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LESSONS FROM A GLOBAL PANDEMIC

WHAT HAVE WE LEARNED?

Acknowledgements

This study is a collaboration among several researchers who are experts in their respective fields. The principal investigator of this study was Dr. Julie Gentile of Wright State University. The primary research team included Jeanne Farr of National Association for the Dually Diagnosed (NADD) and Dr. Kristin McGill of Osceola Research and Evaluation LLC. This project would not have been successful without the the expertise, support, and insights of Dr. Stacie Rivera of Rivera Consulting, LLC., Dr. Richard Blumberg of Sonoma State University and our various national and international partners and participants.

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Abstract

The COVID-19 pandemic required creative approaches to meeting the support needs of individuals with intellectual disabilities (ID). Service and clinical treatment approaches had to adapt quickly to the rapidly changing environment. The focus of this study was to learn from clinical professionals and service providers from around the world regarding what they did to pivot and respond quickly to the unplanned circumstances we all faced in our work with individuals with intellectual disabilities and mental health challenges. Clinical experts and service providers from twenty countries participated in the survey: Afghanistan, Australia, Canada, China, Croatia, Denmark, Finland, Germany, India, Israel, Japan, Kenya, Mexico, the Netherlands, Paraguay, the Philippines, Slovakia, Spain, Uganda, and the United States. In order to learn how the identified professionals work to promote the mental health and well-being of the people they support, the survey questions focused on specific strategies employed by these professionals. Participant responses provided insight into what strategies worked and what did not. This exploration gave us a glimpse into the support and treatment practices of the international community of professionals dedicated to supporting the health and well-being of people with intellectual disabilities during extraordinary times. The data demonstrated that we can learn a great deal from the collective wisdom of our fellow professionals across the world and work together to be better prepared for the next global crisis impacting our shared community.

Keywords: intellectual and developmental disabilities, mental illness, COVID-19, provider care

Introduction

In early 2020, the World Health Organization's International Health Regulations Emergency Committee declared the COVID-19 virus an infectious outbreak quickly spreading to all corners of the world. Less than one month later, more than 25 countries had recorded cases with reported mortality rates of up to 5% (Wu et al., 2020). In response to preliminary data which suggested that persons with compromised immune systems, including persons with intellectual and developmental disabilities (IDD), were at an increased risk of infection and severe side effects, many state and federal health agencies mandated protocols requiring individuals to isolate themselves from their communities, families, and jobs.

The research described in this report reflects the perspectives of providers, caregivers, and family members of persons with IDD regarding how the pandemic influenced and impacted their ability to provide treatment, services, and care within their local IDD community. The Research Team was interested in learning about these individuals' views of the pandemic's impact on the IDD community and their thoughts on effectively planning for similar events. The data collected generated recommendations for supporting access to care and minimizing barriers to services during a significant crisis.

As part of this project, under the guidance of Wright State University, the National Association for the Dually Diagnosed (NADD) partnered with public health, public policy, and IDD experts to assess existing research and establish a nexus to bridge IDD resources and public policy. The findings of this study may be used to inform policymakers in creating more effective and responsive treatement access processes for persons with IDD, their families, caregivers, and providers, during a public health emergency.

Background & Literature Review

This research was conducted to understand how the pandemic impacted the delivery of care and services for persons with a diagnosis of IDD and mental illness (MI), their caregivers, and their providers. The Research Team sought to elicit lessons learned from the COVID-19 pandemic in order to develop recommendations for new or revised guidelines to utilize in providing services and support to people with IDD, their caregivers, and their providers during future crises like the global pandemic. Research with this focus is sparse but is required to find the best opportunities for healthcare access, delivery of treatment, and ongoing support for adults with IDD and their caregivers and providers (Lunsky et al., 2021).

