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

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Surrey Place Centre
March 15, 2013 Videoconference

Those joining via webinar can e-mail questions to: megan.primeau@surreyplace.on.ca

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 (i.e. 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


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
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

<table>
<thead>
<tr>
<th>General Population</th>
<th>People with Developmental Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cancer</td>
<td>1. Respiratory diseases</td>
</tr>
<tr>
<td>2. Ischemic heart disease</td>
<td>2. Heart disease due to obesity, congenital malformations, side effects of neuroleptics</td>
</tr>
<tr>
<td>3. Cerebrovascular disease</td>
<td>3. Gastrointestinal diseases</td>
</tr>
</tbody>
</table>

## 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

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 those patients.

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.

Guidelines/Lignes directrices
Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines

Clinical Review
Primary care of adults with developmental disabilities
Canadian consensus guidelines

William F. Sullivan MD CCP MA, Joseph M. Berg MBCS MD FCP FCP MGH, Elspeth Bradley NPO MLIS MD MGH, Tom Cheatham MD CCP, Richard Denton MD CCP FCP FMS, John Heng MA, Brian Hennek MA MD CCP, David Joyce MD CCP, Maureen Kelly RN NPA, Marika Korosy, Yona Lumsy NPO CCP CP, Shirley McMillan RN MN CCP

VOL 57: MAY - MAI 2011 | Canadian Family Physician - Le Médecin de famille canadien
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)

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”
Today’s Visit Tool

- Tool to help with optimizing limited time allotted for medical appointments
### Examples of Tools – Health Watch Tables

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

**Health Watch Table — Down Syndrome**

*Forster-Gibson and Berg 2011*

<table>
<thead>
<tr>
<th>CONSIDERATIONS</th>
<th>RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. NEENT (HEAD, EYES, EARS, NOSE, THROAT)</strong></td>
<td></td>
</tr>
<tr>
<td>Children and Adults: Vision: 15% have cataracts; 20-70% have significant refractive errors; 5%-15% of adults have keratoconus. Hearing: 50%-60% have a hearing deficit.</td>
<td>□ Neurally refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus, or poor vision is identified. □ Arrange ophthalmological assessment: Test 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 ambiguous. □ During childhood, screen hearing annually with history and exam; review risks for frequently occurring sensori neural hearing loss. □ Undertake auditory testing: First at 6-12 months, then every 6 months up to 3 years, annually until adulthood, then every two years.</td>
</tr>
</tbody>
</table>

| **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. Rerer to an endodontist if needed. □ Undertake clinical exams every six months with referral, as appropriate. |

| **3. CARDIOVASCULAR** | |
| Children: 30%-50% have congenital heart defects (CHD) | □ 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. |

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### Fragile X Syndrome HWT

**Health Watch Table — Fragile X Syndrome**

*Forster-Gibson and Berg 2011*

<table>
<thead>
<tr>
<th>CONSIDERATIONS</th>
<th>RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. NEENT (HEAD, EYES, EARS, NOSE, THROAT)</strong></td>
<td></td>
</tr>
<tr>
<td>Children: strabismus, refractive errors are common. Hearing: recurrent otitis media is common. Nose: sinusitis is common. Adults: strabismus and refractive errors are common.</td>
<td>□ Undertake newborn vision and hearing screening and an auditory brainstem response (ABR) test. □ Refer for a comprehensive ophthalmologic examination by 4 years of age. □ Visualize tympanic membranes at each visit.</td>
</tr>
</tbody>
</table>

| **2. DENTAL** | |
| Children and Adults: High arched palate and dental malocclusion are common. | □ 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. Adults: MVP is common (60%). Aortic root dilation usually is not progressive. Hypertension is common and exacerbated by anxiety. | □ Auscultate for murmur or diastolic 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. |

| **4. RESPIRATORY** | |
| Children & Adults: Obstructive Sleep Apnea (OSA) may be due to enlarged adenoids, hypotonia or connective tissue dysplasia. | □ Ascertain a sleep history and assess for evidence of OSA. □ Obtain a sleep study as appropriate. |

| **5. GASTROINTESTINAL** | |
| Children: In infants, feeding problems are common with recurrent oromotor associated with Starling in Dodge Reflex Disease (GERD) in 40% of infants. | □ Refer for assessment of GERD. Thickened liquids and upright positioning may be sufficient to manage GERD. |
Guideline 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..."
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

- Individual communicating concerns verbally?
  - Yes: Further assessment
  - No: Questionnaire, screening tool

- Caregivers express concern?
  - Yes: Further assessment
  - No: Questionnaire, screening tool

- Should there be concerns?
  - Yes: Refer to mental health
  - No: Define the problem
    - Medical condition?
      - Yes: Treat condition
      - No: Problem with supports/Expectations?
        - Yes: Adjust supports or expectations
        - No: Emotional issues?
          - Yes: Address issues
          - No: Psychiatric disorder?
            - Yes: Treat disorder
            - No: Further assessment
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 B: CAREGIVER SECTION

**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?  □ 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:

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### Understanding Adaptive Functioning

