



Primary Care Guidelines & Tools for Adults with Intellectual / Developmental Disabilities (I/DD) – An Introduction for Post-Secondary Students

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Community Networks of Specialized Care (CNSC)

- Link specialized services and professionals to pool their expertise to treat and support adults who have developmental disabilities and mental health needs and/or challenging behaviours (ie. dual diagnosis) in the communities where they live.
- Bring together people from a variety of sectors including developmental services, health, research, education and justice in a common goal of improving the coordination, access and quality of services for these individuals who have complex needs.

Handouts and Questions

- Copies of handouts and video archives for this and other videoconferencing events can be found under the “Videoconferencing” tab at <http://www.communitynetworks.ca/>
- Those joining via webinar can e-mail questions to: megan.primeau@surreyplace.on.ca

Learning Outcomes:



- Participants will be able to:
- Be knowledgeable about the Canadian primary care consensus guidelines
- Discuss disparities & physical health considerations specific to persons with I/DD
- Be knowledgeable about developmental services resources
- Apply evidence from DD primary care guidelines & tools to a case study



Definition of 'Primary Care'

- The 1st level of contact with the medical care system provided primary care providers (e.g. office visits, emergency room visits and house calls) operating inside the larger context of primary health care
- In our current system, primary care is provided by family physicians, nurse practitioners, nurses, pharmacists, physiotherapists and dentists, among others

Reference: <http://www.toolkit.cfpc.ca/en/glossary.php>



Definition of Intellectual Disability

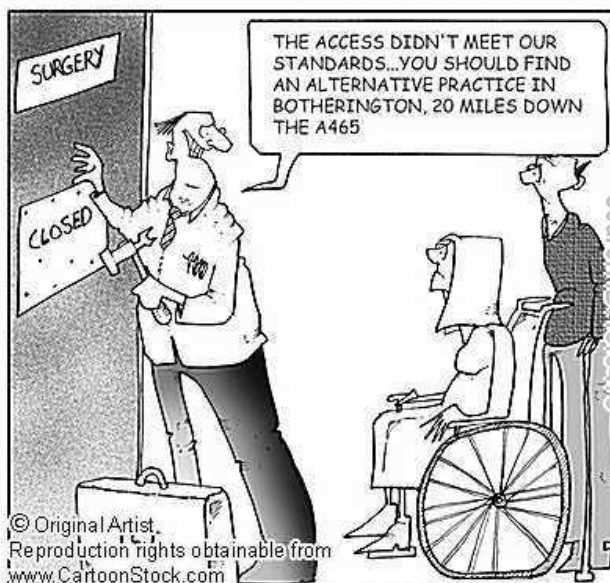
- The American Psychiatric Association defined intellectual disabilities as significantly below average intellectual & adaptive functioning with onset before age 18 years (DSM-IV-TR, 2000)
- General intellectual functioning is measured by an individually administered standardized test of intelligence that results in an overall intelligence quotient (IQ) for the individual
- Criteria is an IQ score of 70 or below
- Adaptive behavior refers to the effectiveness with which an individual meets demands of daily living for individuals of his/her age & cultural group, e.g. skills for eating & dressing, communication, socialization & responsibility

Reference: <http://thenadd.org/resources/information-on-dual-diagnosis>



'Special Needs' & Access to Primary Care

Sometimes we face barriers in access to mainstream primary care services due to 'special needs.' Mainstream programs, approaches, environments, etc. may not be deemed appropriate for individuals with I/DD.



What health care challenges & barriers do adults with DD often have?

- Limited reading & writing ability, limited knowledge of health, self-care & health resources
- Problems understanding complex information e.g., a doctor's explanation about tests or illnesses, unless given in everyday language
- Problems with tests & procedures:
 - Fear and anxiety about needles, tests & medical exams
- Difficulty communicating





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Challenging issues : From Survey of FP's

- Problems communicating, including consent
- Complicated medical issues
- Aggression & other “behavioural problems”
- Finding enough time
- Lack of educational materials to help patients understand what the clinician is doing
 - Why & how they can contribute to their health
- Lack of community resources for psychosocial rehabilitation



Health Inequities & Health Care for People with DD: Canadian Context

- Canadian research indicates that individuals with developmental disability are more likely to be hospitalized for ‘ambulatory care sensitive conditions’ than others without developmental disability who also have those conditions (Balogh, 2010)
 - Indicator of poor primary care
- “Disparities in primary care exist between adults with developmental disability & the general population. The former often have poorer health, increased morbidity, & earlier mortality. Assessments that attend to the specific health issues of adults with developmental disability can improve their primary care” (DDPCI guidelines)
- Developmental disability is taught to varying degrees in Canadian Medical Schools



