

# Disability and complex medical needs - advice

This advice provides information regarding managing child protection clients who have a disability and/or complex medical need.

Document ID number 2428, version 4, 31 December 2018.

[hide all content](#)

## Introduction hide content

<http://www.cpmanual.vic.gov.au/advice-and-protocols/advice/health-and-medical/disability-and-complex-medical-needs>

Children and young people with a disability and/or complex medical need and their families are a particularly vulnerable group within child protection and the broader service system.

Care of this vulnerable group of children and their parents is best achieved through a partnership approach between major stakeholders including disability and health services as well as child protection. Child protection practitioners are not, and not expected to be, experts in the areas of medical diagnosis and complex disabilities. If there are clear and identifiable child protection concerns present, it is expected that child protection practitioners will consult widely and effectively with other professionals as they investigate and plan for the child with complex medical needs, in the context of their family. Professional consultation and collaboration should occur within a continuum of services including disability services, community health centres, maternal and child health services, general practitioners, paediatricians, children's hospitals, and other medical specialists.

The primary documents that guide and inform child protection's assessment and case planning for children with a disability and/or complex medical need includes:

- [Best interests case practice model](#)
- [Suspicious or unclear hospital admission or discharge - advice](#)
- [Disability and complex medical needs - advice](#)
- [NDIS procedure for intake and case management](#)
- [Healthcare that counts: A framework for improving care for vulnerable children in Victorian health services](#)
- [Practice guidelines for Child FIRST, The Orange Door, Integrated Family Services, Child Protection and Out-of-Home Care.](#)

## Definitions hide content

The *Disability Discrimination Act 1992* defines disability as:

- total or partial loss of the person's bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing disease or illness

- the malfunction, malformation or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour

A complex medical need is a health need which requires a high and persistent level of supervision and individualised health care support. A child might have complex medical needs from birth, or after an illness or injury.

When speaking with medical professionals and disability support services to understand and record information about a child's disability and or/complex medical need, ask questions that will clarify:

- the nature and extent of the child's disability or complex medical need on the child's day to day functional capacity
- the formal diagnoses and prognosis
- all current medications
- the existing treatment plan

### **Factors underpinning the risk of abuse and neglect of children with a disability and/or complex medical need:** hide content

- Children with disabilities and complex medical needs are statistically more vulnerable to abuse and neglect than other children due to their physical dependencies and barriers to communication..
- Children with complex medical needs and/or disability face distinct challenges being heard. The challenges associated with caring for a child with a disability and/or complex medical need can lead to stress and parental mental health issues which may result in increased risk of abuse or neglect.
- Presence of enormous stress may overwhelm a parent, especially if they lack supports and respite, which can lead to abuse and neglect.
- Other complicating parental factors including violence, mental health issues, substance abuse and intellectual disability may be present.
- For children in OOHC, inadequate behaviour support planning for children with behaviours of concern associated with their disability can lead to the child placing themselves, and others around them, at risk of physical, sexual and emotional harm. It can also lead to an over-reliance on residential care and limit the child's opportunity to securing a home based care placement.
- Effective and person centred behaviour support plans will form an integral part of the child's daily safety and development needs where behaviours of concern are present. Refer to the department's Positive practice framework: A guide for behaviour support practitioners for further information about behaviour support planning for children with a disability.
- Where the child is a participant of the NDIS, these plans should be funded as part of the child's NDIS plan. Behaviour and other specialist plans must be regularly reviewed by Child Protection alongside other professionals involved, and included, as appropriate, in

the child's case plan. Where the child is in out-of-home care, the plan should be reviewed at each care team meeting, and when the case plan is being reviewed.

- Collaborative case planning and information sharing with community medical and support services are vital to address and reduce safety concerns for the child, as well as coordinating the provision of all their health and medical needs.

