



Launch of joint dementia guidance – what have we learnt in the last 5 years?

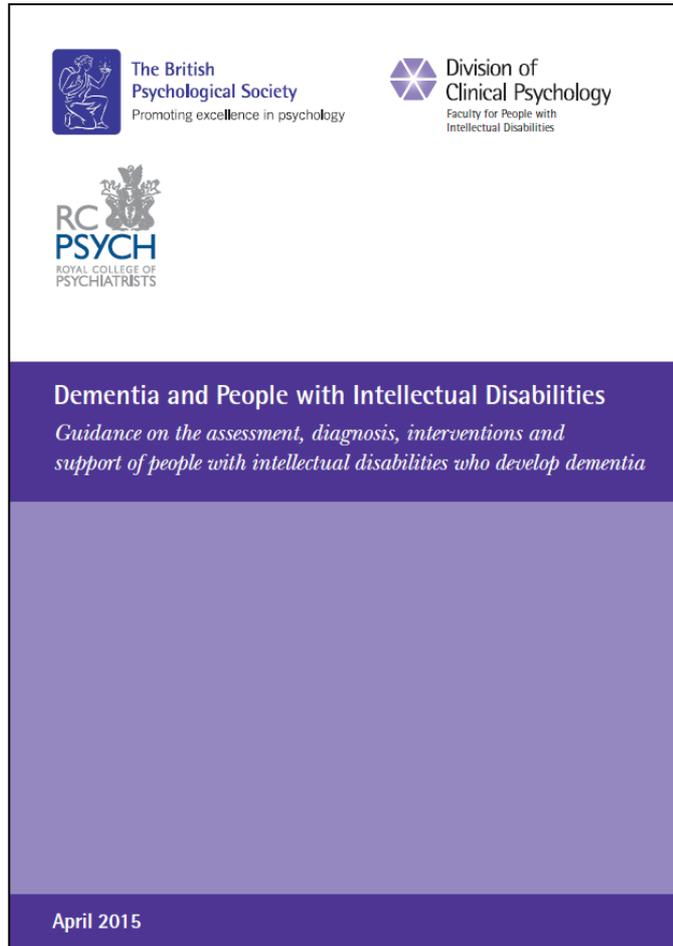
Dr Karen Dodd – BPS

Dr Mark Scheepers - RCPsych

About today

- 10.05** **Keynote 1: Launch of Joint Dementia Guidelines**
Karen Dodd / Mark Scheepers
- 10.30** **Keynote 2: Epidemiology and Prevalence - Andre Strydom**
- 11.00** **Keynote 3: Assessment - Karen Dodd / Tony Holland**
- 11.30** **Tea**
- 12.00** **Workshops**
- a) Diagnostic Issues and Breaking the News**
 Suzanne Wilson / Simon Bonnell
- b) Supporting Families and Staff**
 Tessa Lippold / Satheesh Kumar
- c) End of Life**
 Sarah Coles/ Tracey Finnamore
- 13.00** **Lunch**
- 14.00** **Keynote 4: Interventions**
Sarah Coles / Mark Scheepers
- 14.30** **Keynote 5: Outcomes**
Karen Dodd
- 15.00** **Tea**
- 15.30** **Workshops - repeated**
- 16.30** **Keynote 6: Future Directions and Research**
Tony Holland
- 17.00** **Finish**

Launching the updated guidance



The cover features logos for The British Psychological Society, Division of Clinical Psychology, and the Royal College of Psychiatrists (RC PSYCH). The title and subtitle are in a white box on a purple background, and the date 'April 2015' is in a dark purple box at the bottom.

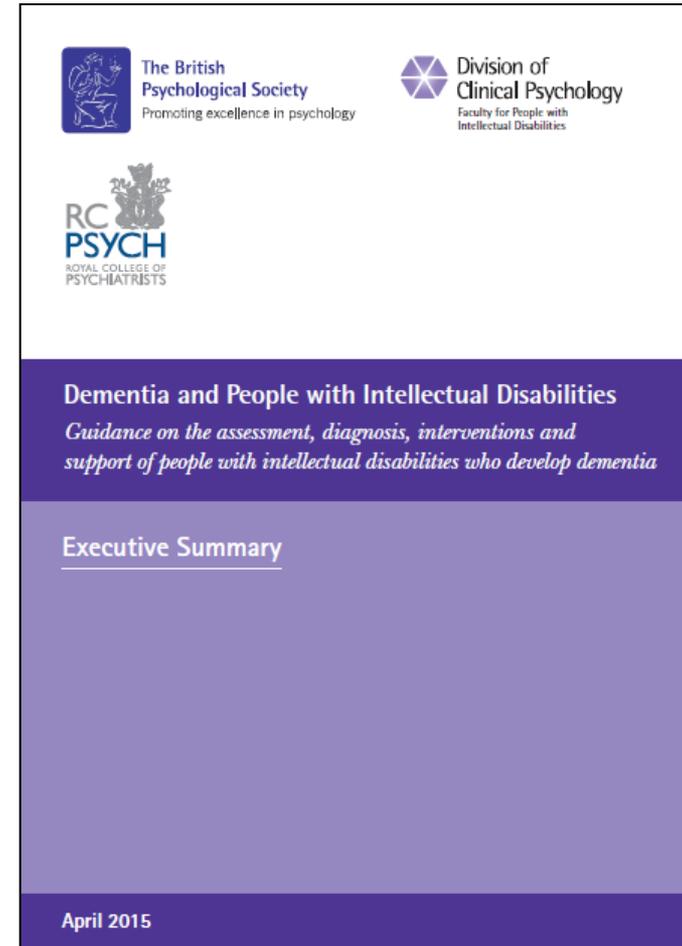
 The British Psychological Society
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 Division of Clinical Psychology
Faculty for People with Intellectual Disabilities

 RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

Dementia and People with Intellectual Disabilities
Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia

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Executive Summary

April 2015

Foreword

It is a great pleasure to be asked to provide a foreword for this excellent guidance on dementia and people with intellectual disabilities. The awareness of dementia has never been higher and the emphasis on providing support to people following a diagnosis is most important. We know that dementia attracts stigma and that is of at least equal if not more relevance in people with intellectual disabilities. Professionals and the public are generally more aware of the increased risk of developing dementia in people with intellectual disabilities.

The guidance is comprehensive across the pathway from diagnosis, post diagnostic support including assessment, through management and end of life care. Its strength is in its comprehensive nature, including, in the same breath, those practical and clinical suggestions which are so important in the day-to-day care of people as well as the evidence base for these actions. The multi-professional nature of the guidance is so important.

One of the things which has been achieved in dementia in the general population, particularly older people, is to convey a message that dementia is a challenge for everybody. Information and guidance has been key to this and the information provided in this guide will go a long way to reassuring people that issues regarding cognitive impairment and dementia in people with intellectual disabilities are not, in all cases and as a matter of course, the purview of the expert and the specialist. Everyone knows that, thanks to advances in medical care and the social environment, people with intellectual disabilities are now living longer, a great success and a tribute to society, and that brings with it some challenges in terms of the need for more services for people with cognitive impairment and intellectual disabilities.

This guidance has been created carefully by the recognised authorities in the arena and has been woven together expertly. It is accessible and yet comprehensive, it is practical but not simplistic but most importantly it whets the appetite of the reader to learn more. Although concentrating on initiatives in England, an international audience could read it with benefit.

I certainly learnt more about dementia in people with intellectual disabilities in reading this than I have ever before.

Professor Alistair Burns

National Clinical Director of Dementia

NHS England Guidance

Updating the guidance

- Asked all original contributors
- Lost some and gained some others

Current group:

BPS: Karen Dodd, Sarah Whitwham, Suzanne Wilson, Sarah Coles

RCPSych: Tony Holland, Satheesh Kumar, Mark Scheepers, Andre Strydom

RCN: Tracey Finnamore

Ageing

- People are getting older, and as a result, the challenge of “benign senile senescence” or “mild cognitive impairment” increases
- The challenge is identifying those most at risk and quantifying function in people with reduced cognitive reserve
- Need to be mindful of associated health conditions (epilepsy and head injury, hypertension and CVA, VSD and Eisenmenger syndrome etc.)

What else is in the guidance?

- Updated the context
- Reasons for decline – no substantive change
- Clinical presentation – updated for DSM-V
- Additional health issues – now includes gastrointestinal disorders and intercurrent infections
- Conceptual Understanding – included description of different stages and vignette
- Philosophy of care – more on life story work and greater description of what constitutes good care and what needs to be achieved

- Environments – more detail on what are the features of a capable environment
- Safe Eating and Drinking – whole new section
- Capable commissioning – rewritten to reflect changing commissioning landscape



Door & Drawer Sticker Pack



150mm x 150mm

200mm x 80mm



Appendices

1. Self Assessment framework for services – not significantly changed
2. QOMID
3. Updated Commissioners leaflet

What does a good service look like?

- Not just about assessment and diagnosis

Good is:

- Ensuring that all involved have a shared vision of what we want for people with dementia
- Care is delivered in a person centred way
- Knowing the cohort of people who are at risk
- Offering timely and appropriate baseline and follow-up assessments and diagnosis
- Offering team based training and support to staff to ensure a capable workforce
- Offering ongoing support to families, carers and peers
- Ensuring people's health needs are met promptly and diagnostic overshadowing is avoided

- Ensuring that environments are dementia friendly
- Offering a range of multidisciplinary interventions that are appropriate for the stage of dementia, and enhance the quality of life for the person
- Working with all agencies to ensure people are kept within familiar settings with appropriate staffing, and that care is regularly reviewed
- End of life care is discussed with the person as appropriate and ensures that the person is cared for within their own home whenever possible
- The person's quality of life is measured and enhanced throughout the dementia

Questions and Discussion?

