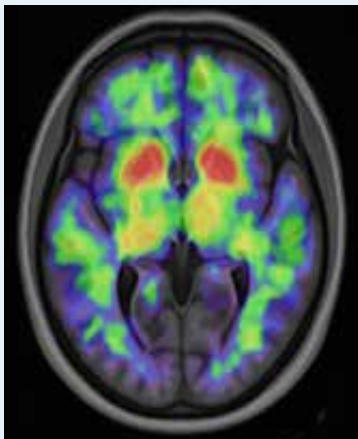
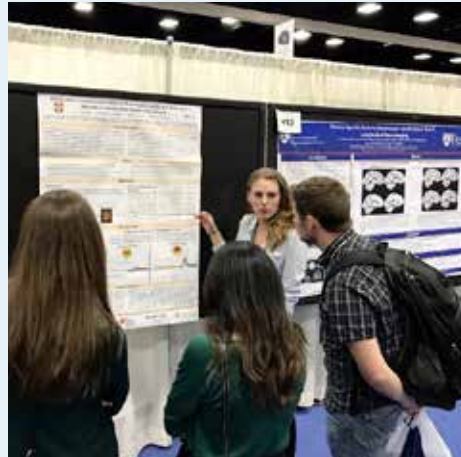




UNIVERSITY OF
CAMBRIDGE

Department of Psychiatry



Cambridge Intellectual and Developmental Disabilities Research Group: 2002 to 2017

Complexity, Inter-disciplinarity and Partnerships

Background and summary of research group activity, prepared for the end of grant meeting held on 29th September 2017 at Clare College, Cambridge.

Supported by  The Health Foundation

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Introduction

Tony Holland CBE, Emeritus Professor, University of Cambridge



In 2001 the Health Foundation offered funding of £3,000,000 over 15 years to support a University Chair in Learning Disabilities and invited university departments across the UK to apply. The University of Cambridge submitted an application with myself as the named candidate. We were successful and, together with some matched funding from the Clinical School and the Beebe Trust, this led to the establishment in 2002 of the research group. The 15 years of this award has now ended. Today's workshops, reception and dinner are to mark and celebrate the work undertaken over these 15 years, as well as to provide an opportunity to reflect on 'complexity, inter-disciplinarity, and partnership', the three terms we have used to try to capture some of the key aspects of our research in this field.

From the beginning, our aim was to be inter-disciplinary in our approach; to undertake our research in partnership with clinical services and also public, private and third sector organisations and to capitalise on the expertise and facilities available by building links with academics and University departments in Cambridge, across the UK and beyond. Given the privilege of 15 years of core funding, our wish was to fully engage in this complex area of intellectual (learning) disabilities research, bringing together perspectives and techniques from the biological, behavioural and social sciences.

None of this would have been possible without the support of the many people with intellectual disabilities, their families and paid support workers, who have given their time and enthusiasm. This day is also to acknowledge the importance of these relationships and their centrality to the research we have undertaken. I very much hope that all of you will enjoy today, and that it will provide a catalyst for future research and ensure that the potential of research to answer important questions is fully recognised. Thank you for your support and for joining us today.

Dr Jennifer Dixon CBE, Chief Executive, The Health Foundation



I am very pleased to introduce this report on the work of Professor Holland and his team at the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG). The Health Foundation awarded funding for the establishment and funding of a Chair in Learning Disabilities at Cambridge University in 2002. Over the last 15 years, Professor Holland has built an impressive multidisciplinary team, including psychiatrists, a sociologist, and a clinical and forensic psychologist, which has also supervised over 21 completed PhDs in research in the field.

The team has not only developed skills and capacity in the field of intellectual and developmental disability, but has undertaken a wide range of pioneering research. This spans from clinical studies of the link between Alzheimer's disease and Down's syndrome, and the link between Prader-Willi syndrome and over-eating, behaviour problems and mental ill-health to research related to practice and policy, such as work on the barriers to access to health care experienced by people with intellectual disabilities, and involvement in the legal system, including the needs of people with intellectual disabilities who have offended. The results of this work have been widely disseminated through peer-reviewed journals, conference presentations and other media. The involvement of people with intellectual disabilities and their families in the research process has been an important feature of the work of the team.

Professor Holland's work provides an excellent model for researchers. It has been gratifying to see that stable long term and core funding for a university chair has enabled Professor Holland and his team to bring in a significant amount of additional research funding from other funders such as the Department of Health, Wellcome Trust and the MRC. In addition, the Research Group has built relationships with its local Collaboration for Leadership and Applied Health Research and Care (CLAHRC) and learning disability charities – developing the link between research, practice and policy.

Since 2002 there have been many changes in the wider context for researchers on intellectual disability. The establishment of the chair came one year after the publication of 'Valuing People: A New Strategy for Learning Disability for the 21st Century' – which set out key principles of rights, independence, choice and inclusion for people with intellectual disabilities. The optimism and aspiration of 'Valuing People' and its successor 'Valuing People Now' has withstood a blow by the scandal publicised in 2011 of the appalling care of people with intellectual disabilities at Winterbourne View. And the NHS currently has a clear programme of work with other partners to transform care for people with learning disabilities, not least to orientate care away from hospitals and more into homes. There is a lot to do.