Fear, Isolation, and Uncertainty

Isolation, fear, anxiety, and uncertainty were common themes for both caregivers and persons with IDD (Courtney & Perera, 2020; Kim et al., 2021). Kim et al. (2021) found that interruptions to daily routines, isolation, and lack of community gathering opportunities amidst the pandemic led to barriers to in-person treatment. 29% of respondents reported negative experiences with in-person visits as opposed to 21% who reported positive experiences; 50% of responses were neutral (Lunsky et al., 2021). Similarly, social distancing and isolation adversely impacted healthcare workers who may have suffered moral distress (Sarwer et al., 2020). The findings of Lunsky et al. (2021) support the notion that it is critical to understand how the pandemic impacted both the treatment and access to health care for those with IDD, alongside the consequences experienced by direct support professionals (DSPs). Boden et al. (2021) found that depression, moral distress, fear, and anxiety heightened the adverse outcomes of the pandemic in persons with IDD, their caregivers, and providers. In their qualitative study, which explored the impact of the pandemic on family caregivers through the lens of non-governmental organizations (NGOs) in the United Kingdom and the Republic of Ireland, Linden et al. (2022) surmised that the global pandemic disrupted care to persons with IDD while exacerbating feelings of isolation, fear, and exhaustion. While some persons with IDD may not have been cognitively aware of the impact of COVID-19, caregivers observed behaviors that exhibited evidence of stress. One study participant shared how her once easygoing son showed signs of anger and aggression when cared for during the pandemic (Linden et al., 2022).

Access to Health Care and Continuity of Care

Desroches et al. (2022) contended that the pandemic presented challenges in providing person-centered care, particularly for supporting persons with IDD. Lack of sustained government services and the inability to access health care led to decreased trust. Many respondents felt forgotten and voiced that they had to fight to meet basic needs (Linden et al., 2022). Poor guidance and limited, ineffective information sources adversely impacted caregivers and DSPs. There were no policies to provide guidelines for continuous treatment, social support, and access to health care services during the pandemic. NGOs may have played an outsized and vital role in the continuity of care for persons with IDD and their caregivers. Despite gaps in healthcare access, NGOs "played an important role in supporting families of people with intellectual disabilities and had regular contact with families during the COVID-19 pandemic" (Linden et al., 2022).

Lack of Awareness

Disability is a complex and growing social problem. The World Health Organization (WHO) estimates that more than 1 billion people, or 15% of the world population, live with some degree of disability. The COVID-19 global pandemic stressed an already fragile healthcare landscape for persons with IDD. Emergency lockdowns, social distancing requirements, and mask-wearing may have disproportionately impacted the psycho-social stress of persons with IDD and their caregivers and providers (Senjam, 2021). Courtenay and Perera (2020) found that there is little known about the pandemic's impact on people with IDD, an especially vulnerable population (Senjam, 2021). The authors contend that families and caregivers of people with IDD may have been forgotten during the pandemic even though they were at greater risk of infection due to living circumstances, e.g., community settings, family congregate situations, and elderly caregivers. In a qualitative study designed to explore parents' concerns about challenges faced because of COVID-19, two themes emerged: concerns related to keeping an adult child with IDD safe from infection of COVID-19 and challenges in the adult child's life due to the pandemic. The study found that a lack of cognitive awareness about the virus, along with difficulty following public health measures (e.g., masking, frequent hand-washing, and social distancing), adversely impacted daily routines and safe community settings necessary for the sustained care and treatment of persons with IDD (Kim et al., 2021). Mello et al. (2020) found evidence suggesting that persons with disabilities were excluded from access to treatment due to their disability. The authors report that the pandemic revealed biases and discriminatory practices resulting from poor guidelines and scarce resources.

A study completed by Linden et al. (2022) found that respondents felt as though they had a "black mark against their name" as they had to battle and argue for support. Further, findings from another study noted that access, quality, and continuity of care and support were themes in a multi-country mixed methods study in which nurses revealed limited access of persons with IDD to primary, specialist, and mental health care. In addition, reports of these practitioners observed that patients with IDD were refused services despite Article 25 of the United Nations (UN) Convention on the Rights of Persons with Disabilities. Article 25 reinforces the need to provide the highest possible standard of health care and well-being to persons with a disability. Further, it calls for an enabling and supportive environment focusing on person-centered care (Desroches et al., 2022; Senjam, 2021).

Despite this backdrop, the pandemic amplified existing health and social disparities. Lack of disability-inclusive public health plans and a design-equitable healthcare system resulted in a greater risk and exposure of persons with IDD to the COVID-19 virus (Kamalakannan et al., 2021). There was also a greater risk of mortality in patients with IDD and COVID-19. In their cross-sectional study of patients in various healthcare organizations in the United States, Gleason et al. (2021) found that having an intellectual disability was a decisive, independent risk factor for contracting COVID-19. Risks associated with the need for daily care, shared transportation, cognitive impairments, and the sensory issue of mask-wearing may explain this increase in mortality. Healthcare providers did not always recognize these medical limitations. Therefore, access to health care was inconsistent at best and, at worst, unavailable for persons with IDD (Linden et al., 2022).

