



# **Community Networks of Specialized Care**

**Health Care Facilitators  
Educating Tomorrow's  
Healthcare Providers**



# Developmental Service History - Ontario

- 1876 – First institute
- 1974 – 16 Institutions supported 10,000 individuals
- 1977 – Deinstitutionalization started
- 2009 - Last Institution closed
- 50,000 people supported in institutions between 1876 and 2009
- 2015 - Government apology
- 2016 - \$103.7 million in 3 class action lawsuits

# Developmental Services Now

- Inclusion: local schools, jobs, social activities, community resources
- Single points of access using SIS, Common Application Tool, & Prioritization Tools
- Person directed planning
- Individualized funding options
- Range of supported residences
- Specialized Clinical Services when required
- Urgent Response Mechanism to address risk
- Multi sector care planning for people with complex support needs



## Community Network of Specialized Care

Through collaboration and coordination, we build efficient and effective cross-sectoral specialized service systems that support people with a developmental disability and mental health needs and/or challenging behaviour.

# Community Network of Specialized Care

- 4 Regions
- 7 Coordinators
- 1 French Language Coordinator
- 9 Health Care Facilitators
- Region Specific Coordinators (Research, Training, Video Conferencing)
- Administration Support
- \* Evolving to meet extraordinary support needs of people with complex multisector involvement

# Health Care Facilitator Initiative - 2011

Response to:

- Health care advocates / providers and educators within the former Institutes
- Health care research focused on intellectual developmental disability
- Canadian Consensus Guidelines on Primary of Adults with Developmental Disability (2006, 2011, 2018).

Hosted by CNSC due to correlation between physical and mental health. Nurse Practitioner, RN, RPN, Developmental Service Professionals

# Health Care Facilitator Roles

- Education & training of regulated health care professionals and students (English & French)
- Education & training of developmental services providers, clinicians, and students
- Development of health sector & developmental service sector partnerships: communication, collaboration, partnerships, protocols (Annual Health Checks, Crisis Protocols)
- Health care service navigation



# Education of Health Care Students

6 Ontario Medical Schools with 13 campuses

- All schools have DDME champions (Assistant Dean)
- All schools offer some DDME to medical students
- All schools would like to share DDME resources
- All would like to provide more DDME, but little room to add it to core curriculum
- 5 schools have direct involvement of CNSC Health Care Facilitators & Champion Educators



Northern Ontario  
School of Medicine  
École de médecine  
du Nord de l'Ontario  
פּוֹנְדוֹן אֶרֶץ  
לְיִשְׂרָאֵל אֶרֶץ



MD Program  
UNIVERSITY OF TORONTO



Queen's  
UNIVERSITY

# Education of Health Care Students

## Other:

- 14 Nursing Schools with multiple campuses in Ontario. 2 schools have direct involvement of Health Care Facilitator.
- Many more regulated health care professions (Dietitian, SLP, OT, PT, RT). HCF's always looking for opportunities (lectures, IPE...)
- 1 Dental Hygienist School has direct involvement of Health Care Facilitator
- 1 School of Kinesiology - Research Partnership with Health Care Facilitator

# Hamilton, Niagara, Brantford, Haldimand Norfolk Region

- 2,700 square miles (> half size of Connecticut )
- 1.3 million population (Dallas, Texas)
- 1,200 Family Physicians
- 10 Hospitals
- 1 Medical School (McMaster U – 2 campuses)
- 2 Nursing Schools (McMaster U & Brock U)
- 30 DS Organizations (3 Clinical)
- 1 Health Care Facilitator

# Nursing Students

**Brock**

McMaster  
University



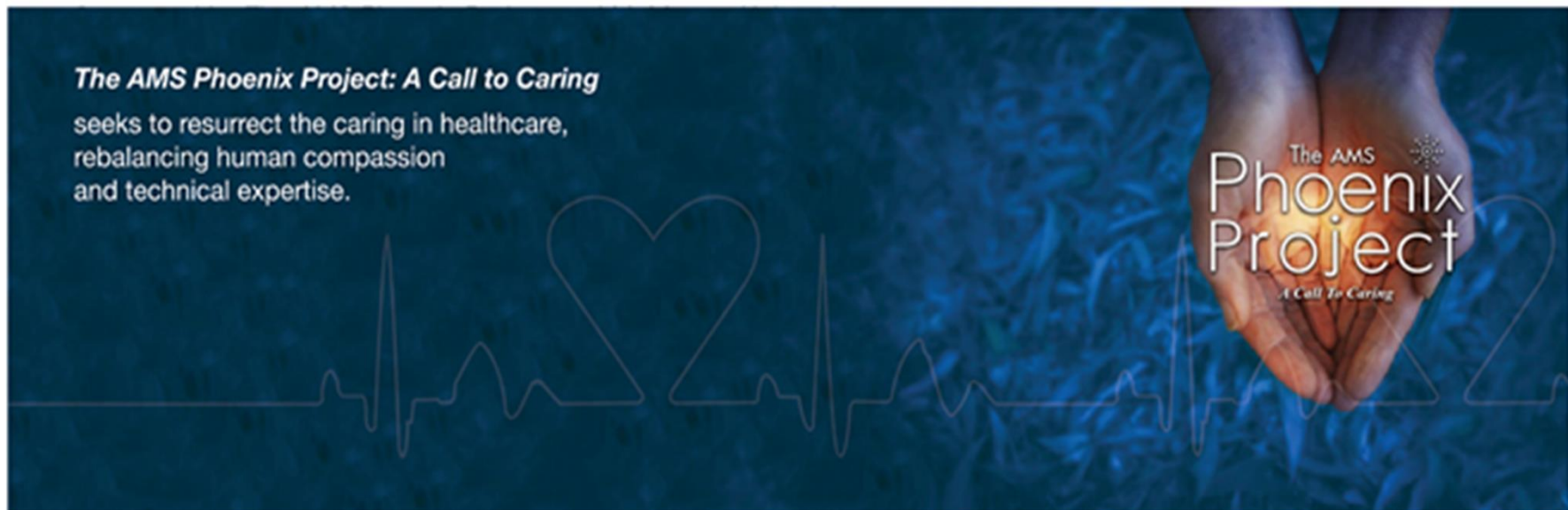
Inspiring Innovation and Discovery



School of Nursing

# Curriculum of Caring

Supported by The AMS Phoenix Project and McMaster University



**CommunicateCARE.machealth.ca**

[https://machealth.ca/programs/curriculum\\_of\\_caring/](https://machealth.ca/programs/curriculum_of_caring/)



