



ROAD TO RECOVERY PROJECT

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**Roundtable discussion event:
Summary report**

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Executive summary

Four stakeholder groups were gathered respectively to discuss their views and experiences on how the COVID-19 pandemic has impacted, and continues to impact, families with children with intellectual difficulties (ID). The four groups included representatives from charity and advocacy groups, the education sector, practitioners, and parents and carers.

The discussions within each group followed similar themes, whereby participants discussed issues under three main themes: experiences during the pandemic; continued challenges faced as we move through current recovery phases; and future recommendations.

Discussion group 1: Parents and carers 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. 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.

Discussion group 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.
- 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).

Discussion group 3: Education sector

- Parents and children with ID are anxious about returning 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.
- 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.

Discussion group 4: Practitioners

- Practitioners reported that parents struggled with their children returning 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

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.

Introduction

On Monday 1st November, the Road to Recovery project team hosted an online roundtable discussion event, which brought together key stakeholder groups including practitioners, parents and carers, education, and charity and advocacy groups.

The main aim of this discussion event was to hear about the experiences of these key groups during lockdown restrictions, as well as more recent experiences as we begin to adjust to a new normal. With this information we hoped to learn more about how best to support families with children with intellectual disabilities following the COVID-19 pandemic. Further, from this discussion we hope to inform a policy briefing on the pandemic recovery for families with children with intellectual disabilities in the UK.

We want to thank everyone who attended this event; we greatly appreciate you taking the time to share your experiences with us. In this report, you will find detailed summaries of each breakout room discussion. Please note that all names and identifiable information have been removed for anonymity.

Thank you again for attending. We hope to welcome you all to the next event.

The Road to Recovery Team,



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Charity and Advocacy Groups

Representatives attended from a range of charities and advocacy groups, which included: Fragile X Society, Williams Syndrome Foundation, National Autistic Society, ENABLE Group, Breakthrough Learning, CdLS Foundation, Action for Children, Kindred and SeeAbility.

1. DURING THE PANDEMIC AND LOCKDOWN PHASES

According to the charity and advocacy groups, the pandemic exacerbated existing inequalities and there was a consensus that families cannot just “go back” to how their lives were before the pandemic, without addressing the short, medium and long-term impacts of the pandemic.

A. Access to care and support services

It is commonly reported that services were reduced during the pandemic but charities reported that many services were simply halted, leaving families that had relied on the services, such as respite care, in crisis. One charity that had supported a single mother of a teenager with intellectual disabilities described the experience as:

‘Just literally a cliff edge, the guillotine came down. There was nothing, so she found herself on her own 24 hours a day looking after her [teenager] with no support whatsoever and she had no family support. That was replicated up and down the country.’

This was partially due to a lack of clear guidance from the UK government on what was classed as an essential service, with some ambiguity around how ‘at risk’ children and adolescents with intellectual disabilities were. The lack of clarity in guidance around safety led to some services stopping operations completely, rather than adapting services to the restrictions. Access to CAMHS services was either interrupted or there were significant delays, due to a shortage of staff. This left new families awaiting assessments or receiving a diagnosis and other families waiting for adequate follow-up support.

B. Access to information and communication

Unclear and/or inconsistent guidance from the UK government made it difficult for charities to advise clients. It was noted that it was unclear which diagnoses were regarded as vulnerable. Young people with intellectual disabilities were not provided with adequate and accessible information about the pandemic and safety measures through news and media outlets. One charity also

mentioned that the lack of access to rapid data about the pandemic in relation to children with intellectual disabilities affected planning of services.

C. Access to adequate healthcare

There were concerns about lack of prioritization of persons with intellectual disabilities in healthcare. For example, clients reported that those on waiting lists for medical care were deprioritized due to their intellectual disabilities.

D. Access to education

Online education was not accessible for many children with intellectual disabilities. “Informal” exclusions were evident.

E. Impact on mental health and challenging behaviours

Charities reported significant increases in stress and anxiety for young people and their families. This was a result of difficulties in assessing risk, leading to fears about illness and death, difficulties in adapting to continual changes in routine, as a result of changing guidance. Some children may have developed other difficulties while staying at home, and/or developed more challenging behaviours. Charity staff are often also parents of children with intellectual and/or other disabilities and have had to deal with the double impact of the pandemic: being personally affected by the pandemic and having to manage operational challenges at the charity level. Some charities expressed concern over the term “coping”, whereas most families merely had to survive, but this did not mean they were coping well. Although children and families showed resilience through the pandemic, it was a forced resilience. The severity of the impact needs to be acknowledged and can even be associated with trauma. It was clear that there would be no ‘return to normal’ for some families.

