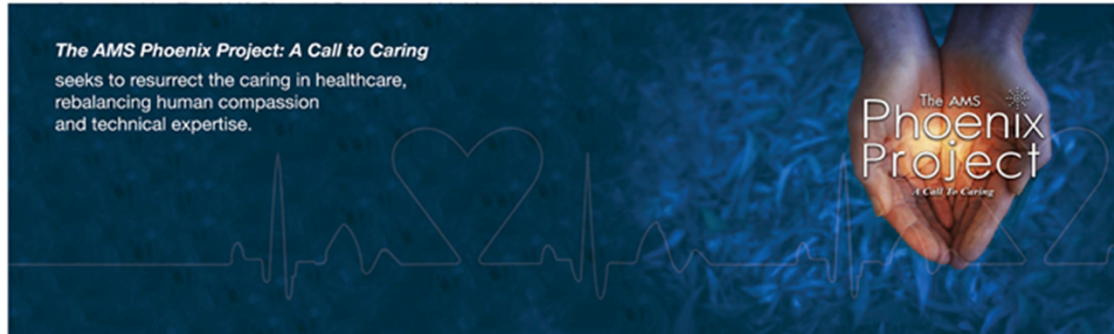


Curriculum of Caring

Supported by The AMS Phoenix Project and McMaster University



Southern Network of Specialized Care Video-Conference Sept 19th 2014

Curriculum of Caring Introduction Video

http://machealth.ca/programs/curriculum_of_caring/p/videos.aspx (0 - 1:24)



Curriculum of Caring



Agenda

1. Welcome
2. Introduction & Motivation
3. Foundation & Collaboration
4. Implementation & Evaluation
5. Innovation & Knowledge Translation
6. Appreciation
7. Discussion
8. Additional Information

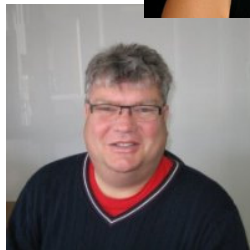


Introduction

Dr. Kerry Boyd



Tom Archer



Motivation

- Ontario's large institutions closed and provincial transformation for service delivery
(Excellent Care for All Act; The Social Inclusion Act)
- Health needs and health care disparities
- Identified need for more experience in training

(Ward, Nichols & Freedman, 2010 Wilkinson, Dreyfuss, Ceretto & Bokhour, 2012)



Curriculum of Caring



http://machealth.ca/programs/curriculum_of_caring/p/videos.aspx

How can we foster
**Compassionate
Person / Family Centered
Care**

for people with developmental disabilities
among health care providers?



Curriculum of Caring



Providing health care learners with
**Early experiences
Communication / Clinical skills
Application**



Curriculum of Caring



Generating



**Capable
Compassionate
Collaborative**



Health Care Providers



Curriculum of Caring



Foundation

Niagara collaboration:

- **Bethesda Services:** a regional provider of a wide array of residential and clinical programs for children and adults with developmental disabilities
- **Brock University:** the unique Centre for Applied Disability Studies (CADS) as well as Health Sciences, **Department of Nursing**
- **McMaster University:** Michael G. DeGroote **School of Medicine**, Niagara Regional Campus began in 2008



Curriculum of Caring



Implementation

Phase 1: Early exposure

Phase 2: Communication/clinical skills training

Phase 3: Application



Curriculum of Caring



Phase 1: Early Exposure



Curriculum of Caring



Curriculum of Caring Bethesda Day



Medical and nursing small groups with host

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

(Tools for the Primary Care of People with DD Guidelines-2011)



Curriculum of Caring



Curriculum of Caring Phase 1: Early Exposure



Curriculum of Caring



http://machealth.ca/programs/curriculum_of_caring/p/videos.aspx



Curriculum of Caring



Case Study

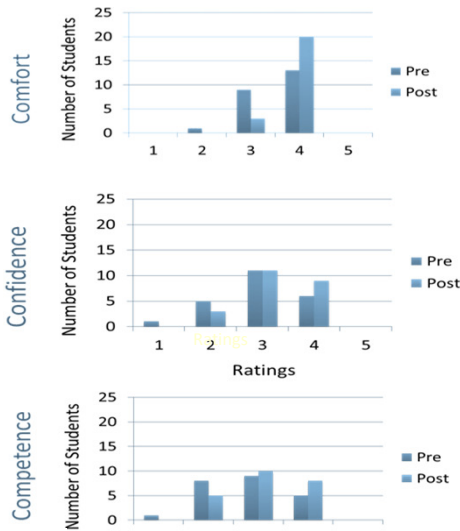
- Overview of health disparities & why they occur
- Introduction of 2011 Primary Care Guidelines & Tools
- Case presentation
- Discussion: Barriers to Assessment, Diagnosis considerations (DD - no DD)
- Community Resources



Curriculum of Caring



Evaluation



Curriculum of Caring

Early Exposure

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."



Early Exposure Learner Comments

- Great learning experience and I would now love to look into nursing jobs that work with people with disabilities.