**Dr. Kerry Boyd**

**Tom Archer**





Video:

<https://vimeo.com/134753630>





# Collaboration



## Curriculum of Caring



# Implementation

1) McMaster University Undergrad Medical Education - Niagara Regional Campus (2010-2013)

## Three Phases of NRC Medical Student Intervention

- 1) Early Exposure
- 2) Clinical/Communication Skills
- 3) Application in Clinical Setting

2) Brock Nursing & McMaster University Undergraduate Medical Education (2013-2014)

## Introduction into UME Curriculum

- 1) Developmental Disabilities Day
- 2) Pro Competency Session on Developmental Disabilities
- 3) Opportunity for Application

3) Communicate CARE (2013-2015)

## Web-Based Resources

- 1) Narratives of people with DD
- 2) Clinical Skills Primer with Modelling
- 3) Community of Practice (Expect Interviews with Links to Resources)



# Bethesda Day

Medical and nursing small groups with host

- Food
- Icebreaker
- Introduction to DD
- Rotation through three interactive activities with:
  - > DS Clinicians
  - > Adult day program
  - > Parents & Siblings
  - > Case discussion
  - > Evaluation



# Bethesda Day – Parent Perspective

Video:

<https://vimeo.com/92931697>



# Bethesda Day – Champion Educator Meet & Greet

Video:

<https://vimeo.com/92860026>



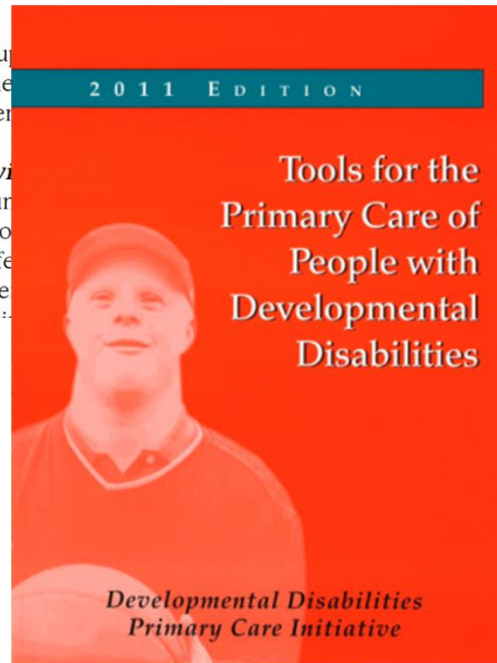
# Bethesda Day – Dev Dis Health Care Resources & Case Study

[www.surreyplace.on.ca/resources-publications/primary-care](http://www.surreyplace.on.ca/resources-publications/primary-care)

Clinical Review

## Primary care of adults with developmental disabilities *Canadian consensus guidelines*

William F. Sullivan MD CCFP PhD Joseph M. Berg MB BCh MSc FRCPsych FCCMG Elspeth Bradley PhD MBBS FRCP C 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 Lunskey PhD CPsych Shirley McMillan RN MN CDDN



| Health Watch Table — Down Syndrome   |   |
|--|---|
| Forster-Gibson and Berg 2011   |   |
| CONSIDERATIONS   | RECOMMENDATIONS   |
| <b>1. HEENT (HEAD, EYES, EARS, NOSE, THROAT)</b>   |   |
| <p>Children and Adults: Vision:<br/>- 15% have cataracts;<br/>- 20%-70% have significant refractive errors</p> <p>5% - 15% of adults have keratoconus</p> <p>Hearing: 50% - 80% have a hearing deficit</p> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Neonatally; refer immediately to an ophthalmologist if the red reflex is absent or if strabismus, nystagmus or poor vision is identified</li> <li><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</li> <li><input type="checkbox"/> During childhood: screen vision annually with history and exam; refer as needed</li> <li><input type="checkbox"/> Arrange auditory brainstem response (ABR) measurement by 3 months if newborn screening has not been done or if results were suspicious</li> <li><input type="checkbox"/> During childhood: screen hearing annually with history and exam; review risks for frequently occurring serous otitis media</li> <li><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</li> </ul> |
| <b>2. DENTAL</b>   |   |
| <p>Children and Adults: tooth anomalies are common</p> <p>Increased risk of periodontal disease in adults</p>  | <ul style="list-style-type: none"> <li><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</li> <li><input type="checkbox"/> Undertake clinical exams every six months with referral, as appropriate</li> </ul>  |
| <b>3. CARDIOVASCULAR</b>   |   |
| <p>Children: 30% - 60% have congenital heart defects (CHD)</p>   | <ul style="list-style-type: none"> <li><input type="checkbox"/> Newborn screening: Obtain an echocardiogram and refer to a cardiologist, given in the absence of physical findings</li> <li><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"> <li>• Refer for an echocardiogram if not previously done</li> <li>• Undertake SBE prophylaxis as indicated by findings</li> </ul> </li> </ul>  |
| <p>Adults: - 50% have cardiovascular concerns, commonly acquired mitral valve prolapse (MVP) and valvular regurgitation</p>  | <ul style="list-style-type: none"> <li><input type="checkbox"/> Ascertain a comprehensive cardiovascular history</li> <li><input type="checkbox"/> Undertake an annual cardiac exam, with echocardiogram to confirm new abnormal findings and follow-up depending on the type of cardiovascular problem present or refer to an Adult Congenital Heart specialist or Disease clinic</li> <li><input type="checkbox"/> Monitor regularly those that have had surgery in childhood</li> <li><input type="checkbox"/> An echocardiogram is indicated to assess new abnormal physical findings or if unable to assess adequately by physical exam. Consider echocardiogram to establish baseline cardiac anatomy and function if not previously done or records are unavailable<sup>1</sup></li> </ul>   |



Curriculum of Caring





# Communication / Clinical Skills Training



# Clinical Skills Training

Clearly

Attentively

Responsively

Engage





# Communicate CARE (2013-2015)

## Web-Based Resources:

- 1) Narratives of people with DD
- 2) Clinical Skills Primer with Modelling
- 3) Community of Practice (Expert Interviews and with Links to Resources)



# Communicate CARE – Narratives

Video:

<https://vimeo.com/92860026>



# Communicate CARE – Clinical Skills Primer with Modelling

Video:

<https://vimeo.com/125909092>



# Communicate CARE – Community of Practice (Expert Interviews)

Video:

<https://vimeo.com/145154734>



# Communicate CARE – Bio-Psycho-Social Wrap Around

Video:

<https://vimeo.com/146780581>



# Evaluation

How do we know we are making an impact?