Through the contribution of excellent research and the training of young researchers in the field, Professor Holland and his team will help people with intellectual disabilities, their families and those working with them, to face the challenges ahead. The Health Foundation is delighted to have been a core funder, and this report shows why.



CIDDRG Principal Investigators

Emeritus Professor Tony Holland



My background is as a psychiatrist specialising in the field of intellectual disabilities. Two main areas of research interest have included: investigating the relationship between particular genetic syndromes and associated psychiatric and behavioural disorders (e.g. Prader-Willi syndrome and over-eating, and Down's syndrome and Alzheimer's disease) and clinical-legal studies, including studies relating to the Mental Capacity Act, the Mental Health Act, and to the criminal justice system.

I am a Fellow of the International Association for the Scientific Study of Intellectual Disability (IASSID), a Fellow of the Academy of Medical Sciences, President of the International Prader-Willi Syndrome Organisation, Patron of the UK Prader-Willi Syndrome Association, psychiatric advisor to the Down Syndrome Association and Trustee of Hft, a large social care provider for people with intellectual disabilities.

Dr Isabel Clare



I am a Consultant Clinical and Forensic Psychologist in the NIHR's CLAHRC (Collaboration for Leadership in Applied Health Research and Care) East of England, an Affiliated Lecturer in the Department of Psychiatry, and a Fellow of Lucy Cavendish College. My research interests reflect my academic background in psychology and criminology and clinical experience in services for adults with intellectual and/or other developmental disabilities.

Dr Marcus Redley



The exciting aspects of my post, as a social scientist in a multidisciplinary environment, are researching the practical aspects of how people with intellectual disabilities can become part of mainstream society, and how we, the affluent and mentally able, understand our responsibilities towards people who are financially poorer and mentally less able. I have researched access to secondary healthcare; the support people receive to eat and drink safely; the decisions about the treatment of epilepsy; efforts to address health inequalities; welfare reform; voting rights and aspects of the Mental Capacity Act 2005.

Dr Howard Ring



I am a university lecturer in Developmental Psychiatry (Learning Disability). My interests relate to research, education and clinical service development in neuropsychiatry and the psychiatry of intellectual disabilities (ID). Current research initiatives include the study of non-pharmacological approaches to epilepsy management in adults with ID and the application of EEG and psychophysiological measures to investigate biological associations of behavioural symptoms in people with neurodevelopmental disorders.

Dr Shahid Zaman



I am a consultant psychiatrist and a neuroscientist who has published in the following areas: the molecular pharmacology of GABAA receptors, neurosteroids, hippocampal synaptic plasticity (long-term potentiation), familial Alzheimer's disease (presenilin) and female autism. I am interested in understanding the neuronal mechanisms that underlie deficits in learning and memory in people with intellectual disabilities and exploring ways of ameliorating or treating these. I am currently involved in research in dementia in Down's syndrome.

History of the Group

Research in intellectual (learning) disabilities in the Department of Psychiatry at the University of Cambridge started in the late 1980s with the creation of a senior academic psychiatry post, linked to the local clinical services for adults with intellectual disabilities. Until 1992 the University Lecturer's post was held by the late Dr Gregory O'Brien. In 1992, with the appointment of Tony Holland to the University Lecturer's post in learning disabilities, the Section of Developmental Psychiatry was established at Douglas House under the leadership of Professor Ian Goodyer to support research in child and adolescent psychiatry and learning disabilities. Later, the Autism Research Centre, led by Professor Simon Baron-Cohen, was established and these three research groups then formed the Section of Developmental Psychiatry, part of the University's Department of Psychiatry.

Professor Peter Jones, as the then Head of the Department of Psychiatry, led the application to the Health Foundation from the University of Cambridge to establish the chair in learning disabilities. The aims stated in the application included: to undertake fundamental and applied research in the field of intellectual disabilities; to develop new treatments and intervention strategies; to contribute to the development of best practice in social care and healthcare; to inform the development of policy; to engage with other disciplines in the undertaking of research to benefit people with ID; to use developing technologies to address questions relevant to the needs of people with intellectual disabilities; to train junior academic and clinical staff from different disciplines; and to disseminate findings to inform treatment development, policy and practice, seeking to bridge what was referred to in the Cooksey report as the type 2 gap.