Important Statistics

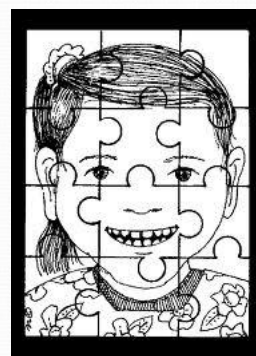
- How many people have developmental disabilities (DD) in Ontario?
 - 1-3% of population
 - Approx. 275,000 in Ontario
- Approx 80 - 90% have DD in the “mild” range
- How many people with DD have a known cause of the DD?
 - < 50% have a known cause of the DD, e.g. diagnoses such as Down syndrome, Williams syndrome, Fetal Alcohol Spectrum Disorder
- More medical conditions?
 - 2-5x more than general population
- Increasingly aging population



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Co-morbidities

- Higher rates of some health problems (e.g. seizures, CVD, dental caries & gingivitis, GERD, constipation, sensory impairments, obesity, mental health problems)
- Earlier onset of some conditions (e.g. dementia)
- Atypical presentation/symptoms (e.g. dysphagia, GERD or pain)
- Complicating factors (e.g. multiple & long-term medications, vulnerabilities)



Leading Causes of Death due to Illness

General Population	People with Developmental Disability
1. Cancer	1. Respiratory diseases
2. Ischemic heart disease	2. Heart disease due to obesity, congenital malformations, side effects of neuroleptics
3. Cerebrovascular disease	3. Gastrointestinal diseases

Context

- Last 4 decades: closure of institutions
- 2005 MCSS established Community Networks of Specialized Care (CNSC)
- Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities first published in 2006 & 2011 to assist primary care physicians





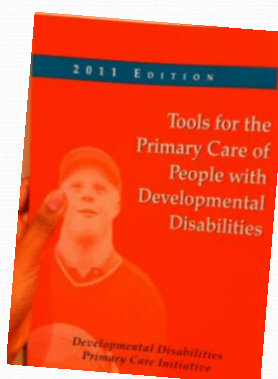
Primary Care of Adults with DD: Canadian Consensus Guidelines 2011

- Describe best practices in caring for adults with Developmental Disability
- Reviewed & published in Canadian Family Physician May 2011
- Available on SPC website
 - <http://www.surreyplace.on.ca/Primary-Care/Pages/Home.aspx>



Tools for the Primary Care of People with Developmental Disabilities

- Developed to assist Primary Care Providers in the “how-to” of applying the guidelines
- Tools are available on Surrey Place Centre’s website
 - <http://www.surreyplace.on.ca/Primary-Care/Pages/Home.aspx>





DD Primary Care Guidelines, Tools for Primary Care Providers & for Caregivers

<http://www.surreyplace.on.ca/Primary-Care/Pages/Home.aspx>

Surrey Place Centre > Primary Care Initiative

Developmental Disabilities Primary Care Initiative

The Developmental Disabilities Primary Care Initiative has brought together clinicians with expertise in the care of adults with developmental disabilities (DD) to improve primary care and quality of life for these persons.

With leadership and coordination from Surrey Place Centre, and funding from the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care, and Surrey Place Centre Foundation, Guidelines and Tools have been developed to help primary care providers to follow best practices in the care of these patients.

Initiative pour les soins primaires en déficience intellectuelle

L'Initiative pour les soins primaires en déficience intellectuelle a réuni des cliniciens capables de fournir des services de santé aux adultes ayant une déficience intellectuelle (DI) dans le but d'améliorer les soins primaires et la qualité de vie de ces adultes.

Avec le leadership et la coordination du Surrey Place Centre, le financement du Ministère des Services Sociaux et Communautaires et du Ministère de la Santé et des Soins de longue durée de l'Ontario, et de la Fondation du Surrey Place Centre, des lignes directrices et des outils ont été développés pour aider les professionnels de soins primaires à suivre les meilleures pratiques quand ils soignent ces patients.

Guidelines/Lignes directrices

[Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines](#)

[Soins primaires aux adultes ayant une déficience développementale: Lignes directrices consensuelles canadiennes](#)

Tools/Outils

Tools for primary care providers / Outils à l'intention des professionnels de soins primaires

Tools for caregivers / Outils à l'intention des dispensateurs de soins

DSO
Developmental Services Ontario
Des services pour les adultes à déficience intellectuelle

SOPDI
Service de l'Éducation pour les personnes ayant une déficience intellectuelle
Service de l'éducation pour les personnes ayant une déficience intellectuelle

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Clinical Review

Primary care of adults with developmental disabilities

Canadian consensus guidelines

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Canadian Consensus Guidelines for the Primary Care of Adults with DD (2011)

- **31 guidelines, 74 evidence-ranked recommendations:**

- General issues (9)
- Physical health issues (12)
- Behavioural & mental health issues (10)



DD Primary Care Guidelines - Disparities

Table 3. Preventive care checklist for adults with developmental disabilities: The level of evidence is indicated for each recommendation and is based on the cited reference or references.