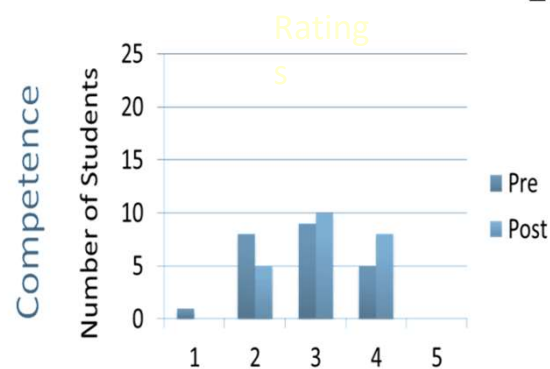
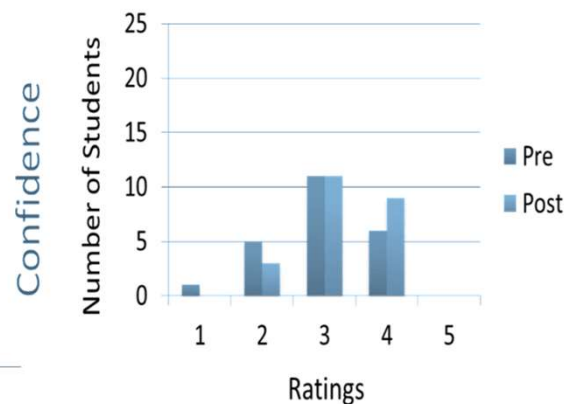
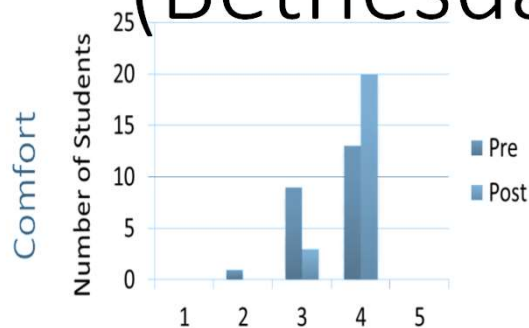
- Student Evaluations

How do we know that we are focusing on the right things?

- Health Care Focus Groups



# Evaluation - Student Evaluations (Bethesda Day)



## After Bethesda Day:

- “More comfortable now that I know I have more resources.”
- “The more exposure the better; great to hear from the mother.”
- “Level of confidence, competence, and comfort stems mainly from inexperience.”
- “I would be concerned about communication.”



# Evaluation - Student Evaluations (Bethesda Day)

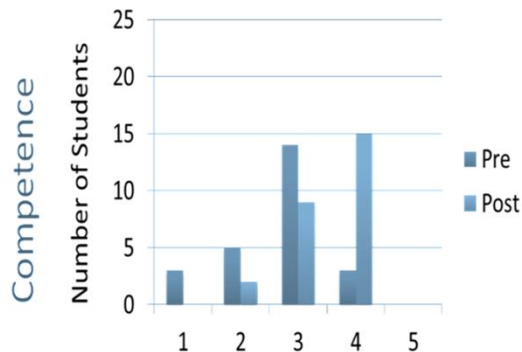
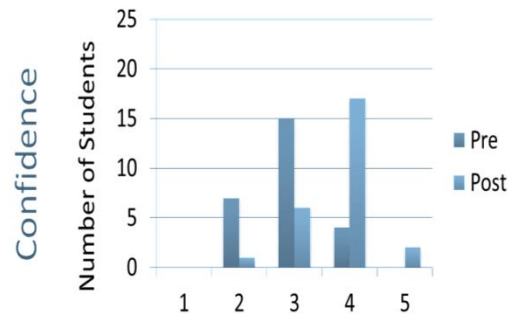
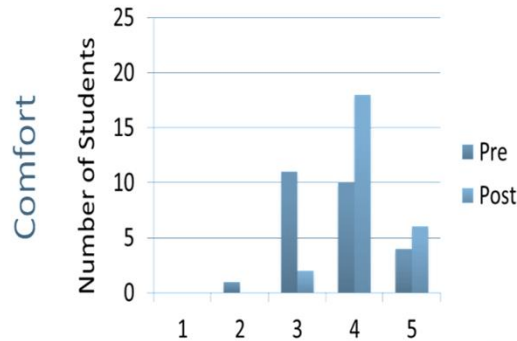
*The more experience the better!  
Every encounter makes me feel more  
confident and determined to learn  
more in order to best serve this  
population as a future family doc.*

- Everyone seems to love working here and it shows that I could totally manage it and be confident. Very eye-opening and enlightening.
- I would love the future experience of working with this population.
- This experience definitely improved my confidence in working with this population.
- Keep up the passion! Keep hosting Bethesda Day!!
  - I don't yet have enough experience to feel competent.
- Great learning experience and I would now love to look into nursing jobs that work with people with disabilities.
- I enjoyed each discussion group. It was very informative, well planned and interesting to meet the people in person.
- *Wonderful day, the presenters were all very informative and engaging and we received great resources.*
- The ability to hear different peoples stories. The heartache, the trouble in dealing with health teams and how they have improved.





# Evaluation – Communication Clinical Skills Training



Comments:

*“Clinical skills training helped immensely.”*

*“Clinical skills training made me more comfortable dealing with these people.”*

*“Our clinical skills sessions helped me feel more competent with this population. But more clinical experience will definitely be helpful.”*

*“...importance of collateral histories.”*





# A Curriculum of Caring for People with Developmental Disabilities: An Associated Medical Services Phoenix Project

Kerry Boyd<sup>1</sup>, Courtney Phillips<sup>2</sup>, Stephanie Stobbe<sup>1</sup>, Becky Ward<sup>2</sup>, Dawn Prentice<sup>2</sup>, Karl Stobbe<sup>2</sup>, Nick Kates<sup>2</sup>  
<sup>1</sup>McMaster University, <sup>2</sup>Brock University



## INTRODUCTION

A Curriculum of Caring for People with Developmental Disabilities (CD) for Clinical and Allied Health Students (CD) Phoenix Project was developed and presented to a number of campus leaders, administrators, and faculty providing health care services, with nearly unanimous support.

"A common history" of clinical skills training  
 "A common history" for a special class

The goal of the CD is to provide clinical skills training that is relevant and meaningful to all students, as well as to provide a forum for ongoing education and research for all students. Research into special needs training in educationally diverse (special education) students (CD and identity) has not been well represented in our literature. In addition, communication and interpersonal skills training is an essential component of the curriculum. The course suggests a theoretical approach, experiential learning approach, and reflection for all students (special needs, knowledge and skill) to provide a forum for a special class for all students. This course addresses the needs of students with disabilities, for any student, including those without disabilities, who are in a common history training course. A Curriculum of Caring for People with Disabilities is the goal.



