

Impact of the COVID-19 Pandemic on the Pennsylvania ID/A Service System

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Abstract

This paper summarizes a series of studies on the impact of the COVID-19 pandemic on the Intellectual Disability/Autism service and support system. The impacts on consumers, staff, and programs were quantified.

Introduction

The COVID-19 pandemic fell upon an already weakened unstable Intellectual Disability and Autism (ID/A) service system. Systematically underfunded by state legislatures for year, the system was characterized by a chronic workforce crisis, the inability to pay a living wage to Direct Support Professionals, individuals and families waiting for critical services, and provider agencies operating without sufficient fiscal margins. In a sense, the pandemic created a perfect storm for the ID/A service system.

The Center for Disability Information (CDI) has been empirically monitoring the workforce crisis over the past seven years, and the pandemic only enhanced efforts to quantify the health of our service system, providers' ability to staff the system, and ultimately, the health of the individuals served. Over the past two years, the Center for Disability Information has released numerous reports regarding the impact of the pandemic. The purpose of this document is to summarize some of key information regarding the impact of the COVID-19 Pandemic on the ID/A Service System within a single document. We propose to address five specific topics:

1. The Impact on the Workforce
2. The Impact on Service Capacity
3. The Impact on the Health of Individuals with Intellectual Disability/Autism
4. The Fiscal Impact on Provider Organizations
5. The Impact of a recently Revised Rate Structure

Impact on the Workforce

The Intellectual Disability/Autism workforce was in crisis prior to the onset of the COVID-19 Pandemic. Pennsylvania research (Spreat, 2020) suggested that the annual turnover rate for Direct Support Professionals was about 31%, and the direct support professional (DSP) vacancy rate was almost 20%. The high turnover rate drives recruitment and training costs upward, and the critical DSP vacancy rate increases overtime costs (up 76.5%) and eventually impacts the quality of care provided.

An August 2021 Pennsylvania survey (Davis, Spreat, & Gruber, 2021), conducted by CDI during a lull between COVID-19 peaks, suggested that annualized turnover had increase to 55.5%, and the DSP vacancy rate had increased from almost 20% to 23.2%. Another Pennsylvania research (Edley & Sharp, 2021) suggests that the 55.5% turnover rate may be an underestimate. Note that this study included behavioral health workers as well as intellectual disability workers. At this same time, providers reported that callouts were increasingly frequent (up 62%), and that the typical front-line supervisor in Pennsylvania was working about 20 hours per week as a DSP (in addition to maintaining their regular supervisory responsibilities). The closure of most day program services enabled many providers to reassign day program workers to assist in residential areas, thereby somewhat mitigating the crisis. Despite these efforts, Edley & Sharp (2021) reported that 77% of Pennsylvania provider agencies were relying on senior management staff to work at least some shifts as direct care workers.

During this phase of the pandemic, relief funding did enable provider agencies to pay staff slightly more. With this one-time relief funding and through various strategies (hazard pay, specialty pay, bonuses, etc.) providers were able to pay DSPs about 8.6% more. This increase resulted in an average hourly pay rate of \$14.33 for Direct Support Professionals, up from \$13.20 pre-pandemic (Davis, Spreat, & Gruber, 2021). It must be recognized, however, that these increases were based on emergency relief funding, and that there was no guarantee that they could be carried into the future.

As would be reasonably expected, recruitment of replacement staff was inadequate to meet the demands. Davis, Spreat, & Gruber (2021) reported that approximately 10,476 individuals applied for work as DSPs, across 74 provider organizations, but only 12.6% were hired, and only 9.4% actually worked more than 30 days. Similar findings were reported by Edley & Sharp (2021). While it is possible that the number of applicants is overestimated by the practice of individuals applying for positions with multiple agencies, the low hiring rate remains striking. The low hire rate seems surprising given that almost every participating agency reported that they had reduced their selectivity in hiring of DSPs in response to the pandemic. The low hiring rate persisted despite efforts such as hiring bonuses, referral bonuses, and wage increases. The potential causes for this low hiring rate warrant further investigation in the hopes that barriers to hiring might be identified and mitigated.

When DSPs were asked to provide their biggest barriers to continuing as a DSP, issues that started long before the pandemic made up 39% of responses. This includes insufficient wages,

work life balance, difficulty finding childcare, family instability, food insecurity, issues accessing healthcare and adequate health insurance, transportation to and from work, and housing concerns. This testifies to the fact that these issues were present long before the pandemic and that long-term significant change to the infrastructure of the system as whole is needed in order to meet the needs of people with ID/A.

Impact on Service Capacity

Several Pennsylvania studies assessed the impact of the COVID-19 Pandemic on the ID/A Service System capacity. The PAR provider association reported (PAR, 2021) that service capacity reductions ranged from 3% to 67%, with an average service capacity reduction of 24%. The greatest reductions were in Transportation (67%) and 2390 Vocational Services (61%). The 2380 Adult Training Facility programs experienced a reduction 49%, even group homes reported a reduction in service capacity of 3%. It should be noted, however, that this particular survey may underestimate the magnitude of reductions because it focused on changes in head counts of those receiving service rather than the total number of hours of service. Thus, the study did not reflect any reduced hours of support/service, nor the consolidation of group homes.

