

Ms. Anne Rabbitte TD,
Minister of State, Department of Health
and Department of Children, Equality, Disability, Integration and Youth,
Houses of the Oireachtas,
Leinster House,
Kildare Street,
Dublin 2.

Sent to: anne.rabbitte@oireachtas.ie; Noel.Byrne@equality.gov.ie

23 June 2023

IASW Briefing Paper re. equitable access to respite, provision of enhanced supports for families in crisis, and regulation of residential placements, for children with complex disabilities.

Dear Minister Rabbitte,

As representatives of the Irish Association of Social Workers' (IASW) Disability Special Interest Group, we are writing to highlight the views and concerns of Social Workers working in Progressing Disability Services (PDS).

These views and concerns relate specifically to respite provision for children with complex disabilities, enhanced supports for families in crisis and residential placements for children with complex disabilities.

We appreciate that you are acutely aware of many of these issues from your own engagement with families and from recent high-profile cases. As Social Workers we are actively engaged and professionally trained in supporting families of children with complex disability needs. As a collective of social workers working in PDS, we have a number of proposals which we believe could form part of the solution to the challenges experienced and really improve the lives of those impacted.

We are enclosing a short briefing document which summarises some of the key issues and our proposals. The gravity of the current situation facing many families requires, in our opinion, a national and standardised approach.

As members of a specialist subgroup of the IASW we are seeking an opportunity to meet with you to discuss these issues and proposals.

We look forward to hearing back from you.

Sincerely,



Vivian Geiran
Chair, IASW
SW00319

Ciara Lynam
Chair of Social Workers in Disability SIG
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IASWU

Irish Association of Social Workers
Cumann na hÉireann um Oibrithe Sóisialta

Briefing Document for Minister for Disability

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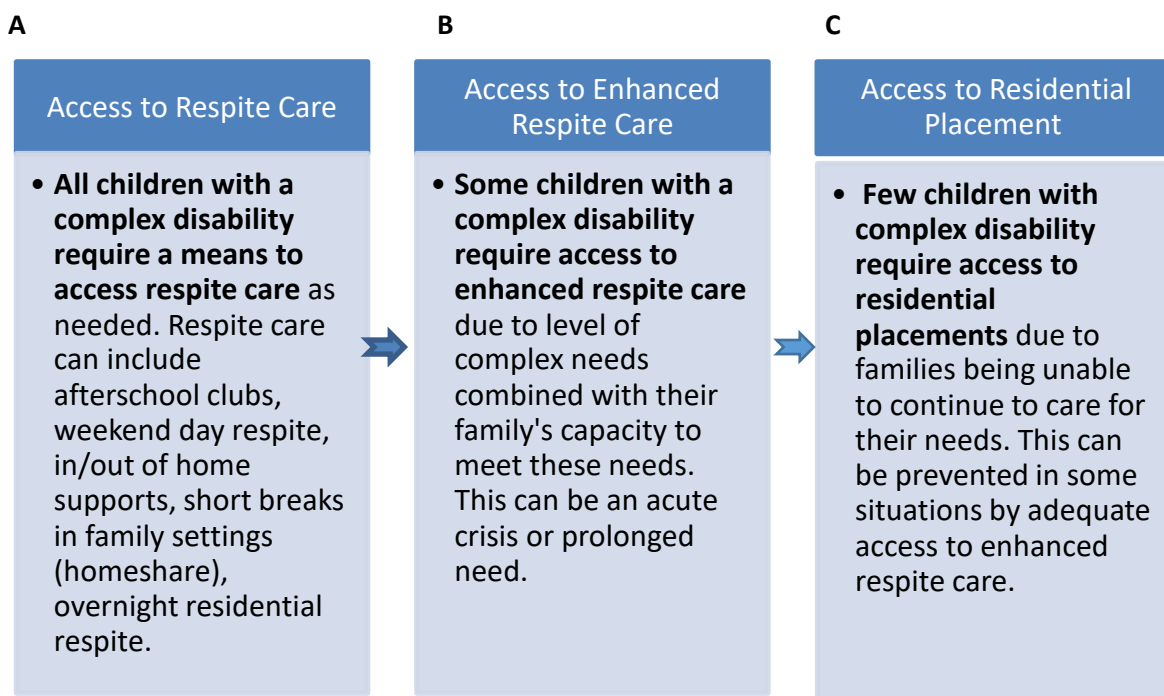
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23 June 2023

Briefing document for Minister for Disabilities in relation to; equitable access to respite, provision of enhanced supports for families in crisis, and regulation of residential placements, for children with complex disabilities.