## ACQUISITION OF CARING

The Ministry of Education (M.E.) of Ontario's Ministry of Health and Long-Term Care (M.H.L.C.) has been a leader in the Department of Learning and Health Services Disability Studies.

A Curriculum of Caring for People with Disabilities (CD) has been presented to a number of campus leaders, administrators, and faculty providing health care services, with nearly unanimous support.

- 1) Early exposure to clinical skills training and research in the special needs class and are provided with an overview of CD students' research and experiential learning from nursing research studies.
- 2) Common history of clinical skills training and research in the special needs class and are provided with an overview of CD students' research and experiential learning from nursing research studies. This is followed by an experiential learning approach.
- 3) Application of research in clinical skills training and research in the special needs class and are provided with an overview of CD students' research and experiential learning from nursing research studies. This is followed by an experiential learning approach.

## PROGRAM EVALUATION

Used local students from the Ministry of Education (M.E.) of Ontario's Ministry of Health and Long-Term Care (M.H.L.C.) for the CD. Research into special needs training in educationally diverse (special education) students (CD and identity) has not been well represented in our literature. In addition, communication and interpersonal skills training is an essential component of the curriculum. The course suggests a theoretical approach, experiential learning approach, and reflection for all students (special needs, knowledge and skill) to provide a forum for a special class for all students. This course addresses the needs of students with disabilities, for any student, including those without disabilities, who are in a common history training course. A Curriculum of Caring for People with Disabilities is the goal.

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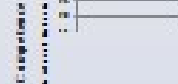
Initial Early Response 2012



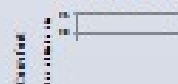
Enrolled Early Response 2012



Enrolled Early Response 2012



Enrolled Early Response 2012



Enrolled Early Response 2012



Enrolled Early Response 2012



Initial Early Response 2012



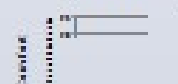
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Enrolled Early Response 2012



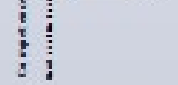
Enrolled Early Response 2012



Enrolled Early Response 2012



Enrolled Early Response 2012



## DISCUSSION AND CONCLUSIONS

The purpose of the Curriculum of Caring for People with Disabilities (CD) for Clinical and Allied Health Students (CD) Phoenix Project was developed and presented to a number of campus leaders, administrators, and faculty providing health care services, with nearly unanimous support.

The CD is a common history of clinical skills training and research in the special needs class and are provided with an overview of CD students' research and experiential learning from nursing research studies.

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## ACKNOWLEDGEMENTS

We would like to thank all participants in the Curriculum of Caring for People with Disabilities (CD) for Clinical and Allied Health Students (CD) Phoenix Project. We would like to thank all participants in the CD for their research and experiential learning from nursing research studies. This is followed by an experiential learning approach.

# American Medical Association Journal of Ethics

April 2016, Volume 18, Number 4: 384-392

## MEDICAL EDUCATION

The Curriculum of Caring: Fostering Compassionate, Person-Centered Health Care

Kerry Boyd, MD





## INTRODUCTION

- Individuals with a developmental disability (DD) experience disparity in their access to care, quality of service, and health care outcomes<sup>1, 2</sup>.
- The McMaster University, Michael G. DeGroote School of Medicine and Brock University, Department of Nursing are developing a Curriculum of Caring for Health Care Professionals (HCP) and students to address inequalities and training needs.
- There is a paucity of research asking individuals with a DD how health care providers can improve care.

## OBJECTIVE

- To involve people with DD as educators by soliciting their perceptions of health care experiences and advice to enhance the curriculum of caring for health care learners and professionals.

## METHODS

### SAMPLE

- 22 adults (5 male, 17 female).
- Urban and rural residents evenly distributed across Hamilton and Norfolk, Grandford, Hamilton, & Niagara.

### RECRUITMENT & DATA COLLECTION

- 2 pilot focus groups were held to test the study design.
- The study (approved by the Hamilton Integrated Research Ethics Board) was designed to reduce bias during recruitment and ensure participants were informed, involved and comfortable during recruitment and focus group discussions (3-4 people x 7 focus groups).
- A Health Care Facilitator and two students solicited participant responses to questions about health care experiences as well as advice to health care students and faculty.
- Focus group discussions were audio recorded and transcribed.
- Transcripts were independently analyzed for emerging themes and collated.
- Themes are being translated into recommendations for further curriculum development by study investigators.

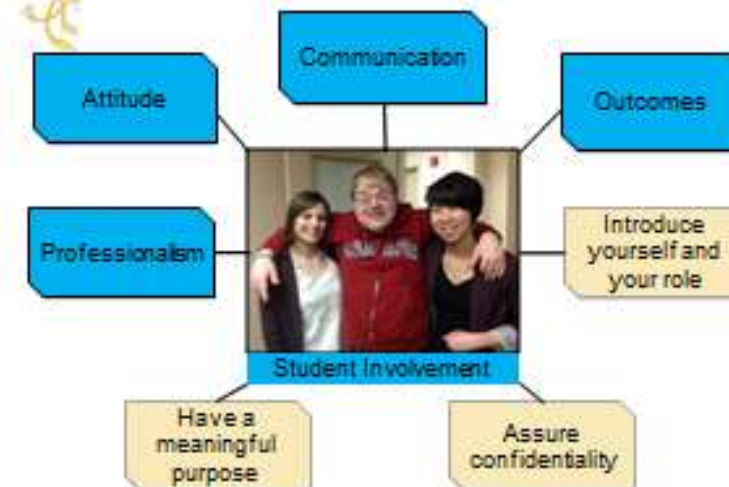
## REFERENCES

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- Luscky V, Klein-Galinski, JE, Yakes, EJ, eds. *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*. Toronto, Ont: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health; 2012.
- Sullivan, W, Berg, J, Bradley, E, et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician*. 2011 May; 67: 61-67.

## Health Care Experiences



## Student Experiences and Advice



## DISCUSSION

- Volunteers shared positive and negative health care experiences and expressed common themes for HCP encounters.
- Attitudes of HCP contributed to positive or negative experiences. Approaches that respected the person, fully included/informed them, and demonstrated kindness were praised (as with any person seeing a HCP).
- Barriers/challenges related to access and communication were frequently noted.
- There were various common, chronic and complex health concerns requiring a range of urgent, continuous or collaborative multi-disciplinary care. They want good care and outcomes.
- There was recognition students need to learn. Informed choice and consent, respectful attitudes, professionalism and purposeful involvement, were noted.

