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

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# Acronyms

|  |  |
| --- | --- |
| ABA | Applied Behaviour Analysis  |
| ABI | Antecedent-based Interventions |
| ACT | Acceptance and Commitment Therapy |
| AIM HI | An Individualised Mental Health Intervention |
| ASD  | Autism Spectrum Disorder  |
| BBTP | Building Bridges Triple P |
| BFDS | Brief Family Distress Scale  |
| BPT | Behaviour Parent Training |
| CAMHS | Child and Adolescent Mental Health Services  |
| CAMHS-ID | Child and adolescent mental health services- Intellectual Disability  |
| CASP | Critical Appraisal Checklists |
| CBD | Cannabidiol  |
| CBIS | Cognitive Behavioural/Instructional Strategies |
| CBT | Cognitive Behavioural Therapy  |
| CBT-CI | Cognitive Behavioural Therapy – Challenging Insomnia |
| CCAT | Crowe Critical Appraisal Tool |
| CD | Carmel Doyle |
| CETRs | Care, Education and Treatment Reviews  |
| C-HOPE | COMPASS for Hope |
| C-SSRS | Columbia Suicide Severity Rating Scale  |
| CYA | Child and young adult/children and young adults  |
| ED | Emergency Department  |
| EI | Early intervention |
| ER | Emotion regulation |
| ERT | Emotion-Regulation Training  |
| ESDM | Early Start Denver Model |
| FAUT-E | Frankfurter Autismus-Elterntraining |
| FGA | First-generation antipsychotics |
| FBA | Functional Behavioural Assessment |
| FBT | Function-based Treatment |
| FCT | Functional Communication Training |
| FMBEAP | Family-based Management of Behavioural Excesses of Autism Program  |
| FS | Fintan Sheerin |

|  |  |
| --- | --- |
| GP | General Practitioner |
| HSE | Health Service Executive |
| ID | Intellectual Disability  |
| IPPN | Irish Primary Principals’ Network  |
| IYPT-DD | Incredible Years Parent Training For Children with Developmental Disabilities |
| JEC  | Jessica Eustace Cooke  |
| KM | Katie Moore |
| MAPS | Mindful Awareness for Parenting Stress |
| MBPBS | Mindfulness-based Positive Behaviour Support |
| MBSR | Mindfulness-based Stress Reduction |
| MBW-P | Mindfulness-based Well-Being Course for Parents |
| MC | Michelle Cleary |
| MM | Martin McMahon  |
| NAC | N-acetylcysteine  |
| NASS | National Ability Supports System |
| NCSE | National Council for Special Education  |
| NDA | National Disability Authority |
| NHS | National Health Service |
| NI | Naturalistic Intervention |
| NICE | National Institute for Clinical Guidelines  |
| PBS | Positive Behaviour Support |
| PCIT | Parent–Child Interaction Therapy  |
| PEP | Parent Education Programme |
| PEERS | Program for the Education and Enrichment of Relational Skills |
| PFI | Positive Family Intervention  |
| PII | Parent-Implemented Intervention |
| PP | Predictive Parenting  |
| PT-F | Parent Training Program |
| PTR-YC | Prevent-Teach-Reinforce-for-Young-Children |
| RCT | Randomised Control Trial |
| RT | Regulating Together |
| RUBI | Research Unit on Behavioural Interventions |
| SF | Sandra Fleming  |
| SGAs | Second-generation antipsychotics  |
| SPD | Sensory processing dysfunction |
| SST | Social Skills Training |
| SSTP | Stepping Stones Triple P |
| STAMP | Stress And Anger Management Program |
| START  | Systemic Therapeutic Assessment, Resources and Treatment |
| STP-PreK | Summer Treatment Program For Pre-Kindergarteners  |
| TCD | Trinity College Dublin  |
| UAE | United Arab Emirates |
| UK | United Kingdom |
| USA | United States of America  |
| VS | Visual Supports |

# Statement on language

In this report the operational term ‘children and young adults (CYA) with disability’ refers to children and young adults up to the age of 24 with autism and/or intellectual disability (ID) which may be accompanied by a mental illness.

Autism spectrum disorder (ASD) refers to any one of a group of disorders with an onset typically occurring during the preschool years and characterised by varying but often marked and persistent deficits in social communication and social interaction, including difficulties with social-emotional reciprocity, nonverbal communication behaviours, and social relationships, along with restricted and repetitive patterns of interests, behaviours, and/or activities.1

For the purpose of this report, the term autism/autistic will be used instead of autism spectrum ‘disorder’, in keeping with the preferred language and terminology identified by the National Disability Authority (NDA).2

Intellectual disability (ID) means a significantly reduced ability to understand new or complex information and to learn and apply new skills. This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child’s health conditions or impairments but also and crucially on the extent to which environmental factors support the child’s full participation and inclusion in society.3

For ease of understanding one term has been adopted throughout this report and that is ‘behaviours that challenge’. However, there are many phrases and terms used interchangeably within the literature. The term ‘behaviours that challenge’ here is not intended as a label used to describe people who display it, but rather to describe the effect of the behaviour on those around the person, as it is them who are ‘challenged’ by the behaviour.

The term ‘crisis’ is also referred to throughout the document. ‘Crisis’ can have different meanings depending on the persons perception of an incident, setting or circumstances and can be defined as a subjective experience of an event or situation as an intolerable difficulty that exceeds the persons current resources and coping mechanisms.4 It also refers to an acute disruption of psychological homeostasis in which usual coping mechanisms fail and there is evidence of distress and functional impairment.5

For further information on disability-related language and terminology, please refer to the NDA’s Advice Paper on Disability Language and Terminology.2

# Executive summary

## Background

Behaviours that challenge is a term often used interchangeably with challenging behaviour. While behaviours may be a challenge to services, teachers and educators, family members or carers, it may serve a purpose for children and young adults (CYA). Whatever the reason for behaviours that challenge, it is important for the individual, and those around them, that their needs are understood and addressed. CYA who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems may be more likely to develop behaviours that challenge.6 Many families caring for young people with complex and sometimes challenging needs can find things difficult and crisis situations arise with behaviours having a considerable impact on CYA and their families.7 Multiple factors are likely to underlie behaviours that challenge, what they communicate and the possibility of crisis. Hence, understanding what leads to the development of and prevents behaviours that challenge, and crisis situations is paramount. Therefore, this scoping review of the published literature explores the factors that may lead to development of behaviours that challenge and prevention and management of crisis situations among CYA with disability.

## Methods

A scoping review methodology guided by Arksey and O’Malley’s scoping review framework was adopted to address the aim.8 This involved five key steps: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarising, and reporting the results.

## Key findings

It is clear there are many factors identified that are associated with behaviours that challenge with several attributed to parental behaviour and stress, mental health issues, poor sleep and poor social skills. Other attributable factors relate to communication difficulties, poor feeding/dietary habits, environmental factors, generally feeling unwell, sensory processing difficulties, transitions and escape. Lesser noted factors concern age, gender, diagnosis of ASD and altered neuronal activity.

Behaviours that challenge are evidenced as factors that may also lead to crisis occurring when usual coping mechanisms fail and there is evidence of distress and functional impairment.5 Key factors include parental stress and depressive symptoms impacting on family functioning. CYA experiencing suicidal thoughts is also a possible predictor of crisis. Lack of access to support services and difficulty navigating these services if available is also a challenge for CYA with disability and their families. Unsurprisingly, a portion of crisis situations present out of hours or at weekends when access to services is extremely limited. The clear negative impact of behaviours that challenge on the family unit is significant and often resulting in out-of-home or emergency placement.

Several nonpharmacological interventions exist with the aim of improving or mediating behaviours that challenge, in turn improving family functioning and reducing parental stress. A total of 98 papers explored specific interventions that can be used in either community, school, residential or respite settings. Multicomponent interventions using a variety of techniques are widely adopted9 and the importance of providing interventions and support to strengthen parental mental health and family functioning is noted.10 As parents are the primary person using most of the interventions, parent implemented interventions (PII) are largely the focus of all papers. What is clear in the first instance is the need for non-pharmacological interventions to be explored that may consider both physical and environmental factors for de-escalation of behaviours that challenge prior to prescription of pharmacological interventions.11 Many of these interventions comprise behavioural education elements.

Pharmacological management of behaviours that challenge is evident in the literature also, although many pharmacological interventions are not licensed for use with children and therefore objective data is limited. It is also worth noting that in many instances, multiple or combination interventions are used whereby a non-pharmacological intervention is also being used alongside pharmacological management options.

Crisis situations are traumatic for both CYA with disability and their families. While there are clear models and frameworks that support crisis prevention, these require consistent implementation and evaluation along with multi-disciplinary resources. While Child and Adolescent Mental Health Services (CAMHS)12 and Child and Adolescent Mental Health Services – Intellectual Disability (CAMHS-ID)13 are national specialist services there appears to be no specific model or framework in place in the Irish context that addresses CYA with disability and behaviours that challenge.

## Conclusion

This scoping review shows the importance of understanding the impact of behaviours that challenge on CYA with disability and their families. It also demonstrates the gap in evidence about how crises occur and how crisis intervention impacts the family unit, family functioning and the resilience of the family. It is clear there is no simple or easy solutions to preventing and managing crisis situations. The review was comprehensive in nature identifying a broad range of literature exploring factors that lead to development of behaviours that challenge and prevention and management of crisis situations among CYA with disability. It is expected this scoping review will provide direction for researchers, but in particular inform policy and practitioners working in the field.

Recommendations arising from this scoping review of the literature include:

* A review of respite care as an intervention for CYA with disability in prevention or management of behaviours that challenge and in prevention of crisis.
* Examination of the current CAMHS and CAMHs ID model of service in promoting an integrated care approach and in particular access to these services.
* Development of improved community-based supports aimed at preventing crisis.
* Development and implementation of a crisis intervention plan with CYA, family and key multidisciplinary stakeholder involvement.
* Examination of the use and availability of emergency residential placements if required.
* Examination of the National Action Plan for Disability Services and implementation programme for this.
* Further research relating to:
	+ Interventions that may be used in preventing and managing behaviours that challenge e.g. sensory rooms, use of Cubbies, movement breaks, use of headphones, weighted blankets, regulation stations and communication systems.
	+ Interventions focusing on the various transitions in the lives of CYA with disability e.g. transitions such as those associated with pubertal changes and the related sensory challenges, sexuality and sexual identity changes.
	+ Development and implementation of longitudinal studies that assess the long-term effect of interventions.
	+ Pharmacological interventions aimed at preventing and/or managing behaviours that challenge and their impact on CYA.
	+ Research studies that explore the CYA and family voice in relation to their experiences of interventions.
	+ Exploration of how crisis occur and how crisis intervention impacts the family unit, family functioning and the resilience of the family.

#  Introduction

Behaviours that challenge is not a diagnosis per se and is a term used in this review to indicate that although such behaviour is a challenge to services, teachers and educators, family members or carers, it may serve a purpose for CYA with disability. The literature is diverse in terminology with phrases such as ‘challenging behaviour’ and ‘behaviours that challenge’ used interchangeably throughout. 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’.14These behaviours are often categorised into internalising (focused on self) and externalising (occurring in interactions with others or the environment). There are many examples of such behaviours that may include hitting, kicking, spitting, throwing things, self-harming, self-injury, biting, scratching, trichotillomania (pulling hair out), damaging the environment or clothing, screaming, pica and smearing.6 Challenging behaviour is the result of the interaction between underlying vulnerabilities which may be biological (sensory or physical health problems) or psycho-social (such as poor communication skills or social networks), serving a function for the individual, and have a social impact.15 All behaviour is deemed a form of communication, with a reason and purpose. For those with intellectual disability (ID), autism or both, difficulties in understanding and using language can make it difficult to communicate needs effectively.

While behaviours may be a challenge to services, family members or carers, it may serve a purpose for CYA. Whatever the reason for behaviours that challenge, it is important for the individual, and those around them, that their needs are understood and addressed. Careful analysis of behaviour can often reveal what is going on, to better understand what the person is trying to communicate.16

Prevalence rates across populations are difficult to determine with approximate rates for behaviours that challenge across the lifespan ranging between 5–15% in educational, health or social care services for people with an ID.17 One UK study determined the prevalence of behaviours that challenge at 18.1% of the total study population (adults) with stereotypy, the persistent repetition of an act, the most frequent type of behaviours that challenge.18 Furthermore, communication difficulties and severe to profound ID were most systematically related to the presence of behaviours that challenge.

It is thought that behaviours that challenge are more frequent among autistic children than among children with ID with a prevalence estimated from 56 to 94%.19 In Ireland, 45,068 children aged 18 years and under were registered on the National Ability Supports System (NASS) in 2022 with 63% of children presenting for services with a primary diagnosis, 39% (11,416) with autism and a further 5% with a secondary diagnosis of autism while 24% (6992) has a diagnosis of ID.20 With gaps in information for half of those registered on the NASS, it is estimated that the figures are likely to be far higher for both diagnosis of autism and ID. Since 2018 the figures have increased, and NASS suggest that approximately 40% of school leavers (18+years) seeking day services are autistic with around 1,700 adolescents profiled each year for adult day services. Additionally, an increase in prevalence of autism may be attributed to better access to diagnostic practices and increased public and professional awareness.21 Increased prevalence may also reflect changes in the definition of autism from a narrowly defined population to a wider and more inclusive spectrum.22

Young people who have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems may be more likely to develop behaviour that challenges.6 The behaviour may appear in only certain environments, and the same behaviour may be considered challenging in some settings or cultures but not in others. Some care environments increase the likelihood of behaviour that challenges such as those with limited opportunities for social interaction or meaningful activity, lack of choice or excessive noise.7Sudden and unpredictable upsurges in behaviours can leave families exhausted, affecting mood and wellbeing.

Many families caring for CYA with complex and sometimes challenging needs can find things difficult and crisis situations arise with behaviours having a considerable impact on CYA and their families.7 ‘Crisis’ can have different meanings depending on the persons perception of an incident, setting or circumstances and can be defined as a subjective experience of an event or situation as an intolerable difficulty that exceeds the persons current resources and coping mechanisms.4 It also refers to an acute disruption of psychological homeostasis (balance or equilibrium) in which usual coping mechanisms fail and there is evidence of distress and functional impairment.5

Reasons for crisis can be multifaceted. However, in Ireland, access for children to primary care and community supports is unequal and can be untimely and geographically dependent resulting in long delays in accessing assessment of need which can hinder the receipt of services for the child.23,24 While services can be sought at primary care level, an Assessment of Need will formally identify a child’s health needs and what services are required to meet those needs.25 There is also significant levels of unmet need for respite, with 75% of all families of children with disability getting no respite care.23

The demand for emergency residential placements appears to be increasing with numbers of CYA with intensive support needs on waiting lists rising.23While statistics are vague, in 2019 the Health Service Executive (HSE) had listed 24 children as emergencies in need of residential placement.23 The majority of these were teenage males with a dual diagnosis of mental health issues and/or autism alongside an ID, manifesting extreme behaviours that challenge, and their family situations had broken down completely or were on the point of breaking down.23 Experiencing high levels of stress associated with the challenges of caring for CYA with disability and associated behaviours that challenge while trying to navigate support systems often lends itself to difficulties. For many families, a buildup of stressors can result in crisis, and it is a common reason for residential placement with associated high costs.23 While these placements are aimed at being temporary in nature, often they lead to more long term permanent residential placements.23

Multiple factors are likely to underlie behaviours that challenge and the possibility of crisis. Therefore, understanding what factors may lead to development of behaviours that challenge and what prevents crisis situations is paramount. Exploring the range of supports offered and how these evidence-based interventions are implemented is essential. Thus, this literature review is important in informing the field and establishing a basis for further research.

**Aim:** To produce a report based on the literature on the factors that lead to development of behaviours that challenge and prevention and management of crisis situations among CYA with disability.

## Research questions

The following research questions will be addressed:

1. What are the factors that may lead to the development of behaviours that challenge in children and young adults with disability?
2. What are the existing supports provided or used by service providers, families and carers and children and young adults with disability to prevent and manage behaviours that challenge (for example early intervention, respite care, in school supports, building family resilience, teaching the young person coping strategies etc.)
3. How effective are these supports in preventing and managing behaviours that challenge and preventing family breakdown and other crisis situations?
4. What is the evidence (if any) on the cost effectiveness of evidence-based preventative and management practices in relation to behaviours that challenge in this group?
5. What is the evidence (if any) of positive outcomes where the young person is transferred to residential care. For example, is there any evidence of less challenging behaviour, restoration of relationship with the family, return home etc.?

# Methodology

## Study design

A scoping review methodology guided by Arksey and O’Malley’s scoping review framework8 was adopted to address the aims. This involved five key steps: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarising, and reporting the results. In ensuring transparency, the review was also guided by the PRISMA Extension for Scoping Review checklist26 which ensures methodological rigour and reporting of the key elements of a scoping review according to acceptable standards.

## 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 January 2014 and February 2024. The aim of the search strategy was to source publications significant to the topic area and was developed to identify the most current and relevant articles for this scoping review. A search that identified index terms, relevant synonyms and additional keywords using key terms and descriptors was undertaken.

Included terms were concepts ‘autistic’ AND/OR ‘intellectual disability’ AND/OR ‘situational/personal crisis’ AND/OR ‘Challenging behaviour’. To increase the sensitivity of the search a proximity operator was applied in concept one, ensuring that results are focusing on CYA. The second concept also applied a proximity operator to increase the precision of results focusing on crisis from personal, social, family and school environments. It is important to note that there was no focus on the description of how the challenging behaviour presents, but on the fact the individual/family feels that they are in a crisis or a critical or emergency situation. The final search combined both index terms and keywords, forming a comprehensive search based on each concept, and created the basis of the final search. Each database was chosen for its relevance to the subject area and to ensure a wide coverage of the literature. A manual review of reference lists for selected papers was also conducted. Grey literature was also included following searches of grey database and web searches (see Appendix 1 for detail on concepts).

The eligibility criteria for inclusion were designed using the Joanna Briggs manual of scoping review methodology, consisting of Population, Concept, Context, and Study Design27(see Table 1).

**Table 1. Population, concept, context, and study design**

|  |  |
| --- | --- |
| **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.  |
| Settings | There were no restrictions placed on study settings.  |
| Language | English language only  |
| Year | January 2014 – February 2024 (10-year span) |

Once searching was completed, all results were exported into Covidence (a web-based collaboration software platform that streamlines the production of literature reviews). A two-step screening process was used to ensure consistent application of criteria while managing a high number of articles. Following deduplication, authors (CD, MC, KM, FS, MM, SF) independently reviewed titles and abstracts applying the inclusion criteria. Papers retained for full text screening were reviewed in parallel by the same authors and discrepancies resolved through consensus.

**Statement on Quality**

The quality assessment in this scoping review aimed to evaluate the methodological rigor and reliability of the included studies. The assessment was conducted using established critical appraisal tools:

1. Critical Appraisal Checklists (CASP)28: Used for assessing systematic, scoping and literature reviews, randomized controlled trials (RCTs), experimental studies, and qualitative research designs.
2. Crowe Critical Appraisal Tool (CCAT)29: Applied to all other research designs.

A total of 40 studies, representing 20% of the total database identified studies, were randomly selected using the Microsoft Excel randomisation function for the quality assessment. The studies were categorised by design and appraised by two independent reviewers. Each reviewer employed the appropriate critical appraisal tools to evaluate the methodological quality of the studies. Reviewer 1 (MC) assessed evaluation studies (n=4), RCTs and experimental studies (n=6) and cross-sectional and descriptive studies (n=9). Reviewer 2 (KM) assessed qualitative studies (n=5), systematic reviews (n=5), scoping and literature reviews (n=5) and ‘other' research designs (n=6). The quality assessment revealed a broad range of methodological rigor across the included studies. Systematic reviews and RCTs generally demonstrated higher quality, reflecting well-established protocols in these designs. In contrast, cross-sectional, descriptive, and other varying research designs exhibited greater variability, highlighting opportunities for improvement in methodological rigor and reporting standards.

