

State of the Science on COVID-19 and People with IDD

Introduction

The purpose of this brief is to provide an overview of what the research to date reveals about people with intellectual and developmental disabilities (IDD), COVID-19, and vaccination.

The research to date indicates that people with IDD (a) are more likely to be exposed to COVID-19 and have poorer COVID-19-related health outcomes than the general public; (b) are as likely as the general population to engage in preventive health strategies; and (c) have experienced massive disruption in health, home, and community services, exacerbating existing inequities in health care, and putting additional pressure on already over-taxed formal and informal support networks.

People with IDD and COVID-19 Risk

People with IDD are more likely to be exposed to COVID-19 and have poorer outcomes than the general public. People with IDD who live in congregate settings or with older family members are in particularly precarious positions.

- Roughly 7.38 million people in the U.S. (2.28% of the population) have IDD (Residential Information Systems Project, 2020).
- Only 10% of people with IDD in the U.S. live in a supervised residential setting; the majority of people with IDD (72%) in the U.S. live with family members. Of the estimated 5.35 million family caregivers in the U.S., 24% are over the age of 60 years (Tanis et al., 2020), a high-risk group for contracting COVID-19.
- People with IDD who are Black, Asian, Hispanic, or Native American have a greater positivity rate of COVID-19 as compared to their White, non-Hispanic counterparts (Chakraborty, 2020).
- People with IDD who live in congregate settings, such as institutions, nursing homes, and group homes, are at higher risk of exposure to COVID-19 than the general population (Desroches et al., 2020; Landes, Turk, & Ervin, 2020), with their increased risk directly related to the number of people living together (Landes, Turk, & Wong, 2020); however a survey by Drum et al. (2020) found that only 2% with people with IDD reported receiving a COVID-19 test.
- People with IDD and COVID-19 in congregate settings are more likely to have severe cases (Turk et al., 2020), poorer outcomes in general (Landes, Turk, & Wong, 2020), and are more likely to die from the condition (Landes, Formica, et al., 2020).
- People with IDD have a higher incidence of COVID-19-related deaths than the general population (Cuypers et al., 2020; with dramatically greater rates of COVID-19-related deaths among adults 70 and older with IDD (West Health Institute & Makary, 2020) and adults over 40 with Down syndrome (Hüls et al., 2020).

People with IDD and Vaccines

Most people with IDD have received prior vaccinations and currently engage in preventive health strategies.

- In general, people with IDD engage in preventive health measures: a recent survey of adults with IDD revealed that 93% reported compliance with public health recommendations (Drum et al., 2020).
- Children with and without IDD are equally likely to receive routine childhood vaccinations (Smith et al., 2015), and among adults with IDD who receive services through their state agencies, 74% reported having received a flu vaccination in the last 12 months (National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute, 2020).

Health, Home, and Community Services

Most people with IDD who had received in-person supports prior to the COVID-19 pandemic have since experienced substantial changes in the type and duration of their services, which has had negative effects on their well-being.

- Physical distancing from health and other direct service providers is not possible for people with IDD who require direct personal assistance (Kavanagh et al., 2020; Drum et al., 2020).
- During the pandemic, access to health, mental health, and education services has been seriously disrupted for people with IDD who live in the community. One study found that more than 70% of people with IDD living in the community experienced a loss of at least some health services stemming from COVID-19 with 24% reporting a loss of critical care services; however, only 2% reported a disruption in prescription access (Drum et al., 2020).
- Another survey revealed that 74% of people with IDD had lost one or more services entirely, with only 39% reporting that at least one of their services had been delivered virtually (Jeste et al., 2020).
- Some support services can and have been successfully provided virtually (Zaagsma et al., 2020; Taddei & Bulgheroni, 2020); however, there are real concerns about the impact of greater screen time on adolescents with Autism Spectrum Disorder (Garcia et al., 2020) and the long-term impact of service reductions related to COVID-19 on families of young children with IDD (Neese et al., 2020).
- A survey of national disability organizations regarding COVID-19 lockdowns revealed significant concerns about its impact on the mental health and challenging behaviors of those they serve (Tromans et al., 2020). Access to mental health services for people with IDD has been disrupted by the pandemic, which has further exacerbated inequities already present in these systems (Sheehan et al., 2020).

- A comparison of pre- and post-COVID-19 incident reports of a large residential service provider revealed that against a background of generally lowered level of incidents—both actual and near-miss—aggressive behaviors rose during the lockdown period (Schnegele et al., 2020).

Caregivers and COVID-19

COVID-19-related disruptions in services has resulted in greater pressure on a workforce that was already thinly-stretched and an increased reliance on family members to deliver necessary supports, which has taken a toll on both paid and unpaid caregivers.

- Among adults with IDD, disruptions in or loss of services has resulted in greater reliance on family members for supports (Redquest et al., 2021). Family members providing supports to both children and adults with IDD report significantly greater levels anxiety and depression when compared to both their pre-pandemic levels and the families of children and adults without IDD (Willner et al., 2020).
- The COVID-19-related loss of routine educational and therapeutic supports has introduced new stressors and challenges to daily life among all families with young children with IDD, with greater inequities likely experienced among Hispanic families, whose children with IDD are more likely to be underserved (Neece et al., 2020).
- A survey of direct service providers revealed that in addition to their fear of getting infected themselves—and possibly transmitting COVID-19 to their own families—those surveyed reported both a decreased ability for coping with life stressors and increased isolation (Embregts et al., 2020).
- Hewitt et al. (2020) reports that 74% of workers who directly support people with IDD are the primary wage earners in their households, with a pre-COVID-19 median wage of \$13.63/hour. Their survey revealed that only about a quarter of those workers received any increase in hourly compensation due to COVID-19 risks, and of those who received such “hazard pay” the majority received an increase of two or less dollars an hour.

Conclusion

Research to date underscores that people with IDD are (a) at higher risk for poor outcomes and have a higher incidence of COVID-19-related deaths than the general population, (b) just as likely as the general public to get childhood and adult vaccinations, and (c) undergoing substantial disruptions in crucial services which exacerbate existing inequities in health care and other supports and are further straining already overburdened paid and unpaid caregivers.

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