Lost in Translation: Lessons about moving research in developmental disabilities into practice and policy

Yona Lunsky
October 10, 2019
National Research Consortium on MH in IDD
"There are two main ways to speak truth, one is through stories; the other is through studies. But people don’t care about what you know, until they know that you care"

Cormac Russell
Let’s START at the very beginning.....
Clinical model of services, replicated across the US

Standardized measures employed at set time periods.

Using a common infrastructure, have summarized behavior outcomes, family experience, medication profiles, ED visits and hospitalizations, as well as predictors of hospitalization

https://www.centerforstartservices.org/annual-reports-0
Psychological Therapies – NHS Scotland
Comparison of behavioural activation with guided self-help for treatment of depression in adults with intellectual disabilities: a randomised controlled trial

Andrew Jahoda, Richard Hastings, Chris Hatton, Sally-Anne Cooper, Dave Dagnan, Ruqin Zhang, Alex McConnachie, Nicola McMeekin, Kim Appleton, Rob Jones, Katarzyna Scott, Lauren Fulton, Rosie Knight, Dawn Kneen, Chris Williams, Andrew Briggs, Ken MacMahon, Helen Lyon, Ian Smith, Gail Thomas, Craig McWlze

Summary
Backgroud Psychological therapies are first-line interventions for depression, but existing provision is not accessible for many adults with intellectual disabilities. We investigated the clinical and cost-effectiveness of a behavioural activation intervention (Beatt1) for people with intellectual disabilities and depression. Beatt1 was compared with a guided self-help intervention (StepUp).

Methods
We did a multicentre, single-blind, randomised, controlled trial with follow-up at 4 months and 12 months after randomisation. Participants aged 18 years or older, with mild to moderate intellectual disabilities and clinically significant depression were recruited from health and social care services in the UK. The primary outcome was the Glasgow Depression Scale for people with a Learning Disability (GDS-LD) score at 12 months. Analyses were done on an intention-to-treat basis. This trial is registered with ISCRCTN, number ISRCTN07953005.

Findings
Between Aug 8, 2013, and Sept 1, 2015, 161 participants were randomly assigned to 84 to Beatt1; 77 to StepUp); 141 (88%) participants completed the trial. No group differences were found in the effects of Beatt1 and StepUp based on GDS-LD scores at 12 months (12-03 [SD 7-99] GDS-LD points for Beatt1 vs 12-43 [SD 7-64] GDS-LD points for StepUp; mean difference 0.26 GDS-LD points [95% CI −1.18 to 2.70]; p=0.833). Within-group improvements in GDS-LD scores occurred in both groups at 12 months (Beatt1, mean change −4.2 GDS-LD points [95% CI −6.0 to −2.4]; p=0.0001; StepUp, mean change −4.5 GDS-LD points [−6.2 to −2.7]; p=0.0001), with large effect sizes (Beatt1, 0.59 [95% CI 0.337−0.844]; StepUp, 0.627 [0.380−0.873]). Beatt1 was not cost-effective when compared with StepUp, although the economic analyses indicated substantial uncertainty. Treatment costs were only approximately 3−6−8% of participants’ total support costs. No treatment-related or trial-related adverse events were reported.

Interpretation
This study is, to our knowledge, the first large randomised controlled trial assessing individual psychological interventions for people with intellectual disabilities and mental health problems. These findings show that there is no evidence that Beatt1 is more effective than StepUp; both are active and potentially effective interventions.
STEPUP

A Guided Self-Help Intervention for People with Intellectual Disabilities and Low Mood

Treatment Manual for Therapists

A good night’s sleep

Part of the Step Up self-help pack: Booklet 2

Well done

So far you have:

✓ Thought about your sleep
✓ Made a sleep routine
✓ Looked at your bedroom
✓ Made choices about your lifestyle.

