

# Nothing About Us Without Us: A Patient-Informed, Inter-professional Health Check Model for Adults with Intellectual and Developmental Disabilities

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**St. Michael's**

Inspired Care.  
Inspiring Science.



# Disclosure

No conflicts of interest

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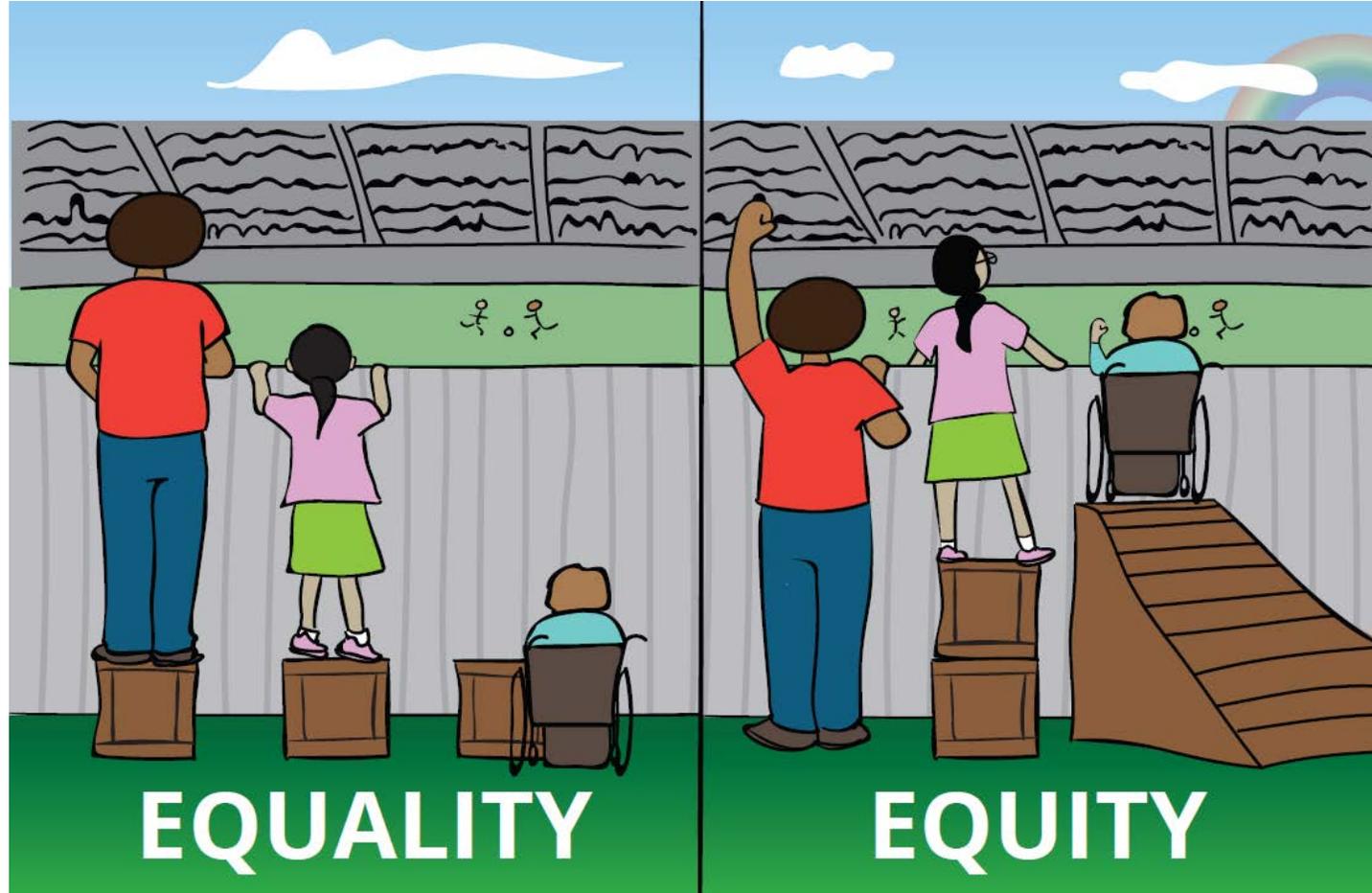
Consulting Fees: none

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# Objectives

- Understand how to complete the annual health check in an inter-professional team.
- Understand how to solicit and incorporate the priorities of patients with IDD.
- Learn about the co-construction of the roles of inter-professional disciplines/clinic staff.
- Learn how to use educational links and EMR tools to provide guideline-based care.

# Before we begin



**EQUALITY**

**EQUITY**

# Definition of IDD

- Onset <18 years old
- Lifelong
- Affect areas of major life activity (such as personal care, language, learning, independent living etc.)
- Intellectual disability (low IQ)

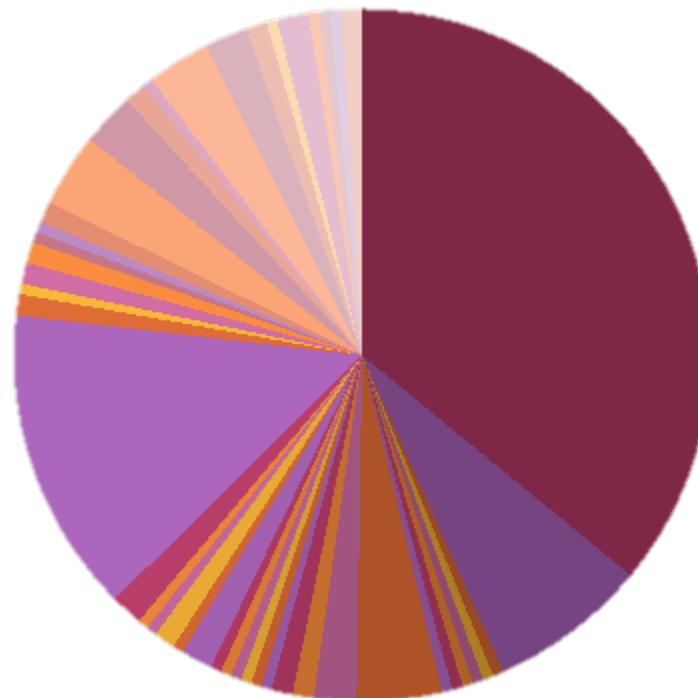
- Borderline: 71+
- Mild: 55-70
- Moderate: 40-50
- Severe: 25-35
- Profound: <25