With the award from the Health Foundation and the establishment of the Chair in Learning Disabilities, an interdisciplinary research group initially known as the Learning Disabilities Research Group, later changed to the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG), was formed. With the Health Foundation grant and some matched funding, additional senior clinical and academic appointments were made (Dr Isabel Clare as Affiliate Lecturer and Dr Marcus Redley as Senior Research Associate), Dr Anthony Isles was appointed to a research post at the Babraham Institute and Dr Howard Ring was appointed to the University Lecturer's post vacated by Tony Holland. Dr Shahid Zaman joined the group later following his appointment to a consultant psychiatric post in Cambridgeshire, and he now holds an Associate Lecturer's position in the Department. From the beginning, the research themes drew upon the expertise of the senior staff in the group and on the expertise and facilities within the University. Research themes included:

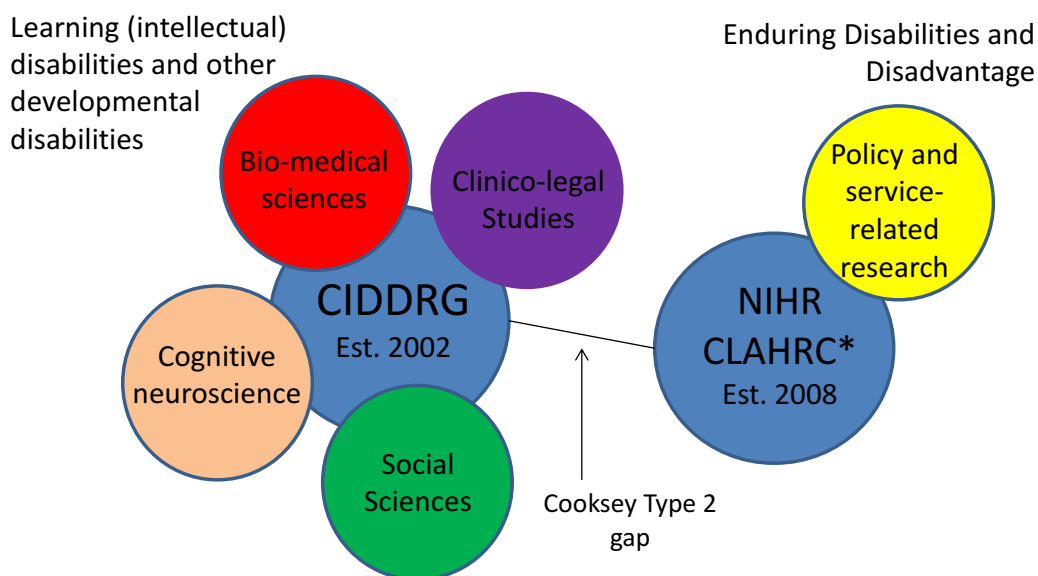
1. Biologically-based research, for example, investigating the association between having a particular syndrome and the development of specific behavioural and/or psychiatric disorders.
2. Clinical-legal studies that aim to inform the development of legislation, policy, guidance and practice, including studies related to the Mental Capacity Act 2005, the Mental Health Act 1983 and the criminal justice system.
3. Social science-based studies, broadly around the themes of inclusion and citizenship.
4. Neuropsychological and neuropsychiatric studies, including the investigation of epilepsy in people with intellectual disabilities and the use of brain scanning, neurophysiological and physiological techniques.

In 2008, under the leadership of Professor Peter Jones, Cambridgeshire and Peterborough Foundation NHS Trust, in partnership with the Department of Psychiatry, was awarded funding from the NIHR to host the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC for Cambridgeshire and Peterborough). Tony Holland and Isabel Clare led the theme of this CLAHRC, devoted to intellectual disability and acquired brain injury. In 2014 an additional five years of funding was awarded for what then became the NIHR CLAHRC for the East of England. Our group continues to lead the Enduring Disability and Disadvantage (EDD) theme.

The figure below illustrates the present structure of interlinking research themes.

Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG)