CONSIDERATIONS	RECOMMENDATIONS
GENERAL ISSUES IN PRIMARY CARE OF ADULTS WITH DD	
1. Disparities in primary care exist between adults with DD and the general population. The former often have poorer health, increased morbidity, and earlier mortality. ⁹ Assessments that attend to the specific health issues of adults with DD can improve their primary care. ⁹	a. Apply age- and sex-specific guidelines for preventive health care as for adults in the general population. ^{15,16} Perform an annual comprehensive preventive care assessment including physical examination and use guidelines and tools adapted for adults with DD. ⁹
2. Etiology of DD is useful to establish, whenever possible, as it often informs preventive care or treatment. ¹²⁻¹⁴	a. Contact a genetics centre for referral criteria and testing protocols concerning etiologic assessment of adults whose DD is of unknown or uncertain origin. ¹⁵⁻¹⁷
Advances in genetic knowledge continue to enhance detection of etiology. ^{13,18}	b. Consider reassessment periodically if a previous assessment was inconclusive, according to the criteria of the genetics centre. ¹⁸

Guideline 1: "Disparities in primary care exist between adults with DD and the general population. The former often have poorer health, increased morbidity, and earlier mortality. Assessments that attend to the specific health issues of adults with DD can improve their primary care"

Guideline 2: "Etiology of DD is useful to establish, whenever possible, as it often informs preventative care of treatment"

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?	<p>The chances of individuals having a genetic etiology for their DD generally range from greater to lesser likelihood in the following order:</p> <ul style="list-style-type: none"> • 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?	<p>Optimal medical management</p> <ul style="list-style-type: none"> • 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.



Today's Visit Tool

- Tool to help with optimizing limited time allotted for medical appointments

SECTION I: Tools for General Issues in Primary Care

TODAY'S VISIT		Name: _____ (last, first)	Gender: _____
Main Reason for Today's Visit to the Physician or Nurse (To be filled out by the Patient with DD and Caregiver)		Address: _____	
<ul style="list-style-type: none"> • Please bring an updated form for each visit to the physician's name. • Bring an updated medication list, or all medications being taken. • Bring any monitoring forms being used (i.e., sleep or behavior charts). • Keep a copy of this completed form for the patient's home medical files. 		Tel. No: _____	
Up-to-date Medication List attached? <input type="checkbox"/>		DOB (dd/mm/yyyy): _____	
What is the main health problem the patient with DD or caregivers are concerned about? When did it start? _____ List new symptoms. _____ List possible contributing factors. _____		Health Card Number: _____	
Circle or list other needs – e.g., prescription renewals, test results, forms to be filled out, appointment for annual exam		Date of Visit: _____	
Patient / Caregiver (see back of page)	Any Recent Changes or Stressors? <input type="checkbox"/> No <input type="checkbox"/> Yes: _____ (e.g., staff changes, family illness or stress, changes in living or social environment)		
	Any recent visit to the dentist or other doctor? <input type="checkbox"/> No <input type="checkbox"/> Yes: _____		
	Any recent medication changes or additions? <input type="checkbox"/> No <input type="checkbox"/> 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			
Physician / Nurses	Assessment:		
	Treatment Plan including Medication Changes:		
	Advice to Patient and Caregivers:		
Next Planned Visit / Follow-Up: _____		MD / RN Signature: _____	

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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.

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Examples of Tools – Health Watch Tables

- Down Syndrome
- Fragile X Syndrome
- Prader-Willi Syndrome
- Smith-Magenis Syndrome
- 22q11.2 Deletion Syndrome





Down Syndrome HWT

<http://www.surreyplace.on.ca/Documents/Down%20Syndrome.pdf>

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	<input type="checkbox"/> Neonatally: refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus or poor vision is identified <input type="checkbox"/> Arrange ophthalmological assessment: first by 6 months for all; then every 1-2 years, with special attention to cataracts, keratoconus, and refractive errors <input type="checkbox"/> During childhood: screen vision annually with history and exam; refer as needed <input type="checkbox"/> Arrange auditory brainstem response (ABR) measurement by 3 months if newborn screening has not been done or if results were suspicious <input type="checkbox"/> During childhood: screen hearing annually with history and exam; review risks for frequently occurring serious otitis media <input type="checkbox"/> 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	<input type="checkbox"/> Undertake initial dental exam at 2 years, then every 6 months thereafter. Encourage proper dental hygiene. Refer to an orthodontist if needed <input type="checkbox"/> Undertake clinical exams every six months with referral, as appropriate
3. CARDIOVASCULAR	
Children: 30%-60% have congenital heart defects (CHD)	<input type="checkbox"/> Newborn screening: Obtain an echocardiogram and refer to a cardiologist, even in the absence of physical findings <input type="checkbox"/> In children and adolescents: review cardiovascular history and assess for physical signs with specialist referral if indicated <ul style="list-style-type: none"> • Refer for an echocardiogram if not previously done • Undertake SBE prophylaxis as indicated by findings

