

Institution: University of Kent
Unit of Assessment: 22, Social Work and Social Policy
Title of case study: Behaving badly? Managing challenging behaviour among people with intellectual and developmental disabilities (IDD)
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>This research on those with Intellectual and Developmental Disabilities (IDD) who exhibit challenging and/or criminal behaviour has impacted on public policy, professional practice, and carers' and service users' quality of life, both in the UK and internationally (e.g. Japan, New Zealand). The impact has been maximised by the researchers serving on government advisory committees, writing government policy documents and delivering training to service providers and their staff. The research was also fundamental in establishing the need for networks to support service users and their families, leading to the formation of the Challenging Behaviour Foundation.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>One of the most important factors shaping quality of life for parents and carers of those with IDD is the presence of challenging, abnormal or criminal behaviour. In the 1980s, following scandals in institutions for people with IDD, the established view was that, even if most people with IDD could be resettled into the community, those exhibiting challenging behaviour would have to remain in hospital or prison. Research by Professor McGill (who joined Kent in 1986 as a Lecturer), Professor Murphy (who, aside from a break between 2004 – 2006, has worked at Kent since joining as a Senior Lecturer in 1993) and others at Kent has contradicted this view by demonstrating that resettlement and deinstitutionalisation can have very positive impacts in terms of reducing challenging behaviour, as long as care and interventions are organised in very specific ways [ref 3.4]. In this regard, McGill laid the groundwork for the integration of values-based and more technical approaches to managing challenging behaviour: this later became known as Positive Behaviour Support (PBS). This approach was developed through the work of the Special Development Team, resulting in a highly influential 1994 book and associated publications [see reference 3.1]. Subsequent research has highlighted that:</p> <ul style="list-style-type: none"> • There is a lack of innovative residential services for people labelled as challenging, with early intervention programmes not widely available [ref 3.1; 3.4]. • Services for people with more severe IDD can be set up and sustained in the community, provided Positive Behaviour Support is employed [ref 3.1]. • Extended training in Positive Behaviour Support is associated with improvements in staff knowledge of challenging behaviour, the attributions they made of its causes and their emotional and practical responses, with research by McGill and Bradshaw (who joined Kent in 1995 as a Teaching Fellow becoming a Lecturer in 1998, working until 2003 prior to returning in 2010) demonstrating the effectiveness of staff training in PBS [ref 3.3; 3.5]. • Challenging behaviour amongst people with mild IDD often brings them into contact with the Criminal Justice System (CJS). Research by Murphy and Mason using an innovative learning disability screening tool (LIPS) has revealed a significant minority (around 7%) of those on probation have IDD [ref 3.2], with estimates for prison populations being similar. • Those with IDD are significantly disadvantaged in police stations, courts, prisons and on probation, having difficulty understanding complex justice procedures, written documents and forms [ref 3.2]. This is likely to affect the effectiveness of time spent in the CJS: for example, those on probation with IDD appear to have been in prison more than their counterparts. • Serious offenders with IDD, such as those committing arson and sex offences, can be successfully treated through cognitive behavioural interventions [ref 3.6].

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In sum, the research shows that challenging behaviour among those with IDD can be managed effectively through a combination of resettlement, Positive Behaviour Support, cognitive behavioural treatment and appropriate intervention.

3. References to the research (indicative maximum of six references)

3.1 - Mansell, J., McGill, P. and Emerson, E. (2001) 'Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behaviour' in L.M. Glidden (Ed.) *International Review of Research in Mental Retardation* San Diego, CA: Academic Press (pp.245-298).

3.2 – Mason, J. and Murphy, G.H. (2002) 'Intellectual disability amongst people on probation: prevalence and outcome' *Journal of Intellectual Disability Research* 46: 230-238.

3.3 - McGill, P., Bradshaw, J. and Hughes, A. (2007) 'Impact of extended education/training in positive behaviour support on staff knowledge, causal attributions and emotional responses' *Journal of Applied Research in Intellectual Disabilities* 20: 41-51.

3.4 - Murphy, G., Estien, D. and Clare, I.C.H. (1996) 'Services for people with mild intellectual disabilities and challenging behaviour' *Journal of Applied Research in Intellectual Disabilities* 9: 256-283.

3.5 - Murphy, G., Kelly-Pike, A., McGill, P., Jones, S. and Byatt, J. (2003) 'Physical interventions with people with intellectual disabilities: Staff training and policy frameworks' *Journal of Applied Research in Intellectual Disabilities* 16: 115-125.

3.6 - Sex Offender Treatment Services Collaborative – Intellectual Disabilities (SOTSEC-ID) (2010) 'Effectiveness of group cognitive-behavioural treatment for men with intellectual disabilities at risk of sexual offending' *Journal of Applied Research in Intellectual Disabilities* 23: 537-551 (Murphy is lead author) [submitted to REF2, output ID SSPSSR123].

