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International Journal of Developmental Disabilities (2020)

DOI: [10.1080/20473869.2020.1764257](https://doi.org/10.1080/20473869.2020.1764257)

## **The effect on and experience of families with a member who has IDD of the COVID 19 pandemic in the UK: Developing an Investigation.**

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The coronavirus disease 2019 (COVID-19) pandemic is the most pressing issue we now face and has had major implications on the way we all live our lives. There are clearly specific issues faced by people with Intellectual and Developmental Disabilities (IDD) and many of these have been summarised in a recent guidelines document (Alexander et al, 2020). While these guidelines have a specific focus on the UK they highlight the difficulties faced by all people with IDD during the current crisis. They make a clear case for them to be considered, as *at risk* of severe illness from COVID-19 category and many will be assigned to the *very high risk* of severe illness from COVID-19, due to associated comorbidity. Within the media, there has been a focus upon the provision of care during the pandemic and the guidelines produced for people with IDD are centred on the responsibilities of staff, in this case staff in community teams and residential services. However, they also highlight the vital role that family carers play in supporting people with IDD (Alexander et al. 2020).

While many families report positive aspects of supporting their offspring with IDD (Heer, Larkin, and Rose, 2012), they can also experience significant amounts of stress (Hill & Rose, 2009; Willner & Goldstein, 2002). Some of these stressors can be the result of obtaining appropriate health care, which can be challenging for people with IDD even when health systems are not subject to significant demands (Tuffrey-Wijne, et al., 2014). There have been concerns that these inequalities are exacerbated in the current situation (Alexander et al, under review).

The COVID 19 pandemic is having an added and unprecedented impact upon families through the imposition of social distancing and isolation measures. It is most likely that these measures will impair the mental health of many people in society (Brooks et al 2020). This is of particular concern for family carers as families with a relative who has IDD are likely to have many additional burdens. Initial reports from clinical services and families about the impact of the pandemic are mixed. Some clinicians are reporting less challenging behaviour in people with IDD, possibly as the result of fewer demands and a quieter lifestyle as a result of social isolation (Davis, Personal Communication). Some families are also reporting that there can be benefits to living a less complex lifestyle, with more opportunities for positive interaction with their offspring. However these benefits can quickly be offset by the intensity of the demands of continual caring, often with work commitments being managed alongside the support of their offspring require in the home. Additionally the response of external agencies such as schools and community teams to providing continued support, albeit remotely seems to have been mixed with some agencies attempting to provide continued support but others providing very little if any assistance (Cooper, Personal Communication). These difficulties seem to have compounded the normal stressors encountered in caring, as a result, charities and other organisations have recently been inundated with requests for help and Cooper (Personal Communication) reports a number of extraordinary requests being made of families:

- Having a child assessed as needing 1:1 support in school, being sent home to the family with no support (despite all the messages from government in England about expecting children with Education Health and Care Plans continuing to attend school).
- Adult relatives with IDD who normally live in residential care services (with 1:1 or greater support) being sent to live with the family at home (with no additional support).
- Some families are managing complex packages of support and often employing many staff – who are also feeling very stressed. This means they are having to deal with the employment issues (without any support, legal advice etc) as well as physically maintaining the care and support of their relative
- Concerns about their relative with IDD in a service where access to them is being restricted or prohibited, especially where they believe other residents have COVID-19

These examples illustrate the complex range of potential stressors resulting from the new restrictions but they also reflect existing support structures breaking down with no prospect of immediate and effective replacement. There has been some recognition of the specific difficulties faced by families who support their relatives with IDD in England in that the government has recently announced a relaxation in the social distancing rules for this group. In response to a legal challenge focusing on human rights people with IDD can now access the community more flexibly than others for exercise and therapeutic programmes (Bindmans, 2020). A number of different organisations have developed practical advice and suggestions to support families (National Autistic Society; 2020; The Challenging Foundation, 2020). While this advice is timely and is likely to provide useful support to families, we need to develop an evidence base to refine and improve the information and support available to families.

There are a range of psychological models and ideas that can help our understanding and guide research in this area (Hill & Rose, 2010; Rose, Nelson & Hardiman, 2016). When psychological theory is considered in relation to the difficulties families are reporting this can guide our investigation of what may be needed. Key elements that can contribute to increased stress are a reduction in support combined with changes in individual psychological factors (Dean & Lin, 1977; Hassall, Rose & McDonald, 2005). It will therefore be important to examine these areas in detail while trying to reflect upon the specific changes that are being thrust upon families. For example, as social distancing measures are being implemented it is important to know how effective new methods of electronic communication are in filling the gap created by reduced face to face contact. Much social support is currently provided through electronic means such as through video conferencing or on the telephone, so it is important to know what the impact of these changes are and how effective these changes are in supporting families. Gaining some insight into the ways in which families are psychologically adjusting to new lifestyles is also important. While there are a huge range of psychological factors to investigate, one particularly important area that has previously been identified as associated with stress, is the use of coping strategies (Hatton & Emerson, 1995). Gaining an insight into the way that individuals are coping effectively (or ineffectively) is important in relation to providing the support families need.

An additional dimension to the pandemic is time, with the prospect of a return to normality being some way off and with no clear exit strategy from the lockdown in the UK at the time of writing. It seems that some form of social restriction is likely to be with us for a significant period. If restrictions are maintained with services and support reduced, it will be important to try to understand the impact of this on families over the course of the pandemic. Trying to understand how people adapt (or not) will provide valuable information as to how their needs can be both understood and responded to dynamically. . If appropriate support can be provided it is likely to have a significant economic benefit by reducing the breakdown of family support which could lead to more residential placements. Collecting both cross sectional and longitudinal data should provide the best opportunity to understand what is going on for families so that the best way forward can be found.

It is imperative that we devote resources and research effort to find out what is going on in families where there is a member with IDD over the course of the COVID 19 pandemic and how adaptations can be made to provide the most effective help. We have developed and disseminated a brief survey that investigates the levels of stress reported by family carers of people with IDD during this period. We are also examining the key sources of social support available to families and the ways in which this is provided, either directly or remotely and the implications of these. We are also asking what coping strategies are being used in order to focus on the most effective ones. We will be requesting carers of children without IDD to complete the survey as well, so that we can get a better idea of how families are coping during the pandemic. While we appreciate that these families are not necessarily comparable, they will provide a reference group to help us understand how the population is adapting to these extraordinary times.

Surveys by their nature restrict the information that can be collected and we do not wish to increase the stress on families at this challenging time by making the length of the survey

excessive. We will be supplementing the survey by asking a small number of respondents to contribute to a series of qualitative interviews whereby family carers will report on their experiences to provide an in depth account of what is challenging, rewarding and what they have found to be helpful.

The results of this research will be analysed and reported as quickly as possible to highlight the reality of providing care and support during such a challenging time. We hope that the research will inform personal adaptation and best practice for those in a position to provide support.

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