**Data extraction and analysis**

The key findings of all the relevant articles, reviews and grey literature was extracted and pooled into Microsoft Office Excel for ease of management. Thereafter, a thorough synthesis of findings was developed using sub-headings that included: date and year of publication, name of authors, name of journal, title, aim of study or review, sample, methodology, summary of findings, conclusions and limitations. From this information, a set of themes was generated that represents the findings and respond to the research questions. These findings were categorised by the similarity in meaning and presented in narrative form as overall themes (See Appendix 2 for summary of papers and associated themes).

# Results

The database search yielded 7692 articles and after deduplication, 5101 publications were carried forward. Title and abstracts were screened resulting in a total of 442 articles referred for full text screening. Following the full text review, 202 studies were carried through for data extraction. A search of the grey literature was conducted to identify resources outside of the academic literature. The initial search of the grey literature identified 50 additional sources. Following a review of the sources and the application of the inclusion criteria, 45 grey literature papers were included for data extraction. The final scoping review sees 247 papers included in the synthesis. A PRISMA diagram for scoping reviews is presented below (Chart. 1).

In summarising the published evidence, a thematic analysis of the literature was conducted using Braun and Clarke’s30 six phase analytical process. The themes presented reflect the aim of the scoping review, to summarise the factors that may lead to development of behaviours that challenge and prevention and management of crisis situations among CYA with disability. Findings are framed using the five research questions identified earlier.

## Study characteristics

In total 247 publications were included in the review. Of the included literature one study had a global focus, another was from both Ireland and the United Arab Emirates (UAE). The remaining papers originated from 33 countries. The bulk (44%) of the literature was published in the United States of America (USA) (n=108), the United Kingdom (UK) and Australia had the second and third largest volume of publications n=36 and n=20 respectively. A breakdown of the origins of the papers in presented in Table 2.

**Chart 1. PRISMA-ScR diagram**



**Table 2. Origins of reviewed publications**

|  |  |
| --- | --- |
| **Country of Origin** | **Number of titles** |
| Argentina | 1 |
| Australia | 20 |
| Austria | 1 |
| Belgium | 2 |
| Canada | 16 |
| Germany | 1 |
| Global | 1 |
| Hong Kong | 2 |
| India | 1 |
| Indonesia | 1 |
| Iran | 1 |
| Ireland | 11 |
| Ireland and UAE | 1 |
| Israel | 3 |
| Italy | 12 |
| Japan | 1 |
| Kenya | 1 |
| Korea | 1 |
| Netherlands | 1 |
| New Zealand | 1 |
| Pakistan | 1 |
| Portugal | 1 |
| Qatar | 1 |
| Romania | 1 |
| Saudi Arabia | 1 |
| Singapore | 1 |
| South Africa | 1 |
| South Korea | 1 |
| Spain | 5 |
| Switzerland | 1 |
| Taiwan | 7 |
| Turkey | 2 |
| UAE | 1 |
| UK | 36 |
| USA | 108 |
| Total  | 247 |

Of these studies, the majority 76.1% (n=188) were original research articles, 5.2% (n=13) were guidelines, 2.8% (n=7) were commentary papers, 0.4%(n=1) was an editorial and 15.3% (n=38) were other kinds of grey literature publications including reports, briefs, non-academic articles and website articles.

Measures used to assess the findings in the reviewed material were diverse and varied between papers and across parent and child outcome measures, and included assessments of autism severity and intellectual functioning, behavioural inventories, stress, functioning and coping indices, and sleeping and eating related assessment scales. A total of 142 measurement tools were used in the reviewed publications and an overview is presented in Appendix 3.

## Study populations and sampling

The population groups included in the research studies were CYA with autism and/or ID which may be accompanied by a mental illness, parents and caregivers of these CYA, medical professionals and teachers and education providers engaging with this cohort. In all, a total sample size of 30,972 was reported across the studies and a breakdown per population group can be found in Table 3. In addition, a total of 236,577 medical records including emergency room notes were reviewed across the included publications.

**Table 3. Sample size per population group**

|  |  |
| --- | --- |
| **Population group** | **Total sample** |
| Children and young people | 17,536 |
| Parents and caregivers | 10,398 |
| Teachers and education staff | 1388 |
| Medical professionals | 573 |

# Findings

## Terminology and definitions

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 149 of the 247 papers adopted terms to describe behaviour that challenges, 46 of which provided definition for the term. The most frequently cited terms were 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 (n=6), behavioural disturbance/s (n=2), behaviour/al difficulties, difficult behaviour/s, behaviour/al dysregulation, disruptive symptoms, distressed behaviour, unpredictable behaviour, irritability and conduct problems were each referenced once. Some papers used a few terms, interchanging between behaviour/al problems, problem behaviour/s, destructive and disruptive behaviours and behaviours that challenge and challenging behaviour/s.

The term challenging behaviour has been in use for at least three decades and was aimed at bringing about a shift in perception and practice that would emphasise severely problematic or socially unacceptable behaviours as posing a challenge to carers, professionals and services.31 Emerson initially defined challenging behaviour as: Culturally abnormal behaviour(s) 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 use of, or result in the person being denied access to, ordinary community facilities.32 The Royal College of Psychiatrists defined ‘challenging behaviour’ very similarly 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.14 Rather than focusing on behaviour as a problem located solely within the individual, it was suggested that services 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. Challenges still exist in using this term with it poorly understood by some and a tendency to use it as a diagnostic label locating the problem or challenge solely with the individual. The frequent use of personal pronouns and verbs (such as ‘his challenging behaviour’ or ‘she has challenging behaviour’), imply that the problem is within the person. Therefore, it is important to recognise that ‘challenging behaviour’ is rather the result of an interaction between the person and their environment, and as such is largely socially constructed. For an individual’s behaviour to be viewed as challenging, a judgement is being made that this behaviour is dangerous, frightening, distressing or annoying and that these feelings, invoked in others, are in some way intolerable, overwhelming, or seen as inappropriate. 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.

There has been some discussion around the use of the phrase behaviours of concern and this phrase is viewed as indicating concern about the human rights of the individual displaying the behaviour. That said, its currency in the literature is minimal with only six of the included papers adopting the phrase.

While challenging behaviour is the most frequently cited term within the literature in this scoping review, there appears to be inconsistency in use of language and where alternative terms are adopted little or no rationale is supplied for using the chosen terms. It is evident that language used can shape individuals’ thoughts, beliefs and emotions and has the ability to influence wider society.33Therefore, taking cognisance of the National Institute for Clinical Guidelines (NICE) guidelines7 and the NDA guidance on disability language and terminology2 and what is deemed acceptable person-centred terminology by individuals, the term ‘behaviours that challenge’ is preferred as an alternative, and this phrase has been adopted throughout this report.

## Research question 1. What are the factors that may lead to the development of behaviours that challenge in CYA with disabilities?

In understanding behaviours that challenge as a possible reason for crisis, it is important to determine what the common factors are that may lead to development of behaviours. Table 4 presents a number of common factors that may lead to development of behaviours that challenge with 89 papers focusing on this concept. These are further explored below.

**Table 4. Common Factors that may lead to development of behaviours that challenge**

|  |  |
| --- | --- |
| **Themes related to development of behaviours that challenge** | **Number of papers**  |
| Feeling unwell | 8 |
| Genetics | 4 |
| Poor sleep/insomnia/tiredness | 15 |
| Poor feeding/dietary habits | 9 |
| Communication difficulties | 8 |
| Environmental factors | 8 |
| Transitions (any) | 9 |
| Mental health issues (e.g. anxiety, depression) | 16 |
| Social attention/poor social skills | 13 |
| Learned behaviour  | 2 |
| Sensory processing difficulties/ overload | 9 |
| Emotion regulation (ER) | 6 |
| Parenting behaviour and stress | 25 |
| Altered neuronal activity | 1 |
| Age | 5 |
| Gender | 1 |
| Diagnosis of ASD  | 4 |
| Escape – seeking to avoid  | 6 |
| Low electrodermal activity | 1 |

Feeling unwell was identified as a factor that may lead to development of behaviours that challenge.34-41 This was related to acute pain36,37,39 for example, exhibiting a reaction to something that hurts such as banging a head on the wall may be expressing that the person has earache.39 Other associations with feeling unwell included epilepsy37 or a general feeling of tiredness.41 Some children experience specific health conditions associated with behaviours that challenge42,43 such as a related psychiatric disorder.42

Genetics as a possible association with behaviours that challenge was identified also34,44-46 with specific aggressive behaviours such as scratching or biting others likely to occur in a genetic condition such as Fragile X.34 Poor sleep, insomnia or tiredness were presented also as factors that may lead to development of behaviours that challenge. 35,38,47-59 Aggressive and stereotyped behaviours were more prevalent in children with more sleep difficulties and sleep difficulties also resulted in problematic mealtime behaviours.49 Furthermore, it was evident that poor sleep was associated with problematic daytime behaviour with children exhibiting higher rates of self-injury, anxiety, hyperactivity, and inattention.52,56 Core symptoms of autism such as repetitive behaviours and difficulty in social reciprocity are also increased in children with poor sleep duration.52 The relationship between sleep quality and social functioning is interconnected and suggested to be bi-directional given poor sleep can increase negative mood and social withdrawal.52 Yet, anxiety can negatively impact sleep onset, duration, and can increase sleep disturbance.56 Interestingly, poor parental sleep quality especially in mothers who have persistently poor sleep, has important associations with resultant increased behaviours that challenge displayed by the autistic child.60

Poor feeding and dietary habits were also identified as potential factors that lead to development of behaviours that challenge46,49,55,61-66 with autistic children at high risk of disordered feeding patterns.62 High food selectivity and specific mealtime behaviour problems, elevated both child and parental stress.46,64,66 Parenting maladaptive feeding strategies in autistic children were found to be a greater stressor than child disruptive behaviour.62 These could include coercive feeding tactics to persuade the child to eat or permissive feeding styles such as indulging the child by preparing only what the child likes to eat.62 The school setting was also a place where mealtime behavioural problems were common in autistic children.63 The presence of sensory stressors such as noise or smells in the classroom was reported as main triggers for mealtime behavioural problems.63 Changes in routine were reported as the other major trigger for mealtime behavioural problems in the classroom such as changes in break-time schedule, or a change in the food item that was sent in their lunch box.63 Interestingly, mealtime behaviour strategies adopted to overcome poor feeding habits also addressed other associated skills such as sharing of food, communication, and mealtime etiquette.63 In one study, the feeding challenge of food selectivity and food refusal such as the way that children relate to food and problems with mealtime routines was found to be more common than mealtime behaviour problems.65 Autistic children appear to have a major predisposition to present with atypical feeding marked by limitations in food repertoire and by the presence of mealtime behavioural problems related to their relationship with food or mealtime routines.65

Additionally, communication difficulties were identified as a factor contributing to the development of behaviours that challenge.35,38,40,42,50,67-69 Autism itself often results in difficulty developing language skills and understanding what is being said to the individual resulting in challenges in non-verbal communication.35 Similarly, CYA with ID also experience associated communication difficulties which can result in negative behaviours as a means of non-verbal communication.67,70,71 Environmental factors such as loud noises, unfamiliar places or spaces were also linked to the possible development of behaviours that challenge.35,37,38,44,46,50,72,73

In the context of transitions as a factor leading to development of behaviours that challenge, this can be related to changes in routine, transitions between activities,35,38,41,45,47,74 more focused on specific transitions such as within the school setting74 or dependent on life stage triggers such as moving house or bereavement.75 Transition relating to changes in family life involving family members or daily routines were also identified.35,45 Changes in daily routines resulted in higher anxiety levels in autistic children.73 Furthermore, when infrequent interventions were required such as visits to healthcare setting for bloods, an increase in agitation was experienced.72

Mental health issues including anxiety and depression as a factor leading to development of behaviours that challenge were highlighted.37,38,40,44,55,76-85 Autistic children often display signs of physical aggression related to their mental health frequently leading to anti-social behaviours such as physical aggressive behaviour towards others and self-injury.80 Additionally, anxiety as a predictor of negative behaviour has been highlighted with autistic children displaying more self-injurious behaviours when meeting the clinical cut off for anxiety using appropriate assessment scales.81 Autistic children are typically unable to communicate their feelings of anxiety and may present with behaviours that you do not typically associate with feeling worried or anxious. These might include tantrums and aggressive behaviour, becoming withdrawn and resisting any interaction with others, complaining of pain or illness, or engaging in repetitive behaviours hurting themselves.83 Development of significant behavioural reactivity including suicidality can occur when communication and behavioural challenges lead to significant stressors such as bullying or social isolation.82 Irritability is also evident as a factor leading to development of behaviours that challenge.86

Social attention and poor social skills were identified as factors leading to development of behaviours that challenge.3 ,36,40,41,57,68,87-92 Social attention via behaviours that challenge is seen as good way of gaining attention, even if perceived negatively.36 Sometimes, autistic children don’t understand other people's social cues or expectations41 and therefore engage in socially inappropriate attention-seeking.87 Poor levels of emotion regulation (ER) were reported in autistic children who had decreased social skills and increased mental health difficulties, with poor social skills a strong predictor of mental health difficulties.88 More specifically, preschool age children were reported to have more social withdrawal problems than school aged children, with associations found between sensory processing dysfunction (SPD) and both externalising and internalising problem behaviours in preschool children.89

Two papers cited learned behaviour as a contributing to the development of behaviours that challenge. For example, to get something, a child may learn behaviours that get them things they want such as food or objects.36 Seeking to avoid things known as escape can also be associated with behaviours that challenge.36,72,73,77,87 Sensory processing difficulties and sensory overload were identified as a possible factors that lead to development of behaviours that challenge also.35,36,57,68,73,86,92,93 At times, autistic children enjoy the feeling certain repetitive behaviours give them such as rocking or humming, despite these being at times deemed socially unacceptable.36,92 In particular, when travelling, sensory processing disorders can be very challenging for parents and a stressful event for the child leading to behavioural problems, such as verbal tantrums and physical tantrums, as well as self-injurious behaviour.93 Under arousal of the sympathetic nervous system measured though electrodermal activity is associated with higher externalising behaviour problems. One study measured child electrodermal activity in a laboratory setting during play and problem-solving tasks through wireless wrist sensors and found that low electrodermal activity predicted higher externalising behaviours.94

Other factors leading to development of behaviours that challenge identified included exhibiting behaviours as a symptom of autism such as altered neuronal connectivity and plasticity in the brain cortex.95 However, it is worth noting that while altered connectivity and plasticity within the brain may be present, not all autistic children would present as this being the primary contributor to behaviours that challenge.95 Age was also identified as a factor associated with development of behaviours that challenge50,57,96 with being younger in age a risk factor for disruptive child behaviour.50,96 The concept of ER was also addressed as a possible factor.41,88,97-100 Emotion dysregulation leading to behaviours that challenge is an impairment in modulating the experience, expression, and intensity of emotions in an adaptable and contextually appropriate manner and relates to significant behavioural and emotional difficulties.99

Parent behaviour and stress as a possible factor that leads to development of behaviours that challenge was most frequently identified.44,97,101-120 When parents are stressed, they may have less cognitive resources to support their child sometimes imposing their own needs above those of the child resulting in behaviours that challenge .97,105,106,114 Autistic children with parents exhibiting signs of stress, are more likely to exhibit internalising behaviour problems such as withdrawal and avoidance and externalising behaviour problems such as aggression and impulsivity.103,107,115,116 Negative parenting behaviours often known as intrusive parenting can result in overwhelming the child with constant stimulation leading to the development of problematic child outcomes.97 Evidently parent behaviour plays a significant role in the expression of disruptive behaviour in young children with autism, more than child clinical characteristics.121

One paper suggested that gender can be a predictor of behaviours that challenge with females having more severe emotion dysregulation than males.122 Having a diagnosis of autism may contribute to the likelihood that children will develop behaviours that challenge with prevalence rates of behaviours that challenge high in this cohort.43,122-124 Children with a previous autism diagnosis are also more likely to exhibit behaviours that challenge specifically, self-injury, aggression and property destruction with severity of autism increasing frequency and intensity of behaviours.43

In summary, it is clear there are many identified factors that may lead to the development of behaviours that challenge with several attributed to parental behaviour and stress, mental health issues, poor sleep and social skills. Other attributable factors relate to communication difficulties, poor feeding, environmental factors, generally feeling unwell, sensory processing difficulties, transitions and escape. Lesser noted factors related to age, gender, diagnosis of autism and altered neuronal activity. When considering all of the factors it is worth noting that those identified may be associated with how autism manifests in the individual and are common in this cohort.19 Furthermore, they are often unmanaged elements of autism leading to eventual display of behaviours that challenge.

### Behaviours that challenge – factors that may lead to crisis

While factors that may lead to the development of behaviours that challenge are identified above, it is important to consider these in the context of possible predictors of crisis or crisis situations for CYA with disability as well. If families experience an upsurge in behaviours that challenge for whatever reason and have difficulty getting support, family functioning can be negatively affected.

A key finding within the literature was that behaviours that challenge was associated with parental stress with the impact of stress on the family evident and understood as a predictor of possible crisis for families. Parental stress appeared to increase with type and severity of child disability,126-128 severity of autism symptoms, adaptive/maladaptive behaviours, sensory processing difficulties, sleeping problems,107,110,117,127,129-137 emotional problems138,139 and challenging feeding behaviours.66 Increased intensity and frequency of behaviours that challenge are predictive of greater parental depression and stress.140

While parental stress as a factor that may lead to development of behaviours that challenge has been considered above, the mutual influence and bi-directional relationship between the psychological wellbeing of mothers and the behavioural wellbeing of autistic children and behaviours that challenge is evident.78,141 Decreased parenting self-efficacy111 and reduced feelings of empowerment112 was seen to increase parenting stress especially when family supports were low. Poor social and family supports with poor family functioning resulted in increased stress also.10,96,114,115,142

Depressive symptoms in parents were also reported143-145 with one paper suggesting single young mothers displaying poor coping skills are at high risk for increased levels of parental stress and poor mental health outcomes.130 Greater burden was experienced by parents whose child had disruptive behaviours and poor sleep patterns.51 One study suggested parents reported high levels of sleep problems themselves which in turn increased their anxiety.144 Feeding is also a daily caregiving activity that can evoke stress with children with feeding difficulties exhibiting more problematic behaviours at mealtime resulting in increased parental stress.64

Stress was also reported by teachers largely associated with children talking about suicidal ideations.71 Furthermore, physical aggression was reported as the most difficult to deal with.71 Additionally, parents often had negative perceptions of school because they had negative experiences and interactions with school personnel.146

Another contributor to stress and possible crisis identified was suicidal ideations.147-150 One study with 183 participants found that approximately 33% of autistic youth transitioning out of school reported experiencing suicidal ideation in their lifetime with a portion of these discussing a previous attempt to self-harm, reported having thought specifically about how they would hurt themselves and some reported an intent to act on thoughts of hurting themselves in the next month.148 Almost 42% of participants in the study met the clinical cut off for depression.148 School aged autistic children and comorbid anxiety disorders represent a particularly vulnerable population to suicidal ideation.149 Presentation to a hospital with self-harm is one of the strongest risk factors for later suicide.149 A large retrospective UK study with 2492 autistic adolescents that routinely gathers data on CYA mental health found that autistic adolescents are at higher risk than the general population of presenting to emergency care with self-harm.151

A common theme was that of presentation to hospital or the emergency department (ED). This could then lead to admission to hospital for inpatient treatment. Examples of reasons for hospital admission included suicidal ideation, aggression with or without homicidal ideation or disruptive behaviour, psychosis, acute mania, and for a major depressive episode.152 Of concern findings in one study suggested that children with ID had more ED visits than those autistic children, whereas, autistic children in specific age groups 7-12 and 13-18 year had more ED visits .153,154 Furthermore, autistic youths with a suicidal ideation or intentional self–inflicted injury were three times more likely to have an associated mild ID.153 Autistic youths aged 0-17 years were 30 times more likely to present to the ED than those without autism of a similar age.155 A proportion of these visits were due to behavioural and psychiatric problems (13%) presenting with externalising behaviour problems or psychotic symptoms requiring admission to either a psychiatric or medical unit.155 More recently, another study indicated that autistic children are 4 times more likely than neurotypical peers to present to the ED, and the number of ED visits in autistic youths has increased over the past 2 decades with many visits related to emotional and behavioural health concerns.82 In Ireland, self-injurious behaviours are one of the commonest reasons why children present to health services causing parents great stress.156

Difficulty navigating the healthcare system and accessing appropriate community supports was often a precursor to the last resort of presenting to the ED, with parents citing their inability to manage risk or contain their child’s behaviour, compounded further by their own experience of burn-out.157 Unfortunately, parents indicate that often the ED is unable to assist in supporting the family to manage behaviours that challenge.157 Interestingly in this study, almost three quarters of presentations happened out of school hours, on weekends or during holiday periods with the crisis event that led to presentation often occurring after a long period of deterioration in the child behaviour.157 This is further supported in other papers where behaviours such as aggression, self-injury and suicidal ideation preceded ED presentation52,158 especially when frequency and intensity of behaviours increased.92 Furthermore, parents' ability to cope with the demands of their child and their resilience may be a possible precursor to seeking emergency supports as many of these families experience poor quality of life.159,160 At times regulation strategies that seem to help the child such as comforting strategies like self-soothing and deep exhalation, are actually deemed maladaptive and socially unacceptable in the family context.160 The negative impact of behaviours that challenge on the family unit is significant with children at higher risk for out-of-home, residential placement.42

Unsurprisingly, repeated presentation for crisis evaluation to EDs were also more likely if the child communicated non-verbally.161 Long waiting times to access CAMHs and lack of understanding by mainstream services may result in crisis presentations.162 One paper suggests the strongest predictor of crisis presentation to ED is those families where a child has a history of aggression, no structured daytime activities and family members in a state of distress.163 Presentation at ED in crisis does not always result in positive outcomes. ED staff require a high degree of understanding and experience of autism to provide the right response and recommendation of services. This is where families get frustrated because those required multi-disciplinary services may not come together quickly.164

As mental health crisis and behaviours that challenge are factors that lead to parental burden113 and given the increased rates of psychopathology in autistic CYA, this cohort are at risk of experiencing a mental health crisis.165 One study described child psychiatrists as having less access to external consultation resources, such as a crisis evaluation centre or other mental health professionals, compared with those caring for youths without autism. Child psychiatrists also expressed concerns about the ability of ED professionals and emergency responders to manage mental health crises among youths in a safe and developmentally appropriate manner, particularly among those with autism.165

Receiving timely and appropriate support for mental health crisis is important for CYA and their families. This is especially true for young autistic people with ID whose needs often labelled as ‘complex’ can reflect a myriad of social, cognitive and behavioural difficulties to which additional mental health difficulties may easily add.166 Crisis as a result of behaviours that challenge can have negative outcomes for both the individual in terms of self-injury, restrictive practices, intensive services, exclusion from community/community supports and social stigma and the family in terms of injury, increased stress, poorer family functioning, unemployment and financial strain.167

In summary it is evident that behaviours that challenge may lead to crisis. Key issues include parental stress and depressive symptoms impacting on family functioning. CYA experiencing suicidal thoughts is also a key predictor. Lack of access to support services and difficulty navigating these services if available is also a challenge for CYA with disability and their families. Unsurprisingly, a portion of crisis situations present out of hours or at weekends when access to services is extremely limited. The clear negative impact of behaviours that challenge on the family unit is significant and often results in out-of-home or residential placement.