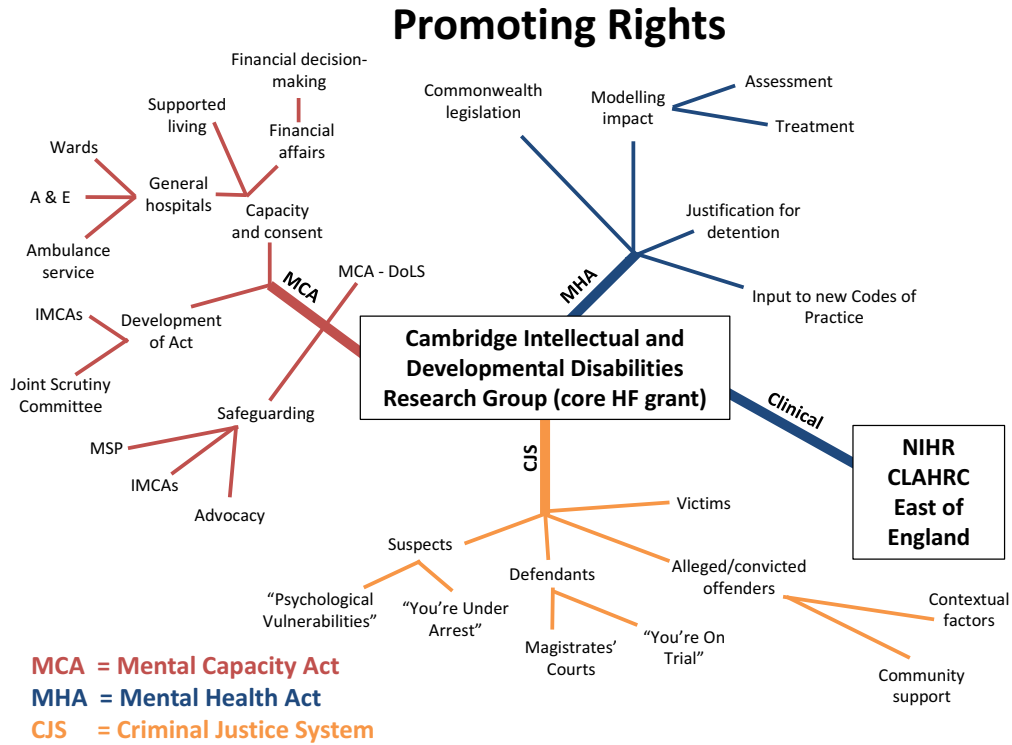
Core funding from the Health Foundation



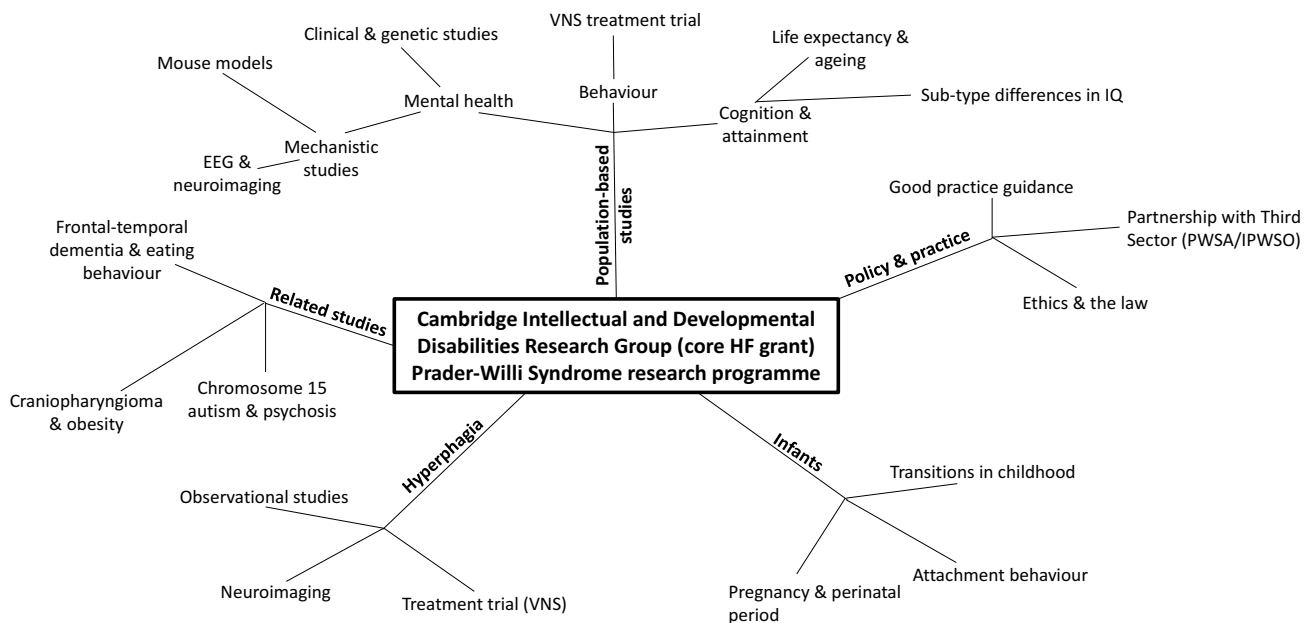
*Collaboration in Leadership for Applied Health Research and Care

The long-term funding provided by the Health Foundation has enabled iterative programmes of research to be undertaken, responding to changing circumstances, be they scientific, legal or policy related. Examples of this approach are illustrated by the two diagrams below, the first of the diagrams illustrating research focused on promoting rights and clinical and legal issues and the second, on the genetically determined neurodevelopmental disorder, Prader-Willi syndrome, led by Joyce Whittington, Research Associate. This evolving iterative approach has also been applied to other areas of investigation, such as research including neuropsychiatric studies and investigations of the link between Down's syndrome and dementia. In some areas of study new possibilities sometimes emerge in response to, for example, the availability of new molecular biological or neuroimaging technologies, or arise because of new findings that require further study or investigation from a different perspective.

Examples of two programmes of iterative research



Prader-Willi Syndrome research programme



Outcomes of the CIDDRG

The Health Foundation grant provided core funding, and in this booklet we have listed the principal organisations and individuals who have provided additional funds for the research, collaborators, the peer-reviewed papers and chapters members of the group have published, and the names and subjects of PhDs awarded. The outcomes of the CIDDRG have been diverse and different examples of such outcomes are given below.