IQ below 70-75\* is generally required to access publicly-funded developmental services

# Finding Patients with IDD

|                               |    |
|-------------------------------|----|
| Developmental Delay           | 73 |
| Developmental Disability      | 15 |
| Developmental Delay Severe    | 1  |
| Mild Developmental Delay      | 1  |
| Mild Developmental Disability | 1  |
| Severe Developmental Delay    | 1  |
| Profound Developmental Delay  | 1  |
| Borderline DD                 | 1  |
| ? Developmental Delay         | 8  |
| Intellectual Disability       | 4  |
| Intellectual Impairment       | 2  |
| Intellectual delay            | 2  |
| intellectual                  | 1  |
| Intellectually delayed        | 1  |
| IQ #                          | 1  |
| mild intellectual delay?      | 1  |
| mild intellectual delay       | 1  |

|                                     |    |
|-------------------------------------|----|
| mild intellectual delay?            | 1  |
| mild intellectual delay             | 1  |
| Borderline Intellectual Functioning | 1  |
| Mild MR                             | 3  |
| Borderline Mental Retardation       | 1  |
| MR                                  | 2  |
| Low Functioning MR                  | 1  |
| Severe MR                           | 1  |
| Mild/moderate MR                    | 3  |
| Autism                              | 29 |
| Autism?                             | 2  |
| Autistic Spectrum                   | 1  |
| Autistic                            | 2  |
| ASD                                 | 2  |
| Severe Autism                       | 1  |
| Autism mild                         | 1  |
| Asperger's                          | 2  |



46 different terms were found in a chart audit at St Mikes FHT

# Health of Adults with DD – Ontario Data

## Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario

December 2013



camh  
Centre for Addiction and Mental Health  
Centre de recherche et d'intervention en santé mentale



<http://www.hcardd.ca>

St. Michael's

# Health of Adults with DD – Ontario Data

## More likely to:

- Live in poorer neighbourhoods
- Have higher rates of chronic disease & morbidity
- Present to the ED
- Have avoidable hospitalization
- Have higher rates of polypharmacy

## Less likely to:

- Have a comprehensive health exam (22%)
- Be screened for breast, colon, & cervical cancer
- Receive guideline-recommended inter-professional care.



# Health of Adults with DD – SMH Data

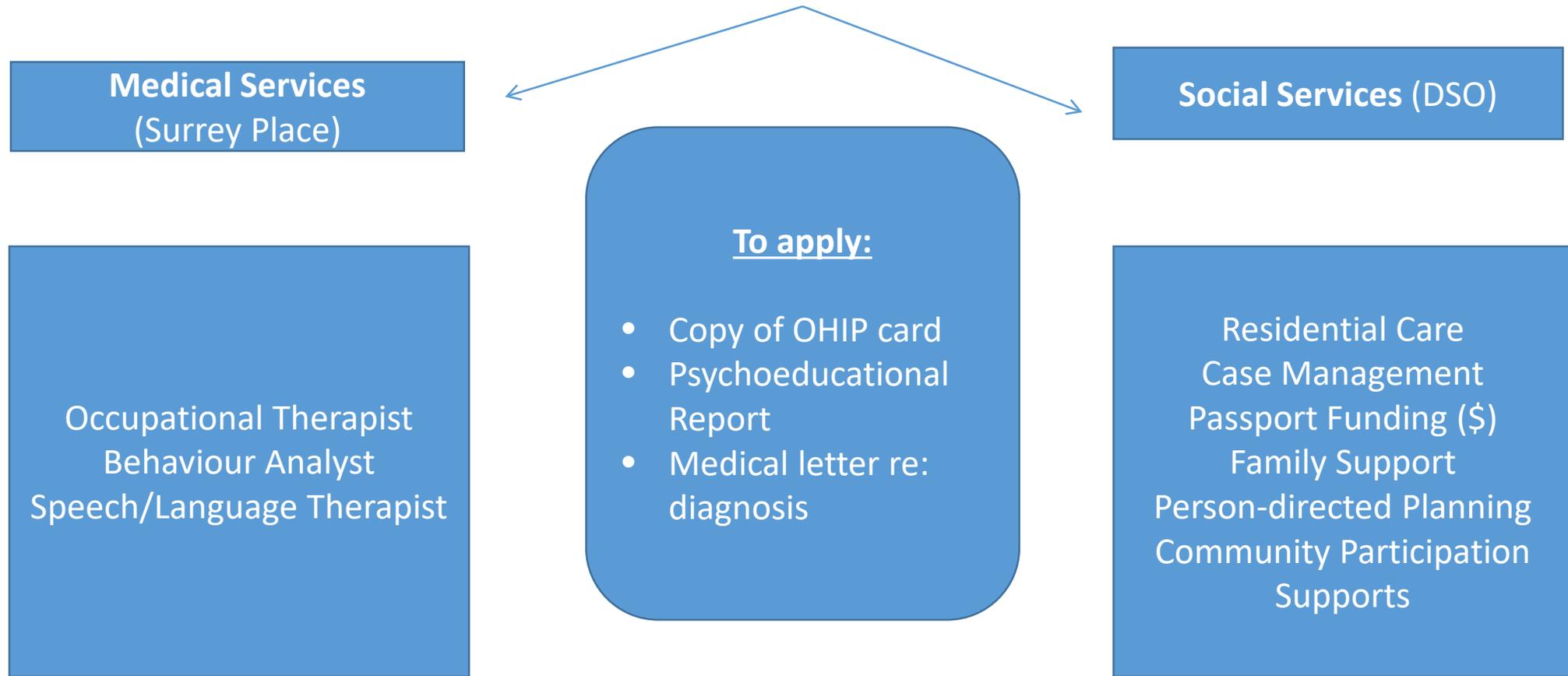
- lowest 2 income quintiles: 55%
- Residence: 42% with family (44% completed health check)
  - 24% independent (22% completed health check)
  - 17% group home (30% completed health check)
  - 12% boarding/shelter ( 4% completed health check)
- DSO registration
  - 30% are connected (but what waiting lists are they on?) ✓
  - 30% have had contact (but we don't know if eligible or not)
  - 40% no connection (but could be eligible?)

