



**Scoping review on
adults with learning
disabilities and
behaviours that
challenge
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Professor Gavin Davidson
Praxis Chair of Social Care
School of Social Sciences, Education
and Social Work
g.davidson@qub.ac.uk

Overview of the presentation

- Scoping review approach
- NICE (2018) Learning disabilities and behaviour that challenges: service design and delivery
- NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges
- NICE (2015) Violence and aggression: short-term management in mental health, health and community settings
- Ali et al. (2015) Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities
- Hassiotis et al. (2018) Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT.
- Flynn et al., 2018, Effectiveness of Active Support for adults with intellectual disability in residential settings: Systematic review and meta-analysis
- McCarron et al. (2018) Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability
- Perera, B. & Courtenay, K. (2018) "Mental health services for people with intellectual disability in the United Kingdom", Advances in Mental Health and Intellectual Disabilities, Vol. 12 Issue: 3/4, pp.91-98.
- Ramsay, H. & Dodd, P. (2018) "Mental health services for people with intellectual disability in Ireland: evidence, barriers and opportunities", Advances in Mental Health and Intellectual Disabilities, Vol. 12 Issue: 3/4, pp.105-113.
- Bramley et al., 2018, Using telemonitoring to support personal care planning for adults with learning disabilities

Scoping reviews

- This type of review provides a preliminary assessment of the potential size and scope of available research literature
- It aims to identify the nature and extent of research evidence
- Identify areas where a full systematic may be needed
- Don't tend to include process of quality assessment
- Cannot usually be regarded as a final output in their own right

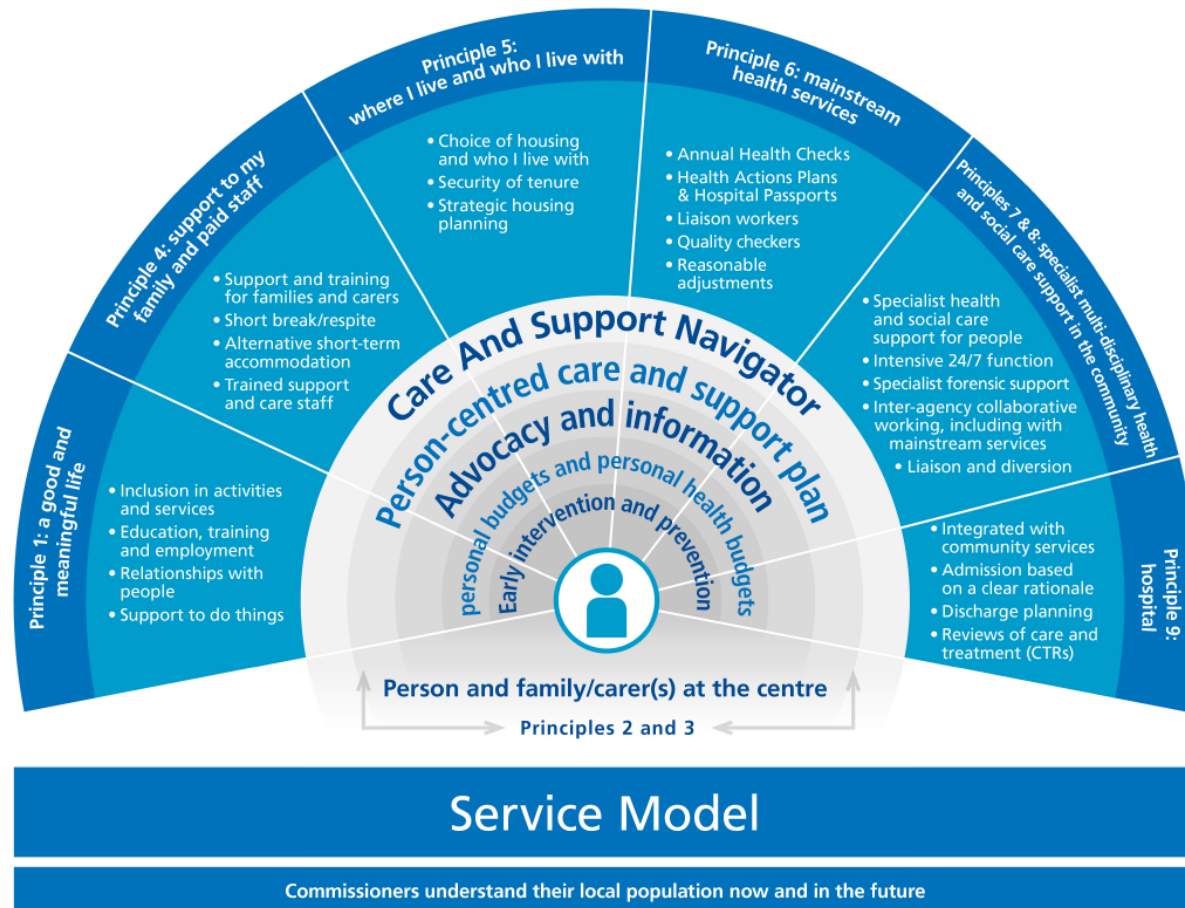
(Grant and Booth, 2009)

