This is because their speech or cognitive impairments inhibit communication. In fact, caregivers frequently note that the amount and intensity of the self-talk reflects the number and emotional intensity of the daily life events experienced by the individuals with Down syndrome.

For children, the elderly, and adults with Down syndrome, self-talk may be the only entertainment available when they are alone for long periods of time. For example, a mother reported that her daughter "Mary" spent hours in her room talking to her "fantasy friends" after they moved to a new neighborhood. Once Mary became more involved in social and work activities in her new neighborhood, she did not have the time or the need to talk to her imaginary friends as often.

Thus, that adults with Down syndrome use self-talk to cope, to vent, and to entertain themselves should not be viewed as a medical problem or mental illness. Indeed, self-talk may be one of the few tools available to adults with Down syndrome for asserting control over their lives and improving their sense of well-being.

When to Worry

The distinction between helpful and worrisome self-talk is not easy to cast in stone. In some cases, even very loud and threatening self-talk can be harmless. This use for self-talk by the adult with Down syndrome may not be that different from someone who rarely swears but screams out a four-letter word when hitting her thumb with a hammer. Such outbursts may simply be an immediate, almost reflexive outlet for some of life's frustrations.

Our best advice about when to worry is to listen carefully for changes in the frequency and context of the self-talk. When self-talk becomes dominated by remarks of self-disparagement and self-devaluation, intervention may be warranted. For example, it may be quite harmless when "Jenny" yells "I am a dummy," once, right after her failure to bake a cake from scratch. However, if Jenny begins to tell herself over and over "I am a dummy and can't do anything right," it may be time to worry and to do something.

A marked increase in the frequency and a change in tone of the self-talk also may signal a developing problem. For example, a caregiver reported that "Bob" had begun to talk to himself more frequently and not just in his room at the group home. Bob seemed to lose interest in his housemates and spent more time in these conversations with himself. Bob talked to himself, sometimes loudly and in a threatening manner, at the bus stop, at the workshop, and at the group home. Bob was diagnosed as experiencing a severe form of depression. Over an extended period of time, Bob began to respond to an anti-depressant and to his participation in a counseling group.

In another case, "Jim" (like Bob) showed a dramatic increase in self-talk. Jim refused to go to his workshop and to participate in the social activities that he once enjoyed. It turned out that Jim's change in behavior was not due to depression. Instead, Jim's family and staff at his workshop discovered that Jim was being intimidated and harassed by a new co-worker. With the removal of the bully from his workshop, Jim gradually regained his sense of trust in the safety of the workshop. His self-talk and interest in participating in activities returned to earlier levels.

Further study of the content, context, tone, and frequency of the self-talk of adults with Down syndrome may provide more insight into their private inner worlds. What we have observed and heard from family and caregivers suggests that self-talk is an important coping tool and only rarely should it be considered a symptom of severe mental illness or psychosis. A dramatic change in self-talk may indicate a mental health or situational problem. Despite the odd or disturbing nature of the self-talk, our experience at the Center indicates that self-talk allows adults with Down syndrome to problem-solve, to vent their feelings, to entertain themselves, and to process the events of their daily lives.

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Brian Chicoine, MD is Medical Director of the Adult Down Syndrome Center of Lutheran General Hospital.

Elaine Greenbaum, Ph.D. was Research Coordinator at the Adult Down Syndrome Center of Lutheran General Hospital.

Footnotes:

1. Chicoine, B., McGuire, D., Hebein, S., and Gilly, D., "Development of a Clinic for Adults with Down Syndrome," *Mental Retardation*, Vol. 32, No. 2, 1994, p. 100-106.
2. Private speech is the term used for self-talk in literature on child development. For a wide range of references on the uses of private speech: Diaz, R., Berk, L. *Private Speech: From Social Interaction to Self-Regulation*. Lawrence Erlbaum Associates, 1991. ISBN: 0805808868.
3. L. S. Vygotsky is the Russian psychologist credited with explaining how higher thought and our inner silent dialogues emerge from childhood's private speech: Vygotsky, L., in Diaz, R., Berk, L. *Private Speech: From Social Interaction to Self-Regulation*. Lawrence Erlbaum Associates, 1991. ISBN: 0805805568.
4. McGuire, D., Chicoine, B., "Depressive Disorders in Adults with Down Syndrome," *The Habilitative Mental Healthcare Newsletter*, Vol. 15, No. 1, 1996, p. 1-7.

"The Groove "

Dennis McGuire, PhD.

One of the most interesting and consistent findings from the Adult Down Syndrome Center is the discovery that people with DS need sameness, repetition and order in their lives. We call this tendency the "groove" because thoughts and actions of people tend to follow fairly well worn paths, or grooves.

TYPES OF GROOVES

One of the most common grooves is a set pattern or routine in one's day to day activities. Many will often have set methodical and meticulous morning routines for dressing and grooming, daily work routines, as well as evening routines for relaxing and preparing for bed. We have also found that many individuals are meticulous in the care of their rooms and possessions. Much time and effort is spent in making things "just so". Beds are often made and rooms are neat and tidy. Closets and drawers are quite often in perfect order. In addition, people often have a set place for furniture and other personal items in their rooms or living spaces. Parents and caregivers have found that if any of these items are moved or disturbed by others they will be returned to the original location in short order.

A wide array of other grooves also exists. The most common centers on personal preferences for such things as music, sports teams, or celebrities. Grooves may also include such personal issues as a favorite relative or a love interest. Also common are grooves which have independence issues as a theme. These are often expressed as "I want to do it

(a particular activity) by myself and in my own way". Some people may also develop self-absorbing grooves around emotionally charged experiences. These may involve positive experiences, such as an award, or negative experiences, such as the loss of a loved one.

ADVANTAGES OF GROOVES

There are numerous advantages to grooves. They give an important sense of order and structure to peoples' lives. They also help persons, who process things more slowly in a fast moving world, have some control over their lives. Routines help to organize and manage daily living tasks which increase independence. Once an activity is learned and becomes part of a daily routine, there is rarely a need for "prompting" or supervision from others.

The ability to follow routines at set times each day can be of great benefit. For example, independence is greatly enhanced when a person is able to get up and off to work on his own. Independence and performance may also be enhanced in the work environment. Employers are often impressed with an employee's reliability in completing routine work tasks and in adhering closely to work time schedules.

Grooves may also offer a refuge from the stresses and strains of daily life. This may be especially important to persons with DS because communicating with others may be

tiring and frustrating due to expressive language limitations. In dealing with daily stresses, people will often repeat a specific, enjoyable activity in a quiet or private space. In the worksite, many people will also schedule time during their daily routine, or when needed, to be alone. The most common and often only place for privacy in the work site is the washroom.

Grooves involving the conscientious care of one's appearance, room and personal items can be of great benefit. Such care of one's appearance conveys an image of pride, self-respect and dignity, which will often help develop a good self image. Meticulous care of one's room and possessions may also increase pride and self respect. As an added benefit, family members and caregivers in other settings who share living spaces often appreciate this kind of groove.

Finally, and most importantly, the groove is a powerful means of expression and communication. This is especially true for people with DS, who have limited ability to express themselves verbally. Each groove is a clear and unambiguous statement of a personal choice or preference. For example, daily grooves and routines express how people choose to organize and manage such things as the care of their own grooming, appearance and personal items, their participation in social, recreational, and work activities, as well as personal preferences in music, hobbies and artistic endeavors. Each person's choices will in turn help to shape and define their own unique style and personality.

DISADVANTAGES AND MINOR PROBLEMS

Although there are many benefits and advantages, there are also some disadvantages to grooves that sometimes cause problems. Some of the problems need not be serious if handled appropriately by caregivers. For example a person may be interested in a particular issue, such as a favorite sports team, which they retell over and over to family and friends. While this may be a minor irritant to caregivers, it is not necessarily a problem that interferes with important spheres of living. Additionally there are grooves that may be adaptive if done at the appropriate time or place. For example, a groove for cleaning the bathroom may be greatly appreciated by family members unless it is done in the morning when everyone in the family needs to prepare for work. Similarly, a restaurant manager may be pleased with clean washrooms unless patrons have to wait for long periods while a meticulous job is done.

At the Adult Down Syndrome Center we have also found that a person's need for order or sameness may ironically clash with their need for meticulousness and cleanliness. This is because some people prefer to wear the same shirt or comfortable pair of jeans, over and over, rather than a stiff new pair. Similarly, others may fold and put away dirty clothes rather than have them sit in a rumpled pile in the laundry basket.

MORE SERIOUS PROBLEMS

On the other hand, a groove may become a maladaptive rut when it interferes with functioning in the important spheres of living. There are a number of ways in which this may happen. Some persons may become inflexible about the completion of grooves and routines that may interfere with their participation in other important life activities. For example, one may rigidly adhere to an evening room cleaning and organizing groove rather than choose an opportunity for social or recreational activities which may be beneficial to their health and well being. Some may also make poor decisions, which then become "bad habits". For instance, we have seen a number of people who have serious problems with sleep deprivation. This may happen if one gets in the habit of staying up late to watch movies or TV, even though he or she must get up early for work or school. Others may acquire unhealthy food habits, such as the intake of too much junk food or soda. Some may get stuck on a particular issue such as a love interest, a favorite celebrity, or the loss of a close relative. Others may get stuck on certain behaviors, which are either part of a regular routine, such as housekeeping tasks, or activities outside one's normal routine, such as flushing toilets or turning lights on and off.

Additionally, the benefits of a groove, derived from sameness, order, and repetition, may become a serious disadvantage in the face of change. For example, gains to one's independence from following a set routine at a set time may be lost if the person is not able to adjust to inevitable changes that occur in daily life. For instance, some may have difficulty changing a morning routine to prepare for an earlier arrival of the bus to school or work. In the workplace people may have trouble adapting to changes in the schedule or in doing activities which are not part of their regular routine.