# Connection to Developmental Services Ontario

- Gateway to developmental services (waiting lists)
  - Passport funding (\$ to buy services)
  - Residential waiting list
  - Person-directed planning
  - Family Support
  - Community Participation supports (i.e. funded day program spot)
  - Short-term Case management
- **Obtain consent** to know if patient is a) eligible, and b) on any of the waiting lists.
  - 30% are connected (but what waiting lists are they on?) ✓
  - 30% have had contact (but we don't know if eligible or not)
  - 40% no connection (but could be eligible?)



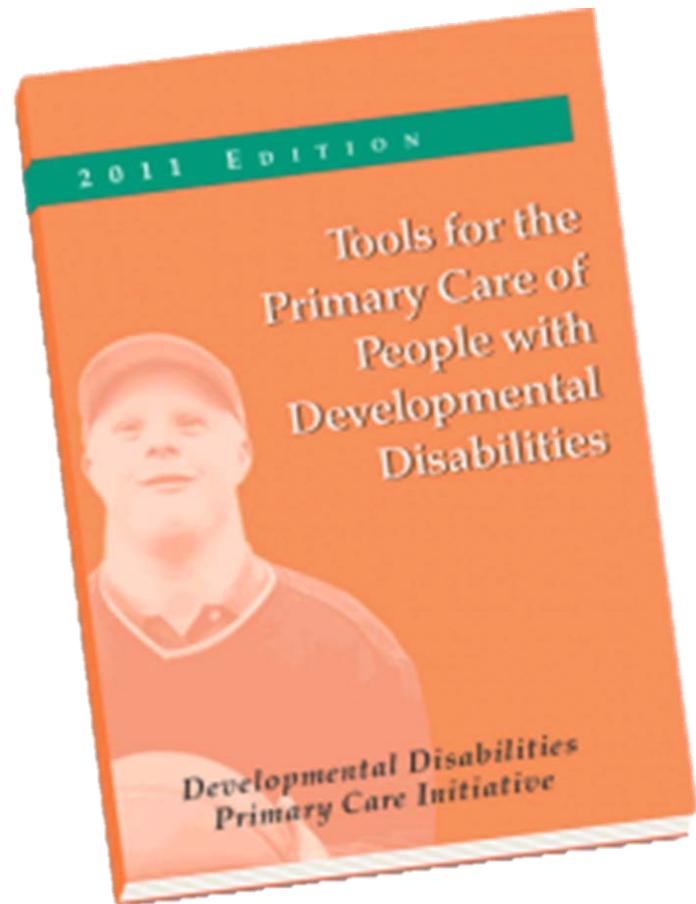
# Connection to Developmental Services Ontario



# COMPLETING THE ANNUAL HEALTH CHECK



# Primary Care Guidelines and Tools for Adults with IDD



## Clinical Review

### Primary care of adults with developmental disabilities

#### *Canadian consensus guidelines*

William F. Sullivan MD CCFP PhD Joseph M. Berg MBBCh MSc FRCPsych FCCMG Elspeth Bradley PhD MBBS FRCPC FRCPsych  
Tom Cheetham MD CCFP Richard Denton MD CCFP FCFP FRRMS John Heng MA Brian Hennen MA MD CCFP  
David Joyce MD CCFP Maureen Kelly RN MPA Marika Korossy Yona Lunsky PhD CPsych Shirley McMillan RN MN CDDN

#### Abstract

**Objective** To update the 2006 Canadian guidelines for primary care of adults with developmental disabilities (DD) and to make practical recommendations based on current knowledge to address the particular health issues of adults with DD.

**Quality of evidence** Knowledgeable health care providers participating in a colloquium and a subsequent working group discussed and agreed on revisions to the 2006 guidelines based on a comprehensive review of publications, feedback gained from users of the guidelines, and personal clinical experiences. Most of the available evidence in this area of care is from expert opinion or published consensus statements (level III).

**Main message** Adults with DD have complex health issues, many of them differing from those of the general population. Good primary care identifies the particular health issues faced by adults with DD to improve their quality of life, to improve their access to health care, and to prevent

KEY POINTS As a group, adults with developmental disabilities (DD) have poorer health and greater difficulty accessing primary care than does the general population. They have different patterns of illness and complex interactions among comorbidities. These guidelines update the general, physical, behavioural, and mental health recommendations for adults with DD, especially for those conditions not screened for by routine health assessments of the general population. Ethical issues, such as informed consent and assessment of benefits in relation to risks, are addressed. Among the most important updates are consideration of atypical manifestations of pain and distress in adults with DD and a strong recommendation

# Efficacy of Health Checks

## Comprehensive health exam leads to:

- 6.6 fold increase in detection of vision impairment
- 30 fold increase in hearing testing
- Increase in immunization rates
- Increase in women's health screening
- Increase in new disease detection



# Primary Care Guidelines and Tools for Adults with IDD

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## Tools for primary care providers

[Introduction and Acknowledgments](#)

*Forms which may be helpful in care of adults with developmental disabilities (DD) are in italics*