## Research Question 2. What are the existing supports provided or used by service providers, families and carers and disabled young people to prevent and manage behaviours that challenge (for example early intervention, respite care, in school supports, building family resilience, teaching the young person coping strategies etc.)

Existing supports for CYA with disability are largely divided into nonpharmacological and pharmacological interventions to mediate or reduce behaviours that challenge, in turn improving family functioning and reducing parental stress. Consequently, the literature surrounding nonpharmacological interventions and how they might benefit CYA with disability and their families are investigated. The total number of papers exploring nonpharmacological interventions was 98 with 21 exploring pharmacological interventions. Some papers solely describe the intervention while others have engaged in pre/post-test intervention studies and discuss effectiveness or impact on the child and family. A variety of outcome measures were adopted in studies determining the effectiveness of interventions and these are summarised in Appendix 3. Other interventions are reported on once, while some may be reported on several times in various papers. Multicomponent interventions using a variety of techniques are widely adopted9,168 and the importance of providing family centred structured interventions and support to strengthen parental mental health and family functioning is noted.10,169-170 As parents are the primary person using most of the interventions, parent implemented interventions (PII) are the focus of the majority of papers.

What is clear is the need for non-pharmacological interventions to be explored that may consider both physical and environmental factors for de-escalation of challenges.11 All interventions evaluated in this scoping review can be considered for implementation in the community setting as well as other settings such as school or respite settings. The specific interventions identified in this scoping review are further explored here.

### Nonpharmacological interventions for behaviours that challenge

A range of nonpharmacological interventions are discussed further here divided into 16 categories: early intervention, emotion regulation interventions, interventions related to feeding challenges, interventions related to managing sleep challenges, mindfulness interventions, applied behaviour analysis, positive behaviour support, function-based interventions, positive family intervention, parent-child interaction therapy, Triple P, social skills interventions, school-based intervention, transition interventions, emergency department/specialist care and specific child focused interventions. Table 5 provides a summary of nonpharmacological interventions further discussed below.

**Table 5. Nonpharmacological Interventions**

|  |  |  |
| --- | --- | --- |
| **Category of intervention** | **Intervention name** | **Frequency of occurrence** |
| **Early interventions (n=14)** | Frankfurter Autismus-Elterntraining (FAUT-E) | 1  |
| The EarlyBird Programme | 1  |
| Poly Kids Program | 1  |
| ‘Balance’ home-based parent implementation program | 1  |
| Summer Treatment Program For Pre-Kindergarteners (STP-PreK)  | 1  |
| Hospital-provided hybrid parental support program  | 1  |
| Prevent-Teach-Reinforce-For-Young-Children (PTR-YC)  | 1  |
| The Stepping Stones Triple P  | 3  |
| Early Start Denver Model (ESDM)  | 1  |
| Predictive Parenting  | 1  |
| The Incredible Years Parent Training For Children with Developmental Disabilities (IYPT-DD)  | 1  |
| Parent Education Programme  | 1  |
| **Emotion Regulation Interventions (n=4)** | Emotional regulation delivered via parent training.  | 1  |
| Emotion-Regulation Training (ERT)  | 1  |
| Regulating Together (RT)  | 1  |
| Stress And Anger Management Program (STAMP)  | 1  |
| **Managing Feeding Challenges (n=1)**  | Behaviour Parent Training (feeding) (PT-F)  | 1  |
| **Managing Sleep Challenges (n=2)**  | Cognitive Behavioural Therapy – challenging insomnia (CBT-CI)  | I  |
| The Sleeping Sound Intervention  | 1  |
| **Specific Interventions (n=5)**  | Hand bandage  | 1  |
| Autism Hug Machine Portable Seat  | 1  |
| Use Of Transdermal Nicotine  | 1  |
| The Ayres Sensory Integration therapy  | 1  |
| Wearable Biosensor  | 1  |
| **Mindfulness Interventions (n=13)** | Mindfulness for parents | 4  |
| Mindfulness parenting programs  | 1  |
| Mindfulness-based Wellbeing Course For Parents (MBW-P)  | 1  |
| Mindfulness-based Stress Reduction (MBSR)  | 3  |
| MYmind, A Concurrent Mindfulness Program  | 1  |
| Mindfulness-based Positive Behaviour Support (MBPBS)  | 3  |
| **Applied Behaviour Analysis (ABA) (n=9)** | Applied Behaviour Analysis (ABA) approaches  | 3  |
| Family-based Management of Behavioural Excesses of Autism Program (FMBEAP)  | 1  |
| Acceptance And Commitment Training (ACT)  | 2  |
| Acceptance And Commitment Training (ACT) with Behaviour Parent Training (BPT)  | 1  |
| Behaviour Parent Training (BPT)  | 1  |
| Naturalistic Intervention (NI)  | 1  |
| **Positive Behaviour Support (PBS) (n=12)** | Positive Behaviour Support (PBS) Interventions  | 3 |
| Functional Behavioural Assessment (FBA)  | 4  |
| Visual Supports (VS)  | 1  |
| Antecedent-based Interventions (ABI)  | 4 |
| **Function-based interventions (n=5)** | Functional Communication Training (FCT)  | 2  |
| Telehealth Function-based interventions  | 3  |
| **Positive Family Intervention (PFI) (n=2)** | Combining principles of PBS and Cognitive Behavioural Therapy (CBT)  | 1  |
| Cognitive Behavioural/Instructional Strategies (CBIS)  | 1  |
| **Parent–Child Interaction Therapy (PCIT) (n=10)** | Positive Family Intervention (PFI)  | 7 |
| Tele-PCIT  | 1  |
| COMPASS For Hope (C-HOPE)  | 2  |
| **Triple P (n=4)** | Building Bridges Triple P (BBTP) | 1  |
| Teen Triple P  | 1  |
| Triple P for Parents  | 1  |
| Research Unit On Behavioural Interventions (RUBI) training  | 1  |
| **Social Skills Interventions (n=5)** | Social skills development | 1 |
| Instructional interventions  | 1  |
| Social skills training (SST)  | 1  |
| Program for the Education and Enrichment of Relational Skills (PEERS) ® Intervention  | 1  |
| An Individualized Mental Health Intervention (AIM-HI)  | 1  |
| **School-based intervention (n=3)** | Multiple treatment component school-based interventions  | 1  |
| PBS in the school environment  | 1  |
| Video-based intervention  | 1  |
| **Transition interventions (n=2)** | The Transitioning Together Program  | 1  |
| TrASDition Training  | 1  |
| **Emergency department/specialist care (n=5)** | Plan on arrival | 1  |
| Coping kits | 1 |
| Family centred care approach  | 1  |
| Low Arousal Approach  | 1  |
| Specialised units  | 1  |
| **Child focused interventions (n=2)** | Exercise interventions  | 1  |
| Anger Can Go!”  | 1  |

#### Early intervention

Early intervention (EI) is important in preventing development of behaviours that challenge for the child and family98 and a number of interventions are cited in the literature supporting EI programs. FAUT-E a German, 8-session parent training program delivered in a group setting is aimed at those who have received a first diagnosis, informing parents about autism and effective parenting strategies.172 This training program resulted in a medium positive effect on child behaviour post intervention.172 Another, 8-session parent training program delivered in a group setting is The EarlyBird program aimed at informing parents about autism and empowering skill development also addressing behaviour management, although more input on this subject was desired by parents after undertaking the programme.173 Unlike other programmes, this intervention included 3 home visits by a facilitator.173 While effectiveness was not measured in this study, positive changes were noted post intervention.173The Poly Kids program specifically targets parents of pre-school children with developmental disabilities, incorporating multiple domains to include behaviour, with behaviour management skills deemed effective post intervention.174 Balance, a home-based parent implementation program established there were decreases in emergent behaviours that challenge with 4 parents and children (3 years) following twice weekly in-home training with a behaviour analyst.175 An 8-week multimodal summer treatment program for 37 parents of pre-kindergarteners (STP-PreK) involved summer attendance by the children and a weekly 2-hour parenting program for the duration.176 This program included a behaviour modification element in addition to academic and social and emotional curriculum. Post treatment, parents reported improved parenting and better parenting practices also citing engagement in more positive parenting skills.176 Another EI was a hospital provided hybrid parental support program designed to reinforce parents’ capabilities and promote the development of toddlers at risk of or diagnosed with autism.177 Of relevance, following this intervention, 15 parents observed a decrease in their toddler negative behaviour.177

Prevent-Teach-Reinforce-for-Young-Children (PTR-YC) is a 12-week program reporting decreases in 35 families parenting stress and child behaviours that challenge and an increase in what is deemed to be appropriate or acceptable behaviours by the participants, in this instance parents.178 Likewise, the Triple P parenting programme is a well-known early intervention with a specific programme Stepping Stones designed for parents of children aged 2-8 years with disability.179 The Stepping Stones programme is seen as effective for parents of autistic children and is widely used.180,181 One Stepping Stones RCT reported that relative to the care as usual group of 29 parent participants, significant short-term improvements were found in the intervention group (35 parents) on parent-reported child behaviour problems.180 While another Stepping Stones pre/post intervention study also reported on 109 parents experiences, with improvements in behaviours that challenge, specifically conduct challenges, hyperactivity/inattention and prosocial behaviours.181

The Early Start Denver Model (ESDM) is a 6-week intervention aimed at children between 12-48 months, reporting improvements for 72 preschoolers in social communication behaviours, directly affecting maternal child-related stress.182 A 12-week group Predictive Parenting (PP) intervention was piloted with 52 families of 4–8-year-olds with autism. Minimal impact of the intervention was noted in terms of reductions in externalising behaviour problems although it was acknowledged the small sample size resulted in small effect size and a larger study may show larger effect.183 Another EI group-based intervention The Incredible Years was tailored for parents of autistic children and has potential to improve family well-being around emotion regulation strategies, parental stress management strategies and social support with one study demonstrating its feasibility with 17 parents of preschool aged autistic children.184

A Parent Education Programme (PEP) (versus a basic parent training program) was discussed consisting of 12 sessions and a home visit over a 24-week period. While sessions provided 91 parents of children (4 years-mean age) with autism with information, support and educational planning, it provided no specific instruction on management of behaviours that challenge and had mixed responses to intervention from some response to no response.185

#### Emotion regulation interventions

Interventions that target child ER were evident and delivered via parent training.98 Emotion-Regulation Training (ERT) can increase individual emotional awareness, thereby recognising triggers and building individuals own ‘toolbox’ of ER strategies as identified in a systematic review of 95 papers focusing on ER.186 Likewise, Regulating Together (RT) is a 10 session, 5-week, intensive outpatient, caregiver assisted group program aimed at teaching cognitive behavioural strategies and mindfulness skills that also aid ER.99 RT showed improvements in reactivity, ER knowledge, and flexibility post-treatment in 44 children (8-18 years). Importantly, a reduction in inpatient hospitalisation rates by 16% from the 12 months pre-RT to 12 months post-RT was observed.99 The Stress and Anger Management Program (STAMP) is a cognitive-behavioural treatment designed to address ER deficits in young autistic children through child skill-building and parent training seen to have some small effect on regulating behaviours.187 This RCT reported increased parental confidence regarding the child’s ability to manage anger and anxiety increased from pre- to post treatment.187

#### Interventions related to feeding challenges

While interventions that target food selectivity and parent behavioural training to address feeding problems and mealtime behaviours are important46 few of these were specifically described. One study described a behavioural parent training program (PT-F) for parents of autistic children and feeding problems encompassing 9 sessions aimed at determining the function of the feeding problem, prevention strategies and consequences.61 This study included parents of 14 children (4 years-mean age) who reported reductions in disruptive feeding behaviours and a resultant decrease in parenting stress.61

#### Interventions related to managing sleep challenges

Specific targeted interventions that focused on sleep difficulties were identified and it was noted that improved sleep resulted in better outcomes for autistic children.52 Screening for sleep problems should be a precursor to behavioural interventions and standard when parental stress is obvious with suggestions that this assessment form part of baseline assessments when a diagnosis of autism is suspected/given.50,52 Cognitive Behavioural Therapy – Challenging Insomnia (CBT-CI) an 8-week intervention for treatment of insomnia was found to be helpful with high parent satisfaction arising from improvements in child sleep patterns and resultant improved daytime functioning.54 The Sleeping Sound intervention, a 2-session child and parent/caregiver program focused on assessing sleep difficulties and setting goals to resolve some of the issues.55 The subsequent session focused on reinforcing sleep strategies and addressed implementation difficulties followed by a phone call 2 weeks later.55 This intervention was viewed as efficacious and practical resulting in a reduction in sleep difficulties.55

#### Targeted specific interventions

Specific interventions are identified in the literature such as the hand bandage reported in a case study where a child with ID engaged in self-biting, and would bite the bandage in place of the hand itself, resulting in no new tissue damage 2 weeks after commencement of wearing.188 Worth noting is that the bandage did not restrict hand movement and was easy to apply not causing further distress to the child. Another intervention device used with 20 autistic children was a short-term Autism Hug Machine deep pressure portable seat, aimed at having a calming effect, demonstrating improvement in conduct problems, hyperactivity behaviour and anxiety.93 A single case report highlighted the use of transdermal nicotine in an autistic adolescent admitted to hospital for persistent aggression despite high use of antipsychotic medications.189 The transdermal nicotine was used as an adjunct to other medication to manage aggression and found to be well tolerated and reduced the need for emergency medication and restraint in the hospital environment.189 The Ayres Sensory Integration therapy intervention aimed at developing skills to process and integrate sensory information, involved 24 face-to-face sessions in an occupational therapy clinic with both a parent/parents and their autistic child, followed by two telephone calls with the carer, however the therapy was not significantly better than usual care and was considered a more expensive intervention.190 Prediction of aggression using a wearable biosensor was used with 20 autistic children (6-17 years) during observation sessions in an inpatient psychiatric setting and cited as potentially supporting a better response to behaviours that challenge allowing for more attention, adaptation of the environment as a safety measure or promotion of other self-management techniques, thereby pre-empting or allowing for de-escalation of a situation.191

#### Mindfulness interventions

Mindfulness may be important in mediating the effect of depression and stress for parents of CYA with autism, acting as a protective factor.133,192-194 Furthermore, mindfulness parenting programs aimed at improving parent-child interaction and reducing parental reactivity may be effective in reducing parental stress by improving the level of communicative interaction between parents and children.195 An 8-week Mindfulness-based Well-Being Course for Parents (MBW-P) aims to increase parent awareness, whilst recognising shared experiences and difficulties encountered by other parents.196 One study with 21 parents demonstrated increased mindfulness and self-compassion and decreased stress over time post intervention.196

Mindfulness-based Stress Reduction (MBSR) is an intervention that teaches mindfulness meditation practice to reduce physiological and psychological symptoms of anxiety and panic, improving parents’ ability to act with awareness and interact non-judgmentally with their CYA.104,192,197 Used as an early intervention it may prevent the development of internalising problems. One RCT undertaken with 46 parents of young children up to 5 years old reported less stress and depression with greater life satisfaction while also reporting fewer child behavioural problems.192 Another program, MYmind, was developed specifically for CYA with autism and their parents with the aim of improving awareness, distress tolerance, and self-control in youth with autism through various mindfulness techniques (e.g., meditations, breathing techniques, yoga poses).198 This study reported improvements from 23 parent/youth (aged 12-23 years) participants in child ER and adaptive skills and parent mindfulness following intervention.198

Mindfulness-based Positive Behaviour Support (MBPBS) is a customised mindfulness program that enables parents and other caregivers to reduce their perceived psychological stress to normative levels through mindfulness procedures and to support autistic children or children with ID to self-manage their behaviours that challenge through positive behaviour support (PBS).199-201 This was found to be equally beneficial to mothers of autistic children or children with ID and significant reductions in aggression and disruptive behaviour and increases in compliant behaviours were observed in the adolescents in both groups of children.199-201

#### Applied behaviour analysis

The behaviour analytic approach applied behaviour analysis (ABA) is a well-known intervention that is comprehensive, and problem focused using a range of techniques: modelling, prompting, reinforcement and shaping.42,202 The goal of these interventions is to reduce behaviours that challenge, while also establishing and strengthening adaptive behaviours. One case study reports the use of ABA procedures with two autistic children as well received, demonstrated by a decrease in child behaviours that challenge as an effect of increased social abilities.203 Likewise, the Family-based Management of Behavioural Excesses of Autism Program (FMBEAP) is a 10-session group therapy aimed at parents developing skills around prevention of negative behaviours using the ABA framework.204 This intervention study involved 17 parents of autistic children (2-4years) demonstrating sustained decreases in behaviours one month post intervention.204

Incorporating the ABA principles as well as stress reduction strategies and mediation practice based on acceptance and commitment therapy (ACT) principles, is the 3-week online group parenting program ACT cognitive-affective strategies.205 The implementation of this programme in a pilot study with 23 parents of autistic children (4-8 years) resulted in improvements in measures of child behaviour and reductions in self-reported stress for parents specific to their child.205 Similarly, ACT principles were adopted in another study alongside mindfulness exercises delivered via 2, 4-hour workshops for parents of 5 autistic children with ID and behaviours that challenge. This study reported an increased ability of parents to cope with stress thereby having positive effects on those around them.206 Furthermore, ACT was also adopted alongside behaviour parent training (BPT) with reported positive experiences by parents in addressing child behaviours.88 BPT is an intervention with the specific purpose of improving or modifying parental practices in order to promote the child's well-being, increasing parenting skills in the daily management of the child, problem solving and reducing the level of parenting and family stress in turn reducing behaviours that challenge.207 Naturalistic intervention (NI) is an intervention adopting a range of techniques and strategies that are embedded in typical activities or routines and are designed to encourage specific behaviours based on the child’s interests.187 NI practices emerge from ABA approaches while also adopting naturalistic development approaches with some early evidence of positive effect with younger children.187

The principles of ABA have informed intervention methods for implementation with autistic CYA for over half a century. The first evaluations of the application of behaviour analytic principles since called ABA were described in relation to a young autistic boy and were seen to be effective for developing skills and ameliorating negative behaviours.208 It is clear that interventions using various forms of behaviour analysis such as ABA can demonstrate improvements.209 However, despite the evidence of effectiveness of ABA interventions, it is worth noting that concerns have been expressed about the intervention with discontent with the procedures and goals targeted through its use.210 ABA interventions can be intense in nature, requiring a number of hours of intervention per day/week and is rigid and formulaic in nature.211 ABA is akin to a one size fits all therapy in an attempt to make the autistic child ‘normal’ and more socially acceptable. This ‘normalcy’ is what makes ABA somewhat controversial as it can be stigmatising, emphasising teaching skills out of context, unlearning stereotypical autistic behaviours and does not focus on self-regulatory skills for the CYA.210 While ABA is still used families and autism activists support acceptance of diversity and respect for difference, something not always evident in ABA interventions. The importance of evaluating significance of interventions and listening to the child and family perspective ensuring rights are being upheld is key and therefore use of ABA as an intervention needs consultation with each stakeholder but especially CYA and their families.

