

Institution: University of Kent		
Unit of Assessment: 20 Social Work and Social Policy		
Title of case study: Leading the Development of National Guidelines, Inspection Methods, Service Models, and Training Programmes to Protect and Improve the Lives of People with Intellectual and Developmental Disabilities		
Period when the underpinning research was undertaken: 2010-2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Peter McGill	Professor of Clinical Psychology of Learning Disability	1986-present
Glynis Murphy	Professor of Clinical Psychology and Disability	1993-2003; 2007-present
Peter Langdon	Professor of Clinical and Forensic Psychology	2014-2019
Nick Gore	Senior Lecturer in Learning Disability	2007-present
Period when the claimed impact occurred: August 2014-2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact (indicative maximum 100 words)		
<p>Staff from the Tizard Centre at the University of Kent have worked extensively with a broad range of key stakeholders and service providers, including NICE, the Care Quality Commission, the Department of Health Reference Group, Health Education England, and Local Authorities to improve service provision for those with, and working with, people with intellectual and developmental disabilities (IDD). Improvements include being instrumental in developing: national guidelines that directly impact clinical practice; new inspection methods to address serious failures; specialist care models adopted by large providers; and specialist training programmes that reduce harmful sexual behaviour and improve the lives of caregivers. These impacts are based on a considerable body of research in the field, are evidenced in official reports and letters from Ministers, and span a spectrum of health and social care settings both in the UK and internationally.</p>		
2. Underpinning research		
<p>Research undertaken by the Tizard Centre has focused in particular on the development and evaluation of systems of care within health and social care settings, including psychological interventions for children, adolescents, and adults with IDD and caregivers, as follows:</p>		
<p>Challenging Behaviour: Following demonstrations by McGill and Murphy that challenging behaviour can lead to restrictive and at times abusive services, McGill et al. (2018) have shown that the implementation of setting-wide Positive Behavioural Support (PBS) within social care settings leads to substantial reductions in challenging behaviour for people with IDD [R1]. PBS is an evidence-based framework, integral to research at the Tizard Centre for best practice support of people with IDD, and, as well as proving effective in reducing challenging behaviour, has been well-received by staff, families, and professionals [R1]. MacDonald, McGill, and Murphy (2018) have also demonstrated that delivery of PBS through a staff-training model within care-providing organisations leads to reductions in challenging behaviour [R2].</p>		

Mental Health and Offending: Murphy and colleagues have shown how offenders can be screened for IDD when entering probation or prison, to allow for better support (Murphy et al., 2017a) [R3]. Murphy has further shown that on release from prison, men with IDD have very poor services, reduced social networks, and substantial mental health problems that are not being addressed and that place them at risk of future offending. Murphy et al. (2013) and Langdon et al. (2016) have also shown, however, that psychological therapies, such as cognitive-behavioural therapy, lead to direct improvements in mental health and reductions in offending behaviour for people with IDD [R4, R5]. This research has shown that better quality mental health and offending services for people with IDD are needed (establishing service development as a fundamental impact goal). Likewise, the research has identified the mechanisms and practices that are required to impact on mental health difficulties and offending behaviour for people with IDD.

Caregiver Support: Gore has developed innovative methods of maximising engagement and support for caregivers of people with IDD that address both their own personal emotional and behavioural needs and those of their relatives. Gore has continued to build on his prior research (Gore and Umizawa, 2011), which demonstrated that a co-produced training resource, implemented by professional and family co-facilitators, could lead to important outcomes for families and positively influence the behaviour of children with IDD [R6]. Based on these findings and premise, Gore has continued to lead on practical methods of supporting staff and caregivers raising children with IDD through early intervention that is the subject of a current RCT (Early Positive Approaches to Support). This research-informed programme has underscored the needs and potential of family caregivers, and has informed how services might best deliver support that impacts on caregiver wellbeing and child emotional and behavioural outcomes at scale.

