Disclaimer:





Intellectual Disability and Dementia

Evidence Review

The information contained in this PowerPoint presentation, is directly related to the work of the project on:

"Canadian Best Practice Guidance for Quality Community Supports and Care for Adults with Intellectual Disabilities and Dementia and Their Caregivers"

Professor Karen Watchman, University of Stirling







Intellectual Disability and Dementia

Evidence Review

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Overview

- The brief
- Professionals and families
- Screening and assessment tools
- Training
- Individuals with intellectual disability
- Academic review
- Canadian guidelines
- Discussion

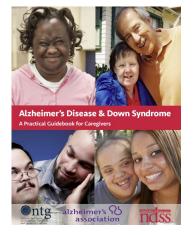


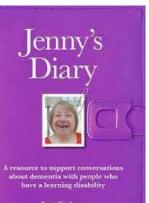
Image reproduced with permission from Stand by Me (Watchman et al., 2023)

The brief

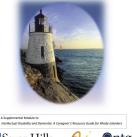
- Summary of freely available resources and tools practice based information:
 - \circ for professionals, families and people with intellectual disability
 - overview of screening and diagnostic tools
 - training courses or resources available
- Rapid review of academic databases, 2016-2023, searching for:
 - interventions, community support, service provision
 - experiences of people with intellectual disability and caregivers
 - o screening and assessment tools (non clinical)

Sample of resources and tools – all links provided





Kares Watchman, Irene Taffrey-Wijne, Sam Qaina Talking About Dementia: A Guide for Families, Caregivers and Adults with Intellectual Disability



Seven Hills Rhode Island



Behaviour that challenges

Physical
Health
Get to know the
person

Mental Health
Physical
Environment



Evaluation of Down's Syndrome Scotland Life Story Project

My Life My Future

Evaluation Report Dr Karen Watchman Dr Kate Mattheys Faculty of Health Sciences and Sport, University of Stirling

Information for health and social care professionals and family members - consensus

- Training required
- Multidisciplinary approach
- Need to communicate about dementia
- Palliative care
- Typically used assessment tools not appropriate
- 'It might not be dementia'
- Pain management
- Co-morbidity and medication review

- Ageing in place (stay at home) as first option, but...
- Environmental changes
- Focus on the persons strengths and choices, maintaining independence for as long as possible
- Communicate in the way the person wants
- Non-drug support
- Reminiscence including music and life story

Sharing positive experiences and memories can be important to people with a learning disability



Visit scld.org.uk/stand-by-me/ to learn more

Lack of consensus

- Age of first baseline assessment for people with Down's syndrome
- Where someone lives as dementia progresses – referral out seen as last choice, but...
- Care home

- Best practice?
- Who provides support?
- Memory clinics/services
- Training what and for who?
- Recognition/awareness of differences when person with dementia has an intellectual disability

- Previous cognitive ability
- Process of diagnosis
- Increased misdiagnosis
- Age at diagnosis and early signs
- Disclosure of diagnosis
- Diagnostic overshadowing
- Progression of dementia
- Change in gait/walking
- Family support
- Where people live
- Apparent change in personality
- Frequency of medication review
- Late onset seizures



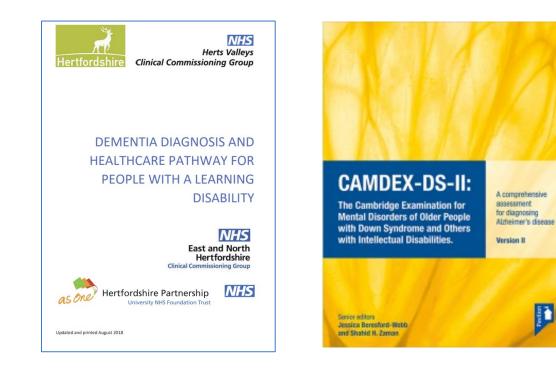
What may be different?



Image reproduced with permission from Jenny's Diary (Watchman et al., 2015)

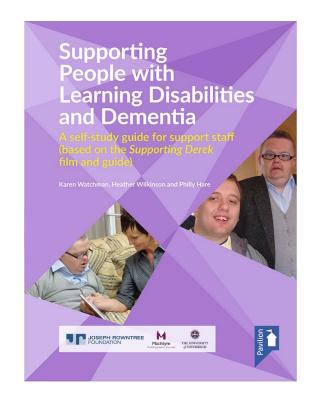
Screening and assessment tools

- Mostly screening information, some locally adapted or developed
- Baseline assessment
- Range of assessment tools – limited evidence base



Training

- Some PowerPoint presentations online however, evidence base not always clear
- US, Canadian, UK and Ireland
- Some 'off the shelf' packages, limited face to face/real time online



Let's talk about dementia with people who have a learning disability



Visit scld.org.uk/stand-by-me/ to learn more

Information for people with intellectual disability

- Range of pictorial booklets and guides to explain dementia
- Resources for peers and friends
- Resources for couples
- Mostly in English language

Hare Been Brave been been been been been been been be		Le journal de Jenny fuit de Je
		Karen Watchman, Irene Tuffrey-Wijne, Sam Quinn
Understanding dementia		
people with learning disabilities finding out and raising awareness together	About my friend This booket is for you if your friend has derentia. Denoted is when ports of the brain also purching as well as they did. It can be uported in the proof finded to not have been did allow your than blain the not be uported in the proof finded to proof the second of the proof finded to the the proof the second of the proof finded to the proof the second of the proof finded to the proof the proof the second of the proof finded to the proof proof to the proof finded to the proof finded to the proof proof the second of the proof finded to the proof finded to proof the proof finded to the proof finded to the proof proof to the proof the proof finded to the proof of the proof finded to the proof of the proof finded to the proof finded to the proof of th	About my friend For frinds of people with Down's syndrome and dementia
	Other booklets in this series The journey of the how people change from bothers to defor people Noted demonstratic for people with serving disobilities	Kenn hode Web the ear Web the ear Material of the earlier of the e

HE DIFFERENCE

Rapid review of academic studies

- Lack of co-production
- Staging of dementia may not be appropriate
- Role of allied health professionals
- Importance of training
- Lack of advanced dementia awareness

- Impact of transitions on people with intellectual disability
- Reinforces gap between intellectual disability and dementia services/supports
- Lack of recognition in dementia national plans and strategies

What is new?

- Brain health and dementia risk reduction
- Care home (how the 'referral out' option may be supported)
- Talking about/sharing the diagnosis
- Strengths/asset/rights based
- Increased focus on end of life care
- Wider knowledge of health inequalities

- Inclusion of people with intellectual disability and dementia in research
- People with intellectual disability as carers
- Recognising couples and the importance of relationships/marriages
- Concurrent mental health
 problems

People with a learning disability are carers too



Visit scld.org.uk/stand-by-me/ to learn more ß

Updating the Canadian Guidelines – further discussion points

- In isolation or as part of more holistic approach to aging?
- Caution over some specific service provider information
- Baseline and NTG screening tool
- Voice of people with intellectual disability
- Impact on peers

- Timeline?
 - Edinburgh Principles,2001
 - My Thinker's Not
 Working report, 2012
 - Glasgow summit, 2016
 - Toronto summit, 2023

People with a learning disability can live well with dementia



Visit scld.org.uk/stand-by-me/ to learn more



Thank you

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