Mental health of children with intellectual disabilities: assessment and support in the paediatric clinic

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Abstract

Children with intellectual disabilities may present to child health services with changes in their mood, behaviour and functioning secondary to mental health difficulties, but also for a range of other reasons like responses to pain or changes to their environment. These clinical features can significantly affect their quality of life, access to education and community resources, as well as the wellbeing of their families and carers. Assessment and support for this clinical presentation can occur meaningfully in child health services and the paediatric clinic as well as in school, in addition to mental health services. This short article aims to support paediatricians and other child health professionals adopt a holistic, rights-based and person-centered approach; and suggests practical strategies when assessing and supporting children with intellectual disability who present with altered mood, behaviour and functioning.

Keywords adolescents; behaviours that challenge; capable environments; children; intellectual disabilities; learning disabilities; mental health; positive behaviour support; restrictive practice

Introduction

An intellectual disability is a lifelong condition characterised by significant limitations in both intellectual functioning and adaptive behaviour, with onset during childhood. Intellectual functioning refers to abilities such as reasoning, learning, problem-solving, and understanding complex information, while adaptive behaviour covers everyday practical, social, and communication skills needed for independent functioning. Intellectual disabilities (ID) are commonly referred to as learning disabilities (LD) in child health services in the UK, and we will use the two terms interchangeably.

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Severity of ID can be defined from mild to profound, based on functional abilities rather than intellectual functioning alone. Table 1 gives examples of the presentation and needs commonly associated with different severities of ID. Children with more severe ID are at greater risk of communication difficulties, physical comorbidities, and behavioural distress.

Children with ID present with higher rates of mental illness (e.g. a tenfold increase in schizophrenia compared to the general population) and neurodevelopmental disorders (e.g. autism co-occurs in about 40% of children with ID). These conditions may present with affected children displaying a range of emotional and behavioural features, as well as changes to their daily functioning. As such, they may be referred to a range of health services including for assessment in the paediatric clinic.[1]

Assessment in the paediatric clinic

Reasonable adjustments

Prior to the child with ID being seen in a health setting, there should be the consideration of making reasonable adjustments based on their individual profile. This can be facilitated by their families and others who know them well like school staff, by completing a health and care passport - free templates are available from the NHS (www.england.nhs.uk/publication/health-and-care-passports/). This ensures that considerations like sensory aspects of the waiting area and clinical spaces, and preparation with information to reduce uncertainty, are progressed to support the child's communication and engagement with any clinical assessment or review.

Behaviours that challenge

Children with ID may be referred to paediatrics after presenting with behaviours that challenge. These are behaviours that others (typically family members or school staff) find difficult to manage, and that may get in the way of the child's education, relationships and everyday activities. Behaviours that challenge should be understood primarily as a form of communication, particularly in children with limited expressive language. Distress, sensory overload, or unmet needs may further reduce communication capacity, resulting in increased reliance on behavioural expression.

A functional behaviour assessment is a systematic method for people supporting the child with ID to identify and understand what the behaviours that challenge are communicating or achieving. Table 2 gives examples of common functions.

There are a range of helpful tools for families, schools and clinicians to conduct a functional behaviour assessment and inform an evidence-based approach to understanding such behaviours that challenge. These include structured behaviour logs like ABC (Antecedent Behaviour Consequence) charts and comprehensive questionnaires. Figure 1 gives an example of an ABC chart.

Physical health

Children with ID are more likely than their typically developing peers to present with co-occurring physical health conditions. These commonly include other neurodisabilities, such as cerebral palsy, as well as sensory impairments affecting hearing and vision (including cerebral visual impairment). Additionally,

Communication profile and support needs commonly associated with different severities of intellectual disability

Severity of ID	Communication profile	Common support needs
Mild	Usually communicates verbally but may have variable comprehension	Requires support in education and with social skills
Moderate	Limited verbal skills and usually needs visual supports	Requires structured routines and close supervision
Severe	Minimal verbal communication or non-verbal	Requires support for daily tasks almost all the time
Profound	Non-verbal and has complex physical needs	Requires full-time care and/or specialist services

Table 1

Examples of different functions for a child with LD presenting with behaviours that challenge

Function	Description	Example
Social attention	Gaining interaction or reassurance	Aggression leading to increased carer contact
Access	Obtaining preferred items or activities	Tantrum followed by access to tablet
Escape/avoidance	Reducing demands or tasks	Behaviour resulting in school exclusion
Sensory regulation	Self-stimulation or sensory modulation	Rocking, increased vocalisations
Pain or discomfort	Expression of physical distress	Self-injury associated with constipation

Table 2

many genetic syndromes associated with ID are characterised by multi-system involvement. For example, Smith–Magenis syndrome is frequently associated not only with ID but also with cardiovascular, gastrointestinal and ocular abnormalities.

