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Prevalence of Challenging Behaviour in Adults with Intellectual Disabilities, Correlates, and Association with Mental Health

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Abstract

Purpose of Review To summarise findings about the prevalence and correlates of challenging behaviour in adults with intellectual disabilities from robust research. We also describe findings on the interplay between challenging behaviour and mental health.

Recent Findings Recent studies that have utilised psychometrically evaluated tools, with clear operational definitions, show similar findings on the prevalence of challenging behaviour of about 1 in every 5–6 adults known to services. We describe common correlates identified such as communication impairments, severity of intellectual disability, and living in institutional settings or congregate care. We also describe the complex and multifaceted relationship between challenging behaviour and mental health.

Summary Based on recent studies, we propose a revised framework model to help understand challenging behaviour. We propose a number of areas where more research is required, particularly the development of risk tools clinicians can utilise in practice.

Keywords Intellectual disability · Challenging behaviour · Prevalence · Correlates · Risk factors · Mental health

Introduction

There is a high prevalence of challenging behaviour (CB) [1, 2, 3••] and mental health (MH) issues [4, 5•] in adults with intellectual disabilities (ID). For adults with ID, CB can lead to negative personal outcomes and diminished quality of life [6]. It can result in poor integration, exclusion from services, limit friendships, and interfere with learning and development [7, 8]. Studies have shown that CB may lead to long-term inpatient care with an associated increased risk of physical harm and abuse [6, 9]. CB can also lead to an increased reliance on

restrictive practices such as seclusion or restraint [10–12], and results in negative consequences for carers, including risks of physical harm and psychological distress [7, 13].

In this paper, we review literature on the prevalence of CB in adults with ID. We will examine factors that have been correlated with CB, explore the differences between correlates and risk factors, and consider the cumulative impact of risk factors. We will discuss the complex and multi-faceted relationship between CB and MH issues. Based on a review of recent studies, we propose a revised framework model for CB [14••] that includes reference to MH issues, updates vulnerability factors, and refers to the impact of increased psychotropic medication use.

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Prevalence of Challenging Behaviour in Adults with ID

Understanding the prevalence of CB in adults with ID is important for service planning and resource funding. Research on the prevalence of CB in individuals with ID to date has been largely restricted to a focus on specific clinical populations in specific clinical settings [6]. Reported prevalence

shows considerable variation between 4–22% in previous total population studies [1•, 8], to as high as 50–80% in studies looking at specific settings, subpopulations, or behaviours [15, 16].

The most robust methodology to estimate prevalence of CB is to sample at the population level. Some variation in population studies can be explained by differences in study designs and methodologies (for summaries see 1, 7). CB has been a particularly difficult variable to define consistently and validly [17]. Some earlier studies (e.g., 18) attempted to discriminate between CB that is “more” or “less” demanding. “More demanding” CB was defined as occurring daily, restricting engagement, requiring physical intervention, or causing injury. Using this definition, prevalence estimates for CB varies between 3.8 and 10% [6, 8, 18–20]. Studies that included “less demanding” CB (problem behaviour including aggression, destruction, or self-injury which did not meet the “more demanding” criteria) had increased prevalence estimates of 10–15% [6, 8].

A number of studies have been restricted in their sampling methods by extracting data from sources not designed to hold quantifiable data, such as clinicians’ notes (e.g., [21, 22, 23•]), or by postal surveys utilising numerous informants who may lack precise information regarding the occurrence of CB (e.g., [24]). In a previous meta-analysis [25] exploring risk factors in CB studies, only 22 of the 86 studies considered were found to contain enough information to be included, fewer than half of these used a questionnaire type instrument, and very few any psychometrically evaluated tools. There have been few robust, population studies that have estimated prevalence of CB utilising psychometrically evaluated assessment and classification tools developed specifically for adults with ID [1•].

In a 2017 study [3••], Bowring, Totsika, Hastings, Toogood, and Griffith used a definition of CB derived from ratings on the Behaviour Problems Inventory–Short Form [26] in a total population sample of adults with ID in Jersey. This study revealed a prevalence rate of CB of 18.1% (95% CI, 13.94–23.19%) which was similar to other population studies that had used classification tools for adults with ID–18.7% [1•, 2]. The Bowring et al. study also examined the prevalence of sub-types of CB data that have often been missing in earlier population studies. The prevalence of aggressive and destructive behaviour (ADB) was 8.3% (95% CI, 5.54–12.25%), self-injurious behaviour (SIB) 7.5% (95% CI, 4.94–11.37%), and stereotyped behaviour (SB) 10.9% (95% CI, 7.73–15.27%) [3••]. Prevalence of SB has only been reported in one other population study studies [2] and given potential impact on quality of life requires further research. Other studies have similarly found ADB to be more prevalent than SIB (e.g., ADB 9.8%, SIB 4.9% [7]; ADB 11.9%, SIB 8.4% [2]).