In line with one of the stated objectives of the group, we have established collaborations with experts in developing research technologies including: neuroimaging, electrophysiology, genetics, and the use of pluripotential stem cells. Our aim initially was to establish the feasibility of using these new research techniques so they could then be applied systematically to address key clinical questions of relevance to the wellbeing of people with specific neurodevelopmental syndromes. We have held open days and produced films and newsletters to ensure that participants and their families and others who support them, are kept fully informed about the technologies themselves and the outcomes. With this approach, research on Down's syndrome and dementia and on Prader-Willi syndrome over the years has moved from being primarily clinical to investigating mechanisms with a view to trials of novel interventions. Similarly, neuropsychiatric studies have evolved over time including, for example, investigations of the long-term effects of childhood brain tumours, and investigating early indicators of seizures and service models for the management of epilepsy in people with intellectual disabilities. This has only been possible with the existence of long-term core funding and through the partnerships we have developed with the third sector and academic colleagues.

As part of the research undertaken as part of the NIHR CLAHRC we have worked in collaboration with the Cambridgeshire Learning Disabilities Partnership (LDP) and with other services across the Eastern Region to both collect data about specialist services for people with intellectual disabilities and to disseminate findings from the research in order to inform policy, practice and service design. This included jointly hosting clinical research days with those working in local specialist services for people with intellectual disabilities and direct feedback to the local community teams for adults with intellectual disabilities. In the context of the transforming care agenda and through contacts with NHS England, we have sought to inform policy nationally, providing written evidence, being part of Government advisory groups, and by meeting directly with key stakeholders. We have supervised CLAHRC Fellows from across the Eastern Region. The Fellows have been supported by CLAHRC funds to enable them to take time away from their regular work to gain additional training and to undertake research projects. This training and their research have then informed their own practice and helped to shape local services.

Members of the group have also contributed to the development and publication of specific guidance including: assessments of financial decision-making capacity (published by BILD), the diagnosis of dementia in people with Down's syndrome (CAMDEX-DS, published by CUP), best practice in the care of people with Prader-Willi syndrome, and best practice in the care of people with intellectual disabilities and dementia (published jointly by the Royal College of Psychiatrists and the British Psychological Society). Howard Ring also produced a position paper on The role of Neuropsychiatry in the treatment of neuro-oncology patients, which contributed to NICE Guidance on Cancer Services: Improving outcomes in brain and

other CNS tumours. Our present and proposed future publications arising from the work of CLAHRC aim to inform the design of integrated interagency community services for adults with intellectual disabilities.

Our research has directly informed policy and practice through the submission of evidence to Government Departments. This has included submissions relating to: the Mental Capacity Act 2005 and its Code of Practice; the pilot Independent Mental Capacity Advocates (IMCAs) programme as it developed; the Parliamentary enquiry into the human rights of people with learning disabilities; the interface between the Deprivation of Liberties Safeguards (DoLS) and the Mental Health Act; the consultation on 'No Secrets' (relating to the abuse of vulnerable adults); and the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Tony Holland was one of two advisors to the Joint Houses of Parliament Pre-legislative Scrutiny Committee that examined the then Mental Incapacity Bill. Our work undertaken on voting by people with intellectual disabilities has been quoted in Parliamentary papers in Canada and Australia and has informed policy in those countries.

In addition to the core support from the Health Foundation, we would also like to acknowledge the support we have received from many organisations, from people with intellectual disabilities and their families and others who support them, and also the commitment of PhD students, research assistants and associates, administrative staff and many others over the 15 years. The future of research in intellectual disabilities rests with those who have worked in this field as research assistants and PhD students.

As a group we strongly believe that the close integration between clinical services and academia, the availability of core funding, and the inter-disciplinary nature of the group have been critical to the work that we have done and continue to do. A central role of the group has been to contribute to a strong peer-reviewed evidence base that can inform treatment development and policy and practice in the field of intellectual disabilities. Below we list our main collaborators, research funders and the papers we have published and the PhDs completed.

PhD research

Current:

Claire Barker: An examination of the quality of hospital care received by adult patients with learning disabilities: A single site study. Funded by the Health Foundation.

Rashmi Becker: Meeting the aspirations of learning disability policy: The role of paid support workers. Funded by NIHR CLAHRC East of England.

Madeleine Walpert: Early indicators and biomarkers of Alzheimer's disease in the eyes in people with Down's syndrome using optical coherence tomography (OCT) and new technology for the Detection of Apoptosing Retinal Cells (DARC). Funded by Stevenage Biomedical Catalyst and the Health Foundation.

Completed:

Dr Sally Jennings: Using EEG to investigate premature aging and cognitive decline in adults with Down's syndrome. Funded by a departmental MRC studentship. PhD awarded 2017.

Dr Andrew McCombie: Understanding magistrates' courts: Implications for individuals with intellectual disabilities. Funded by a 2012 Sims Scholarship, University of Cambridge, winner of the 2014 Cambridge Society for Applied Research award. PhD awarded 2017.

Dr Liam Wilson: Brain connectivity in people with Down's syndrome: influences of atypical development and Alzheimer's disease neuropathology. Undertaken as a Research Assistant on an MRC grant. PhD awarded 2016.

Dr Katie Manning. Brain structure and behaviour in young adults with Prader-Willi syndrome. Supported by the Pinsent Darwin Studentship in Mental Pathology. Funding for research costs came from the Prader-Willi Syndrome Association UK (PWSA UK). PhD awarded 2016.