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 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.
- I don't yet have enough experience to feel competent.



Curriculum of Caring



Phase 2: Communication/ Clinical Skills Training



Communicate CARE

Clearly

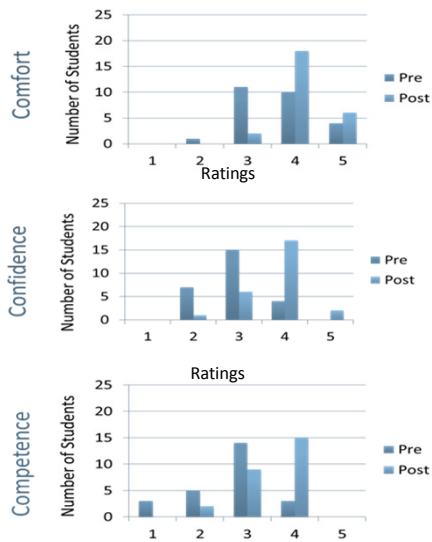
Attentively

Responsively

Engage



Evaluation



Communication/ Clinical Skills Training

"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."



Phase 3: Application



Conclusion

- Higher levels of comfort, confidence and competence.
- Both medicine and nursing praised the early exposure phase as beneficial and expressed a **desire to learn/interact more** with this population.
- More experience and clinical application for competence.
- Personal encounters and stories stir **compassion** that leads to **person/family centered care**.
- They **enjoyed** each other!
- Successful **interprofessional** education.



Curriculum of Caring



Champion Educators



Curriculum of Caring



Innovation and Knowledge Translation

1) 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) 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 (Expert Interviews with Links to Resources)



Curriculum of Caring



McMaster University Undergraduate Medical Education

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



Curriculum of Caring



Communicate Care

Web-Based Resources

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



Curriculum of Caring



CommunicateCARE.machealth.ca



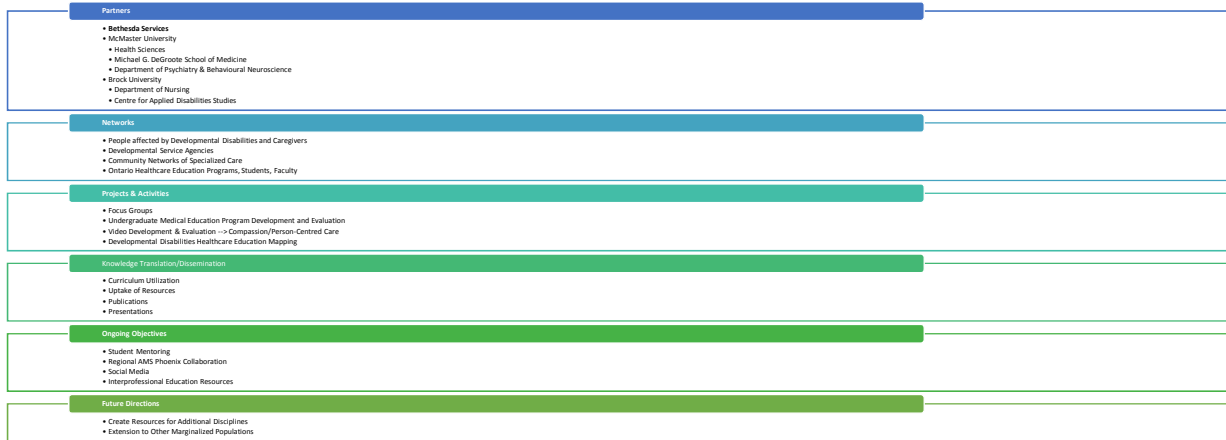
http://machealth.ca/programs/curriculum_of_caring/default.aspx



Curriculum of Caring



AMS Phoenix Project: Call to Caring Curriculum of Caring



Curriculum of Caring



Partners

Bethesda Services

Southern Network of Specialized Care

McMaster University

Health Sciences

Michael G. DeGroote School of Medicine

Department of Psychiatry & Behavioural Neuroscience

Brock University

Department of Nursing

Centre for Applied Disabilities Studies



Curriculum of Caring



Networks

People affected by Developmental Disabilities and Caregivers

Developmental Service Agencies

Community Networks of Specialized Care

Ontario Healthcare Education Programs, Students, Faculty



Curriculum of Caring



Projects & Activities

Focus Groups

Developmental Disabilities Healthcare Education Mapping


Undergraduate Medical Education Program Development
and Evaluation

Video Development and Evaluation



Curriculum of Caring






**SOUTHERN NETWORK
OF SPECIALIZED CARE**

Tell us more: Advice for health care learners and practitioners from people with developmental disabilities

Kerry Boyd MD^{1,2}, Tom Archer BA¹, Ginette Moore BEd³, Natalie Lister BSc⁴, Stephanie Stobbe MSc⁴, Nick Kates MD⁴, Karl Stobbe MD⁴, Kerri Pudehn BScN Candidate⁵
¹McMaster University, ²Bathesda Services, ³Southern Network of Specialized Care, ⁴Brock University



Health Sciences

Brock University

INTRODUCTION

- Individuals with a developmental disability (DD) experience disparity in their access to care, quality of service, and health care outcomes^{1,2,3}.
- 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-Norfolk, Brantford, 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.
- Transcriptions were independently analyzed for emerging themes and collated.
- Themes are being translated into recommendations for further curriculum development by study investigators.


