Children’s Law Centre

BRIEFING

CHILDREN'S RESPITE SERVICES

SEPTEMBER 2024

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This briefing paper has been prepared by the Children’s Law Centre in response to issues highlighted by the BBC Spotlight NI feature documentary entitled *I am not okay*, which aired in September 2024.

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Children’s Rights
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INTRODUCTION

'I AM NOT OK'

On Tuesday 24th September 2024, BBC Spotlight NI aired *I am not okay*, a special feature documentary which through four families, explores the experience of caring for children with autism and learning disabilities and the crisis in Health and Social Care which is failing them and their children.

The Children’s Law Centre (CLC) supports many children with complex needs, and their families who are being failed by the Health and Social Care system. Whether in workforce shortages leading to delays in allocation of social workers, the ongoing decline in respite and residential care provision or the impact of lengthy waiting times resulting in children and young people not receiving timely diagnoses. There is an ever increasing range of issues which require urgent attention as children and families grow increasingly frustrated and exhausted.

Many of the issues highlighted in this new BBC Spotlight NI documentary are familiar to CLC and regularly feature in the cases we have been, and continue to be, engaged in through the children and families we support.

A FOCUS ON THE CHILDREN

While *I am not okay* explores the experiences of four families, we know from CLC’s legal advice and representation service that the challenges which have been brought into focus by the documentary are not uncommon to a wider group of families across Northern Ireland.

The children at the heart of the stories of each family impacted by these issues are some of the most vulnerable children in our society. They deserve nothing less than public services which are capable of meeting their complex needs and fulfilling their human rights to live in dignity and have their potential realised.

THE CHILDREN'S LAW CENTRE

CLC is Northern Ireland’s leading children’s rights NGO. We are a multi-disciplinary children’s rights charity and legal centre. Our model of practice is very different to that provided by solicitors and practitioners working in private practice. We operate a child-accessible and jurisdictionally unique free expert legal advice, support and representation service for children,

including children with severe and complex health and mental health needs, special educational needs and disabilities, social and emotional or additional learning support needs.

While we work on behalf of all children in NI, our focus is on vindicating the rights and unmet legal needs of the most marginalised and disadvantaged groups of children.

THE ISSUES

CAPACITY WITHIN THE SYSTEM

Respite services which had already been insufficient before the pandemic have become increasingly inadequate and unstable. During the pandemic some of these support packages were reduced or stopped entirely. Not all respite capacity which had been repurposed during the pandemic has been restored to its original purpose yet. Many of the children’s respite units in four out of the five Health and Social Care Trusts have been repurposed for residential services and are therefore unable to provide respite. There are also a number of respite units which have not been able to reopen due to a lack of staff. This is having a devastating impact on many families who rely on respite for essential breaks from their caring role. Respite services need to not only resume but to be significantly expanded to provide greater choice and availability for carers.

The inadequacy of respite provision is exacerbated by the lack of appropriate residential facilities across Northern Ireland for children with complex needs, meaning a continued reliance on repurposed respite facilities is a ‘sticking plaster’ solution.

STAFFING

Staffing pressures in the social and care workforce is having a significant and detrimental impact upon the provision of family support packages. Evidence from our casework suggests that staff who left these parts of the workforce during the pandemic have not or cannot be replaced either because of funding shortages and/or recruitment difficulties. The inability of Health and Social Care Trusts to effectively resource assessed care packages is having a significant impact on those children and families who need them.

DIRECT PAYMENTS

As a result of the increasing instability in the workforce, Health and Social Care Trusts are relying heavily on the use of direct payments as a means of meeting assessed needs. In practice, this means that many families have now been allocated a certain amount of funding by their relevant Trusts in lieu of provision of direct support. The effect of this is that it becomes the responsibility of the parent(s) / carer(s) to administer the funding themselves by recruiting, employing and managing staff directly. This has

the effect of placing the recruitment and employer responsibilities upon the carer.

Our experience is that families face the very same difficulties in recruiting staff as the Trusts themselves are facing. In cases where a child may have particularly complex needs, it is often impossible for families to recruit staff. In these circumstances, Trusts claim they have fulfilled their obligations by providing direct payments, regardless of whether they are used. If families cannot recruit staff and therefore do not use the funding, it is returned to the Trust. In effect, the Trusts are outsourcing the problem to families who are already under immeasurable pressure.