Dr Tiina Annus: Brain morphology, β -amyloid and Alzheimer's disease in adults with Down's syndrome. Undertaken as a Research Assistant on an MRC grant. PhD awarded 2016.

Dr Emily Ruzich: The measurement of autistic traits using the Autism-Spectrum Quotient. Self-funded. PhD awarded 2015.

Dr Kate McAllister: An investigation of the role of mitochondrial dysfunction in people with Down's syndrome. Funded by the Pinsent Darwin Studentship in Mental Health. PhD awarded 2015.

Dr Felicity Larson: The relationship between autism and psychosis and the role of CNVs on chromosome 15. Funded by the Health Foundation and a departmental MRC studentship. PhD awarded 2014.

Dr Jo Illingworth: Seizure precipitants in people with intellectual disability and epilepsy. Funded by an Epilepsy Action Studentship. PhD awarded 2014.

Dr Sara Simblett: Facilitating and measuring psychological adjustments following acquired brain injury. Funded by the NIHR CLAHRC for Cambridgeshire and Peterborough. PhD awarded 2013.

Dr Ana Catarino. An fMRI investigation of detection of semantic incongruities in Autism Spectrum Conditions. Funded by and registered at University of Lisbon. PhD awarded 2012.

Dr Alexander Phillips: An investigation of physical activity in individuals with intellectual disabilities with and without Down's syndrome. Funded by the Down's Syndrome Association. PhD awarded 2011.

Dr Elizabeth Fistein: An examination of philosophy, law and practice in involuntary psychiatric treatment. Funded by The Wellcome Trust (Studentship in Biomedical Ethics). PhD awarded 2011.

Dr Jessica Wheeler: Environmental factors and alleged offenders with learning disabilities. Funded by a PhD training fellowship, National Forensic Mental Health R & D Programme (Department of Health). PhD awarded 2011.

Dr Lydia Luke: Decision-making capacity in autism spectrum conditions. Funded by the 2007 Pinsent-Darwin Scholarship in Mental Pathology, University of Cambridge and a Domestic Research Studentship, University of Cambridge, with additional awards from the Marmaduke Shield Fund and the Charles Slater Fund, School of Biological Sciences, University of Cambridge, and the Health Foundation. PhD awarded 2011.

Dr Elizabeth Fistein: How can compulsory detention in hospital for psychiatric treatment be justified? An analytic and empirical investigation. Funded by the Wellcome Trust. (Studentship in Biomedical Ethics). PhD awarded 2011.

Dr Peter Langdon (registered at The Tizard Centre, University of Kent): Moral reasoning and offenders with intellectual disabilities, funded by a Personal Award Scheme Researcher Development Award, National Coordinating Centre for Research Capacity Development (NCCRCD), Department of Health. PhD awarded 2010.

Dr Owen Churches: The psychophysiology of face perception in Autism-Spectrum Conditions. Funded by a Cambridge Commonwealth Scholarship. PhD awarded 2010.

Dr Michael Dunn: 'Best interests'? An examination of substitute decision-making for adults with intellectual disability in social care settings. Funded by The Wellcome Trust (Studentship in Biomedical Ethics). PhD awarded 2009.

Dr Panagiotis Siaperas: Movement performance in Asperger's syndrome: An investigation of sensorimotor processing. Funded by an Academic Studentship from the Government Of Greece. PhD awarded 2008.

Dr Rebecca Hawkins: Caring: the policies and practices of care in a residential home. Funded by Gretton Homes. PhD awarded 2008.

Dr Clare Bolton: Pro-social decision-making by men with learning disabilities. Funded by Care Principles Ltd and The Health Foundation. PhD awarded 2007.

Dr Alison Stansfield: What factors influence decisions about the sterilisation of people with learning disabilities? Self funded. MD awarded 2007.

Dr Sarita Soni: An investigation into psychiatric illness in people with Prader-Willi syndrome: Evidence for a genetic basis for psychosis. Undertaken as a Research Assistant on a Wellcome Trust grant. PhD awarded 2006.

Dr Elanor Hinton: The neural basis of the motivation to eat in Prader-Willi syndrome. Funded by a private donation to the UK Prader Willi Syndrome Association. PhD awarded 2005.

Dr Marc Woodbury-Smith: An investigation of offending among adults with High Functioning Autism or Asperger Syndrome, funded by the NHS Executive Eastern Region Research & Development Scheme. PhD awarded 2005.

Dr Sarah Ball: The course of Alzheimer's disease in adults with Down's syndrome: Evidence for the early compromise of frontal lobe function. Undertaken as a Research Assistant on a Big Lottery grant awarded to the Down's syndrome Association. PhD awarded 2005.

Dr W. M. Irenka Suto: Psychological constructs of financial decision-making capacity: Implications for adults with learning disabilities. Funded by The Nightingale Trust. PhD awarded 2003.