Neurological disorders represent the largest and most clinically significant group of co-occurring physical disorders, particularly in children with severe to profound ID. Epilepsy is a prominent example. Seizures may present in atypical ways, with some focal seizures manifesting primarily as changes in mood or behaviour. Furthermore, poorly controlled epilepsy and the adverse effects of anti-seizure medications can contribute to, or exacerbate, behaviours that challenge in children with ID. Epilepsy also occurs at increased rates in a number of genetic syndromes associated with intellectual disability, including Angelman syndrome and tuberous sclerosis, further compounding clinical complexity and care needs.

Physical health difficulties like pain, constipation and reflux may be common and frequently overlooked drivers of new or escalating behaviours that challenge, and assessment in the paediatric clinic may be a valuable opportunity to identify and treat such issues. These physical health difficulties may be missed when the child's ID and limited communication impacts the clinical assessment, leading clinicians to attribute behaviours that challenge to the disability itself, rather than recognising them as possible indicators of co-occurring physical health, mental health or neurodevelopmental conditions – this is termed diagnostic overshadowing. Behaviour then becomes the focus rather than a signal of unmet need or underlying pathology. Table 3 lists common examples of physical health difficulties and conditions which may be prone to diagnostic overshadowing. Table 4 lists various online resources which both clinicians and non-professionals can use to progress a functional behaviour assessment or aid paediatric clinic reviews when children with ID present with behaviours that challenge.

There may be difficulties conducting a physical examination or progressing investigations like phlebotomy as impacted by the child's limited communication or anxiety, but what we have learned from multiple child death reviews and the Learning from lives and deaths - people with a learning disability and autistic people (LeDeR) reviews, is that relatively simple health issues when neglected can often lead to serious health consequences and even death. (see https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-lives-and-deaths/ for more details).

It is therefore critical that child health professionals work with families and other support staff (e.g. hospital learning disability nurse or play therapist) to ensure that the appropriate physical examination and investigations are completed.

In view of the increased morbidity and mortality associated with having ID, child health professionals should also ensure that children with ID in the UK are registered on their GP practice's learning disabilities register and accessing annual health checks from age 14. This national initiative is an important opportunity for prevention and early intervention for both physical and mental health conditions.

Putting the assessment together: framework for a clinical formulation

A clinical formulation using the 4 Ps framework (Box 1) is a helpful way to summarise the findings from the functional behaviour assessment and physical health assessment, alongside any other significant factors and events identified in the paediatric assessment. The formulation can then serve as a helpful