### General Issues in Care of Adults with DD

- [Genetic Assessment: Frequently Asked Questions](#)
- [Intellectual and Adaptive Functioning in Adults with Developmental Disabilities \(DD\)](#)
- [Psychological Assessment: Frequently Asked Questions](#)
- [Informed Consent in Adults with Developmental Disabilities \(DD\)](#)
- [Communicating Effectively with People with Developmental Disabilities \(DD\)](#)
- [Office Organizational Tips](#)
- [Today's Visit – Main Reason for Today's Visit](#)
- [Advocacy Role of Primary Care Providers](#)
- [Community Resources in Ontario](#)

### Physical Health Tools

- [Cumulative Patient Profile \(CPP\)](#)
- [Preventive Care Checklist – Females](#)
- [Preventive Care Checklist – Males](#)

### Health Watch Tables for Specific Syndromes

Health Watch Table – Down Syndrome

## Health Watch Table – Down Syndrome

Forster-Gibson and Berg 2011

| CONSIDERATIONS                                                                                                                                                                            | RECOMMENDATIONS                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)</b>                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Children and Adults: Vision:<br>~15% have cataracts;<br>~20% - 70% have significant refractive errors<br>5% - 15% of adults have keratoconus<br>Hearing: 50% - 80% have a hearing deficit | <input type="checkbox"/> Neonatally: refer immediately to an ophthalmologist if th absent or if strabismus, nystagmus or poor vision is ider<br><input type="checkbox"/> Arrange ophthalmological assessment: first by 6 months every 1-2 years, with special attention to cataracts, kera refractive errors.<br><input type="checkbox"/> During childhood: screen vision annually with history an as needed.<br><input type="checkbox"/> Arrange auditory brainstem response (ABR) measurem months if newborn screening has not been done or if re suspicious.<br><input type="checkbox"/> During childhood: screen hearing annually with history a review risks for frequently occurring serious otitis media<br><input type="checkbox"/> Undertake auditory testing: first at 9 – 12 months, then i up to 3 years, annually until adulthood, then every two y                                                                                                                                                                                                                                             |
| <b>2. DENTAL</b>                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Children and Adults:<br>Tooth anomalies are common<br>Increased risk of periodontal disease in adults                                                                                     | <input type="checkbox"/> Undertake initial dental exam at 2 years, then every 6 m thereafter. Encourage proper dental hygiene. Refer to a needed.<br><input type="checkbox"/> Undertake clinical exams every six months with referral, appropriate.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>3. CARDIOVASCULAR</b>                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Children: 30% - 60% have congenital heart defects (CHD)<br>Adults: ~ 50% have cardiovascular concerns, commonly acquired mitral valve prolapse (MVP) and valvular regurgitation           | <input type="checkbox"/> Newborn screening: Obtain an echocardiogram and ref cardiologist, <b>even in the absence of physical findings.</b><br><input type="checkbox"/> In children and adolescents: review cardiovascular hist for physical signs with specialist referral, if indicated. <ul style="list-style-type: none"> <li>• Refer for an echocardiogram if not previously done</li> <li>• Undertake SBE prophylaxis as indicated by findings</li> </ul> <input type="checkbox"/> Ascertain a comprehensive cardiovascular history.<br><input type="checkbox"/> Undertake an annual cardiac exam, with echocardiogra new abnormal findings and follow-up depending on the cardiovascular problem present or refer to an Adult Con specialist or Disease clinic.<br><input type="checkbox"/> Monitor regularly those that have had surgery in childho<br><input type="checkbox"/> An echocardiogram is indicated to assess new abnorm findings or if unable to assess adequately by physical e: echocardiogram to establish baseline cardiac anatomy i not previously done or records are unavailable. |
| <b>4. RESPIRATORY</b>                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Children and Adults: 50% - 80% have obstructive sleep apnea (OSA)<br>Adults: 50% - 80% have obstructive sleep apnea (OSA)                                                                 | <input type="checkbox"/> Newborn: Refer to an ENT surgeon if recurring otitis me<br><input type="checkbox"/> Treat infections promptly and aggressively.<br><input type="checkbox"/> Ascertain a detailed sleep history, with special attention symptoms. Refer to an ENT surgeon, including sleep st suspected.<br><input type="checkbox"/> If aspiration pneumonia is suspected, investigate for poi swallowing disorder and gastro-esophageal reflux disea                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |

Preventive Care Checklist Form – Female

**Preventive Care Checklist Form for adult females with a developmental disability (DD)**

*Original developed by: Dr. V. Dubey, Dr. R. Mathew, Dr. K. Igar. 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.

Name: \_\_\_\_\_ (last, first)  
 Address: \_\_\_\_\_  
 Tel. No: \_\_\_\_\_  
 DOB (dd/mm/yyyy): \_\_\_\_\_  
 Health Card Number: \_\_\_\_\_  
 Date of Visit: \_\_\_\_\_

**Etiology of DD, if known:**  
 Capable  Guardian  Substitute Decision Maker  
 Power of Attorney  Public Guardian & Trustee  
**Advance Care Planning Needs:** \_\_\_\_\_

**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, Fibre, Calcium, Sodium  
 Exercise/Obesity: \_\_\_\_\_  
 Day Program/Work: \_\_\_\_\_  
 Family: \_\_\_\_\_  
 Relationships (recent changes?): \_\_\_\_\_  
 Smoking: \_\_\_\_\_  
 Alcohol: \_\_\_\_\_  
 Illicit Drugs: \_\_\_\_\_  
 Sexual History: \_\_\_\_\_  
 Family Planning/Contraception: \_\_\_\_\_  
 Sleep: \_\_\_\_\_

**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"/> |                                      |
| Fail assessment (if indicated): | <input type="checkbox"/> |                                      |
| Derm:                           | <input type="checkbox"/> |                                      |
| Neuro:                          | <input type="checkbox"/> |                                      |