Apart from daily changes, grooves may also create serious problems for people when they are confronted with major life changes or events, such as transition from school, a move into a residential facility, or the loss of a parent or primary caregiver. These changes often interrupt the bedrock of established grooves and routines which people use to manage their daily lives. In response to these changes some will persist in following old routines or they may get stuck on a particular issue or behavior.

Serious problems may also result if caregivers misinterpret a person's need to complete routines or grooves as oppositional behavior. For example, many persons with Down syndrome try to finish a routine before starting a newly assigned task. Unfortunately, if the careprovider believes the motivation for delaying the new task is to resist authority, then an escalating conflict may ensue. Pressure by the careprovider may cause further entrenchment by the individual with Down syndrome.

A similar problem may occur if the rules in a residential facility interfere with the completion of grooves. For example, in an attempt to be fair, many group home policies specify that residents can only do a particular housekeeping task for one week. As you might expect, some would much prefer to do the same task for extended periods rather than to change every week. Predictably, conflicts occur when the staff tries to enforce this rule. We have encountered these types of problems most often in residential settings

with careproviders who have had little experience with persons with DS. We have also found similar problems in workshop settings. We believe this misinterpretation of the groove is one of the reasons people with DS have a reputation for being "stubborn".

RECOMMENDATIONS TO CAREGIVERS

When faced with a person seemingly stuck in a groove, we recommend that caregivers first identify and minimize any possible stressors or precipitants to the problem. In some cases, reducing stress may be sufficient to free up someone that is stuck. In other cases action by caregivers may still be necessary after stress is reduced.

When action is needed, caregivers should be careful with how they approach the person who is apparently stuck. Attempts to directly force the person having difficulty with a groove will usually worsen the problem. Caregivers who are most successful at helping in these circumstances, understand the need and benefits of grooves. Instead of a direct and forceful approach, they will slowly and gently help the person resolve the issue in a positive way. This approach will encourage new steps which will become the basis of a new, more productive groove.

Caregivers also need to be mindful that problems with grooves may masquerade as behavior problems. This may occur if a groove is misinterpreted as oppositional behavior. We have found that once caregivers understand and accept the fact that grooves can be helpful, problems are more easily resolved. The tension and hostility derived from misinterpretation of a groove and an ensuing power struggle will often be replaced by a more conciliatory and cooperative interaction between caregiver and the person with DS.

Parents and other careproviders who seek professional help for a person dealing with a stuck groove need to choose a professional who has experience in working with persons with DS. Professionals may be experts about certain things but parents have a lifetime of experience and are experts on their son or daughter. In our experience parents' instincts are usually accurate and they understand the grooves that their family member has developed. This is also true for other caregivers that have had a long relationship with the individual. Be sure that the professional listens carefully and looks at all areas of the person's life (health, significant changes in social, school or work environments or other stressors) for possible causes of the problem. Be sure that the professional does his or her homework before making a diagnosis.

Finally, there are a number of preventive measures which may reduce the chance of problems. One of the best ways to learn to deal flexibly with changes is to have persons with DS begin early in life to gain mastery over small day to day changes and challenges. The earlier and more consistently these opportunities are presented, the more likely people will be able to adapt to life changes when they occur. In this way, individuals develop a comfortable pattern or groove for dealing with change. Another important preventive measure is for parents and other caregivers to attend school or workplace staffings to ensure that others have a clear understanding of the nature and benefits of grooves.

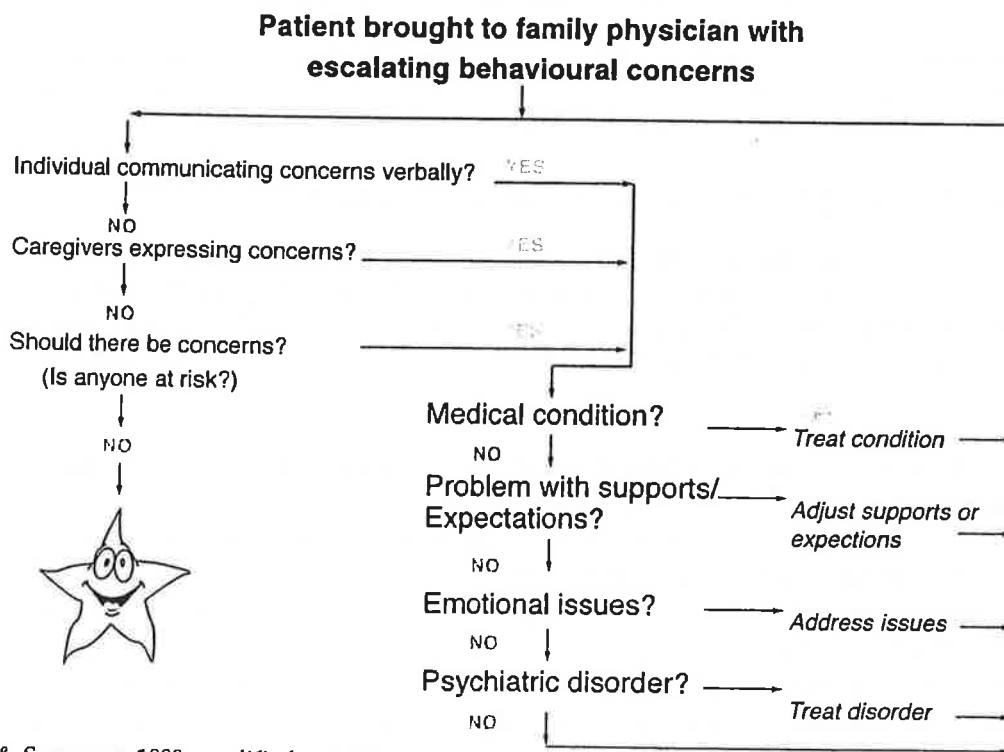
Initial Management of Behavioural Crises in Family Medicine

Consider the crisis behaviour as a **symptom** and not a **disorder**. Behaviour change is often the only way people with developmental disabilities (DD) can express that something is wrong and communicate a need. Very frequently, the "something wrong" is not a psychiatric problem. It may be a signal that the person has a physical health problem causing pain or discomfort or that his/her environment is not an "enabling environment" that meets his/her needs.

Assess and manage the behavioural crisis by working with the patient, caregivers and available interdisciplinary team supports.

- Use **Diagnostic Formulation of Behavioural Concerns** to clarify the cause of the behavioural crisis, and assess and manage sequentially any discernible contributing factors, such as medical issues, supports and expectations, emotional issues and psychiatric disorders (see Diagram 1 below).
- **Risk Assessment:** Assess risk to the patient and others.

Diagram 1: Diagnostic Formulation of Behavioural Concerns



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Note: People with DD are often in a fine balance between their health challenges (physical, emotional and psychiatric) and the available supports and expectations in their environment.

Changes in any of these considerations can upset the balance and precipitate behavioural crises, which signify that help is needed to re-establish or find a better balance. The person may go in and out of crises, until a comprehensive assessment is done, precipitating factors are identified, and a proactive treatment and management plan is initiated.

BEHAVIOURAL CRISIS MANAGEMENT PLAN: FIRST 24 - 72 HOURS

Immediate options to manage risk and escalating or concerning behaviours:

1. **Re-stabilize the situation in the short term**
Plan, with patient and caregivers, how to re-stabilize the situation and manage the behaviour. These strategies need to reflect the uniqueness of the patient with DD, his/her triggers and coping strategies, helpful environmental changes and modifications, and caregiver resources.
Consider:
 - What has been helpful or not for this patient with DD in the past.
 - De-escalation strategies:
 - Have patient go to a quiet, safe place (outside the home if indicated)
 - Use existing policies and plans (e.g., agency safety response plans)
 - Increasing environmental supports and/or decreasing environmental stressors:
 - Additional family/agency/staff supports
 - Change in expectations
 - What to do if symptoms worsen or caregivers are unable to manage, including the option of going to an Emergency Department (ED)
2. **Send to Emergency Department, if indicated:**
 - Complete form: *Essential Information for Emergency Department*
 - Information for caregivers: *Guidance about Emergencies for Caregivers*
3. **Use Medications, if indicated, e.g., PRNs.** Consider short-term medication options to stabilize the immediate situation and ensure safety, with a plan for review when the situation stabilizes. See *Rapid Tranquillization of Adults with Crisis Behaviours*.

BEHAVIOURAL MANAGEMENT PLAN: POST-BEHAVIOURAL CRISIS

Plan and manage the underlying problem(s) that *caused or contributed* to the behaviour concerns, in order to meet the needs and enhance the quality of life of the patient with DD, and to prevent recurrences of behavioural crises. See *A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities*.

Debriefing:

- Schedule an appointment to debrief. Involve the patient with DD, as appropriate, key caregivers, and interdisciplinary team professionals.
 - If a case manager or other needed interdisciplinary resources (e.g., a behaviour therapist) are not in place, access local/regional resources.
- Use/review *Antecedents-Behaviour-Consequences (ABC) Chart* to better understand triggers for behaviours of concern.
- Review crisis strategies, actions taken, and what was effective or ineffective.
- Make recommendations for management and prevention of future behavioural crises. With caregivers and available interdisciplinary resources, begin to develop a comprehensive and proactive *Crisis Prevention and Management Plan* to meet the patient with DD's needs and enhance his/her quality of life.
- For patients who visit the Emergency Department frequently for behavioural causes, it may be helpful to develop a dialogue with local Emergency Department staff.

Review medications: Include regular, PRN, over-the-counter medications, and any possible recreational drugs used. In particular, review any new medications prescribed during behavioural crises.

Risk Assessment Tool for Adults with DD in Behavioural Crisis

Utilize risk assessments applicable to the general population. Take into account how the patient's developmental disabilities (DD) affect both risks and protective factors. Note whether recent changes have occurred in any risk or protective factors.