<table>
<thead>
<tr>
<th>Level of Severity</th>
<th>IQ</th>
<th>Mental Age Equivalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>55-70</td>
<td>9-12 years old</td>
</tr>
<tr>
<td>Moderate</td>
<td>40-50</td>
<td>6-9 years old</td>
</tr>
<tr>
<td>Severe</td>
<td>25-35</td>
<td>3-6 years old</td>
</tr>
<tr>
<td>Profound</td>
<td>&lt; 25</td>
<td>&lt; 3 years old</td>
</tr>
</tbody>
</table>
## Adaptive Functioning & Communication Tool

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

<table>
<thead>
<tr>
<th>INTELLECTUAL FUNCTIONING **</th>
<th>ADAPTIVE FUNCTIONING ** (McCrae 2006)</th>
<th>COMMUNICATION (Anderson 2002)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MILD</td>
<td>- Unskilled job capability</td>
<td>- Uses a variety of sentence types (simple to complex) to communicate opinions, ideas, news, events, aspirations</td>
</tr>
<tr>
<td>IQ: 55-70 (± 5) Percentile</td>
<td>- May need income support if job</td>
<td>- Vocabulary is extensive compared to adults with DD in the moderate to profound range</td>
</tr>
<tr>
<td>scores: First to third Age</td>
<td>are scarce</td>
<td>- Uses language to initiate and interact</td>
</tr>
<tr>
<td>equivalence (AE): 9-12 years</td>
<td>- Often develops stable relationships but parenting skills are poor</td>
<td>- Conversational difficulties may exist</td>
</tr>
<tr>
<td>Grade: up to Gr: 8</td>
<td>- Decision making: likely capable of making familiar medical decisions</td>
<td>- Uses the phone and communicates in writing</td>
</tr>
<tr>
<td></td>
<td>- Decision making: support with medical decisions is required</td>
<td>- Able to understand and use abstract language but may have difficulty expressing ideas in sequence</td>
</tr>
</tbody>
</table>

| MODERATE                    | Uses phrases and simple sentences to communicate for various purposes, including expression of preferences, emotions, interests, and experiences |
| IQ: 40-50 (± 5) Percentile | - Ask and respond to questions about concrete information |
| scores: Below the first AE: | - Some abstract language use in talking about past events |
| 6-9 years                   | - Follows meaningful 2-step commands without support |
| Grade: up to Gr: 2          | - Follows meaningful 2-step commands without support |

## Adaptive Functioning & Communication Tool

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

| SEVERE                      | Uses single- and two-word combinations, gestures and/or signs to indicate basic needs and to comment about his/her environment |
| IQ: 25-35 (± 5) Percentile  | Vocabulary limited |
| scores: Below the first AE: | Gives and shows objects, points |
| 3-6 years                   | Comprehension still limited to the immediate environment but able to understand some action words |
| Grade: up to Gr: 1          | Can follow meaningful 1-step commands with or without support (e.g., repetition, gestures) |

| PROFOUND                    | Uses nonverbal or single words, gestures and/or signs to indicate basic needs |
| IQ: < 20-25 (± 5) Percentile| A few words possible |
| scores: Below the first AE: | May appear non-interactive |
| 0-3 years                   | 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**: Includes the ability to perform daily activities and manage self-care.
- **Communication**: Refers to the ability to convey messages effectively.
Adaptive Functioning & Communication Tools

www.tdsb.on.ca

Informed Consent Tool

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 healthcare 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.
Informed Consent Tool

Other Tools Available Online

- 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

Caregiver Tools: Weight Chart

<table>
<thead>
<tr>
<th>Week</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
<th>Sept</th>
<th>Oct</th>
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<th>Dec</th>
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</tbody>
</table>

Notes: ____________________________

Adapted from New York State Source
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: ________

PROTOCOL IN PLACE

YES  NO

When recording B.M.'s, note both SIZE:  L = Large  M = Medium  S = Small
and TYPE:  H = Hard  S = Soft  D = Diarrhea
e.g., Large soft stool = L S or L 3 or L 4

(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 |
|------|---|---|---|---|---|---|---|---|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
| 1st Stool |   |   |   |   |   |   |   |   |   |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| 2nd Stool |   |   |   |   |   |   |   |   |   |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| 3rd Stool |   |   |   |   |   |   |   |   |   |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
| 4th Stool |   |   |   |   |   |   |   |   |   |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |

Protocol used, when?

Notes:

Adapted from New Vista's Bowel

Bristol Stool Chart

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

Use M for when sleep medication is given

<table>
<thead>
<tr>
<th>TIME</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12 (Midnight)</th>
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</thead>
<tbody>
<tr>
<td>AM</td>
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<th>DATE</th>
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</table>

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
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

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
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/m^2
- 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?**
“Death By Indifference”

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

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

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 Heath and Wellbeing in Developmental Disabilities conference at [http://www.healthandwellbeingindd.ca/](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
Selected Primary Care References


Selected Primary Care References

- Primary Care of Adults with Developmental Disabilities Canadian Consensus Guidelines (and tools): http://www.surreyplace.on.ca/Primary-Care/Pages/Home.aspx