**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:

**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 IUI; 800-1000 IUI > 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

**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

**Oral Hygiene (q6mths)**  
 regular dental care  
 brushing/flossing teeth  
 fluoride (toothpaste/supplement)  
 tooth scaling and prophylaxis  
 smoking cessation

# Common co-morbidities

- GERD
- H. pylori
- Epilepsy
- Osteoporosis
- Mental health
- Syndrome-specific common conditions
  - E.g. Down Syndrome: hypothyroidism, obesity, early-onset dementia

## Commonly Missed Diagnoses: Head-to-Toe Assessment

- H** Headache and other pain, or Hydrocephalus related issue (ex. Shunt Malfunction)
- E** Epilepsy
- A** Aspiration pneumonia or dysphagia
- D** Drugs! Patients are at high risk for adverse effects or polypharm  
*Have a follow up plan if prescribing psychot*
- T** Teeth! Dental abscesses or impacted teeth can cause pain, egg food refusal
- O** Ocular or Otolaryngology issue – Vision problem, Hearing issue, (Sleep Apnea (up to 80%))
- T** Tummy – GERD, Constipation, Bowel obstruction and volvulus
- O** Osteoporosis and atypical fractures, pressure sores
- E** Etiology or cause of IDD - Is it known? – some genetic syndromes (ex. Cal)
- S** Serious illness can present atypically – ask caregivers how this p is then
- S** Screen for abuse

### All Behaviour is Communication!

\*Listen to Caregivers \*Ensure access (reduce noise, community supports) \*Look for a Care Plan \*Wallet

**Do you suspect a patient you are seeing has not been identified? Refer to Develop**

(Do you think your patient might benefit from a Coordinated Care needs? Refer to "Health Link")

## Systems Review in Primary Care for People with DD

**Endo:**

- Thyroid: higher incidence in DD
- DM : increased rates in Down Syndrome
- Low testosterone: increased prevalence

**Neuro:** Increased prevalence of seizure activity.

**Vision:**

- Check annually in office;
- Optometry q 5 yrs if >45

**Hearing:**

- Whisper Test in office;
- Check for/remove cerumen;
- Audiogram q 5 years if >45

**Dental:**

- Check dentition in office
- \*common trigger for behavior change

**Cardiac:**

- Screen earlier;
- Prevalence of CVD

**GI:**

- Screen for GERD , constipation, PUD – annually and if behaviour;
- H-Pylori if symptomatic or if living in group home; retest H-Pylori 3-5 yrs.

**Sexuality:**

- Assess fertility and genetic risks
- Discuss masturbation, contraception, menses
- Higher likelihood/history of abuse

**Cancer Screening**

- Cervical: pap (if sexually active/remember abuse)
- Breast: **annual** breast screening > 50 years
- Testicular: testicular exam
- Colon: rectal exam > 45 years, colon cancer > 50 years

**Resp:**

- Screen aspiration annually
- (Risks: group home; frequent throat clearing; drooling; long meal times; chronic infections; choking)

**Weight/Height/BMI:**

- Treat obesity;
- Use waist circumference if non-ambulatory

**MSK:**

- Higher prevalence of Scoliosis, Contracture, spasticity, Osteoporosis
- Assess risk at all ages.
- Consider BMD at earlier age
- Refer to OT/PT/Physiatry

**Immunizations**

- Influenza
- Strep pneumonia (if at risk)
- HPV (if at risk)
- Hep A/B

### Common causes for Behaviour Change:

Pain/discomfort/infection (dental, GI etc.) environmental stressor/change, loss/grief

Adapted from Sullivan et al. (2011) Primary Care of Adults with Developmental Disabilities, *Can Fam Physician*, 57, 541-553.



# Importance of inter-professional team in the health check

**9. interdisciplinary health care** is effective in addressing the complex needs of adults with DD. Ideally this would involve a family physician, nurse, and other health practitioners as required, with a coordinator, who might be the family physician, to ensure continuity of care.<sup>46, 47</sup>

→ Involve other available health professionals as needed.<sup>46</sup> To address complex physical, behavioural or mental health needs, consult available regional service coordination agencies or specialized interdisciplinary teams.<sup>48, 49</sup>

# Improving inter-professional access at our site

- Inter-professional faculty development (low level of confidence – Durbin 2016)
- Consultation with adults with IDD re: health care experience
- Feedback /consultation with inter-professional teams by study leads and self-advocates:
  - Dietitians
  - Pharmacists
  - RNs
  - NPs
  - Social Workers
  - Income Promoters
  - Clerical Staff
  - MDs
- Use of EMR tools to create patient-specific pathways for health check
- Evaluation of staff perceived knowledge and comfort
- Payment to participants

# Inter-professional Referral Template

- Check-list that is at end of each DD-CPX
- Prompts for inter-professional referral
- Ideally, linked to a live referral (not in place yet)

Inter-professional Check List – “DD” CPX (DRAFT)