Use of Alternative Solutions

Boden et al. (2021) reported that community living centers shuttered due to COVID-19 restrictions, which led to additional challenges to the usual support provided for caregivers. The research of Kim et al. (2021) revealed the need to develop and target better support services for patients with IDD and to provide guidance to their caregivers and providers. Problems in providing traditional services for persons with IDD due to the restriction of in-person visits led to the adoption of new treatment modalities, including telehealth services using video and phone. Boden et al. (2021) posited that technology-delivered care may be helpful as an early-stage intervention during a global pandemic. Their research suggested that the use of technology as an option may help mitigate stress and anxiety resulting from risk factors related to the pandemic while maintaining continuity of care. Similarly, Rosenbaum et al. (2021) found that telehealth options offered flexibility and opportunity to maintain the patient-provider relationship. Consistent with the findings of existing literature, telehealth was a welcomed alternative but came with drawbacks (Desroches et al., 2022).

The necessarily quick adoption of telehealth services posed both opportunities and challenges. Courtenay and Perera (2020) found that though telehealth services were a viable alternative, sometimes caregivers needed more technology skills and may need more tools to utilize telephone or video alternatives—similarly, technology-delivered solutions required training for providers and caregivers of persons with IDD. Access to equipment, privacy and security concerns, and diminished patient-provider relationships were considered barriers (Boden et al., 2021). Recognizing that telehealth was a novel approach to caring for people with IDD due to the pandemic, Rosenbaum et al. (2021) argued that telehealth provided a flexible alternative and may have increased *in situ* observation. These authors determined that this delivery alternative may have advanced treatment of patients with IDD closer to the WHO’s focus on dynamic and holistic health care.

Understanding and Complying

Rosenbaum et al. (2021) identified several pandemic-related barriers to treatment opportunities, including the emphasis on traditional, biomedically focused treatment versus a more holistic approach to treating a patient with IDD. Other barriers included a lack of universal guidance on continuity of care for patients with IDD during a health pandemic, lack of access to authoritative information about safety measures and how to mitigate risk, diminished social networks, and lack of access to or knowledge of alternative treatment modalities, e.g., video and telephone options (Boden et al., 2021; Kim et al., 2021; Courtenay & Perera, 2020).

Using an international, mixed methods study of nurses’ perspectives, Desroches et al. (2022) explored the myriad challenges faced by persons with IDD and their caregivers. Since nurses are an integral part of the support team for people with IDD, their firsthand accounts corroborated the findings of existing literature. Specifically, the study revealed that despite the United Nation's published guidance related to COVID-19 and the human rights of people with IDD, guidelines often lacked consideration of the unique needs of patients with IDD. Patients with IDD were not only at greater risk of mortality due to the coronavirus, but they were often misunderstood as a population when providers were unaware of medical limitations despite the Americans with Disabilities Act (Gleason et al., 2021).

In the wake of the pandemic, Mello et al. (2020) assessed the impact of biases and discrimination practices on people with IDD. Despite scarce resources, they opined that policymakers and hospitals must apply guidelines that honor their commitments to antidiscrimination practices. They reported that abrupt guideline changes in all global regions adversely hindered the care of “those with IDD who thrive on order and routine” (Desroches et al., 2022). Lunsky et al. (2021) suggest that DSPs should adapt the type of visit to the patient's needs and offer the best fit for the individual. Tailored tip sheets, checklists, and video demonstrations should be considered and would be helpful to DSPs.

Summary of Lessons Learned

Through assessments of existing research, studies have shown that many evidence-based protocols for working with people with IDD, their caregivers, and their providers needed policy and implementation reform. The following key concepts and treatment modalities were identified as effective practices that would likely ensure a positive quality of life outcome for treating persons with IDD in a public crisis:

- Adapt the use of video and telephone visits while recognizing their limitations.
- Include in-person intake practices for persons with IDD for continued quality of care, effective decision-making, and triage checklists.
- Design and deploy public health information and awareness campaigns targeting individuals with IDD to mitigate safety and quality of life issues.
- Build online portals of evidence-based resources for caregivers of persons with IDD.
- Develop guidance and policies to systematically support persons with IDD, their caregivers, and their providers.

