



Day 3: Aging Transitions

Fri Mar 11th, 2016

Participant's Guide

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Introduction

Overview

Description

The Toronto Networks of Specialized Care in partnership with the DSTO Shared Learning Forum and ConnectABILITY.ca will develop a 3 part Certificate Series for direct support professional's to help meet the complex needs related to Transition Planning. It will be 3 training modules (Day 1: youth; Day 2: adult; Day 3 aging) that will cover a 3 week period and will include DS sector agencies as well as our community partners from Health, Education and Justice. The presentations will be available on video and access to the videos and supporting resources can be found on ConnectABILITY.

Learning Outcomes

With respect to transitions across the lifespan and sectors, this 3-day event will help participants to:

1. Identify effective strategies to improve system access and navigation for clients and families
2. Use effective planning and decision-making to improve client wellbeing
3. Support client needs relating to their rights and lifestyles
4. Construct a network of individuals who can provide expertise and support

Agenda

Time	Activity
9:00am	<i>Breakfast, Registration</i>
9:30am	Introduction: Welcome, Overview, Activity
9:45am	After 65, You Still Have Rights <i>We will take a short break at approximately 10:45am</i>
11:30am	Grief and Bereavement for Persons with Developmental Disabilities who are Aging <i>We will break for a 45min lunch at approximately 12:15pm</i>
1:45pm	Developmental Disabilities, Aging, Supports & Resources <i>We will take a short break at approximately 2:30pm</i>
3:30pm	Wrap-up: Evaluations, Activity, Summary <i>We will ensure we have you out the door by 4:00pm</i>

Case Study - Maria

During the day we will refer to the case of Maria (see below and on a handout in your package).

Maria 57 year old woman with a mild intellectual disability who lives with her 87 year old mother. Her mother has been diagnosed with a terminal illness a few months ago. Most of Maria's adult life has been around doing activities independently while spending time and supporting her mother with things around the home, like errands, outings, shopping etc. Maria also attends a day program that she has been at for many years which she would like to retire from. She currently attends once a week so that she can be with and continue caring for herself and mother. Maria receives APSW support and now some CCAC support for her and her mother in their home. What are some

considerations for Maria? How would you support her to transition from work? What are some things that you would need to empower her to continue making choices?

Working Together

Previous participants in our sessions have agreed to some basic working principles, as follows:

- Respect confidentiality; what is said in the room, stays in the room.
- Recognize diversity as a strength and an asset; participants may have different knowledge, experience, styles of participation and points of view.
- Make every effort to be timely, e.g., with breaks/lunch.
- What else would you like to add to ensure that the learning experience is enjoyable and productive for you?

Session Evaluation and Knowledge Transfer

- Your feedback is critical to help ensure the continued quality and effectiveness of this session. At the end of the day, please complete the evaluation form provided.
- Around three to six months after the course has been completed, we will e-mail you a brief online survey asking for your feedback about how you have applied the knowledge you acquired from the course and how you are doing on your personal commitments

Welcoming Activity

Self-Reflection

In what ways have your learnings from the past two sessions been applied on-the-job? Have any of your actions lead to improved client outcomes?

Table Discussion

At your tables, take turns introducing yourself (name, title, agency); briefly mention the kind of work you do and/or services you provide. Share/discuss your responses to the questions above.

After 65, You Still Have Rights

Presented by:

Peter Park
Co Founder Respecting Rights
Sue Hutton, BSW, MSW
ARCH Disability Law Centre, huttons@lao.on.ca



ARCH Disability Law Centre

- ARCH is a community legal aid clinic that helps people with disabilities in Ontario with legal issues

“Old age ain’t no place for sissies!” Bette Davis

Transition into Aging

Peter Park

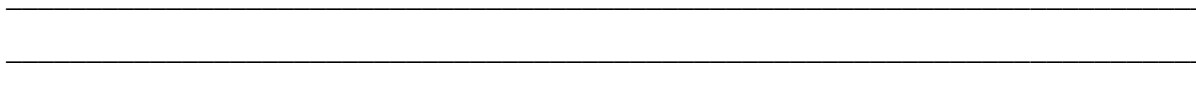
- -Co-Founder of Respecting Rights at ARCH
- -Godfather & Co-Founder of People First of Ontario

A little bit about my Life....

I’ve always been concerned about social justice

*Let’s Talk About..
Your Funeral*

Video



Circle Of Support

- I had a desire to have a circle of support and what it would look like when I was 56
- I would ask for the opinion of the circle, but my wife and myself would be in control. It was our circle
- My circle is made up of friends whom I trust

Honest Talks about the Hard Stuff

- At our circle meetings, we talk about the difficult things...