In summary, the reported prevalence of CB in historical studies (e.g., [8, 16]) shows considerable variation (4–80%) with much of this due to the lack of a consistent, conceptual,

consensual, or operational definition of CB. Recent total population samples [1•, 2, 3••], which have used psychometrically evaluated tools to measure and classify CB, appear to have quite consistent estimates (18.1–18.7%) of CB in adults with ID known to services. Whilst psychometrically sound informant measures are helpful in population size samples, they are not direct measures of the frequency of CBs.

Correlates of Challenging Behaviour

Hastings et al. 2013 [14••] argued that CB is the product of the interaction between vulnerabilities, maintaining processes, and impact factors. Psycho-social vulnerabilities include negative life events, lack of communication skills, impoverished social networks, lack of meaningful activity, and psychiatric or mood problems [14••]. Biological vulnerability factors include health, sensory, and genetic factors [14••]. CB can be maintained by environmental responses such as other people’s reactions or internal reinforcement such as pain reduction. CB can impact on a person’s quality of life and lead to exclusion from communities and cause harm to self or others. These effects can then feedback to influence further vulnerability. For example, dedicated ID services that reduce community presence for individuals following aggression may then increase social isolation and reduce engagement [14••].

Findings on correlates or “comorbidities” of CB may highlight populations at risk of developing CB, thus it is imperative that these factors are considered in the design of preventative intervention models. Whilst it is important, that we understand the correlates of CBs, they only provide a first-level identification of likely risk factors for CB. Identifying actual risk factors requires longitudinal research designs.

Previous studies have been criticised for conducting analyses on correlates only for specific populations with CB and not total population groups [2, 7]. There is little robust literature to compare correlates of CB [1•] in population samples. In studies that have considered this issue, some vulnerability factors appear to have been consistently associated with higher levels of CB, such as lack of communication skills/increased severity of ID [1•, 3••, 6, 8], as well as living in institutional or congregate care settings [1•, 8, 20]. Some population studies have reported association between CB and younger age [8], but not consistently across different studies. Research on associations between gender and CB have led to mixed results, with some studies identifying men at greater risk of CB [6, 18], some women [1•], and others with no gender association [3••, 8]. Incontinence [7] and autism [2, 20, 25] have all been reported as correlates of CB in some specific studies. Epilepsy has previously been identified as a correlate for CB [27], but not in all recent population-based samples [1•, 2].

In the Bowring et al [3••] adult population study, correlates of CB were explored as well as correlates of specific CBs (aggressive destructive behaviour, ADB; self-injurious behaviour, SIB; stereotyped behaviour, SB)—see Figure 1. Communication impairments (being non-verbal, having limited understanding of communication) and having a severe-profound ID were consistently associated with all four categories of CB, but there were otherwise different sets of correlates associated with different behaviours. Mobility problems, impaired visions, presence of seizures, epilepsy, autism, presence of another genetic syndrome, no clear speech, having no daytime engagement, and living in paid or congregate care were associated with some categories of CB but not consistently across all CB categories.