You might start sleeping better now. Sometimes you need to give it time. Stick to your routine. Keep trying.
A Behavioural Activation Intervention for People with Intellectual Disabilities and Low Mood
Beat-it and Step-Up

- Funding stream through NIHR on effectiveness, costs and impacts of NHS health care delivery
- Psychological therapies are available through the NHS
- History of CBT and ID research
- NICE guidance includes psychological therapies and ID
- Capacity building of therapists with skill set to deliver treatment
- Community partnerships
- Sustained effort and leadership
3DN – University of NSW
### Research area

<table>
<thead>
<tr>
<th><strong>Health inequality and Epidemiology</strong></th>
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<tbody>
<tr>
<td>Established ID population cohorts</td>
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<tr>
<td>Analysis of ambulatory mental health data</td>
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<tr>
<td>Analysis of mortality data</td>
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<tr>
<td>Cohort study of elderly with ID</td>
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<tr>
<td>Analysis of national GP dataset (BEACH)</td>
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<tr>
<th><strong>Understanding risk factors</strong></th>
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<tr>
<td>Analysis of cause of death data</td>
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<tr>
<td>Review of cardiometabolic risk factors</td>
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<td>Mixed methods analysis of barriers to healthcare</td>
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<thead>
<tr>
<th><strong>Contextual determinants of health inequality</strong></th>
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<tbody>
<tr>
<td>National audits of medical &amp; nursing schools</td>
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<tr>
<td>Statewide analysis of competence &amp; training needs of mental health professionals</td>
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<tr>
<td>National analysis of ID psychiatrist workforce</td>
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<tr>
<td>National and State Policy analysis</td>
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<tr>
<th><strong>Formulation and testing of interventions</strong></th>
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<tr>
<td>Developed/piloted healthy lifestyle intervention</td>
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<tr>
<td>Delphi and scoping of tertiary ID mental health service</td>
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<tr>
<td>Design and implementation of training curriculum in ID mental health</td>
</tr>
<tr>
<td>Development and evaluation of cardiometabolic framework and toolkit</td>
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<tr>
<td>Co-hosted 1st and 2nd National Round Table</td>
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</table>

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<thead>
<tr>
<th><strong>Knowledge transfer</strong></th>
</tr>
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<tr>
<td>Inclusive KT platform established, developed:</td>
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<tr>
<td>National Guide ID and 2018 Communique</td>
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<td>Comprehensive e-learning portal for health, disability professionals and carers</td>
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<tr>
<td>Core competencies framework and toolkit</td>
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<td>Responsible prescribing resources</td>
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### Projects to date

- Prevalence of mental illness in people with ID
- Mental health outcomes and their predictors
- Prevalence of physical health comorbidities in people with ID and mental illness
- Health service use, avoidable service use & predictors

### Projects in the future

- Determinants of mental illness in people with ID
- Risk factor analysis in ultra high risk groups
- Participation in preventative health programs

- Predictors of mental health outcomes
- Interagency integration & continuity of care
- Costs and markers of service inefficiency
- Psychopharmacology and its relationship to outcomes

- Develop model of care and model costs
- Develop interagency services model
- Pilot a deprescribing intervention
- Host 3rd National Round Table on ID mental health to determine future priorities

- Collaborate with NDIA, Health department on policy revisions and services development initiatives
- Implement a state-wide service based on trial results
- Develop and launch a ‘closing the physical health gap’ strategy for people with ID and mental illness
Knowledge Cycle

**Generating Knowledge**
- Data Linkage
- Policy Analysis
- Systematic Review
- Qualitative Study

**Developing Knowledge Outputs**
- Data Visualisation
- Papers
- Fact Sheets
- Easy Read Docs
- Presentations
- National Roundtable

**Delivering Outcomes:**
- Dissemination strategy
- Partners
- Consumer Groups
- Service Providers

Delivering Outcomes: Improving Mental Health Outcomes for People with Intellectual Disability
National Roundtable on the mental health of people with intellectual disability 2018