### **Principles that guide child protection work with children with a disability and/or complex medical need:**hide content

- Determining the capacity of the child or young person's parents to care for the child or promote their safety is paramount.
- Children with a disability and/or complex medical need require early intervention services with a link to a comprehensive medical system.
- Communication and collaboration with community medical and support services are vital to promote the child with a disability or complex medical needs' safety and wellbeing. Child protection must collaborate, share information about protective concerns and provide a copy of the child's case plan to the child's NDIS funded supports, other disability services and/or medical professionals involved.
- Child protection or the contracted case manager are always responsible for undertaking lead case management and working with the child and family/carer toward the permanency objective, regardless of how many other medical and/or disability professionals are involved.
- Protective concerns must be acted upon promptly and thoroughly by child protection to promote the child's safety, including children who reside in OOHC . Additional specialist risk assessments may be required to meet the safety, development and wellbeing needs of the child and those around them. The Child Protection Practitioner or Contracted Case Manager must oversee the implementation of any recommendations from these assessments, and review their ongoing effectiveness at each care team meeting.
- Siblings of children with a disability and/or complex medical need are also vulnerable and must have their safety, development and wellbeing needs met.

### **Key questions for assessing vulnerability of the child and their siblings:**hide content

- What is the nature and extent of the child's disability or condition and are all medical terms, reports, diagnoses, and the prognosis understood?
- What amount of time does the child spend in facility based respite care? Research supports the view that overreliance on facility based respite care can lead to a climate of increased vulnerability and feelings of powerlessness.
- What is the child's ability and opportunity to communicate their needs and any abuse being experienced? Consult with the parent/carer or other professionals involved in the child's life about the best way to communicate with a child who is non-verbal or has communication issues associated with their disability.
- Is the child stigmatised, depersonalised or devalued by their parents if they have assumed an almost professional nursing role? This may be an indication of lack of parenting attachment and can be a risk factor.

## Key questions for assessing the parents and parenting capacity<sup>hide content</sup>

- What are the parents requesting? Do they need further support or are they directly or indirectly looking for placement?
- Can the parents identify and seek out needed supports and services for their child and themselves? Can they self-manage their child's NDIS plan or do they require NDIS funded Support Coordination?
- What are the views, opinions and assessments of other professionals involved regarding the protective concerns?
- If parents are asking for placement – what is the timeframe and motivation? Are they saying they may harm the child, need a break, or are they considering permanent relinquishment?
- How does the parent describe the disabled child and what is the observed level of attachment and bonding to the child? A secure attachment is known to be an important safety factor.
- Was there a long separation, or multiple separations, of parents and child caused by hospitalisations, facility based respite, or otherwise? This circumstance may result in disrupted early bonding and attachment which is a risk factor for harm.
- How isolated is the family? Do they have formal and informal networks of support? Does the extent of care the child requires result in minimal or no outside social contact?
- Do the parents themselves have a disability or complex health need, and do they receive appropriate supports for themselves?
- What is the level of stress in the family? A parent may become overwhelmed in caring for a child with a disability, or child with a complex health needs, especially if there is minimal support and respite.
- How do the parents view the other children in the family? How much do they rely on them to care for each other or act independently in an age-inappropriate manner due to the parents' involvement with the child with a disability or complex health need? Are the parents emotionally available to each other and to the other children in the family?
- Are there other risk factors When assessing risk for children with disability and/or complex medical needs consider:
  - the child's daily needs and care requirements including any behaviour support requirements
  - the extent to which the parents understand the specific care needs of the child
  - the extent to which parental intellectual disability, family violence, substance misuse or mental illness impact on the parents ability to meet the child's daily needs and care requirements. Assess if the child's heightened care needs are likely to exacerbate the protective concerns further.
  - the attachment style between the child and parent, including when relevant, how long the child spends in hospital and/or respite care
  - parental ability to prioritise all of the child's daily needs and care requirements
  - pattern and history in relation to previous reports or information about the care of other siblings.
- Parents may experience feelings of guilt, shame, depression, and victimisation that require professional counselling. Parents' needs also have to be considered.
- Have the grief and loss issues experienced by parents with a child with a disability or limited life expectancy been assessed?
- Does the family have adequate financial support?