Dr Johnny Sei Hoe Hon: A new approach to studying prevalence and incidence of cognitive decline and dementia in older adults with Down syndrome. Self-funded. PhD awarded 1997.

Principal collaborating organisations and institutions

Anglia Ruskin University
British Institute of Learning Disabilities
Cambridge University Hospitals NHS Foundation Trust
Cambridgeshire County Council
Cambridgeshire Learning Disability Partnership
Cerebra Centre for Neurodevelopmental Disorders, Birmingham University
Challenging Behaviour Foundation
Department of Health
The Division of Brain Science, Imperial College
Down's Syndrome Association
East and North Hertfordshire NHS Trust
Edmund Trust
Epilepsy Action
Faculty of Education, University of Cambridge
Hertfordshire County Council
Hft
Imperial College Ophthalmic Research Group, Imperial College
International Association for the Scientific Study of Intellectual and Developmental Disabilities
Kenya Society for the Mentally Handicapped
Kings College London
Mencap
Mental Health Research Network
NIHR CLAHRC East of England at Cambridgeshire & Peterborough NHS Foundation Trust
Prader-Willi Syndrome Association UK
Primary Care Research Network
Respond
Tizard Centre
University of Birmingham
University College London
University of Cardiff
University of East Anglia
University of Glasgow
University of Lisbon
University of Pittsburgh
VoiceAbility (formerly Speaking Up)
Wolfson Brain Imaging Centre, University of Cambridge

Principal funders (in addition to the Health Foundation)

Addenbrooke's Charitable Trust
Baily Thomas Charitable Fund
Beebe Trust
The Big Lottery (grant awarded to the Down's Syndrome Association)
Alzheimer's Research UK
Cambridgeshire County Council
Cambridgeshire Learning Disability Partnership
Cambridgeshire & Peterborough NHS Foundation Trust
Cambridgeshire Community Services NHS Trust
Cerebra
Commonwealth Trust
Department of Health
Down's Syndrome Association
Dunhill Medical Trust
Dunhill Serendipity Trust
Epilepsy Action
European Union FP-6 Life Sciences, Genomics and Biotechnology for Health Programme
Foundation for Prader-Willi Research
Foundation for the Sociology of Health & Illness
The Gambi Family (Sam's Foundation)
The Government of Greece
Gretton Homes
Intelesens Ltd
Isaac Newton Trust
Mr Chris McKenna
Medical Research Council (MRC)
MRC Lifelong Health & Wellbeing Collaborative Development Network
National Alliance for Autism Research (USA)
National Institute for Health Research (NIHR): RfPB and Policy Research Programmes
National Institutes of Health (USA)
NIHR Cambridge Brain Injury Health Technology Cooperative
NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) for
Cambridgeshire and Peterborough
NIHR Collaboration for NIHR CLAHRC East of England at Cambridgeshire and
Peterborough NHS Foundation Trust
NIHR Health Technology Assessment Programme
NIHR School for Social Care Research
The Nuffield Foundation
Samantha Dickson Brain Tumour Trust
SCIE (Social Care Institute for Excellence)
Special Olympics Healthy Athletes Health Professions Student Grant
Stevenage Biomedical Catalyst
UK Prader-Willi Syndrome Association
University of Cambridge (Pinsent Darwin Studentship in Mental Health, Domestic Research
Studentship, Sims Scholarship, Marmaduke Shield Trust)
Wellcome Trust

List of publications (CIDDRG and CLAHRC)

For ease of reading these papers have been divided into broad categories, we acknowledge that many of these papers would fit under more than one heading. The categories are listed in alphabetical order with the papers in chronological order under each heading. For a full searchable list please see our website.

Acquired Brain Injury

Ford, C. E. L., Malley, D., Bateman, A., Clare, I. C., Wagner, A. P., & Gracey, F. (2016).

Selection and Visualisation of Outcome Measures for Complex Post-Acute Acquired Brain Injury Rehabilitation Interventions. *NeuroRehabilitation*, 39, 65–79. <https://doi.org/10.3233/NRE-161339>

Simblett, S. K., Ring, H., & Bateman, A. (2016).

The Dysexecutive Questionnaire Revised (DEX-R): An extended measure of everyday dysexecutive problems after acquired brain injury. *Neuropsychological Rehabilitation*, 1–18.

Gracey, F., Olsen, G., Watson, S., & Malley, D. (2015).

Integrating psychotherapy into neuropsychological rehabilitation of the brain injured child. In *Neuropsychological rehabilitation of childhood brain injury: A practical guide* (pp. 191–214). Basingstoke: Palgrave Macmillan.

Gracey, F., Malley, D., Wagner, A. P., & Clare, I. C. H. (2014).

Characterising neuropsychological rehabilitation service users for service design. *Social Care and Neurodisability*, 5(1), 16–28.

Carroll, C., Watson, P., Spoudeas, H. A., Hawkins, M. M., Walker, D. A., Clare, I. C., Holland, A.J., Ring, H. A. (2013).

Prevalence, associations, and predictors of apathy in adult survivors of infantile (<5 years of age) posterior fossa brain tumors. *Neurological Oncology*, 15, 497–505. <https://doi.org/10.1093/neuonc/nos320>

Rathinam, C., Bateman, A., Peirson, J., & Skinner, J. (2014).