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

[R1] McGill, P., Vanono, L., Clover, W., Smyth, E., Cooper, V., Hopkins, L., Barratt, N., Joyce, C., Henderson, K., Sekasi, S., Davis, S., and Deveau, R. (2018). 'Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behavior support'. *Research in Developmental Disabilities* 81:143-154. <https://doi.org/10.1016/j.ridd.2018.04.020>

[R2] MacDonald, A., McGill, P., and Murphy, G. (2018). 'An evaluation of staff training in positive behavioural support'. *Journal of Applied Research in Intellectual Disabilities* 31:1046-1061. <https://doi.org/10.1111/jar.12460>

[R3] Murphy, G. H., Gardner, J., and Freeman, M. (2017). 'Screening prisoners for Intellectual Disabilities in three English prisons'. *Journal of Applied Research in Intellectual Disabilities* 30: 198–204. <https://doi.org/10.1111/jar.12224>

[R4] Murphy, G. H., and Heaton, K. (2013). 'Men with Intellectual Disabilities who have attended sex offender treatment groups: A follow-up'. *Journal of Applied Research in Intellectual Disabilities* 26: 489-500. <https://doi.org/10.1111/jar.12038>

[R5] Langdon, P. E., et al. (2016). 'The People with Asperger Syndrome and Anxiety Disorders (PAsSA) trial: A pilot multi-centred single blind randomised trial of group cognitive-behavioural therapy'. *British Journal of Psychiatry Open* 2:179-186. <https://doi.org/10.1192/bjpo.bp.115.002527>

[R6] Gore, N., and Umizawa, H. (2011). 'Challenging Behaviour Training for Teaching Staff and Family Carers of Children with Intellectual Disabilities: A Preliminary Evaluation'. *Journal of Policy and Practice in Intellectual Disabilities* 8(4): 266–275. <https://doi.org/10.1111/j.1741-1130.2011.00315.x>

Grants

[G1] NIHR 2010-18 combined grants: £1,141,190. The individual grants are too numerous to list here, and are supplied in full in the contextual data. Funded studies include; the quality of health service support for children with IDD; preventing challenging behaviour of adults with complex needs; cognitive behavioural therapy for people with Asperger Syndrome; costs and benefits of social care support for ex-offenders; and people with autism detained within hospitals: the MATCH study.

[G2] Paul Hamlyn Foundation, 2013. 'Keep safe – development of group treatment for children and young people with learning disabilities and harmful sexual behaviour'. Murphy, G.M. Value: £84,391.

[G3] Royal College of Psychiatrists, 2016. 'A review of in-patient services for people with intellectual disabilities, mental health behaviour and forensic problems'. Langdon, P. Value: £15,000.

4. Details of the impact

National Guidelines

In recognition of Murphy's research, she was appointed Chair of the National Institute for Health and Care Excellence (NICE) development group regarding challenging behaviour and learning disabilities, **2013-15**. As part of this appointment, she played a significant role in leading a group of experts to develop national guidelines, published in **2015**, which set out specific 'interventions and support for children, young people and adults with a learning disability and behaviour that challenges' **[a]**. These guidelines are used nationwide by 'healthcare professionals, commissioners and providers in health and social care', as well as 'parents, family members or carers of children, young people and adults with a learning disability and behaviour that challenges' **[a]**. They comprise key changes to safeguard adults and children with challenging behaviour and learning disabilities, including the use of medication. One of the key changes relates directly to a longstanding Tizard programme of research (of which **R1** and **R2** are recent examples), and impacts clinical practice by stipulating that psychotropic medication is only prescribed to people with IDDs alongside psychosocial interventions such as 'Positive Behavioural Support' **[a]**.