Research Design and Methodology

Design and Rationale

The Research Team analyzed the existing policies and procedures for pandemic responses. They evaluated medical and clinical provider care and support for persons with IDD and perceptions of care needs from service providers for persons within the IDD communities globally. The analysis utilized online surveys and the evaluation of existing protocols for providing care during the pandemic to gain insight into what gaps exist, where improvements or changes are needed, and to make suggestions for future planning in the event of another global health crisis.

Methodology

The Research Team conducted a mixed-methods approach incorporating a multiple-choice and open-ended questionnaire deployed through the online SurveyMonkey platform. The questions probed respondents to learn more about their experiences prior to and during the pandemic to determine how the pandemic impacted their ability to provide support, treatment, and care for persons with IDD. The information derived from the survey centered around strategies, barriers, and future measures that can be taken to ensure optimal care and support for persons with IDD and mental illness (MI), including:

- How has the pandemic impacted persons with IDD and MI?
- How has the pandemic influenced the way providers and caregivers of persons with IDD and MI treat, care for, and support their patients/ clients/family members?

- How has the pandemic helped extend care for persons with IDD and MI?

Using purposive sampling, the Research Team recruited participants from the medical and clinical fields who work directly with persons with IDD. These participants represented a vast geographic population spanning many countries, demographics, socioeconomic circumstances, and care options. The Research Team utilized the survey data and an extensive literature review to assess the current situation for providers and its implications for future service delivery policies and methods.

Participant Recruitment Logic

Medical, clinical, family/non-family care, and support providers of persons with IDD participated in this comprehensive global study. Recruitment included emailing organizations, agencies, and institutions globally working primarily within the given field. This outreach used existing relationships and partnerships with the National Association for the Dually Diagnosed, providing for focused recruitment efforts to ensure efficient and timely survey completion.

The recruitment email detailed information on the inclusion criteria and a link to the online survey, available in multiple languages representative of over 20 countries worldwide. Each participant was required to electronically consent to participate in the study using the online consent form, which was also provided in various languages and hosted by the SurveyMonkey online platform.