Davis, Spreat, & Gruber (2021) reported that Pennsylvania residential census for people with ID/A declined 4% during the pandemic. 48% of agencies capped their services, and 22% of agencies closed at least one home. In many cases, these closures were largely due to staffing shortages.

Another provider association, RCPA, surveyed approximately 100 Pennsylvania providers of a variety of types of social services. They (Edley & Sharp, 2021) reported that approximately half of the ID/A providers reported a reduced service capacity. High turnover among all types of agencies was noted, with a 24% vacancy rate noted in direct service positions.

Impact on the Health of Individuals with Intellectual Disability/Autism

A number of studies have been published on the impact of COVID-19 on the health of individuals with ID/A. Using a California medical data base, (Landes, Turk, & Wong (2021) reported that people with Intellectual Disability were 2.8 times more likely to die from a COVID-19 infection. Landes and colleagues (Landes, Turk, Formica, McDonald, & Stevens, 2020) repeated this study in New York group homes, where they found that people with intellectual disability were roughly 1.8 times more likely to die from a COVID-19 infection. A national data base study (Gleason, Ross, Fossi, Blonsky, Tobias, & Stephens, 2021) reported that people with intellectual disability were 5.9 times more likely to die from a COVID-19 infection.

The largest single study of the impact of COVID-19 on people with intellectual disability was the product of collaboration between the Center for Disability Information, The New York Alliance for Inclusion and Innovation, Lee Specialty Clinic, Temple University, Woods Services, and ANCOR (Davis, Spreat, Cox, Holder, Burke, & Martin, 2021). This study compared infection and mortality rates between persons with intellectual disability and members of the general public in eight large states. These eight states had a total population of approximately

110 million, comprising roughly 1/3 of the US population. Data were collected in May 2020 and in January 2021, thereby providing insight into the early-stage impact of the pandemic. The authors reported that infection rates during the early pandemic were roughly equal for people with intellectual disability and members of the general public, but that the death rate was roughly twice as high for people with intellectual disability. Data collected eight months later, in January 2021, suggested that the infection rate was actually higher for members of the general public, but that the mortality rate remained largely unchanged. People with intellectual disability were about twice as likely to die from a COVID-19 infection. Similar findings had been reported in the 2017/2018 influenza outbreak in the Netherlands (Cuypers, Schalk, Koks-Leensen, Nägele, Bakker-van Gijssel, Naaldenberg, and Leusink, 2020).

The difference in the infection rate in January 2021 was important. It suggested that despite the challenges of staff rotating into group homes and similar challenges to social distancing, people with intellectual disability were protected to a greater extent than were members of the general public. Perhaps the protections are reflected in the reductions in transportation expenses and day program activities noted elsewhere in this report. Infection, however, is less the issue than is mortality. The 2% difference in infection rate between members of the general public and people with intellectual disability translates into an estimated 12,000 fewer infections. Given the calculated probability of death from a COVID-19 infection, these data suggest that the protections saved an estimated 500 lives in the sample which included the population of roughly 1/3 of the United States.

Although the numbers vary across the various studies, it seems reasonable to conclude that the mortality rate associated with a COVID-19 infection is higher for persons with intellectual disability than it is for members of the general public. The reasons for this increased mortality rate are largely speculative, and they have tended to focus on the impact of comorbid conditions. Turk and Mitra (2021) noted that people with intellectual disability tend to have more comorbid conditions, and in research with the general public, the number of co-morbid conditions was found to be associated with increased mortality risk. An Irish study (Perera, Laugharne, Henley, Zabel, Lamb, Branford, Courtanay, Alexander, Purandare, Wijeratne, Radhakrishnan, McNamara, Daureeawoo, Sawhney, Scheepers, Taylor, & Shankar, 2020) of persons who died with a COVID-19 infection reported an increased number of comorbid conditions. Similarly, Clift, Coupland, Keogh, Hemingway, & Hippisley-Cox, (2020) suggested that the greatly increased mortality risk of COVID-19 for people with Down syndrome was likely associated with the cardio and pulmonary conditions typically associated with Down syndrome. It should be noted that this study largely predated the availability of vaccines for COVID-19, so vaccination would not be a likely mitigating factor. The long-term effects on people with ID/A who recovered from COVID-19 is not apparent and should be studied carefully. With a significantly higher rate of co-morbidities (Turk & Mitra, 2021) people with ID/A may be at risk for higher incidence of “long haulers” than the general population.

As the pandemic progressed, several vaccines became available. While several studies have addressed the issue of staff reticence to get vaccinated, (Cox, Davis, & Spreat 2021) reported that approximately 94% of Pennsylvanians within the ID/A System had received vaccines. A second study (Edley & Sharp, 2022) was largely supportive of this finding, reporting that 72.3% of staff

were vaccinated. Breakthrough infections have attracted attention in the press, but do not appear to have been a significant problem within the Pennsylvania ID/A system. With over 60,000 individuals in the Pennsylvania ID/A system, at the time of the study, there had been only 78 breakthrough infections (0.6%). Only seven (7) were hospitalized, and none had died. A similar breakthrough rate was reported in New York state however, three deaths were noted.

