The COVID-19 public health emergency (PHE) had a major impact on people with disabilities and the services they receive. Due to the COVID-19 pandemic, public agencies, day and employment service providers, people with disabilities, and family members had to quickly adjust to changes in how services were provided. These changes were reflected in the data state agencies provided to the National Survey of State Intellectual and Developmental Disabilities Agencies’ Employment and Day Services (IDD survey).

The Institute for Community Inclusion (ICI) administers the IDD survey annually. It is part of a longitudinal study commissioned by the Administration on Disabilities to analyze community-based employment and day service trends. Data are available for services received between FY 1988 and FY 2021 for individuals with IDD and closely related conditions. The ICI administered the survey between 1988 and 2004 on a semi-annual basis and began collecting data annually in 2007. The most recent version of the survey is focused on state IDD agency data from FY 2021.

The survey is designed to provide the following information:

- Trends in the number of people served in integrated employment, facility-based employment, and facility-based and community-based non-work programs
- Trends in the number of individuals waiting for services
- Funding sources that support day and employment services
- The allocation of funds across day and employment services

When survey staff collected IDD survey data for FY 2020 and FY 2021, they observed substantial changes in the data that states reported compared to previous years. For example, in 2019 immediately prior to the PHE 657,826 individuals received an employment or day service (StateData.info, 2023). In 2021 the number had declined to 595,101 individuals (StateData.info, 2023). Researchers anticipated such changes due to the onset of the pandemic in 2020, but wanted to understand the mechanisms behind these changes. Some states provided relevant information about the shifts in service provision through comments within the survey. ICI staff sent a follow-up email to states that did not provide comments asking for additional information about large shifts in their reported data. The questions included:

- How did you adjust funding for providers to support them during the pandemic?
- What strategies or changes did you implement to keep individuals engaged in employment and other services?
- To what does your state attribute changes in employment and day services trends?

Once ICI received responses from most state agencies, survey staff analyzed these data for patterns and overarching themes. This brief presents those themes to explain some of the ways the public health emergency impacted service provision. While findings are limited by the researchers’ flexible follow-up protocol and missing data from some states, this brief provides some basic insights into why there are changes in employment and day services trends reported in FY 2020 and FY 2021.
IMPACT ON DATA

When asked about how COVID-19 impacted trends in service provision, state agency staff pointed toward four specific items: 1) limitations on large, indoor, in-person gatherings and settings, 2) safety concerns for individuals with heightened health risks, 3) business closures (temporary or permanent) reducing the availability of integrated employment opportunities, and 4) staff shortages in state agencies.

LIMITATIONS ON LARGE, INDOOR, IN-PERSON GATHERINGS AND SETTINGS

When asked about the significant decline in facility-based services during the first years of the pandemic, state agency representatives referenced COVID restrictions on indoor gatherings. Due to the reliance of facility-based services on indoor group gatherings, these restrictions rendered it impossible to continue providing such services. One state agency representative shared:

“The funding and individual count drop for SFY 2021 is all related to COVID. The reasons for the disparity between the drop-in services is that providers could not aggregate IDD individuals inside a facility and there is no reimbursement model for individualized services inside a facility unlike community.” (Emphasis added)

SAFETY CONCERNS FOR INDIVIDUALS WITH HEIGHTENED HEALTH RISKS

Another, less commonly cited concern was related to personal health and safety decisions. State agency representatives mentioned that people with IDD who were employed prior to the start of the pandemic or had been looking for employment chose (or their family, or community living support provider chose) to stay out of employment and day services to reduce their risk of catching COVID.

For example, a representative from one state noted the impact of “...families concerned with exposing their family members to the virus outside of their residence.” A representative from another state acknowledged that “…waiver members chose not to attend [programs] due to personal health concerns.”

