

# Out of the Ivory Tower

Page 1

## Giving research context from different stakeholder perspectives

**Out of the Ivory Tower** is an opportunity for multiple stakeholders to comment on a published article and discuss how it relates to their work, or life. Reviews are welcomed from service providers, people with lived experience, program directors, policy makers, and other researchers.

### Today's reviewers are:

- **Karen Chartier**, Program Director  
Lakeridge Community Support Services,  
Whitby, ON
- **Angie Gonzales**, RN MN, Health Care Facilitator,  
Community Networks of Specialized Care,  
Toronto ON
- **Andrew Torrens**, Peer Navigator  
Inpatient Mental Health Unit,  
Kitchener ON

### Article: Sullivan W., et al. (2011) **Primary Care of Adults with Developmental Disabilities.**

*Canadian Family Physician*, 57; 541-553. Available at: <http://www.cfp.ca/content/57/5/541.full.pdf>

### Overview of Article:

The objective of these guidelines is to offer primary care providers an overview of physical, behavioural and mental health difficulties that may exist among adults with developmental disabilities (DD). The guidelines have been developed out of recognition that people with DD have complex health issues, which may differ from those of the general population.

Adequate primary health care is necessary to identify these issues and to prevent morbidity and premature death among adults with DD. Primary care providers are urged to be particularly attentive to the interactions of biological, psychological, and social factors that contribute to health, since these interactions can be easily overlooked in adults with DD.

The guidelines are presented in a chart form for easy reference and includes both the health consideration (the issue) and assessment or treatment recommendations, as well as the level of supporting evidence.

This review was completed as part of a Community of Interest (CoI) focused on Dual Diagnosis. For additional information on the CoI, please contact:

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



# Out of the Ivory Tower

Page 2

Giving research context from different stakeholder perspectives

## Review 1: Perspective of a Program Director

### What was of most value to you in this article?

The authors provided an impressive comprehensive description of the physical, behavioural and mental health issues of adults with DD. It would be reassuring to think that the majority of primary health care providers of persons with DD share the same understanding of these issues, but in actuality this is not the case. The author's preventative health care checklist is a resource that could make it easier for many more health care professionals to begin to understand the complexities of persons with DD.

### How do you envision incorporating the messages from this article into your work?

As a behaviour support service agency for persons with intellectual disabilities, we are faced with the task of trying to understand what may influence maladaptive behaviour in persons with DD. This task can be successfully accomplished if primary health care providers are able to understand and account for physical and mental health influences on behaviour. As clinicians, whenever we have the opportunity to work in interdisciplinary models that include primary health care providers, opportunities should be made to reference and discuss these guidelines.

**About Karen:** I am the Program Director of a Community Behaviour Therapy Program who has worked in the field of applied behaviour analysis for 20 years with a special interest in adults with DD.



### Do you see any challenges incorporating this into your work?

The challenge arises when health care providers and health care systems do not share the same opinions as the authors of the consensus guidelines. This may lead to undiagnosed medical and mental health issues, which continue to contribute to problem behaviour, thus continuing to make it difficult for caregivers to support their needs.

### How do the findings in this paper relate to your own experiences or knowledge of the subject matter?

For me, these findings reinforced the need for service providers to understand the complexities of behavioural, medical, and mental health issues in persons with DD. Therefore there is a great need have different disciplines to work together to understand the complexities of adults with DD.



# Out of the Ivory Tower

Page 3

Giving research context from different stakeholder perspectives

## Review 2: Perspective of a Service Provider

### What was of most value to you in this article?

The article provides valuable Canadian evidence to inform health care providers' preventative care for people with DD. It comprehensively but concisely presents the particular health issues and clinical care recommendations that are specific for adults with I/DD. Individuals with I/DD may experience very complex health issues, communication barriers and complex behaviours. However, I often receive health care providers' and health care students' feedback that education about I/DD is taught too varying, sometimes very limited degrees. These guidelines can offer helpful evidence with recommendations in our current medical context that lacks knowledge for how to systematically approach providing primary care for an individual with I/DD.