Health Watch Table — Fragile X Syndrome

Forster-Gibson and Berg 2011

CONSIDERATIONS	RECOMMENDATIONS
1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)	
Children Vision: strabismus, refractive errors are common	<input type="checkbox"/> Undertake newborn vision and hearing screening and an auditory brainstem response (ABR)
Hearing: recurrent otitis media is common	<input type="checkbox"/> Refer for a comprehensive ophthalmologic examination by 4 years of age
Nose: sinusitis is common	<input type="checkbox"/> Visualize tympanic membranes at each visit
Adults: strabismus and refractive errors are common	<input type="checkbox"/> Undertake hearing and vision screening at each visit with particular attention to myopia and hearing loss
2. DENTAL	
Children and Adults: High arched palate and dental malocclusion are common	<input type="checkbox"/> Refer to a dentist for an annual exam
3. CARDIOVASCULAR	
Children: Mitral Valve Prolapse (MVP) is less common in children (~10%), but may develop during adolescence	<input type="checkbox"/> Auscultate for murmurs or clicks at each visit. If present, do an ECG and echocardiogram; refer to cardiologist, if indicated
Adults: MVP is common (~80%). Aortic root dilation usually is not progressive. Hypertension is common and exacerbated by anxiety	<input type="checkbox"/> Undertake an annual clinical exam. Based on findings, obtain an ECG and echocardiogram. Refer to cardiologist, as appropriate <input type="checkbox"/> Measure BP at each visit and at least annually <input type="checkbox"/> Treat hypertension when present
4. RESPIRATORY	
Children & Adults: Obstructive sleep apnea (OSA) may be due to enlarged adenoids, hypotonia or connective tissue dysplasia	<input type="checkbox"/> Ascertain a sleep history and assess for evidence of OSA <input type="checkbox"/> Obtain a sleep study as appropriate
5. GASTROINTESTINAL	
Children: In infants, feeding problems are common with recurrent emesis associated with Gastroesophageal Reflux Disease (GERD) in ~30% of infants	<input type="checkbox"/> Refer for assessment of GERD. Thickened liquids and upright positioning may be sufficient to manage GERD

Health Watch Table — 22q11.2 Deletion Syndrome^a

Forster-Gibson and Berg 2011

CONSIDERATIONS	RECOMMENDATIONS
1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)	
<p>Children and Adults:</p> <ul style="list-style-type: none"> ~ 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 	<ul style="list-style-type: none"> 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
2. DENTAL	
<p>Children and Adults: Retrognathia (overbite) is common and may cause dental malocclusion</p> <p>Significant dental issues are a recognized part of the syndrome</p>	<ul style="list-style-type: none"> Refer to a dentist in early childhood Advocate and ensure for appropriate dental care
3. CARDIOVASCULAR	
<p>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)</p>	<ul style="list-style-type: none"> At the time of diagnosis, complete a cardiovascular assessment, including EKG and echocardiogram Refer to a cardiologist as warranted by clinical findings
4. RESPIRATORY	
<p>Children: Congenital malformations may lead to upper and/or lower airway obstructions and obstructive sleep apnea (OSA)</p> <p>Most airway concerns resolve spontaneously with time but some require surgical intervention (e.g., Robin sequence)</p>	<ul style="list-style-type: none"> 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



DD Primary Care Guidelines – Problem Behaviour

BEHAVIOURAL AND MENTAL HEALTH GUIDELINES FOR ADULTS WITH DD

22. Problem behaviour, such as aggression and self-injury, is not a psychiatric disorder but might be a symptom of a health-related disorder or other circumstance (eg, insufficient supports).^{25,126,127}

Problem behaviours sometimes occur because environments do not meet the developmental needs of the adult with DD.¹²⁸

Despite the absence of an evidence base, psychotropic medications are regularly used to manage problem behaviours among adults with DD.^{129,130} Antipsychotic drugs should no longer be regarded as an acceptable routine treatment of problem behaviours in adults with DD.¹³¹

a. Before considering a psychiatric diagnosis, assess and address sequentially possible causes of problem behaviour, including physical (eg, infections, constipation, pain), environmental (eg, changed residence, reduced supports), and emotional factors (eg, stress, trauma, grief).¹²⁷

b. Facilitate “enabling environments” to meet these unique developmental needs as they will likely diminish or eliminate these problem behaviours.¹²⁸

c. Regularly audit the use of prescribed psychotropic medication, including those used as needed.¹³² Plan for a functional analysis (typically performed by a behavioural therapist or psychologist) and interdisciplinary understanding of problem behaviours. Review with care providers psychological, behavioural, and other nonmedication interventions to manage problem behaviours. Consider reducing and stopping, at least on a trial basis, medications not prescribed for a specific psychiatric diagnosis.¹³³

Guideline 22: “Problem behaviour, such as aggression and self-injury, is not a psychiatric disorder but might be a health-related disorder or other circumstance...”