Funeral Planning

- One of the things was hard to plan: our funeral
- We wanted to make sure that we were looked after in a way that our wishes were honoured
- We decided we wanted to be cremated

Celebration of Life

- We want a celebration of life at our funeral – the positive things
- It’s all written down in a book

Advance Care Planning

- Start planning what you want for your old age now
- And who you want to help make decisions for you

You have the right
to make decisions
all the way to the
end of your life

Advance Care Planning; Health Care Consent Act Section 5

- A person may express “wishes” about future health care in a power of attorney for personal care, in any written form, orally, or in any other manner
- Later wishes expressed while capable prevail over earlier wishes
- Even if wishes have been expressed in a written form, that later oral wishes may override those earlier written wishes

Convention on the Rights of Persons with Disabilities

- The CRPD is an international law that sets out the rights of people with disabilities.
- Article 12 states that:
 - people with disabilities have the right to legal capacity on an equal basis as others
 - Governments must provide access to supports to help people to exercise their legal capacity
 - Governments must put safeguards in place to prevent abuse of people with disabilities who try to exercise their legal capacity
- Canada ratified the CRPD in 2010

Decision-making; Capacity Remains Intact

(Substitute Decisions Act, ss. 6, 45)

A person is considered capable to make a decision if:

- the person is able to understand information that is relevant to making the decision
- and
- the person is able to appreciate the potential consequences of making or not making the decision

The Hierarchy of SDMs in the Health Care Consent Act

The Hierarchy

- The following is the Hierarchy of SDMs in the Health Care Consent Act, s.21:
 1. Guardian of the Person with authority for Health Decisions
 2. Attorney for personal care with authority for Health Decisions
 3. Representative appointed by the Consent and Capacity Board
 4. Spouse or partner
 5. Child or Parent or CAS (person with right of custody)
 6. Parent with right of access
 7. Brother or sister
 8. Any other relative
 9. Office of the Public Guardian and Trustee

Express Your Wishes; Advance Care Plan

(Wahl, JA, B.A., L.L.B. 2016)

- You may decide who you may want as a future Substitute Decision Maker. This is done either by:
- Confirming that you know who is your automatic future SDM (Under the HCCA) and that you are satisfied that that person should so act as SDM when incapable

OR

- Choose someone else to act as SDM by preparing a Power of Attorney for Personal Care

Be Prepared - Medical Care

- I had to prepare for all the different kinds of doctors I would have
 - Podiatrist
 - GP
 - Neurologist
 - Cardiologist
 - Dentist
 - Optometrist

Long Term Care

- We explored long term care homes as an option
- Tried respite out for Rhea....
- Had to watch TV and listen to the radio whether they liked it or not

Complaints in Long Term Care

- I complained once and 6 months later I got a phone call

Be Mindful; Developmental Services History of Institutions

Senior's Secretariat

- The Ontario Seniors' Secretariat (OSS) advocates for, undertakes and supports policy and program initiatives that help seniors.
 - Phone Toll Free: 1-888-910-1999
 - TTY (for the hearing impaired) 1-800-387-5559
 - Fax 416-326-7078
 - E-mail infoseniors@ontario.ca
 - <http://www.seniors.gov.on.ca/en/about/index.php>

Advocacy Centre for the Elderly

- The Advocacy Centre for the Elderly is a legal clinic for low income senior citizens.
 - Contact: 1-855-598-2656 or 416-598-2656
 - Legal Rights for the Elderly Publications
 - http://www.advocacycentreelderly.org/advance_care_planning_-_publications.php

ARCH ALERT

- ARCH Alert is a quarterly newsletter published by ARCH Disability Law Centre.
- To receive the ARCH Alert by email, go to our website:
 - www.archdisabilitylaw.ca
- If you do not have email or want to receive the ARCH Alert by mail, contact us by telephone or TTY:
 - Tel.: 416-482-8255 Toll-free: 1-866-482-2724
 - TTY: 416-482-1254 Toll-free: 1-866-482-2728

The information provided in these presentation materials are not intended to be legal advice. Consult a lawyer or legal worker if you need legal advice on a specific matter. The information in the presentation materials are current as of the date of the presentation. (Mar 11, 2016)

Case Study – Maria

Self-Reflection

What are some considerations for Maria relating to rights and decision-making?

What could you or your agency do to support Maria?

Table Discussion

Assume your table represents a community that will need to work together to support Maria relating to rights and decision-making. How will you collaborate to support her?

What other information do you need? Who else might you need to collaborate with?