Flag all areas where there are risk issues – also consider factors which may protect from harm

RISK AREA	PATIENT WITH DD – RISK FACTORS	CAREGIVERS / ENVIRONMENT (includes possible protective factors)
SUICIDE	Is the patient verbalizing suicidal thoughts or intent? Is there evidence of suicidal behaviours, poor judgment or mental illness? Is there a history of suicidal or para-suicidal behaviour? Is the patient not able to identify reasons to keep on living?	Is a means available for the person to commit suicide? Are caregivers unable to supervise and protect the person?
SELF HARM	Is the patient engaging in, or is there evidence of, self harm? Is the patient verbalizing intent to self harm? Does the patient have a history of self harm behaviour?	Are means available for the person to harm self? Are caregivers able to supervise and protect the person?
SELF NEGLECT	Is the patient unable to care for self? Is the patient unwilling to accept support from others? Is there evidence of neglect and behaviours that put the patient at risk?	Are others available and able to assist in the person's care?
VICTIMIZATION OR EXPLOITATION	Is the patient being victimized or exploited? Has the patient been victimized or exploited in the past? Is the patient unable to protect self? Does the patient lack insight into possible dangers of the situation? Has the patient failed to show evidence that he/she would ask for help? Has the patient been unable to get help or protection from others in the past?	Are caregivers able to supervise and protect the person?
RISK TO OTHERS	Is the patient verbalizing intent to harm others? Is the patient making physical gestures about hurting others? Has the patient caused physical harm to others? Does the patient have sufficient mobility and strength to potentially harm others? Does the patient's aggression/harmful behaviour tend to escalate quickly and/or unpredictably?	Are there vulnerable individuals in the setting who cannot protect themselves? Can caregivers recognize cues and intervene safely? Can the person be supervised safely in current setting without caregivers being at risk of harm while trying to prevent harm to others?
RISK TO ENVIRONMENT	Has the patient damaged or attempted to damage property in recent past? If yes, what was the nature and extent of damage? Does the patient have sufficient mobility and strength to be able to cause damage to his/her environment? Does the patient escalate rapidly and/or unpredictably?	Are there caregivers able to recognize the escalation, and intervene effectively? Do caregivers feel comfortable about being able to predict and prevent it?

Developed by: *Elspeth Bradley, Psychiatrist, Surrey Place Centre and Yona Lunskey, Psychologist, Centre for Addiction and Mental Health*

Reference

Stein W. Modified Sainsbury tool: An initial risk assessment tool for primary care mental health and learning disability services. *J Psychiatr Ment Health Nurs* 2005 Oct;12(5):620-33.

A Guide to Understanding Behavioural Problems and Emotional Concerns

in Adults with Developmental Disabilities (DD) for Primary Care Providers and Caregivers

Name: _____ Gender: _____
(last, first)
Address: _____
Tel. No: _____
DOB (dd/mm/yyyy): _____
Health Card Number: _____

This guide is intended for use by primary care providers and, where available, an interdisciplinary team (Part A), with input from patient's caregivers or support persons (Part B). It aims to help identify the causes of behavioural problems, in order to plan for treatment and management, and prevent reoccurrence.

PART A: PRIMARY CARE PROVIDER SECTION

Date (dd/mm/yyyy): _____ Presenting Behavioural Concerns: _____

Etiology of developmental disability, if known:

Additional disabilities:

- ☐ Autism spectrum disorder ☐ Hearing impairment ☐ Visual impairment ☐ Physical disability
☐ Other disability (specify): _____ ☐ Previous trauma ☐ Physical ☐ Emotional

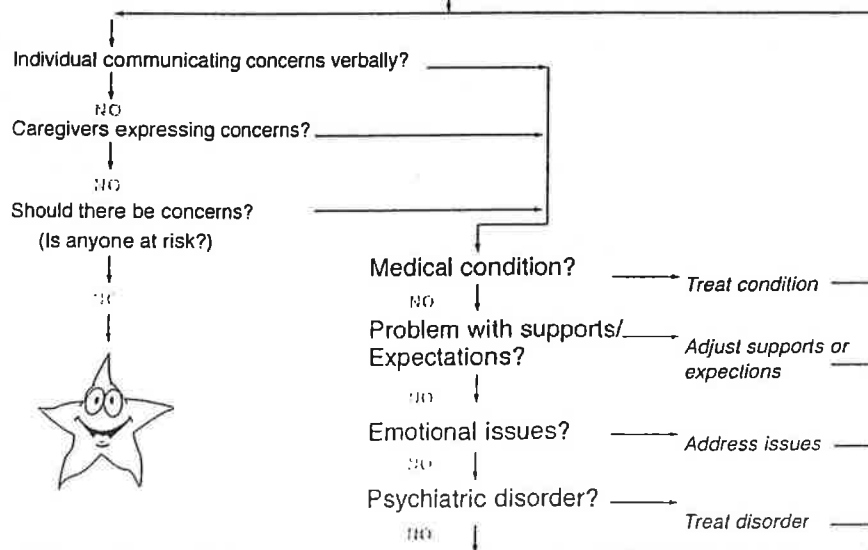
Family history of: ☐ Medical disorders (specify)
☐ Psychiatric disorders (specify)

What is the patient's most recent level of functioning on formal assessment? Year done: _____

- ☐ BORDERLINE ☐ MILD ☐ MODERATE ☐ SEVERE ☐ PROFOUND ☐ UNKNOWN

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS

Patient brought to family physician with escalating behavioural concerns



PART A: PRIMARY CARE PROVIDER SECTION

Name: _____

DOB: _____

1. REVIEW OF POSSIBLE MEDICAL CONDITIONS [See also Preventive Care Checklist]

Many medical conditions present atypically in people with developmental disabilities. In some cases the only indicator of a medical problem may be a change in behaviour or daily functioning. Consider a complete review of systems, a physical exam, and necessary investigations until the cause of the behaviour change is identified.

Would you know if this patient was in pain? ☐ No ☐ Yes: If yes, how does this patient communicate pain?

☐ Expresses verbally ☐ Points to place on body ☐ Expresses through non-specific behaviour disturbance (describe):

☐ Other (specify): _____

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behaviour change?

☐ No ☐ Yes ☐ Possibly: _____

Assess/Rule out: _____

- | | |
|--|---|
| <input type="checkbox"/> Medical condition giving rise to physical discomfort (e.g., rash or itch) | <input type="checkbox"/> Dysmenorrhea/Premenstrual syndrome |
| <input type="checkbox"/> Medication side effect | <input type="checkbox"/> Peri-menopausal/menopausal (may start earlier) |
| <input type="checkbox"/> Change in medication | <input type="checkbox"/> Musculoskeletal (arthritis, joints) |
| <input type="checkbox"/> Allergies | <input type="checkbox"/> Osteoporosis |
| <input type="checkbox"/> Vision problem (e.g., cataracts) | <input type="checkbox"/> Degenerative disc disease (DDD) |
| <input type="checkbox"/> Hearing problem | <input type="checkbox"/> Spasticity |
| <input type="checkbox"/> Dental problem | <input type="checkbox"/> Neurological (e.g., seizures, dementia) |
| <input type="checkbox"/> Cardiovascular | <input type="checkbox"/> Dermatological |
| <input type="checkbox"/> Respiratory | <input type="checkbox"/> Sensory discomfort (e.g., new clothes, shoes) |
| <input type="checkbox"/> Pneumonia | <input type="checkbox"/> Hypothyroidism |
| <input type="checkbox"/> GERD/Peptic ulcer disease/H.pylori infection | <input type="checkbox"/> Diabetes (I or II) |
| <input type="checkbox"/> Constipation, or other lower GI problems | <input type="checkbox"/> Sleep problems/sleep apnea |
| <input type="checkbox"/> UTI | |
| <input type="checkbox"/> Other: _____ | |

Comments: _____

2. PROBLEMS WITH ENVIRONMENTAL SUPPORTS OR EXPECTATIONS

Review Caregiver Information Identify possible problems with supports or expectations

- ☐ **Stress or change in the patient's environment?** (e.g., living situation, day program, family situation)
- ☐ **Insufficient behavioural supports?**
- ☐ **Patient's disabilities not adequately assessed or supported?**
(e.g., sensory and communication supports for patients with autism)
- ☐ **Insufficient staff resources?**
(e.g., to implement treatment, recreational, vocational or leisure programs)
- ☐ **Inconsistencies in supports and staff approaches?**
- ☐ **Insufficient training/education of direct care staff?**
- ☐ **Signs of possible caregiver burnout?** (e.g., negative attitudes towards person, impersonal care, difficult to engage with staff, no or poor follow through in treatment recommendations)

Do caregivers seem to have inappropriate expectations associated with:

Recognizing or adjusting to identified patient needs ☐ Yes ☐ No ☐ Unsure

Over- or under-estimating patient's abilities (boredom or under-stimulation) ☐ Yes ☐ No ☐ Unsure

Comments: _____

**PART A: PRIMARY CARE
PROVIDER SECTION**

Name: _____

DOB: _____

3. REVIEW OF EMOTIONAL ISSUES

Review Caregiver Information Identify possible emotional issues

Summary and comments re emotional issues (e.g., related to change, stress, loss):

4. REVIEW OF POSSIBLE PSYCHIATRIC DISORDERS

History of diagnosed psychiatric disorder: ☐ No ☐ Yes – Diagnosis: _____

History of admission(s) to psychiatric facility: ☐ No ☐ Yes (specify): _____

(See Appendix: Psychiatric Symptoms and Behaviours Screen)

Summary and comments re symptoms and behaviours indicating possible psychiatric disorder:

SUMMARY OF FACTORS THAT MAY CONTRIBUTE TO BEHAVIOURAL ISSUES

PART A: PRIMARY CARE PROVIDER SECTION

Name:

DOB:

MANAGEMENT PLAN: Use the “Diagnostic Formulation of Behavioural Concerns” to assess and treat causative and contributing factors

- 1. Physical exam, medical investigations indicated**
- 2. Risk assessment**
- 3. Medication review**
- 4. Referrals for functional assessments and specialized medical assessments as indicated**
 - e.g., to psychologist, speech and language pathologist, occupational therapist for assessments and recommendations re adaptive functioning, communication, sensory needs or sensory diet
 - e.g., genetic assessment/reassessment, psychiatric consult
- 5. Assessment and treatment and referral as indicated for**
 - Supports and expectations
 - Emotional issues
 - Psychiatric disorder
- 6. Review behavioural strategies currently being used, revise as needed**
 - De-escalation strategies
 - Use of a quiet, safe place
 - Safety response plan
 - Supports
 - Use of “as needed” (PRN) medications
- 7. Identify and access local and regional interdisciplinary resources for care of patient**
 - Case management resources
 - Behaviour therapist
 - Other
- 8. Focus on behaviours**
 - Identify target symptoms and behaviours to monitor
 - Institute use of Antecedent-Behaviour-Consequence (ABC) Chart
- 9. Develop a proactive and written Crisis Prevention and Management Plan with caregivers and an interdisciplinary team**
 - Applicable for all environments in which the behaviour could occur, e.g., home, day program or community
 - Caregivers to monitor for triggers of behaviour problems and use early intervention and de-escalation strategies
 - Periodic team collaboration to review issues, plan and revise, as needed
 - If hospital and/or Emergency Department (ED) involved, consider including ED staff in developing the Crisis Prevention and Management Plan
- 10. Regular and periodic medication review**
 - Use Auditing Psychotropic Medication Therapy tool for review of psychotropic medications

PART B: CAREGIVER SECTION

(Caregiver to fill out or provide information)

Name: _____

DOB: _____

What type of Developmental Disability does the patient have (i.e., what caused it?)

(e.g., Down syndrome, fragile X syndrome) _____ ☐ Unsure/don't know

What is the patient's level of functioning?

☐ BORDERLINE ☐ MILD ☐ MODERATE ☐ SEVERE ☐ PROFOUND ☐ UNKNOWN

BEHAVIOURAL PROBLEM

When did the behavioural problem start?

(dd/mm/yyyy) _____

When was patient last "at his/her best"? (i.e., before these behaviour problems)

(dd/mm/yyyy) _____

Description of current difficult behaviour(s):

Has this sort of behaviour happened before?

What, in the past, helped or did not help to manage the behaviour?
(include medications or trials of medications to manage behaviour[s])

What is being done now to try to help the patient and manage his/her behaviours? How is it working?

Risk?	<input type="checkbox"/> To self	<input type="checkbox"/> Aggression to others	Severity of Damage or Injury	Frequency of Distressing (Challenging) Behaviour
	<input type="checkbox"/> To others		<input type="checkbox"/> mild (no damage)	<input type="checkbox"/> more than once daily
	<input type="checkbox"/> To environment	<input type="checkbox"/> Self-injurious behaviour	<input type="checkbox"/> moderate (some)	<input type="checkbox"/> daily
			<input type="checkbox"/> severe (extensive)	<input type="checkbox"/> weekly
				<input type="checkbox"/> monthly

Please check (✓) if there has been any recent deterioration or change in:

- | | |
|---|---|
| <input type="checkbox"/> mood | <input type="checkbox"/> seizure frequency |
| <input type="checkbox"/> bowel/bladder continence | <input type="checkbox"/> self care (e.g., eating, toileting, dressing, hygiene) |
| <input type="checkbox"/> appetite | <input type="checkbox"/> independence |
| <input type="checkbox"/> sleep | <input type="checkbox"/> initiative |
| <input type="checkbox"/> social involvement | <input type="checkbox"/> cognition (e.g., thinking, memory) |
| <input type="checkbox"/> communication | <input type="checkbox"/> movement (standing, walking, coordination) |
| <input type="checkbox"/> interest (in leisure activities or work) | <input type="checkbox"/> need for change in supervision and/or placement |

When did this change/deterioration start?

Caregiver comments:

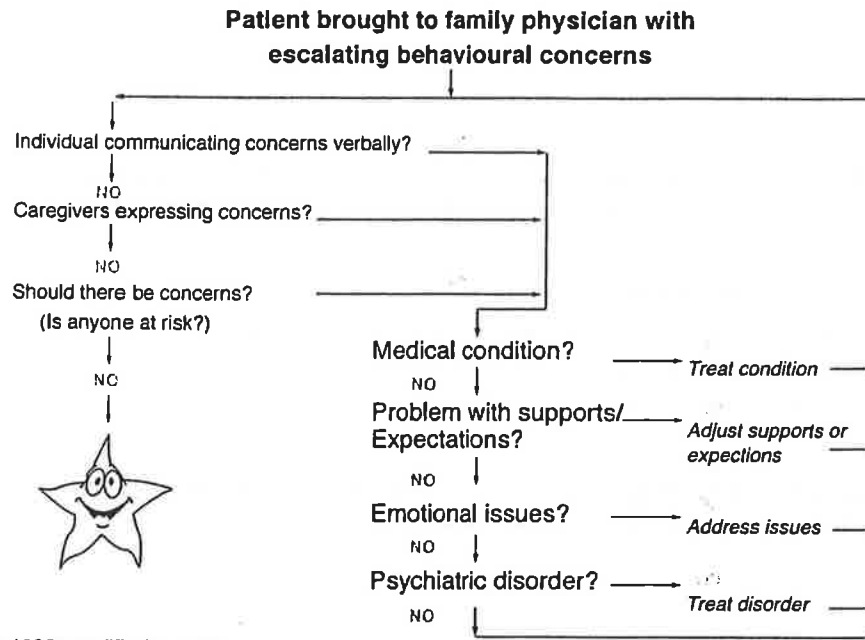
PART B: CAREGIVER SECTION

(Caregiver to fill out or provide information)

Name:

DOB:

DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS



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1. POSSIBLE PHYSICAL HEALTH PROBLEMS OR PAIN

Are you or other caregivers aware of any **physical health or medical problems** that might be contributing to the patient's behaviour problems? ☐ No ☐ Yes: If yes, please specify or describe:

Could pain, injury or discomfort be contributing to the behaviour change? ☐ No ☐ Yes ☐ Possibly

Specify: _____

Would you know if this patient was in pain? ☐ No ☐ Yes: How does this patient communicate pain?

☐ Expresses verbally

☐ Points to place on body

☐ Expresses through non-specific behaviour disturbance (describe): _____

☐ Other (specify): _____

Are there any concerns about medications or possible medication side effects?

2.1: CHANGES IN ENVIRONMENT before problem behaviour(s) began

Have there been any recent changes or stressful circumstances in:

☐ **Caregivers?** (family members, paid staff, volunteers)

☐ **Care provision?** (e.g., new program or delivered differently, fewer staff to support)

☐ **Living environment?** (e.g., co-residents)

☐ **School or day program?**

PART B: CAREGIVER SECTION

Name:

DOB:

2.2: SUPPORT ISSUES

Are there any problems in this patient's support system that may contribute to his/her basic needs not being met?

Does this patient have a ☐ hearing or ☐ vision problem? ☐ No ☐ Yes: If yes, what is in place to help him/her?

Does this patient have a **communication problem**? ☐ No ☐ Yes: If yes, what is in place to help him/her?

Does this patient have a problem with **sensory triggers**? ☐ No ☐ Yes: If yes, what is in place to help him/her?

If yes, do you think this patient's environment is ☐ over-stimulating? ☐ under-stimulating? or ☐ just right for this patient?

Does environment seem **too physically demanding** for this patient? ☐ No ☐ Yes

Does this patient have enough opportunities for **appropriate physical activities**? ☐ No ☐ Yes

Does this patient have **mobility problems** or **physical restrictions**? ☐ No ☐ Yes: If yes, what is in place to help him/her? If yes, does he/she receive physiotherapy?

Are there **any supports or programs** that might help this patient and which are not presently in place?

☐ No ☐ Yes: If yes, please describe:

Caregiver comments:

3: EMOTIONAL ISSUES Please check (✓) if any of these factors may be affecting this patient:

Any recent change in relationships with significant others
(e.g., staff, family, friends, romantic partner)

- ☐ **Additions** (e.g., new roommate, birth of sibling)
- ☐ **Losses** (e.g., staff change, housemate change)
- ☐ **Separations** (e.g., decreased visits by volunteers, sibling moved out)
- ☐ **Deaths** (e.g., parent, housemate, caregiver)

Issues of assault or abuse

	Past	Ongoing	Date(s)
<input type="checkbox"/> Physical	<input type="checkbox"/>	<input type="checkbox"/>	_____
<input type="checkbox"/> Sexual	<input type="checkbox"/>	<input type="checkbox"/>	_____
<input type="checkbox"/> Emotional	<input type="checkbox"/>	<input type="checkbox"/>	_____
<input type="checkbox"/> Exploitation	<input type="checkbox"/>	<input type="checkbox"/>	_____

Comments:

- ☐ **Teasing or bullying**
- ☐ **Anxiety about completing tasks**
- ☐ **Issues regarding sexuality and relationships**
- ☐ **Disappointment(s)**
(e.g., being surpassed by siblings; not being able to meet goals, such as driving or having a romantic relationship)
- ☐ **Growing insight into disabilities and impact on own life**
(e.g., that he/she will never have children, sibling has boyfriend/girlfriend)
- ☐ **Life transitions** (e.g., moving out of family home, leaving school, puberty)
- ☐ **Other triggers** (e.g., anniversaries, holidays, environmental, associated with past trauma)
- ☐ **Being left out of an activity or group**
- ☐ **Stress or upsetting event, at school or work**
- ☐ **Inability to verbalize feelings**

Specify:

Caregiver Comments:

PART B: CAREGIVER SECTION

Name: _____

DOB: _____

Has this patient ever been diagnosed with a psychiatric disorder?