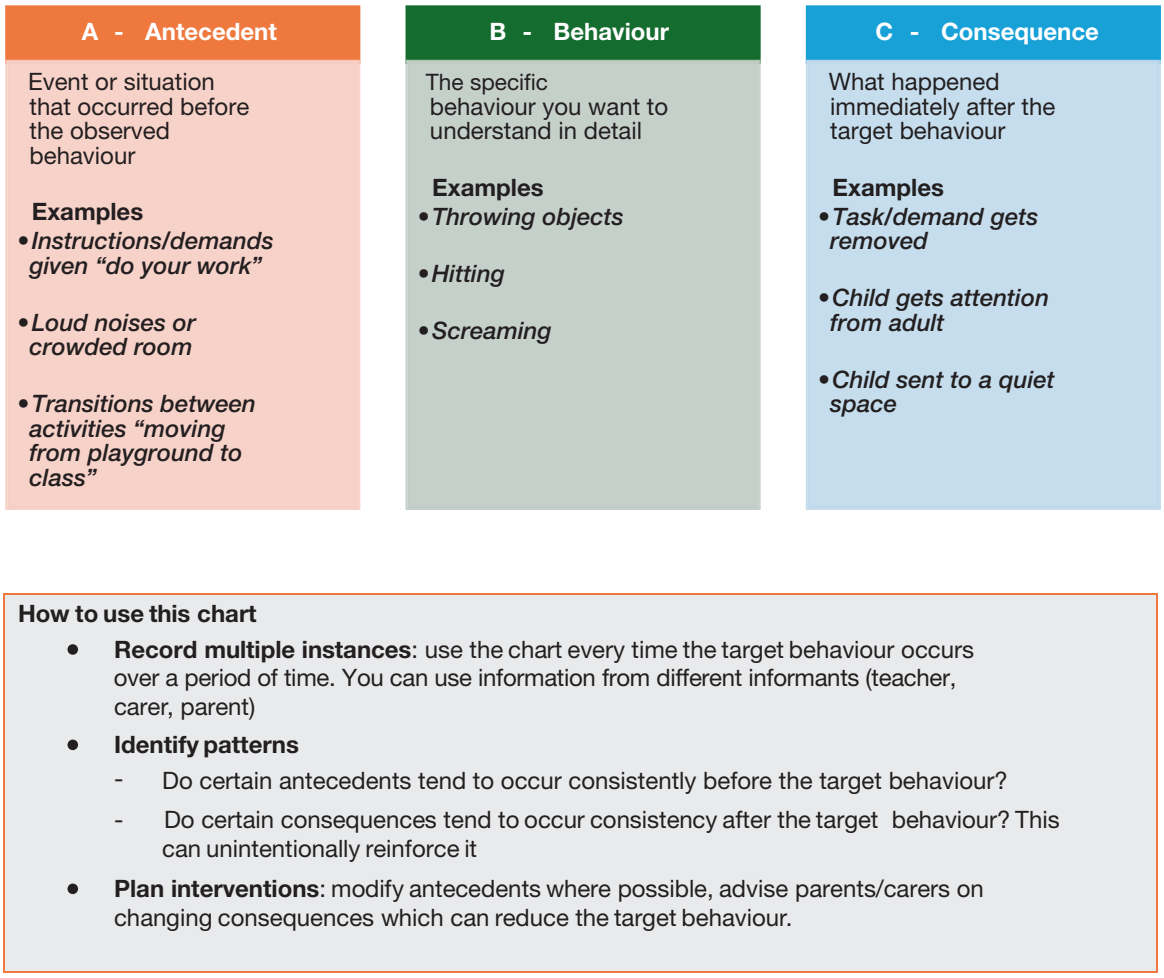

Figure 1 ABC (antecedents behaviour consequences) chart.

Examples of physical health difficulties which may present with behaviours that challenge and possible assessment tools

Health issue	Behavioural presentation	Possible assessment tools
Constipation	Irritability, aggression, self-injury	Bristol stool chart
Pain	Withdrawal, agitation	FLACC pain scale
Gastro-oesophageal reflux	Distress, feeding refusal	Paediatric gastro-oesophageal reflux disease symptom and quality of life questionnaire (PGSQ)
Dental disease	Facial touching/hitting, aggression around mealtimes	Dental examination
Infection (e.g. ear infection, urinary tract infection)	Sudden behaviour change alongside other systemic signs of infection including pyrexia	Bloods. Otoscopy. Urine dipstick, urinalysis and culture

Table 3

way to share an understanding with the family and other professionals about relevant factors, diagnoses and the impact of the child's presentation, so that this informs referrals to other services (e.g. CAMHS Learning Disabilities services, Disabled Children's services in social care) or guides the delivery of evidence-based interventions.

Relevant ethical principles and legal frameworks

It is important when working with children with ID to balance having the voice of the child at the centre of the assessment, while safeguarding them and ensuring their wellbeing and safety. Gillick competence and principles of mental capacity legislation (e.g. Mental Capacity Act 2015 in England) therefore applies. It

Online resources to help with assessment of children with ID presenting with behaviours that challenge

Resource by	Suitable for	Web address
Challenging Behaviour Foundation	Family carers and professionals	www.challengingbehaviour.org.uk/information-and-guidance/positive-behaviour-support/
British Institute of Learning Disabilities (bild)	Professionals	www.bild.org.uk/about-pbs/
Mencap	Family carers	www.mencap.org.uk/advice-and-support/social-care/childrens-social-care/support-parents-and-carers-children-and-young
Cerebra — Behaviour Checklist	Family carers and professionals	https://cerebra.org.uk/get-advice-support/emotional-mental-health/behaviour-checklist/

Table 4

should not be presumed that due to the diagnosis of ID, that the child automatically cannot be part of the decision process. Mental capacity is time and decision specific. For a child (if under 16) to have Gillick competence or mental capacity (if over 16), they need to be able to understand, retain, weigh up the pros and cons, and communicate the decision in question. When they are found not to have competence or capacity, decisions can be made by a parent(s) who has parental responsibility, or in the case of a young person over age 16, as part of a best interest decision by carers and other relevant professionals.