• major research translation event
• over 130 key experts from health and disability sectors from around the country
• generated a set of clear and actionable recommendations for the sector
• catalyst for ongoing improvement in mental health services and outcomes for people with ID
• consensus on priorities for action in contentious areas
Intellectual Disability Mental Health

1. Collection of researchers from different disciplines through Chair in ID/MH within Faculty of Medicine
2. Working together with community partners
3. Combining big data with little data
4. Efforts that are inclusive of people with IDD
5. Tangible KT products to impact policy & practice
Medications: STOMP UK
STOMP
Stopping the over medication of people with a learning disability, autism or both

Everyone working together to stop the over use of psychotropic medicines and to improve people’s quality of life.
RESEARCH ARTICLE

Improving knowledge of psychotropic prescribing in people with Intellectual Disability in primary care
Roshi Shankar1,2,*, Mike Wilcock1,2

1. Cornwall PiMAT/NIHR Foundation Trust, Truro, United Kingdom; 2. University of Stavanger Medical School, Stavanger, United Kingdom; 3. Royal Cornwall Hospitals Trust, Truro, United Kingdom
*These authors contributed equally to this work.

Abstract

Purpose
People with Intellectual disability (ID) are likely to be prescribed psychotropic medication particularly antipsychotics without a clear clinical indication. This has given rise to a national initiative in the UK to stop overprescribing medication in this vulnerable population. While the goals are simple it is unclear if specialist ID services or primary care services in the UK should take a lead. Further, it is uncertain if primary care practitioners (GPs) can be systematically educated of the latest good practice developments and concerns in this specialised area. This study surveyed the knowledge level of a sample of GPs in Cornwall UK (county of 588,000) post a structured tutorial on psychotropic medication and people with ID.

Methods
A 21-item questionnaire was delivered in meetings organised for all the county GPs a year after a talk given to the same demographics. The questionnaires conducted an assessment of the knowledge of national guidance on use of psychotropic medication in ID based on the subjects covered in the tutorial.

Results
Of the 40 expected GP participants the tutorial was attended by 44 GPs (73%) and the follow up meeting by 42 (70%). Ninety percent GPs in the follow up meeting filled the questionnaires. For 16 questions, more than 80% GPs gave correct responses whereas five questions attracted a correct answer from less than 60%. Majority of the GPs felt psychotropic medication management in people with ID should be specialist led.

Conclusions
GPs’ knowledge of issues relevant to prescribing in people with ID benefitted from the tutorial. However a clear need for the psychotropic medication management to be delivered via specialist care emerged. This raises issues of resource allocation and debate on whether...
STOMP
Pledge for Social Care
Stopping Over-Medication of People with a Learning Disability, Autism or Both

Supported by NHS England
STOMP Pledge for Social Care
Stopping Over-Medication of People with a Learning Disability, Autism or Both

We pledge to act in the best interests of the people we support at all times by:

- Actively promoting alternatives to medication such as active support, intensive interaction or positive behaviour support.
- Ensuring the people we support, and their circle of support, are involved in decisions about their care, including their medication.
- Ensuring all staff have an understanding of psychotropic medication, including its main uses and side effects.
- Encouraging staff to speak up if they have a concern that a person we support may be over-medicated.
- Maintaining accurate records about the health, wellbeing and behaviour of the people we support.
- Supporting people to have regular reviews of their medication.
- Monitoring the use of psychotropic medication.
- Working with people with a learning disability, autism or both, their families, health professionals, commissioners and others to stop over-medication. This includes working closely with prescribers.

We will set out the actions we will take and report annually on the progress we have made.