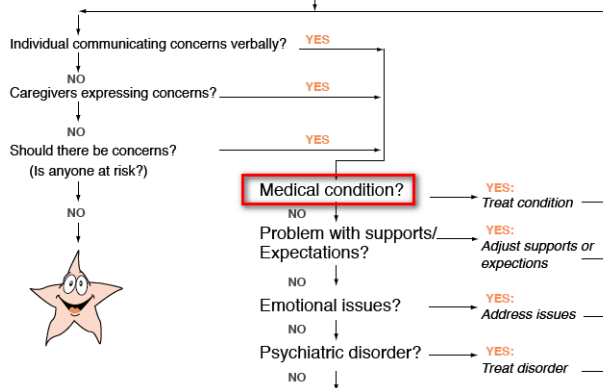
Behavioral & Mental Health

- A Guide to Understanding Behavioral Problems & Emotional Concerns
- This guide aims to help identify the causes of behavioral problems, in order to plan for treatment and management, and prevent reoccurrence



DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS

Patient brought to family physician with escalating behavioural concerns



© Bradley & Summers 1999; modified in 2009



DD Primary Care Guidelines – Physical Health

14. Respiratory disorders (eg, aspiration pneumonia) are among the most common causes of death for adults with DD. Swallowing difficulties are prevalent in those patients with neuromuscular dysfunction or taking certain medications with anticholinergic side effects, and they might result in aspiration or asphyxiation.⁷⁷⁻⁷⁹

15. Gastrointestinal and feeding problems are common among adults with DD. Presenting manifestations are often different than in the general population and might include changes in behaviour or weight.⁸¹⁻⁸³

Adults with DD might have an increased risk of *Helicobacter pylori* infection related to factors such as having lived in a group home, rumination, or exposure to saliva or feces due to personal behaviour or environmental contamination.^{81,85,88}

a. Screen at least annually for possible signs of swallowing difficulty and overt or silent aspiration (eg, throat clearing after swallowing, coughing, choking, drooling, long mealtimes, aversion to food, weight loss, frequent chest infections). Refer as appropriate.⁸⁰

a. Screen annually for manifestations of GERD and manage accordingly. If introducing medications that can aggravate GERD, monitor more frequently for related symptoms.^{82,84}

b. If there are unexplained gastrointestinal findings or changes in behaviour or weight, investigate for constipation, GERD, peptic ulcer disease, and pica.^{82,84}

c. Screen for *H. pylori* infection in symptomatic adults with DD or asymptomatic ones who have lived in institutions or group homes. Consider retesting at regular intervals (eg, 3-5 y).⁸¹

d. Consider urea breath testing, fecal antigen testing, or serologic testing depending on the indication, availability, and tolerability of the test.^{81,85}

E.g. guidelines 14 & 15: “Respiratory disorders, (e.g. aspiration pneumonia) are among the most common causes of death for adults with DD...” & “Gastrointestinal and feeding problems are common among adults with DD. Presenting manifestations are often different...”

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: _____

- ☐ Medical condition giving rise to physical discomfort (e.g., rash or itch)
- ☐ Medication side effect
- ☐ Change in medication
- ☐ Allergies
- ☐ Vision problem (e.g., cataracts)
- ☐ Hearing problem
- ☐ Dental problem
- ☐ Cardiovascular
- ☐ Respiratory
- ☐ Pneumonia
- ☐ GERD/Peptic ulcer disease/*H. pylori* infection
- ☐ Constipation, or other lower GI problems
- ☐ UTI
- ☐ Other: _____
- ☐ Dysmenorrhea/Premenstrual syndrome
- ☐ Peri-menopausal/menopausal (may start earlier)
- ☐ Musculoskeletal (arthritis, joints)
- ☐ Osteoporosis
- ☐ Degenerative disc disease (DDD)
- ☐ Spasticity
- ☐ Neurological (e.g., seizures, dementia)
- ☐ Dermatological
- ☐ Sensory discomfort (e.g., new clothes, shoes)
- ☐ Hypothyroidism
- ☐ Diabetes (I or II)
- ☐ Sleep problems/sleep apnea