☐ No ☐ Unsure

☐ Yes: _____

Has this patient ever been hospitalized for a psychiatric reason?

☐ No ☐ Unsure

☐ Yes: _____

CAREGIVER CONCERNS AND INFORMATION NEEDS

Do you, and other caregivers, have the information you need to help this patient, in terms of:

- The type of developmental disability the patient has and possible causes of it? ☐ Yes ☐ No ☐ Unsure
- What the patient's abilities, support needs, and potential are? ☐ Yes ☐ No ☐ Unsure
- Possible physical health problems with this kind of disability? ☐ Yes ☐ No ☐ Unsure
- Possible mental health problems and support needs with this kind of disability (e.g., anxiety more common with fragile X syndrome)? ☐ Yes ☐ No ☐ Unsure
- How to help if the patient has behaviour problems/emotional issues? ☐ Yes ☐ No ☐ Unsure
- Recent changes or deterioration in the patient's abilities? ☐ Yes ☐ No ☐ Unsure

Are there any issues of **caregiver stress** or potential burnout?

☐ Yes ☐ No ☐ Unsure

Caregiver comments:

Caregiver's additional general comments or concerns:

Thank you for the information you have provided. It will be helpful in understanding this patient better and planning and providing health care for him or her.

Crisis Prevention and Management Plan

for Adults with Developmental Disabilities (DD) at Risk of or During a Behavioural Crisis

Consider escalating behaviour problems as symptoms and not as disorders in themselves. Escalating behaviour problems that build to a crisis may be the best or only way that a person with DD can communicate his/her needs and that something is bothering him/her.

Understanding what is underlying the behaviour problems is the key to preventing and managing these problems.

When a person with DD has already experienced a behavioural crisis and there is a risk of recurrence, **debrief and develop a Crisis Prevention and Management Plan.**

1. *Debrief* after the behavioural crisis with the person with DD, caregivers, and team. Identify what may have contributed to or caused the crisis, and which interventions used were effective or ineffective.

Make recommendations regarding preventing and managing possible future crises.

- **Identify and treat the underlying conditions** that caused or contributed to the crisis behaviours.
- **Review medications**, particularly psychotropics, and any medication changes made in the Emergency Department (ED).

2. *Develop the Crisis Prevention and Management Plan*

- A **case manager or behaviour therapist** is often the most appropriate person to coordinate the care planning meeting and to take the lead in developing the *Crisis Prevention and Management Plan*. If there is no case manager in place:
 - Contact the local office of the Ministry of Community and Social Services (MCSS).
 - For patients with Dual Diagnoses (i.e., developmental disabilities and a possible or diagnosed mental health problem), contact the regional Community Network of Specialized Care (CNSC) to request a case manager.
- Meet as a team with the patient with DD, appropriate caregivers, and interdisciplinary team (e.g., residential caregivers, psychiatrist, nurse, behaviour therapist, service coordinator). If indicated, include Emergency Services (ED, police, ambulance services).
- Inclusion of the person with DD and caregivers in development of the plan will help to promote consistency in responses to escalating behaviour problems, and will provide a shared way to document stages of escalation for treatment and evaluation.
- In the **first column** (page 80), identify what the patient's behaviour looks like at each stage. Identify signs of escalation to Stage B (Escalation Stage) and Stage C (Crisis Stage). Early identification of signs of anxiety or agitation provides opportunities for prompt interventions to keep the patient and others in the environment safe and, if possible, to prevent the situation from reaching a crisis.
- In the **second column** (page 80), identify usually successful de-escalation or intervention strategies that caregivers can use for the given stage. Include when to use them, for how long, how often, and where to record them.
 - Clearly identify when to administer "as needed" (PRN) medication.
 - Clearly identify the circumstances under which the patient should be taken to the ED.
- Identify the care provider most responsible for regularly reviewing and updating the *Crisis Prevention and Management Plan*.
- Develop a schedule with the patient and caregivers from all environments for a regular, patient-centred review of the individual and his/her needs, the behaviour problems, the escalation continuum, and corresponding interventions.

Crisis Prevention and Management Plan

Overview – Escalation Stages and Recommended Interventions for Agitated or Aggressive Patients with Developmental Disabilities ¹

Stage	Intervention
A: Prevention: Anxiety or Agitation	Ensure safety of patient and staff. Strengthen environmental supports, decrease stressors.
B: Escalation: Defensive/Verbal Threats	Be Directive - Verbal de-escalation and modelling As above, modify environment to meet patient's needs and ensure safety for everyone.
C: Crisis: Acting Out/Overt Aggression	Crisis Intervention and Safety Strategies: <ul style="list-style-type: none">• Continue attempts at verbal de-escalation.• Use physical interventions.• Get PRN medication if ordered and indicated.• Consider calling for help or calling 9-1-1.
R: Post-Crisis Calming: Crisis Resolution	Support patient's return to normal behaviour and activities. Document, and debrief with patient, caregivers, team.

Management of crises and abnormal behaviour may be different for patients with DD than for patients in the general population.

- Patients with DD may behave atypically or unpredictably. For example, attempts to de-escalate the situation verbally may worsen the patient's agitation.
- Approaches to interviewing adapted to patients with DD generally help to engage them and avoid further escalation. (See *Communicating Effectively with People with Developmental Disabilities*.)
- At each stage of your interaction with the patient with DD, make use of the caregivers' knowledge and experience of this individual. Caregivers often have a protocol and recommendations for managing out-of-control behaviour, and protocols may be uniquely tailored to specific individuals. Ask about these and apply them if this can be done safely.

Overview of Behaviours and Recommended Responses → P.79

Template: Crisis Prevention and Management Plan → P.80

Example of completed Crisis Prevention and Management Plan → P.81

See also:

- *Initial Management of Behavioural Crises in Family Medicine*
- *A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities*
- *Communicating Effectively with People with Developmental Disabilities (DD)*

¹Bradley E, Lofchy J. Learning disability in the accident and emergency department. *Advances in Psychiatric Treatment* 2005, 11:45-57.

Crisis Prevention and Management Plan ²

Overview of Behaviour Stages and Recommended Responses

Stage of Patient Behaviour	Recommended Caregiver Responses
Normal, calm behaviour	<p>Use positive approaches, encourage usual routines</p> <ul style="list-style-type: none"> • Structure, routines • Programs, conversation, activities, antecedent interventions, reinforcement
<p>Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.)</p> <p>Anxiety may be shown in energy changes, verbal or conversational changes, fidgeting, sudden changes in affect, attempting to draw people into a power struggle.</p>	<p>Be supportive, modify environment to meet needs</p> <ul style="list-style-type: none"> • Encourage talking, be empathetic, use a non-judgemental approach, be supportive, increase positive feedback, offer choices. • Use calming object or usual calming approach (e.g., deep breathing) • Use distraction and environmental accommodation (e.g., noise stimuli, personal space).
<p>Stage B: Escalation (Identify signs the patient with DD is escalating into possible behavioural crisis.)</p> <p>Increasing resistance to requests, refusal, questioning, challenging, change in tone and volume of voice, sense of loss of control, increasing physical activity, loud self talk, swearing to self.</p>	<p>Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety</p> <ul style="list-style-type: none"> • Use verbal intervention techniques, set limits, remember distance. Use visual aids if helpful. • Reassure, discuss past successes, show understanding. • Describe what you see, not your interpretation of it. • If the patient with DD is able to communicate verbally, identify his/her major feeling state (angry, frustrated, anxious), provide answers to questions, generate discussion, state facts, ask short clear questions. • For a non-verbal patient with DD, adjust responses to him/her.
<p>Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)</p> <p>Verbal threats of aggression, or aggression:</p> <ul style="list-style-type: none"> • Swearing at people • Explosive, threatening • Using threatening gestures to others or self <p>Physical aggression to self or others:</p> <ul style="list-style-type: none"> • Hurting self • Kicking, hitting, scratching, choking • Using objects to hurt self or others 	<p>Use safety strategies</p> <ul style="list-style-type: none"> • Ensure your own safety, safety of others, and safety of individual. • Use personal space and supportive stance. • Remove potentially harmful objects. • Use clear, short, calm and slow statements. • Remind the patient with DD of pre-established boundaries; remind him/her about the consequences of his/her behaviour but do not threaten him/her. • Get assistance to keep safe. <p>Use crisis response strategies</p> <p>Everyone should agree on a plan for what happens at the time of a crisis and the follow-up. For example:</p> <ul style="list-style-type: none"> • Phone 9-1-1 • In Toronto: call the Mobile Crisis Unit 416-289-2434 • Have caregiver accompany distressed patient to Emergency <p>Take the patient to ED with the following:</p> <ul style="list-style-type: none"> • List of medications from pharmacy • Essential information for Emergency Department • Crisis Prevention and Management Plan
<p>Stage R: Post-crisis resolution and calming</p> <ul style="list-style-type: none"> • Stress and tension decrease • Decrease in physical and emotional energy • Regains control of behaviour 	<p>Re-establish routines and re-establish rapport</p> <ul style="list-style-type: none"> • Attempt to re-establish communication and return to "calm" and normal routines.