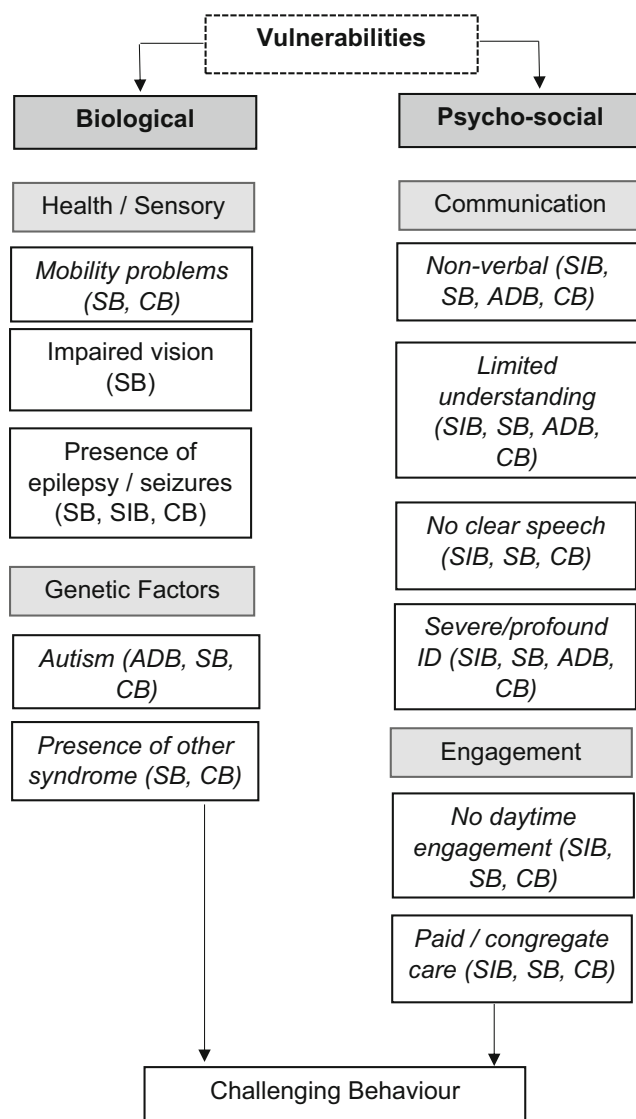


Fig. 1 Vulnerability factors associated with challenging behaviours from Bowring et al. 2017 (SIB = Self-injurious behaviour; ADB = Aggressive destructive behaviour; SB = Stereotyped behaviour; CB = Challenging behaviour)

Other adult population studies that have examined specific CBs like aggression have found greater prevalence in institutional or congregate care settings and in younger adults [24, 28], higher levels of verbal aggression for those with mild/moderate ID [24], and higher levels of physical aggression for those with severe/profound ID [24, 28]. Adult population studies that have examined higher levels of SIB have found associations with lower ability, not living with a family carer, ADHD, and visual impairments [7]. There has been a lack of research into the correlates of stereotyped behaviour, which is concerning given its potential impact on quality of life.

Further research is required to identify correlates of specific CBs in population samples. Identifying correlates or vulnerability factors for CB is important for developing preventative intervention approaches. Whilst several correlates have been identified for CB, they are not necessarily factors conferring risk. To identify risk factors requires establishing temporal precedence [3••, 29], which would require longitudinal designs, which are lacking in adult ID population samples. Having greater understanding of factors conferring risk of CB in individuals with ID will help clinicians target these vulnerability factors for intervention and allow the development and testing of tools to identify adults at risk of developing CB (e.g., [29, 30]).

Combined Effects of Correlates/Risk Factors

Bowring et al. [3••] also considered that CB may be explained more clearly using the concept of cumulative risk (or the presence of multiple correlates) as previously proposed by Rutter [31] as opposed to considering individual correlates acting independently. Bowring et al. [3••], uniquely for CB population research, explored five different ways of combining correlates into “risk” indices to predict CB. These included a simple dichotomously coded cumulative risk index (CRI) where participants received a score of 1 if a “risk” indicator (such as being non-verbal) was present and a score of 0 if absent, and the number of risk factors out of 20 were estimated for each participant. Other methods included a weighted CRI considering the intensity of risk exposures, an outcome specific CRI (i.e., different for each type of CB), a cumulative domain risk index (CDRI) which involved grouping factors in conceptually similar domains of risk (e.g., communication impairments), and a weighted CDRI (using information from the strength of statistical association with CB). Each of the methods explored led to similarly effective prediction of CB. Given that some of the tested methods were more complex in terms of calculation, Bowring et al. concluded that a simple count of dichotomously coded CB correlates might represent a viable method for use in clinical practice. However, this as yet, remains untested.

Identifying individuals with ID in community settings, with multiple risk factors is likely to assist clinicians to prioritise adults for services [32] and addressing multiple risk factors is likely to be more effective in the development of intervention approaches [33]. Having tools that help clinicians predict the risk of individuals with ID displaying CB, and specific CBs, will likely be helpful to help identify adults who would benefit from intervention approaches such as positive behavioural support [34, 35, 36]. Further longitudinal research is required on the predicative utility of combining information about correlates/risk factors for CB.