F. Impact on family dynamics

The stresses of the pandemic had led to some families splitting up or children being taken into care.

G. Impact on household livelihoods and access to funds

Parents/caregivers having to significantly change their work routines, some parents had to stop working during the pandemic to cover childcare, resulting in a drop in income. Charities mentioned some families being pushed into poverty, or are at risk of poverty. Applications for access to public funds remained a relatively long and difficult process.

H. Social impacts

The effects of social isolation varied across groups. For example, children with Williams Syndrome found the reduced social contact particularly challenging. Families that were particularly challenged experienced family break-ups or children being taken into care.

I. “Positive impacts”

Positive impacts included services being able to diversify and flex to accommodate to the needs of individuals. Remote working and digital technology enabled many opportunities for families to engage, with the result that these were partially retained as a means of connecting people who could not attend in-person events. The pandemic was identified by some charities as an opportunity to come together and collaborate by pooling staffing and resources: ‘It was about charities coming together to collaborate and I felt that that was the only way that we can make this work, particularly around funding and staffing.’

2. DURING CURRENT TRANSITION AND RECOVERY PHASES

Many charities felt that the current period had more challenges than the previous year, as the aftermath of the pandemic came to light. Some charities have felt concern over the government’s approach to “going back to normal” without acknowledging and/or addressing the medium-term and longer-term impacts of the pandemic on children and their families. Some of these include:

A. Service provision

The pandemic exacerbated existing issues for families. Many of the families were in crisis pre-pandemic and were reliant on a high level of support in the form of respite care, residential care or outreach. The reduction in service provision seems to be maintained even in the recovery phases, which could be due to shortage of staff (possibly exacerbated by Brexit and workers leaving the UK) and/or due to salaries of care staff: The difficulties in recruiting and retaining social care staff was viewed as a major impediment to recovery:

“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.”

One charity noted an instance where local authorities are reducing funds for service provision under the pretext that families had been “coping well” during the pandemic and did not require the same level of services as before the pandemic. Although public health strategies were coordinated, there was no attempt to co-ordinate community approaches.

B. Education

The phrase ‘catch up’ was viewed as being misleading. Some children had developed new challenging behaviours or anxiety issues that were unaddressed. On the return to school, there have

been fewer additional support staff in schools, meaning that some children and young people are having to manage independently. The reduction in support staff was viewed as a result of retirements during the pandemic and the impact of Brexit on care staff numbers. Difficulties in re-adjusting to the full-time education has exacerbated the mental health issues of some children. Informal exclusions, lack of staff in mainstream schools, staff not recognizing that children need mental health support after their return to school. The difficulties with ensuring the safety of children with intellectual disabilities – going back face-to-face. The longer-term impact of the pandemic on educational outcomes still needs to be assessed.

C. Mental health

Many charities felt that children and adolescents with intellectual disabilities had experienced significant negative impacts on their mental health and education that are unlikely to simply resolve during the recovery period. Increased anxiety in some children and adolescents, had contributed to an exacerbation of existing challenging behaviours or new challenging behaviours in children and adolescents that hadn't previously. At the extreme end, it was recognised that some families had experienced the pandemic as a trauma and trauma-informed approaches were required to address it.

D. Economic consequences

Many pointed to a 'lag factor' where negative effects were likely to intensify over the short term. For example, families who had experienced financial stresses during the pandemic were likely to accrue debt, with future negative consequences.

E. Social aspects

During this recovery phase, social interaction is not back to pre-pandemic levels, which reduces access to the development of social skills.

F. Positive aspects

Despite the ongoing challenges, many viewed this period as an opportunity to redress issues of inequalities for families of children with intellectual disabilities and to reflect on issues of coordination across services:

“I would love it if government and all public agencies took this as our new moment of reset..there was a lot that was challenging about the pandemic, but the fact that it's creating the opportunities for us to have these conversations, I see that as a potentially very good thing to reset that narrative and the design of public services, staffing and workforce development across the piste in education, health and social care”

3. RECOMMENDATIONS FOR POLICES AND PRACTICE MOVING FORWARD

A. Need for reflective action in policy and practice:

Charities viewed the recovery period as an opportunity to improve services for children and young people, but only if time is taken to reflect on impacts of the pandemic and current provision.