Summary of Findings

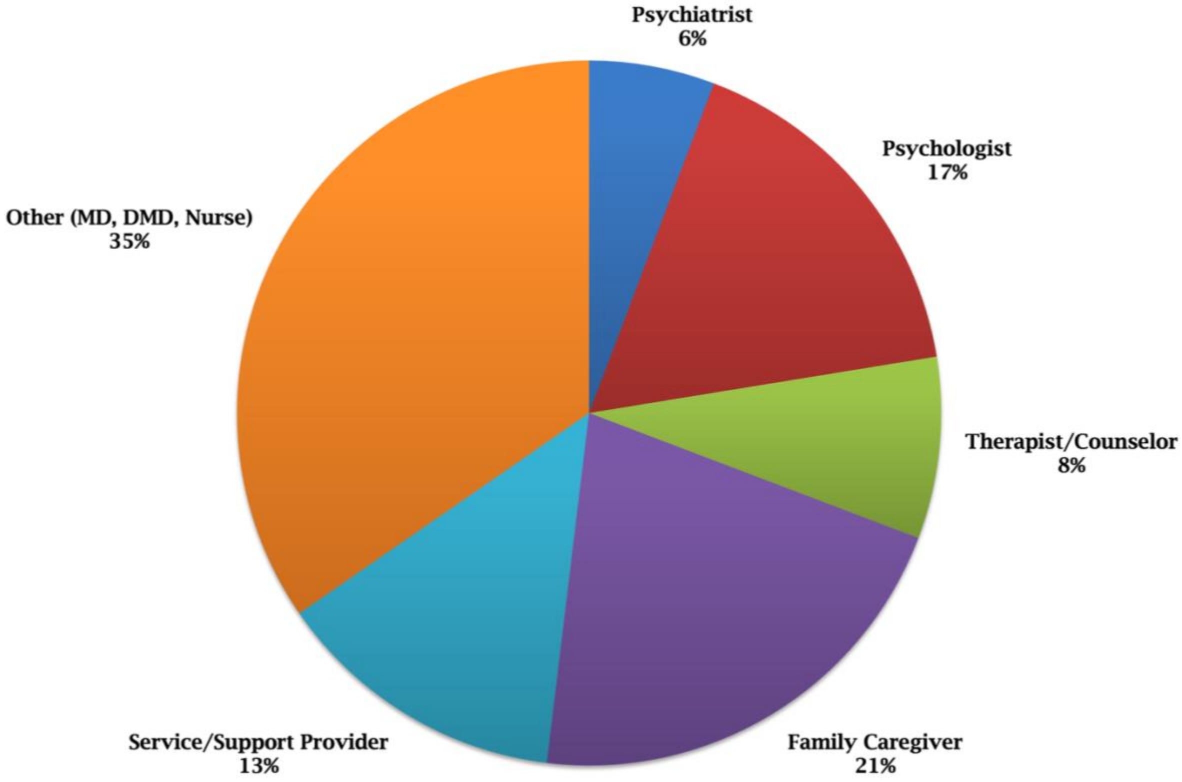
Pilot Project

A pilot project was conducted to provide a preliminary analysis and test the survey design across cultures. The pilot project comprised 158 participants and was active between November 4 and November 11, 2021. Respondents resided in the United States, Canada, the United Kingdom, France, Germany, and Italy. All respondents had to provide electronic consent using the online adult consent form before accessing the study questionnaire. Each participant completed an inclusion questionnaire, which required participants to be 18 years or older and care for, treat, or provide support for persons with IDD. The consent form and survey questionnaire were provided in over 20 languages to accommodate the respondents' demographic and geographic backgrounds.

Most participants (44.2%) worked as clinical providers (e.g., psychiatrist, psychologist, therapist, or counselor), with the majority of the remaining population (34.6%) represented by medical personnel. A breakdown of the affiliations identified by participants is shown in **Figure *1***.

Figure 1

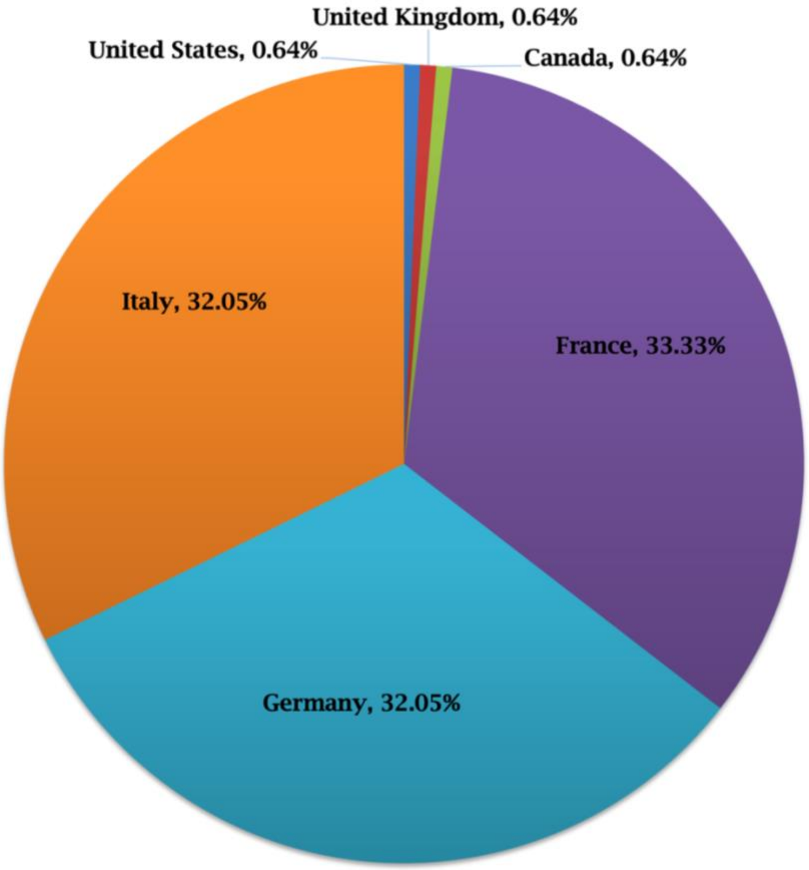
Affiliation of Participants



As **Figure** *2* shows, France, Germany, and Italy accounted for more than 97% of the participants surveyed, while the United States, United Kingdom, and Canada represented less than 3% of the participant pool.