Sign up to the STOMP pledge for social care at www.vodg.org.uk/campaigns/stompcampaign/
Getting it right for me

- work with me and the people who support me, my family, the doctor and others to get my treatment right

- make sure I have regular medicine reviews

- help me look after my physical health

- make sure I take psychotropic medicine for the right reasons, in the right amount and for the shortest time possible

- find other ways to help me stay well and safe

- give me information I can understand so I know what things mean and can ask questions

- involve me in decisions about my care and treatment

- give my family and carers the information and support they need to help me.
Medication Pathway

SECTION A
Introduction
This resource is for family carers of someone with a learning disability, autism or both who are looking for information about psychotropic medication. The pathway focuses on how to make sure that your relative only takes medication that they need and that your relative is taking medication safely.

SECTION B
Medication Facts and National Guidance
NHS England led a pledge in 2016 to stop over-medication, which is supported by many organisations in health and social care. This was intended as a ‘call to action’ and a commitment to reducing the levels of inappropriate psychotropic medication prescribed for people with a learning disability, autism or both.

SECTION C
Medication has been suggested
Before medication is prescribed, there are several checks that should be carried out in partnership with your relative and a professional.
Medication should not be the only option considered in response to challenging behaviour and should only be used if alternative strategies have not reduced the behaviour.
Ingredients

Clinical guidelines
Research studies using big and little data
Commitment of professional colleges
National reports, and media attention
Engagement of community agencies, families, people with disabilities
NHS indicators related to this initiative
H-CARDD: Our great Canadian adventure
Partnering For Progress
Numbers matter…

If we don’t count,

they don’t count
Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario

December 2013
What did we find?

66,484 adults between 18 and 64.
Comorbidities

<table>
<thead>
<tr>
<th>Condition</th>
<th>With</th>
<th>Without</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congestive heart failure*</td>
<td>2.6</td>
<td>0.8</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease*</td>
<td>10.9</td>
<td>5.8</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10.4</td>
<td>6.5</td>
</tr>
<tr>
<td>Asthma</td>
<td>17.5</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>14.5</td>
<td>14.5</td>
</tr>
<tr>
<td>Psychiatric disorder**</td>
<td>48.6</td>
<td>26.4</td>
</tr>
</tbody>
</table>
Health Care Visits

<table>
<thead>
<tr>
<th>Health Care Visits</th>
<th>With</th>
<th>Without</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care visits</td>
<td>76.1</td>
<td>74.5</td>
</tr>
<tr>
<td>Emergency department visits</td>
<td>33.9</td>
<td>20.2</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>7.5</td>
<td>4.4</td>
</tr>
</tbody>
</table>
Preventable Hospitalizations
Medication Use

![Bar Chart: Medication Use]

- Adults (%)
- Mediations (n)
- 0: 39.5%
- 1: 13.0%
- 2-4: 26.0%
- 5-7: 13.0%
- 8-10: 5.7%
- 11+: 2.8%
Note: The categories displayed are not mutually exclusive. Some individuals were dispensed medications from multiple classes.
Antipsychotics common for adults with intellectual and developmental disabilities

Six-year Canadian study shows prescriptions often occur in adults with no psychiatric diagnosis

Study looked at health care data of 51,881 adults 18 to 64 years of age with intellectual and developmental disabilities (IDD) from 2010 to 2016.

IDD includes conditions such as Down syndrome, fetal alcohol syndrome and autism.

39% of Ontario adults with IDD were dispensed antipsychotic medication.

Among them:

Almost 1/3 did not have a documented psychiatric diagnosis.

Researchers say more scrutiny is needed in how antipsychotics are prescribed for this vulnerable population.


Institute for Clinical Evaluative Sciences
ices.on.ca

ODPRN

2017
Family Health Teams

Implementing Health Checks for Adults with Developmental Disabilities

What is the problem?
Health Check Toolkit

Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers

This toolkit aims to provide primary care providers with tools and resources to support the provision of Health Checks for patients with developmental disabilities. To reach this end we have compiled both clinical tools - which may be useful at the point of care (these start on page 24), in addition to implementation resources for those sites interested in formalizing a Health Check program. The latter includes strategies and resources to raise awareness in your site, mechanisms to identify patients with developmental disabilities, and suggestions on how to invite them in for a Health Check.