### How do envision incorporating into your work?

The guidelines are very useful as a framework and evidence needed for assessing gaps in care for clients with I/DD. I incorporate the guidelines as a framework for advocacy, and for requesting preventative care when diagnostic overshadowing limits care to focusing on the I/DD as the primary cause of responsive behaviours rather than further investigating possible underlying issues.

### Do you see any challenges to incorporating this into your work?

Challenges have been that the necessary creativity and person-centred approaches for implementing some of the recommendations may require a level

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of inter-professional and caregiver communication and collaboration that the systems that health care providers work in may not support well. For example, primary care providers may order the necessary tests to investigate possible health issues, but finding ways to inform and help the person with I/DD tolerate the tests can be very challenging. Using person-centred approaches may be limited by the environment that the tests are available in. It can be difficult to advocate for modifying approaches, environments or the tests to better support the person with I/DD through health assessments. However, there have been many successful experiences with team work that used recommendations from the guidelines to improve outcomes.

### How do the findings of the article relate to your own experiences or knowledge of the subject matter?

The article discussed considerations that are being experienced as major current issues. The statements about general issues including the disparities in accessing appropriate primary care are very obvious in most situations or experiences.

### Do you have any questions for the authors?

I greatly respect and appreciate the authors' work towards improving Canadian guidelines for primary care for people with I/DD. A question to them could be whether the authors would support or provide a similar version that could inform self-advocates or caregivers.

**About Angie:** I am a Registered Nurse with a graduate degree in community health nursing, working as a Health Care Facilitator (HCF) in the Toronto Network of Specialized Care, based at Surrey Place Centre. Prior to being a HCF for adults with I/DD, my experience was in the areas of brain injury rehab and neuromuscular conditions in the Child Development Program at Holland Bloorview Kids Rehabilitation Hospital.



# Out of the Ivory Tower

Page 4

Giving research context from different stakeholder perspectives

## Review 3: Perspective of a Service Provider with Lived Experience

### What was of most value to you in this article?

We have a number of people in our care living with dual diagnosis (comorbid mental illness and developmental disability) and reading this article was the first time I personally have seen the full breadth of issues facing those with DD. It has also provided some connections to tools and education both for the people themselves and for their caregivers, and had some good, practical suggestions on our approach, and a clear rationale behind their decisions.

### How do you envision incorporating the findings from this article into your work?

We already provide a great deal of transitional support for people as they approach discharge, with their team accompanying them to and/or visiting them at their home during leaves of absence, allowing for a smooth transition to the new staff, services, and life post-discharge. The team has a particularly strong community involvement for those with dual diagnosis. I intend to advocate for more precise goals during those transitions that include not only making the transition easier for the person in our care, but also to facilitate their new support staff in understanding the individual's typical and atypical behaviour, along with means of identifying the meaning behind the atypical behaviour. That being said, while there is always a thorough and detailed discharge plan, I feel that there is always more we can do and more we can learn about how to ensure that people have the greatest quality of life and the best chance of success possible.

### Do you envision any challenges to implementing the findings from this article into your work?

A big challenge is in information gathering. There are quite a number of recommendations on what should be done, but precious little direct information on how such assessments/care can be accomplished. For example, in the attempt to find more detail about a particular recommendation, I followed the reference to a dead link, found a contact e-mail for the university program in question, and five e-mails later, had my hands on the material. Having a living document with direct links to resources and assessment materials where appropriate would be most helpful. Also, while I understand the appeal of organizing the recommendations categorically by the aspect of their care, I feel it would be more useful to the clinicians to have the recommendations and plans organized by frequency; a list of which items should be done every visit, every six months, once per year, and so on. This would reduce the possibility that an item gets overlooked.

From a practical perspective, the effort required to track down the resources and incorporate them into their existing standard of practice would be daunting to say the least, which brings me to the biggest challenge we all face in the health care system – the demands on our time. We currently involve family and other caregivers in care planning and decision making as was recommended, but ensuring that all of these recommendations are incorporated into our practice as well as tracking that information, while important, also puts additional demands on our time. The recommendations appear to be best practice, but we all have our own limitations on our time, and we must balance our priorities, ensuring that our time and resources do the most good to the most people.