#### Positive behaviour support

Positive behaviour support (PBS) is a framework to better understand and reduce CYA behaviours that challenge, thereby enhancing quality of life.212-214 PBS often involves functional behavioural assessment (FBA), a systematic way of determining the underlying function or purpose of a behaviour allowing for an effective intervention plan to be developed.42,186,215 Conducting a functional analysis of a problem behaviour is seen as a positive step.92 Use of alternative aids such as visual supports or role play can assist the communication process for the CYA when using this intervention.186 Antecedent-based interventions (ABI) are those interventions where the participants' environments were altered before they engaged in behaviours that challenge to allow them to engage in different, non-challenging behaviours.9,84 These interventions provide individuals with visual or verbal cues to forewarn them of changes in activities.186 ABI are well supported as de-escalation strategies to support CYA.216

#### Function-based interventions

Function-based interventions are those in which the participants are taught what is deemed to be socially appropriate communication responses that could be used to obtain the same reinforcers as their behaviours that challenge and are also helpful in crisis prevention and intervention.9 Function-based treatment (FBT) is based on identifying the function of the behaviour and is based on two principles: the withholding of reinforcement that maintains the targeted problem behaviour (extinction) and the precise use of consequences to strengthen an appropriate alternative behaviour (reinforcement).42 Using reinforcement interventions involves delivery of the reinforcements when appropriate behaviour is displayed.9,186 Like function-based interventions, functional communication training (FCT) comprises implementing a baseline phase involving extinction of the targeted problem behaviour and then an individualised plan to reduce that behaviour using a functional analysis.217 Parents of 32 autistic children(2-6 years) reported significant decreases in targeted behaviours, as well as decreases in parenting stress following successful completion of FCT via telehealth.217 This was also supported in a subsequent study that delivered FCT for boys with Fragile X.218 This RCT reported on 57 boys participating in either an intervention or usual care group and reported significant decreases in irritability for the intervention group. 218 Delivery of both FCT and ABA principles via telehealth resulted in parental stress reduction and diminished problem behaviours in autistic children as reported in one systematic review.219 Another pilot online parent training intervention was undertaken with 29 parents of children (1-7 years) with ID aimed at managing behaviours that challenge for families awaiting specialised services and demonstrated that the online training led to reductions in the frequency of perceived problem behaviours and parenting stress while improving caregivers’ self-efficacy.220 Similarly, a newly developed psychoeducation intervention for 62 mothers of autistic children (2-6 years) was delivered via WhatsApp by a facilitator as well as use of a booklet on self-guided intervention.221 Management of maternal stress and mood resulted in reduced autism symptoms as reported by mothers to include reduction in negative behaviours.221

#### Positive Family Intervention

Positive Family Intervention (PFI) involves 8, weekly sessions aimed at teaching the principles of PBS and the principles of cognitive behavioural therapy (CBT).222 There may be benefits to incorporating aspects of CBT with PBS including decreasing parents’ pessimism as well as improving their perceptions of the severity and frequency of problem behaviour.222 Likewise, Cognitive Behavioural/Instructional Strategies (CBIS) based on CBT is an intervention adopting instruction on management or control of cognitive processes that lead to changes in behavioural, social, or academic behaviour through using step-by-step strategies to change their thinking, behaviour, and self-awareness.186

#### Parent–Child Interaction Therapy

Parent–Child Interaction Therapy (PCIT) is an intervention for autistic children with behaviours that challenge and adopts child directed interaction and parent directed interaction.223-226 In a case report with 3 parent/child (3-7years) participants, after 12 weekly treatment sessions, outcome measures showed improvements in parenting behaviour, decreases in disruptive behaviour and intensity, and reductions in parenting stress.224 Use of PCIT demonstrated significant and clinically meaningful improvements in child disruptive and externalizing behaviour, parenting skills and parenting stress.227,228 Similarly, findings of a more recent study suggest that 55 families of children (4-10years) with a range of autism presentations were highly satisfied with PCIT and saw decreases in parent–child conflict.223 Specific child directed interaction training is considered important in parents developing specific communication skills with their child with the aim of improving social cognition and reducing disruptive behaviour.229 Tele-PCIT was also proposed as successful when delivered via telehealth to parents of autistic children(2-6 years) noting improvements in parent and child outcomes specifically in child behaviour.230 Another parent intervention highlighted was COMPASS for Hope (C-HOPE), an 8-week parent-mediated intervention that has been reported in one study of 20 parents of autistic children (3-12 years) as effective in enhancing parent competency and reducing parent stress and child problem behaviour in autistic children231 while another study reported increasing parental competence and skills with 20 parents divided into face to face and telehealth delivery of the intervention.232

#### Triple P

Building Bridges Triple P (BBTP) is an 8-session behavioural family intervention designed to meet the needs of parents with an adolescent with developmental disability drawing together elements of 2 other evidence-based programs, Teen Triple P for parents of typically developing adolescents and Stepping Stones Triple P for parents of children with a developmental disability.233 Parent report of behavioural problems following this intervention were significantly decreased and the 9 parent participants of autistic adolescents (12-16 years) also reported greater self-efficacy in managing their behaviours.233 RUBI training (Research Unit on Behavioural Interventions (RUBI) Autism Network) delivered via telehealth to 13 parents of autistic children was related to an increase in the caregiver’s knowledge of behavioural principles and a decrease in noncompliance and severity of behaviours that challenge of their children in the home.234

#### Social skills interventions

Interventions supporting social skills development are promoted as preventors of mental health difficulties and are sometimes paired with strategies to support ER skills also.89 Instructional interventions involve participants being prompted or instructed to engage in socially appropriate behaviours or being taught to recognise relevant social and physical cues in certain contexts, thereby helping them to develop socially appropriate behaviours.9 Social Skills Training (SST) is a group or individual intervention designed to teach learners ways to appropriately and successfully participate in their interactions with others.186 The Program for the Education and Enrichment of Relational Skills (PEERS) covers topics aimed at promoting the development of social skills in autistic adolescents.235 This collaborative program includes parents and allows for troubleshooting on challenges.

An individualised mental health intervention (AIM HI) is also a package of evidence-based caregiver and child-directed strategies aimed to reduce behaviours that challenge in autistic children ages 5 to 13 years.236 It comprised 11 meetings with 38 parents and autistic children and was found to be helpful in managing emergent life events that place additional unexpected stress on the child and family often resulting in crisis. Furthermore, difficulty in managing unexpected events can lead to feelings of loss of control and poor coping resulting in crisis.124

#### School based interventions

Specific school-based interventions are important in decreasing behaviours that challenge for autistic individuals.237 A variety of school-based programs are in operation, many consisting of multiple treatment components such as social narratives, FCT, antecedent (what has preceded the behaviour) training, reinforcement, prompting, modelling, visual supports, sensory-based interventions, social skills training and restricted access.238 PBS is well supported for use in the school environment with a whole school approach promoting positive behaviour helpful with a clear analysis of the antecedent, behaviour and consequence.72 Interestingly, video-based intervention was cited by one author who adopted videoing of 8 child/staff interactions and analysis of same in order to change perceptions i.e., child was no longer viewed as the problem. However, the problems remained, and the value of this intervention was questionable.239

#### Transition interventions

Interventions specifically aimed at supporting CYA with transitions are limited. The Transitioning Together Program is an 8-week psychoeducation program targeted at families with adolescents with autism who are approaching high school exit, a difficult transition stage for individuals often marked by negative changes in behaviour problems.240 Preliminary data from a case study reports improvements in one parent child relationship in turn improving the home environment.240 An online psychoeducational parental training program TrASDition Training for families of autistic children with or without ID also focused on the transition to adult age. The program demonstrated with 23 adolescents/young adults that family inclusion in a transition program is positively related to a better functioning of the child and to a reduced parental stress.241

#### Emergency Department/Specialist Care

Developing a plan on arrival to the ED is an important intervention aimed at reducing wait times for the CYA and anticipating certain behaviours.73 When visits are more common, sometimes rehearsing the intervention i.e., clinical procedure, can be an effective way to prepare the child and pre-empt possible responses. Coping kits are also a positive tool and may include written schedules, social stories, sensory regulation items or sensory activities.73 Additionally, a collaborative family centred care approach is recommended with the ED provider capacity building in terms of skills for CYA with disability and behaviours that challenge that address such areas as preparedness for procedures, proactive strategies for sedation and restraint and clear signposting for follow up.242 Active consultation with parents as the experts on their child and also intentionally engaging autistic children, as opposed to making assumptions on their abilities and needs is essential.242

A crisis management intervention, the Low Arousal Approach is a person centred, non-confrontational, multi component strategy for recognising anxiety and intervening early using a range of proactive and reactive strategies.243 Such an approach is helpful for parents, families and professionals. Interestingly, interventions not widely discussed are those that involve specialist inpatient care. One study compared admission to a specialised or a general child psychiatry unit for CYA aged between 4-20 years.162 Serious problem behaviour including aggression and self-injury were reduced from admission to discharge in CYA from both units. However, those CYA that attended the specialised unit were less likely to experience an ED visit in the following 2-month period, thereby demonstrating there is some merit in specialist care, albeit possibly due to pharmacological intervention as well as non-pharmacological intervention.

#### Specific child focused interventions

Child focused interventions included exercise interventions consisting of jogging, horseback riding, martial arts, swimming or yoga/dance resulted in some improvements to behavioural outcomes including stereotypic behaviours, social-emotional functioning, cognition and attention.244 A systematic review of 13 studies reported horseback riding and martial arts interventions as producing the greatest results.244 One paper discussed an intervention “Anger Can Go!” designed to treat anger regulation problems in autistic children (8 to 13 years). The 9-session intervention demonstrated that these children could acquire self-regulation skills reducing some aspects of aggressive behaviour problems, namely temper tantrums and arguing, and improving the use of adaptive anger coping strategies.245

To summarise, EI for CYA with disability is important and recognised in the frequency of papers (n=14) citing a variety of interventions delivered in the early years of the child's life. This is not surprising given the emphasis on early diagnosis and detection of disability and the resultant prevention of exacerbation of difficulties as the child grows. Interventions comprising behavioural education elements are cited frequently with a variety of interventions outlined above. PBS (n=12), functional based interventions (n=5), applied behavioural analysis (n=9), PFI (n=2) and PCIT (n=10) are all examples of interventions that have a specific behavioural education focus. With parental stress a key factor that may lead to development of behaviours that challenge and the bi-directional nature of this stress for CYA also, mindfulness interventions were cited in 13 papers and these interventions also contained some elements of behavioural support plans or positive behavioural support. Notably mindfulness interventions all contained elements that were focused on the child's mindfulness as well as the parent. Lesser cited interventions in the literature tended to be targeted interventions with a specific outcome, for example managing sleep, feeding or transition. Specific child focused interventions were only cited by 2 papers, an indicator that more studies focused on child participants are required to demonstrate inclusive and objective research findings.

A number of nonpharmacological interventions have been outlined and where relevant effectiveness cited. Some papers are research papers outlining study data and measures of effectiveness or impact while other papers are descriptive in nature and provide an outline of an intervention. A mix of RCTs and cross-sectional data was provided but the focus of papers on research studies was to discuss a single study where an intervention had been implemented.

Delivery of intervention training is largely outpatient based or within primary care with only a handful being delivered while CYA are in the hospital setting. Most of the interventions were delivered without cost to the participant and were delivered by public health or social services with cost to the provider not discussed. Much of the practical elements of the training are for implementation by parents in the home/community setting. Some interventions are clearly targeted at a specific outcome, for example feeding or sleeping. Notably, the bulk of interventions are holistic with multiple outcome measures targeting both a positive change in child behaviour but also a positive change in parental coping skills. All of the interventions are focused on empowering parents to support their child and could be undertaken by one or both parents. Interventions tend to comprise written guides, manuals, PowerPoint presentations and also telehealth or face to face interaction. Many of the interventions take place over a period of weeks or months and include 1-2 hourly weekly or fortnightly sessions where training occurs either in individual or group format.

Content of programs may be very specific but many of the interventions comprise of content relating to similar topic areas such as parent child interaction, positive behavioural support techniques, incentives and reinforcement, child behaviour advice, parental stress management techniques, conflict management and have an overall aim of increasing child and parental wellbeing. Some interventions cited did not have specific intervention names, possibly due to being pilot studies and often would contain elements of other interventions that were being redeveloped or piloted.

Interventions are delivered by professionals who have trained in the use of the named intervention and are certified trainers (where relevant). These professionals are educators, occupational therapists, dieticians, child psychologists, social workers, program managers, facilitators who have undertaken specialist training.

Where fidelity was maintained by participants in undertaking interventions, positive outcomes were reported. Most of the papers reported good fidelity with the intervention or research study but this may possibly because the participants had a specific interest in undertaking an intervention at that time to meet their child and family needs.

### Pharmacological management of behaviours that challenge

An exploration of the literature evidenced the use of pharmacological interventions that may be considered when an autistic child exhibits behaviours that challenge including aggression, irritability, and impulsive behaviours that could cause harm to self or others. See Table 6 for more detail.

**Table 6. Pharmacological Interventions**

|  |  |  |
| --- | --- | --- |
| **Category of intervention**   | **Intervention name**   | **Frequency of occurrence**   |
| Psychotropic medications   | 5  |
| Second generation antipsychotics  | Aripiprazole and Risperidone  | 5  |
| Quetiapine  | 1  |
| First generation antipsychotics  | Haloperidol  | 1   |
| Other  | N-Acetylcysteine (NAC)   | 1  |
| Stimulants  | 1  |
| Sedatives  | 1  |
| Cannabidol CBD   | 2  |
| Melatonin   | 1  |
| General pharmacological intervention  | 3  |

Twenty-one papers cited use of pharmacological interventions for different effects. 11,34,47,53,58,83,87,96,215,246-256 Commonly reported psychotropic medications included antipsychotics, sedatives/anxiolytics, antidepressants, stimulants, medical cannabis.34,83,255,257 One of the papers recommended that psychotropics should be used as an adjunct to behavioural interventions.87 Psychotropic medications have been prescribed for autistic CYA , with one study reporting their use for aggression associated with Fragile X.34 There are two types of antipsychotic drugs: first generation (FGAs) or 'typical' antipsychotics are older medications while second generation (SGA) or 'atypical' antipsychotics are newer drugs.258 Several drugs, but in particular SGAs, risperidone and aripiprazole are used to treat comorbid behaviours that challenge in autistic children with findings showing objective improvement in behaviours, reduced irritability and aggression and a reduction in inappropriate language.96,215,247,253,254 An antioxidant, N-acetylcysteine (NAC) has been identified as a potential treatment agent for irritability and self-injurious behaviours in autism252 but research on this is limited.

SGAs are sometimes prescribed to manage irritability and aggressive behaviour, however, there are few published studies supporting the effectiveness of these medications for this population. FGAs such as haloperidol may also be used to target irritability and aggression in autistic children.254 All these drugs have significant side effects, should be available in oral formulations for CYA and may require metabolic monitoring as well. Stimulants are sometimes prescribed particularly if hyperactivity and impulsivity are a challenge.254 Quetiapine, a SGA medication, was the focus of one paper discussing its lesser efficacy for the management of psychiatric behaviour associated with autism.253 Medications used for treatment of agitation should focus on addressing the cause of the agitation.11 While administration of sedation is a last resort and physical restraint a preferred alternative in most cases,251 some children may require such drugs as Midazolam, a sedative or to a lesser extent, intramuscular ketamine, an anaesthetic drug.250

While cannabis use is not a new phenomenon, only two papers by the same author discussed its use with CYA. In one study with 60 autistic children, behavioural outbursts were suggested to have improved supporting the feasibility of cannabidiol (CBD) based medical cannabis as a possible treatment option for refractory (treatment/management resistant) behavioural problems in autistic children.248 In a later study (a RCT), the same author discussed how cannabinoid treatment has the potential to decrease disruptive behaviours associated with autism, with acceptable tolerability. Importantly for autistic individuals who are overweight, cannabinoid treatment was associated with net weight-loss in contrast to the substantial weight gain usually produced by antipsychotics.249

Medications are also used to treat sleep initiation and/or maintenance insomnia (difficulty staying asleep) resulting in longer sleep duration, although approved medications for use with children are limited. There is evidence that melatonin is effective in treating the insomnia often experienced by autistic children, but this is considered a dietary supplement and not a drug.53

While pharmacological management of behaviours that challenge is evident in the literature outlined above, many pharmacological interventions are not licensed for use with children and therefore objective data is limited. It is also worth noting that in many instances, multiple or combination interventions are used whereby a nonpharmacological intervention is also being used alongside pharmacological management options. Furthermore, explicit examination of the side effects of these medications when used with CYA is not offered in many papers. However, a systematic review did explore the efficacy and safety of pharmacologic treatments citing sedation effect, extrapyramidal side effects and possibility of weight gain for CYA.247

## Research Question 3. How effective are these supports in preventing and managing behaviours that challenge and preventing family breakdown and other crisis situations?