See also: Caring for your adult patients with developmental disabilities: Tools for completing a DD health check (Brief guide). This short guide is meant to serve as a quick reference resource. It includes screening tools, samples of health check templates, quick reference assessment guides, and health promotion and communication resources for patients.

Table of Contents

About this Toolkit, Health Checks: What's the Evidence?, Top 10 Tips for a DD Health Check, Four Steps to Implementation, Before you get Started
Case based learning videos

https://www.porticonetwork.ca/web/hcardd/resources/videos
The health check: What is it and what do staff need to know?

This newsletter is just what the doctor ordered (four doctors actually, and a psychologist). This is a no-nonsense discussion on the importance of the health check and how you as staff can make a difference with the individuals that you support.

A health check is like an annual physical at your family doctor's office, but with special attention to issues important to the health of adults with developmental disabilities. The health check is about promoting good health (e.g., advice regarding diet, activity and sleep), early detection of health problems (e.g., screening for cancer, high blood pressure or blood sugar), preventing diseases (e.g., Hepatitis immunizations), and managing health problems (e.g., diabetes). It is the most important recommendation of the Canadian Developmental Disabilities Primary Care Guidelines (document link). To learn more about what a health check is and why it is important, watch Dr. Casson explain it (video link).

What happens at a health check?

The health check is an opportunity to take a good look at everything going on. It might take more than one visit. It involves the family doctor,
Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

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Elspeth Bradley MBBS PhD FRCPCP  RCPCP  Ian Casson MD MSC FCFP  Brian Hennen MD MA FCFP FRCP
Maureen Kelly MPA  Marika Korossy  Karen McNeil MD CCFP FCFP  Dara Abells MD CCFP MScCH
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Amanda Lepp MD PhD  Yona Lunsky PhD CPsych  Shirley McMillan RN MN CDDN PhD  Ullanda Niel MD CCFP
Samantha Sacks MD CM CCFP  Sarah Shea MD FRCPCP  Katherine Stringer MBChB CCFP FCFP
Kyle Sue MD MHM CCFP-PC  Sandra Witherbee RN

Abstract

Objective  To update the 2011 Canadian guidelines for primary care of adults with intellectual and developmental disabilities (IDD).

Methods  Family physicians and other health professionals experienced in the care of people with IDD reviewed and synthesized recent empirical, ecosystem, expert, and experiential knowledge. A system was developed to grade the strength of recommendations.

Recommendations  Adults with IDD are a heterogeneous group of patients and have health conditions and factors affecting their health that can vary in kind, manifestation, severity, or complexity from those of others in the community. They require approaches to care and interventions that are adapted to their needs. These guidelines provide advice regarding standards of care. References to clinical tools and other practical resources are incorporated. The approaches to care that are outlined here can be applied to other groups of patients that have impairments in cognitive, communicative, or other adaptive functioning.

Conclusion  As primary care providers, family physicians play a vital role in promoting the health and well-being of adults with IDD. These guidelines can aid their decision making with patients and caregivers.

http://www.cfp.ca/content/64/4/254.full.pdf
HELP for behaviours that challenge in adults with intellectual and developmental disabilities

Laurie Green MD CCFP(EM)  Karen McNeil MD CCFP  Marika Korossy  Kerry Boyd MD FRCP  Elizabeth Grier MD CCFP
Mackenzie Ketchell MS BCBA  Alvin Loh MD FRCP  Yona Lunsky PhD CSPSYCH  Shirley McMillan APN
Amanda Sawyer MD FRCP  Anupam Thakur MBBS MD MSC  Elspeth Bradley MBBS PhD FRCP  FRCPsyCh

Abstract

Objective To provide primary care physicians with an understanding of the causes of behaviours that challenge (BTC) in adults with intellectual and developmental disabilities (IDD), as presented in the 2018 Canadian consensus guidelines for primary care of adults with IDD; to offer a systematic approach to the assessment and treatment of such behaviours; and to link to tools to support these assessments.