Children with ID are more vulnerable to abuse and neglect. The Children Act 1989 & 2004 therefore defines children with disabilities as "children in need", placing a duty on local authorities to safeguard and promote their welfare and support family upbringing. Children in England and Wales can also access support through Education, Health and Care Plans (EHCPs), single assessments, and personal budgets for Special Education Needs and Disabilities (SEND) up to age 25 as per the Children and Families Act 2014. The Act also includes the right of parents to have their own needs assessed to ensure they can continue caring for the young person with additional needs.

The Equality Act 2010 protects disabled children from discrimination, harassment, and victimisation, and enforces a duty to make "reasonable adjustments". Such adjustments should also aim to reduce restrictive practices. Children with ID are disproportionately exposed to restrictive practices, including physical restraint and restrictive equipment (e.g. wheelchairs, arm gaiters, or helmets). Ethical practice requires adherence to the principle of least restriction, ensuring that any support or intervention is necessary, proportionate, time-limited, and regularly reviewed. Table 5 lists other ethical principles to consider when delivering support.

The 4 Ps framework to construct a clinical formulation

Predisposing factors e.g. family history, genetic syndrome, previous exposure with adverse childhood experiences (ACEs)

Precipitating factors include any antecedents identified in the functional behaviour assessment e.g. wanting social attention, as well as significant events e.g. bullying or a school transition

Perpetuating factors include any consequences identified in the functional behaviour assessment e.g. removal from the source of anxiety, as well as ongoing stressors e.g. parental stress and mental illness

Protective factors e.g. collaborative approach between parents and school staff, or robust communication supports like augmentative and alternative communication (AAC)

Box 1

Ethical principles to guide the reduction of restrictive practices

Principle	Good practice example
Necessity	Dan shows aggression when overwhelmed by noise and transitions. A functional assessment shows risk to peers during unstructured times, justifying targeted support (e.g. adult supervision and sensory breaks) rather than blanket restrictions.
Proportionality	Instead of excluding Dan from class, staff provide a small, quiet workspace and visual timetable, allowing him to remain included while reducing distress and risk.
Review	Dan's plan is reviewed every 3—6 months in MDT meetings involving school, paediatrics, SALT and OT, with adjustments made as his communication and coping skills improve.
Transparency	Parents are given a clear explanation of why strategies are used (e.g. visual supports, staff consistency) and are involved in all decisions about changes to Dan's care and education plan.
Rights-based	Dan is supported to express preferences (e.g. choosing activities, using drawing as communication), attends school trips with reasonable adjustments, and is treated as an active participant rather than a "problem to manage".

Table 5

Ensuring children with ID and their families are meaningfully involved in shared decision-making

Preparing a child with ID with relevant and accessible information before a clinical encounter, and using appropriate communication and environmental strategies during any interaction may help the child and their family be more meaningfully involved when understanding clinical information and the formulation. This can then enhance participation in shared decision-making which research has demonstrated improves clinical care, safety and the experience of the child and their family. An example of how the health system can promote this meaningful involvement is shown in Box 2.

A fictional case example of ensuring meaningful involvement of children with ID and their families in shared decision-making

Michelle is a 10 year old girl with severe intellectual disability and limited expressive language, who attends a community paediatric clinic due to concerns about escalating behaviours that challenge, including aggression directed at herself and others, during transitions and medical appointments. Previous clinic visits had been distressing for Michelle, often resulting in heightened anxiety, refusal to enter the consultation room, and limited engagement with clinicians.

To promote meaningful involvement, Michelle's paediatrician implemented a series of reasonable adjustments. Prior to the appointment, Michelle's parents were asked to share a communication passport, detailing her preferred communication methods (e.g. use of gestures and symbols), sensory sensitivities (e.g. noise and crowded environments), and effective calming strategies (e.g. drawing and access to quiet spaces). A social story was developed to explain the clinic visit using simple language and pictures, and this was shared with Michelle both at home and in school, several days before the appointment.

On arrival at clinic, the waiting environment was adapted by offering a quieter room and minimising waiting time. The clinician used visual aids to explain what would happen during the consultation and allowed Michelle to choose between activities, including drawing, to support emotional regulation. Rather than directing questions solely to the parents, the clinician addressed Michelle directly using symbols and simple choices, reinforcing her role as an active participant.