A range of interventions have been explored earlier that were aimed at managing behaviours that challenge. A further exploration of the literature demonstrated some guidance on how to prevent crisis as it relates to the child and family experiencing behaviours that challenge, not always guidance that was linked to specific discreet interventions as identified earlier. Pre-emptive prevention and management of behaviours that challenge is key in crisis prevention and explored further here. Foremost is the ability of the child and adolescent to develop coping mechanisms although these are not cited for CYA with ID. For autistic CYA with behaviours that challenge developing coping mechanisms such as stress management is key for the individual with benefits of listening to music, reading books and engaging in physical exercise all possible strategies.260 Other identified approaches included focusing on individual interests, playing videogames, and talking to a therapist or family member.149 Peer support was also identified as a source of comfort, as was chatting with online friends, hanging out with friends in-person, and hearing from older autistic adults who experienced similar struggles.149

Coping mechanisms for parents are also essential with stress management possibly helping prevention of crisis.124 One study indicated that mothers who used active coping strategies such as those aimed at solving a problem or getting help, experienced lower levels of parenting stress.116 Some parents go as far as adapting their lifestyle, avoiding public outings or modifying family activities to avoid further stress.260 The National Council for Special Education (NCSE) discuss the importance of ‘tuning in’ using parenting observations to recognise that behaviours happen at certain times with certain people in certain places and pre-empting behaviours that challenge can allow for de-escalation.261 This de-escalation is also supported by Pavlov who suggests that the immediate objective should be to eliminate the cause or trigger of crisis and may involve providing attention from preferred individuals or giving time out.168 Additionally, developing a crisis plan is viewed as helpful for the family, considering such things as vital information and strategies to keep everyone safe during episodes of aggression or self-injury.40

Appropriate assessment and identification of underlying psychiatric co-morbidities is important and can allow providers to better care for autistic individuals in the acute care setting.83 The Iceberg Assessment Interview tool is positively adopted as part of the admission process to a specialised psychiatric unit for CYA in one study with the aim of assessing issues that underly behaviours that challenge.56 Assessment should also include detection of anxiety and one paper discusses the use of a parent interviewing approach to assess potential anxiety in their child.262 Acknowledgement of suicidal ideation and how to assess and address it is essential. Autistic CYA are at increased risk of suicidal ideation and therefore recognising this cohort as at risk for suicide is key.150,153,155 However, this does require a validated suicide risk assessment tool and evidence-based adaptations of these to be developed, evaluated and disseminated.153,155 One such tool cited in the literature is the Columbia Suicide Severity Rating Scale (C-SSRS) a widely used, clinician-rated measure of suicide risk, however, it has not been tested with CYA with autism.151 Moreover, a tool to measure crisis would allow for rapid communication with families.153 Another tool is the Brief Family Distress Scale (BFDS) which has been psychometrically tested in clinical settings and could provide a precise depiction of a family’s perception of a crisis and their relative distress in a given situation.153

Supporting families of children with behaviours that challenge is highlighted in the literature. Having a full understanding of autism and the available resources and services is critical.263 Parents are more likely to seek out information to their specific needs and therefore, it would be beneficial to have information about local supports available so parents can be appropriately directed to the support they need.93 As parental stress is commonly attributed to child negative behaviours, resources that can reduce the behaviours may help to reduce stress.127,128,179

While various supports exist, social supports are deemed one of the most effective factors influencing parental wellbeing often reducing isolation, providing validation by peers and providing an informal network. 107,116,265,266 Social support was also a vital predictor of family quality of life supporting parents’ well-being.114 Professional supports are also necessary for families, with training in core skills essential to include stress management strategies and problem-solving skills for behaviours that challenge263 while also considering the various transitions the family may experience.114 Additionally, support systems for parents that allow for sharing of caregiving through family or respite support can help alleviate parental stress.127 Staff working with autistic CYA and those with ID also need professional training in working directly with children presenting with associated behaviours that challenge, employing strategies tailored to individual needs.265 Collaborative approaches to care working in partnership with CYA and their families is advocated when providing support and interventions.7 While interventions may not always be responsive and have the desired effect, support in ensuring their successful implementation is key.179

In Ireland, the needs of children with complex behavioural presentations may be best served by established teamwork with the Children’s Disability Network Team through clear agreed ways of working together.265 However, this model of support for children has been beset by problems with resources and long waiting lists for services a concerning issue.24

Another route is CAMHS a publicly funded national model of service that provides assessment and treatment for young people and their families who are experiencing mental health difficulties up to 18 years of age through a multidisciplinary team. Initial referrals are made via the general practitioner (GP). However, this model of service is not without its problems. Waiting lists to access services have approximately 4400 children waiting for CAMHS services.267 A recent report exploring the experiences of 736 families accessing CAMHS services highlighted the difficulties at each stage of the process from trying to get through the referral process, lengthy periods spent on waiting lists, difficulty accessing therapeutic supports when in the service and children being discharged or aging out of the service before either they or the family feel ready to leave the service.268 This study included 439 (64%) autistic children and 76(11%) children with ID. Notably, 70% of respondents reported that their child being autistic impacted access to CAMHS and/or mental health supports offered while 77% of children with ID had no access to a CAMHS-ID service and only 14% were receiving any interim support.268 CAMHS-ID is a specialist mental health service for children and adolescents who have both a moderate to profound ID and a moderate to severe mental disorder and work in conjunction with primary care and children’s disability network teams.13 For autistic children, difficulties arise with CAMHS operational guidelines having access criteria of having a moderate to severe mental health difficulty. This deciding factor for access to services is not always clearly implemented and often autistic children fall out of this criterion and may not be eligible for CAMHS-ID either, resulting in confusion around dual diagnosis of autism and ID and some children not gaining access to essential services.

Additionally, teacher support and forging alliances with parents was also found to support family quality of life.114 Teacher management of behaviours that challenge should include specific education and collaborative leadership teams to support CYA 266,269 in addition to specialist skills in the use of physical intervention for the management of crisis situations.270,271 Furthermore, similar to a family crisis plan, it is recommended that schools also have a crisis plan should they need to respond to particular behavioural episodes.40 This is especially important to halt a decline in behaviour that may result in exclusion from school.272 Running school-based early mental health identification programmes alongside follow-up evaluations and treatment services is beneficial.167

What is clear within the literature is the need for new models of care to better support children with behaviours that challenge.250 A clear understanding by professionals of what crisis means and the difficulties which cause distress is important. This requires a co-ordinated effort to ensure services work together for better child and family outcomes.165 If specialised or general psychiatric units are to be accessed, professionals need to be able to apply specific intervention strategies adapted to the needs of CYA with disability.165

One such effort might be the development of crisis intervention teams involving several disciplines which may in turn divert individuals away from ED presentation.165 One study described experiences of 462 CYA who were in crisis, acknowledging the majority had met with a behavioural therapist, psychologist or psychiatrist in the previous 3-month period and while signs of crisis were evident these were not assessed as crisis.273 Use of respite services, in-home support, crisis intervention teams and crisis hotlines were less commonly accessed as they were often not available.235 There appear to be limited opportunities for accessing acute care once a child’s behaviour has reached crisis point as the pathways or services are not available, with presentation to the ED often the only option, sometimes exacerbating the issues further due to environmental distress and inadequate professional skillsets.158 One paper advocated for the introduction of primary care pathways to identify and initiate treatments for irritability and behaviours that challenge in autistic children independently or in collaboration with other providers.274

A new model of care should adopt novel approaches to care such as an acute behavioural crisis phone line or specialised mobile team who could assist in managing children in their own homes.158 If ED attendance is required, the environment could be modified with a specific area for those with sensory difficulties,158 addressing differences in sensory perception, possibly using social stories, in turn preventing escalation of behaviours in the ED.158,277,278 It is also important to out rule other causes of aggression or behavioural changes that may be caused by pain or an acute medical condition.277 Furthermore, very little research is reported on first responders management of emergency or crisis situations when tasked with dealing with CYA with disability and behaviours that challenge. There are skills first responders require around the unique learning and behavioural needs including specific tactics that can be used to quickly interpret and respond to behaviours.278

However, while all the above may be helpful and demonstrate some effectiveness in preventing and managing behaviours that challenge, they are required as part of a multi-faceted approach where combinations of intervention and preventive strategies are adopted together. Family experience of crisis with their child with CYA is not voiced in the literature in any great depth. A UK charity Bringing Us Together gave voice to 86 families (83% of which were parents to CYA with disability under the age of 25) who were experiencing crisis with half of the families involved reporting no advice given to them on where to seek help or follow up.279 Even when advice and guidance was given, families often found that help was hard to get and inadequate. Generally, telephone help lines were not felt to be useful, while internet access, discussion groups and support from other parents were found to be more helpful. When families found and accessed support there was a 50/50 split between those who found the support package helpful and those for whom it was not helpful. Families identified emotional support, specialist advice, circles of support, advocacy and legal advice as the top priorities to sustain and support them.

While many of the interventions identified are helpful, a multi-pronged, multidisciplinary approach is preferable, irrespective of location of care either community or hospital/inpatient.280 A coordinated approach involving health professionals such as doctor, nurse, psychologist and behaviour specialist, guide the implementation of a management plan, supported at times by either in or out of home respite care providing clear supports to CYA and their families.164

The National Health Service (NHS) England Transforming Care programme was developed to help improve health and care services so that more people with ID, autism or both who have a mental illness or whose behaviour is seen as challenging services, can live in their own communities, with the right support and close to home.281 This would mean that fewer people need to go into hospital for their care. Care, Education and Treatment Reviews (CETRs) form a key part of the process and focuses on reducing the number of people reaching crisis in their community and ending up in hospital for assessment and treatment, making sure that care meets the person’s needs fully if in hospital and trying to reduce the length of inpatient stays by focusing on current and future care planning, including plans for leaving hospital. These reviews for children include education to ensure that educational needs are considered alongside health and social care. Four questions are posed from the perspective of the child with reviews carried out at pre-defined periods:

* Am I safe?
* What is my current care like?
* Is there a plan in place for my future?
* Do I need to be in hospital for my care and treatment?

This model of CETRs is well accepted and supported with national policy and a specific toolkit for implementation.282

The START (Systemic Therapeutic Assessment, Resources and Treatment) model is an evidence-based, community crisis prevention and intervention service model for individuals aged 6 and older with intellectual and developmental disabilities (IDD) and co-occurring behavioral health conditions who are at risk of crisis, in crisis or recovering from crisis.283 This comprehensive model of service developed in the USA supports optimisation of independence, treatment, and community living for individuals. It adopts a person-centered approach and encompasses training for individuals, families, and caregivers by applying core principles of positive psychology, use of therapeutic tools, provision of multi-modal clinical assessments, promoting enjoyable therapeutic recreational experiences, and optimal utilisation of existing resources. It is underpinned by engagement with the individual, family and other circles of support and professional expertise across the various elements of care. This model has 3 levels of care (Table 7) and is based on a health prevention model.

**Table 7. The START model – Levels of care283**

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| --- |
| **The START model – Levels of care** |
| Crisis Prevention (Primary Care) | Improving access to services, treatment planning, integration of health and wellness and development of service linkages. |
| Crisis Intervention (Secondary) | Identification of individual/family stressors, crisis planning/prevention, respite services, medication monitoring and crisis intervention services.  |
| Crisis Management (Tertiary) | Emergency department, hospitalisation, law enforcement interventions.  |

The START model is adopted widely in the USA 283,284 and Canada.164

More recently, another US 4-stage crisis model has been developed to help clinicians gauge an autistic child's stage of crisis and provide guidance to families.284 This framework is adapted from existing generalist crisis models such as Professional Crisis Management285 and behaviour escalation models such as Positive Behaviour Intervention Supports (PBIS)286 and includes specific crisis management strategies for children with autism. This 4-stage crisis model represents the stages in the evolution of a crisis: not in crisis, pre-crisis, crisis and post crisis (Table 8).

 **Table 8. 4 stage crisis model**

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| **4 stage crisis model284** |
| Stage 1 | Not in Crisis  | Child’s behaviour is manageable |
| Stage 2 | Pre- Crisis  | Child’s behaviour is becoming unmanageable |
| Stage 3 | Crisis | Child’s behaviour is unmanageable |
| Stage 4 | Post-Crisis | Crisis has resolved  |

The child and family move in and out of the stages slowly or rapidly based on interventions and other factors. For example, a child presenting at pre-crisis stage may not progress to crisis with appropriate interventions. It is envisaged that primary care providers take an active role in adopting this model to prevent escalation to a crisis situation.

Crisis situations are traumatic for both CYA with disability and their families. While there are clear models and frameworks that support crisis prevention, these require consistent implementation and evaluation along with multi-disciplinary resources. There appears to be an absence of a successful model or framework in place in the Irish context that addresses CYA with disability and behaviours that challenge. While CAMHS and CAMHS-ID are models of service that show promise, these are services that are fraught with resourcing and access issues for CYA with disability. A Crisis Resolution model of care published in 2023287 recognises that those experiencing mental health crisis need specialist services and intensive support but focuses on those over the age of 18. While the CAMHS12 and CAMHS ID Model of Service13 are published, their success in terms of preventing and managing crisis is not evident.

## Research Question 4. What is the evidence (if any) on the cost effectiveness of evidence-based preventative and management practices in relation to behaviours that challenge in this group?

While a large volume of material was included in this review, interestingly only one of the papers addressed cost effectiveness citing the Ayres Sensory Integration therapy intervention as more expensive than usual care.190 This lack of information on cost effectiveness is not surprising given most papers are seeking to establish the success of an intervention in response to a challenge, in this instance behaviours that challenge. Many interventions cited are being run through public services that are already in place and may be pilot programmes with a view to scaling up the intervention for more long-term implementation. Furthermore, most papers address single intervention use when in reality CYA with disability and behaviours that challenge are likely to require a more holistic approach to care receiving more than one intervention.

## Research Question 5. What is the evidence (if any) of positive outcomes where the young person is transferred to residential care. For example, is there any evidence of less challenging behaviour, restoration of relationship with the family, return home etc.?

Unsurprisingly, there was no evidence reviewed that addressed the outcomes of transfer to residential or emergency care. What can be concluded is that there are interventions available that can address the needs of CYA with disability and behaviours that challenge. When successfully implemented these interventions are helpful and can support family functioning and resilience. However, many interventions require training and once completed by parents, there is no long-term evaluation of the success of these.

# Discussion and conclusion

This scoping review shows the importance of understanding the impact of behaviours that challenge on CYA with disability and their families.

Surprisingly, interventions such as use of sensory rooms and Cubbies for sensory regulation and relief of anxiety and stress were not cited in the literature that was reviewed. While there is a breadth of literature available on the topic it is largely considered singularly in relation to sensory processing and not cited as an intervention in preventing or managing behaviours that challenge. Yet anecdotally sensory rooms are used widely and can prevent escalation of difficulties and is an intervention worthy of consideration. Furthermore, there was little or no mention of movement breaks, use of weighted blankets, use of headphones, attention to sensory zones of regulation or regulation stations that are particularly used in the school setting. While communication training217 was cited as an intervention, there was minimal literature to support constructive communication interventions that would support development of communication skills using augmentative or alternative communications. This is of particular importance for autistic CYA and children with ID who are more likely to have communication deficits.

While transitions such as changes in routine, moving between activities and moving from school to adult care were associated with behaviours that challenge, interventions focusing on the various transitions in the lives of CYA with disability were not largely considered apart from transitioning from school to adult care. Transitions such as those associated with pubertal changes and the related sensory challenges, sexuality and sexual identity changes were not considered. Therefore, there is a need to explore interventions focusing on various transitions experienced by CYA with disability. Additionally, respite services that are responsive to CYA with disability and their families' needs are advocated as a positive intervention to ensure families gain some form of short break either in home or out of home from their caring role.288 Yet, respite care did not appear in the literature search as an intervention for CYA with disability in prevention or management of behaviours that challenge. This may be as a result of it largely being considered as part of caregiver burden within the literature and viewed as a holistic service as opposed to one that would specifically prevent de-escalation and possible crisis for families. However, families have great difficulty accessing respite services and when accessed they can often be infrequent and unsuitable for the needs of CYA.23 This is important to note and further research on the impact of respite on prevention of crisis is of paramount importance.

Interestingly, none of the nonpharmacological interventions cited in this review had negative effects and all cited positive impacts with at a minimum some small effect. However, sample size in some studies were small and notably many of the nonpharmacological interventions cited discussed short-term impact pre and up to 3 months post intervention. Therefore, there is a clear need to study intervention implementation over a longer time period possibly within longitudinal studies to assess long term effect of such interventions as the child grows and develops.

Pharmacological interventions while helpful need to be considered further in terms of effect and side effect. There are minimal RCTs exploring this cohort of CYA in using pharmacological interventions due to the specific child cohort and difficulty in accessing medications that are licensed for use with children. Therefore, this is an area in need of longitudinal objective data.

This review shows there is little evidence to inform effective crisis prevention and data around the successful implementation of prevention strategies is limited or non-existent for this cohort of CYA with disability and behaviours that challenge. Reasons for crisis can be multifaceted and the negative impact of behaviours that challenge on the family unit is significant. Access to primary care and community supports is fraught with delays with a significant level of unmet need for supports and specifically respite support. Families are at risk of crisis and children are at higher risk for out-of-home, emergency residential placement. However, emergency placements are not always available and therefore many children and families have nowhere to turn.24

Little is known about crisis prevention and an appropriate model of care and while there is clear evidence of interventions, they are largely evaluated as a single therapy when in fact in reality multiple holistic approaches are what are required with many families using both pharmacological and nonpharmacological interventions. Anecdotally, many families have experienced the use of interventions where they have found little success and yet the voices of these families are unheard in the literature. Furthermore, the interplay between having autism and ID is obvious with difficulties arising in responding to the needs of CYA with both diagnoses. The CAMHS and CAMHs ID model of service promotes an integrated care approach but families are dissatisfied with access to these services.268 Without adequate community-based supports crisis situations will continue to develop resulting in the need for presentation at emergency departments and emergency residential placement options. Many of these emergency placement options are out of area and therefore further exacerbate the challenges families experience.

Crisis interventions need to be developed and implemented in partnership with families. Many of the cited interventions are parent implemented and once the intervention training has been undertaken there is little or no support and evaluation for implementation. Ensuring access to services and support is a critical part of an effective crisis prevention strategy for CYA with disability and behaviours that challenge. The National Action Plan for Disability Services sets out a 3-year programme to tackle deficits in disability care.289 Much of what is laid out in this plan is aimed at minimising the need for expensive crises driven services. For CYA with disability and associated behaviours that challenge, this plan includes greater access to respite care to promote family resilience, more effective approaches to managing behaviours that challenge, packages of intensive home supports and multidisciplinary supports to avert crisis situations that might otherwise result in emergency residential care. More specifically, as part of key objective 2 in this national plan, there is an intended workstream 11 on intensive supports with a breakdown of suggested evidence-based Harvard programme (although no description of this or what it entails is provided), a review of emergency placements and a plan for temporary therapeutic placements as an alternative response to crisis situations. However, details on the implementation of this plan are limited.

While factors that lead to development of behaviours that challenge were identified and several discreet interventions highlighted, this scoping review also demonstrates the gap in evidence about how crisis occur and how crisis intervention impacts the family unit, family functioning and the resilience of the family. The findings are not surprising, and it is clear there is no simple or easy solution to preventing and managing crisis situations.

The review was comprehensive in nature identifying a broad range of literature exploring factors that lead to development of behaviours that challenge and prevention and management of crisis situations related to behaviours that challenge, among CYA with disability. It has demonstrated the breadth of material available on the topic with a total of 247 papers specifically addressing the topic with a variety of paper types. Among interventions cited, it is clear EI plays a key role in preventing behaviours that challenge and empowering CYA with disability and their families. Additionally, interventions comprising behavioural education elements are frequently cited. However, there is a clear gap in evidence for interventions such as sensory rooms, respite, communication and transition with scope to explore these topics further in future research. There is also a need to address interventions' cost effectiveness, especially when CYA with disability usually requires a holistic approach adopting multiple or combination interventions. The majority of studies cited explored parent and child participants although parents tended to supply the information for their child in research studies, therefore giving voice to CYA with disability is something that needs to be considered in future studies. It is expected this scoping review will provide some direction for researchers, but in particular inform policy and practitioners working in the field.