Scoping review methodology

- Searched Google Scholar, National Institute for Health and Care Excellence (NICE) Evidence Search, Zetoc, Social Care Online and Web of Science
- Main search terms: “adults with learning disabilities”; “adults with intellectual disabilities”; AND “violence”; “aggression”; behaviour that challenge”; “challenging behaviour”
- Selection: focused on systematic reviews if available, most recent research and innovative service developments

Principles and guidance

- NHS England (2015) Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition



NICE, 2018, Learning disabilities and behaviour that challenges: service design and delivery

- Covers services for children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges
- The most commonly used definition of behaviour that challenges is: 'behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities' (Emerson et al. 1987)
- Guideline developed to support the Transforming Care programme (post Winterbourne View)

NICE, 2018, Learning disabilities and behaviour that challenges: service design and delivery

- Services in the community should fulfil the following core functions:
- specialist prevention and early intervention
- developing capacity in non-specialist community services to prevent unnecessary inpatient admissions
- giving support and training to families and carers
- quality assurance and service development
- short-term assessment and intervention
- longer-term complex intervention
- crisis response and intervention

NICE, 2018, Learning disabilities and behaviour that challenges: service design and delivery

- Match the specific skills of staff to the characteristics of the person with a learning disability and behaviour that challenges.
- As part of staff recruitment and training, ensure that staff have the skills, knowledge and qualities they need to support the children, young people and adults they are working with. This includes:
- the skills and knowledge recommended in staff training, supervision and support in NICE's guideline on challenging behaviour and learning disabilities: prevention and interventions
- being resilient and compassionate
- showing that they care
- understanding and respecting the person's human rights, faith, culture, identity and values

NICE, 2015, Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

- Person-centred; least restrictive; aim to improve quality of life; and prevent, reduce or stop the development of future episodes of behaviour that challenges
- General guidance on assessment and risk assessment
- For recent-onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool or Motivation Assessment Scale to identify relationships between the behaviour and what triggers and reinforces it

NICE, 2015, Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

- Consider personalised interventions that are based on behavioural principles and a functional assessment of behaviour, tailored to the range of settings in which they spend time, and consist of:
- clear targeted behaviours with agreed outcomes
- assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
- addressing staff and family member or carer responses to behaviour that challenges
- a clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
- a specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).

NICE, 2015, Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

- Research recommendations
- Are interventions based on the science and practice of applied behaviour analysis or antipsychotic medication, or a combination of these, effective in reducing the frequency and severity of behaviour that challenges shown by adults with a learning disability?
- What factors (including service organisation and management, staff composition, training and supervision, and the content of care and support) are associated with sustained high-quality residential care for people with a learning disability and behaviour that challenges?

NICE (2015) Violence and aggression: short-term management in mental health, health and community settings

- Training should enable staff to develop:
- a person-centred, values-based approach to care, in which personal relationships, continuity of care and a positive approach to promoting health underpin the therapeutic relationship
- an understanding of the relationship between mental health problems and the risk of violence and aggression
- skills to assess why behaviour is likely to become violent or aggressive, including personal, constitutional, mental, physical, environmental, social, communicational, functional and behavioural factors
- skills, methods and techniques to reduce or avert imminent violence and defuse aggression when it arises (for example, verbal de-escalation)
- skills, methods and techniques to undertake restrictive interventions safely when these are required
- skills to undertake an immediate post-incident debrief
- skills to undertake a formal external post-incident review in collaboration with experienced service users who are not currently using the service