² Based on Nonviolent Crisis Intervention Training (NVCIT) from Crisis Prevention Institute – www.crisisprevention.com

• Staff working in agencies serving persons with Developmental Disabilities must be trained, and re-certified annually in NVCIT

• Input provided by Carol Drummond, Behaviour Therapist, Surrey Place Centre

Crisis Prevention and Management Plan ³

for Adults with Developmental Disabilities (DD) at Risk of or During Behavioural Crises

A Crisis Prevention and Management Plan for an adult patient with DD addresses serious behaviour problems and helps prevent, or prepare for, a crisis. It describes how to recognize the patient with DD's pattern of escalating behaviours. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioural crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behaviour escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient with DD should go to the Emergency Department (ED).

Crisis Plan for: _____ DOB: _____ Date _____

Problem behaviour: _____

Stage of Patient Behaviour	Recommended Caregiver Responses
Normal, calm behaviour	Use positive approaches, encourage usual routines
Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.)	Be supportive, modify environment to meet needs (Identify de-escalation strategies that are helpful for this patient with DD).
Stage B: Escalation (Identify signs of the patient with DD escalating to a possible behavioural crisis.)	Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety
Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)	Use safety and crisis response strategies
Stage R: Post-crisis resolution and calming	Re-establish routines and re-establish rapport

Individual responsible for coordinating debriefing after any significant crisis, and for regularly updating the Crisis Plan:

Name: _____ Tel. #: _____
Name, Designation, Agency

³ See next page for example of completed Crisis Prevention and Management Plan

Example of Completed Crisis Plan

A Crisis Prevention and Management Plan for an adult patient with DD addresses serious problem behaviours and helps prevent, or prepare for, a crisis. It describes how to recognize the patient with DD's pattern of escalating behaviours. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioural crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behaviour escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient with DD should go to the Emergency Department (ED).

Crisis Plan for: Jack Doe

DOB: February 20, 1952

Date: May 13, 2010

Problem behaviour: Verbal threats, swearing, physical aggression

Stage of Patient Behaviour

Normal, calm behaviour

Talks well about work, people, follows routine, enjoys others, laughs, good rapport with peers. Prefers quiet, dislikes loud noises from radio, TV.

Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.)

- Complaining about work or co-worker or anyone he has had contact with on arrival at the group home.
- Says that they shouldn't be able to do that or they didn't follow the rules.

Stage B: Escalation (Identify signs the patient with DD is escalating to possible behavioural crisis.)

- Swearing about people or situations in a loud voice and pacing (walking back and forth from one end of the living room or hallway to the other without stopping).

***PRN: Administer the PRN if Jack swears and paces for five continuous minutes (Stage B) or refuses to calm down and breathe slowly with staff member (Stage C) after two requests.**

Stage C: Crisis (Risk of harm to self, others, or environment, or seriously disruptive behaviour, e.g., acting out.)

- Throwing objects at the walls or floors.
- Jack's pacing becomes quicker and he begins to dart toward things, grabs them and throws them.
- Threatening bodily harm and hitting/ kicking others and saying demeaning words or swearing (e.g., "Get out of my way you _____ or I'll hit you.")

Stage R: Post-crisis resolution, calming

Jack will go to his own room and talk quietly. He will ask politely if he can talk about what happened when he is calm.

Recommended Caregiver Responses

Use positive approaches, encourage usual routines

Positive instructions (when you do... then you can...); joke with Jack; clear directions; reinforcement for pleasant conversation about work, others; following routine; being proud of himself.

Be supportive, modify environment to meet needs

1. Take Jack to quiet room. Talk with him about what is wrong. (What happened? How does he feel? Illness?)
2. Ask him to develop a solution – what will make it better? (with your help if necessary).
3. Have him write down the problem and solution for later reference when he thinks about it again. Continue to redirect verbally with positive words.
4. Reinforce any calm behaviours.

Go to next stage if behaviour escalates.

Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety

1. Ask Jack to sit, sit with him (remember distance).
2. Ask to help him discuss or read the solution he wrote earlier.
3. Ask if there is another problem. Resolve.
4. Have him engage in relaxation techniques, e.g., breathing slowly with you. If he refuses to comply, follow direction or escalates, go to next stage.

Use safety and crisis response strategies

1. Keep critical distance. Put something between you and Jack; ensure you have an exit.
2. Say "Stop, Jack, time to calm down, breathe with me" (model breathing). If no reduction/refusal, say, "Jack, stop, I'm calling people to help."
3. Remove or tell others to leave the area.
4. Leave the area – call 9-1-1.
5. Have patient taken to ED by ambulance, with Essential Information for ED, Crisis Prevention and Management Plan, list of medications being taken, and accompanied by a staff member.

Re-establish routines and re-establish rapport

When Jack has calmed, talk with him for a few minutes and have him re-engage in his routine as soon as possible. Reinforce Jack's calm activity.

Individual responsible for coordinating debriefing after any significant crisis, and for regularly updating the Crisis Plan:

Name: Michael Smith, Behaviour Therapist, Smalltown Regional Services

Tel. #: 705 123 4567

Name, Designation, Agency

* In this example a PRN medication had been prescribed. Team and patient agreed on the circumstances and stage of escalation when it should be given. A line was drawn across this chart to make clear to everyone at what stage of escalation to give the PRN.

Essential Information for Emergency Department (ED)

Name: _____ Gender: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

CLIENT INFORMATION

Prefers to be called: _____

Lives with: ☐ Family ☐ Group home ☐ Foster home
☐ Independent ☐ Other

EMERGENCY CONTACT INFORMATION:

Name: _____

Relationship: _____

Tel #: Home: _____

Work or cell: _____

Substitute Decision Maker ☐ Yes ☐ No

HEALTH AND SOCIAL AGENCY CARE PROVIDERS:

Family Physician: _____

Tel. #: _____

Psychiatrist: _____

Tel. #: _____

Case Manager: _____

Agency: _____

Name: _____

Tel. #: _____

Preferred hospital / treatment centre: _____

Other agencies involved, contact person's name _____

Tel. #: _____

REASON FOR REFERRAL TO ED: Safety risks to self, others or environment? ☐ No ☐ Yes (specify): _____

BRIEF OVERVIEW OF HEALTH STATUS: Include diagnoses, allergies, etiology of developmental disability (DD) & level of functioning, health issues and risks – physical and behavioural or mental health

Special needs: _____

NB: ATTACH LIST OF CURRENT MEDICATIONS

☐ attached

Copy of Medication Administration Record (MAR) or List from Pharmacy, and send or bring medications

Signature: _____ Date: _____
Print Name, Designation dd/mm/yyyy

Best contact #: _____

Guidance About Emergencies for Caregivers

ATTEND TO SAFETY ISSUES

How can the person in crisis, staff, other residents and the environment be kept safe?

- Use existing successful strategies to manage escalating behaviours
- Can the person with developmental disabilities (DD) be safely contained in a quiet, safe place?
- What changes can be made in his/her environment to make him/her, other people, and the environment safe?
- Is there "as needed" or PRN medication that generally helps the person, and that can safely be given?
- Physical restraint is against policy, and not a legal option in group homes
- Person with DD and caregiver preferences in decision-making process
- Attend to uniqueness of the person with DD

KEEP IN MIND

POINT OUT

- Any possible medical symptoms that family/staff may have noticed, for Emergency Medical Services (EMS) and Emergency Department (ED) staff
- How the person typically communicates pain and distress

IF SENDING THE PERSON WITH DD TO EMERGENCY DEPARTMENT OR CALLING 911:

- Complete and send Essential Information for Emergency Department (ED)
- Attach list of all **current medications** from Medication Administration Record (MAR) or pharmacy list and bring medications
- If **PRN medication** is already part of the behavioural management, consider whether an **additional PRN** would assist the person with DD prior to going to the ED
- Consider bringing photos or video showing how this person acts when calm and not calm

WHEN CONTACTING 911

- Explain that the person has a developmental disability
- Alert EMS staff to any special needs, for example:
 - Best way to communicate
 - Importance of caregiver presence to help the person feel safe and comfortable
 - Sensitivity to sensory issues (e.g., noise, lights, textures, personal space)
 - Sensitivity to restraints
 - Reaction of the person with DD to uniformed police, and other people in uniforms or strangers

PATIENT COMFORT PACKAGE FOR ED/HOSPITAL VISITS

Encourage patient/caregivers to bring:

- Comforters (e.g., security blanket, stuffed animal, favourite book, photos)
- Favourite food/drink and snacks (the wait can be long and food may be limited)
- Communication strategies that work (communication aids)
- Someone who knows the person well and knows how hospitals work
- Ways (e.g., photos - video/digital) to illustrate what the person with DD is usually like
- Explanation about how hospitals work (social story appropriate for the person's developmental level)

Bring all medications for the next 12 hours as ED will not dispense regular medications.

Psychotropic Medication Issues in Adults with Developmental Disabilities (DD)

Overview

Primary care of adults with developmental disabilities: Canadian consensus guidelines (2001) addresses several issues related to psychotropic medication use in this population.

- **Guideline 22** points out that antipsychotic drugs should no longer be regarded as an acceptable routine treatment for problem behaviours.
- **Guideline 26** stipulates that interventions other than medications are usually effective for preventing or alleviating problem behaviours.
- **Guideline 27** notes that psychotropic medications may be problematic for adults with DD and therefore should be used judiciously. Patients may be on multiple medications and thus be at increased risk of adverse medication interactions. Some adults with DD may have atypical responses or side effects at lower doses. Some cannot describe harmful or distressing side effects of the medications they are taking. This Guideline advocates a “start low, go slow” approach in initiating, increasing or decreasing psychotropic medications, and review every three months.
- **Guideline 28** clarifies that antipsychotic medications should not be prescribed as routine treatments of problem behaviours in adults with DD without a robust diagnosis of a psychotic illness.
- **Guideline 29** addresses behavioural crises and identifies circumstances in which psychotropic medications may be used temporarily to ensure safety. Debriefing with caregivers and review of crisis events and response (including medications) after the crisis is recommended to minimize the likelihood of their recurrence.