Grief and Bereavement for Persons with Developmental Disabilities who are Aging

Presented by:

John Guido, Outreach Officer

John@larchetoronto.org; 416-406-2869 ext. 35

30 years in L'Arche, accompanying many persons with intellectual disabilities as they aged



Learning Outcomes

In this workshop, participants will explore

- Grief about aging particular to persons with developmental disabilities
- Ways to support individuals to grieve well and find new life as they age

Grief and Mourning about Aging for all adults

- What are possible losses that come with old age?

- What are possible gains?

- What are typical Characteristics of Grief?

“The clouds and rain are a symbol for being sad in your heart.
The sun represents the light of God and choosing to be open to new things as well as sad.
The heart reminds you of being loved and listening.
The tree can be a sign of protection, spending time together, and forgiveness.
The flower invites us to be light and love for others and reminds us we cannot do it alone.”
Greg Lannan, L’Arche Toronto

See handout: “Characteristics of Grief” form William J Worden, *Grief Counselling and Grief Therapy* at the end of the guide

Grief, Mourning and New Life as we Age

“And so we can’t help but grieve. Grief is the constellation of internal thoughts and feelings we have when we lose something or someone we love or deeply value. Grief is the anxiety, bewilderment, anger, sadness and other emotions we feel on the inside. We are here to tell you that grief in aging is normal and necessary—so necessary, in fact, that it is only by embracing it that you can go on to live the life you yearn for. Mourning is this embrace. It is the acknowledgment and outward expression of your grief. We all grieve as we age, but if we are to live a continued life of confidence, meaning, and grace, we must also mourn.”

“Yes, aging can liberate you from your previous roles and offer you the chance to be authentic, genuine, congruent, and honest. Old age gives you the opportunity to be more of who you’ve always been. Growing older invites an awareness of your inherent value while recognizing you are so much more than the sum of your accomplishments or your work product. Growing older invites you to remember the gifts you have to offer your family, friends, and the world around you.”

From Healing Your Grief About Getting Older, Alan D. Wolfelt, PhD <http://www.centerforloss.com/>

Aging, Grief and Persons with Developmental Disabilities

- What might be different in the losses persons with disabilities experience as they age? What particular challenges do those who support them face?

“There is evidence that men and women with developmental disabilities are subject to some differences in the onset and progress of aging due to hereditary, environmental and lifestyle factors. This adds to the complexity of the aging process for this population and increases the challenge facing caregivers.”

From Transition Guide For Caregivers <http://www.opadd.on.ca>

Aging, Grief and Persons with Developmental Disabilities

“Intellectual disability is a broad category... The greater the handicap, the less likely the individual's grief will be recognized. Caregivers tend to ignore or misunderstand the effects of such losses. Research has shown that some people with intellectual disabilities will have a delayed understanding of the ageing process. It seems likely that the irreversibility, universality, and the inevitability of death will all be difficult concepts to understand, despite many years of experience as an adult. The capacity to integrate their experiences and to learn from them will be limited unless sensitive help is available.

From Managing Grief Better: People with Intellectual Disabilities, Sheila Hollins;

www.connectability.ca/2015/03/09/grief-and-bereavement-2/

“... people with developmental disabilities, given the opportunity and support, can grieve in a healthy and transformative manner. Indeed, because they are often much more in touch with their hearts and somewhat less inhibited than many so-called normal people, they can call the rest of us to take the time we need to grieve, and to express our feelings in ways that can bring healing.” From Grieving in the Context of a Community of Differently-abled People, Jane Powell; www.aging-and-disability.org

Supporting the person who is grieving to mourn and discover new life

Each person is unique.

What support can we provide individuals who are grieving?

People need friends to listen to them and give them permission to express their feelings about loss and change

“In order to emerge from this state of loss and grief, and begin a new life, people need not so much a therapist as friends who are prepared to walk with them. These friends cannot nor should they try to take away the grief, but rather accept it with them. The grieving process has its own particular rhythm in each person. It needs time. We should not try and make it disappear quickly through artificial ways and distractions. Sometimes people need to cry, scream and shout their pain, anger and frustration in order to free themselves gradually from the pain and find new life.” Jean Vanier Seeing Beyond Depression

Let's talk about Getting Older

- The Down Syndrome Society of Scotland has created this workbook and another called “Let's talk about Death” that some will find helpful. www.dsscotland.org.uk

Discuss the changes of aging, both the losses and gains, to educate and create space to talk.