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                   |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------|
| <b>Area of Care</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |                                                   |
| <b>Medicine and NP</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                                   |
| <ul style="list-style-type: none"> <li>• Patient presenting for DD-CPX – complete and indicate <u>inter-professional referrals</u> (below)</li> <li>• Optimize patient understanding using the <b>Today's Visit</b> to summarize</li> </ul> Comments:                                                                                                                                                                                                                                                                    |                                                   |
| <b>Nursing</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                                                   |
| <ul style="list-style-type: none"> <li>• Ask 3 communication or care tips of patient/caregiver (things pt likes/dislikes) and put this in the <b>personal section - Communication</b></li> <li>• Use the <b>DD-CPX</b> (including a review of patient's vision, hearing and dental history).</li> <li>• Offer health education to patients re: screening prep and procedures (<b>using Easy Read guides</b>)</li> <li>• Optimize patient understanding using the <b>Today's Visit</b> to summarize.</li> </ul> Comments: |                                                   |
| <b>Social Work</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                   |
| <input type="checkbox"/> Does patient need service navigation? Unsure whether receiving appropriate services? (DSO)<br><input type="checkbox"/> Are there informal caregivers? Do you worry about burnout? Needing respite? Caregiver mental health?<br><input type="checkbox"/> Are there long-term planning needs? (i.e. how long is housing tenable for)?<br><input type="checkbox"/> Would patient be interested in counselling? (anxiety, trauma, depression)                                                       | <input type="checkbox"/> Refer to SW              |
| Comments/Notes:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                   |
| <b>Dietician</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                   |
| <input type="checkbox"/> Is patient over weight, or under weight? (BMI <18; >25)<br><input type="checkbox"/> Would patient benefit from nutritional counselling, low-cost meal planning?                                                                                                                                                                                                                                                                                                                                 | <input type="checkbox"/> Refer to RD              |
| Comments/Notes:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                   |
| <b>Income Support</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                   |
| <input type="checkbox"/> Does patient need income optimization? (applications to ODSP, DTC, Passport Funding, RDSP, funding for equipment, etc.)                                                                                                                                                                                                                                                                                                                                                                         | <input type="checkbox"/> Refer to Income Promoter |
| Comments/Notes:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                   |
| <b>Pharmacy</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                   |
| <input type="checkbox"/> Is patient receiving more than 5 medications?<br><input type="checkbox"/> Are any <u>psychotropics</u> prescribed?<br><input type="checkbox"/> Formulation issues (e.g. G tube options)                                                                                                                                                                                                                                                                                                         | <input type="checkbox"/> Refer to Pharmacy        |
| Comments/Notes:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                   |
| <b>Need for specialist consultation services?</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |                                                   |
| OT, Behaviour Therapy, SLP → <u>Adult Services at Surrey Place Centre</u> (requires DSO eligibility)<br>All others: See the <u>DD Consult &amp; Resource List</u> (link on DD-CPX & in EMR handouts)                                                                                                                                                                                                                                                                                                                     |                                                   |

# Templates for inter-professional staff

| Discipline     | Areas                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Nursing</b> | <ul style="list-style-type: none"><li>• Ask 3 communication or care tips of patient/caregiver (things pt likes/dislikes) and put this in the <b>personal section - Communication</b></li><li>• Use the <b>DD-CPX</b> (including a review of patient's vision, hearing and dental history).</li><li>• Offer health education to patients re: screening prep and procedures (<b>using Easy Read guides</b>)</li><li>• Optimize patient understanding using the <b>Today's Visit</b> to summarize.</li></ul> |

| Discipline         | Areas                                                                                                                                                                                                                                                                                                   |
|--------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Social Work</b> | <ul style="list-style-type: none"><li>• Support referral to DSO; navigation.</li><li>• Assess caregivers for compassion fatigue; respite referrals</li><li>• Explore long-term housing needs/wishes</li><li>• Support patient mental health (trauma, abuse, anxiety, depression, attachments)</li></ul> |

# Templates for interprofessional staff

| Discipline             | Areas                                                                                                                                                                                                              |
|------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Dietician</b>       | <ul style="list-style-type: none"><li>• Provide intervention and education to patients with obesity, reflux, constipation.</li><li>• Access already existing clear language patient education materials.</li></ul> |
| <b>Income Promoter</b> | <ul style="list-style-type: none"><li>• Review patient's income to see if any optimizations available</li><li>• Offer assistance re: budgeting, planning.</li></ul>                                                |

# Templates for interprofessional staff

| Discipline                  | Areas                                                                                                                                                                                                                                     |
|-----------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Pharmacy</b>             | <ul style="list-style-type: none"><li>• Med review for any patient prescribed 5+ medications</li><li>• Review guidelines on Rapid Tranquilization, Antipsychotics</li><li>• Offer input re: alternate routes, formulations</li></ul>      |
| <b>Psychology</b>           | <ul style="list-style-type: none"><li>• Provide input on psychoeducational assessments and interpretation; support diagnostic clarification</li><li>• Offer short-term counselling, particularly for those with dual diagnosis.</li></ul> |
| OT, Behaviour Therapy, SLP? | <p>→ <u>Adult Services at Surrey Place Centre</u> (requires DSO eligibility)</p> <p>→ See the <u>DD Consult &amp; Resource List</u> (link on DD-CPX &amp; in EMR handouts)</p>                                                            |
| <b>All others:</b>          |                                                                                                                                                                                                                                           |

# Slide decks for each discipline

The Interprofessional care  
of Adults with  
Developmental Disabilities  
***Nursing***

The Inter-professional care  
of Adults with  
Developmental Disabilities  
***Social Work &  
Income Security Health Promotion***

# INVOLVING PATIENTS AND CAREGIVERS



- Patients/Community member with IDD
- Caregivers/family
- Research assistant
- Volunteers
- Project lead

# Invitation to Focus Groups

- Email to site leads to circulate using individual MD patient lists
- Email to site champions (RN's/NP's/social workers)
- Calls to patient by familiar medical staff
  
- Held on weekend
- Lunch provided/transportation if needed
- Wheelchair accessible venue
- Compensation \$

**Hello!** We would like to invite you to a meeting about health care!

We work at the St. Michael's Family Health Team. We would like to learn how to make health care better for people with disabilities.



#1) We are looking for people with disabilities who would like to share their ideas with us! Caregivers are welcome too! 

#2) We will have food, drinks and prizes! 

#3) Everyone will be paid for their time! 

**Interested? Yes!**

Date: Sunday, September 18th, 2016  
Time: 12:30-3:30 (lunch is included)

Where: 73 Regent Park Blvd. (at St Michael's Family Practice)  
To RSVP: Please email Andrea, at [perryan@smh.ca](mailto:perryan@smh.ca)



**We look forward to seeing you!**

St. Michael's  
Inspired Care.  
Inspiring Science.