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# Appendices

## Appendix 1 Search concepts

**Concept 1: Autistic and/OR ID**

**EMBASE:** ('mentally disabled person'/exp OR 'autism'/exp OR 'mental deficiency'/exp OR 'autism'/exp

**Medline:** (MH "Mentally Disabled Persons") OR (MH "Mentally Ill Persons") OR (MH "Intellectual Disability+") OR (MH "Learning Disorders+") OR (MH "Mental Retardation, X-Linked+") OR (MH "Developmental Disabilities") OR (MH "Autistic Disorder") OR (MH "Autism Spectrum Disorder+") OR (MH "Rett Syndrome")

**CINAHL:** (MH "Developmental Disabilities") OR (MH "Intellectual Disability") OR (MH "Mentally Disabled Persons") OR (MH "Mental Retardation, X-Linked+") OR (MH "Autistic Disorder") OR (MH "Rett Syndrome") OR (MH "Asperger Syndrome")

**PsycINFO:** (DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease") OR (DE "Developmental Disabilities" OR DE "Autism Spectrum Disorders" OR DE "Intellectual Development Disorder" OR DE "Learning Disorders")

**Keywords (TI/AB):** “Intellectual Disabil\*” OR “Intellectually disabled” OR “mentally disabled” OR “mental disabil\*” OR “learning disabil\*” OR “Intellectual Development Disorder\*” OR “Learning Disorder\*” OR “Learning disabil\*” OR “mental handicap\*” OR “mentally handicapped” OR “mentally impaired” OR “mental impairment\*” OR “intellectual impairment\*” OR “developmental disabil\*“ OR “mental defici\*” OR “intellectual retard\*” OR “mental retard\*” OR “mentally retarded” OR “intellectually challenged” OR “intellectually deficient\*” OR “intellectually handicapped” OR “intellectually impaired” OR “intellectually retarded” OR “mentally challenged” OR “mentally defici\*” OR “mentally disabled person\*” OR “cognitive disab\*” \*” OR “down syndrome\*” OR “downs syndrome\*” OR “down disease” OR “Downs syndrome” OR mongol\* OR autism\* OR autistic\* OR ASD OR “on the Spectrum” OR asperger\* OR aspie OR AUDHD

**Embase Keywords(TI/AB):** Intellectual Disabil\* OR Intellectually disabled OR mentally disabled OR mental disabil\* OR learning disabil\* OR Intellectual Development Disorder\* OR Learning Disorder\* OR Learning disabil\* OR mental handicap\* OR mentally handicapped OR mentally impaired OR mental impairment\* OR intellectual impairment\* OR developmental disabil\* OR mental defici\* OR intellectual retard\* OR mental retard\* OR mentally retarded OR intellectually challenged OR intellectually deficient\* OR intellectually handicapped OR intellectually impaired OR intellectually retarded OR mentally challenged OR mentally defici\* OR mentally disabled person\* OR cognitive disab\* OR OR autism\* OR autistic\* OR ASD OR “on the Spectrum” OR asperger\* OR aspie OR AUDHD OR “down syndrome\*” OR “downs syndrome\*” OR “down disease” OR “Downs syndrome”

**Concept 2: Situational/Personal Crisis**

**EMBASE:** 'crisis intervention'/exp OR 'crisis intervention'/exp OR 'identity'/exp 'family stress'/exp

**CINAHL:** (MH "Crisis Intervention") OR (MH "Identity Crisis") OR (MH "Family Crisis Oriented Personal Evaluation Scales")

**Medline:** (MH "Crisis Intervention") OR (MH "Identity Crisis")

**PsycINFO:** DE "Crisis Intervention Services" OR DE "Crisis Intervention" OR DE "Identity Crisis" OR DE "Stress Reactions"

**Web of Science**

Keywords: (crisis\* OR crises OR stress\* OR emergenc\* OR breakdown\* OR disaster\* OR catastroph\* OR traged\* OR tragic\* OR upheaval OR clamat\* OR upheaval\* OR critical\*)

**Concept 3: Population/age**

**EMBASE:** ('adolescence'/exp OR 'child'/exp OR 'minor (person)'/exp OR 'young adult'/exp OR 'pediatrics'/exp)

**CINAHL:** (MH "Child+") OR (MH "Infant+") OR (MH "Minors (Legal)") OR (MH "Adolescence+") OR (MH "Young Adult")

**Medline:** (MH "Infant+") OR (MH "Adolescent") OR (MH "Child+") OR (MH “Young Adult”)

**EMBASE:** 'child'/exp OR 'adolescent'/exp OR 'infant'/exp

**PsycINFO:** no appropriate terms use keywords only ti/ab

Web of Science Keywords run on topic only

**Keywords:** child\* OR pediatr\* OR paediatr\* OR young OR youth OR ”young adult\*” OR teen\* OR adolesc\* OR 'under age\*' OR underage\* OR minor\* OR “school aged” OR schoolaged

**Concept 4: Challenging Behaviour**

**EMBASE:** 'challenging behavior'/exp OR 'disruptive behavior'/exp OR 'violence'/exp OR 'aggression'/exp

**CINAHL:** (MH "Disruptive Behavior") OR (MH "Adolescent Behavior") OR (MH "Competitive Behavior") OR (MH "Harm Reduction") OR (MH "Self-Injurious Behavior") OR (MH "Wandering Behavior") OR (MH "Impulsive Behavior+") OR (MH "Compulsive Behavior+") OR (MH "Risk Taking Behavior+") OR (MH "Disengagement")

**Medline:** (MH "Problem Behavior") OR (MH "Dangerous Behavior") OR (MH "Risk-Taking+") OR (MH "Impulsive Behavior+") OR (MH "Adolescent Behavior+") OR (MH "Violence+") OR (MH "Runaway Behavior") OR (MH "Juvenile Delinquency")

**PsycINFO:** DE "Adolescent Behavior" AND DE "Antisocial Behavior" OR DE "Criminal Behavior" OR DE "Cruelty" OR DE "Dangerousness" OR DE "Emotional Abuse" OR DE "Harassment" OR DE "Patient Abuse" OR DE "Persecution" OR DE "Physical Abuse” OR DE "Runaway Behavior" OR DE "Terrorism" OR DE "Torture" OR DE "Verbal Abuse" OR DE "Violence" AND DE "Behavior Problems" OR DE "Tantrums" OR DE "Compulsions" OR DE "Repetition Compulsion" OR DE "Coping Behavior" OR DE "Coping Style" OR DE "Instinctive Behavior" OR DE "Neophobia" OR DE "Self-Preservation" OR DE "Spontaneous Alternation" OR DE "Resistance" OR DE "Psychotherapeutic Resistance" OR DE "Wandering Behavior"

**Web of Science:** Keywords only on topic search

**Keywords:** (Challeng\* OR threat\* OR danger\* OR violen\* OR difficult\* OR concern\* OR defian\* OR provok\* OR provoc\* OR resist\* OR agress\* OR injur\* OR harm\* OR self-injur\* OR self-harm\* OR selfharm\* OR anger\* OR dysregula\* OR disrupt\* OR problem\* OR dysfunctional\*) N2 (behav\* OR conduct\* OR situat\* OR event\* O) .