Blueprint for Transition Planning

- Planning for changing needs and end of life helps identify the wishes, abilities and needs of the individual, focus on quality of life, build a support circle, identify community supports, etc.
- It gives the individual a measure of control and a safe space to grieve and mourn as well as set goals for new life. www.opadd.on.ca

The importance of Rituals

- Rituals may be customs within the group or public rituals (e.g. wakes, funerals). Usually, everyone can be involved in a ritual. Rituals can symbolically express experiences and feelings and help achieve clarity.
- Ritual can be as simple as sipping that morning cup of coffee. Or it can be more weighted and complex—a structured act or rite to ease life's losses, such as the death of a loved one, retirement or even “giving up the car keys.”

Visiting and Supporting friends and family who are dying

- With support, individuals can be present to the people they cherish who are dying. They can discover their ability to give support and comfort.

Remembering loved ones who have died - stories, photos and mementos can help

- For people with developmental disabilities, creating a book of memories may be a concrete way to help them remember deceased loved ones
- The anniversary of a loved one's death can be a difficult time as it brings back memories of the death. Having a plan for the day often helps. (www.connectability.ca/2015/03/09/grief-and-bereavement-2/)

Life Story Book

- A Life Story Book provides a means to integrate, share and celebrate one's friendships, lives touched, and important moments. It becomes a person's voice as they begin to lose their words and memories. (www.aging-and-disability.org)

Personal Care

- We can support individuals to care for themselves in ways that help them relax and find peace. Music, prayer, a bath, exercise, massage, a scented candle, meditation, a cup of tea are ways that might help.

Grief is stressful

Grief Groups

- A grief group is a way that people who are experiencing and also anticipating change and loss can come together to learn and share together and to give each other support as they grieve and mourn. (www.aging-and-disability.org)

Seek Specialists with Bereavement Experience

- How do we know when grief is too great and that the individual needs professional supports?
 - It is important to make referrals, especially mental health referrals, as soon as any serious grief reactions are noted, such as aggressive behaviour, persistent irritability, mutism, loss of skills, inappropriate speech (i.e., asking "where is Dad?" all the time), self-injury, tearfulness and absconding. (Sheila Hollins)

What are possible ways to discover new life as we mourn the losses of aging?

- Seniors Clubs offer peer support, the opportunity for belonging and new relationships, and creative and relaxing activities; watch Community a Sense of Belonging www.opadd.on.ca/
- New relationships and connections to younger generations can be a ways to share wisdom and experience new life.
- With support from people and community, loss and change are opportunities for transformation See Shared Learning Forum: From Heartbroken to Heart Open- Grieving and Bereavement by Linda Ger Walters and Nadia Mia; <http://connectability.ca/2013/06/06/from-heartbroken-to-heart-open-grieving-and-bereavement/>

Case Study – Maria

Self-Reflection

What are some considerations for Maria relating to grief and bereavement?

What could you or your agency do to support Maria?

Table Discussion

Assume your table represents a community that will need to work together to support Maria relating to grief and bereavement. How will you collaborate to support her?

What other information do you need? Who else might you need to collaborate with?

Developmental Disabilities, Aging, Supports & Resources

Presented by:

Angela Gonzales, RN MN
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Care Coordinator, Adult Supportive Care Team, AS05,
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Learning Outcomes

- As a result of participating in this workshop, participants will be able to:
 - Understand current research that informs us about aging transitions for adults with DD
 - Identify effective strategies to access aging services' and navigation for people with DD and caregivers
 - Identify ways to improve collaborative care planning to support people with issues related to aging with DD

Historical Aging Context

- Most individuals with any level of DD lived and received their health care in Ontario's institutions prior to the 1970s
- Ontario's 3 remaining institutions serving people I/DD closed in 2009
- In the last 4 decades there's been gradual 'deinstitutionalization' into the community
- Studies indicate positive outcomes for individuals with I/DD who transitioned from the remaining 3 Ontario institutions
- Aging in institutions was dramatically different than aging with DD in the community

Aging and Health Issues

- Disparities in preventative care and health promotion, e.g. lack of access to health programs/interventions, challenges due to persons' developmental disability
- DD Primary Care Initiative (DDPCI) was established in response...

