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Rethinking Language: From ‘Challenging Behaviour’ to ‘Behaviours That Challenge’

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17th October 2025

IASSID 5th Asia-Pacific Congress

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Outline of Presentation

- The aim of this presentation is to give you an insight into the use of the term ‘challenging behaviour’.
- The objectives are to provide an outline of:
 - Background to scoping review
 - Aim
 - Scoping review methods
 - Specific Findings
 - Conclusions

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Background

- Challenging behaviour is defined as behaviour ‘of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion’ (Royal College of Psychiatrists 2016).
- These behaviours are often categorised into internalising (focused on self) and externalising (occurring in interactions with others or the environment) and may include hitting, kicking, spitting, throwing things, self-harming, self-injury, biting, scratching, trichotillomania, damaging the environment or clothing, screaming, pica and smearing (Emerson and Einfeld 2011).
- For those with intellectual disability, who are autistic or both, difficulties in understanding and using language can make it difficult to communicate needs effectively. It is thought that behaviours that challenge are more frequent among autistic children than among children with intellectual disability with a prevalence estimated from 56 to 94% (Rattaz *et al.* 2018).

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Scoping review

- **Aim of this presentation** - The aim of this presentation is to explore the use of the term ‘challenging behaviour’ and/or alternative terms.
- **Aim of Scoping review** - to explore the factors that may lead to development of behaviours that challenge and prevention and management of crisis situations among CYA with disability (more specifically intellectual disability and autism).
- **Design** - Guided by the PRISMA Extension for Scoping Review checklist (Tricco *et al.* 2018) and Arksey and O’Malley’s (2005) scoping review method.
- **Identification of studies** - Peer review searches within online databases: **EMBASE (Elsevier), CINAHL (EBSCO), MEDLINE (EBSCO), PsycInfo (EBSCO) and Web of Science (Clarivate)** were conducted for publications between 2014 and 2024.
- **Search terms** - A search that identified index terms, relevant synonyms and additional keywords using key terms and descriptors was undertaken. Included terms were ‘autistic’ OR ‘intellectual disability’ AND ‘situational/personal crisis’ AND ‘child/young adult’ AND ‘challenging behaviour’.

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Inclusion criteria

Criteria	Description
Population	Population of interest are children and young adults with disability, specifically autism and/or intellectual disability which may be accompanied by a mental illness.
Concept	The concept of interest is the factors that lead to development of behaviours that challenge and prevention and management of crisis situations.
Context	The context is that many of these children and young people demonstrate behaviours that challenge possibly due to mental health related issues, stressors related to school, family life or other issues. Note: Studies that focus on young people who have mental illness only are excluded.
Study design	Study designs for inclusion are review articles, editorials, guidelines, quantitative and qualitative research designs, grey literature.

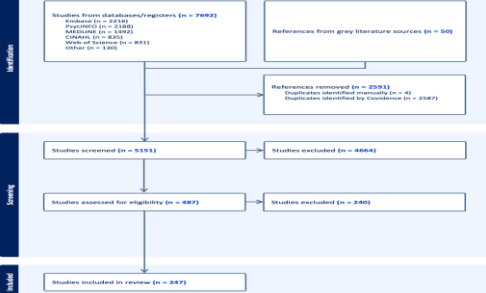
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PRISMA Flow Diagram



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graph TD
    subgraph Identification
        A["Studies from databases/registers (n = 7002)  
Embase (n = 2044)  
CINAHL (n = 2582)  
MEDLINE (n = 2402)  
Web of Science (n = 602)"]
        B["References from grey literature sources (n = 500)"]
        A --> C["Studies screened (n = 7502)"]
        B --> C
    end
    subgraph Screening
        C --> D["Studies excluded (n = 4504)"]
        C --> E["Studies assessed for eligibility (n = 2502)"]
    end
    subgraph Eligibility
        E --> F["Studies excluded (n = 2460)"]
        E --> G["Studies included in review (n = 2462)"]
    end
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Data Extraction and Analysis

- Key findings were extracted and pooled into Microsoft Office Excel.
- A thorough synthesis of findings was developed using sub-headings.
- From this information, a set of themes (aligned with the review aim) was generated that represents the findings.
- Grading evidence/quality appraisal - A total of 40 studies, representing 20% of the total database identified studies, were randomly selected.