1. Recommendations for use of medications for behaviour problems outside of a behavioural crisis, for adults with DD (Deb 2009, Banks 2008):

- The goal is not to treat the behaviour per se but to identify the underlying cause of the behaviour disturbance and treat that.
- Identifying the underlying cause often requires an interdisciplinary team approach.
- Where the cause of the behaviour remains elusive, despite thorough investigation for medical conditions, environmental contributors to the behaviours of concern, emotional issues or psychiatric disorders, consideration may be given to a trial of medication appropriate to the patient’s symptoms.
- Medication trials should be targeted against specific symptoms (e.g., irritable mood) or behaviours (e.g., incidents of self injury), time limited, and monitored carefully for effectiveness and side effects.

Rapid Tranquillization of Adults with Crisis Behaviours

This tool was developed to help primary care providers in community and Emergency Department settings whose patients with DD are exhibiting crisis behaviours and require rapid tranquillization.

TABLE 1: GOALS AND CONSIDERATIONS IN RAPID TRANQUILLIZATION OF ADULTS WITH DD

Goals	<ul style="list-style-type: none"> • Similar for all people exhibiting crisis behaviours, including those with DD. • Reduce agitation and associated risk of harm to the patient, and where applicable, to others, in the safest and least intrusive manner possible.
Specific Considerations regarding Psychotropic Medications for Adults with DD	<ul style="list-style-type: none"> • Should guide management decisions, including in crisis situations. • Often on multiple medications and at increased risk of adverse medication interactions. • Some may have atypical responses or side-effects at lower doses, and some cannot describe harmful or distressing effects of the medications that they are taking ¹. • Adults with DD associated with Autism Spectrum Disorders (ASD), about 30% of adults with DD, may react paradoxically to new psychotropic medications (e.g., when given a benzodiazepine, they may become agitated rather than sedated). • When considering psychotropic medications for adults with DD it is important to elicit their history with such medications and the patient's or caregivers preferences.
Initial treatment	<ul style="list-style-type: none"> • Use a single medication initially, preferably a benzodiazepine at a sufficient dose (e.g., lorazepam 4 mg), and wait the indicated time prior to repeating the dose. Experienced Emergency Department psychiatrists who work with adults with DD report that most crisis behaviours can be managed with 10 mg or less of lorazepam. This is preferable when effective, as it avoids the distressing side effects that often accompany antipsychotics. • Given that antipsychotic medications are often inappropriately prescribed for adults with DD ¹, reducing the exposure of adults with DD exhibiting crisis behaviours to these medications would help to mitigate this problem.

Staff involved in rapid tranquillization should understand risks, and consider various precautions and interventions to avoid or manage possible complications. Monitoring of patients receiving rapid tranquillization in Emergency Department settings should adhere to local protocols and should include parameters outlined below.

TABLE 2: RISKS, PRECAUTIONS, MONITORING

Risks	<ul style="list-style-type: none"> • Over sedation • Respiratory depression • Cardiovascular complications (e.g., QT prolongation) • Acute dystonic reactions
Precautions	<ul style="list-style-type: none"> • Crash cart with bag-valve mask (BVM) and airway equipment available • Staff trained in Basic Life Support • Review prior EKG before introducing antipsychotic medications • Benztropine available for acute dystonic reactions • Flumazenil IV available for oversedation
Physical Monitoring	<ul style="list-style-type: none"> • Temperature (if increased, urgently assess for neuroleptic malignant syndrome) • Blood pressure • Pulse • Respiratory rate (with continuous pulse oxymetry in unresponsive patients)

TABLE 3A: INITIAL STEPS TO RAPID TRANQUILLIZATION ²

	Modifying Circumstances	Choice(s)	Usual Oral Dosage	Notes
STEP 1	Attempt non-medication interventions, if appropriate	1. De-escalation 2. Time out in a safe seclusion room		
STEP 2	PATIENT IS ALREADY RECEIVING AN ORAL OR DEPOT ANTIPSYCHOTIC; AVOID GIVING ANOTHER ANTIPSYCHOTIC MEDICATION ^a	Lorazepam ^d	1-4 mg SL (sublingual)	Repeat once after 45-60 minutes if insufficient effect. Go to step 3 if two doses fail to produce desired effect or sooner if the patient or others are at significant risk for harm
	PATIENT IS NOT ALREADY RECEIVING AN ORAL OR DEPOT ANTIPSYCHOTIC OR IF PATIENT IS ACUTELY PSYCHOTIC ^{a,b,c}	Olanzapine ³ OR	10 mg PO	Rapidly dissolving form is Zydys [®] AVOID combining with lorazepam or other benzodiazepine ^e
	AVOID combining two antipsychotics	Quetiapine OR	100-200 mg PO	ANY <u>ONE</u> of these CHOICES WITH or WITHOUT
	WAIT 4 hours before repeating same antipsychotic	Risperidone ^{4,5,6,7} OR	1-2 mg PO	Lorazepam ^d 1-4 mg SL (sublingual)
	GO TO STEP 3 if second dose of lorazepam or antipsychotic fails to produce desired effect or sooner if the patient or others are at significant risk for harm	Loxapine OR Haloperidol ^b	25 mg PO 5 mg PO	Repeat lorazepam once after 45-60 minutes if insufficient effect

a. The choice of a new medication depends on other medications being taken. If the adult with DD is established on antipsychotic medications, lorazepam alone may be added. If the adult with DD is receiving benzodiazepines regularly, an antipsychotic alone may be added. Most patients respond best to a combination of an antipsychotic and lorazepam but an antipsychotic or benzodiazepine can also be used alone. Monitor vital signs as appropriate (see Table 2).

b. Before giving antipsychotics (particularly haloperidol) consider reviewing a prior EKG (or obtaining one), if possible, to assess the presence of QT prolongation. On an EKG, the QT interval should be less than 450-500 milliseconds.

c. **Due to the risk of acute dystonic reactions** (incidence is about 6% with haloperidol) ensure benztropine 1-2 mg IM or procyclidine 5-10 mg IM is available.

d. In patients receiving clozapine, lorazepam is contraindicated.

e. Combining olanzapine with lorazepam or other benzodiazepines should be avoided due to the risks of excessive sedation.

**TABLE 3B: NEXT STEPS TO RAPID TRANQUILLIZATION –
ADDITIONAL STEPS IN EMERGENCY DEPARTMENT AND HOSPITAL SETTINGS ^{i,g,h,i}**

	Modifying Circumstances	Choice(s)	Usual IM Dosage	Notes
STEP 3	Oral therapy is refused, has failed or is insufficient for the level of crisis ^f	Lorazepam ^g	1-4mg IM Mix 1:1 with sterile saline	Flumazenil IV should be available for benzodiazepine-induced respiratory depression Flumazenil dosing ¹² Initial: 0.2 mg IV over 15 seconds Max: 1 mg
		OR		
	If PO or IM antipsychotic given then WAIT 4 hours before repeating the same antipsychotic IM ^{f,g,h}	Olanzapine ^{i,9,10}	10 mg IM	DO NOT combine with IM benzodiazepine ¹¹
		OR		
		Loxapine	25 mg IM	Either <u>ONE</u> of these CHOICES WITH or WITHOUT
		OR		
		Haloperidol ^{9,10}	5 mg IM	Lorazepam 1-2 mg IM Mix 1:1 with sterile saline
				Use separate syringes for loxapine and lorazepam Repeat lorazepam 1-2 mg IM after 45-60 minutes if insufficient effect
STEP 4	Refractory severe symptoms ^j	Consider intravenous (IV) medications (e.g., diazepam), the use of which is beyond the scope of these guidelines		

f. Consider intramuscular (IM) medication when oral therapy is refused, has failed or is insufficient for the level of crisis. Most patients respond best to a combination of an antipsychotic and lorazepam but an antipsychotic or benzodiazepine can also be used alone. Monitor vital signs as appropriate (see Table 2).

g. Before giving antipsychotics (particularly haloperidol) consider reviewing a prior EKG (or obtaining one), if possible, due to the risk of cardiac arrhythmias associated with QT prolongation. On an EKG, the QT interval should be less than 450-500 milliseconds. IM haloperidol should be considered a third line treatment option due to its increased risk of adverse effects.

h. **Due to the risk of acute dystonic reactions** (incidence is about 6% with haloperidol) ensure benztropine 1-2 mg IM or procyclidine 5-10 mg IM is available.

i. Recommended by National Institute for Clinical Excellence (NICE – UK) for moderately severe behavioural disturbance only.

j. **Refractory, severe symptoms:** a) Confirm the patient's incapacity to consent and document. Even if incapable, seek the patient's views on treatment options and their assent to a plan; b) Proceed with management while making efforts to involve his or her Substitute Decision Maker; c) Consult with an experienced colleague in psychopharmacology or anaesthesia.

Tool Development Process:

*Primary care of adults with developmental disabilities: Canadian consensus guidelines*¹ address considerations and make recommendations regarding the use of psychotropic medications for adults with developmental disabilities.

For development of this tool, guidelines on rapid tranquillization were reviewed. Currently there are no published standard Canadian guidelines regarding rapid tranquillization for the general population or for adults with DD. The recent paper of Taylor² from the United Kingdom, which gave recommendations for management of acutely disturbed behaviour involving mainly the non-DD population, was used as a base. Emergency physicians and psychiatrists with clinical expertise in DD-specific considerations in rapid tranquillization were consulted and their input was incorporated. Recommendations were adapted to reflect common practices and available medications in Canada.

Adapted from Taylor² by William F. Sullivan MD and David Joyce MD.

Thanks to the following physicians and pharmacist for their review and helpful input:

Ian Dawe MD, Jody Lofchy MD, Frank Martino MD, Elspeth Bradley MD and Laurie Dunn MSc, BScPhm.