Observational gait assessment tools in paediatrics – A systematic review. *Gait & Posture*, 40(2), 279–285. <https://doi.org/10.1016/j.gaitpost.2014.04.187>

Simblett, S. K., Badham, R., Greening, K., Adlam, A., Ring, H., & Bateman, A. (2012).

Validating independent ratings of executive functioning following acquired brain injury using Rasch analysis. *Neuropsychological Rehabilitation*, 22, 874–89. <https://doi.org/10.1080/09602011.2012.703956>

Caracuel, A., Bateman, A., Teasdale, T. W., Verdejo-Garcia, A., & Perez-Garcia, M. (2011).

Spanish, French, and British cross-cultural validation of the European Brain Injury Questionnaire. *Journal of Head Trauma and Rehabilitation* 26, 478–88. <https://doi.org/10.1097/HTR.0b013e3181fc042c>

Bateman, A., Teasdale, T. W., & Willmes, K. (2009).

Assessing construct validity of the self-rating version of the European Brain Injury Questionnaire (EBIQ) using Rasch analysis. *Neuropsychological Rehabilitation*, 19, 941–54. <https://doi.org/10.1080/09602010903021170>

Evans, J. J., Greenfield, E., Wilson, B. A., & Bateman, A. (2009).

Walking and talking therapy: improving cognitive-motor dual-tasking in neurological illness. *Journal of the International Neuropsychological Society*, 15, 112–20. <https://doi.org/10.1017/S1355617708090152>

Fish, J., Evans, J. J., Nimmo, M., Martin, E., Kersel, D., Bateman, A., Wilson, B.A., Manly, T. (2007).
Rehabilitation of executive dysfunction following brain injury: “content-free” cueing improves everyday prospective memory performance. *Neuropsychologia*, 45, 1318–30.
<https://doi.org/10.1016/j.neuropsychologia.2006.09.015>

Bellhouse, J., Holland, A., & Pickard, J. (2003).
Psychiatric, cognitive and behavioural outcomes following craniopharyngioma and pituitary adenoma surgery. *British Journal of Neurosurgery*, 17, 319–26. <http://dx.doi.org/10.1080/02688690310001601207>

Autism Spectrum Condition

Vella, L., Ring, H. A., Aitken, M. R. F., Watson, P. C., Presland, A., & Clare, I. C. H. (2017).
Understanding self-reported difficulties in decision-making by people with autism spectrum disorders. *Autism*. <https://doi.org/doi/10.1177/1362361316687988>

Larson, F. V., Wagner, A. P., Jones, P. B., Tantam, D., Lai, M. C., Baron-Cohen, S., & Holland, A. J. (2016).
Psychosis in autism: comparison of the features of both conditions in a dually affected cohort. *The British Journal of Psychiatry*. <https://doi.org/10.1192/bjp.bp.116.187682>

Ruzich, E., Allison, C., Smith, P., Ring, H., Auyeung, B., & Baron-Cohen, S. (2016).
The Autism-Spectrum Quotient in Siblings of People With Autism. *Autism Research*.
<https://doi.org/10.1002/aur.1651>

Ruzich, E., Allison, C., Smith, P., Watson, P., Auyeung, B., Ring, H., & Baron-Cohen, S. (2015).
Measuring autistic traits in the general population: a systematic review of the Autism-Spectrum Quotient (AQ) in a nonclinical population sample of 6,900 typical adult males and females. *Molecular Autism*, 6(2).

Ruzich, E., Allison, C., Smith, P., Watson, P., Auyeung, B., Ring, H., & Baron-Cohen, S. (2015).
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The future

Specific grant funded projects in intellectual disability will continue in the Department of Psychiatry. Dr Shahid Zaman leads the work on Down's syndrome and dementia with funding from AR-UK and from the NIH, linking more closely with Professor John O'Brien, Professor of Old Age Psychiatry, and his group. Projects on Prader-Willi syndrome continue, including basic science research, investigation of infants, the use of vagus nerve stimulation to treat the problematic behaviours associated with the syndrome and a PhD to be undertaken by Lucie Aman on the mechanisms that underpin the psychosis associated with that syndrome. These PWS studies will link more closely with Professor Paul Fletcher, Bernard Wolfe Professor of Health Neuroscience, and his group in the Department of Psychiatry, and also with colleagues in the Gurdon Institute, the Laboratory of Molecular Biology, and the Department of Psychology. The NIHR CLAHRC for the East of England continues to the end of 2018, with Isabel Clare overseeing the Enduring Disability and Disadvantage Theme, and supervising a PhD student as part of a Wellcome Trust funded initiative based at the Institute of Psychiatry, Kings College London.

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Contact us

CIDDRG
Department of Psychiatry
University of Cambridge
Douglas House
18b Trumpington Road
Cambridge CB2 8AH

Tel: 01223 465 216
dh-admin@medschl.cam.ac.uk
www.cidдрg.org.uk