## Appendix 2. Summary of papers and associated themes

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Authors**   | **Date**   | **Title**   | **Study Design**  | **Factors that lead to behaviours that challenge**   | **Factors that may lead to crisis**   | **Prevention and management of behaviours that challenge (interventions)**   | **Supports for prevention and management of behaviours that challenge and other crises**   |
| Afif et al.   | 2022   | Effect of Short-Term Deep-Pressure Portable Seat on Behavioral and Biological Stress in Children with Autism Spectrum Disorders: A Pilot Study   | Randomised/experimental   | X   |     | X   |     |
| Agazzi et al.   | 2017   | Does Parent-Child Interaction Therapy Reduce Maternal Stress, Anxiety, and Depression Among Mothers of Children with Autism Spectrum Disorder?   | Case study   |     |     | X   |     |
| Al Sharif and Ratnapalan.   | 2016   | Managing Children With Autism Spectrum Disorders in Emergency Departments   | Case report   | X   |     | X   |     |
| Allen et al.   | 2023   | Parent–Child Interaction Therapy for Children with Disruptive Behaviors and Autism: A Randomized Clinical Trial   | Randomised/experimental  |     |     | X   |     |
| Alsayouf et al.   | 2020   | Pharmacological Intervention in Children with  Autism Spectrum Disorder with Standard Supportive Therapies Significantly Improves Core Signs and Symptoms: A Single-Center, Retrospective Case Series   | Retrospective case series  | X   |     | X   |     |
| Ambitious about Autism.   | 2022   | Behaviours that challenge   | Website   | X   |     |     |     |
| Amstad and Mueller.   | 2020   | Students' Problem Behaviors as Sources of Teacher Stress in Special Needs Schools for Individuals With Intellectual Disabilities   | Quantitative   |     | X   |     |     |
| Anderson, C.   | 2020   | Children With Autism and Aggression   | Website  | X   |     | X   |     |
| Andrews et al.   | 2022   | Efects of Acceptance and Commitment Training Plus Behavior Parent Training on Parental Implementation of Autism Treatment   | Randomised/experimental   | X   |     | X   |     |
| Ang and Loh.   | 2019   | Mental Health and Coping in Parents of Children with Autism Spectrum Disorder (ASD) in Singapore: An Examination of Gender Role in Caring   | Quantitative   | X   |     |     |     |
| Aran et al.   | 2018   | Cannabidiol based medical cannabis in children with autism-a retrospective feasibility study   | Retrospective case series  |     |     | X   |     |
| Aran et al.   | 2021   | Cannabinoid treatment for autism: a proof-of-concept randomized trial   | Randomised/experimental  |     |     | X   |     |
| Argumedes et al.   | 2018   | Brief Report: Impact of Challenging Behavior on Parenting Stress in Mothers and Fathers of Children with Autism Spectrum Disorders.   | Evaluation | X   |     |     |     |
| Ariza et al.   | 2022   | Predictors of Suicidal Thoughts in Children with Autism Spectrum Disorder and Anxiety or Obsessive-Compulsive Disorder: The Unique Contribution of Externalizing Behaviors   | Quantitative cross sectional  |     | X   |     | X   |
| Autism Awareness Centre.   | 2023   | Low Arousal Approach   | Website  |     |     | X   |     |
| Autism CRC.   | 2023   | Behavioural interventions   | Report   |     |     | X   |     |
| Autism Nova Scotia.   | 2019   | In Crisis with Autism Spectrum Disorder Review of the Evidence   | Report   |     | X   |     | X   |
| Autism Speaks.   | 2018   | Challenging Behaviors Tool Kit   | Toolkit   | X   |     |     | X   |
| Autism Spectrum Australia.   | 2021   | Mental health and well-being   | Guidance   | X   |     |     |     |
| Autism Spectrum Australia.   | 2022   | Aspect Policy: Positive Behaviour Support   | Report   |     |     |  X   |     |
| Autistica   | 2020   | Supporting autistic children and young people through crisis   | Support resource  | X   | X   |     | X   |
| Azeem et al.   | 2016   | Autism spectrum disorder: An update   | Narrative literature review  |     |     | X   |     |
| Bagner et al.   | 2023   | Telehealth Treatment of Behavior Problems in Young Children With Developmental Delay: A Randomized Clinical Trial.   | Randomised/experimental  |     |     | X   |     |
| Baker et al.   | 2018   | Sympathetic Under-Arousal and Externalizing Behavior Problems in Children with Autism Spectrum Disorder.   | Intervention study  | X   |     |     |     |
| Beasley, J.B.   | 2017   | START program overview systemic, therapeutic, assessment, resources and treatment. 2017   | Framework  |     |     |     | X   |
| Beauvois and Kverno.   | 2020   | Challenges in Treating Children With Autism Spectrum Disorder: Implications for Psychiatric-Mental Health Nurse Practitioners.   | Narrative Literature review  | X   |     | X   |     |
| Beer et al.   | 2013   | The relationship between mindful parenting and distress in parents of children with an autism spectrum disorder   | Quantitative cross sectional  |     | X   |     |     |
| Bennie, M.    | 2020   | Understanding Why Individuals and Families with ASD Experience Crisis Situations   | Website  |     | X   |     | X   |
| Benninger and Witwer.   | 2017   | Psychometric properties of two measures of crisis and distress in parents of children with Intellectual and Developmental Disabilities   | Quantitative cross sectional   |     | X   |     | X   |
| Beqiraj et al.   | 2022   | Short report: Correlates of behaviours that challenge in children with intellectual disability in special education settings.   | Quantitative cross sectional    | X   |     |     |     |
| Berloco et al.   | 2024   | Insomnia in Children with Autism Spectrum Disorder: A Cross-Sectional Study on Clinical Correlates and Parental Stress.   | Cross-sectional/descriptive   | X   |     |     |     |
| Biswas et al.   | 2015   | What are the factors that influence parental stress when caring for a child with an intellectual disability? A critical literature review   | Scoping/literature review   |     | X   |     |     |
| Boulton et al.   | 2023   | Mental health concerns in children with neurodevelopmental conditions attending a developmental assessment service.   | Quantitative cross sectional   | X   |     |     |     |
| Bourke et al.   | 2023   | Acute Severe Behavioral Disturbance Requiring  Parenteral Sedation in Pediatric Mental Health  Presentations to Emergency Medical Services:  A Retrospective Chart Review   | Retrospective case report  |     |     | X   |     |
| Brashaw et al.   | 2018   | Parent Education for Young Children With Autism and Disruptive Behavior: Response to Active Control Treatment   | Randomised/experimental  |     |     | X   |     |
| Bradshaw et al.   | 2022   | Advances in Supporting Parents in Interventions for Autism Spectrum Disorder   | Narrative literature review  |     |     | X   |     |
| Brei et al.   | 2015   | Predictors of Parenting Stress in Children Referred for an Autism Spectrum Disorder Diagnostic Evaluation   | Cross-sectional/descriptive  |     | X   |     |     |
| Bremer et al.   | 2016   | A systematic review of the behavioural  outcomes following exercise interventions  for children and youth with autism spectrum disorder   | Systematic review  |     |     | X   |     |
| Bresciani et al.    | 2023   | Gastrointestinal Disorders and Food Selectivity: Relationship with Sleep and Challenging Behavior in Children with Autism Spectrum Disorder   | Mixed method cross sectional  | X   |     | X   |     |
| Brian et al.   | 2021   | Effectiveness of Group Stepping Stones Positive Parenting Program for  Children with Autism Spectrum Disorder and Disruptive Behaviour: Program  Evaluation from a Large Community Implementation    | Evaluation |     |     | X   |     |
| Bringing Us Together.   | 2017   | Crisis Prevention - A Family Survival Guide.   | Guidelines  | X   |     |     |     |
| Bringing Us Together.    | 2016   | Avoiding Crisis Support Needed Justice Together Project with Bringing Us Together and Respond.   | Research report  |     |     |     | X   |
| Britton et al.   | 2020   | Examining the Specificity of Forms and Functions of Aggressive  Behavior in Boys With Fragile X Syndrome   | Cross-sectional/descriptive  | X   |     | X   |     |
| Brockman et al.   | 2016   | Managing Child Behavior Problems in Children With Autism Spectrum Disorders: Utilizing Structural and Solution Focused Therapy With Primary Caregivers   | Evaluation |     |     | X   |     |
| Brown et al.   | 2023   | Predictors of Aggression, Disruptive Behavior, and Anger   Dysregulation in Youths with Autism Spectrum Disorder   | Cross-sectional/descriptive  | X   |     |     |     |
| Burton et al.   | 2020   | Self-reported emotion regulation in children with autism spectrum  disorder, without intellectual disability   | Retrospective quantitative cross sectional  | X   |     | X   |     |
| Catalano et al.   | 2018   | Mental Health Interventions for Parent Carers of  Children with Autistic Spectrum Disorder: Practice  Guidelines from a Critical Interpretive Synthesis  (CIS) Systematic Review   | Systematic review  |     |     |     | X   |
| Cervantes et al.   | 2023   | Assessing and Managing Suicide Risk in Autistic Youth: Findings   from a Clinician Survey in a Pediatric Psychiatric Emergency Setting   | Quantitative cross sectional  |     | X   | X   | X   |
| Cervantes et al.   | 2023   | Suicidal ideation and intentional  self-inflicted injury in autism spectrum  disorder and intellectual disability:  An examination of trends in youth  emergency department visits in the  United States from 2006 to 2014   | Retrospective case series  |     | X   |     | X   |
| Chan and Neece.   | 2018   | Parenting Stress and Emotion Dysregulation among Children with Developmental Delays: The Role of Parenting Behaviors   | Randomised/experimental  | X   |     | X   |     |
| Charman et al.   | 2021   | A Novel Group Parenting Intervention for Emotional and Behavioral Difficulties in Young Autistic Children: Autism Spectrum Treatment and Resilience (ASTAR): A Randomized Controlled Trial   | Randomised/experimental  |     |     | X   |     |
| Chen et al..   | 2023   | Impact of Child Behavior Problems on Parenting Stress  and Depressive Symptoms Among Mothers of Children  with Autism Spectrum Disorder: Mediation of  Coping Strategies   | Cross-sectional/descriptive  | X   |     |     |     |
| Chiang et al.   | 2019   | Exploring Sensory Processing Dysfunction,  Parenting Stress, and Problem Behaviors in  Children With Autism Spectrum Disorder   | Cross-sectional/descriptive  | X   |     |     |     |
| Chin et al.   | 2023   | Exploring Coping Strategies of Parents of  Children With Autism Spectrum Disorder in  Taiwan: A Qualitative Study   | Qualitative  |     |     | X   |     |
| Chin et al.   | 2017   | Coping strategies of Taiwanese children with autism spectrum disorders   | Qualitative  |     |     | X   |     |
| Clifford et al.   | 2022   | The effectiveness of an attention-based intervention for school-aged autistic children with anger regulating problems: A randomized controlled trial   | Randomised/experimental  |     |     | X   |     |
| Conner et al..   | 2021   | Emotion Dysregulation is Substantially Elevated in Autism Compared to the General Population: Impact on Psychiatric Services   | Cross-sectional/descriptive  | X   |     |     |     |
| Cook et al..   | 2024   | Suicide risk in transition-aged autistic youth: The link among executive function, depression, and autistic traits   | Cross-sectional/descriptive  |     | X   |     | X   |
| Crea et al.   | 2016   | Proband Mental Health Difficulties and Parental Stress Predict Mental Health in Toddlers at High-Risk for Autism Spectrum Disorders   | Cross-sectional/descriptive   | X   |     |     |     |
| Crnic et al.   | 2017   | Intellectual Disability and Developmental Risk: Promoting Intervention to Improve Child and Family Well-Being   | Scoping/literature review   | X   |     |     |     |
| Croner-i   | 2023   | Challenging Behaviour, Violence and Aggression — Children and Young People (England) Policy   | Website  |     |     |  X   |     |
| Curtin et al.   | 2015   | Food Selectivity, Mealtime Behavior Problems, Spousal Stress, and Family Food Choices in Children with and without Autism Spectrum Disorder   | Cross-sectional/descriptive  | X   |     | X   |     |
| D'Alò et al.   | 2021   | Impact of antipsychotics in children and adolescents with autism spectrum disorder: a systematic review and meta-analysis   | Systematic review  |     |     | X   |     |
| Dababnah et al.   | 2022   | ‘I am so fearful for him’: a mixed-methods exploration of stress among caregivers of Black children with autism   | Mixed method |     | X   |     |     |
| Dababnah and Parish.   | 2016   | Feasibility of an empirically based program for parents of preschoolers with autism spectrum disorder.   | Cross sectional mixed method  |     |     | X   |     |
| Dahiya et al.   | 2022   | Efficacy of a Telehealth Parent Training Intervention for Children with Autism Spectrum Disorder: Rural versus Urban Areas   | Pre/post intervention study  |     |     | X   |     |
| Daly et al.    | 2016   | An Evaluation of Education Provision for Students with Autism Spectrum Disorder in Ireland   | Evaluation  | X   |     |     |     |
| DiRenzo et al.   | 2020   | Parental perception of stress and emotional-behavioural difficulties of children with autism spectrum disorder and specific language impairment   | Cross-sectional/descriptive  | X   |     | X   | X   |
| Dimian et al.   | 2017   | Potential Risk Factors for the Development of Self-Injurious Behavior among Infants at Risk for Autism Spectrum Disorder.   | Cross-sectional/descriptive   | X   |     |     |     |
| Doubet et al.   | 2015   | The Impact of Challenging Behavior on Families: I Don’t Know What to Do.   | Qualitative  |     |     |     | X   |
| Dukmak et al.   | 2023   | Child Behavior Problems as Predictors of Stress in Parents of Children with Developmental and Intellectual Disabilities in Four Emirates of the United Arab Emirates   | Cross-sectional/descriptive  |     | X   |     | X   |
| Efron et al.   | 2023   | Patterns of presentation to a Children’s Hospital Emergency Department of patients with autism and/or intellectual disability with behaviours of concern   | Retrospective audit  |     |     | X   | X   |
| Eldridge, D.   | 2021   | A guide to adaptations for children and young people with behaviours that challenge   | Guidance   | X   |     |     |     |
| Enea and Rusu.   | 2020   | Raising a child with autism spectrum disorder: A systematic review of the literature investigating parenting stress   | Systematic review   |     | X   |     |     |
| Esteves et al.   | 2021   | Occurrence and Predictors of Challenging Behavior in Youth with Intellectual Disability with or without Autism   | Cross-sectional/descriptive  | X   |     |     |     |
| Factor et al.   | 2019   | Teaching emotion regulation to children with autism spectrum disorder: Outcomes of the Stress and Anger Management Program (STAMP)   | Randomised/experimental  |     |     | X   |     |
| Fieiras et al.   | 2021   | Risperidone and aripiprazole for autism spectrum disorder in children: an overview of systematic reviews.   | Systematic review  |     |     |  X   |  X   |
| First et al.   | 2019   | Youth perceptions of stress and coping when transitioning to adulthood with autism: A photovoice study   | Qualitative  |     |     |     |  X   |
| Fitzpatrick et al.   | 2016   | Aggression in autism spectrum disorder: Presentation and treatment options   | Narrative literature review  |     |     | X   |     |
| Fung et al.   | 2016   | Pharmacologic Treatment of Severe Irritability and Problem Behaviors in Autism: A Systematic Review and Meta-analysis.   | Systematic review  |     |     | X   |     |
| Fung et al.   | 2015   | Depression in Youth With Autism Spectrum Disorder: The Role Of ASD Vulnerabilities and Family-Environmental Stressors   | Quantitative cross sectional  | X   |     |     |     |
| Furukawa et al.   | 2018   | Effectiveness of Child-Directed Interaction Training for Young Japanese Children With Autism Spectrum Disorders.   | Randomised/experimental  |     |     | X   |     |
| Gallai et al.   | 2017   | The behavioral parenting interventions (BPT) for support and mandatory integrative therapy for children and adolescents affected by disruptive behavioural disorders: a brief review   | Narrative literature review  |     |     | X   |     |
| Galli et al.   | 2022   | Sleep Disturbances in Children Affected by Autism Spectrum Disorder   | Observational study  | X   |     |     |     |
| Gerson et al.   | 2018   | Crisis in the Emergency Department: The Evaluation and Management of Acute Agitation in Children and Adolescents   | Narrative literature review  |     |     | X   |     |
| Giovagnoli et al.   | 2015   | Behavioral and emotional profile and parental stress in preschool children with autism spectrum disorder   | Cross-sectional/descriptive  |     | X   |     |     |
| Goodwin et al.   | 2019   | Predicting aggression to others in youth with autism using a wearable biosensor.     | Randomised/experimental  |     |     |     | X   |
| Government of Ireland.   | 2022   | Autism Good Practice Guidance for Schools Supporting Children and Young People   | Guidance  |     |     | X   |     |
| Grenier-Martin et al.   | 2022   | Randomized Controlled Trial on an Online Training to Support Caregivers of Young Children with Intellectual and Developmental Disability managing Problem Behaviors at Home.   | Randomised/experimental  |     |     | X   |     |
| Grey et al.   | 2018   | An evaluation of positive behavioural support for children with challenging behaviour in community settings.   | Randomised/experimental  | X   |     |     |     |
| Griffin, M.   | 2015   | Physical intervention training for parents and carers.   | Narrative literature review  |     |     |     | X   |
| Guldberg et al.   | 2022   | Investigation of the causes and implications of exclusion for autistic children and young people   | Scoping/literature review   |     |     |     | X   |
| Hall et al.   | 2020   | Telehealth-enabled behavioral treatment for problem behaviors in boys with fragile X syndrome: a randomized controlled trial   | Randomised/experimental  |     |     | X   |     |
| Harmony and Woodard.    | 2020   | Mindfulness training for staff in a school for children with autism and other developmental disabilities: Effects on staff mindfulness and student behavior   | Randomised/experimental  | X   |     |     |     |
| Hemdi and Daley.   | 2017   | The Effectiveness of a Psychoeducation Intervention delivered via WhatsApp for mothers of children with Autism Spectrum Disorder (ASD) in the Kingdom of Saudi Arabia: A randomized controlled trial.   | Randomised/experimental  |     |     | X   |     |
| Hodgins et al.   | 2022   | Pharmacotherapy of Disruptive Behaviors in Children with Intellectual Disabilities.   | Cross-sectional/descriptive  | X   |     | X   |     |
| Hou et al.   | 2018   | Parenting stress and depressive symptoms in Taiwanese mothers of young children with autism spectrum disorder: Association with children's behavioural problems   | Cross-sectional/descriptive  | X   |     |     |     |
| Hourihan, J   | No date   | De-escalation Strategies to Support Autism Spectrum Disorders   | Website  |     |     | X   |     |
| Health Service Executive   | 2016   | Progressing Disability Services for Children and Young People: Guidance on  Specialist Supports   | Guidance   |     |     |     | X   |
| Huber et al.   | 2023   | Development of a Novel Multi-Disciplinary Specialized Care Service for Children and Adolescents with Autism Spectrum Disorder and/or Intellectual/Developmental Disability in a Tertiary Children's Hospital Setting   | Evaluation |     |     |     | X   |
| Hutchins and Prelock.   | 2014   | Using communication to reduce challenging behaviors in individuals with autism spectrum disorders and intellectual disability   | Evaluation | X   |     |     |     |
| Hwang et al.   | 2015   | Cultivating Mind: Mindfulness Interventions for Children with Autism Spectrum Disorder and Problem Behaviours, and Their Mothers.   | Randomised/experimental  | X   | X   |     |     |
| Iadarola et al.   | 2018   | Teaching Parents Behavioral Strategies for Autism Spectrum Disorder (ASD): Effects on Stress, Strain, and Competence.   | Randomised/experimental   | X   |     |     |     |
| Irish National Teachers’ Organisation.   | 2019   | Guidance on Managing Challenging Behaviour in Schools   | Guidance   | X   |     | X   |     |
| IPPN Leading and Learning.   | 2019   | The use of physical intervention for the prevention and management of crisis situations   | Recommendations  |     |     |     | X   |
| Iwamoto et al.   | 2023   | Exploring Bidirectional Relationships: Child Sleep Duration, Child Behavior Problems, and Parenting Stress in Families of Children with Autism Spectrum Disorder.   | Observational cross-sectional design  | X   |     |     |     |
| James et al    | 2021   | Challenging behaviour around challenging behaviour   | Intervention study  |     |     | X   |     |
| Jellett et al.    | 2015   | Family functioning and behaviour problems in children with Autism Spectrum Disorders: The mediating role of parent mental health.   | Cross-sectional/descriptive  |     | X   | X   |     |
| Jimenez-Gomez et al   | 2023   | Adaptation of the Research Unit on Behavioral Interventions Caregiver Training Program for Remote Group Delivery: Preliminary Analysis of Clinical Outcomes   | Pre/post intervention study  |     |     | X   |     |
| Johnson et al.   | 2015   | Behavioral Parent Training to Address Feeding Problems in Children with Autism Spectrum Disorder: A Pilot Trial   | Pre/post intervention study   | X   |     | X   |     |
| Johnson et al.   | 2018   | Exploring sleep quality of young children with autism spectrum disorder and disruptive behaviors.   | Randomised/experimental  | X   | X   | X   |     |
| Johnson and Zarrinnegar   | 2021   | Autism Spectrum Disorder and Sleep   | Scoping/literature review  | X   | X   | X   |     |
| Jones et al.    | 2018   | A mindfulness parent well-being course: evaluation of outcomes for parents of children with autism and related disabilities recruited through special schools   | Pre/post intervention study   |     |     | X   |     |
| Jones et al.    | 2014   | Child behavior problems and parental well-being in families of children with autism: the mediating role of mindfulness and acceptance.   | Cross-sectional/descriptive  |     | X   | X   |     |
| Kalb et al.    | 2017   | Management of Mental Health Crises Among Youths With and Without ASD: A National Survey of Child Psychiatrists   | Cross-sectional/descriptive  |     | X   | X   | X   |
| Khasakhala et al.    | 2023   | Comorbidity of mental health and autism spectrum disorder: perception of practitioners in management of their challenging behaviour.   | Cross-sectional/descriptive  | X   |     |     |     |
| Koller et al.    | 2022   | The Role of Family Accommodation of RRBs in Disruptive Behavior Among Children with Autism   | Cross-sectional/descriptive  | X   |     |     |     |
| Kuravackel et al.    | 2018   | COMPASS for Hope: Evaluating the Effectiveness of a Parent Training and Support Program for Children with ASD   | Randomised/experimental  |     |     | X   |     |
| Laister et al.    | 2021   | Enhancement of Social Communication Behaviors in Young Children With Autism Affects Maternal Stress   | Randomised/experimental  |     |     | X   |     |
| Lamy and Erickson.   | 2018   | Pharmacological management of behavioral disturbances in children and adolescents with autism spectrum disorders   | Scoping/literature review  |     |     | X   |     |
| Lanyi et al.    | 2022   | Relationship between Comorbid Psychopathology in Children and Adolescents with Autism Spectrum Disorder and Parental Well-being   | Cross-sectional/descriptive  |     | X   |     |     |
| Lee and Chiang.    | 2018   | Parenting stress in South Korean mothers of adolescent children with autism spectrum disorder   | Cross-sectional/descriptive  |     | X   |     |     |
| Leung et al.    | 2020   | Effectiveness of a multidisciplinary parent training program for children with developmental disabilities: A single-blind randomized waitlist controlled trial.   | Randomised/experimental  |     |     | X   |     |
| Lin et al.    | 2021   | Parenting Stress and Child Behavior Problems in Young Children with Autism Spectrum Disorder: Transactional Relations Across Time   | Cross-sectional/descriptive  | X   |     |     |     |
| Lind et al.    | 2020   | Emergent life events in the delivery of a caregiver-mediated evidence-based intervention for children with autism spectrum disorder in publicly funded mental health services   | Cross-sectional/descriptive  |     |     | X   |     |
| Lyons et al.    | 2016   | Assessing the Social Skills and Problem Behaviors of Adolescents With Severe Disabilities Enrolled in General Education Classes   | Cross-sectional/descriptive  | X   |     |     |     |
| Lytle et al.    | 2018   | Youth With Autism Spectrum Disorder in the Emergency Department   | Scoping/literature review  |     | X   |     |     |
| Madarevic et al.    | 2022   | Parenting behaviours among mothers of pre-schoolers on the autism spectrum: Associations with parenting stress and children’s externalising behaviour problems   | Cross-sectional/descriptive   | X   | X   |     |     |
| Manikiza, J.   | 2020   | Autism: A Guide for Early Years Settings   | Guidance   | X   |     | X   |     |
| Martinez et al.    | 2016   | School-based interventions targeting challenging behaviors exhibited by young children with autism spectrum disorder: A systematic literature review   | Systematic review  |     |     | X   |     |
| Masi et al.    | 2015   | Use of Quetiapine in Children and Adolescents   | Scoping/literature review  |     |     | X   |     |
| Masi et al.    | 2020   | Suicidal ideation and suicidal attempts in referred adolescents with high functioning autism spectrum disorder and comorbid bipolar disorder: A pilot study   | Cross-sectional/descriptive  |     | X   |     |     |
| Mazzucchelli et al.    | 2018   | Building Bridges Triple P: Pilot study of a behavioural family intervention for adolescents with autism spectrum disorder   | Pre/post intervention study   |     |     | X   |     |
| McCafferty and McCutcheon.   | 2023   | Parenting a Child with Autism: Considering the Stresses, Supports and Implications for Social Work Practice   | Scoping/literature review  |     | X   |     |     |
| McCrae et al.   | 2020   | Cognitive behavioral treatment of insomnia in school-aged children with autism spectrum disorder: A pilot feasibility study.   | Randomised/experimental  | X   |     | X   |     |
| McGregor et al.     | 2020   | Effects of MBSR parent intervention on internalizing problems in children: ASD status as a moderator   | Randomised/experimental  | X   |     | X   |     |
| McGuire et al    | 2016   | Irritability and Problem Behavior in Autism Spectrum Disorder: A Practice Pathway for Pediatric Primary Care   | Quality improvement  |     |     |     | X   |
| McStay et al.    | 2014   | Parenting stress and autism: the role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism   | Cross-sectional/descriptive  |     | X   |     |     |
| Medda et al.    | 2021   | Pre-Post Effects of the Psychoeducational, Autism-Specific Parent Training FAUT-E   | Pre/post intervention study   |     |     | X   |     |
| Mello et al.    | 2022   | Symptom Severity, Internalized and Externalized Behavioral and Emotional Problems: Links with Parenting Stress in Mothers of Children Recently Diagnosed with Autism   | Cross-sectional/descriptive  |     | X   |     |     |
| Menezes et al.    | 2021   | Relations among co-occurring psychopathology in youth with autism spectrum disorder, family resilience, and caregiver coping   | Cross-sectional/descriptive  |     | X   |     |     |
| Mihaila and Hartley.   | 2018   | Parental sleep quality and behavior problems of children with autism   | Cross-sectional/descriptive  | X   |     |     |     |
| Mira et al.    | 2022   | Exploring the profiles of children with autism spectrum disorder: Association with family factors   | Randomised/experimental  | X   |     |     |     |
| Miranda et al.    | 2019   | Parenting Stress in Mothers of Children With Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies   | Cross-sectional/descriptive  |     | X   |     |     |
| Mueller and Moskowitz.   | 2020   | Positive Family Intervention for Children with ASD: Impact on Parents' Cognitions and Stress   | Randomised/experimental  |     |     | X   |     |
| Murphy et al.    | 2020   | Impact of Disruptive Behavior in Childhood Feeding Difficulties   | Cross-sectional/descriptive  |     |     |     |     |
| Muskett et al.    | 2019   | Repetitive behaviors in Autism Spectrum Disorder: Associations with depression and anxiety symptoms   | Cross-sectional/descriptive  | X   |     |     |     |
| National Autistic Society.   | 2024   | Distressed behaviour - a guide for all audiences.   | Guidance   | X   |     |     |     |
| National Institute for Health and Care Excellence.   | 2018   | Learning disabilities and behaviour that challenges: service design and delivery.   | Guidelines  |     |     |     | X   |
| National Institute for Health and Care Excellence.   | 2015   | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges   | Guidelines   |     |     |     | X   |
| National Health Service.    | 2015   | Building the Right Support.   | Policy guidelines  |     |     |     | X   |
| National Health Service.   | 2023   | Dynamic support register and Care (Education) and Treatment Review policy and guide.   | Policy guidelines   |     |     |     | X   |
| National Health Service, London.   | 2017   | Children and young people with autism spectrum disorder Case for change and recommendations for London   | Recommendations  |     | X   |     |     |
| Neece, C.   | 2014   | Mindfulness-Based Stress Reduction for Parents of Young Children with Developmental Delays: Implications for Parental Mental Health and Child Behavior Problems   | Randomised/experimental  |     |     | X   |     |
| Newcomb and Hagopian.   | 2018   | Treatment of severe problem behaviour in children with autism spectrum disorder and intellectual disabilities   | Scoping/literature review  | X   | X   | X   |     |
| Nichols et al.   | 2018   | Prevalence and correlates of challenging behaviour in children and young people in a special school setting   | Cross-sectional/descriptive  |     | X   |     |     |
| Nicholls et al.   | 2023   | Challenging behaviour and its risk factors in children and young people in a special school setting: A four wave longitudinal study   | Longitudinal study  |     |     |     | X   |
| Nicholas et al.    | 2016   | Toward Practice Advancement in Emergency Care for Children With Autism Spectrum Disorder   | Qualitative study  |     |     | X   |     |
| Nuske et al.    | 2023   | Systematic Review: Emotion Dysregulation and Challenging Behavior Interventions for Children andAdolescents with Autism with Graded Key Evidence-Based Strategy Recommendations.   | Systematic review  |     |     | X   |     |
| Nuske et al.    | 2018   | Emotion Regulation Strategies in Preschoolers with Autism: Associations with Parent Quality of Life and Family Functioning   | Randomised/experimental  |     | X   |     |     |
| O'Brien et al.    | 2022   | Parent Ratings of Generalized and Indirect Effects of Functional Communication Training for Children with Autism Spectrum Disorder.   | Cross-sectional/descriptive  |     |     | X   |     |
| O'Connor et al    | 2023   | Prospective Association of Parenting Stress with Later Child Behavior Problems in Early Childhood Autism   | Cross-sectional/descriptive  | X   |     |     |     |
| O’Nions et al    | 2018   | How do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis   | Scoping/literature review  | X   |     |     |     |
| O'Regan et al.   | 2022   | Reducing challenging behaviours among children and adolescents with intellectual disabilities in community settings: a systematic review of interventions   | Systematic review   |     |     | X   |     |
| Önder et al.    | 2020   | The efficiency and safety of N-acetylcysteine augmentation in the autistic children with severe irritability and aggression: Six cases   | Qualitative   |     |     | X   |     |
| Orji and Sharkey   | 2020   | Self-Injurious Behaviours in Children and Adolescents with Intellectual Disability and Autism Spectrum Disorder   | Case report  |     | X   |     |     |
| Orji and Sharkey   | 2021   | Crisis Presentations of Children and Adolescents with Neurodevelopmental Disorders   | Retrospective case series  | X   |     |     |     |
| Operto et al.    | 2021   | Adaptive Behavior, Emotional/Behavioral Problems and Parental Stress in Children With Autism Spectrum Disorder   | Cross-sectional/descriptive   |     | X   |     |     |
| Padmanabhan and Schroff.   | 2022   | Addressing mealtime behaviours of children with autism spectrum disorders in schools: a qualitative study with educators in Mumbai, India   | Qualitative  | X   |     |     |     |
| Page et al.    | 2022   | Correlates of Feeding Difficulties Among Children with Autism Spectrum Disorder: A Systematic Review.   | Systematic review  | X   | X   |     |     |
| Palmer et al.    | 2020   | Feasibility study of the National Autistic Society EarlyBird parent support programme   | Mixed method  |     |     | X   |     |
| Palmer et al.    | 2023   | Parent, Teacher and Observational Reports of Emotional and Behavioral Problems in Young Autistic Children   | Cross-sectional/descriptive  |     | X   |     |     |
| Pan et al.    | 2023   | Meta-analysis of effectiveness of parent-mediated telehealth interventions in children with Autism spectrum disorder   | Systematic review  |     |     | X   |     |
| Papadopoulos et al.    | 2022   | Sleeping Sound Autism Spectrum Disorder (ASD): a randomised controlled trial of a brief behavioural sleep intervention in primary school-aged autistic children   | randomised/experimental  | X   |     | X   |     |
| Parlade et al.    | 2020   | Parent-Child Interaction Therapy for children with autism spectrum disorder and a matched case-control sample.   | Randomised/experimental  |     |     | X   |     |
| Pavlov, A.   | 2021   | Crisis Management in Children with Autism and First Responders   | Website  |     | X   |     | X   |
| Pennefather et al.    | 2018   | Evaluation of an online training program to improve family routines, parental well-being, and the behavior of children with autism   | Cross-sectional/descriptive   |     |     | X   |     |
| Phetoe et al.   | 2022   | The Experiences of Families Raising an Autistic Child: A Rapid Review   | Literature Review  |     | X   |     |     |
| Pillai et al   | 2016   | Parent-reported factors associated with the emergency department presentation of children and adolescents with autism spectrum disorder and/or intellectual disability with behaviours of concern: a qualitative study   | Qualitative  |     | X   |     | X   |
| Pinto-Silva et al.    | 2022   | Feeding problems in children with autism spectrum disorders: A systematic review   | Systematic review  | X   |     |     |     |
| Postorino et al.    | 2019   | Clinical Correlates of Parenting Stress in Children with Autism Spectrum Disorder and Serious Behavioral Problems   | Randomised/experimental  |     | X   |     | X   |
| Raising Children Australia.   | 2024   | Challenging behaviour: autistic children and teenagers   | Website  | X   |     |     |     |
| Raising Children Australia.   | 2024   | Anxiety: autistic children and teenagers   | Website  | X   |     |     |     |
| Randell et al.    | 2022   | Sensory integration therapy for children with autism and sensory processing difficulties: the SenITA RCT   | Randomised/experimental  |     |     | X   |     |
| Rauf et al.   | 2018   | Association of autism child characteristics with maternal and paternal stress   | Cross-sectional/descriptive  |     | X   |     |     |
| Raulston et al.   | 2021   | Mindful Parenting, Caregiver Distress, and Conduct Problems in Children With Autism.   | Cross-sectional/descriptive  |     |     | X   |     |
| Raulston et al.   | 2019   | Effects of a brief mindfulness-infused behavioral parent training for mothers of children with autism spectrum disorder   | Randomised/experimental  |     |     | X   |     |
| Reed, P.   | 2020   | Child behaviour problems moderate effectiveness of coping strategies except for reframing for mothers of children with ASD   | Cross-sectional/descriptive  | X   |     |     | X   |
| Reid et al.   | 2016   | New ways of seeing and being: Evaluating an acceptance and mindfulness group for parents of young people with intellectual disabilities who display challenging behaviour.   | Evaluation |     |     | X   |     |
| Richards, B.   | 2017   | Caring for children with autism spectrum condition in paediatric emergency departments.   | Cross-sectional/descriptive  |     |     |     | X    |
| Rivard et al.    | 2021   | Using Prevent Teach Reinforce for Young Children to Manage Challenging Behaviors in Public Specialized Early Intervention Services for Autism.   | Mixed method  |     |     | X   | X   |
| Rodriguez et al.   | 2019   | Transactional Relations Between Parenting Stress and Child Autism Symptoms and Behavior Problems.   | Randomised/experimental  | X   | X   |     |     |
| Rojas-Torres et al.   | 2023   | Mindfulness Parenting and Childish Play: A Clinical Trial With Parents of Children With Autism Spectrum Disorders.   | Randomised/experimental  |     |     | X   |     |
| Ros-DeMarize, et al.   | 2023   | Tele-PCIT: Initial Examination of Internet Delivered PCIT for Young Children with Autism.   | Randomised/experimental  |     |     | X   |     |
| Ros, and Graziano.   | 2019   | Group PCIT for Preschoolers with Autism Spectrum Disorder and Externalizing Behavior Problems.   | Evaluation |     |     | X   |     |
| Roselló et al.   | 2022   | Personal and Family Childhood Predictors of Functional Outcomes of Adolescents With Autism Spectrum Disorder.   | Cross-sectional/descriptive   |   |     | X   |     |
| Roubinov et al.   | 2022   | Is it me or my child? The association between maternal depression and children's behavior problems in mothers and their children with or without autism   | Cross-sectional/descriptive  | X   |     |     |     |
| Royal College of Occupational Therapists.   | undated   | Adaptations for autistic children and young adults with behaviours that challenge   | Guidance  | X   |     |     |     |
| Ruppel et al.   | 2021   | An Evaluation of "Balance": a Home-Based, Parent-Implemented Program Addressing Emerging Problem Behavior.   | Evaluation |     |     | X   |     |
| Salem-Guirgis, et al.   | 2019   | MYmind: a Concurrent Group-Based Mindfulness Intervention for Youth with Autism and Their Parents.   | Evaluation |     |     | X   |     |
| Sanner and Neece.   | 2018   | Parental Distress and Child Behavior Problems: Parenting Behaviors as Mediators.   | Cross-sectional/descriptive  |     |     | X   |     |
| Salomone et al.   | 2014   | Emotional and behavioural problems in children and young people with autism spectrum disorder in specialist autism schools   | Cross-sectional/descriptive  |     | X   |     | X   |
| Scagnelli et al.   | 2017   | Does a treatment for increasing social skill affect the occurrence of challenging behaviors?   | Mixed method  |     |     | X   |     |
| Schiltz et al.   | 2018   | Examining the Links Between Challenging Behaviors in Youth with ASD and Parental Stress, Mental Health, and Involvement: Applying an Adaptation of the Family Stress Model to Families of Youth with ASD.   | Randomised/experimental  |     |     | X   | X   |
| Schnabel et al.   | 2020   | An Initial Examination of Post-Traumatic Stress Disorder in Mothers of Children with Autism Spectrum Disorder: Challenging Child Behaviors as Criterion A Traumatic Stressors.   | Qualitative  |     | X   |     |     |
| Schwartzman et al.   | 2023   | Assessing suicidal thoughts and behaviors and nonsuicidal self-injury in autistic and non-autistic early adolescents using the Columbia Suicide Severity Rating Scale   | Cross-sectional/descriptive  |     | X   |     | X   |
| Scudder et al.   | 2019   | Parent–child interaction therapy (PCIT) in young children with autism spectrum disorder.   | Randomised/experimental  |     |     | X   |     |
| Severini et al.   | 2018   | Systematic Review of Problem Behavior Interventions: Outcomes, Demographics, and Settings   | Systematic review  |     |     | X   |     |
| Shaffer et al.   | 2023   | Regulating Together: Emotion Dysregulation Group Treatment for ASD Youth and Their Caregivers.   | Pre/post intervention study  | X   |     | X   |     |
| Shawler and Sullivan.   | 2017   | Parental Stress, Discipline Strategies, and Child Behavior Problems in Families With Young Children With Autism Spectrum Disorders.   | Cross-sectional/descriptive  | X   |     |     |     |
| Shepherd et al.   | 2020   | The Cold Shoulder or a Shoulder to Cry on? Mechanisms of Formal and Informal Social Support in the ASD Parenting Context   | Cross-sectional/descriptive  |     |     |     | X   |
| Shiri et al.    | 2020   | A pilot study of family-based management of behavioral excesses in young Iranian children with autism spectrum disorder.   | Randomised/experimental  |     |     | X   |     |
| Simó-Pinatella et al.   | 2023   | Addressing Challenging Behaviours in Children with Autism: A Qualitative Analysis of Teachers' Experiences.   | Qualitative  |     |     |     | X   |
| Singh et al.   | 2019   | Effects of Mindfulness-Based Positive Behavior Support (MBPBS) Training Are Equally Beneficial for Mothers and Their Children With Autism Spectrum Disorder or With Intellectual Disabilities.   | Evaluation |     |     | X   |     |
| Singh et al.   | 2021   | A Component Analysis of the Mindfulness-Based Positive Behavior Support (MBPBS) Program for Mindful Parenting by Mothers of Children with Autism Spectrum Disorder.   | Randomised/experimental  |     |     | X   |     |
| Singh et al.   | 2014   | Mindfulness-based positive behavior support (MBPBS) for mothers of adolescents with autism spectrum disorder: Effects on adolescents’ behavior and parental stress   | Randomised/experimental  |     |     | X   |     |
| Siracusano et al.   | 2021   | TrASDition Training: An online parental training for transition-age youth with autism spectrum disorder.   | Evaluation |     |     | X   |     |
| Siu et al.   | 2019   | The Role of Child Problem Behaviors in Autism Spectrum Symptoms and Parenting Stress: A Primary School-Based Study.   | Cross-sectional/descriptive  | X   | X   |     |     |
| Smith et al.   | 2014   | The family context of autism spectrum disorders: influence on the behavioral phenotype and quality of life.   | Narrative literature review  |     |     | X   |     |
| Stark et al.   | 2015   | Brief Report: Understanding Crisis Behaviors in Hospitalized Psychiatric Patients with Autism Spectrum Disorder--Iceberg Assessment Interview.   | Retrospective Case series  | X   |     |     | X   |
| Stephenson et al.   | 2023   | Child Behavior Problems and Parenting Stress in Underserved Families of Children with ASD: Investigation of Family Resources and Parenting Self-efficacy.   | Cross-sectional/descriptive  | X   | X   |     |     |
| Suh et al.   | 2023   | Effectiveness of a Training Program for Parents of Toddlers with or at Risk of Autism Spectrum Disorder   | Randomised/experimental  |     |     | X   |     |
| Tarver et al.   | 2019   | Child and parent outcomes following parent interventions for child emotional and behavioral problems in autism spectrum disorders: A systematic review and meta-analysis.   | Systematic review  | X   | X   |     |     |
| Taylor et al.   | 2019   | Inpatient Psychiatric Treatment of Serious Behavioral Problems in Children with Autism Spectrum Disorder (ASD): Specialized Versus General Inpatient Units.   | Pre/post intervention study  |     | X   | X   |     |
| Teksöz, E.   | 2019   | Introducing a New Nursing Intervention Developed for Self-Injury Behaviour in Children with Intellectual Disabilities.   | Case report  |     |     | X   |     |
| Tellegen and Sanders.   | 2014   | A randomized controlled trial evaluating a brief parenting program with children with autism spectrum disorders.   | Randomised/experimental  |     |     | X   |     |
| Tevis and Matson.   | 2022   | Challenging behaviour in children with developmental disabilities: An overview of behavioural assessment and treatment methods   | Narrative literature review  | X   |     |     |     |
| The Challenging Behaviour Foundation.   | 2014   | Early intervention for children with learning disabilities whose behaviours challenge   | Report  |     |     | X   |     |
| The National Council for Special Education   | 2020   | Promoting Learning and Positive Behaviour at Home Behaviour Support Pack for Children and Young People with Additional Needs   | Support resources  |     |     |     | X   |
| The Spectrum.   | 2024   | Autism behavioural strategies   | Website |     |     | X   |     |
| Thullen and Bonsall.   | 2017   | Co-Parenting Quality, Parenting Stress, and Feeding Challenges in Families with a Child Diagnosed with Autism Spectrum Disorder.   | Mixed method   | X   | X   |     |     |
| Tucker V.   | 2015   | Managing Challenging Behavior Due to Autism during Emergencies: Advice for First Responders.   | Website  |     |     |     | X   |
| Valencia Medina, et al.   | 2020   | Exploring patterns between school perceptions, child behavior, and maternal well-being among Latina mothers of children with autism spectrum disorder (ASD).   | Qualitative  |     | X   |     |     |
| Van Schalkwyk et al.   | 2015   | Reduction of Aggressive Episodes After Repeated Transdermal Nicotine Administration in a Hospitalized Adolescent with Autism Spectrum Disorder   | Case report  |     |     | X   |     |
| Vasa et al.   | 2020   | Investigating Mental Health Crisis in Youth with Autism Spectrum Disorder   | Cross-sectional/descriptive  |     |     |     | X   |
| Vasa et al.    | 2024   | Mental Health Crises in Autistic Children: A Framework for Prevention and Intervention in Primary Care. Pediatric clinics of North America   | Framework  |     |     |     | X   |
| Vasquez et al.   | 2017   | The Effects of Advance Notice on Problem Behavior Occasioned by Interruptions of an Ongoing Activity in a Young Girl with Autism.   | Evaluation | X   |     | X   |     |
| Weiss et al.   | 2015   | Empowerment and parent gain as mediators and moderators of distress in mothers of children with autism spectrum disorders   | Cross sectional descriptive  | X   | X   |     |     |
| Whelan et al.   | 2022   | Examining the Relationship Between Sleep Quality, Social Functioning, and Behavior Problems in Children with Autism Spectrum Disorder: A Systematic Review.   | Systematic review  | X   |     |     |     |
| Widnall et al.   | 2022   | Autism spectrum disorders as a risk factor for adolescent self-harm: a retrospective cohort study of 113,286 young people in the UK.   | Retrospective cohort study  |     | X   |     |     |
| Wieckowski et al.   | 2020   | Gender Differences in Emotion Dysregulation in an Autism Inpatient Psychiatric Sample.   | Cohort (descriptive)  | X   |     |     |     |
| Winder-Patel et al.   | 2022   | Often Undiagnosed but Treatable: Case Vignettes and Clinical Considerations for Assessing Anxiety Disorders in Youth with Autism Spectrum Disorder and Intellectual Disability   | Narrative literature review  |     |     |     | X   |
| Wolpert et al.   | 2023   | Behavioral Management of Children With Autism in the Emergency Department.   | Narrative literature review  | X   | X   | X   | X   |
| Wong et al.   | 2020   | Predicting the Outcomes of Parents of Transition-Age Youth or Young Adults with ASD.   | Quantitative descriptive  | X   | X   |     | X   |
| Zaidman-Zait et al.   | 2014   | Examination of bidirectional relationships between parent stress and two types of problem behavior in children with autism spectrum disorder.   | Quantitative descriptive   | X   | X   |     |     |
| Zaidman-Zait et al.   | 2017   | Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder.   | Longitudinal cohort study  | X   | X   |     | X   |
| Zanotti, J.M.    | 2018   | Handle with care: Caring for children with autism spectrum disorder in the ED.   | Narrative literature review  |     |     |     | X   |

