

Accepted / will be accepted:

Challenging behaviour or untreated ADHD? (case study x2)
Reducing Antipsychotic Medication in ID Using QI Methodology (service evaluation)
Transforming Care: Developing a Community Enhanced Intervention Service (service evaluation)
It put control back into my family situation: family experiences of PBS (qualitative study)
Direct care staff knowledge about medication for individuals with intellectual disabilities (questionnaire study)
Using positive behavioural support (PBS) for STOMP medication challenge (service evaluation)
Systematic review of fidelity of measurements in complex interventions (systematic review)

Challenging behaviour continues to be a common and disabling condition in people with intellectual disabilities and their family carers as evidenced by many recent reports on the quality of support for those individuals with intellectual disabilities who display it. Whether low level and requiring minimal intervention or severe enough to warrant multidisciplinary assessment and treatment, it presents a significant challenge to community intellectual disability services. There is currently no single approach or service model that can help all individuals at all times and often evidence particularly around effective services is poor and/or limited. Two complementary NICE guidelines published in 2015 and 2018 alarmingly show that treatments for adults with intellectual disabilities do not extend beyond Positive Behaviour Support and little to recommend use of antipsychotic medication bar risk to others. The recommendations on services are a long wish list of suggestions that may or may not find their way in local interpretation.

The debate on how to best manage the display of challenging behaviour is by no means concluded. It is within this context that we believe a special issue is still topical and important. The included papers cover a number of clinically relevant and applied methodologies taking the perspective both of the carer and of the individual with intellectual disability. Quality improvement projects are at the forefront of service developments and their value is not only on the process and outcomes they may achieve but also on the involvement of multiprofessional staff who work together to accomplish the objectives at each step of the pathway.

Challenging behaviour is highly comorbid and the paper by [ref] show the intricacies of making the distinction between the challenging behaviour and a developmental disorder such as ADHD. Diagnostic skill is imperative as is the awareness that not all behaviour is “challenging” but evidence of additional morbidity.

Positive Behaviour support is central to 2 papers within different contexts. A family carer describes the use of the framework and reflects on her family’s experience [ref] and a service implements it as an alternative to overmedication [ref].

Reduction in antipsychotic medication is the focus of a quality improvement programme which may motivate professionals in other services to possibly take up a similar approach [ref]. A survey of antipsychotic medication knowledge in paid carers presents a current picture of what direct support staff know and which complements other data on the drivers behind antipsychotic prescribing [ref].

Enhanced support has been put forward as a factor in the successful maintenance of adults with intellectual disabilities in the community. [ref] describe such a service, the availability of which is still very much a postcode lottery issue.

Finally interventions are as good as the fidelity with which they are implemented. [Paulauskaite and Hassiotis] present a systematic review of the fidelity of psychosocial interventions for challenging behaviour. Improving the reporting of intervention fidelity in publications and enhancing the delivery in real world conditions must be actively considered by reviewers, practitioners and commissioners.

It is our view that there must never be a short cut to the basics of the assessment and treatment of an adult with intellectual disability who displays challenging behaviour. Possible physical causes should be investigated, diagnostic options should be considered and the relative success or failure of previous treatments should be taken into consideration.

The papers in this special issue provide a snapshot of the concerns of researchers, practitioners and family carers with lived experience and we hope that they will provoke debate and reflection providing further impetus for the quest for better services and more effective treatments.