Challenging Behaviour and Mental Health Problems

As previously suggested, the high prevalence of MH problems and CB, both separately [4, 5] and concurrently [37] in adults with ID, is generally recognised. In addition, existing research suggests that mental ill health may be a correlate of CB. However, there is less certainty regarding exactly how and why CB and MH problems are related in adults with ID [38, 39].

Some researchers have argued that MH and CB in people with ID are independent constructs. Tsiouris and colleagues [40] for example, found no statistical difference in CB between outpatients “with depression” and those “without depression” in a cross-sectional analysis of ratings from the Clinical Behaviour Checklist for Persons with ID. Sturmey et al. [41] additionally concluded that CBs could not be viewed as depressive equivalents in their similar correlational study as there were no particular CBs reliably associated with depression. Melville et al. [42] surmised that CB was not indicative of depression because the measurement items related to depression and CB were located in different factors of an analysis of the Psychiatric Present State-Learning Disabilities Examination Scale. Other researchers also found that CB was not associated with MH problems [43, 44].

In contrast, other studies have found associations between CB and mental health problems. Felce and colleagues [45] employed moderated multiple regression techniques to analyse the characteristics of people with ID in primary care settings. Here they detected a significant relationship between MH problems and CB, which was more pronounced in people with lower levels of adaptive behaviour. Replicating elements of this robust study in secondary care services, Painter et al. [46] also found the severity of MH problems to be associated with measures of aggression, self-injurious behaviours, and overall ratings of CB, again finding the strongest associations in participants with more severe ID. Poppes et al. [47] also found higher rates of CB in those participants already diagnosed with a MH condition when focusing solely on individuals with profound ID.

Thus, existing research is inconclusive in relation to an association between CB and MH in adults with ID when the two constructs are examined in the context of correlation/regression designs. Whilst this may vary according to the combination of specific type of CB and MH conditions examined [48], there is however, some consistent evidence that CB and MH globally are more strongly associated in those with more severe to profound ID. This pattern of findings is consistent with a hypothesis that CB may be indicators of underlying MH problems in those with more severe ID [45–47].

In addition to these correlational, cross-sectional designs, cluster analysis has been used as a means of identifying homogenous sub-groups of individuals with ID [49, 50]. These studies provide a different way to examine associations between MH and CB: Do they tend to co-occur in groups of individuals identified statistically as similar? Crocker et al. [51] for example, gathered data on 296 individuals with mild-moderate ID using a range of clinical measures and case note analysis. After further limiting the sample to include on those who displayed outward aggression, they found six distinct clusters. One was typified by low levels of CB and low levels of MH problems, with a second yielding relatively high levels of both variables. These findings were mirrored in a more recent study by Painter et al. [52] who analysed data gathered from 1692 adults with a broad range of ID and associated needs. Using demographic information in conjunction with a battery of six different clinical measures including general ability/disability, overall risk, severity of MH problems, CB, autism symptoms, and physical health problems. Painter and colleagues also identified six statistically robust groupings. Low CB and MH problems clustered together in one sub-group, and a contrasting group had high levels of CB and MH problems. Thus, CB and MH problems do seem to co-occur in adults with ID.

Due to a range of limitations, none of the existing research studies allowing an examination of the association between CB and MH can be considered definitive. The main limitations include fundamental differences in diagnostic constructs in the field of ID [42, 53], inconsistent definitions of CB (as mentioned earlier, and [54]), overlap between these two problems [55], and the practical challenges of categorical diagnoses in both clinical and research settings [56]. In addition to these conceptual challenges, much of the research has been adversely affected by methodological limitations including modest sample sizes [42], cross-sectional designs [57], and tautological issues such as studying people with ID already diagnosed with a psychiatric condition to elicit the presentation of MH problems in people with ID [5]. Latterly, some of the statistical approaches employed have been questioned due to a failure to control for confounding variables, the use of techniques unsuited to categorical data, and a failure to validate (confirm) exploratory factor analyses [38, 42].

Therefore, although we argue that MH and CB interact in some way, we acknowledge that some ambiguity remains and all that three of Emerson's [58] concisely articulated hypotheses remain plausible:

- That MH problems might serve to maintain pre-existing CB. For example, a depressed person with ID might lack the motivation to engage socially and may equally have learned that exhibiting certain behaviours typically leads to their isolation from others. In this way, their CBs may be reinforced.
- Secondly that, in individuals who struggle to express their emotions (due to their ID), CBs may be secondary features of MH problems. For instance, somatic symptoms of depression (aches and pains) could result in sleep disturbance, agitation, and other CBs.
- Finally, in individuals with more severe ID, CBs may be atypical manifestations of a mental health problem.