Figure 2

Nationality of Participants



Respondents disclosed three main success measures that they felt had benefitted their ability to provide support, treatment, and care to persons with IDD and MI during the pandemic. These measures included 1) increasing technology use to expand services and treatment, 2) prioritizing vaccine accessibility, and 3) expanding opportunities to develop and use additional medical and clinical support services.

Participants also noted the perceived impacts the pandemic had on persons with IDD and MI and their families. Due to the restrictions on in-person visits, many respondents acknowledged an increased deficiency in communication between providers and families. They suggested that these restrictions limited the availability of specific medical and mental health care because direct, in-person facilitation of these treatment and support services was non-existent. Further, the isolating nature of the pandemic manifested a new level of social and community seclusion, impairing the quality of life for a person with IDD. Additionally, providers experienced workforce deficiencies, prolonged delays in services and treatments, and ineffective care evaluations because of limited in-person visits.

The results of this pilot study suggested that universal changes to policies and practices are required to ensure adequate care, support, and treatment for persons with IDD should another global health crisis disrupt care.

Participants in this pilot study suggested that:

1. Future planning should focus on overall health and wellness as a holistic approach rather than looking at separate parts of a person in isolation.
2. Education and training should be provided on an ongoing basis to ensure alignment with the changes in policy and information.
3. Develop preventative planning strategies to ensure a smooth transition if and when future events occur.
4. Improvements to communication plans between providers, caregivers, and social services support agencies are necessary to guarantee that persons with IDD and their families have prioritization.

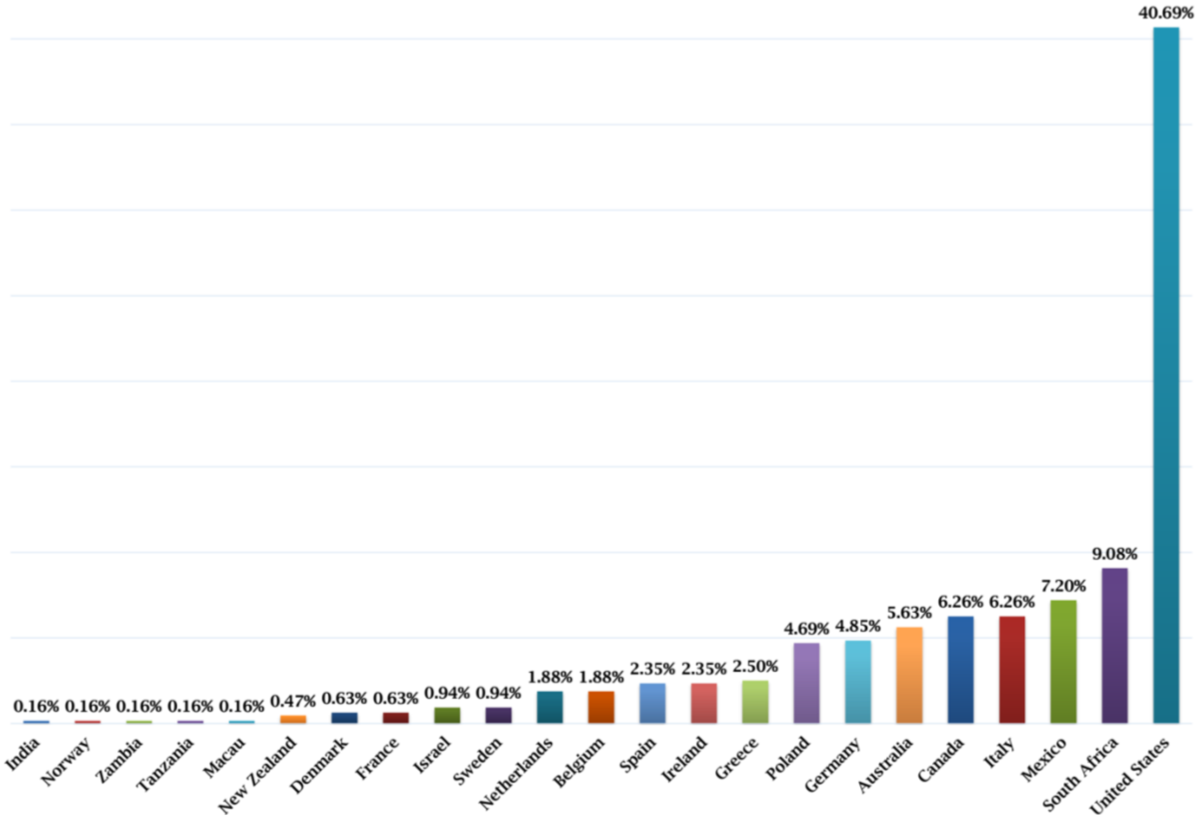
A preliminary release of the study's findings (results from the pilot) were shared during the 2021 European Association for Mental Health in Intellectual Disability's *Improving Mental Health in Persons with Intellectual Disability: From Science to Practice* conference held in Berlin, Germany. The results of this pilot study contributed to the expansion of the full-scale global study, ensuring that lessons learned from the preliminary findings informed the research questions and literature review moving forward.