# Out of the Ivory Tower

Page 5

Giving research context from different stakeholder perspectives

## How do the findings from the article relate to your knowledge and experiences?

The findings resonated to an extent, but as mentioned in their conclusions, the individual is often lost in any attempt to generalize a population. It was disconcerting seeing how little information was based on formal studies and how much was based on anecdotal evidence or expert opinion. To paraphrase a quote from H.G. Wells: "A theory can make sense, fit all available evidence, be logically consistent, yet still be utterly and completely wrong." I see a need for the beliefs outlined in these recommendations to drive more formal research, which will, in turn, strengthen our understanding of this population so we may better serve them. I understand the many challenges and barriers in performing these studies, as outlined in the limitations and implications section, but I feel that the vastness of the needs demonstrated in the paper can motivate individuals to find ways to navigate through these barriers and produce the more evidence-based results we need, particularly when the recommended practice is intrusive on the individual, or has any sort of negative impact on the person's routine or quality of life.

I am particularly happy to see the recommendations for the involvement of the person's caregivers and other support staff in the process of interpreting behaviour, communicating with the individual, and helping to express what the individual might not be able to. In my experience the involvement of the family and caregivers in the whole process can go a long way to improve the quality of care of the individual.

## Do you have any questions or comments for the authors?

- What can you do in terms of the format of your recommendations that might shorten the time it takes for clinicians to move from paper to practice?
- How can you better connect people to the information and resources referred to in your paper?
- What recommendations can you make to facilitate inter-agency communication to ensure that the people we support receive not only excellent care, but consistent care as well?

I feel that one of the biggest challenges, particularly for individuals with complex health issues as well as the aging population, is differential diagnosis. Abuse, boredom, pain, infection, medication side-effects, worsening mental health, and behaviour issues can all often manifest as the same pattern of behaviour from the individual. Involvement of those most familiar with the individual can sometimes mitigate the confusion and help facilitate communication, but it would be helpful to have tools or methods to differentiate between different issues and ailments that have similar presentations.



# Out of the Ivory Tower

Page 6

Giving research context from different stakeholder perspectives

*(continued)*

I feel that more can be done to bridge the gap between mental health services and those for individuals with DD. Individuals with dual diagnoses are often caught in the middle between the two sectors, with developmental disabilities disqualifying them for certain mental health services and vice versa. We need to do a better job of supporting these individuals; it is quite unsettling when those most in need of such supports, and even social contact with peers, often have quite limited access compared to those who have fewer challenges.

I also feel that though the article does make mention of the importance of recognizing the individuality of the people we support, I don't think it can get stressed enough. People are individuals, not diagnoses, and they get the best medical care when we recognize their individual's strengths, means of communicating, background and culture, and tailor our care to the individual, rather than try to find a universal method that will equally serve the entire population. The better we know and understand the individual, the more we are able to walk with them in their recovery or support them where they are, and the less we're trying to drag them forward at a pace set by our own agenda or mandate.

**About Andrew:** I am a Peer Navigator within a mental health inpatient unit in Kitchener ON.

## Update!

Out of these Consensus Guidelines has emerged the **Developmental Disabilities Primary Care Initiative**. The Initiative brings together clinicians who have expertise in the care of adults with DD and who share the goal of improving the health and quality of life among this patient population.

The Initiative has received funding from the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care and the Surrey Place Centre Foundation to create tools and resources to help primary care providers and caregivers to follow the best practices outlined in the Guidelines. These tools and resources are available online in both English and French.

### Tools for Primary Care providers:

<http://www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-primary-care-providers.aspx>

Examples include:

- Cumulative Patient Profile
- Comprehensive Health Assessment
- Preventive Health Checklist
- Informed Consent
- Health Watch Tables
- Office Organizational Tips
- Advocacy Role for Primary Care Providers

### Tools for Caregivers:

<http://www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx>

Examples include:

- Community Resources
- Caregiver Health Assessment
- Guidance about Emergencies

Evidence Exchange Network (EENet) is a mental health and addictions knowledge exchange network that connects stakeholders across Ontario. One of the goals of the network is to promote the use of research evidence into decision-making.