B. Staffing:

The recruitment and retention of care staff was viewed as a key priority in supporting children and families in the recovery phase. This is related to a failure to recognise support staff as key workers, that are essential to the survival of vulnerable families. Lower wages for care workers were also mentioned as a major contributing factor to shortage of staff. The current UK employment market means that vacancies are often left unfilled, as many European applicants are no longer available.

C. Educational system

Charities felt that being able to support children in school requires policy change to allow social care staff being present in classrooms. The pandemic was viewed as a significant adverse event for some families; trauma informed practice in schools had the potential to be beneficial in the return to education.

Parents and Carers

Six parents joined us for this discussion all of whom had children of varying ages and support needs.

1. DURING THE PANDEMIC AND LOCKDOWN PHASES

A. Difficulties for parents

i) Respite facilities: When asked about difficulties faced during lockdown a number of parents discussed the removal and subsequent unavailability of respite services. Parents discussed that a lot of services were operating under a 'crisis management' protocol, which in their eyes, did not provide help or support to families who really needed it. Parents acknowledged that for most of them with children at home with an intellectual disability and/or complex health needs that they were already struggling prior to the pandemic, but this was only made worse during lockdown and with the removal of services. While parents recognised that some services needed to be cut back as a safety concern; parents talked about the need to 'beg' or 'fight' to have support for their child and themselves during the lockdown period, which they felt was unacceptable.

“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”

“But what I'm tending to find that as a family, we often have to fight for a lot of things that actually we shouldn't really be fighting for”

ii) Home-schooling and learning loss: Most parents who still had a child in education, commented on the fact that educational support was lacking. For parents with children with more complex health needs meaning their child was unable to attend school at all, found that the school was also not offering any online schooling options for children to feel included in class activities. Parents recognised the need for schools to offer support to children of key workers, but felt that there was a great inconsistency with guidelines and regulations (e.g., if one assisted support needs school was open, they all should have been). Parents felt that there was a lack of understanding or recognition that not only did schools provide for the child’s mental and physical needs, but also provided parents with some much-needed respite.

Further, parents talked about their child’s lack of home schooling during lockdown, primarily due to little to no support from the school. Parents raised how this was seriously affecting their children, specifically those who were due to leave school soon.

“But unlike the kids in mainstream schools who have been supported and given qualifications, our kids will come out without any qualifications, and I find that really, really distressing”

Lastly, staffing for Additional Support Needs schools was also discussed as an issue. A number of parents discussed instances where a teacher had tested positive for COVID and all children in their class were then unable to go to school. Again, comparing this to mainstream education whereby a substitute teacher would be used in this situation. Given the more complex needs of their children, a substitute teacher was not possible and therefore their children lost out on more schooling. Overall, there was a consensus from parents that they felt there was a complete ‘institutional discrimination’ from education and support services, especially when comparing support provided to children in mainstream education

B. Difficulties for children

Parents talked a lot about a number of difficulties their children had experienced during lockdown restrictions.

i) Collapse of normality and routine

All parents talked about how routine was best for their child. It helped them cope and understand the world. When lockdown restrictions were put in place their child’s normal routine was extremely disrupted and this caused children a great deal of distress. Parents also discussed difficulties explaining the rules of lockdown restrictions and why this was happening to their child, as many children struggled to understand this due to their mental capacity. Some parents opted not to allow their child to watch any news updates about COVID (although their child was aware there was a lockdown), due to worries that it may upset their child or cause some distress. In addition, parents

talked about the fact children could and would overhear meetings or discussions about COVID and even if they were not voicing it, they were aware of what was happening and internalising this. Parents talked about not being able to take their child to activities that they had previously enjoyed (e.g., going to the shops, cafes, social groups or swimming), and children did not understand why they were no longer able to do these things. Further, being unable to see extended family face-to-face was difficult for some children, although through the use of technology children had found a way to adapt and speak to family on a daily basis, which was positive.

ii) Physical health

For some children with more complex needs, the lockdown restrictions meant that they were a lot less mobile than they had been previously. This, combined with the closure or removal of support services, meant that some parents' children were now facing surgical options to aid their child's pain management due to loss of muscle tone caused by immobility.