## CURRICULUM RECOMMENDATIONS

- Increase exposure to individuals with DD to influence attitudes of HCP (direct and video-based).
- Further enhance communication and clinical skills of health care students. Involve individuals with DD as simulated patients and include their input in evaluation.
- Reinforce the practice of multi-disciplinary and inter-professional approaches where there are complex needs.
- Promote learning resources that equip health care professionals to engage in best practices for assessment and treatment of this population.
- Partner as an agent of change to address barriers to excellent health care for all Canadians.

## ACKNOWLEDGEMENTS

McMaster University (Niagara-Regional Campus), Wilfrid Laurier University (Grandford Campus), Norfolk Association for Community Living, Community Living Hamilton, Mainstream, WACS Hamilton, Community Living Grant, Bethesda Services, and the Southern Network of Specialized Care.  
Sincere thanks to Jennifer Jeffrey (Bethesda), Nao Kiran (McMaster) and focus group facilitators: Lisa Whittingham (student Brock Centre for Applied Disability Studies), Gita Singh (student Brock Nursing) and Mariana Sanabro (student Brock Nursing). This study would not have been possible without the willing and active participation of the focus group members and their caregivers who provided a wide range of support for their participation. This is an *ISS Phoenix Project: A Curriculum of Caring*.



patients as educators

## Presence with purpose: attitudes of people with developmental disability towards health care students

Ginette Moores,<sup>1</sup> Natalie Lidster,<sup>1</sup> Kerry Boyd,<sup>1,2</sup> Tom Archer,<sup>2,3</sup> Nick Kates<sup>1</sup> & Karl Stobbe<sup>1</sup>

*Medical Education* 2015; 49: 731–739

doi: 10.1111/medu.12751

Discuss ideas arising from the article at  
[www.mededuc.com/discuss](http://www.mededuc.com/discuss).



<sup>1</sup>Michael G DeGroote School of Medicine, McMaster University, Hamilton, Ontario, Canada

<sup>2</sup>Bethesda Services, St Catharine's, Ontario, Canada

<sup>3</sup>Southern Networks of Specialized Care, Hamilton, Ontario, Canada

*Correspondence.* Ginette Moores, McMaster University Niagara Regional Campus, Cairns Family Health and Bioscience Research Complex, Brock University, 500 Glenridge Avenue, St Catharine's, Ontario L2S 2A1, Canada. Tel: 00 1 905 378 5717; E-mail: [ginette.moores@medportal.ca](mailto:ginette.moores@medportal.ca)



Rating  
**Curriculum of Caring**



# Antidotal Indicators

- Stories from Emergency Department
- Invitations to present to colleagues
- Invitations to Care Planning / Discharge Planning
- Prodding for additional projects (EQUIP: Hospital Passports)
- Request for resources (self and their residents)
- Upper year students assisting with Bethesda Day, Videos
- Involvement in updated Primary Care Guidelines





# Knowledge Translation

- Journal Publication
- Sharing & collaboration with other health care education centres
- Using Champion Educators and Videos with practicing Healthcare Professionals: Conferences, Grand Rounds, hospitals, Family Health Teams, Community Health Centres, Long Term Care Homes



# Additional DDME Resources

- American Academy of Developmental Medicine and Dentistry: <https://aadmd.org>
- MacHealth:  
[https://machealth.ca/programs/curriculum\\_of\\_caring](https://machealth.ca/programs/curriculum_of_caring)
- Health Care Access Research and Developmental Disability (HCARD):  
[www.porticonetwork.ca/web/hcardd/healthcareresources/clinicians-and-service-providers](http://www.porticonetwork.ca/web/hcardd/healthcareresources/clinicians-and-service-providers)
- Developmental Disabilities Primary Care Initiative:  
[www.surreyplace.on.ca/resources-publications/primary-care/](http://www.surreyplace.on.ca/resources-publications/primary-care/)



# Additional DDME Resources

- Dual Diagnosis Toolkit for Primary Care Providers:  
<https://dualdiagnosis.camh.ca>
- Vanderbilt Kennedy Center for Research on Human Development:  
<http://vkc.mc.vanderbilt.edu/etoolkit>
- Community Network of Specialized Care:  
[www.community-networks.ca/health-care](http://www.community-networks.ca/health-care)

# Transitional Planning Protocol

Cindy Chatzis, Healthcare Facilitator  
Southern Network of Specialized Care  
[cchatzis@wgh.on.ca](mailto:cchatzis@wgh.on.ca)



*Why did we start this project?*

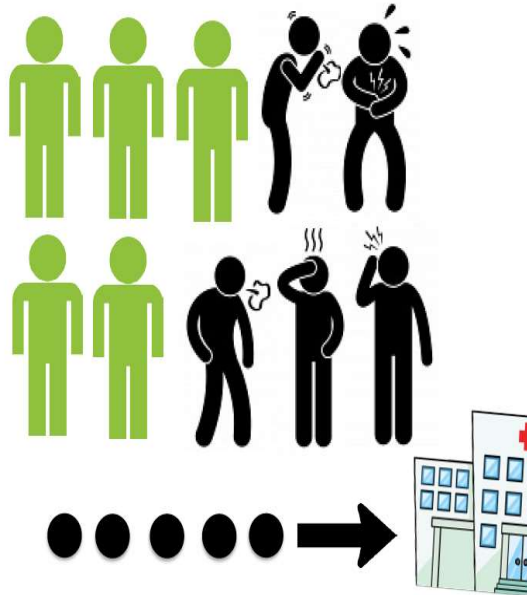






# What Does the Research Tell Us?

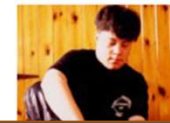
1 in 2 adults with a DD will go to the ED



## Epidemiology

Ontario population study on ED and DD, Lunskey et. al

- Average # of visits among ED users = 3.0 vs 1.7
- 1.7 times more likely to be admitted
- ED visits can be VERY IMPACTFUL



## Research Findings

Predictors of emergency visits in DD

- No crisis plan
- Living with family
- Previous emerg visits
- Gaps in primary care