## Appendix 3. Measures identified in reviewed papers

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| **Listed Measures** |
| 3 Day Food Records (3DFRs) |
| Aberrant Behavior Checklist (ABC) |
| Aberrant Behavior Checklist, Irritability subscale (ABC-I) |
| ABCX - Includes Three Predictors Of Adaptation (X)—Stressors (A), Resources (B), And Family Coping And Perception (C) |
| Abbreviated Battery of the Stanford-Binet Intelligence Scales Fifth Edition (SB-V) |
| Adaptive Behavior Assessment System-Second Edition (ABAS-II) |
| Arabic Scale of Happiness |
| Assessment of Concerning Behaviors scale (ACB) |
| Autism Diagnostic Interview, Revised (ADI-R) |
| Autism Diagnostic Observation Schedule—Second Edition (ADOS-2) |
| Autism Diagnostic Observation Schedule-Generic (ADOS-G) |
| Autism Impact Measure (AIM) |
| Autism Spectrum Disorder-Comorbid for Children (ASD-CC) |
| BAMBI (Brief Autism Mealtime Behavior Inventory) |
| Bangor Mindful Parenting Scale (BMPS) |
| Barratt Impulsiveness Scale-11 (BIS-11) (measures impulsivity) |
| Bayley Scales of Infant Development – Second Edition (BSID-II-NL) |
| Beach Family Quality of Life [quality of life] (FQOL) |
| Beck Depression Inventory-II (BDI-II) |
| Behavior Problem Inventory (BPI) |
| Brief Autism Mealtime Behavior Inventory (BAMBI)  |
| Brief Family Distress Scale (BFDS) |
| Caregiver Strain Questionnaire (CGSQ) |
| Challenging Behaviour Attribution Scale (CHABA) |
| Child Adjustment and Parent Efficacy Scale—Developmental Disability (CAPES-DD) |
| Child Behavior Checklist (CBCL) |
| Child Behavior Checklist for Ages 1½-5 (CBCL/1½-5) |
| Children's Sleep Habits Questionnaire (CHSQ) |
| Client Satisfaction Questionnaire |
| Clinical Global Impression Improvement (CGI-I) |
| Cognitive Assessment |
| Columbia Suicide Severity Rating Scale (C-SSRS) |
| Consultation Satisfaction Questionnaire (CSQ) |
| CSQ (Consultation Satisfaction Questionnaire) |
| CSHQ (Children Sleep Habits Questionnaire) |
| Depression Anxiety Stress Scales (DASS) |
| Demographic data |
| Dyadic Parent–Child Interaction Coding System, Fourth Edition (DPICS-IV) |
| Dyadic Parent–Child Interaction Coding System, Fourth Edition (DPICS-IV). The DPICS |
| Emotion Dysregulation Inventory (EDI) |
| Family Accommodation Scale for Restricted and Repetitive Behaviors: the FAS-RRB |
| Family Assessment Device – General Functioning Scale (FAD-GF) |
| Family Environment Scale  |
| Fatigue Assessment Scale |
| Five Facet Mindfulness Questionnaire (FFMQ) |
| Freiburg Mindfulness Inventory [mindfulness] (FMI) |
| Frequency of target behaviours |
| Functional Analysis Screening Tool (FAST) |
| Functional behavioral assessment |
| Goal Achievement Scales (GAS) |
| Griffiths Mental Developmental ScaleExtended Revised (GMDS-ER) |
| Group Session Rating Scale (GSRS) |
| Gumpel School Readiness Scale |
| GISSI-17 (AS-ATN GI Signs and Symptoms Inventory-17) |
| Height Weight, & Body Mass Index (BMI) |
| Home Situations Questionnaire–Autism Spectrum Disorders (HSQ-ASD) |
| HoNOS – learning disabilities |
| Hospital Anxiety and Depression Scale (HADS) |
| Knowledge of Applied Behavior Analysis Principles  |
| Leiter-3 test of nonverbal intelligence |
| Maladaptive Behavior Index (MBI) |
| Modified Checklist for Autism in Toddlers (M CHAT) |
| Mullen Scales of Early Learning (MSEL) |
| Mullen Scales of Early Learning (MSEL)  |
| Multidimensional Scale of Perceived Social Support (MSPSS) |
| Multi-Attitude Suicide Tendency Scale (MAST) |
| The Acceptance and Action Questionnaire— Intellectual Disability Parent version (AAQ-ID) |
| Parenting Knowledge Test (PKT) |
| Parenting Scale (PS) – The Parenting Scale  |
| Parenting Sense of Competence (PSCO) |
| Parenting Stress Index – Short Form (PSI-SF) |
| Parenting Stress index-Chinese Short Form (PSI-CSF) |
| Pediatric quality of life inventory (PEDS QL) |
| Periodic service review (PSR), BSP-QE II |
| Pervasive Developmental Disorder Behavior Inventory—Social Approach Behaviors |
| Pittsburgh Sleep Quality Index (PSQI) |
| Positive Gain Scale (PGS) |
| Preschool Anxiety Scale–Revised (PASR) |
| PS (Parenting Scale) |
| PSI-SF (Parenting Stress Index- Short form) |
| Psychological services and other related services |
| Psychotropic medications |
| QoL questionnaire (QoL-Q) |
| Questionnaire Social Behavior (QSB) |
| Repetitive Behavior Scale-Revised (RBS-R) |
| Resilience scale for Adolescent (READ) (measures resilience) |
| Short Sensory Profile - Chinese Version (SSP-C) |
| Snijders-Oomen Nonverbal Intelligence Test (SON-R 2½-7) |
| Stanford-Binet Fifth Edition (SB-V) |
| Strength and Difficulties Questionnaire (SDQ) |
| Subject Diagnostic and Characterization Measures |
| Survey Interview, 2nd edition (VABS) |
| Swedish Eating Assessment for ASDs  |
| The Achenbach System of Empirically Based Assessment |
| The Aberrant Behavior Checklist (ABC) |
| The Acceptance and Action Questionnaire— Intellectual Disability Parent version (AAQ-ID) |
| The Aut-Eat questionnaire |
| The B-COPE  |
| The Beck Depression Inventory-II (BDI-II) |
| The CARS (Childhood Autism Rating Scale) |
| The Children’s Eating Behavior Questionnaire  |
| The Children’s Scale of Hostility and Aggression: Reactive/ Proactive (C-SHARP, version 2.0) |
| The Cognition Scale of the Hong Kong Comprehensive Assessment Scale for Preschool Children (HKCAS-P) |
| The Demographic data |
| The Dysregulation Coding System (DCS) |
| The EDQ |
| The ERICA  |
| The Eyberg Child Behavior Inventory (ECBI) |
| The Family Accommodation Scale for Restricted and Repetitive Behaviors: the FAS-RRB |
| The Family Assessment Device – General Functioning Scale (FAD-GF) |
| The Five Facet Mindfulness Questionnaire (FFMQ) |
| The Food Preferences Inventory |
| The Hospital Anxiety and Depression Scale (HADS) |
| The Hong Kong Preschool Fine Motor Developmental Assessment (HK-PFMDA) |
| The Knowledge of Applied Behavior Analysis Principles  |
| The MABC-2 (Movement Assessment Battery for Children-version 2) |
| The Movement Assessment Battery for Children-version 2 (MABC-2) |
| The Mullen Scales of Early Learning (MSEL)  |
| The Observation Schedule for Children with Autism–Anxiety, Behavior and Parenting (OSCA– ABP23) |
| The Parent and Family Problems Subscale of the Questionnaire on Resources and Stress— Short Form (QRS-F) |
| The Parent Stress Index-Short Form (PSI-SF) |
| The Parent-Child Interaction Rating System (PCIRS) |
| The Parenting Scale (PS) – The Parenting Scale (Arnold et al., 1993) |
| The Positive Gain Scale (PGS) |
| The Preschool Anxiety Scale–Revised (PASR) |
| The PSI-CSF (Parenting Stress index-Chinese Short Form) |
| The Questionnaire Social Behavior (QSB) |
| The Screening Tool of Feeding Problems for Children—STEP-CHILD  |
| The Social Communication Questionnaire  |
| The Social Responsiveness Scale (SRS) |
| The SSIS-RS (Gresham & Elliot, 2008) |
| The Stanford-Binet Fifth Edition (SB-V) |
| The Strength and Difficulties Questionnaire (SDQ) |
| The Swedish Eating Assessment for ASDs  |
| The Teacher Rating Form, a teacher version of the CBCL (TRF) |
| The Treatment Acceptability Rating Form—Revised (TARF-R) |
| The Vineland Adaptive Behavior |