Ali et al. (2015) Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities

- Six studies (309 participants), based on adult populations with intellectual disabilities, suitable for inclusion in the current version of this review. These studies examined a range of cognitive-behavioural therapy (CBT) approaches: anger management (three studies (n = 235); one individual therapy and two group-based); relaxation (one study; n = 12), mindfulness based on meditation (one study; n = 34), problem solving and assertiveness training (one study; n = 28). (No behavioural intervention studies included).
- Improved outcomes in five studies, including reduction in anger ratings and in aggressive incidents, at the end of treatment.
- One study found improvements in anger coping skills as reported by key workers at 16 weeks and 10 months, but no other long-term benefit. One large study did not find improvements in quality of life or reduced costs to health services. Due to differences in the types of interventions, populations and assessments, we could not combine the results of the studies
- Recommended that randomised controlled trials of sufficient power are carried out using primary outcomes that include reduction in outward-directed aggressive behaviour, improvement in quality of life, and cost effectiveness

Hassiotis et al. (2018) Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT

- Background: Preliminary studies have indicated that training staff in Positive Behaviour Support (PBS) may help to reduce challenging behaviour among people with intellectual disability (ID).
- Objective: To evaluate whether or not such training is clinically effective in reducing challenging behaviour in routine care. The study also included longer-term follow-up (approximately 36 months).
- Design: A multicentre, single-blind, two-arm, parallel-cluster randomised controlled trial. The unit of randomisation was the community ID service using an independent web-based randomisation system and random permuted blocks on a 1 : 1 allocation stratified by a staff-to-patient ratio for each cluster.
- Setting: Community ID services in England.
- Participants: Adults (aged > 18 years) across the range of ID with challenging behaviour [≥ 15 Aberrant Behaviour Checklist – Community total score (ABC-CT)].
- Interventions: Manual-assisted face-to-face PBS training to therapists and treatment as usual (TAU) compared with TAU only in the control arm.
- Main outcome measures: Carer-reported changes in challenging behaviour as measured by the ABC-CT over 12 months. Secondary outcomes included psychopathology, community participation, family and paid carer burden, family carer psychopathology, costs of care and quality-adjusted life-years (QALYs). Data on main outcome, service use and health-related quality of life were collected for the 36-month follow-up.

Hassiotis et al. (2018) Positive behaviour support training for staff for treating challenging behaviour in people with intellectual disabilities: a cluster RCT

- Results: A total of 246 participants were recruited from 23 teams, of whom 109 were in the intervention arm (11 teams) and 137 were in the control arm (12 teams). The difference in ABC-CT between the intervention and control arms was not statistically significant. No treatment effects were found for any of the secondary outcomes. The mean cost per participant in the intervention arm was £1201. Over 12 months, there was a difference in Quality-adjusted life years (QALYs) of 0.076 in favour of the intervention and a 60% chance that the intervention is cost-effective compared with TAU from a health and social care cost perspective at the threshold of £20,000 per QALY gained. Twenty-nine participants experienced 45 serious adverse events (intervention arm, n = 19; control arm, n = 26). PBS plans were available for 33 participants. An independent assessment of the quality of these plans found that all were less than optimal. Forty-six qualitative interviews were conducted with service users, family carers, paid carers and service managers as part of the process evaluation. Service users reported that they had learned to manage difficult situations and had gained new skills, and carers reported a positive relationship with therapists. At 36 months' follow-up (n = 184), the mean ABC-CT difference between arms was not significant. The initial cost-effectiveness of the intervention dissipated over time.
- Limitations: The main limitations were low treatment fidelity and reach of the intervention.
- Conclusions: Findings from the main study and the naturalistic follow-up suggest that staff training in PBS as delivered in this study is insufficient to achieve significant clinical gains beyond TAU in community ID services. Although there is an indication that training in PBS is potentially cost-effective, this is not maintained in the longer term. There is increased scope to develop new approaches to challenging behaviour as well as optimising the delivery of PBS in routine clinical practice.