Type of paper	Number
Original Research Articles	188
Commentary	7
Editorial	1
Clinical guidelines	13
Grey Literature – reports, briefs, website papers, non-academic articles	38

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Key Findings

- In reviewing the literature, the most commonly used phrase was challenging behaviour/s.
- Interestingly, much of the literature failed to define what was meant by the term used.
- Therefore, the appropriateness of the terms adopted in the reviewed literature could not be established.
- However, an assessment of the terms adopted in papers was undertaken.
- A total 143 of the 247 papers adopted terms to describe challenging behaviour/s/behaviours that challenge, 46 of which provided definition for the term.

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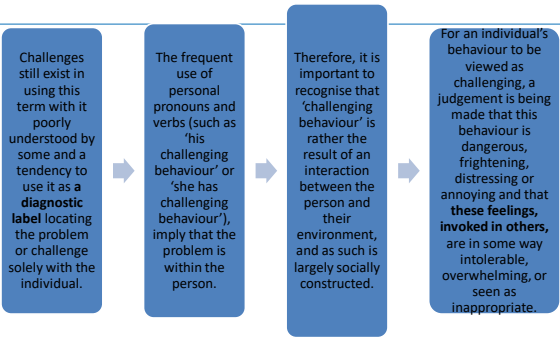
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Term Identified	Frequency
Challenging behaviour/s	n=45
Behaviour/al problems	n=33
Problem behaviour/s	n=22
Behaviours that challenge	n=15
Disruptive behaviour/s	n=12
Behaviours of concern/s	n=6
Behavioural disturbance/s	n=2
Behaviour/al difficulties	n=1
Difficult behaviour/s	n=1
Behaviour/al dysregulation	n=1
Disruptive symptoms	n=1
Distressed behaviour	n=1
Unpredictable behaviour	n=1
Irritability	n=1
Conduct problems	n=1

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Key Points



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Recommendations

- Rather than focusing on behaviour as a problem located solely within the individual, it was suggested that services and carers should adopt the principles of promoting positive behavioural development, reducing the frequency of circumstances in which damaging behaviour can occur, and maintaining a good quality of life for the person despite continuing behavioural difficulties.
- The impact on others, and therefore the characteristics of the observer, should be incorporated in the application and understanding of the term.
- The emphasis on challenging behaviour or alternative terms needs to see the responsibility for change being with the systems around the individual.
- Individuals are central to the language used to describe/label.

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Conclusion

- While challenging behaviour is the most frequently cited term within the literature, there is inconsistency in use of language.
- It is evident that language used can shape individuals' thoughts, beliefs and emotions and can influence wider society (Chan et al., 2012).
- Therefore, taking cognisance of the NICE guidelines (NICE 2015) and the NDA guidance on disability language and terminology (NDA 2022) and what is deemed acceptable person-centred terminology by individuals, **the term 'behaviours that challenge' is preferred as an alternative.**

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Full Report

Doyle C., Cleary M., Eustace Cook J., Fleming S., McMahon M., Sheerin F., Moore K. (2024). *Literature Review on the Factors that Lead to Behaviours that Challenge and Prevention and Management of Crisis Situations among children and young adults (CYA) with disability.*

Literature Review on the Factors that Lead to Development of Behaviours that Challenge and Prevention and Management of Crisis Situations among Children and Young Adults (CYA) with Disability - National Disability Authority

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Acknowledgements

- The Project Team
- TCPHI/TRICC
- Funded by National Disability Authority

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Thank You
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