In addition, Murphy's research concerning offenders with learning disabilities (LD) led her to be invited to join the LD Offenders Steering Group at NHS England, **2008-18**. Here, her past research **[R3]** and the recommendation (from a report for which she was lead author) that 'the National Offender Management Service (NOMS) needs to roll out intellectual disabilities screening to all prisons, as a first step to ensuring that people with intellectual disabilities are not disadvantaged during their time in prison', were instrumental in the inclusion of the requirement to screen prisoners for intellectual disabilities in the '2020 Service specification Primary care service – medical and nursing for prisons in England' (as confirmed by the NHS) **[b]**. The strongest possible case was made in meetings with NOMS that it was 'in breach of the Equality Act 2000 in not making reasonable adjustments for people with intellectual disabilities' **[b]**. The service specification now states: 'adults, children and young people will receive health screening on entering prison', and this will include 'screening, assessment and treatment for health conditions and learning disabilities' **[c]**. As the Director of the Prison Reforms Trust (who was a member of the NOMS committees assessing the change) states: 'Professor Glynis Murphy made a significant contribution to the introduction of screening measures for offenders with IDD, including providing key elements of the evidence base to support the change'; she played a 'pivotal role'; and was 'at the forefront of pushing for the introduction of screening programmes in prisons, and across the criminal justice system' **[d]**.

Following the 2011 Winterbourne View scandal, exposing the abuse suffered by people with learning disabilities and challenging behaviour in hospital, Murphy and Langdon were appointed to the Department of Health National Reference Group to help develop a new national 'service model for commissioners of health and social care services' **[e]**. Published in **2015**, the service

model helps commissioners in the crucial task of judging ‘what services should look like across local areas, based on established best practice’ regarding ‘health, social care and housing services for people with a learning disability and/or autism’ [e]. As the NHS stated in 2017: ‘The service model [now] forms part of a national plan to support commissioners across the country to formulate joint transformation plans for learning disabilities services’ [f]. In addition, Gore’s research [R6] has led to him being commissioned by the NHS, under the Winterbourne View Joint Improvement Programme, to be the lead author of their ‘Core Principles Commissioning Tool’. Since **February 2014**, this has been used by local authorities and clinical commissioning groups throughout England to, *inter alia*, reduce the number of ‘individuals placed in more restrictive settings which are inappropriate for their needs’ [g].

New Inspection Methods to Address Serious Failures

In **2019**, following a televised BBC *Panorama* programme showing abusive care of people with learning disabilities and/or autism in Whorlton Hall (an independent hospital in the North of England), Murphy was appointed by the Care Quality Commission to undertake an independent review of failings. Under the terms of reference, she was charged with not only devising new ‘inspection methodology and practice [...] in order to increase the likelihood of detecting of harm or abuse’, but also recommending ‘actions which can be taken immediately and do not require changes in legislation’ [h]. The recommendations are too extensive to detail in this case study (they can be viewed in full in the supporting evidence files), but include crucial measures such as ‘unannounced inspections, and [...] evening and weekend visits’; the prioritising of ‘in-depth service user interviews, in private’; the use of ‘CCTV or other covert surveillance, despite the ethical issues these methods raise’; and that the ‘CQC should not register services like Whorlton Hall, that are very isolated, in unsuitable buildings, with out-of-date models of care’ [h]. These, and other recommendations, have already had a tangible impact in parliament. In **October 2020**, the Secretary of State for Health and Social Care presented to Parliament, that ‘following the exposure of abuse at Whorlton Hall, the CQC’s work to incorporate Professor Murphy’s recommendations into a new strategy to improve the regulation of mental health, learning disability and/or autism services must continue at a greater pace’ (see 11F of ‘The Government Response to the Joint Committee on Human Rights’) [i]. Furthermore, a letter from the Minister of State for Care, states that ‘the review undertaken by Professor Glynis Murphy was published in March 2020 and CQC have already begun to implement the recommendations and are also taking a number of steps to address closed cultures in inpatient settings where there is a risk to patient safety. Phase Two of the review will be presented in full next year. My officials will continue to work with CQC and NHSE to ensure necessary actions are being taken’ [j]. The importance of the review for the future of care in the UK has also been recognised in the national media, including by the BBC and the *Independent* [k]. The *Independent* stated that, in response to Murphy’s review, the CQC ‘will increase the frequency of out of hours inspections in order to penetrate what it called “closed cultures” in some hospitals’ [k].

