

**Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar y [effaith pandemig COVID-19, a'i reolaeth, ar iechyd a gofal cymdeithasol yng Nghymru](#)**

**This response was submitted to the [Health and Social Care Committee](#) consultation on [the impact of the COVID-19 pandemic, and its management, on health and social care in Wales](#)**

**COV 09**

**Ymateb gan: | Response from: Dr Karri Gillespie-Smith**

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# Having to jump off a bridge for help: Parent and Stakeholder perspectives of what continues to impact children with Intellectual Disabilities (ID) and their families across the UK

**Authors: Dr Karri Gillespie-Smith & Dr Hope Christie; University of Edinburgh**

**Date:** November 2021

Full report can be found [here](#).

## Summary

- Parents of children with Intellectual Disabilities (ID)<sup>1</sup> are reporting increased indicators of distress in their children and also the wider family (i.e. neurotypical siblings).
- Strict criteria used by some services means that a lot of families are still not able to obtain help and support for their children.
- Parents are frustrated about COVID continuing to be used as an excuse for service reduction and would like to see alternative solutions in place.
- Charities and Advocacy Groups report reduced service provision and shortage of support staff has meant these families are not being supported throughout the recovery phase.
- Education professionals report that COVID-19 had caused increased anxiety in parents and children with ID meaning that a lot of children have still not returned to education.
- Clinical and Social Care Practitioners report high levels of burnout and mental health issues across staff.

## Top level recommendations to consider

- Parents of children with ID need targeted and tailored support as we transition throughout the recovery phase to protect against negative mental health outcomes.
- Recovery period is an opportunity to improve services for children with ID by prioritising recruitment and retention of care staff and allowing social care staff to support children with ID returning to education.
- Teaching staff need training and protected time to support children with ID's social, emotional and mental needs as they transition back to the classroom.
- More Clinical and Social Care staff are required to help support children with ID and their families.

## Issue

The World Health Organisation (WHO) declared the virus to be a 'Public Health Emergency of International Concern' in January 2020. The first UK-wide lockdown was implemented on 23<sup>rd</sup> March 2020, which established Public Health Safety Measures (PHSM) to reduce the spread of the virus (1).

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<sup>1</sup> Intellectual disability (ID) is defined as significant limitations in adaptive behaviours and mental functions expressed as social, conceptual, and practical adaptation skills. Children with ID are a heterogeneous group and are divided into four groups according to the level of disability. These are mild intellectual disability (50–55 to 70 IQ), moderate intellectual disability (30–35 to 50–55 IQ), severe intellectual disability (20–25 to 35–40 IQ), and profound intellectual disability (under 20–25 IQ).

Although the implementation of government measures prevented widespread COVID-19 related deaths, the closure/suspension of schools, clinical services and respite put significant pressures on parents of children with ID. England began coming out of Lockdown in March 2021 with Wales, Scotland and Northern Ireland following suit in April 2021. Despite the whole of the UK being out of lockdown, there still remains significant reductions in services and support for children with ID and their families.

We must identify the gaps in service provision and support those parents and children who continue to struggle and are more at risk of negative mental health outcomes. We need to understand what support these families need, what barriers they continue to face as well as the difficulties faced by the services and institutions that aim to provide support.

## Background

Parents of a child with ID are more vulnerable to mental health difficulties when compared to carers of typically developing children (2; 3). Intellectual disabilities are characterised by adaptive skill deficits (4), which can be associated with challenging behaviours (5), including verbal and/or physical aggression, self-injury, disturbed sleep, and destructive tendencies (6; 7).

Challenging behaviours indicate levels of severe mental stress and distress reactions in those with ID (8). These behaviours are exacerbated by disruption to day-to-day routines (adaptive functioning), or restrictions on enjoyed activities (9) and are conditional on the level of disability (10), depression (11) and anxiety (12). It is likely that the COVID-19 pandemic and related limitations to routine and lockdown arrangements (13) have exacerbated these factors.

It is important to examine how continued restrictions to education, respite and support services (all factors that are known to reduce caregiver stress; for a review see 14) still impact both the caregiver and children's mental health. Recent evidence shows that parents are reporting increased levels of psychological distress in their children with ID and themselves (15;16). Our roundtable event aimed to gather parent and stakeholder perspectives on what continued to be the main issues facing children with ID and families throughout the recovery phase. We were also interested to find out what continues to be issues or barriers for services as they try to support these families to 'recovery'.

## Evidence

There were 4 different groups that took part in roundtable discussions.

- Parents of children with ID – 6 parents who had children with a range of age and support needs.
- Charity and Advocacy Groups – Representatives from a range of charities and advocacy groups attended including Fragile X Society; Williams Syndrome Foundation; ENABLE group; National Autistic Society; Breakthrough Learning; CdLS Foundation; Action for Children; Kindred and SeeAbility.
- Education – 5 education experts representing local councils, Department of Education, and Additional Support for Learning Services.
- Practitioner – 8 practitioners representing local councils, Child and Adolescent Mental Health Services (CAMHS) and social work.

### *Roundtable session 1: Parents of children with ID*

Parents continue to raise concern about their children's mental health with all parents reporting higher anxiety indicated by challenging behaviours and refusing to return to activities they had previously enjoyed. Parents explained that it was difficult to get their child access to appropriate support because they weren't meeting specific criteria by service providers.