2. DURING CURRENT TRANSITION AND RECOVERY PHASES

A. Worry for child's mental health

All parents stated they had noticed a dramatic increase in their child's anxiety, both during lockdown and now in the recovery phases as restrictions ease. Many children are now refusing to leave the house or go anywhere that isn't within a normal routine (e.g., a part-time job). Further, children were now either unsure about attending or were refusing to return to activities that children had previously attended, and enjoyed (e.g., a weekly social group).

Parents were also distinctly aware of their child's distress manifesting in other ways such as aggression, self-harm (e.g., hand biting), or loss of mobility (e.g., not walking when walking before). An issue that was raised during this discussion was that assessment criteria to ascertain whether children were experiencing extreme levels of distress are based on typically developing children and are not suitable or appropriate to be used to assess distress in populations with intellectual disabilities. As a result of their children not meeting the criteria set by CAMHS parents were unable to receive any help or support for their child.

“With regards to CAMHS, [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. However, if your child has mobility issues where they have no hand use, they are never going to be at the level where they can self-harm because you can't actually self-harm. But that doesn't mean that their distress is any less than those children who are expressing their distress through self-harm or through suicide attempts. And I think there needs to be a recognition that our children will express these things differently, but should still be prioritized”

There was also a discussion about neurotypical siblings in the home and the fact that their distress levels had also increased over fear and concern about the health and wellbeing of their siblings with more complex needs. Parents talked about the fact that despite lockdown restrictions easing, if their family was still shielding, siblings were unable to go out just in case someone in the household got sick. As restrictions ease, neurotypical siblings are still hesitant to go out over concern for their siblings' health.

B. Positive aspects

While not many positive aspects were discussed, some parents did say that lockdown had allowed them to spend more time with their family than they ever had before. Families spent more quality time together in the house and, when possible were able to exercise more as a family. Some parents also talked about their child enjoying the fact that they had a lot of family around at home, especially elder, neurotypical siblings that had come home from university and were staying with the family.

Moving most systems online, specifically parents' involvement in school activities, meant that parents could be more involved in school issues. Technology was also helpful in allowing children to speak with extended family that they were unable to see face-to-face during restrictions. One parent also mentioned about how their children had carried on using technology to speak to their extended family on a daily basis, despite lockdown restrictions now easing.

3. RECOMMENDATIONS FOR POLICES AND PRACTICE MOVING FORWARD

A. More readily available support

Parents consistently discussed disparities in support provision from different services. Parents also emphasised the pressing need to get groups and services that had been running before lockdown back up and running again, especially those for children with additional support needs. As discussed previously, this is important for the children's social and emotional development, but also provides parents with respite they desperately need. A number of parents discussed the fact that a lot of support services were either still to be reinstated, or had been removed completely. Parents stated that they had experienced being told that because they had 'coped' during lockdown without these services, that they were not seen as a priority for needing them again during the transition phases.

From the parents' perspectives, they felt organisations had started using COVID as an excuse not to provide services. While they recognised and stated that they felt some organisations were doing their hardest to help, it was beginning to feel like COVID was a fall-back, broad brush excuse that was now

getting used all too often. Parents stated that they were aware that services were possibly struggling before with other issues such as financial support, but now parents felt services were broad brushing with using COVID as an excuse as to why they could not provide support or assistance. Parents talked about being aware that some organisations had received COVID-specific funding as well as having 18-months to work on alternative solutions; and therefore, it should not be used as an excuse anymore.

“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”

B. Resources for parents

Some parents raised the need for more tailored resources to be more available, especially for those with younger children who may have missed out on valuable peer support due to lockdown.

“When you have a child with a learning disability you don't fit into all the normal parenting advice and support that's out there. So you have to actively find something that that does fit you. Otherwise you just become very isolated”

Education

Five education experts joined this discussion room representing local councils, the Department of Education, and the Additional Support for Learning services.

1. DURING PANDEMIC AND LOCKDOWN PHASES

A. Support and mental health

The main thing that impacted children with intellectual disabilities and their families was the amount of support that had been on offer and the impact on mental health. Education practitioners noted that families had also really struggled with a lack of structure, support not being available and how to fill the day up with their child. There were additional supports and additional therapies that children have lost out on, speech and language therapy appointments, physiotherapy appointments etc. have been really neglected during the pandemic.

B. Family and Sibling Pressure

Some families faced great challenges because they were struggling for things to do with the child. However, when they were given some schoolwork, they then had the pressure to try and complete it. This was a challenge for families since they had to work out how to balance everyone in the family's needs and get through an unprecedented situation.