Funding

Grant income exceeds £1 million across more than 15 major awards from stakeholder and beneficiary groups, including the Department of Health (DoH), the Baily Thomas Foundation, Mental Health Foundation, Remedi, Wolf Hirschhorn Syndrome Trust, and the National Institute for Health Research. The most significant awards include:

- Peter McGill. Preventing challenging behaviour of adults with complex needs in supported accommodation, **NIHR (SSCR)**, (01/03/12-30/04/14), £277,524.
- Peter McGill. Scoping the development of better commissioning for individuals with behaviour that challenges services, **Department of Health**, (01/07/09-31/12/09), £10,000.
- Glynis Murphy. Follow-up of the Camberwell cohort, **Department of Health (NHS R&D)**, (1995-1998), £117,000.
- Peter McGill. The relationship between aspects of the service environment and challenging behaviour in people with learning disabilities, **Department of Health (NHS R&D)**, (1995-1996), £51,440.
- Glynis Murphy. Costs and benefits of social care support for ex-offenders with learning disabilities, **NHIR (SSCR)**, (15/11/12-30/04/14), £355,177.
- Glynis Murphy: Treatment for men with learning disabilities and sexual offending, **Baily Thomas Foundation**, (01/09/06 - 28/02/08), £28,033.
- Glynis Murphy. Effectiveness of cognitive-behavioural treatment for men with learning disabilities at risk of sexual offending, **Department of Health**, (01/01/02-31/12/03), £105,411.
- Glynis Murphy. Symptoms of abuse in people with severe learning disabilities, **Department of Health**, (01/11/01 – 30/10/02), £45,108.
- Glynis Murphy and Peter McGill. Physical restraint and people with learning disabilities, **British Institute of Learning Disabilities**, (1998-2002), £17,000.

Impact case study (REF3b)**4. Details of the impact** (indicative maximum 750 words)

The research has impacted on policies and practice in the treatment of those with IDD exhibiting challenging, abnormal and criminal behaviour both in the UK and overseas. The beneficiaries have included policy-makers and practitioners in health and social care, the carers who live with those with IDD, and those with IDD themselves who have benefited from more humane and appropriate interventions instead of punitive ones. The Chief Executive of the Care Quality Commission states that the researchers have made 'an outstanding contribution to improving the quality...care and support for people with learning disabilities' [see *corroboration 5.1*]. This is confirmed by the Chief Executive of the Mental Health Foundation who writes that the research has made 'a major contribution' to the treatment of those exhibiting challenging behaviour [*corrob 5.2*].

Impact on government policy and legislation

The Department of Health's (DoH) 2007 policy guidance on services for people with IDD [*corrob 5.3*] and the Government's policy document *Valuing People Now* [*corrob 5.4*] both cited this research, concluding that, 'where individuals with problems are cared for in environments which do not respond well to their needs, challenging behaviour is likely to develop and then to remain in the person's repertoire' and 'the reduction of challenging behaviour is likely to require attention to other factors (such as communication) than just the behaviour itself' [*corrob 5.3, p.7 and p.9*]. The recommendations of Mencap and the Challenging Behaviour Foundation's influential document '*Out of Sight*' [*corrob 5.5*] also drew directly from Mansell's and McGill's research. Following this, and as a result of the research on Positive Behaviour Support (PBS), the DoH commissioned McGill to contribute to a service specification for commissioners, policy-makers and regulators on PBS services which is being integrated with a similar specification for services for young people with IDD commissioned from Gore (Kent, 2007 -). Once integrated, the combined specification will be disseminated through the NHS Commissioning Board and the Local Government Association. McGill is also contributing to the development of guidance on PBS through his membership of steering groups for Skills for Care and the Royal College of Nursing. Following the Winterbourne View scandal, McGill chaired a DoH stakeholder event in 2012 and was invited to chair a Ministerial round table in 2013. Murphy sits on the Ministry of Justice's NOMS (National Offender Management Service) committee on Learning Disabilities, providing advice on screening for IDD in prisons. These interactions evidence the influence of the research on government policy across a range of departments dealing with people with challenging behaviour and IDD.

Improving professional standards and guidelines

The involvement of the researchers in influential policy networks has allowed the research to be disseminated to key stakeholders. For example, in fulfillment of a pledge by the DoH following the Winterbourne View scandal, Murphy chairs the NICE Guideline Development Group concerned with challenging behaviour among people with learning and intellectual disabilities [*corrob 5.6*]. This role ensures that research evidence will guide subsequent practice in health and social care services for people with IDD and challenging behaviour. Murphy also sits on the DoH's National Learning Disabled Offenders Steering Group (NLDOSG), which has produced guidance for professionals from health, social care, police, prison and probation services ([Positive Practice](#), [Positive Outcomes](#)). The Steering Group has also designed training for prison officers and established IDD screening in prisons [*corrob 5.7*].