BUSINESS CLOSURES (TEMPORARY OR PERMANENT)

It is well documented that the general closure of businesses across the country had an impact on labor market conditions. According to the Bureau of Labor Statistics, in June 2021, business closures affected employment for 6.2 million people in the US. This was down from the beginning of the public health emergency, with 49.8 million being originally affected as of May 2020, but demonstrates a long-lasting effect (Bureau of Labor Statistics, 2023).

It is not surprising that the IDD survey follow-up showed the same trend in fiscal years 2020 and 2021. IDD agencies across the country reported that temporary and permanent business closures, as well as layoffs, negatively impacted integrated employment participation. For example:

“We are attributing the decline in funding for integrated employment to the closure of a number of businesses during the public health emergency. Day Services could continue and be delivered in a person’s home, so we did not see such a decline there. However, a number of businesses at least temporarily closed their doors or reduced their workforce.” (Emphasis added)

STAFF SHORTAGES

Lastly, staff shortages at the service provider level impacted service provision. There was already a growing workforce crisis prior to the pandemic (Hewitt & Laws, 2020), but it was exacerbated by the onset of COVID-19. These shortages meant that there were fewer staff employed by service providers and so service provision dropped. State agency staff described the issue:

“The number [of people] who received services and the funds come from the Medicaid 372 report for 1915i and 1915c for FY 2019 and FY 2020. The report indicates a decline in number of people receiving services in FY 2020, which has been reported as COVID-related; person losing jobs; decline in staff to provide one-on-one supports, such as job coaching; job development was limited; and family and parents didn’t want persons to have contact with the public.” (Emphasis added)
IMPACTFUL PRACTICES
While most states saw a decline in service participation, this was not universal across the states. A few states managed to maintain service levels by using Appendix K flexibilities.

WHAT IS APPENDIX K?
Several state representatives identified the use of Appendix K flexibility in keeping services available. Medicaid Section 1915(c) Appendix K allowed providers to continue to provide employment and day services to people with IDD, by adapting service definitions and standards in ways that included in home and remote supports. While not all services could be adapted this way, those that could be maintained were continued through adaptations to policy and funding:

“The increase in use of homebound services was a direct reflection of the impacts of COVID-19 on [people with] IDD. With the IDD community being designated a vulnerable population at the state and national levels, the state developed the Appendix K for the 1915C Waivers that authorized the use of homebound services to supplant the requirements of community, facility, and employment services. People supported were afforded the ability to receive the homebound services in lieu of other day services and the majority of the population did utilize the services.”

Another state agency representative shared:

“Early in the pandemic, the state IDD agency worked to modify how services were delivered (e.g., promoting telehealth, limiting where services can be delivered) to promote health and safety.”

LESSONS LEARNED
It is challenging to interpret the data about services provision collected during PHE, but analyzing these remarks from state agency representatives gives us some valuable context and insight. Here are three main takeaways:

1. **Facility-based work is less flexible than competitive integrated employment:** It seems obvious in retrospect that facility-based work, which requires many people in a single space, would be more at risk during the pandemic than competitive integrated employment. Moving forward we must consider facility-based work’s vulnerability during health crises (or other societal shifts that limit in-person gatherings) when proposing or maintaining these types of services.

2. **Appendix K flexibilities revealed new possibilities for competitive integrated employment:** When Appendix K flexibilities came into effect, they helped maintain the infrastructure of existing services for people with IDD. Like many policy changes during the pandemic, Appendix K was likely intended to be temporary. However, we may find that some of these policies are worth keeping in place. Now that we have seen them in practice, we need to know more about how effective it is to provide services at home, and whether this model is sustainable for service providers.

3. **Policy affecting one Medicaid group can impact people in all Medicaid groups:** The overwhelming majority of employment services and supports for people with IDD are funded through Medicaid HCBS waivers. As helpful as Appendix K flexibilities were to workers with IDD, the policy changes behind this shift primarily reflect Medicaid’s function as part of the health care system. Therefore, it is important for stakeholders to keep up with all Medicaid and health policy developments.
References