There were concerns around siblings in families of children with ID. Siblings had to take on more responsibilities during COVID-19 and the transitions out of lockdown, including helping with their sibling with intellectual disabilities' home learning.

“the learning and things that was being sent home that the siblings were taking on a lot of that as well. So they had a bit more responsibility.”

C. Education and Learning Provision

There was considerable variation in the consistency of education and learning provision across the UK and, although there was a more targeted informed approach during lockdown 2, variation still existed. For some families with children with intellectual disabilities, learning on Microsoft teams was never a realistic option and they instead relied on learning hubs. They referred to this as digital exclusion. However, during lockdown 1 there was greater anxiety accessing these, due to unfamiliar place and unfamiliar staff. This seemed to change during lockdown 2, when the hubs were located in children's

own schools, which worked much better for these families. Further, routines during this time were still disrupted since they were only accessing hub schooling 2-3 days a week and while the hub schooling was highly structured the remaining time at home was largely unstructured. This was also partly due to families originally having days filled with activities like swimming etc. and they weren't able to do these things during COVID-19.

In some areas of England for lockdown 1 this was a bit different where it was down to the local schools to remain open for children with Special Educational Needs and Disabilities (SEND). However, teachers were scared about COVID-19 and at times there was not enough staff to look after the children so the access to education varied across England. For lockdown 2 more support was provided because authorities knew who was more at risk and what measures could be taken to prevent risk.

For the second lockdown, one of the hardest things was transitioning from the hub schools back to normal mainstream classes. This meant the children were going from classes of 10-15 with bells turned off, having lunch in the same room with 4 and 5 adults per class, a few children all with similar needs in the same class then back to mainstream class and a lot of the children struggled with these changes.

It was difficult to set up teaching provision and a differentiated learning routine for the children online. Children were also finding it difficult to engage in home. These factors affecting access to learning were further compounded by the constant changes in COVID-19 rules and guidance.

D. Specialist Services and Interventions

Educational practitioners felt it was more difficult to organize and set up speech and language therapy, additional support and mental health support when most practitioners could not get into the schools to meet with children face to face. Educational services staff found it really difficult to get into schools so had to use Microsoft Teams when trying to support families, especially when some situations would have been better done in person. Speech and language therapists and occupational therapists also noted the difficulty they experienced, as they couldn't go into the school to see and observe the child and online was not as effective.

Lots of supports and interventions offered within schools were taken away including play therapists, lego social groups, forest skills, emotion talk groups and they couldn't have nurture bases. So all of these people that were going into schools and fun activities were lost during the pandemic. This was difficult because some children went to school on certain days looking forward to doing these fun activities.

E. Positives

Children really enjoyed the autonomy of learning on Teams and within their hubs. They could choose what activity they wanted to do and when. They enjoyed being in the smaller hubs making new friendships and relationships and they found it difficult going back to mainstream schools.

2. DURING CURRENT TRANSITION AND RECOVERY PHASES

A. Barriers or concerns about being back at school

Some people still have not returned to the previous educational setting yet because of fears or anxiety of either the child themselves or the parents.

There is anxiety around the support provisions – whether they will be there and whether they will be the same as they were before. There is anxiety about moving into a different and novel situation. This is worse for people with complex physical disabilities as well since they are still anxious about catching COVID-19 and the impact this could have on their lives.

B. Transition Teaching

Transitions are still really limited because some schools are still operating in bubbles (to minimize staff and pupil risk – 6 pupils: 4 adults). This is a real challenge in specialist schools where they are supposed to be teaching the young people transitional skills. Currently curriculum delivery is still very class based and schools are not able to do the work they would like to do: i.e. taking kids to shops, teaching them about public transport. This is really difficult because the children need to have these skills to move onto adult services and others who did have those skills before lockdown have now lost these. Teachers are trying to come up with creative ways to deal with this (i.e. put bus stop in school groups and have children pretend that the school bus is a public bus) but these are not the same as experiencing these things in society. Being kept in a room and only going out within small windows of time and trying to teach children about transitions is difficult.

Maintaining the balance of keeping everyone safe, providing the children with the skills they need and keeping everyone in school is a real challenge. If one staff member becomes unwell, then the whole bubble needs to go off and get tested. So, there is still a lot of disruption.

C. Delivering the ‘Fun’ curriculum

Music and art teachers are coming into the school. However, these are now delivered in the same classroom (rather than being in the art or music rooms) to minimize child and teacher risk.