As a result of the research in relation to mild IDD and challenging behaviour in the criminal justice system, Murphy was also asked to join the Steering Committee for Jenny Talbot's 'No One Knows' programme (Prison Reform Trust), which used Murphy and Mason's learning disability screening tool (LIPS) and Murphy's checklists for action for people with IDD in the CJS [*corrob 5.8; 5.9*]. The Director of the Prison Reform Trust states the research 'has made a significant impact on national policy and practice for people with learning disabilities who find themselves in contact with the criminal justice system' [*corrob 5.9*]. Murphy was also invited to help the Foundation for People with Learning Disabilities (part of Mental Health Foundation) and NOMS to adapt the 'Thinking Skills' Programme for people with IDD: this has been trialled in three prisons [*corrob 5.2*]. Murphy and Sinclair's research on sex offender treatment for men with IDD - the Sex Offender Treatment Services Collaborative-Intellectual Disabilities (SOTSEC-ID) programme - is

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now used across the UK (over 500 therapists have been trained). Therapists in New Zealand (2009) and Japan (2013) have also completed training [*corrob 5.10*] and training has been requested in Australia and US.

Improving the quality of life of service users and their carers

The research has directly supported service users with severe IDD and challenging behaviour and their families and carers. For instance, McGill helped to establish a UK charity in 1997, the [Challenging Behaviour Foundation](#) (CBF) and remains as a trustee and contributor to the charity's [Challenging Behaviour Charter](#). CBF promotes evidence-based approaches to challenging behaviour underpinned by the latest research (i.e. non-institutional services, ethical use of physical intervention, and a PBS approach) through a number of activities: CBF website, telephone helpline (1391 calls in 2012); educational DVDs (including: 'An Introduction to Challenging Behaviour', of which 1286 have sold, and 'Self-Injurious Behaviour', of which 890 have sold) and CBF newsletter (circulation of 5,000). The Chief Executive states 'The CBF has been very successful at raising the profile of this marginalised group of individuals, improving the quality of information and support to family carers... in no small part due to the partnership developed with [*these researchers*], which brings together the expertise of leading academics in the field, with families supporting individuals on a day to day basis' [*corrob 5.11*]. In another example of the research's impact on service users, Murphy has also worked on a number of projects offering direct support by producing 'easy-read guides', both as part of the DoH's National Learning Disabled Offenders Steering Group's work to revise prison guides into 'easy-read' formats (with Mencap) and also co-authoring 'You're under Arrest' and 'You're On Trial' easy-read books for service users.

In sum, the research has led to better standards of care for those exhibiting challenging behaviour by changing policy guidelines, resulting in improved quality of life for service users and their carers.

5. Sources to corroborate the impact (all links correct at time of submission to REF2014)

5.1 – Statement provided by ID 1 – (Chief Executive, Care Quality Commission). This demonstrates the impact of the research on the quality of care and support for people with IDD.

5.2 – Statement provided by ID 2 – (Chief Executive, Mental Health Foundation). Corroboration that the research has resulted in more humane and appropriate interventions for those with IDD.

5.3 – Department of Health (2007) [Services for People with Learning Difficulties and Challenging Behaviour or Mental Health Needs](#) London: HMSO. Cites the research.

5.4- Department of Health (2009) [Valuing People Now: a new 3 year strategy for people with learning disabilities](#) London: Department of Health. Cites the research.

5.5 – Mencap and Challenging Behaviour Foundation (2012) [Out of Sight: Stopping the Neglect and Abuse of People with a Learning Disability](#) London: Mencap Publications.

5.6 – [NICE Guidance in Development – Challenging behaviour and learning disabilities](#) Corroboration that the Guideline Development Group (GDG) which Murphy chairs is overseeing the development of new guidelines.

5.7 – Department of Health (2010) [Positive Practice, Positive Outcomes: A Handbook for Professionals in the Criminal Justice System Working with Offenders with Learning Disabilities](#) London: HMSO. Shows influence of research on criminal justice procedures.

5.8 – See Talbot, J. (2008) [Prisoner's Voices: Experiences of the Criminal Justice System by Prisoners with Learning Disabilities and Difficulties](#) London: Prison Reform Trust.

5.9 - Statement provided by ID 3 (Director, Prison Reform Trust). The corroborates the impact of the research on the support and treatment of prisoners with IDD.

5.10 – Statement provided by ID 4 (President, Protection and Advocacy Japan). This shows the impact of the research on the training of those who work with sex offenders with IDD in Japan.

5.11 – Statement provided by ID 5 (Chief Executive, Challenging Behaviour Foundation). Corroboration of the impact of the research on the support and training activities of the CBF.