*"So they wait until you're on your knees and you're about to jump off a bridge before they actually will sit down and listen to what you've got to say"*

*"[my child] has severe anxiety issues and we were told essentially that unless they were self-harming or actually attempting suicide that then we wouldn't be considered."*

Parents also reported that there were additional pressures on neurotypical siblings of children with ID resulting in increased levels of anxiety and stress. These issues still persist since changing guidelines mean that siblings are often concerned to go out and engage in social activities due to concern they are putting their sibling at risk.

Most parents noted continued frustrations with services using Covid as an excuse not to provide support when parents were aware of the services receiving Covid-specific funding and having enough time to work on alternative solutions. More tailored resources are needed for children with ID who do not fit into all the typical guidelines and missed out on valuable peer support.

*"This is the new norm and they had 18 months to get used to it, but it's very easy just to go 'cause sorry we can't do that. 'It's COVID, you know?' - Yeah, we know if we've been living it for 18 months"*

### *Roundtable 2: Charity and Advocacy Groups*

Pandemic exacerbated existing issues for families. Many families were relying on respite care, residential support and outreach. Reduction in service provision persists despite the end of lockdown which may be due to staff shortages and lack of funding for social care staff. One Charity reported that local authorities were reducing funds for service provision under the pretext that families had been 'coping well' during the pandemic.

*"And I wonder what the plan is in terms of that workforce planning across the whole sector, because ultimately if we don't have enough staffing in place to provide these services and it doesn't matter what the financial position is, you can't provide this service."*

Pandemic also greatly impacted children with ID across many areas including education (e.g. informal exclusions, lack of staff), mental health issues (e.g. increased anxiety exacerbating existing challenging behaviours), social skills (e.g. reduction of social interactions caused reduction in valuable social skill learning).

### *Roundtable 3: Education*

Parents and children with ID are anxious about returning back to school and many have still not returned to the classroom. This is worse for children with ID with complex physical disabilities who are more at risk of negative outcomes if they contract Covid-19. The education professionals mention that to continue teaching education they need to also support the children's mental health and remind them that school can be fun.

*"[When discussing children needing to settle back into school and how teachers can help to ease the child's anxiety of returning to school]... "We need to not have this huge focus on catching up with the reading and the writing. They're going to be fine. Everybody is in the same boat. They're going to be fine but we can still make sure we focus on the art"the music and the drama and the fun and the play because they've missed that 'cause they've missed people."*

Education professionals reported that teachers need training to support the mental health of children with ID in the classrooms. They need protected time to support the children's social, emotional and mental needs first before they can get the children focused back on academic work.

*"Nobody is going to learn anything academic if they are not OK" (Parent 4).*

### *Roundtable 4: Practitioners*

Practitioners reported that parents struggled with their children returning back to school due to their own anxiety around potential changes, school closures and staffing issues. Practitioners felt that parents were still not ready to engage in more clinical work despite needing support and had not 'recovered' from lockdown.

A key issue raised by the practitioners was around the recruitment and retention of staff highlighting that current clinical and social care staff were at risk of burnout. Issues around lack of decompressing and intense workdays highlight the need for staff to set clear boundaries with colleagues and service users. Many practitioners also mentioned higher rates of mental health issues among staff and a need for more embedded peer support from colleagues.

*"If we're actually going to make people feel contained and feel contained ourselves we need to have these things embedded in what we do and they can't just be a thought that maybe I'll find time for that in a months time. You kind of have to prioritize those things. 'cause I think you know from our recruitment point of view, that's going to be really difficult going forward if staff are not feeling like they've got that foundation."*

## Policy considerations

1. Parents of children with ID and children with ID need targeted support as they transition out of restrictions to protect against negative mental health outcomes.
2. Support services need to be improved for children with ID by increasing social care staffing and provision.
3. Teaching staff need more training and allocated time to support children with ID's mental health as they transition back to Education.
4. More Clinical and Social Care staff need to be recruited and retained to reduce staff burnout that is being experienced across social and clinical services.

## Recommendations

1. Both children with ID and their parents are vulnerable groups. They need continued monitoring and support (specifically mental health support) by increasing service check-ins, and improving access to services as the UK transitions through the recovery phase.
2. It is crucial that higher levels of social care staff are recruited and retained to provide increased support to the children, and extending this support to the classroom to help children transition back to education.
3. Teaching staff need the time and training to help children with ID's social, emotional and mental health needs as they return to education.
4. Clinical and Social Care practitioners are experiencing burnout and mental health issues. They need increased levels of staffing, more embedded approaches to peer support and to set boundaries with colleagues and service users.

## Academic expertise

**Dr Karri Gillespie-Smith (Lecturer based in Clinical Psychology, University of Edinburgh), an expert in developmental psychology, is carrying out a UK wide project titled – 'Road to Recovery' which is funded by the Economic & Social Research Council (ESRC), as part of UK Research & Innovation's rapid response to Covid-19. The project aims to explore the impact of COVID restrictions and recovery phases on the mental health of children with ID and their families.**

**Profile:** <https://www.ed.ac.uk/profile/dr-karri-gillespie-smith>

**Research Activity:** <https://www.research.ed.ac.uk/en/persons/karri-gillespie-smith>

**Project Webpage:** <https://www.ed.ac.uk/health/subject-areas/clinical-psychology/research/research-groups/road-to-recovery>

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