- Evidence to suggest a greater rate of:**
- Dental caries & gingivitis
 - Cardiovascular & respiratory diseases
 - Gastrointestinal disorders, e.g. GERD, constipation
 - Obesity
 - Diabetes
 - Neurological conditions, e.g. epilepsy, dementia
 - Endocrine conditions, e.g. hypothyroidism
 - Sensory impairments
 - Mental health/dual diagnoses

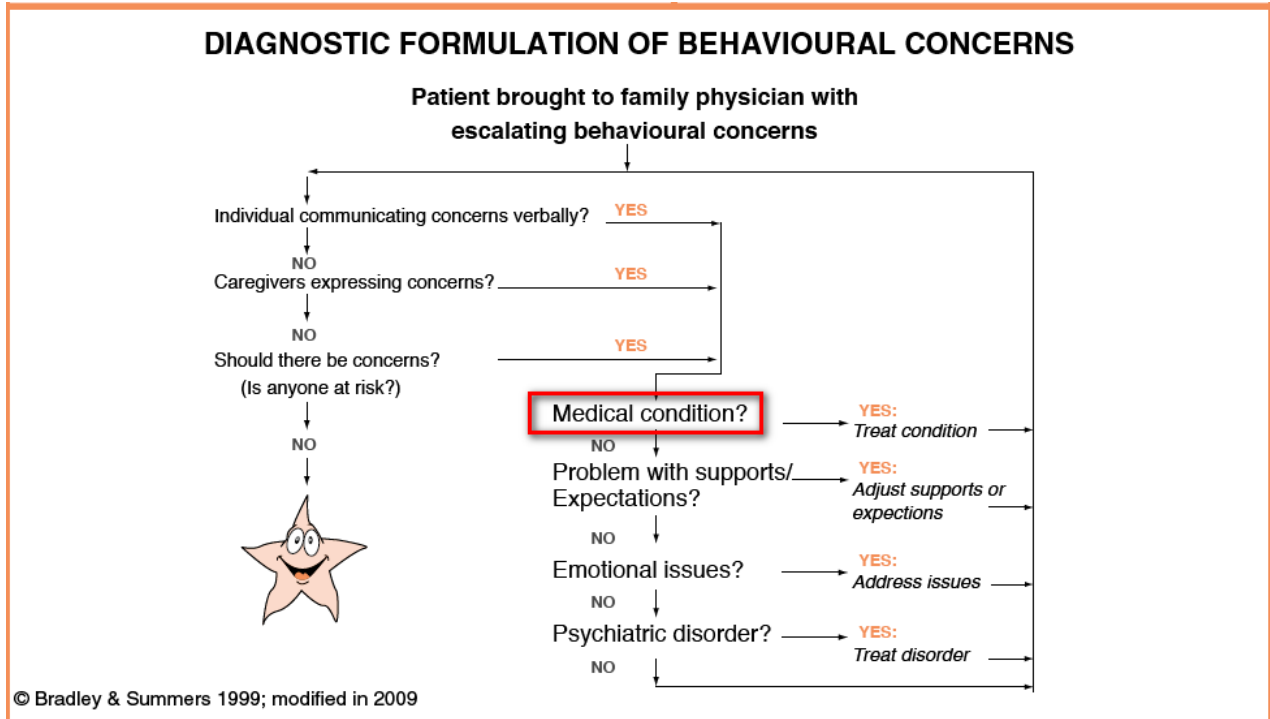
Aging and Importance of Health Checks – H-CARDD snapshot

(<https://www.porticonetwork.ca>)

- Adults with DD have more health problems than other adults and more difficulties accessing health care
- Only 1 in 5 adults with DD receives a “Health Check”
- Advocating for and supporting Health Checks through primary care providers can have significant positive impacts for people with DD
- How can we advocate and support?

A Guide to Understanding Behavioral Problems & Emotional Concerns

E.g. – Behavioral & Mental Health Tool; <http://www.surreyplace.on.ca/Primary-Care>



Advocacy Tools

Help in the “detective work” of identifying possible underlying health issues contributing to complex behaviours; www.surreyplace.on.ca/primary-care

- Signed consent
- DD Primary Care guidelines
- Health Watch Tables
- Information collection tools:
 - Weight chart (& food diary)
 - BM chart, menses chart
 - Sleep chart
 - Seizure Package
 - Non-verbal pain scales

Down Syndrome HWT

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

Health Watch Table – Down Syndrome	
CONSIDERATIONS	RECOMMENDATIONS
9. NEUROLOGICAL	
Children: Epilepsy in up to 22%	<input type="checkbox"/> Take careful neurological history with particular attention to seizures (infantile spasms or tonic-clonic-type) <input type="checkbox"/> Arrange an EEG and refer to a neurologist
Adults: Dementia is frequent and occurs earlier: 11%: 40 – 49 y, 77%: 60 – 69 y, Up to 75% with dementia have seizures with frequency increasing with age	<input type="checkbox"/> Obtain a neuropsychiatric history at every visit with particular attention to change in behaviour, loss of function/activities of daily living, and new onset seizures <input type="checkbox"/> If functional decline and/or signs/symptoms of dementia, use history, exam, and blood work to check for other conditions and treatable causes (e.g., hearing/vision deficits, obstructive sleep apnea, hypothyroidism, chronic pain, medication side effects, depression, menopause, low folic acid/vitamin B12) <input type="checkbox"/> For possible seizures, arrange an EEG and refer to a neurologist