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 ☐ YesDoes this patient have enough opportunities for **appropriate physical activities**? ☐ No ☐ YesDoes 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:****Understanding Adaptive Functioning**

Level of Severity	IQ	Mental Age Equivalence
Mild	55-70	9-12 years old
Moderate	40-50	6-9 years old
Severe	25-35	3-6 years old
Profound	< 25	< 3 years old



Adaptive Functioning & Communication Tool

Adaptive Functioning & Communication associated with Different Levels of Developmental Disabilities (DD)

INTELLECTUAL FUNCTIONING ^{a, b}	ADAPTIVE FUNCTIONING ^{a, c} (McCreary 2005)	COMMUNICATION (Anderson 2002)
MILD IQ: 55-70 (± 5) Percentile scores: First to third Age equivalence (AE): 9-12 years Grade: up to Gr. 6	<ul style="list-style-type: none"> • Unskilled job capability • May need income support if jobs are scarce • Often develops stable relationships but parenting skills are poor • Decision making: likely capable of making familiar medical decisions 	<ul style="list-style-type: none"> • Uses a variety of sentence types (simple to complex) to communicate opinions, ideas, news, events, aspirations • Vocabulary is extensive compared to adults with DD in the moderate to profound range • Uses language to initiate and interact • Conversational difficulties may exist • Uses the phone and communicates in writing • Able to understand and use abstract language but may have difficulty expressing ideas in sequence • Can usually follow meaningful, simple, 3-step commands
MODERATE IQ: 40-50 (± 5) Percentile scores: Below the first AE: 6-9 years Grade: up to Gr. 2	<ul style="list-style-type: none"> • Supported employment • Income support • Regular residential supervision • Help with banking and shopping • Childrearing is beyond level of understanding and capacity • Decision making: support with medical decisions is required 	<ul style="list-style-type: none"> • Uses phrases and simple sentences to communicate for various purposes, including expression of preference, emotion, interests and experiences • Vocabulary adequate for daily functioning • Asks and responds to questions about concrete information • Some abstract language use in talking about past events • Follows meaningful 2-step commands without support

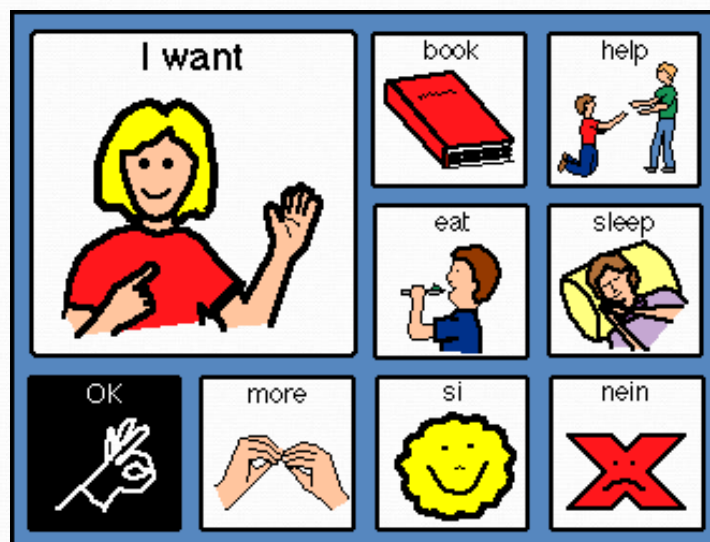


Adaptive Functioning & Communication Tool

SEVERE IQ: 25-35 (± 5) Percentile scores: Below the first AE: 3-6 years Grade: up to Gr. 1	<ul style="list-style-type: none"> • Continuing support and supervision in residential and day care programs needed • Unable to manage family responsibilities • Decision making: not capable of making most medical decisions except if familiar with the issue and provided sufficient support 	<ul style="list-style-type: none"> • Uses single- and two-word combinations, gestures and/or signs to indicate basic needs and to comment about his/her environment • Vocabulary limited • Gives and shows objects, points • Comprehension still limited to the immediate environment but able to understand some action words • Can follow meaningful 1-step commands with or without support (e.g., repetition, gestures)
PROFOUND IQ: < 20-25 Percentile scores: Below the first AE: 0-3 years	<ul style="list-style-type: none"> • Continuing 24-hour support and supervision needed • Unable to manage family responsibilities • Decision making: can be presumed to be not capable of making medical decisions 	<ul style="list-style-type: none"> • Uses nonverbal or single words, gestures and/or signs to indicate basic needs • A few words possible • May appear non-interactive • Comprehension limited to people, objects, and events in the immediate environment • May follow some routine commands due to understanding the situation rather than the actual words



Adaptive Functioning & Communication Tools



www.tdsb.on.ca



Informed Consent Tool

Informed Consent in Adults with Developmental Disabilities (DD)

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.