Specialist Care Models and Intervention Programmes

Tizard Centre staff have used their research to design specialist care models and intervention programmes for professionals working with people with IDD that are now used widely in the UK and internationally to improve outcomes. These programmes include: ‘SOTSEC-ID/Keep safe’ cognitive behavioural therapy CBT programmes that have been shown to reduce sexual offending and improve victim empathy [R4]; ‘Activate’, a new care model that has been shown to improve adaptive skills of people with IDD [R1, R2]; and ‘Early-Positive Approaches to Support’ (E-PATs), a training programme that has improved the lives of family caregivers who have children with IDD [R6]. SOTSEC-ID/Keep safe and Activate have had their outcomes proven in randomised controlled trials. SOTSEC-ID/Keep safe has been used to train 900 health and social care professionals in the UK between 2000 and 2020 (including 500 from 2014). In particular, since **2016** it has used throughout Japan to train ‘social care workers, social care counsellors, teachers, lawyers, and practitioners working in correctional facilities such as prisons and juvenile training centres’ [l]. It has also been used in Australia, New Zealand, and Ireland, but we have only thus far had detailed evidence returned from Japan [l]. Since **2014**, Activate has been adopted by

Dimensions (a large not-for-profit provider of social care services for people with IDD), who were awarded the 2015 Innovative Quality Outcomes Award in the 3rd Sector Care Awards as a consequence. They stress the 'very substantial impact on outcomes' that the model has had 'for the people we support especially in respect of challenging behaviour', and how 'the new model is informing all parts of the organisation with, for example, job descriptions, business plans, quality monitoring all now being linked to the successful implementation of Activate' [I]. In addition, since 2017, E-PAtS has been delivered to 350 families across the UK, with over 240 of these via Mencap, a UK charity that provides services to approximately 10,000 children and adults with a learning disability and their families. Surveys of users demonstrate that over 90% found it valuable, and testimonials from Mencap describe it as 'an excellent example of how research expertise applied and delivered in partnership with the community can have real impact' [I]. E-PAtS is also being implemented by providers in Canada and Norway, utilising fully translated materials, but we are yet to receive detailed evidence.

In sum, Tizard Centre research has led directly to changes in clinical guidelines, the introduction of IDD screening in prisons, and the development and implementation of successful intervention programmes, and has been at the forefront of addressing the largest IDD care failures in modern history. The combined impact of these measures has improved care and protections for an estimated 1.3 million people with IDD in the UK alone.

5. Sources to corroborate the impact (indicative maximum of 10 references)

(Key pages are listed below for each source, with highlights of all relevant material.)

[a] NICE Guidelines, 2015. References to research and Murphy's role as Chair on pp. 5, 46, 49, and 52.

[b] NHS Project Manager, Health and Justice testimonial, 2017 JARID Report. Evidence of Murphy's recommendations regarding screening of prisoners, p. 202.

[c] NHS Service specification, 2020. Primary care service – medical and nursing for prisons in England. Evidence of the adoption of screening for IDD. See pp. 9 and 11.

[d] Letter from the Director of Care not Custody at the Prison Reforms Trust, 2020.

[e] NHS Service Model, 2015. Reference to the role of Murphy and Langdon.

[f] NHS Service Model statement (2017), setting out its impact. See p. 1.

[g] NHS Core Principles Commissioning Tool, 2014. Gore's role as lead author, p. 4.

[h] CQC inspections and regulation of Whorlton Hall, 2015-19: an independent review. See p. 1 for Murphy's appointment to conduct the review; pp. 57 and 58.

[i] Government Response to the Joint Committee on Human Rights reports, 2020. Murphy referenced on pp. 4, 12, 14, 34, 36, and 45. See page 14 for action 11F.

[j] Letter from the Minister of State for Care, 2020. Murphy referenced on p. 1.

[k] The importance of Murphy's Whorlton Hall independent review recognised in the national press (BBC and the *Independent*, 2020).

[l] Testimonials, 2020: President, Protection and Advocacy-Japan, regarding SOTSEC-ID/Keep safe; Dimensions Chief Executive, regarding Activate; Mencap Director NI, regarding Early-Positive Approaches to Support.