“Adults: Dementia is frequent and occurs earlier: 11 % 40-49 y, 77% 60-69 y...” “If functional decline... use history, exam, and blood work to check for other conditions... (e.g. hearing/vision deficits, obstructive sleep apnea, hypothyroidism, chronic pain, medication side effects, depression, menopause, low folic acid/vitamin B12)”

Early detection/screening

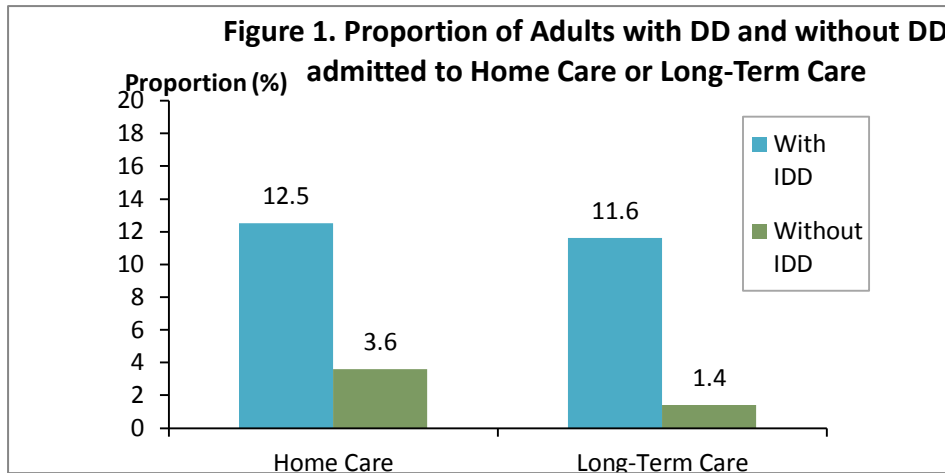
‘NTG-Early Detection Screen for Dementia’ (NTG-EDSD); <http://aadmd.org/ntg/screening>

- Usable by support staff and caregivers to note presence of key behaviors associated with dementia
- Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- Use: to provide information to health care providers on function & to begin the conversation leading to possible assessment/diagnosis
- Pages 1 & 2 Basic Information
- Pages 3 & 4 Information about function and indicators of problem areas associated with dementia
- Page 5 Coincident conditions
- Page 6 Medication & Comments

DD & Aging In Ontario – H-CARDD snapshot

<https://www.porticonetwork.ca/web/hcardd/aging>

- Current research shows adults are living longer and aging earlier
- Need for better understanding of aging with DD to target barriers to accessing aging care services earlier than 65 years of age
- “80 at 50”
- Twice as many adults with DD than general population were admitted to home care between 2009 and 2014... home care users with DD were more likely to be admitted to long-term care (LTC)
- Adults are admitted to LTC 25 years earlier than general population



Individuals with DD are more likely to use Home Care and to be admitted to Long-term Care. (H-CARDD, 2014); <https://www.porticonetwork.ca/web/hcardd>

Aging and Collaborative Care Planning

- Who are our collaborative aging care partners in health?
 - Primary care providers
 - Hospitals and emergency departments
 - Community Care Access Centre
 - Long-Term Care (LTC)

Use evidence and person-centered or person-directed info to advocate and plan for timely access to appropriate aging care services

Collaborative Care Planning with Hospitals

- H-CARDD Emergency Care video - “We do a better job ...when we have more information...” <https://www.youtube.com/watch?v=vIUJf1Sq3A>
- Importance of caregiver support and/or support staffing
- Some times the hospital is the site for a transition ‘tipping point’
- Transition resources to involve:
 - Community Care Access Centre
 - Long-term care
 - DSO, Griffin Community Support Network (GCSN)
 - TNSC and CAIR Program ALC resources

Collaborative Care Planning with CCAC

(<http://healthcareathome.ca>)

- Point of access for care in the home through community care services, e.g.:
 - PSW
 - OT home safety assessment
 - PT for mobility and range of motion assessment
 - Nursing (e.g. controlled acts transition support – injections, wound care, etc.)
 - SLP (e.g. to assess for swallowing issues)
- Centralized point of access to LTC

Long-Term Care CCAC Resources

(<http://healthcareathome.ca>)

- Working closely with the DS sector to inform the conversation and build bridges
- Care Coordinator will support through LTC service decisions and complete application process with client/family
- Types of LTC admissions:
 - Temporary Stays In LTC's, e.g. short-stay respite, short-stay convalescent care
 - LTC placement

Collaborative Care Planning with LTC

(<http://healthcareathome.ca>)

- Long-term care homes can provide a residential alternative for patients with high care needs who meet the following criteria:
 - 18 years of age or older
 - Valid Ontario Health Card
 - Have health care needs that cannot be met with any combination of care giving in the home or community
 - Have health care needs that can be met in a long-term care home
- How can we support collaborative care for people with DD who are transitioning to or already in LTC?