Although the putative association or “comorbidity” between CB and MH was identified several decades ago, the amount and quality of research addressing how or why they may be related remains very limited. Thus, this issue requires future, high quality, and theoretically informed, research attention.

The Association between CB and Psychotropic Medication

Recent population studies have revealed high prevalence of psychotropic medication use in adults with ID. Henderson et al. [59] found a 49.1% prevalence rate of psychotropic medication use with a prevalence rate of antipsychotic drug use of 23.2%. Similarly, Sheehan et al. [23•] found a 49% prevalence of psychotropic medication use with 21% of participants prescribed with antipsychotic medication. These studies used population-based samples, but identified their participants from primary care services. Sheehan et al. [23•] suggest they may have over-estimated prevalence of prescribing due to difficulties identifying adults with mild ID from GP records. Bowring et al. [60] considered prevalence of psychotropic medication use from a population sample identified from multiple routes, not primary care. In this study, the use of psychotropic medication was 37.73% with 21.89% prescribed antipsychotic medication [60].

Research has indicated that individuals with ID and CB are prescribed with more psychotropic medications than those without CB [60–67], despite little evidence of clinical benefit [68–70] where mental health issues are not present. There are significant side effects of these medications with weight gain, somnolence, metabolic syndromes, and behavioural impacts being reported [66, 70–74]. High rates of psychotropic

medication use (49% [23]; 38% [60]) are a major issue for people with ID and CB, and medication reduction should be a priority area for services.

A Revised Framework Model for CB

Hastings and colleagues' framework for organising the more robust findings in the research literature about the development and maintenance of CB [14••] was written 6 years ago. Thus, we have returned to this pragmatic framework to consider how more recent research findings may need to be incorporated.

Firstly, given recent research on vulnerability factors, we have extended the list of potential correlates, and presented these within a biopsychosocial framework (Figure 2).

Secondly, given Bowring et al.'s [3••] exploration of combining correlates/risk factors, we have also represented this in Figure 2 to emphasise that individuals are likely to be exposed to multiple vulnerability factors. The inclusion of this recognition of multiple factors acting together also highlights some questions for future research. It may be that some risk factors combine to incrementally add to the risk of CB, but some risk factors might only contribute to the development of CB in the presence of other risk factors (i.e., an interaction) [75]. Research on combining risk factors is important as it should lead to the development of clinical tools that help to assess and understand individual risk and thus inform preventative intervention.

Thirdly, we have added positive automatic reinforcement to maintaining processes, alongside pain, indicating CB can be maintained by internal reinforcement as well as environmental reinforcement by other peoples' responses (such as through attention, tangible, or escape contingencies).

Fourthly, we represented the additional use of psychotropic medication as an outcome of CB and have included the effects of psychotropic medication as feeding back into additional vulnerability for CB. The physical and behavioural side effects described above [66, 70–74] may also have a cyclical impact on biological vulnerabilities for CB, hence we have included a feedback loop into biological vulnerability factors.

Discussion

Within this paper, we have presented recent research on the prevalence and correlates of CB in adults with ID. There has been some consistency in the prevalence of CB in recent population studies for adults with ID [1•, 2, 3••]. Further research is required in population samples that additionally examines prevalence of specific CBs using classification tools with clear, operational definitions of CB.