Fiscal Impact on Provider Agencies

It should be recognized that Pennsylvania ID/A provider agencies were not in good fiscal health prior to the pandemic. Spreat (2019) reported that 990 tax forms reveal that approximately 1/3 of all Pennsylvania ID/A providers had expenses that exceed revenue each year. This weakened condition increased the challenges imposed by the pandemic. A PAR provider association survey from the summer of 2020 showed ID/A providers having an average of 2.9 days cash on hand. Another PAR survey (2021) revealed that loss of revenue and increased costs were essentially universal during the pandemic. 97% of responding agencies reported increased costs, while 94% reported decreased revenue. The decreased revenue was reported to average 25% of annual revenue. These increased costs were at least partially offset by use of COVID-19 relief funds (90%), drawing from agency fiscal reserves (54%), and requiring exempt staff to work as Direct Support Professionals (45%).

Impact of a Revised Rate Structure

The Pennsylvania Department of Human Services completed the process of revising the rates paid for services under the ID/A Home and Community Based Services waiver. Completed on December 30, 2021, these revised rates will drive the operation of HCBS waiver programs in Pennsylvania for the next several years.

The Center for Disability Information undertook a review of these proposed rates (Davis, Elliot, Gruber, & Spreat, 2022). This analysis identified five potential areas of concern:

1. Rate increases were not evenly distributed across service categories, such that some service categories received greater or lesser degrees of increase.
2. Rate assumptions do not seem to adequately accommodate provider costs, and this may prohibit providers from achieving sufficient levels of DSP wages.
3. Some of the proposed rate increases fall below current inflationary increases, creating a difficult business environment for providers.
4. Rates do not accommodate all concerns from before the pandemic.
5. Some of the rate assumptions do not seem accurate.

It must be recognized that the rate increases and the \$405 million that will be introduced into the system will be beneficial, but concerns were expressed that the increases will not match inflationary increases in the economy and that the increases will not have a significant effect on the workforce crisis.

Policy Recommendations

In order to make progress toward building a sustainable system, the following five steps are proposed:

1. The implementation of a market-based index for provider rates (an inflationary index plus an additional rate adjustment). Our system is fully dependent on state and federal funds, we cannot raise prices to meet competitive wages or cut services to save money. Connecting rates to an inflationary adjuster will allow for predictable and reasonable budgeting, and continued investment in DSPs.
2. The design and implementation of systems reform through LEVEL UP for ID/A, a systems reform bill that:
 - Requires no appropriation from the Commonwealth.
 - Shifts towards an outcome and person-centered approach to services.
 - Reinvests any savings into the waiting list or DSP wages.
3. The permanent end to the punitive practice of ‘prudent pay’, where the state withholds money from providers for three weeks, withholding resources from providers who are already operating with limited reserves.
4. The continuation of regulatory flexibilities that have not impacted quality nor accountability.
5. The reduction of Pennsylvania’s waiting list. The pandemic and workforce shortage halted progress in reducing Pennsylvania’s waiting list. Without the availability of adequate and trained staff, people with ID/A suffer whether they are currently receiving services or are among the 12,120 people who are on the waiting list for ID/A services. Absent needed services, these individuals struggle living at home with aging caregivers or wind up living in an institutional setting. The waiting list impacts people’s families too, who in some cases are unable to work in order to care for the individuals on the waiting list.

Conclusions

1. The protective efforts of the ID/A service community ultimately saved hundreds of lives across the nation. These efforts were bolstered by the enhanced ability to socially separate, high levels of vaccine compliance, and ultimately, the dedication of the Direct Support Professionals who risked their lives to protect people with ID/A.
2. The workforce crisis will continue, almost as a way of life. Recent efforts to increase DSP wages by increasing service rates, without annual inflationary increases, will

ultimately fail. Arguably, the continued practice of governmental price fixing for ID/A services and supports will ensure continuing shortages of both staff and programs for the foreseeable future.

3. Post pandemic services will likely return to the extent made possible by staffing and funding. It does seem likely that the fiscal trauma imposed by the pandemic may result in increased levels of mergers and acquisitions, with small agencies being forced to join with larger agencies.
4. Rate increases, while necessary and appreciated, will not be sufficient to rectify fiscal and staffing problems that were evident prior to the COVID-19 pandemic.
5. The impact of COVID-19 infection on people with ID/A over the longer term may be significant.
6. The impact of the pandemic on the ID/A system is likely to be long term. Families and DSPs have lost faith in our system, the ID/A service structure is crumbling, people are languishing on the waiting list, all levels of staff are experiencing trauma from loss of a work/life balance due to extreme demands on their time and on their loved ones. Many long-time ID/A professionals have reluctantly left the field.

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