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Impact of COVID-19 on Parents of children with Intellectual Disabilities (ID) across the UK

Summary

- Parents of children with Intellectual Disabilities (ID)¹ were put under significant pressures as a result of public health measures taken to reduce the spread of the COVID-19 virus
- Parents of children with ID are more vulnerable to mental health difficulties compared with carers of typically developing children
- Emerging research evidence tells us how lockdown restrictions to education, respite and support services (all factors that are known to reduce caregiver stress) impact both the carer coping strategies and children's challenging behaviours
- Carers of children with ID reported a sense of feeling unsupported and forgotten during the pandemic and lockdown, and highlighted a perceived absence of support from social, health and education services. There was a general feeling that they have been left on their own to meet complex educational, sensory-related, medical and social care needs
- Lack of service provision, respite and school infrastructure during restrictions caused increased children's challenging behaviours and caregiver psychological distress
- New data is emerging rapidly on this, and we can share this timeously with the Committee to aide its work on the long-term impact of the COVID-19 pandemic on children with ID and their families

Top level recommendations to consider

- Parents of children with ID need targeted support as we transition out of restrictions to protect against negative mental health outcomes
- Both children with ID and their parents are vulnerable groups and need continued monitoring and support (specifically mental health support) during this transition
- Information, support and education tools must be provided to parents of children with ID, educating them on best ways to cope that can protect against poor mental health outcomes

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 23rd March 2020, which established Public Health Safety Measures (PHSM) to reduce the spread of the virus (1). Although the

¹ 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).

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.

We must identify and support those parents who were more at risk of negative mental health outcomes following COVID-19 restrictions. Lessons need to be learned so that if lockdown or restrictions ever happen again that these vulnerable groups are better protected.

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) trigger or exacerbate these factors.

Previous research has suggested that disruption to routines and restrictions on social activity not only impact how parents perceive their situation but also the coping strategies they employ (14). Recent research on the impact of COVID-19 on parents of children with neurodevelopmental disorders has highlighted that parents need to spend more time on self-care that focuses on social support and social opportunities and not just traditional areas (i.e. exercise, stress management, smoking cessation, etc.) to improve mental health (15). To date, research has reported a variety of specific coping strategies that positively impact mental health outcomes in carers of children with neurodevelopmental disabilities. These coping strategies include positive re-interpretation of stressors (16) and active emotional coping strategies (17).

It is important to examine how lockdown restrictions to education, respite and support services (all factors that are known to reduce caregiver stress; for a review see 18) will impact both the carer coping strategies and children's challenging behaviours. Indeed, there is evidence showing an increase in requests for prescription medicine across ID services to manage children's challenging behaviour during the pandemic (19). Our research project is examining the impact of the COVID-19 restrictions on both behaviours that challenge in children and parents' coping strategies.

Emerging evidence

We invited parents to complete an online survey that included topics on children's challenging behaviours, parent coping strategies and caregiver psychological distress in the context of the COVID-19 pandemic and related public health restrictions.

- Nearly 70 parents of children who were typically developing, and around 40 parents of children with ID have taken part in the study so far.
- Results showed that levels of children’s challenging behaviours were related to psychological distress (showing that both children’s and parent stress levels were related).
- In addition to children’s challenging behaviours, parent coping strategies posed an additional risk for caregiver psychological distress.
- How children and their parents responded to the stressful external events impacted caregiver mental health.

Theme 1: Unsupported and forgotten

Parents reported a sense of feeling unsupported and forgotten during the pandemic and lockdown, and highlighted a perceived absence of support from social, health and education services. There was a general feeling that they have been left on their own to meet complex educational, sensory-related, medical and social care needs:

“I was frustrated with restrictions on food purchases e.g. for restrictive diet I needed more than 3 of some items to get him fed for one week – I almost cried.” (Parent 1).

“a lack of support from specialist services. No check-ins.” (Parent 2).

Theme 2: Loss of freedom

Individuals and parents have experienced a loss of freedom in terms of not being able to do favourite things, activities-the loss of seeing friends and family, and for some individuals no longer being able to leave the house. Many of the respondents reported the negative impact of a loss of structure, routine and activities:

“lack of routine, lack of going places, lack of activities he can do.” (Parent 3).

Theme 3: Confusing messages and guidance

Parents who had children with ID struggled to understand the media messages and communicate it to their children:

“I can say ‘no school, we need to stay safe’ but what exactly does that mean if you have no concept of a virus, of time, of school not being there, or if it will ever be there again.” (Parent 4).

Policy considerations

1. Parents of children with ID need targeted support as we transition out of restrictions to protect against negative mental health outcomes.
2. Lack of service provision, respite and school infrastructure during restrictions caused increased children’s challenging behaviours and caregiver psychological distress.

3. Regardless of levels of challenging behaviours (i.e. behaviours that indicate stress in children); the parent's coping strategies impacted the psychological distress outcomes.
4. Service providers must listen and involve children with ID and their parents in decision-making to better understand how best to support these families.