Sources of information This review elaborates upon guidelines 26 to 29 in the mental health section of the 2018 Canadian consensus guidelines. Several of the authors participated in the development of these guidelines, which were based on literature searches and interdisciplinary input.

Main message Most adults with IDD are followed by primary care providers but they comprise a small proportion of primary care practices. Unique ways of communicating needs, diagnostic queries, and BTC are common in this population. This complexity can lead to missed diagnoses and inappropriate antipsychotic medication use with attendant risks. This article presents a systematic approach, HELP, to the assessment and treatment of factors of Health, Environment, Lived experience, and Psychiatric conditions that can lead to BTC and includes tools to support these assessments.

http://www.cfp.ca/content/cfp/64/Suppl_2/S23.full.pdf
Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario

February 2019
# Health Care Gaps for Adults with DD

## 6 Year Period (FY 2010-2015)

<table>
<thead>
<tr>
<th>Metric</th>
<th>DD vs. no DD</th>
<th>Ratio</th>
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<tbody>
<tr>
<td><strong>30-Day Repeat ED Visits</strong></td>
<td>Nearly 2× higher</td>
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<tr>
<td>Likelihood of having at least one return visit to an ED within 30 days of an earlier visit or hospitalization.</td>
<td>34.5% vs. 19.6%</td>
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<tr>
<td><strong>30-Day Repeat Hospitalizations</strong></td>
<td>More than 3× higher</td>
<td></td>
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<tr>
<td>Likelihood of having a repeat hospitalization within 30 days of a previous discharge.</td>
<td>7.4% vs. 2.3%</td>
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<tr>
<td><strong>Alternate Level of Care</strong></td>
<td>6.5× higher</td>
<td></td>
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<tr>
<td>Likelihood of having to remain in hospital despite being recovered enough for discharge.</td>
<td>4.6% vs. 0.7%</td>
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<tr>
<td><strong>Long-Term Care</strong></td>
<td>17.5× higher</td>
<td></td>
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<tr>
<td>Likelihood of living in a long-term care facility.</td>
<td>3.5% vs. 0.2%</td>
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<tr>
<td><strong>Premature Mortality</strong></td>
<td>Nearly 4× higher</td>
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<tr>
<td>Likelihood of dying before the age of 75 years.</td>
<td>6.1% vs. 1.6%</td>
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</table>
Outcomes by IDD and Psychiatric Disorder

6 Year Period (FY 2010-2015)
Ingredients

1. Started with partnerships and a topic (primary care)
2. Linked justification and effort to national guidelines group
3. Kept adding, building our team (from outside)
4. Trainee opportunities
5. Strategic level advisory and project advisories
6. Included patient and family voices early
7. Balanced big data studies with little data
8. Focus on Knowledge to action / Implementation science
9. Although not a mental health focus, it always comes back to mental health
Lessons from knowledge to action projects

1. Get buy in / make the case for change
   - Visibility
   - Champions

2. Combined internal – external team

3. It is OK to start small
   - Trialability
   - Build on success

4. Plan for sustainability and system spread
   - Leverage opportunities
   - Support your champions
Be my microphone,
- not my voice

David Hingsburger
Lessons...
Partnerships have give and take

Relationships are fragile, even good ones
Need for tools to help people speak the same language

Know your data and Carpe Diem

Be systematic in determining and evaluating solutions
Be nimble and light hearted

Invest in what you love and don’t get stuck only with what makes you most angry
Learn from existing solutions and collaborate
(from State to State, and ACROSS THE WORLD)

Use social media to be in touch with what is happening, engage with it
Resources

www.hcardd.ca
www.ddprimarycare.surreyplace.ca
www.camh.ca
www.nutsandboltstools.com

https://www.porticonetwork.ca/treatments/disorders-qr/dual-diagnosis

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Thank You