Recognising systemic barriers, including fragmented communication between health and education services, the family was offered support from Ayesha who was a keyworker working with a local charity which supported children with disabilities. Ayesha coordinated input from school, speech and language therapy, and occupational therapy. An advocate also supported the parents during the Education, Health and Care Plan (EHCP) review to ensure Michelle's needs for consistent staff, sensory adjustments, and structured transitions were clearly documented.

As a result, subsequent clinic visits were less distressing, parental confidence increased, and Michelle demonstrated improved engagement and reduced behaviours that challenge. This case illustrates how combining individual communication strategies with system-level coordination can translate the principle of meaningful involvement into practical, effective clinical care.

Box 2

Providing support and advice to families in the paediatric clinic

When a child with ID presents with behaviours that challenge, child health professionals like paediatricians may sometimes be the first professionals families turn to for guidance. Although paediatricians may not provide formal behavioural interventions, the advice they offer can play a crucial role in shaping family understanding, reducing distress, and guiding appropriate support. Central to this advice is a clear reframing of behaviour as communication rather than intentional misbehaviour. Families benefit from understanding that behaviours which challenge usually reflect unmet needs, difficulties with communication, sensory overload, emotional distress, or underlying physical discomfort, rather than willful noncompliance. This should in turn improve the engagement of the parent/carer with the functional behaviour assessment which is the basis for individualised person-centered advice for behavioural and other practical strategies.

Advice can include the importance of adjusting environmental demands during periods of distress. When a child is overwhelmed, expectations may need to be temporarily reduced, tasks simplified, and priorities narrowed to what is essential. Child health professionals can emphasise that learning and skills development are unlikely to occur when a child is emotionally dysregulated, and that supporting regulation helps behaviour to change in a manner that improves that child's quality of life.

Supporting communication is another key strategy. Families can be advised to work with special school staff or speech and language therapists in providing alternative ways for the child with ID to express needs and preferences, e.g. Makaton, visual supports, choice-making through Picture Exchange Communication Systems (PECS), or communication devices where appropriate. Even small changes, such as offering two clear choices or using simple visual cues, can significantly reduce frustration and associated behaviours.

Increasing predictability and structure within the child's daily life is frequently beneficial. Consistent routines, advance preparation for transitions, and the use of "first—then" language or visual schedules can reduce anxiety and help children anticipate what is expected of them. For many children with ID, unpredictability rather than the task itself is the primary source of distress.

Paediatricians can also guide parents and carers to focus on co-regulation rather than punishment when behaviours escalate. Maintaining a calm, supportive adult presence, prioritising safety, and minimising verbal demands during periods of heightened arousal can help prevent further escalation. Punitive strategies are often ineffective for children with ID and may increase distress if the child does not fully understand the consequence or its connection to their behaviour.

Encouraging families to notice and reinforce positive behaviours is another practical recommendation. Acknowledging moments of calm, effort, or successful communication helps strengthen adaptive behaviours and shifts family attention away from a sole focus on difficulties. Building regular opportunities for success, choice, and enjoyment within the child's day supports emotional wellbeing and resilience.

The role of medication

When a function-based assessment identifies physiological factors like pain or poor sleep contributing to behaviours that challenge or increased anxiety in children with ID, paediatricians

can play a crucial role with targeted medication management. Importantly, medication is not used to "treat behaviour" in isolation and rather, it addresses underlying sources of discomfort that increase the likelihood of challenging responses.

Pain is frequently under-recognised in children with LD, particularly in those with limited verbal communication. Conditions such as constipation, dental issues, musculoskeletal abnormalities, and otitis media may all present primarily through irritability, aggression, self-injury, or sleep disturbance. First-line pharmacological management typically involves simple analgesics like paracetamol. Non-steroidal anti-inflammatory drugs (NSAIDs) may be preferred where inflammation is suspected, such as in musculoskeletal pain or inflammatory conditions. For children with chronic pain associated with cerebral palsy and spasticity, paediatricians may consider adjunctive agents such as muscle relaxants or medications for neuropathic pain. A time-limited analgesic trial can be diagnostically informative when pain is suspected but not easily confirmed, but clear outcomes should always be agreed before initiation.

