

Impact of COVID-19 on Provider Organizations Serving Adults with Intellectual and Other Disabilities

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Summary

The current coronavirus pandemic created an urgent need to examine the impact of COVID-19 within community-based organizations (CBOs), mostly agencies serving people with intellectual and other disabilities who are at increased risk of infection and inappropriate or inadequate care and treatment.

An internet-based survey was undertaken of CBOs affiliated with ACCSES, a national provider association, to identify what key issues they faced and with what they were dealing.

Many people with ID have high-risk health conditions and are at risk of contagion, especially when living on their own or in congregate-care settings.



Survey Aim/Objectives

The aim of the project was to undertake an internet-based survey to CBOs affiliated with ACCSES, a national provider association, to ascertain what types of difficulties provider agencies were encountering during a transitional phase of the coronavirus COVID-19 pandemic. The survey had the following three objectives:

1. Identify primary issues noted by CBOs difficulties in adapting their normal services in response to local pandemic mitigation conditions.
2. Identify variations in service adaptation issues dependent upon whether the services were primary residential versus day services and supports.
3. Identify main accommodations and adaptations that CBOs developed and implemented as 'work-arounds' to adapt services in compliance with local and state mitigation requirements.

Methodology

An internet-based survey was undertaken using the Microsoft Forms platform. The survey was initiated by ACCSES, a national provider association, and supported by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and assisted by Dr T. Buckley at the YAI organization in New York. Grant funding was used from the Center for Clinical and Translational Sciences (CCTS) to the HealthMatters™ Program (HMP) at the University of Illinois at Chicago to review provider organization practices in response to the COVID-19 pandemic.

The survey queried about issues and problems CBOs faced with adapting their normal services to the pandemic and to identified strategies being used. Pilot testing of the survey was followed by an email sent out by ACCSES to its membership requesting responses to the survey. The CBOs were given a three-week period in July 2020 to respond to the online survey.

Summary (cont.)

CBOs providing direct services noted experiencing contagion, lockdowns, loss of staff, challenges in obtaining PPEs, and lack of state or federal guidance. Maintaining safe living environments and coping with infected staff and clientele were urgent concerns. CBOs reported financial and clinical support challenges, as well as staffing problems.

As the survey was undertaken in July 2020, following the period of stringent lock-downs and agency closures and during a period of re-openings, the data indicated that CBOs were re-emerging as providers and working hard to cope with conflicting advice and a lack of aid and clear guidelines from the national government.

Respondents

Responses to the survey were received from 173 provider organizations, of which 45% served a small number of clientele (N=<250) and 55% served moderate to larger numbers of clientele (N= 251 to >1000). Of the providers, 89% served people with intellectual disability. CBOs provided residential services (74%), day services (79%), casework (74%), family support services (72%), and medical/health care services (65%). CBOs also provided vocational rehabilitation services (74%), advocacy supports (72%), independent living supports (72%), and education services (72%).

A third of the providers reported having one or more cases of COVID-19 among their services recipients. Of these, 83% had less than 5, 1% had 6 to 10, and 15% had 11 or more. Some 61% of the CBOs noted that their staff had not yet tested positive for COVID-19. Of the other 39%, 81% had less than 5 staff affected, 1% had 6 to 10 staff affected, and 11% had 11 or more staff affected.

Findings

COVID-19 Mitigation Services

CBO respondents reported that COVID-19 mitigation efforts impacted their abilities to provide the following services: respite supports (92%); residential services (91%); care coordination (89%); educational services (88%); in-home services (85%); day services (84%); family support services (84%); and, transportation supports (82%).

Impact of Federal or State Policies on Services

CBO respondents reported that federal policies or regulations generally were not a primary source of difficulties as only 32% reported this was a problem. However, 50% reported that state policies or regulations had a negative impact on their ability to provide services. Most (75%) of the CBOs reported that they did not experience any significant internal governance or administrative issues due to COVID-19.

Key Areas Noted as Problems by CBOs

- 62% stated problems associated with staff
- 62% reported difficulties obtaining PPEs
- 46% noted problems getting aid from their state
- 23% had issues with controlling re-entry

Where Did the CBOs Turn to for Information?

- Centers for Disease Control [CDC] (76%)
 - State intellectual/developmental disabilities agency (54%)
 - State provider association (53%)
 - State regulatory authority (50%)
 - National provider association (41%)
 - Internet searches (29%)
 - Centers for Medicaid/Medicare Services (19%)
 - Other federal agencies (13%)
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Conclusions

Information provided in subjective comments by the respondents validated the impact of the coronavirus on operations, with shutdowns and limits on in-person services capacity leading to losses of funding and challenges in maintaining at-risk staff.

Testing availability, lack of sufficient PPEs, dealing with clientele and staff boredom during lockdowns, and increased costs for equipment and staff (with no commensurate increases in fees) were noted as problems.

Re-opening challenges were reported, including funding, staffing, PPEs, liability, and lack of guidance. CBOs found ways to work-around some programmatic issues, by using telehealth, drive-by visits, instituting rigorous safety measures, and offering virtual services, when possible.

The data showed that CBOs serving adults with ID and their families have been impacted by the COVID-19 pandemic and at the time the survey was undertaken (mid-summer 2020) were seeing a moderate number of the staff and clientele infected with coronavirus.

The degree and nature of the impact of the coronavirus was dependent on what types of services they provided, the numbers of staff and clientele affected, and what resources they could draw upon to get assistance. For mitigation, sources of information that would help were limited, drawn mainly from the CDC and their state agencies.

In the time since the survey, mitigation efforts by states have varied with continued limited guidance at the federal level, and efforts to control spread have seen mixed degrees of effort on the part of state authorities. In comparisons with early efforts in the spring of 2020 (before when the survey took place), many CBOs likely now have more information about spread and mitigation, as well as how to ensure safe service practices which are being reinforced by an expanding body of practical advice.