Access to Respite Care is an essential support for families caring for children with complex disabilities. Respite can help sustain tired parents and enable them to support other children within the family. It can also prevent crisis and reduce the numbers of children with complex disabilities requiring residential placements.

The Roll out of Progressing Disability Services (PDS) has exposed substantial unmet need and inequity in respite and residential support to children with complex disabilities and their families throughout the country.



A. Access to Respite Care

1. When needed, all families who have a child with a complex disability should be able to apply and have access to respite support.
2. Currently there is uneven and inequitable access to the various types of respite support across the country. A family's access to respite care can hinge on their geographical location or sometimes the particular diagnosis of their child or the school they attend. In some CHOs it depends on whether children had previous access. Each CHO also appears to have different budget provisions for respite services per capita.
3. Current respite service provision is very limited and patchy across CHO areas.
4. There is a lack of waitlists for respite services.
5. There are no standardised prioritisation, waitlist or review systems in place nationally for respite services. Each CHO appears to be doing its own thing.

B. Access to Enhanced Respite Care for children and families in crisis.

1. There are growing numbers of children with complex disabilities and their families in crisis and at risk of family breakdown.
2. There is no clear standardised escalation pathway or Standard Operating Procedure for these children and families who require enhanced or crisis respite care. This includes those who are at risk of relinquishment of parental care.
3. Currently Social Workers on Children's Disability Network Teams (CDNTs) are left to manage these high-risk situations with families without any clear guidance or solutions.
4. There is a lack of clear CHO budgets for the small (but regular) number of children each year who go into crisis and require enhanced supports to avoid family breakdown and eventual residential placement.
5. Without access to comprehensive packages of respite, some families are being forced into circumstances where they have no option other than to relinquish their care of their child. Other families are forced to remain in prolonged distress which can escalate to child protection risks. It is unacceptable that in order to access comprehensive packages of respite, the level of risk has to be raised to a level requiring Tusla intervention.

C. Disability Residential Placements

1. Along with enhanced respite care, there are no clear standardised escalation pathways, Standard Operating Procedures or waitlists for children with complex disability who require residential placements.
2. Children in HSE residential placements do not have the same legislative protection or governance structures as children placed in care through Tusla.
3. There is lack of clarity as to the appropriate structures for oversight, governance and agency responsibilities for children with a complex disability in HSE funded residential settings. This has led to confusion as to responsibilities for placement reviews. Social workers in CDNT's are being asked to supervise HSE funded / private provider residential placements without clear Standard Operating Procedures or training.

Recommendations:

1. The establishment of a National Review Group on Respite and Residential Placement Provision for children with complex disabilities.
2. An audit of current Respite and Residential placement provision provided in each CHO.
3. A survey and audit to identify the true level of need including consultation and submissions from parents and professional groups.
4. The review group can make recommendations on the suite of respite options required to meet the varying needs of children with complex disabilities throughout the country. These could include afterschool clubs, weekend day respite, in/ out of home support hours, short breaks in family settings, overnight residential respite.
5. Development of national standardised prioritisation, waitlist, and review protocols for the management of respite services, implemented in an equitable way throughout the country.
6. Establishment of realistic, ring-fenced budgets for Children's Disability Services to provide comprehensive packages of respite and residential placements when needed.
7. Development of clear Standard Operating Procedures and escalation pathways to support children and families in crisis to prevent family breakdown and to smooth the route for those children that need residential placements.
8. Provision of suitable enhanced respite care/high support care packages for those families in crisis, to maintain their child's placement at home and to avoid, where possible, residential care and the blocking of acute hospital beds
9. Clear and standard structures for oversight, governance and agency responsibilities for children with a complex disability in HSE funded residential settings.

This briefing document was produced by a group of experienced senior social workers from different parts of the country who are working in the new CDNT structures.

Relevant Research and Reports:

HSE (2016) Home Sharing in Intellectual Disability Services in Ireland- Report of the National Expert Group [Home Sharing Report.doc \(hse.ie\)](#)

NDA (2019) Exploring the Experiences of Users of Disability Respite Services in Ireland [National Disability Authority \(nda.ie\)](#)

NUIG (2007) [Towards best practice in the provision of respite services.pdf \(nuigalway.ie\)](#)

UCC (2011) [Home Share and BOC research report \(ucc.ie\)](#)

[\(2020\) Respite Care in Families of Children with Disabilities: A Literature Review \(researchgate.net\)](#)