Behavioural Supports Ontario Resources

- Behavioural Supports Ontario (BSO)
 - Trained health professionals and programming helping older people with responsive behaviours
 - enhances the health care services of seniors across Ontario, their families and caregivers, who live and cope with responsive behaviours associated with dementia, mental illness, addictions and other neurological conditions, when they require it and wherever they live, at home, in long-term care or elsewhere.
- BSO resources include:
 - BSO Transition Units
 - Responsive behaviours and complex needs resources
 - <http://seniorscarenetwork.ca>

Regional Geriatric Programs

- The RGP supports health care professionals in Toronto and surrounding regions in the provision of interdisciplinary, senior-friendly, and evidence-based care that optimizes the function and independence of seniors and their ability to “age in place”; <http://rgp.toronto.on.ca>

DD and Advance Care Planning

- Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate
- In general, it has been reported that individuals with I/DD were not involved in advanced care planning and rarely had formal plans in place
- Resources:
 - Speak Up Campaign: www.advancecareplanning.ca
 - Palliative Pain & Symptom Management Consultation; Service for Toronto www.ppsmctoronto.com
 - TC CCAC linkages between ASC and Palliative; Program teams for palliative and end-of-life care at home
- How can we improve advance care planning for our clients?

Advance care planning, is not well understood for individuals with I/DD

- Video: Breaking Bad News: <https://www.youtube.com/watch?v=ArDbAxEZjYU>

Reflect – Your Experiences?

- What are some barriers to transitioning to aging care resources?

- What are some successful strategies that could help with overcoming difficulties during this transition?

Selected References

- Lunskey, Y., Klein-Geltink, J.E., Yates, E.A., eds. (2013). 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. Retrieved from: <http://knowledgex.camh.net/hcardd/Documents/HCARD%20ATLAS.pdf>

- Lunsky, Y., Lin, E., Balogh, R., Klein-Geltink, J., Wilton, A.S., & Kurdyak, P. (2012.) Emergency department visits and use of outpatient physician services by adults with developmental disability and psychiatric disorder. *Can J Psychiatry*, 57, (10), pp. 601-607.
- Primary Care of Adults with Developmental Disabilities Canadian Consensus Guidelines (and tools): <http://www.surreyplace.on.ca/Primary-Care>
- Savage, T.A., Moro, T., Boyden, J., Brown, A., & Kavanaugh, K. (2012.) Advanced care planning for people with intellectual & developmental disabilities. *BMJ Support Palliat Care*, 2, p.198.

Case Study – Maria

Self-Reflection

What are some considerations for Maria relating to health and long-term care?

What could you or your agency do to support Maria?

Maria

- 57 year-old-woman with mild DD, living with her 87-year-old mother
- Mother diagnosed with a terminal illness a few months ago
- Maria attends a day program for many years which she would like to retire from
- She currently attends once a week so that she can be with and continue caring for herself and mother
- Maria receives APSW and CCAC supports

Table Discussion

Assume your table represents a community that will need to work together to support Maria relating to health and long-term care. How will you collaborate to support her?

What other information do you need? Who else might you need to collaborate with?

Wrap-Up

Evaluation/Feedback

Please take a few minutes to complete the feedback form if you haven't already done so.

Personal Commitment Activity:

Self-Reflection

Based on what you have learned today, identify two or three things that you are going to make a personal commitment to do or try in the next three to four months.

What supports will you need to help enable you to be successful in achieving your commitments?

Table Discussion

What are some things you are already doing well regarding supporting people through transitions?

What are some "quick wins" around transitions that would be manageable with the current resources you and/or your agency have?

We hope you have found the day useful and enjoyable. Thank you for attending!