Gastro-oesophageal reflux is more prevalent in children with ID, particularly those with hypotonia, scoliosis, or enteral feeding. Reflux-related discomfort may manifest as back arching, irritability, food refusal, sleep disruption, or self-injurious behaviours. When reflux is suspected, paediatricians may consider prescribing proton pump inhibitors or histamine-2 receptor antagonists. In addition, prokinetic agents may be used under specialist supervision when motility issues are contributing. Constipation is another frequent and under-treated cause of distress - osmotic laxatives such as macrogol preparations are often first-line treatment.

Sleep disturbance can lower behavioural thresholds and exacerbate emotional dysregulation. Where behavioural and environmental strategies are insufficient, paediatricians may consider short-term pharmacological support like melatonin particularly the extended-release formulation, as this can help regulate both sleep onset and maintenance, particularly when circadian rhythm disturbance is identified.

There is a high co-occurrence of epilepsy in children with ID. The formulation may identify temporal associations between seizures or post-ictal states and changes in mood or behaviour. Additionally, subclinical seizures, focal seizures without obvious motor manifestations, or post-ictal confusion may be misinterpreted as behavioural disturbance. The paediatrician managing epilepsy may then consider optimising anti-seizure medications (ASMs) whilst bearing in mind that ASMs can have adverse effects like excessive sedation, cognitive slowing, agitation, or mood lability. In contrast, some ASMs may also be helpful in stabilising mood, for example lamotrigine and carbamazepine.

Medication use should always be embedded within a broader biopsychosocial formulation. Clear hypotheses derived from the functional behaviour assessment should guide prescribing decisions. Baseline data collection, defined treatment goals, and regular review are essential to determine effectiveness and monitor adverse effects. Polypharmacy should be avoided where possible.

Specialist medications to treat mental disorders should be initiated by prescribers with the appropriate skills and experience, typically a child and adolescent psychiatrist or a paediatrician with specific training. This may include ADHD medication e.g. methylphenidate), serotonergic medication (e.g. fluoxetine) to treat depression or OCD, and dopaminergic medication (e.g. risperidone) to help reduce irritability associated with risky behaviours that challenge.[2] All such medications are most effective when prescribed alongside relevant behavioural, communication, environmental or psychological interventions.[3] It should be noted that children with ID display a higher rate of adverse or paradoxical effects and as such require close monitoring and regular review to ensure that specialist medication are only prescribed for as long as is needed.

Mental health services

Specialist mental health services for children with ID (often referred to as CAMHS-LD) are not available in all areas of the UK, but there should always be a clear care pathway commissioned by the NHS for assessing and managing mental health conditions in children with ID. This may include clinicians based in special schools or in community-based behaviour support or mental wellbeing services. It is increasingly common that all these services provide interventions as part of an evidence-based and person-centered framework like Positive Behaviour Support. Due to children with ID presenting with multiple health issues which span between general and specialist paediatric services, as well as mental health services, it is prudent for paediatricians to establish close links with their local mental health clinicians who support children with ID. Globally, the lack of mental health services for children with ID is even more scarce and there is an urgent need to reduce these inequalities.[4]

Conclusion

Children with ID are at significantly increased risk of mental health difficulties, neurodevelopmental conditions, and physical health problems. These may present through changes in mood, behaviour, or functioning. Paediatricians and other child health professionals can play a vital role in recognising behaviours that challenge as meaningful communication rather than simply symptoms of disability or intentional misconduct. Comprehensive assessment requires a holistic and person-centred approach that considers physical health, emotional wellbeing, communication needs, sensory factors, environmental stressors, and family circumstances while avoiding diagnostic overshadowing. Functional behaviour assessment, reasonable adjustments, collaborative formulation, and shared decision-making are central to understanding the child's needs and guiding effective support.

Support in the paediatric clinic can have a profound impact on quality of life for both the child and their family. Practical interventions that enhance communication, predictability, co-regulation, and environmental adaptation can reduce distress and promote participation in education, healthcare, and community life. Medication may have an important role when clearly linked to identified physical or mental health needs, but should always be embedded within a broader biopsychosocial framework. Ultimately, coordinated multi-agency working, respect for children's rights, and equitable access to specialist services are essential to improving outcomes for children with intellectual disabilities and their families. ◆

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Practice points

- When assessing a child with ID in paediatric clinic, ensure reasonable adjustments are made and that relevant physical examination and investigations are completed
- Ensure children with ID and their families are meaningfully involved in shared decision-making through using relevant communication strategies
- A behaviour support plan should always be informed by a comprehensive functional behaviour assessment and be consistent with relevant ethical and legal principles