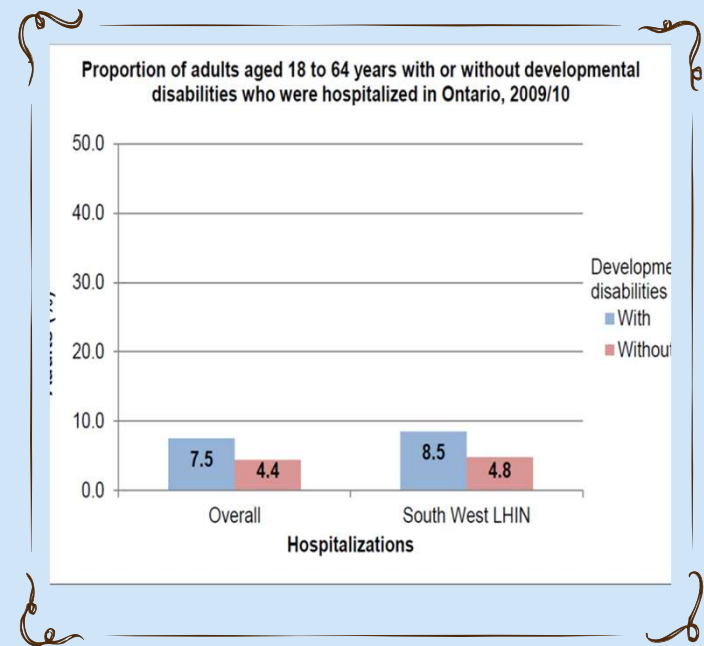
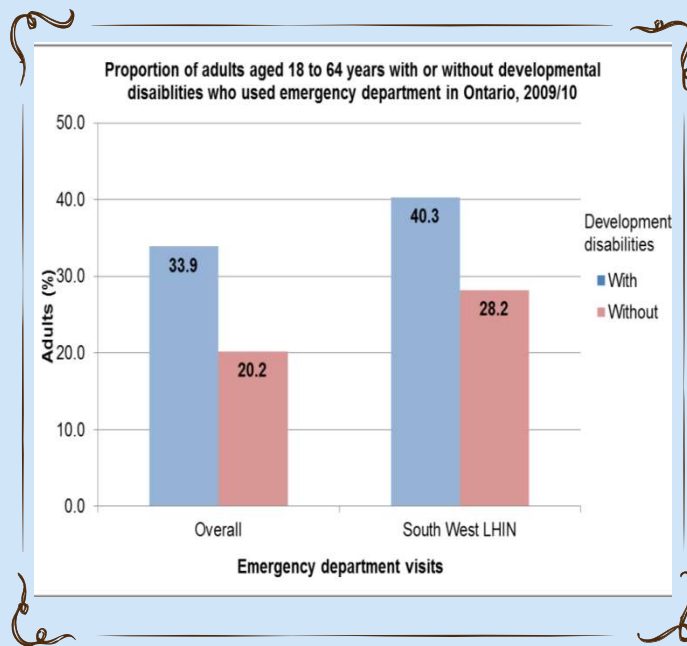
Health Care Access Research  
for Developmental Disabilities



Health Care Access Research  
and Developmental Disabilities

(Lunskey et al.,  
2013)

# Ontario stats...

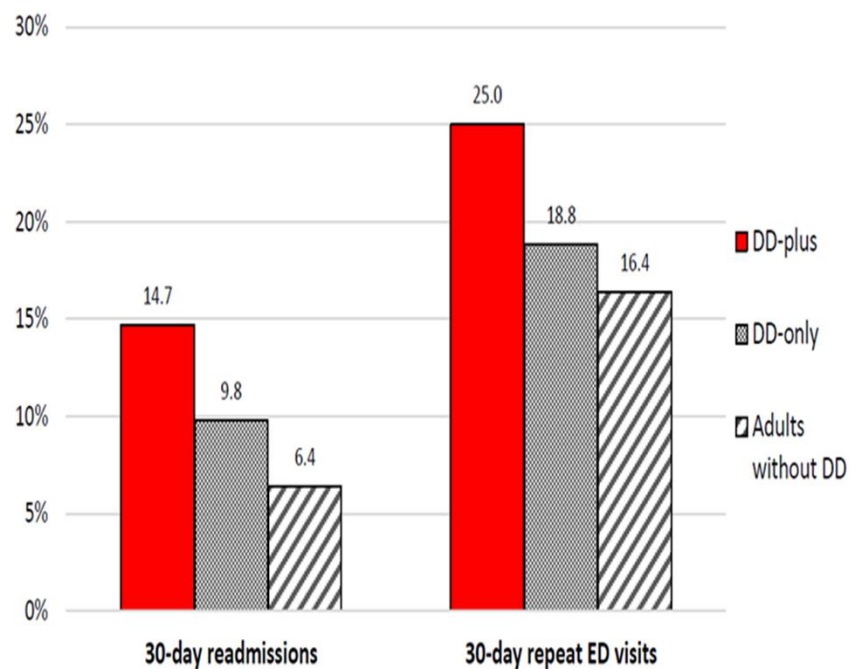


Hospitalizations are particularly stressful for people with I/DD  
They are at higher risk of being hospitalized and re-hospitalized.  
Most common reason is psychiatric or behavioural issues  
(Balogh, Hunter & Outlette-Kuntz, 2005)



# Repeat Visits/Admissions

## Repeat Service Use



| Population                  | Average Days ALC (2010/2011) |
|-----------------------------|------------------------------|
| Gen Pop with Mental Illness | 48 Days                      |
| Developmental Disability    | 59 Days                      |
| Dual Diagnosis              | 102 Days                     |

Balogh, R. 2012



# Overarching Principles

Respect & Understanding

Person-Directed

Diversity

Healthy Development, Hope & Recovery

Excellence & Innovation

Accountability for Quality of Care

# The process...

ED

Assessment

- Quality information provide by community agency (H.I.P.)
- Assess and treat acute condition
- Decision to Discharge or Admit
- Identify/Engage hospital point person
- Alert DSO

Admission

- Inform DSO of any “change in circumstance” at any point during the care path
- Lay out treatment plan and target transition date
- Coordinate case conferences /transition planning meetings
- Gather detailed information from community agency (BSP, full hx, crisis plan)
- Assist family/individual to apply for services if unknown

# Acute Care Needs Met...

## Transitional Case Conferencing

- HPP organizes/leads transitional case conference with community partners
- Develop timeline for transition
- Share relevant health information/treatment results
- Schedule and communicate follow up and community support plan
- Finalize Post-Transition agreement

## Barriers to Discharge

- Clearly identify any barriers
- Create plan for mitigation and timeline for actionable items
- Establish engagement timelines
- Alert DSO