Day 3



Maria

Maria 57 year old woman with a mild intellectual disability who lives with her 87 year old mother. Her mother has been diagnosed with a terminal illness a few months ago. Most of Maria's adult life has been around doing activities independently while spending time and supporting her mother with things around the home, like errands, outings, shopping etc. Maria also attends a day program that she has been at for many years which she would like to retire from. She currently attends once a week so that she can be with and continue caring for herself and mother. Maria receives APSW support and now some CCAC support for her and her mother in their home. What are some considerations for Maria? How would you support her to transition from work? What are some things that you would need to empower her to continue making choices?

Day 3: Aging Transitions – Fri Mar 11th, 2016

Characteristics of Grief

From William J Worden, **Grief Therapy and Grief Counseling: a Handbook for the Mental Health Practitioner**, 4th edition

<p>Emotions</p> <ul style="list-style-type: none"> • Sadness • Anger • Guilt and self-reproach (blaming ourselves) • Anxiety • Loneliness • Fatigue • Helplessness • Shock (feeling stunned, feeling disbelief that this has happened) • Yearning • Emancipation (a feeling of freedom) • Relief • Numbness (no feelings) 	<p>Physical Sensations (feelings we may have in our body)</p> <ul style="list-style-type: none"> • Hollowness in the stomach (emptiness) • Tightness in the chest • Tightness in the throat • Oversensitivity to noise (Noises that would not have bothered us before now seem too loud) • A sense of depersonalization: “I walk down the street and nothing seems real, including me.” • Breathlessness, feeling short of breath • Weakness in the muscles • Lack of energy • Dry mouth
<p>Cognitions</p> <ul style="list-style-type: none"> • Disbelief • Confusion • Preoccupation • Sense of presence (e.g. of the dead person, or of someone else we loved, or of God) • Hallucinations (e.g. seeing or hearing something that is not really there) 	<p>Behaviours</p> <ul style="list-style-type: none"> • Sleep disturbances (e.g. not able to sleep, waking up a lot, sleeping too much, sleep-walking) • Appetite disturbances (being less hungry or more hungry than usual, wanting certain foods) • Social withdrawal (not wanting to be in groups or with other people) • Dreams of the deceased person (the person who died) • Avoiding reminders of the deceased person • Searching and calling out for the person • Sighing • Restless hyperactivity • Crying • Visiting places or carrying objects that remind us of the deceased • Treasuring objects that belong to the deceased

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Grief and Bereavement for Persons We Support Who Are Aging

- **Grief and Mourning about Aging for all adults**

What are possible losses that come in old age?

What are possible gains?

- **Aging, Grief and Persons with Developmental Disabilities**

What might be different in the losses persons with disabilities experience as they age? What particular challenges do those who support them face?

- **Supporting the person who is grieving to mourn and discover new life**

What support can we provide individuals who are grieving?

How do we know when grief is too great and that the individual needs professional supports?

What are possible ways to discover new life as we mourn the losses of aging?

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Participant Self-Reflection

We encourage you to use this page to keep track of key points, action items, and connections you make at today's event and hope that you will refer to it once you are back on the job to help reinforce your learning.

Key Points: Use the space below to make note of key points, insights, or take-aways that stand out for you during the day

Connections: Use the space below make note of any new people you meet today that you may want to connect with in the future

Action Items:

- a) Use the space below to make note of key actions you want to take to apply what you learned once you are back at your job

- b) What are some of the challenges you anticipate in trying to carry out your action items? How might you address these?

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Session Evaluation

1. Overall, I found today's session to be:

1 2 3 4 5
Poor Average Excellent

Please explain why you chose that number:

2. The overall relevance of today's session to my practice was:

1 2 3 4 5
Poor Average Excellent

Please explain why you chose that number:

3. What will you do to apply your learning in your work?

4. What I found most useful about the session:

5. One message to the organizers:

Thanks for your participation! Your comments will be collated.

Transitions Series – Feb 26th, Mar 4th, Mar 11th 2016

Program Evaluation

1. After participating in this training, I feel confident I will be able to (circle number):

	1	2	3	4	5
	Not		Somewhat		Extremely
a) Identify effective strategies to improve system access and navigation for clients and families	1	2	3	4	5
b) Use effective planning and decision-making to improve client wellbeing	1	2	3	4	5
c) Support client needs relating to their rights and lifestyles	1	2	3	4	5
d) Construct a network of individuals who can provide expertise and support	1	2	3	4	5

Comments:

2. Think about what you wanted most out of this program when you signed up; did you get what you wanted? Yes ___ No ___

Please explain:

3. Would you recommend this program to a colleague? Yes ___ No ___

Why/Why not?

4. My words of advice for future Shared Learning Forum sessions:

5. Ideas for topics for future Shared Learning Forum events:

6. Other comments?

Thanks for your participation! Your comments will be collated.

