

CHILD PROTECTION WORK WITH CHILDREN WITH COMPLEX MEDICAL NEEDS AND THEIR FAMILIES: PRACTICE FRAMEWORK

Introduction:

Children and young people with complex medical needs and a limited life expectancy and their families are a particularly vulnerable group within Child Protection and the broader service system. Many children who previously would have died early in life now survive for long periods with high degrees of disability; this has profound implications for families, service providers and the broader community. (J Hynson, "The Dying Child: How is Care Different?" *Medical Journal of Australia*, Vol 179, 15 September 2003). Physical and neurodevelopmental disability, combined with complex care needs, contributes to tremendous emotional and practical challenges that families are variably able to meet.

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 and the 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 complex medical needs include:

1. *The Best Interests framework for vulnerable children and youth – [Best interest series](#)* – assists family services, child protection and placement services to apply the Act and supports a consistent understand of the CYFA.
2. *The Best Interests Case Practice Model* will guide Child Protection's assessment and investigation of protective concerns for the child with complex medical needs and any siblings alongside the extra demands made by the disabilities the child experiences.
3. [Advice number 1110 - Hospital admission and discharge where the child's condition is suspicious or unclear](#): includes information about obtaining medical advice and establishing care planning for children who are admitted to hospital including clarification of roles and responsibilities.
4. [Guide for assessing risk to infants and very young children](#)
5. [Vulnerable babies, children and young people at risk of harm: Best practice framework for acute health care](#)

Factors underpinning the risk of abuse and neglect of children with complex medical needs:

- Children with disabilities and complex medical needs are statistically more vulnerable to abuse and neglect than other children due to their more likely use of residential care, their physical dependency and their barriers to communication
- The stigma of having a child with disabilities can lead to the family's isolation and social rejection resulting in increased risk of abuse
- Disruptions to parental and child attachment due to hospitalisations and early separations may interfere with the parental role and contribute to a lack of attachment which is a known risk factor for abuse and neglect
- Parental denial of the situation may lead to medical neglect and place a child at risk

- Presence of enormous stress may overwhelm a parent, especially if they lack supports and respite, and lead to abuse and neglect
- Presence of other complicating parental factors including violence, mental health issues, substance abuse and intellectual disability.

Principles that guide Child Protection work with children with complex medical needs:

- Children with complex medical needs require an environment that meets their wellbeing needs and integration with other children without illness as much as possible to enhance their quality of life.
 - Children with complex medical needs require early intervention services with a link to a comprehensive medical system
 - Communication and collaboration with community medical and support services are vital to ensure the child with complex medical need's safety and wellbeing
 - Protective concerns must be acted upon promptly and thoroughly to ensure the child with complex medical need's safety.
 - Siblings of children with complex medical needs are also vulnerable and must have their stability, safety and well being needs met.
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Key Questions for assessing vulnerability of the child/siblings

- What is the nature/extent of the child's condition and are all medical terms, reports, diagnosis and prognosis understood?
- What amount of time does the child spend in institutional care? Research supports the view that institutional or residential care can lead to a climate of increased vulnerability and feelings of powerlessness?
- What is the child's ability and opportunity to communicate his needs and any abuse being experienced?
- Is the child stigmatised, depersonalised or devalued by the 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.
- If the disability is linked to a genetic issue, have the other siblings been tested and parent/s advised?

Key Questions for assessing the parents/parenting capacity

- What are the parents requesting? Do they need further support or are they directly or indirectly looking for placement?
- If parents are asking for placement – what is the timeframe and motivation? Are they saying they may harm the child, need a break, or 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 parent/s and child caused by hospitalisations, institutional care, or other? 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 the child's required care result in minimal or no outside social contact?
- Do the parents themselves have a disability and do they receive appropriate supports for themselves?
- Can the parents identify and seek out needed supports and services for their child and themselves?
- What is the level of stress in the family? A parent may become overwhelmed in caring for the disabled child especially if there is minimal support and respite.

- How does the parent/s 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 disabled child? Are the parents emotionally available to each other and to the other children in the family?
- Are there other complicating factors in the family, for example alcohol and other drug issues?
- Are there mental health issues for the parents? Parents may experience feelings of guilt, shame, depression, and victimisation that require professional counselling. Parents' needs also have to be considered.
- Have the parents' grief and loss issues experienced by parents with a child with a disability and/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

- 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. Some research estimates that a significant number of children's disabilities are the direct result of physical abuse by parents.
- How many carers does the child have? Exposure to a wide range of adults increases the potential and opportunity for abuse.
- What is the father's role in the family and what is his level of involvement and support?
- Who is making the notifications and what are the notified protective concerns? Is this a call for additional supports or are they requesting placement?
- Can the disabled child communicate their experience verbally? Is there any other means to allow communication?
- Is it difficult to distinguish if the disabled child's behaviours are an indication of abuse or part of their disability?
- Have parents been known to deny the need for medical care, miss appointment? Medical neglect issues can place a child with a serious disability at particular risk of harm or death.

Key Questions for assessing the stability needs of the child and siblings

- Where does the child spend his time – institutional care, 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 his multiple carers?
- Has a stability plan been considered for the disabled child? Has he ever been referred to the Permanent Care Team?
- Has a family decision-making conference been considered for this family?

Key Questions for assessing the well being needs of the child and siblings

- Are the child's basic care and hygiene needs, including food and clothing, met?
- Is the ethos of the settings in which the child is cared child focused? What is the level of training, social care planning, opportunity for child's input and communication/consultation?
- Do the parents/carers participate in formal/informal social activities with the disabled child and/or his siblings or are they isolated due to the severity of the disability and/or the degree of required care?
- Is the family resistive to available supports and reluctant to engage with outside help?

- Are the developmental needs of the disabled child and their siblings being met?
- Are the parents aware of community activities available for the disabled child and his siblings? Do they attend/engage with them?
- Has child been registered with Disability Services or other advocacy services?
- Do siblings attend school, child-care, kindergarten, and other educationally appropriate services?
- Have all culturally relevant services been identified including Indigenous 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 stability, safety and well being of the child with multiple medical needs and siblings should address:

- The nature and severity of the medical condition and disability
- The capacity of the parent/s to protect the disabled child and siblings and respond to their needs
- Establishment of a care team with a specified lead professional/agency
- Consideration of the needs of all members of the family, especially siblings
- Supports and resources to address the immediate and longer-term stability, safety and well being needs and risks
- The cumulative impact of disability and demands of caring for the disabled child on each member of the family
- The ongoing and long-term nature of the problems including the need for paediatric palliative care services.