REFERENCES

1. Ouellet-Kuntz, H. Understanding Health Disparities and Inequities Faced by Individuals with Intellectual Disabilities. J of App Phys Rehabil. Feb 2005; 18: 113-121.
2. Lundy V, Kohn-Gibson JC, Nader SA, eds. *Atlas on the Primary Care of Adults with Developmental Disabilities* in Ontario. Toronto, ON: Institute for Clinical Evaluative Sciences and Centre for Addiction and Mental Health; 2013.
3. Sullivan W, Berg J, Grayby E, et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician*. 2011 May; 54: 541-57.

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 multidisciplinary 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

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


ACKNOWLEDGEMENTS

McMaster University (Niagara Regional Campus, Witham Laurier University (Brantford Campus), Norfolk Association for Community Living, Community Living Hamilton, Hamilton, WYCA Hamilton, Community Living Trent, Bethesda Services, and the Southern Network of Specialized Care.

Sincere thanks to Jennifer Jeffery (Bethesda), Matt Hearn (McMaster) and focus group facilitators: Lisa Whittingham (Student, Brock Centre for Applied Disability Studies), Lisa Singh (Student, Brock Nursing) and Mariana Savatier (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 AMMS Private Project: A Curriculum of Caring.



**SOUTHERN NETWORK
OF SPECIALIZED CARE**

Tell us more: Advice for health care learners and practitioners from people with developmental disabilities

Kerry Boyd MD^{1,2}, Tom Archer BA¹, Ginette Moore BEd³, Natalie Lister BSc⁴, Stephanie Stobbe MSc⁴, Nick Kates MD⁴, Karl Stobbe MD⁴, Kerri Pudehn BScN Candidate⁵
¹McMaster University, ²Bathesda Services, ³Southern Network of Specialized Care, ⁴Brock University



Health Sciences

Brock University

ELEMENTS THAT AFFECT HEALTH CARE EXPERIENCES – THEMES

Person Centred Health Care: Participants wish to be consulted about their health care needs and preferences.

Barriers to Access: Participants identified a number of significant barriers: reliance on caregivers, convincing others of illness, transportation, cost, clinic hours, emergency department busyness and wait times.

Attitudes: Participants value friendliness, authenticity, and honesty, in their relationships with health care providers.

Communication: Listening, non-verbal communication, speaking, and choice of words (understandable language) are important. Positively reinforcing the person's health/dental maintenance was clearly appreciated.

Professionalism: Respectful communication, explaining/obtaining permission, punctuality, soliciting informed choice/consent, and maintaining privacy are central to successful health care experiences.

Outcomes: Clear diagnosis, treatment success, relief from their discomfort, pain management, and improved health are important outcomes of health care interactions.

Continuity of Care: Consistency and communication among health care practitioners is valued.

Inter-professionalism: Involvement and collaboration from multiple health care disciplines was noted repeatedly.

STUDENT INVOLVEMENT IN HEALTH CARE INTERACTION – THEMES

Introduction: Participants would like students to introduce themselves using their name and role.

Purpose: Whether their role is to observe or take part in care, this should be introduced and the person given the opportunity to decline (a few stated they prefer to see only their own doctor).

Confidentiality: Participants noted they want to be assured that they will maintain privacy.

Advice: Same as elements of Health Care encounters: Attitudes, Communication, Professionalism, and Outcomes should be learned and practiced.

Correspondence:
Tom Archer, Southern Network of Specialized Care, tarcher@bethedsaservices.com

Knowledge Translation/Dissemination

Curriculum Utilization

Uptake of Resources

Publications

Presentations



Curriculum of Caring



Ongoing Objectives

Student Mentoring

Regional AMS Phoenix Collaboration

Social Media

Interprofessional Education Resources



Curriculum of Caring



Future Directions

Create Resources for Additional Disciplines

Extension to other Marginalized Populations



Curriculum of Caring



Appreciation



Curriculum of Caring



Additional Information

<http://CommunicateCARE.machealth.ca>

<http://www.surreyplace.on.ca/primary-care>

<https://knowledgex.camh.net/hcardd/resources/Pages/default.aspx>

<http://dualdiagnosis.camh.ca/Pages/default.aspx>

<http://www.community-networks.ca>

http://www.camh.ca/en/research/news_and_publications/reports_and_books/Documents/ICES-CAMH%20HCARD%20Atlas%20full.pdf

<http://aadmd.org>

<http://vkc.mc.vanderbilt.edu/etoolkit>



Curriculum of Caring



Discussion, Questions, Comments?

For Additional Information / Resources:

Tom Archer, Health Care Facilitator

tarcher@bethesdaservices.com



Curriculum of Caring