**Medication Information**  
"ODSP"  
Drug Plan - Check for Coverage

Pharmacy:

| Health Concerns          | Family of Medications    |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
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UPDATED   
(mm/dd/yy)

**H.I.P.**  
Health Information Profile

I prefer to be called:

Health Card #:

Address:

Telephone #:

**Additional Information**  
Please refer to "Primary Health Guidelines & Tools for the Primary Care of People with Developmental Disability"  
[www.auroplace.on.ca](http://www.auroplace.on.ca)  
click under "clinical"

COMMUNITY NETWORKS OF SPECIALIZED CARE  
RESEAU COMMUNAUTAIRES DE SOINS SPECIALISES  
EASTERN ONTARIO - EST DE L'ONTARIO

**Health Information**

Attention:

Religious Medical Practices:

Diet Restrictions: Yes  No

Psychiatric Admissions: Yes  No

**Communication and Behaviour**

Custom:

Behavioural Triggers:

Barriers Behaviour:

How to Help:

Communication:

Visual Prompts to Exit or Return:

Adapted:

**Contact Information**

Medical and Agency Contacts:

Physician Contact:

Primary Agency contact:

**EMERGENCY CONTACT:**

**SUBSTITUTE DECISION MAKER:**

Section III: Behavioural and Mental Health Tools

**Crisis Prevention and Management Plan<sup>3</sup>**  
for Adults with Developmental Disabilities (DD) at Risk of or During Behavioural Crises

A Crisis Prevention and Management Plan for an adult patient with DD addresses serious behaviour problems and helps prevent, or prepare for, a crisis. It describes how to recognize the patient with DD's pattern of escalating behaviours. It identifies responses that are usually effective for this patient to prevent (if possible) a behavioural crisis, or to manage it when it occurs. The Crisis Prevention and Management Plan is best developed by an interdisciplinary team.

- Describe stage-specific signs of behaviour escalation and recommended responses.
- Identify when to use "as needed" (PRN) medication.
- Identify under what circumstances the patient with DD should go to the Emergency Department (ED).

Crisis Plan for: \_\_\_\_\_ DOB: \_\_\_\_\_ Date \_\_\_\_\_

Problem behaviour: \_\_\_\_\_

| Stage of Patient Behaviour  | Recommended Caregiver Responses  |
|---|--|
| Normal, calm behaviour  | Use positive approaches, encourage usual routines  |
| Stage A: Prevention (Identify early warning signs that signal increasing stress or anxiety.)  | Be supportive, modify environment to meet needs (Identify de-escalation strategies that are helpful for this patient with DD). |
| Stage B: Escalation (Identify signs of the patient escalating to a possible behavioural crisis.)  | Be directive (use verbal direction and modelling), continue to modify environment to meet needs, ensure safety                 |
| Crisis (Risk of harm to self, others, or property; or seriously disruptive behaviour, e.g., aggression, self-harm, or property damage.) | Use safety and crisis response strategies  |
| Post-crisis resolution and calming  | Re-establish routines and re-establish rapport   |

Responsible for coordinating debriefing after any significant crisis, and for regularly reviewing the Crisis Plan: \_\_\_\_\_

APPENDIX E: Collaborative and Individualized Resource Clinical Resource Plan



Collaborative and Individualized Resource Clinical Resource Plan **updated by Hospital Point Person**

**Unique Identifier:**

**Personal Information**

Individual Name:  
Mailing Address:  
Consent Provider/SDM Name:  
(If individual is unable to consent)

Referral Date: (Y/M/D)

DOB (Y/M/D):  
Telephone:  
Telephone:  
Email:

Clinical Conference Review Date:

**Key Specialized Clinical Service Provider Contact Information:**

Agency: Contact Name:

**Case Management/Service Coordination Agency Contact Information:**

Agency: Contact Name:

**Other Key Agencies/Persons:**

Agency: Contact Name:

DRAFT -

CLINICAL PLANS SHOULD:  
(1) Identify Problems or Needs (2) Outline short/long term goals (3) Establish approaches and intervention to meet the goal  
**BIOLOGICAL ELEMENTS (Medical, Physical, Genetic)**

\*Have there been recent medical and dental exams? Any issues, treatment in progress? Is there a history of recurring medical/dietary/dental condition (digestive, ear, urinary, heart, respiratory, abscess)? Any noticeable change in eating, sleeping, physical routine/elimination, self care, energy level, mood, facial communication/behavioral expressions? Any medication? Any side effects? What diagnosis? What else might be causing physical discomfort? Is there any syndromes/ predisposing genetic conditions? Any sensory limitations, sensitivity, vulnerabilities or disabilities (hearing, vision, sensitivity to touch, noise)? **What else?**

*\*Adapted from the "Over-to-Us" tool developed by the Central Network of Specialized Care*

| Identify Presenting Issues or Needs | Short/Long Term Goals/Objectives | Approaches/Intervention/Task | Responsibility | Date Est. | Date Achieved |
|-------------------------------------|----------------------------------|------------------------------|----------------|-----------|---------------|
|                                     |                                  |                              |                | 00/00     | 00/00         |

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ALC: Transitional Resources and Implementation Plan

Date:

Name:

Date of Birth:

Client Profile: Briefly describe the client, their reason for admission, rationale of ALC status, length of stay, and a condensed clinical history.

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## Other Supporting Documents;

- Dual Diagnosis Framework
- Parties to the Protocol

# *Engagement & Education*

*Hospital staff*

*Community DS agencies*

*Community Health Partners*

## Next Steps...

Education &  
Engagement

Implementation

Outcomes Evaluation

Build on this work in  
other communities





Care, Support and Treatment  
of People with a Developmental  
Disability and Challenging Behaviours

Part I: Consensus Guidelines



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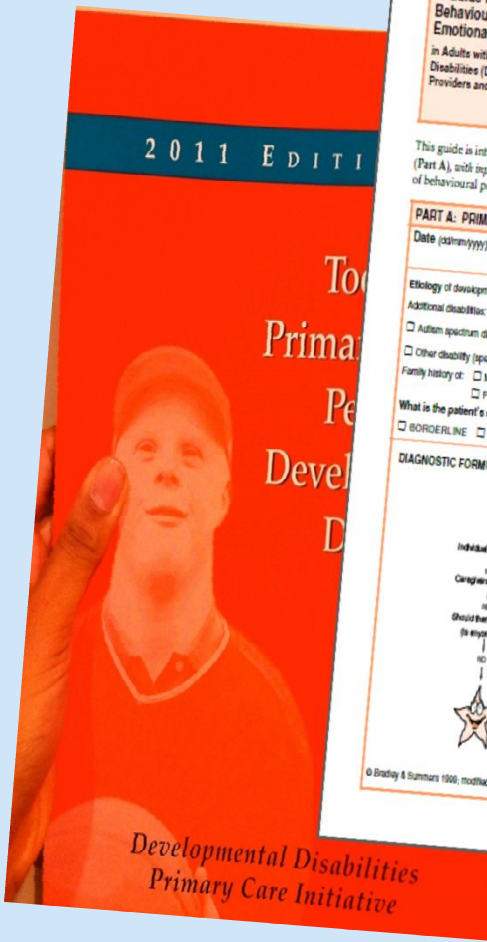
# Consensus Guidelines