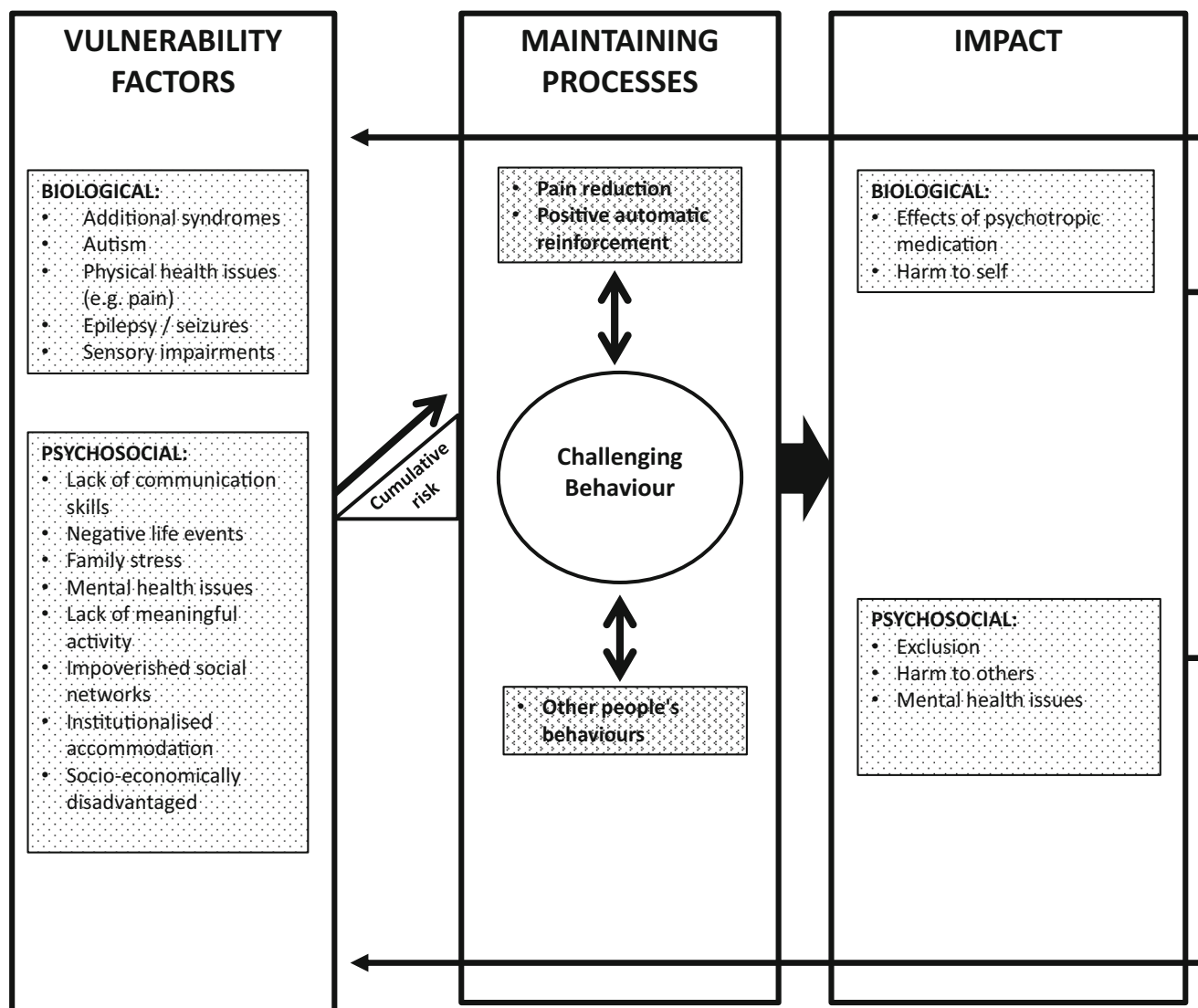


Fig. 2 A revised (building on Hastings et al. 2013) framework for understanding challenging behaviour. Adapted with permission from the International Journal of Positive Behavioural Support

Understanding correlates of CB is important for services to target interventions on vulnerability factors, such as developing communication pathways for adults with communication impairments. There has been a lack of robust research on correlates in population samples and even less investigation into correlates of specific CBs. Further longitudinal studies are required to investigate risk factors of adults with ID developing CBs. It is likely that the risk of CB will increase with multiple risk factors present. From future research, risk tools can be developed to identify adults who should be prioritised for services and understand factors to be tackled in preventative service models.

The relationship between MH, CB, and the subsequent increased likelihood of psychotropic medication use was described. It was concluded that the relationship between CB and MH is not yet fully understood, but potentially bi-directional. Further, theoretically informed research is needed in

population samples to investigate the interplay between MH and CB and approaches to reduce medication use in adults with ID.

Conclusions

The prevalence of CB may be approximately 1 in 5–6 adults with ID known to services, and can have a major impact on quality of life. Interventions for CB and MH need to consider relevant strategies that tackle vulnerabilities, maintaining processes, and impact factors for adults with ID as outlined in the revised CB framework model. Interventions will, therefore, need to focus on multi-element responses [34, 35, 36]. Future development of tools that consider the cumulative impact of risk factors will be very helpful in designing preventative intervention models. The prescribing of psychotropic

medication to manage CB, where there are no MH issues, is common and given the lack of evidence for effectiveness should be reviewed in individual cases [76].

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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