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Informed Consent Tool



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. 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.ccbboard.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)

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.) ☐ Yes ☐ No ☐ Unsure
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?
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.) ☐ Yes ☐ No ☐ Unsure
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?

Assessment:

DATE: _____ PRINT NAME: _____ SIGNATURE: _____



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Other Tools Available Online

<http://www.surreyplace.on.ca/Documents/Down%20Syndrome.pdf>

- Psychological Assessment: FAQs
- Preventative Care Checklists
- Crisis Prevention & Management Plan
- Essential Information for Emergency Dept
- Auditing Psychotropic Medication Therapy



Caregiver Monitoring Tools

- Weight
- Bowel Management
- Menses
- Sleep
- Seizure Package

Health Tools



Caregiver Tools: Weight Chart

WEIGHT – MONTHLY/ WEEKLY MONITORING CHART - ADULT

Name: _____ DOB: (dd/mm/yyyy) _____ Year: _____

Weight must be recorded every month in group homes and residential facilities.
Monitor the person's weight more often if needed, e.g., weekly.

PROTOCOL IN PLACE: ☐ NO ☐ YES
If YES, refer to Protocol.

Please include a recent height below using *centimetres (cm)* or *feet (feet = ' inches =")* and the **date** it was taken.

Height: _____ Date (dd/mm): _____

In the table, write the person's **weight** using the **same scale**, with **shoes off**. Be sure to also write the **date (dd/mm)**. e.g.,
Write whether the weight is in *pounds (lb)* or *kilograms (kg)*.

e.g.,
W = 136 lbs
D = 05/12

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Week 1	W= D=											
Week 2												
Week 3												
Week 4												
Week 5												

Adapted from New Visions Toronto

Notes: _____



Caregiver Tools - Bowel Management

BOWEL MOVEMENT (B.M.) - MONTHLY MONITORING RECORD (FOR PEOPLE WHO HAVE BOWEL PROBLEMS)

Month of _____ 20____

Name: _____ DOB: _____

PROTOCOL IN PLACE: NO YES
If YES, record use in Protocol box, below

When recording B.M.'s, note both **SIZE**: L = Large M = Medium SM = Small e.g., Large soft stool =

L
S

 or

L
3

 or

L
4

and **TYPE**: H = Hard S = Soft D = Diarrhea
(for TYPE, numbered 1 to 7, you can also use the Bristol Stool Chart on back of page)

X = Checked with client and no B.M.

DATE	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
1 st Stool																															
2 nd Stool																															
3 rd Stool																															
4 th Stool																															
Protocol: what used, when?																															

Adapted from New Visions Toronto

Notes:



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Caregiver Tools - Bowel Management

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid



Caregiver Tools – Sleep Chart

Sleep Chart – MONTHLY 24 Hour Sleep Record

Name: _____ DOB: _____ MONTH of _____ 20____

Use for people with sleep-related problems.
Mark an **X** in squares where person is sleeping, day or night.

e.g., for 1 hour of sleep ☐ X ☐
e.g., for 30 minutes of sleep ☐ X ☐

Use **M** for when sleep Medication is given ☐ M ☐

PROTOCOL IN PLACE: NO YES
If YES, refer to Protocol, record when used.

		DATE																															
TIME		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	
AM	12 (Midnight)																																
	1																																
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PM	12 (Noon)																																
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NOTES – USE OTHER SIDE →



Caregiver Tools Seizure Package

- Seizure General Information
- Seizure First Aid Guide
- Seizure Action Plan
- Seizure Resources
- Seizure Tool
- Tips for Caregivers
- Seizure Baseline Chart
- Daily Seizure Monitoring Chart
- Seizure Frequency Yearly Summary Sheet

SEIZURE RECORD TO ESTABLISH BASELINE – NEW OR UNSTABLE SEIZURES

Name: _____ DOB: _____

Call 911 if seizure lasts more than 5 minutes, if there is an impairment of breathing, or if patient continues to go in and out of seizures.
NOTE: Notify physician if there is a change in the duration, frequency, or pattern of the seizures.