*Care, Support and  
Treatment of People with  
Developmental Disabilities  
and Challenging Behaviours*

# *From Guidelines to Practical Application and Capacity-Building*

- Aim to foster best practice and establish consistency in the DS sector*
- Development of accessible and concrete tools*
- Encourage implementation of the guidelines and tools through training and consultation*

# Resources and Evidence Based Tools



**DS Developmental SERVICES**

**BEHAVIOURAL PLAN REFERENCE**

For ADULT DEVELOPMENTAL DISABILITIES

To be used in accordance with the Regulation in Ontario Regulation 299/10 Quality Assurance for Services for Persons with Developmental Disabilities made under the authority of the Service Promotion and Social Inclusion of Persons with Disabilities Act, 2001.

**A Guide to Understanding Behavioural Problems and Emotional Concerns**  
in Adults with Developmental Disabilities (OD) for Primary Care Providers and Caregivers

Name: \_\_\_\_\_ (last)  
Address: \_\_\_\_\_  
Tel. No: \_\_\_\_\_  
DOB (mm/yyyy): \_\_\_\_\_  
Health Card Number: \_\_\_\_\_

This guide is intended for use by primary care providers and, where available (Part A), with input from patient's caregivers or support persons (Part B). It aims to help primary care providers understand behavioural problems, in order to plan for treatment and management.

**PART A: PRIMARY CARE PROVIDER SECTION**

Date (mm/yyyy): \_\_\_\_\_ Presenting Behavioural Concerns: \_\_\_\_\_

Etiology of developmental disability, if known:  
Additional disabilities:  
 Autism spectrum disorder  Hearing impairment  Visual impairment  Physical disability (specify): \_\_\_\_\_  
 Other disability (specify): \_\_\_\_\_  
Family history of:  Medical disorders (specify): \_\_\_\_\_  Previous trauma  Physical disability (specify): \_\_\_\_\_  Psychiatric disorders (specify): \_\_\_\_\_

What is the patient's most recent level of functioning on formal assessment?  
 BORDERLINE  MILD  MODERATE  SEVERE  PROFOUND

**DIAGNOSTIC FORMULATION OF BEHAVIOURAL CONCERNS**

Patient brought to family physician with escalating behavioural concerns

```

    graph TD
      A[Individual communicating concerns verbally?] -- YES --> B[Caregivers expressing concerns?]
      A -- NO --> B
      B -- YES --> C[Should there be concerns? (to anyone or not?)]
      B -- NO --> C
      C -- YES --> D[Medical condition?]
      C -- NO --> E[Problem with supports/Expectations?]
      D -- YES --> D1[Feel condition]
      D -- NO --> E
      E -- YES --> E1[Adjust supports or expectations]
      E -- NO --> F[Emotional issues?]
      F -- YES --> F1[Address issues]
      F -- NO --> G[Psychiatric disorder?]
      G -- YES --> G1[Feel disorder]
      G -- NO --> G1
  
```

© Bradley & Summers 1999, modified in 2009

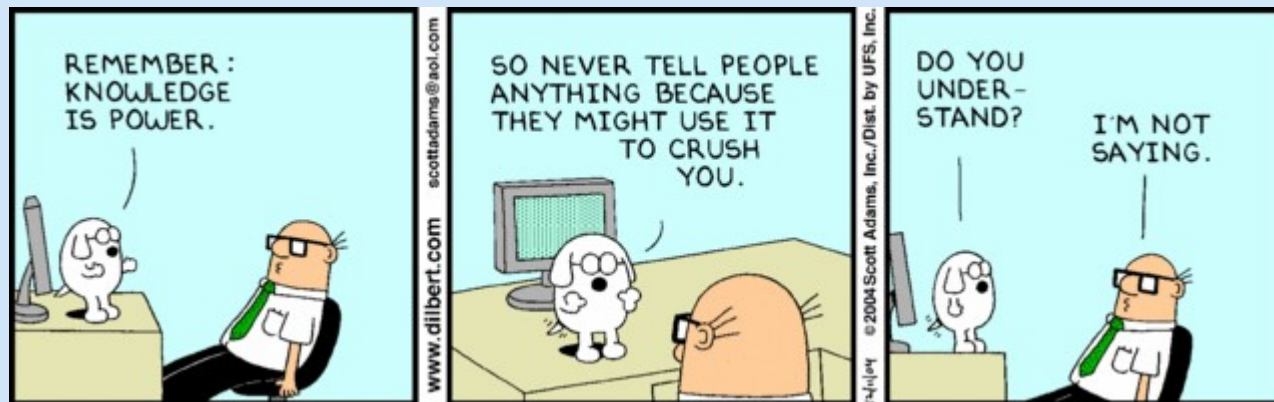
© 2011 Sunny Place Centre 17

**BIO-PSYCHO-SOCIAL MODEL FORMULATION GRID** – when challenging behaviours persist, this grid may help clarify the areas that need to be explored and find potential approaches to address the behaviour effectively.

|  | Biological: medical, psychiatric, genetic, medication, syndromes | Psychological: current psychological features, skill deficits emotional, cognitive, behavioural issues | Social: early childhood experiences informal & formal supports, family, social experiences |
|--|--|--|--|
| <b>Predisposing:</b> What from this person's past may have led to this problem? What is their history? |  |  |  |
| <b>Precipitating:</b> What might be contributing to this problem? Why is it coming up now?             |  |  |  |
| <b>Perpetuating:</b> What is happening that keeps the challenging behaviour going? What prolongs it?   |  |  |  |
| <b>Protective:</b> What are this person's strengths?   |  |  |  |

# Knowledge Transfer Plan

Regional Roll outs  
Provincial Clinical Service  
Providers  
VC Presentations  
Evaluations





[www.community-](http://www.community-networks.ca)  
[networks.ca](http://www.community-networks.ca)