D. The Return of Specialist Services

Educational psychologists are now focusing on priority children. During lockdown educational psychologists were having consultations with teaching staff rather than going into class and observing

the young person. This was something that educational psychologists were moving towards (rather than Educational psychologists coming in and assessing the child – which is quite invasive) and COVID-19 has expedited this change in how educational psychologists make assessments. Educational psychologists are now working with parents and Special Educational Needs And Disabilities (SEND) staff to assess the child.

Now schools have the occupational therapists and speech and language therapists going back in to work with the children which is great and works for most families. For some families however, they prefer doing sessions with educational psychologists over Teams rather than attending sessions in person and having to travel to appointments. For some families there are real benefits for having these specialist services accessed via online platforms.

E. Positives

Educational practitioners reflected that from their experience some families had reported that they felt that they got to know their children better during lockdown; as well as having more involvement in their child's learning. Staff felt that this experience had encouraged more discussion between schools and parents about the skills that the children need to work on and how the parents and school can work together to improve this. So schools are working closely with families moving forward and thinking about target setting together, identifying important skills and planning the work that needs to be done.

Parents evenings also have become more regular because they can be done over Zoom and have led to better relationships between the home and school environments. Parents who could spend time with their child could also focus on particular areas and there would be increased continuity because the parents were at home with their child so there were some children who made a lot of progress.

F. Changing the curriculum for children with intellectual disabilities

Really focusing on what children need to be in the world and opening up the world for curriculum for kids with learning disabilities. To move away from thinking of schools of just somewhere you do your reading, writing and counting, but also as a place that sets the child up for life with the skills needed to manage in the world. Educational staff believed that children had experienced a considerable amount of disruption during the pandemic and recognised children would understandably be feeling highly anxious about returning to school. Staff felt that education authorities need to stop putting pressure on teachers to catch up with reading and writing and instead getting children sitting at their desks again. Local authorities should give teachers more autonomy to mould the curriculum to suit the children that they know best. To have more time doing gentle transition work with the children, to have more time focusing on activities that the children enjoy such as music, art and play. The children need fun and they need to know that school is a nice place again after spending so much time at home with their parents. Letting teachers try some different teaching practices and seeing what works

well for the children with such individualised needs and then sharing that effective practice would be invaluable. Once children were more settled back into the school routine then academic skills could be taught and prioritised once again. Once you have the life skills, you can do all the academic skills later. COVID has given schools a really good opportunity to look at what they are teaching and why. Participants agreed that there is a need to have children, their families and teachers at the centre of these conversations and establishing what provisions and support they need going forward.

Teachers need training to feel confident to support the children in the classrooms. They also need protected time to develop appropriate relationships with children to help their social, emotional and mental needs, rather than pressure to catch up with all things academic. Schools don't need special tools or special lessons they just need to change the focus of the curriculum.

[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

G. Parent and children with intellectual disabilities mental health

Parental stress has been a real issue highlighted with it being clear that some parents have been really impacted by the pandemic compared to others. It has been consistently highlighted that there is an escalation of need in children, particularly social, emotional and mental health needs. These needs could be addressed within schools (as long as schools are provided with adequate support). School is a secure and safe environment, with existing key networks making it an ideal space to deliver support for the children's social, emotional and mental health needs while transitioning out of COVID-19. There is a lot of pressure for schools to do traditional school and catch the children up with learning. However, this won't work if the children are distressed and have mental health issues.

"Nobody is going to learn anything academic if they are not OK."

3. RECOMMENDATIONS FOR POLICES AND PRACTICE MOVING FORWARD

A. Additional support required

Education staff discussed needing more training around how best to support children's mental health as they transition back into education. They collectively recognised that this would be an extremely stressful time for their students and wanted to support them as best they possibly could. Further, staff talked about wanting more time to be allocated to providing this support for children.

Practitioners

Eight practitioners joined us for this discussion representing services that included local councils, CAMHS and social work.

1. DURING THE PANDEMIC AND LOCKDOWN PHASES

A. Impact on service users

Practitioners experienced that children responded differently to education and respite services being disrupted, some children coped better at home, while others struggled with the lack of routine and structure. Practitioners felt that caregiver wellbeing was significantly impacted by this disruption of services.

"...the children going to school, gives them a bit of that break in the day to recharge their batteries or do something else, they didn't have that."

As a result, practitioners who continued to work within the home environment found increasingly that they were caring for and listening to and helping parents, in addition to their work with the child. Referrals for behaviours of concern increased, and parents struggled with the process of navigating education and placement applications without in-person assessments.