Recommendations

1. Both children with ID and their parents are vulnerable groups. They will need continued monitoring and support (specifically mental health support) by increasing service check-ins, and improving access to services as the UK transitions out of Lockdown.
2. It is crucial that information, support and education tools are provided to parents of children with ID, educating them on positive coping strategies that can protect against poor mental health outcomes. This could be achieved by improving access to online support, forums and toolboxes.
3. If lockdown or restrictions happen again, both groups need targeted support and guidance i.e. help to understand and convey public messaging, online and telephone clinical consultations, e-interventions are options to improve communications and support for these vulnerable families.

References

1. UK Cabinet Office. (2020). *Staying at home and away from others (social distancing)*. Retrieved from: <https://www.gov.uk/government/publications/full-guidance-on-staying-at-home-and-away-from-others>
2. Eisenhower, A.S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, 49(9), 657-671. <https://doi.org/10.1111/j.1365-2788.2005.00699.x>
3. Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, 33(10), 1129-1136. <https://doi.org/10.1093/jpepsy/jsn040>
4. Zayac, R. M., & Johnston, J. M. (2008). Contriving establishing operations: Responses of individuals with developmental disabilities during a learning task. *Research in Developmental Disabilities*, 29, 202-216. <https://doi.org/10.1016/j.ridd.2007.03.001>
5. Lee, L. C., Harrington, R. A., Chang, J. J., & Conners, S. L. (2008). Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities*, 29, 247-255. <https://doi.org/10.1016/j.ridd.2007.05.002>
6. Benson, B. A., & Brooks, W. T. (2008). Aggressive challenging behaviour and intellectual disability. *Current Opinion in Psychiatry*, 21(5), 454-458. <https://doi.org/10.1097/YCO.0b013e328306a090>
7. Myrbakk, E., & Von Tetzchner, S. (2008). The prevalence of behavior problems among people with intellectual disability living in community

- settings. *Journal of Mental Health Research in Intellectual Disabilities*, 1(3), 205-222.
8. Courtenay, K., & Perera, B. (2020). COVID-19 and People with Intellectual Disability: impacts of a pandemic. *Irish Journal of Psychological Medicine*, 1-21. <https://doi.org/10.1017/ipm.2020.45>
 9. Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology*, 62(1), 17. <https://doi.org/10.1037/0022-006X.62.1.17>
 10. Davies, L. E., & Oliver, C. (2016). Self-injury, aggression and destruction in children with severe intellectual disability: Incidence, persistence and novel, predictive behavioural risk markers. *Research in Developmental Disabilities*, 49, 291-301. <https://doi.org/10.1016/j.ridd.2015.12.003>
 11. Davies, L. E., & Oliver, C. (2014). The purported association between depression, aggression, and self-injury in people with intellectual disability: a critical review of the literature. *American Journal on Intellectual and Developmental Disabilities*, 119(5), 452-471. <https://doi.org/10.1352/1944-7558-119.5.452>
 12. Koritsas, S., & Iacono, T. (2015). Predictors of challenging behaviour in adults with intellectual disability. *Advances in mental health and intellectual disabilities*.
 13. Anderson, R. M., Heesterbeek, H., Klinkenberg, D., & Hollingsworth, T. D. (2020). How will country-based mitigation measures influence the course of the COVID-19 epidemic? *The Lancet*, 395, (10228), 931–934. [https://doi.org/10.1016/S0140-6736\(20\)30567-5](https://doi.org/10.1016/S0140-6736(20)30567-5)
 14. Cramm, J. M., & Nieboer, A. P. (2011). Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities*, 15(2), 101-113. <https://doi.org/10.1177/1744629511410922>
 15. Chafouleas, S. M., Iovino, E. A., & Koriakin, T. A. (2020). Caregivers of children with developmental disabilities: Exploring perceptions of health-promoting self-care. *Journal of Developmental and Physical Disabilities*, 32(6), 893-913. <https://doi.org/10.1007/s10882-019-09724-x>
 16. Smith L. E., Seltzer M. M., Tager-Flusberg H., Greenberg J. S. & Carter A. S. (2008) A comparative analysis of wellbeing and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders* 38, 876–89. <https://doi.org/10.1007/s10803-007-0461-6>
 17. Ganjiwale, D., Ganjiwale, J., Sharma, B., & Mishra, B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *Journal of Family Medicine and Primary Care*, 5(2), 343. <https://doi.org/10.4103/2249-4863.192360>
 18. Chan, J. B., & Sigafos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children?. In *Child and Youth Care Forum* (Vol. 30, No. 5, pp. 253-263). Kluwer Academic Publishers-Plenum Publishers.
 19. Courtenay, K. (2020). Covid-19: challenges for people with intellectual disability. *BMJ*, 369.

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