# *Before the appointment*

- Staff on the phone speak too fast.
- A reminder phone call is very helpful.
- 15 minutes is too short!
- Using Wheeltrans is hard. If an appointment runs late, some people miss their Wheeltrans. This is horrible. Some people also will miss appointments.
- If we won't be seeing our doctor, we would like to know when we get there.
- People with mobility or behaviour challenges would like more home visits.
- Same day appointments are very helpful for us.
- Relationships are important. It's nice to be greeted by clerical staff with hello and have a conversation (instead of just asking for our health card).

# From a sister:

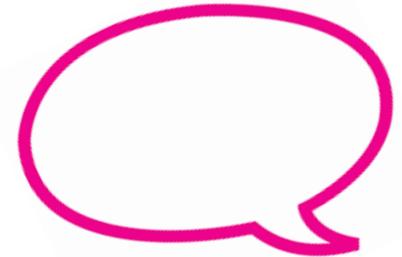
*“My sister gets agitated really quickly.*

*She starts making noises.*

*So when we are in the waiting room with 5 other people and she’s the only person making noise, the attention is all on her.*

*She can’t sit still in the waiting room.*

*We often leave and go for walks.”*



# Communication

- We usually do not understand all of the things you tell us.
- We would like things written out – simple, without big words.
- Sometimes we get voicemail messages. They are too fast.
- Some people find that questions make them feel bad. “Are you getting out more?” “How was your weekend?” – this can make them feel bad.
- Talk to the patient, not just the caregiver.
- It is important to give hope!
- Caregivers have lots of tips – this needs to be kept in the chart!

# From a parent:

*“There are two types – those that talk to us, and those that also talk to our son.*

*That is very nice.*

*When they talk just to me, that doesn’t feel nice.*

*So, even if he does not understand everything, I still want them to explain it to him.*

*He understands more than we think.*

*If you speak slowly, and clearly, he might understand more.”*



# Working with others on the team

- Most people (patients and their caregivers) do not know there are other team members!
- Some people might be nervous – they already have a pharmacist or a social worker. We need to know how this will be different - and that we won't lose the ones we already have!
- Once we learned about the other team members, we would like to meet them!
- It would be helpful if you could introduce us in person.

# Keeping us updated & seeking our feedback

## Ideas for Improving Care at the St. Michael's Family Health Team



Green means Go!

Red means No!



(Yellow means we are working on it) 

| Feedback you gave us                                                                 | Ideas we have talked about                                                                            | Update |
|--------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------|--------|
| <b>Booking appointments</b>                                                          |                                                                                                       |        |
| "Sometimes I might forget when my appointment is"                                    | - Clinic will call you twice (give an extra reminder phone call for your physical).                   |        |
| "15 minutes is too short."                                                           | - You can get a 30 minute appointment, if you ask when you book. (talk to your doctor about it too).  |        |
| "Wheeltrans – if appointment runs late, I can miss the ride home."                   | - let the clerical staff member know when you get there that you are on wheeltrans and can't be late. |        |
|                                                                                      | - we are trying to look at computer alerts                                                            |        |
| "Sometimes need appointment the same day."                                           | - when you call, say you need to be seen today ("it is urgent")                                       |        |
| "Staff speak too quickly on the phone."                                              | - we are reminding staff to speak more slowly.                                                        |        |
| "I would like an appointment the same day."                                          | - Tell the staff on the phone it is 'urgent'. You may not see your own doctor though.                 |        |
| "I sit on hold a long time. Can I book online?"                                      | - Unfortunately, we don't have this technology.                                                       |        |
| <b>In the Waiting Room</b>                                                           |                                                                                                       |        |
| "Sometimes it's really hard to wait in the waiting room. People stare at my sister." | - A separate space to go and wait.                                                                    |        |
|                                                                                      | - "Sensory basket" for each clinic.                                                                   |        |
| "CP24 can be upsetting. Anything else for the TV in the waiting room?"               | - Department is looking into other options.                                                           |        |

## Did you know?

### About Other Health Care Staff

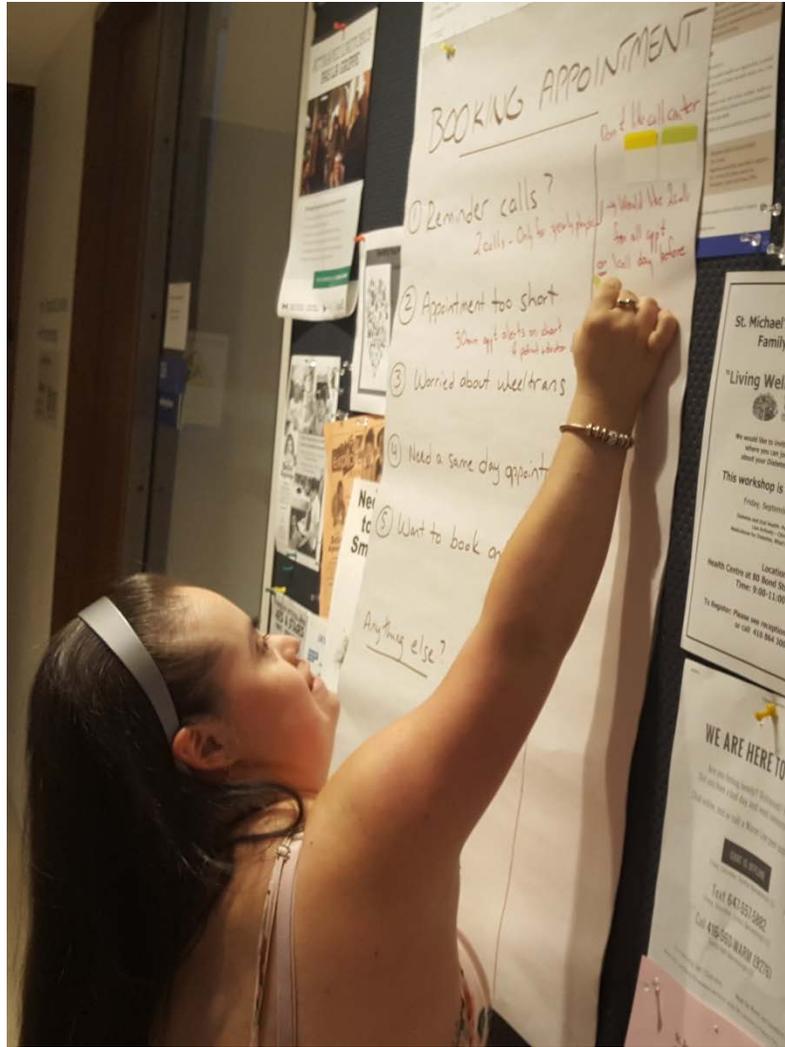
You probably already know Doctors and Nurses, but did you know there are lots of other people who work at the Family Health Team too? They can each help your health in different ways.