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Hamilton Community Crisis Protocol For Individuals with Dual Diagnosis

Definition: For the purposes of this protocol “Individuals with Dual Diagnosis” will be defined as individuals who have intellectual disabilities and co-existing mental health issues and/or challenging behaviours.

Purpose of the Protocol:

Emergency and developmental services agencies often interface when individuals with a dual diagnosis experience a crisis. The goal of this protocol is to ensure that these services work together in a manner that:

1. Recognizes that individuals with a dual diagnosis are entitled to the same services and are required to abide by the same regulations as all other Hamilton citizens, while acknowledging the need for a specialized approach to these crisis situations.
2. Ensures that services are provided by the most appropriate provider(s) and that a team approach addresses the needs of the individual.

Goals of the Protocol:

1. To describe the role of each sector/agency in meeting the crisis needs of citizens of Hamilton who have a dual diagnosis.
2. To promote the use of the Individual Crisis Plan to improve service coordination for individuals who are likely to utilize crisis services.
3. To promote positive working relationships among developmental service agencies and emergency services providers.

Guiding Principles:

1. As full citizens of Hamilton and the Province of Ontario individuals with a dual diagnosis are entitled to the same high quality emergency and crisis services as are all other residents.
2. Individuals with a dual diagnosis may require additional support to make use of emergency and crisis services.
3. All service providers, regardless of funding source are committed to working collaboratively, within their agency mandate to serve individuals with a dual diagnosis.

Scope of the Protocol:

This protocol is inclusive of the following service providers:

- Hamilton Police Services
- COAST
- St. Joseph Healthcare, Psychiatric Emergency Services
- Good Shepherd, Barrett Centre
- Developmental Services Providers
- Adult Mental Health Service Providers

Procedures:

1. Preparation

a. Training and Orientation:

- i. Developmental services agencies will ensure that staff is generally familiar with Hamilton emergency and social services including the purpose and scope of those services, the individuals they serve and the responsibilities of those services.
- ii. Developmental services agencies will provide training upon request to assist emergency service providers with understanding the special needs population.
- iii. Developmental services agencies will provide orientation related to this protocol to all existing and new staff.
- iv. Emergency services providers will provide orientation related to this protocol to their staff as needed.

b. Crisis Planning:

- i. Developmental services agencies will discuss crisis options with individuals in service and their families in cases where crisis response is likely to be needed, preferably before a crisis happens.
- ii. Developmental services agencies will complete a "Crisis Plan" (attached) with individuals who consent and are likely to require additional supports. This plan is developed in conjunction with the team that provides support to the individual.
- iii. Developmental services agencies will ensure that the "Crisis Plan" is updated on a regular basis. The schedule for updating the plan will be established by the agency, the individual who is being planned for and the individual's family member (if applicable) based upon the unique situation. All plans must be reviewed and updated at least once each calendar year.
- iv. With the consent of the individual, Crisis plans will be maintained on file with COAST, St. Joseph Psychiatric Emergency Services, Good Shepherd- Barrett Centre and at the home where the individual resides.

2. Crisis Situation:

a. Police:

- i. Police will respond to 9-1-1 calls in accordance with provincial and local policy.
- ii. Police dispatch and/or police officers responding to a call where a person with a developmental disability is involved will ask if the person has a crisis plan on file at COAST.
- iii. Time permitting, police dispatch will call COAST and relay information that COAST staff provide from the Crisis plan to police officers who are responding to the call.
- iv. Police officers will consider the information provided from the Crisis plan in approaching the individual or residence.

v. The police may transport an individual with special needs to the Barrett Centre or to the hospital for emergency assessment if they deem it necessary.

b. Hospital:

- i. The St. Joseph Emergency Department will triage individuals with special needs for medical and psychiatric concerns in accordance with provincial and local policy and regulations including The Public Hospital Act. Individuals with serious mental health issues will be transferred to the Psychiatric Emergency Services for assessment.
- ii. Where appropriate the Psychiatric Emergency Services will consult with the St. Joseph's Healthcare Mental Health Services for Persons with a Dual Diagnosis Team when an individual with a dual diagnosis presents at the hospital.
- iii. When an individual with a developmental disability requires hospitalization, St. Joseph Healthcare will consult with the individual's case manager to determine an appropriate level of support that the individual will need while in hospital.

c. Barrett Centre

- i. Barrett Centre will respond to the needs of individuals with a dual diagnosis duly identified through crisis planning. These services will involve all aspects of crisis intervention and includes short term residential care/stay.
- ii. Barrett Centre will assess the individual at the point of contact to determine type of need, intervention required and it's capacity to meet those needs.
- iii. If the identified needs supersede Barrett Centre's capacity to provide adequate intervention, Barrett Centre in conjunction with the Developmental Services Provider and/or the Crisis Services Provider involved, will make referrals to appropriate service as outlined in the crisis plan.

d. Developmental Services Agencies – Residential Supports:

- i. Developmental Services agencies providing residential supports will ensure that a crisis plan is completed with each consenting resident who is likely to require crisis supports.
- ii. Developmental Services agencies will ensure that all Crisis Plans are sent to COAST to have on file.
- iii. Developmental Services staff will decide with the individual and /or family members about the need to have the crisis plan on file with Psychiatric Emergency Services and/or the Barrett Centre
- iv. The D.S. agency staff assigned will ensure that the crisis plan is updated on the schedule indicated and ensure that all existing copies of the previous crisis plan are destroyed and updated.

v. When emergency services are contacted, the Developmental Services agency will provide the crisis plan, along with the current MARS sheet, to the emergency service providers and communicate the major concerns or issues.

vi. Wherever able, the Developmental Service agency will accompany the individual to the hospital/Barrett Centre. The crisis service involved will assess whether it is in the person's best interest to have the support staff remain involved. All agency support staff are reminded of their need to keep information regarding other individuals/patients in the crisis service confidential.

vii. Developmental Services agency staff will ensure that the Crisis Response Follow Up Form is completed and submitted to the Facilitator for the Southern Network of Specialized Care.

e. Developmental Services Agencies – Non –Residential Supports:

i. Direct service staff of Developmental Services agencies will assist individuals in non-residential settings and their family members in developing and implementing a crisis plan. Direct service staff may be assigned Case Managers, Adult Protective Service Workers, Day Activity staff or Employment Services staff.

ii. The assigned direct service staff will ensure that the Crisis Plan is sent to COAST.

iii. The assigned direct service staff will decide with the individual and /or family members about the need to have the crisis plan on file with Psychiatric Emergency Services and/or the Barrett Centre.

iv. The assigned direct service staff will be responsible for submitting the plan and updating the plan at the appropriate schedule (not less than once a calendar year).

v. Should there be individuals requiring a crisis plan that are not connected to any Developmental Services agency, they will be directed to the St. Joseph Mental Health Program for Persons with Dual Diagnosis who will assist in the completion of the Crisis Plan.

vi. Assigned direct service staff will ensure that the Crisis Response Follow Up Form is completed and submitted to the Facilitator for the Southern Network of Specialized Care.

f. COAST

i. COAST, when available, can go to the site of the crisis and will take steps to de-escalate the situation at the community site as per the COAST triage protocol.

ii. COAST will maintain a current copy of all Hamilton Crisis Plans on file.

g. Southern Network of Specialized Care

i. The Facilitator for the Southern Network of Specialized Care will act as

co-ordinator of the Crisis Plans and ensure that Crisis Plans are being written in an effective way, are being submitted to COAST and other crisis providers as appropriate.

ii. The Facilitator for the Southern Network of Specialized Care will receive the Crisis Response Follow-Up Forms and provide statistical reports to the Hamilton Service Delivery Network and the Developmental Service System Tables as necessary.

3. Post Crisis:

a. Developmental Services agencies will complete a statistical information report (Crisis Response Follow-Up Forms) in each situation where individuals utilize emergency services and provide notification to the Facilitator of the Southern Network of Specialized Care of the situation without providing identifying information.

b. The Facilitator for the Southern Network of Specialized Care will use the above information to create statistical information regarding the usage of Emergency Services and the effectiveness of the Crisis Plans and Protocol.

c. Should there be a need for other services from the Developmental Sector for the individual, the individual /family member will be encouraged to call Contact Hamilton. With consent, the service provider is able to initiate the referral to Contact Hamilton where this is the preferred option. Contact Hamilton is the single access point agency for Ministry of Community and Social Services funded services for children and adults with developmental disabilities. Adults (18+years) requesting developmental services must have a confirmed developmental disability. Following the intake process and need prioritization and with appropriate consent, Contact Hamilton staff will make the required referrals. Contact Hamilton facilitates the planning of the Resolution process for individuals (please refer to Access Protocol for details).

d. If there are issues with the effectiveness of the Crisis Plan, these issues should be addressed with the case manager who will reconvene the individual's support team to revise the Crisis plan as needed.

e. Gaps in service will be brought to the attention of the Hamilton Service Delivery Network.

f. Where situations were not resolved to the satisfaction of any party who is part of this protocol, they should address their concerns directly to the proper agency and/or follow the complaint mechanisms of their agency.

4. Review

a. The Facilitator from Southern Network of Specialized Care will provide a report on the number of times the protocol was used, relevant information about the nature and resolution of each situation and any service gaps identified by

involved agencies. This report will be circulated in print version to each of the protocol signatories annually and be reviewed at the Hamilton Service Delivery Network.

b. Agencies will be asked to review the protocol each year and re-commit to participation for the coming year.

c. Any signatory to the protocol may request that the protocol be reviewed and/or amended at any time. Should this request be made, the Hamilton Service Delivery Network will reconvene the members of the Hamilton Crisis Planning Steering Committee to review and amend this protocol.

Agencies that sign this agreement are committing to following this protocol as written:

<u>Signature</u>	<u>Agency</u>	<u>Date</u>