THE LACK OF A CONSISTENT AND CO-OPERATIVE APPROACH

The assessment of a child with complex needs is the key to unlocking access to services. However, there have been significant delays in the completion of such assessments and parents / carers also report to us that they are unsure of how the process, in which they are directly involved, actually works. Once an assessment is completed it is referred to a resource panel for a decision on what service(s) needs to be put in place for the child. Parents and carers report to us that this decision making process is not transparent. Parents and carers are not permitted to attend the panels, their views are instead represented by the social worker. Additionally, each Health and Social Care Trust operates its own resource panels. This has led to differing service levels in different Trust areas for similar types of cases. There also appears to be little or no sharing of resources between Health and Social Care Trusts with panels only being able to allocate services which are available in their own particular Trust area. There is no formal mechanism in place to allow for the sharing of respite capacity between different Trusts.

EMERGING ISSUES AS THE CRISIS WORSENS

Due to a lack of specialist residential placements throughout Northern Ireland, Health Trusts have had to place children with special needs who come into care in respite units on a residential basis. This has resulted in closure of respite units for significant periods of time for all children in the area who are assessed as requiring respite. This lack of respite, coupled with a lack of support services for these children, places increased stress upon families and has, in some cases, led to family breakdown and children having to enter care due to a crisis family breakdown. Unfortunately, as there are limited residential placements it is likely that these children will have to be placed in respite units, perpetuating the cycle.

Additionally, it is increasingly the case that when families reach a point of crisis and report to Health Trusts that they require a residential placement, they are being offered out of jurisdiction placements. The rationale for this is particularly difficult to understand given the significant cost of procuring out of jurisdiction placements and the impact upon the child and their family of being separated. Irrespective of the cost, no child should be placed outside of the jurisdiction unless there is a treatment element to the placement. In the case of these families the need is purely for residential placement and such provision should be available and accessible within Northern Ireland. Families, understandably, do not want their children to leave the jurisdiction and many feel confused as to why placements can be obtained and paid for out of jurisdiction rather than within Northern Ireland.

THE IMPACT

Respite is only one of the key services that children with complex needs require in order to be cared for at home by their families. However, it is a vital service that allows carers to have a break from their caring role, in some cases to rest and in others simply to allow them to spend some time with their other children.

Family support services are very limited for children with the most complex of needs. Many of the families CLC is working with have no access to any additional supports. What this means in practice is that when there are limited supports on the ground and respite is either not available or cancelled (which is a common occurrence due to the current instability of service provision), then there is no help and families feel increasingly isolated and invisible.

This lack of a break inevitably leads to burn out and impacts everyone in the family, including the child with complex needs. It is our experience that this pressure is often significantly detrimental for the physical and mental wellbeing of all members of the family. Without the provision of services the chances of family breakdown increases and with it, the risk of the child entering the care system increases too.

RECOMMENDATIONS

The profound difficulties in the delivery of children’s services in Northern Ireland have been well documented in recent years. *I am not okay* is the latest, powerful evidence of the devastating consequences of public services which are not functioning in the best interests of our children and young people. Based on our experience as Northern Ireland’s leading children’s rights NGO, the Children’s Law Centre make the following recommendations to all those with a responsibility to fulfil the rights of children with complex needs.

Decision makers and those who develop, commission and deliver services must:

- Make arrangements for immediate access to respite support for those families currently in crisis.
- Deliver sufficient capacity in specialist residential placements to prevent the need for children to be accommodated in respite units on a residential basis.
- Produce a detailed plan to restore and expand respite capacity which has been closed as a result of repurposing and staffing deficiencies.
- Conduct a systematic review to map current levels of respite service capacity against levels of assessed need.
- Provide assurances that any existing, reopened or newly developed service provision, whether delivered directly by Health and Social Care Trusts or by a third party, is capable of meeting the needs of children with complex needs.
- Secure the necessary funding to deliver both capital and resource investment to ensure the required levels of respite provision are in place now and in the future, with a plan to determine future levels of required provision which has the confidence of all stakeholders.
- Conduct a review of the direct payments system, giving serious consideration as to whether this provision is working for families in receipt of direct payments.
- Take urgent steps to stabilise and develop the children’s health and social care workforce.

- Ensure the full utilisation of the Children’s Services Co-operation Act (NI) 2015 by all aspects of the Health and Social Care system in Northern Ireland to maximise the benefits of meaningful co-operation across Trusts, including sharing and pooling resources to improve practice in the best interests of children with complex needs.

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