#### Who else works at the Family Health Team?

|                           |                                                                                        |                                                                                       |
|---------------------------|----------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| <b>Social workers</b>     | A Social Worker is someone that you can talk to about your feelings and mental health. |    |
| <b>Income Specialists</b> | Income specialists can help you to learn about budgeting and money.                    |    |
| <b>Dieticians</b>         | Dieticians can help you to learn about healthy food and your health.                   |    |
| <b>Pharmacists</b>        | The pharmacist can teach you about the medicines that you take.                        |    |
| <b>Chiroprapist</b>       | This is a foot doctor!                                                                 |    |
| <b>Lawyer</b>             | The lawyer can help you with legal problems (with your landlord, a boss etc.)          |    |
| <b>Physio/Chiro</b>       | The physiotherapist and chiropractor can help your muscles and back.                   |  |

\*\*The other team members work between the different clinic sites, so you might have to travel to another location to meet.\*\*

To learn more about the other team members, please talk with your doctor.



# Optimizing EMR tools

## **To complete annual Health Check:**

- DDCPX (male / female)
- Primary care graphic / Behaviours that Challenge graphic
- Health watch table if appropriate

## **To refer to interprofessional team:**

- Interprofessional template
- Social work / income support template / financial resources handout (patient/staff)

## **To support referrals and resource connections:**

- list of consultants with expertise
- LDSQ screening tool
- Today's visit

# Today's Visit

## TODAY'S VISIT

Please complete this with your patient during each encounter.

Name:

Date:

Why did I come to the clinic today?

What did they do?

When should I come back to the health clinic?

Do I have any other appointments?

*If Yes,*

Name:

Reason:

Where:

Date:

Other information for me or my caregivers:

(Things I should pay attention to? Things I should do differently? Other things?)

Were there changes to my medication? YES or NO

If yes:

1. Medication Name:

\_\_\_\_\_

I am to take this \_\_\_\_\_ times per day.

I am to stay on this for \_\_\_\_\_ days

Why do I need to take this?

2. Medication Name:

\_\_\_\_\_

I am to take this \_\_\_\_\_ times per day.

I am to stay on this for \_\_\_\_\_ days

Why do I need to take this?

Other things I should know about my medication?

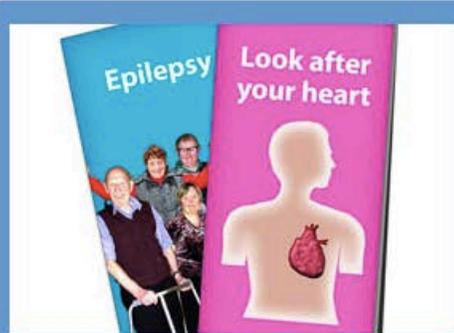
Are there any medicines that I don't need to take any more?

*Do I need any help getting or paying for my medication?*

Are there any questions I want to ask before I leave?

If I have questions once I am home, I can call the St Michael's clinic at:

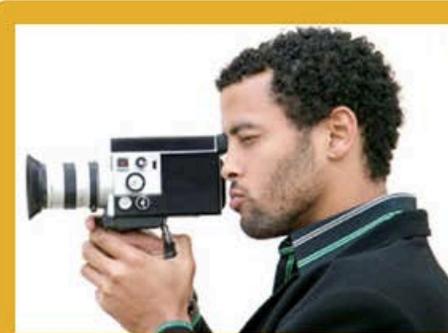
# Easy Read Guides – [easyhealth.org.uk](http://easyhealth.org.uk)



**Health Leaflets**



**Food and Exercise**



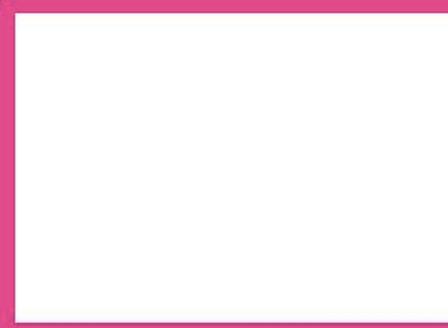
**Health Videos**



**Useful Things for  
your Health Care**



**Useful  
Organisations**



**About this  
website**



# Top 5 summary

- 1) Communication: speak to patient, get top 3 tips from caregivers, use a Today's Visit.
- 2) Take time.
- 3) Annual health check: use tools to help (primary care guidelines/Health Watch Tables) link EMR tools.
- 4) Team approach: inter-professional care, EMR tools.
- 5) DSO: get consent, register, check wait lists (especially Passport!)
  - know some services don't require DSO (i.e. Griffin Centre)

# Thank You!

[greenl@smh.ca](mailto:greenl@smh.ca)

Laurie Green  
Staff Physician  
St. Michael's Family Health Team

St. Michael's