Flynn et al., 2018, Effectiveness of Active Support for adults with intellectual disability in residential settings: Systematic review and meta-analysis

- Background: The review examined the effectiveness of Active Support (maximizing engagement in meaningful activities of daily life) (RQ1) and stakeholders' experiences of the model (RQ2).
- Method: Data were meta-analysed (RQ1; studies = 14) and synthesized narratively (RQ2; studies = 10).
- Results: By follow-up (6 months post-training), effect sizes (RQ1) for resident total activity engagement were significant and ranged from small ($d = 0.33$, 95% CIs: 0.10–0.50) to large (Tau-U= 0.95, 95% CIs: 0.64–1.25) depending on study design.
- Follow-up changes in staff assistance were moderate ($d = 0.56$, 95% CIs: 0.23–0.89; Tau-U 0.63, 95% CIs: 0.32–0.93) and large for quality of support ($d = 1.03$, 95% CIs: 0.61–1.44). Other outcomes did not change.
- Conclusions: Active Support was more effective following complete staff training, in larger settings, at lower staff-to-resident ratios and with less experienced staff. Active Support training and outcomes were valued by staff and residents (RQ2), and staff experienced increased job satisfaction. Lower staff turnover and organizational readiness appear crucial for maintaining implementation.

McCarron et al. (2018) Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability

- 15 studies included. Thirteen of the included studies examined quality of life effects: eight quantitative, two qualitative, and three of mixed methods design. Two of the included studies examined cost-effects.
- The majority of the included individual studies showed that relocation to the community was associated with improved quality of life. Quality of life subdomains assessed in the studies included physical well-being, community access, routines, self-determination, residential well-being, and general life improvements.
- Qualitative studies conveyed an overall positive impact on individuals' quality of life, i.e. improved well-being, freedom, and independent decision-making; more careful consideration of housemate compatibility; and increased family contact and social integration opportunities. Studies specifically examining quality of life have also found freedom and self-determination to be meaningful aspects of community living for individuals. However, potentially negative consequences were also reported, including an increased sense of loneliness and challenges in maintaining family contact.
- Two eligible studies on costs were included, although the definitions of 'community settings' were unclear and included nursing homes. One study reported that a move from a long-stay hospital to community settings was associated with reduced costs, whereas the other reported that such a move was associated with increased costs. In both cost studies, very limited information was provided on both the people moving and the size and environment of their post-move residences. This precludes meta-analysis and prevents substantive recommendations on costs from being drawn.

Perera, B. & Courtenay, K. (2018) "Mental health services for people with intellectual disability in the United Kingdom", *Advances in Mental Health and Intellectual Disabilities*, Vol. 12 Issue: 3/4, pp.91-98.

- Greater awareness and training in Autism and ADHD will need to be incorporated in to training programmes and to strategies used in services
- Allied to this is the recognition that people with ID have received excessive amounts of psychotropic medication to manage behavioural problems that have often not been monitored (Sheehan et al., 2015)
- Adopting behavioural strategies as exemplified by positive behavioural support (PBS) will be essential in supporting people and their carers in managing problem behaviours (Allen et al., 2005)

Ramsay, H. & Dodd, P. (2018) "Mental health services for people with intellectual disability in Ireland: evidence, barriers and opportunities", *Advances in Mental Health and Intellectual Disabilities*, Vol. 12 Issue: 3/4, pp.105-113.

- The MHID national programme is currently focussing on a number of specific areas: mapping all existing resources, establishing/augmenting baseline services and teams for each area, developing a national model of service, establishing a national clinical data collection process, and looking at governance structures between the HSE and voluntary agencies (HSE Mental Health Division, 2017)
- This focus on developing services has resulted in significant extra posts for community child and adult MHID services (HSE Mental Health Division, 2017)
- However, progress in the development of inpatient services and the development of care pathways for MHID in forensic services remains at planning stages (Health Service Executive: Mental Health Division, 2017).

Bramley et al., 2018, Using telemonitoring to support personal care planning for adults with learning disabilities

- The Just Right approach combines using movement sensors to provide data presented graphically about the activity of AWLD within their homes over a period of at least six weeks alongside training and advice about person-centred care (PCC) planning.
- 33 care providers serving 417 adults with learning disabilities.
- Issues relating to implementation included staff acceptance, culture, consent, safeguarding, local authority engagement, interpretation of data and residential setting. Changes to care were identified for 20.3% of individuals, with 66% of providers not identifying any changes because Just Right confirmed that they were providing the right level of support.