Authors: C.M. Perez¹, S.L. Ball¹, A.P. Wagner¹,², I.C.H. Clare¹,²,³, A.J. Holland¹,²,³, M. Redley (corresponding author: mr382@medschl.cam.ac.uk)¹,²

¹Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge, Douglas House, Trumpington Road, Cambridge CB2 8AH, UK

²NIHR CLAHRC for Cambridgeshire and Peterborough, Douglas House, Trumpington Road, Cambridge CB2 8AH, UK

³Cambridgeshire and Peterborough NHS Foundation Trust, Elizabeth House, Fulbourn Hospital, Fulbourn, Cambridge CB21 5EF, UK

ADDITIONAL INFORMATION

Funding: This paper presents independent research commissioned by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0906-11098). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Ethical approval: The project received ethical approval from the NHS Cambridgeshire 3 Research Ethics Committee, UK. All participants with the capacity to do so, gave consent to participate in the study. For individuals invited to take part who lacked the capacity to give or withhold consent, a consultee was appointed (in accordance with the Mental Capacity Act 2005) who was able and willing to make a decision regarding whether the individual would wish to take part, if he or she had the capacity to decide. For all participants who lacked capacity, a consultee agreed to their participation.

Competing interests: None declared.

Acknowledgements: We are grateful to: the NIHR Mental Health Research Network (East Anglia and North London Hubs) and the NIHR Primary Care Research Network (East of England) for their support and assistance with the collection of prevalence data; to the NIHR CLAHRC for Cambridgeshire and Peterborough for support provided to M Redley, ICH Clare and AJ Holland; to SG Panter, who assisted with data collection; to CA Proctor and K Byrne for their methodological advice and collection of clinical data; to C Saville and A Hammerton for their support with the collection of follow-up data; to J Ord and K Leech for their input on the conduct of the study; to P Watson for his statistical advice; to N Lennox for his helpful comments on a previous draft; to the many health and social care professionals who provided information used in the study; and to the people with intellectual disabilities and their paid or unpaid carers who took part.
Contributors: MR, AJH and ICHC planned and designed the study, obtained funding and supervised the collection of data by SLB. SLB was also responsible for the day-to-day running of the study and for refining the methodology in the light of practical constraints. CMP was responsible for analyzing the data (with statistical advice from APW and guidance from SLB) and for writing the manuscript. All authors contributed to the editing of the manuscript for which MR is guarantor.