When	Date (dd/mm/yyyy)	Time of day	HOW LONG IT LASTED minutes/seconds. Use Watch	Possible triggers? Specify	Warning or aurs?	Y/N or as asked
Before seizure						
What happened during seizure						
After seizure						
COMMENTS – describe what seizure looked like, anything you noticed not listed above.						
*Possible triggers – fatigue, exercise, hypoglycemia (low blood sugar), emotional stress, infection, alcohol, abnormal breathing, menses, being startled, flashing lights, temperature changes, missed seizure medications, recent prescription change.						
Information the Doctor will want to know, when the patient has an appointment:						
1. Any seizures since last visit? If yes: how many and detailed description. Any injury from seizure? Any medication used to stop the seizure?						
2. Has there been any change in the patient's behavior/health from his/her baseline? Check as it applies. <input type="checkbox"/> any dizziness <input type="checkbox"/> drowsiness <input type="checkbox"/> sleep disturbance <input type="checkbox"/> any agitation without valid reason <input type="checkbox"/> self-injury <input type="checkbox"/> fainting spell <input type="checkbox"/> changes in way patient walks (gait) <input type="checkbox"/> other symptoms						
3. Up-to-date list of all medications patient is currently taking - & whether any recent changes, or missed medications.						



Autism Speaks Toolkits

<http://www.autismspeaks.ca/family-services/toolkits>

Taking the Work Out of Blood Work: Helping Your Child With ASD



A Parent's Guide



Services & Resources: DSO Toronto Region

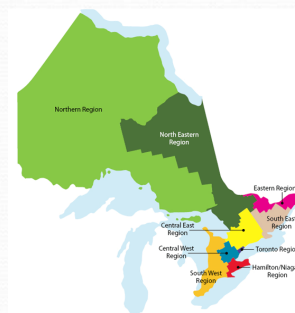
- The single point of access for all 'new' adults with a developmental disability to access Ministry funded adult services & supports





Community Networks of Specialized Care

- In 2005, MCSS established 4 regions to form a provincial network of specialized care to support individuals with developmental disabilities, mental health (dual diagnosis) &/or challenging behaviours
- In 2010, Health Care Facilitators (HCFs) provincially hired – 10 across Ontario



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Toronto Network of Specialized Care

- Specialized
- Clinical services/supports
- Case management
- Crisis response & transition supports
- Respite services
- Residential & day treatment programs
- Inpatient & outpatient hospital treatment programs





COMMUNITY NETWORKS
OF SPECIALIZED CARE



Role of the Health Care Facilitator

- Facilitate referrals & linkages with Family Health Teams, Community Health Centres, CCAC & Long Term Care system
- Toronto region – Clinical Conferencing
- Promote linkages between health care professionals
- Support care providers with implementing health care planning
- Identify & develop strategies for navigating existing generic health services
- Support agencies & Community Network of Specialize Care partners in developing health care networks



Case Example: Frequent ER Visitors

- Paul is an 18-year-old adult with autism, severe/profound DD, seizure disorder & pica
- Prescribed medications: olanzapine, valproic acid & dilantin
- History of pica since childhood but has escalated in the past 6 months along with episodes of severe aggression
- Paul was taken to local emergency department 6 times over the past 2 months with distress behaviours and the last 2 visits were related to ingesting vinyl gloves
- For each emergency visit, he was admitted overnight or for a few days, restrained in a crisis bed and sedated with IM injections of olanzapine and haldol, then discharged when aggression subsides
- What could care/service providers advocate for?



Case Example – Access Barriers

- Laura is a 52-year-old woman with mild/moderate DD of unknown etiology, anorexia nervosa & query dementia
- Her BMI is 13.8 kg/m²
- She lived in semi-independent living residential program for the past 5 years but caregivers notices a more severe decline in weight and mental health in the past 2 years
- Caregivers take her to Emergency department but she is admitted only for re-hydration then discharged next day
- Her family physician referred her to hospital eating disorders programs but the referral is declined due to DD
- CCAC referral for dietician is also declined with response being that she should be referred to an eating disorders program
- What could care/service providers advocate for?



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Your Examples?







mencap
The voice of
learning disability

“Death By Indifference”

NHS accused over deaths of disabled patients
the Guardian: 3 January 2012


Death by *indifference*: 74 deaths and counting
A progress report 5 years on

<http://www.mencap.org.uk/campaigns/take-action/death-indifference>



COMMUNITY NETWORKS
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Questions or Comments?



Resources

- Surrey Place Centre website
 - www.surreyplace.on.ca
- DSO Toronto Region Website
 - <http://www.surreyplace.on.ca/dso/index.html>
- Community Networks of Specialized Care
 - <http://www.community-networks.ca>



Evaluation

- Please complete the survey here
<https://www.surveymonkey.com/s/6DBDJ2S> to
provide additional feedback.
- If you have an app for a QR reader on your
smartphone, use the following code to complete the
evaluation right now



Educational Opportunity

- Please also check out information about the upcoming Health and Wellbeing in Developmental Disabilities conference at <http://www.healthandwellbeingindd.ca/>; the conference welcomes abstract/poster submissions from students (due by Mar 31, 2013) and offers a reduced registration fee for students.

Concluding Remarks





Thank You!

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Selected Primary Care References

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<http://www.surreyplace.on.ca/Primary-Care/Pages/Home.aspx>
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