B. Impact on professionals

Practitioners themselves experienced shifts in job roles and expectations. The focus shifted from helping families develop skills and strategies to better manage their children's behaviour, to assisting families in meeting basic needs by helping with practical tasks and providing a listening ear.

"because it wasn't a time for our families to work (therapeutic work), because the work that we do is big difficult change work. It's work that requires a lot of emotional and physical time and investment and nobody had that."

In addition, practitioners discussed tension arising due to different expectations for different professionals (e.g., Nurses being expected to continue to work in person, while other professions switched to online working); social support services such as respite being disrupted, and some practitioners working from home increased workload for other teams as they felt pressure to bridge the gap in services.

"...because we work for the NHS and because we had that kind of sense of responsibility for the families as well, that you know... that created tensions within our team."

Generally, practitioners discussed being better prepared to work online and integrate digital services. For some, reduced travel time was a clear positive. Communication barriers across locations and agencies were broken down with the transition to online meetings allowing for better multi-agency communication and cooperation; this was highlighted as a key area to continue developing moving forward.

2. DURING CURRENT TRANSITION AND RECOVERY PHASES

A. Service users

Practitioners felt that children responded differently to the return to school similarly to when they were closed. The impact of social bubbles and restrictions within the school environment as well as prolonged closure of resources, play centres and swimming pools meant less opportunities for children to practice key skills leading to difficulties with reintegration to community activity and previous routines.

The shift to online socialisation and social media use presented novel challenges for practitioners to work with. Parents struggled with the transition back to school due to anxiety and uncertainty about potential changes, school closures and staffing issues. Practitioners felt parents were still not ready to engage in more clinical work, needed support and were not 'recovered'.

B. Professionals

A key issue raised in the recovery phase for professionals was the recruitment and retention of staff. Recruitment issues are affecting services available to children and current staff are at risk of burnout.

New staff feel isolated due to not being able to meet colleagues, and many practitioners mentioned higher rates of mental health issues among staff.

Working from home, practitioners experience blurred boundaries between work and personal life with having to undertake challenging therapeutic work within their own home or bedroom (as opposed to a clinic or typical outpatient environments); reduced travel times has led to more sessions and meetings being booked back to back with less time to decompress in between. As services have opened up more and practitioners reported using a more blended approach, as there are challenges with the expectation that you are to be available online and in-person simultaneously. The need to set boundaries in this regard with colleagues and service users was considered vital moving forward.

Additionally, a more embedded approach to peer support among staff was considered important in maintaining staff wellbeing as well as for recruitment. Being able to seek peer support from colleagues was highlighted as important for practitioner wellbeing; working in an office provided easy access to such opportunities, but this has not been prioritised when working remotely especially if other matters arise.

"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."

3. RECOMMENDATIONS FOR POLICES AND PRACTICE MOVING FORWARD

A. Increase in new staff

Practitioners discussed the severe levels of burnout being experienced across all social and clinical services; they suggested a way to decrease this was to hire more clinical and social care staff in order to alleviate the pressures being faced by current practitioners.

B. New approaches to be implemented

Related to mental health and burnout, practitioners also discussed the need for more embedded approaches to be implemented within social and clinical care systems. These approaches would be centred around peer support and boundary setting with colleagues and service users. It was hoped

that by implementing these embedded approaches, this may reduce current pressures on staff, which may help to improve issues around burnout and mental health and wellbeing.

A final thank you

We would like to take this opportunity to once again thank you all for attending this event. We feel, based on the discussions that were had in each group that this event was extremely timely and provided a good platform for those to share their experiences and thoughts about how best to support families with children with intellectual disabilities.

We hope to also take evidence from these discussions to form policy briefs in the hope of encouraging action for change.

We will be holding a similar event in January of 2022 where we hope to present findings from the project; and we hope to welcome you all back again at this time.

We are still looking for participants for ongoing work in the project!

Are you a parent or carer with a child aged 5-18 years? Or do you know someone that is?

If the answer is 'yes':

- Please consider taking part in our online survey where you can share your experiences as a parent or carer during lockdown.
- Or perhaps you may be interested in taking part in a parent/carer interview or have your child take part in a photo/picture session where families can share their experiences in more detail.

If you would like to find out more about either of these projects, please do get in touch with Dr Hope Christie via email: hchrist5@ed.ac.uk

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