## Key questions for assessing the safety needs of the child and

**siblings**hide content

- Are there indicators of physical abuse (unexplained bruising, burns, rough handling)? Research has found a disproportionate number of children with disabilities in recorded cases of physical abuse.
- How many carers does the child have? Exposure to a wide range of carers increases the potential and opportunity for abuse.
- What is the mother's role in the family and what is her level of involvement and support?
- What is the father's role in the family and what is his level of involvement and support?
- Who is reporting to child protection and what are the reported protective concerns? Is this a call for additional supports or are they requesting placement?
- To what extent are services (including medical services and schools) working with the child sharing information and coordinating supports?
- Can the child with a disability or complex health need communicate their experience verbally? Is there any other means to allow communication?
- Is it difficult to distinguish if the child with a disability's behaviours are an indication of abuse or part of their disability?
- Have parents been known to deny the need for medical care or miss appointments? Medical neglect issues can place a child with a serious disability at particular risk of harm or death.

## Key questions for assessing the permanency needs of the child and

**siblings**hide content

- Where does the child spend their time – facility based respite, hospitals, community respite, voluntary placements including grandparents and other relatives? To support the primary carers the disabled child may be cared for in a number of settings. How does the child understand their multiple carers?
- What is the case plan and permanency objective for the child? Are they in need of ongoing alternate out-of-home care? Have they been referred to the permanent care team?
- Has a family-led decision making (FLDM) meeting or Aboriginal family-led decision making (AFLDM) meeting been considered for this family?

## Key questions for assessing the wellbeing needs of the child and

**siblings**hide content

- Are the child's basic care and hygiene needs, including food and clothing, met?
- Do the parents and carers participate in formal and informal social activities with the disabled child and their siblings or are they isolated due to the severity of the disability or the degree of required care?
- Does the family resist using available supports? Are they reluctant to engage with outside help?
- Are the developmental needs of the child with a disability or complex health need and their siblings being met?

- Are the parents aware of community activities available for the disabled child and their siblings? Do they attend and engage with them?
- Is the child receiving sufficient disability and medical supports? Do siblings attend school, child-care or kindergarten as appropriate, and other educationally appropriate services?
- Have all culturally relevant services been identified including Aboriginal and CALD agencies?
- Has the direct effect of the family's stress on siblings been assessed? Has it resulted in physical, emotional harm or neglect?

### **Safety planning including the safety and wellbeing of the child with disability, multiple medical needs and siblings should address:** hide content

- [Considerations when planning for children and young people in out-of-home care](#)
- the nature and severity of the medical condition and disability
- the capacity of the parents to protect the child with a disability or complex health need and their siblings and respond to their needs
- establishment of a care team with a specified lead professional or agency
- consideration of the needs of all members of the family, especially siblings
- supports and resources to address the immediate and longer-term safety, care and wellbeing needs and risks
- the cumulative impact of disability and demands of caring for the child with a disability or complex health need on each member of the family
- the ongoing and long-term nature of the problems including the need for paediatric palliative care services.

## **Considerations when planning for children and young people in out-of-home care**

- promote the child's life story and undertake case planning according to the child's needs and aspirations
- children with behaviours of concern require specialist risk assessments to create a home environment that will meet the safety and wellbeing needs of the child and those around them
- regularly review any specialist or behaviour support plans and work with the care team to include trauma-informed approaches to the child's care as required
- commence early planning with the NDIA for young people leaving care

### **Related procedures** hide content

- [Intake: Children with a disability and/or complex medical needs and NDIS](#)
- [Case management: Children with a disability and/or complex medical needs and NDIS procedure](#)

### **Additional information** hide content

- [Best interests case practice model](#)
- [Suspicious or unclear hospital admission or discharge](#)
- [Practice guidelines for Child FIRST, The Orange Door, Integrated Family Services, Child Protection and Out-of-Home Care](#)
- [Healthcare that counts framework](#)
- [Positive practice framework: A guide for behaviour support practitioners](#)