Full Study

After completing the pilot evaluation, the Research Team launched the full global study between July 11 and November 12, 2022. There were 682 total participants representing over 20 countries. Respondents primarily resided in the United States, South Africa, Mexico, Italy, Canada, Australia, Germany, and Poland, as shown in **Figure** *3*.

Figure 3

Participant Demographics by Country

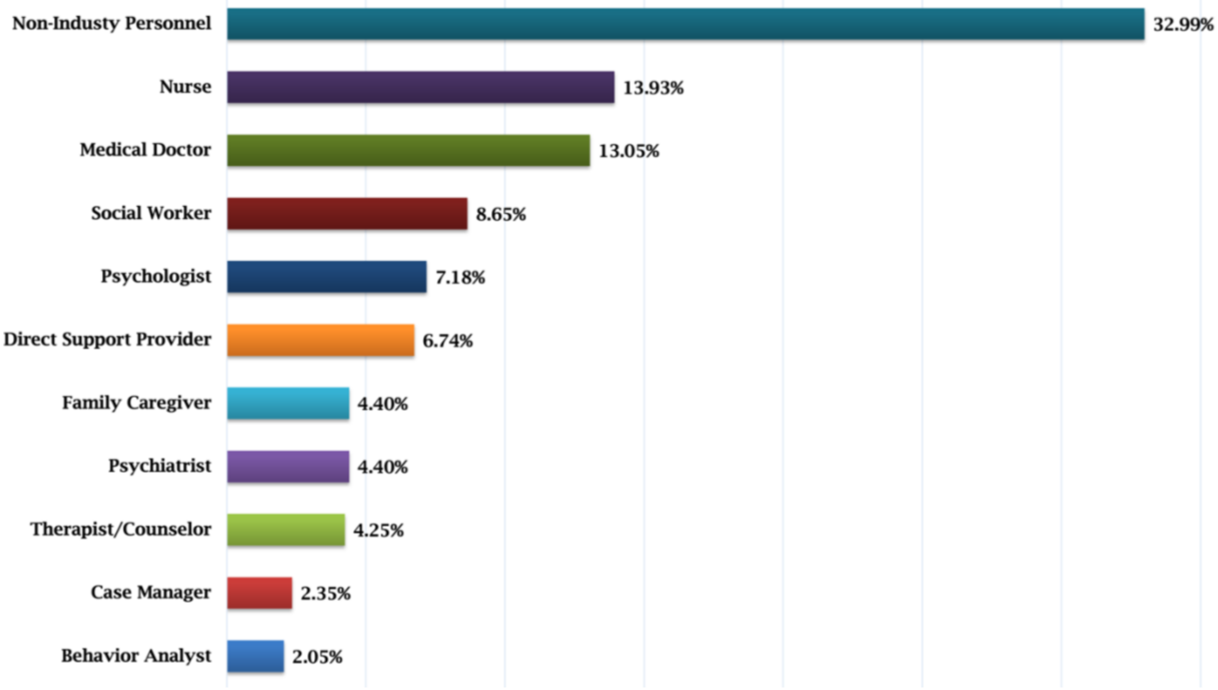


Based on the preliminary data collected during the pilot, the Research Team expanded the survey questions to include information regarding the location of services provided and geographic markers. As in the pilot study, participants provided electronic consent and met the inclusion criteria of being over 18 years of age and providing services, treatment, or care to persons with IDD.

Many participants (33%) identified as support personnel working outside the traditional roles of provider, family caregiver, or social worker. Most respondents represented persons in health care, human services, clinical occupations, and support or caregiver roles. **Figure *4*** represents the respondents' affiliation within and external to the IDD field.

Figure 4

Participant Affiliation by Role/Profession



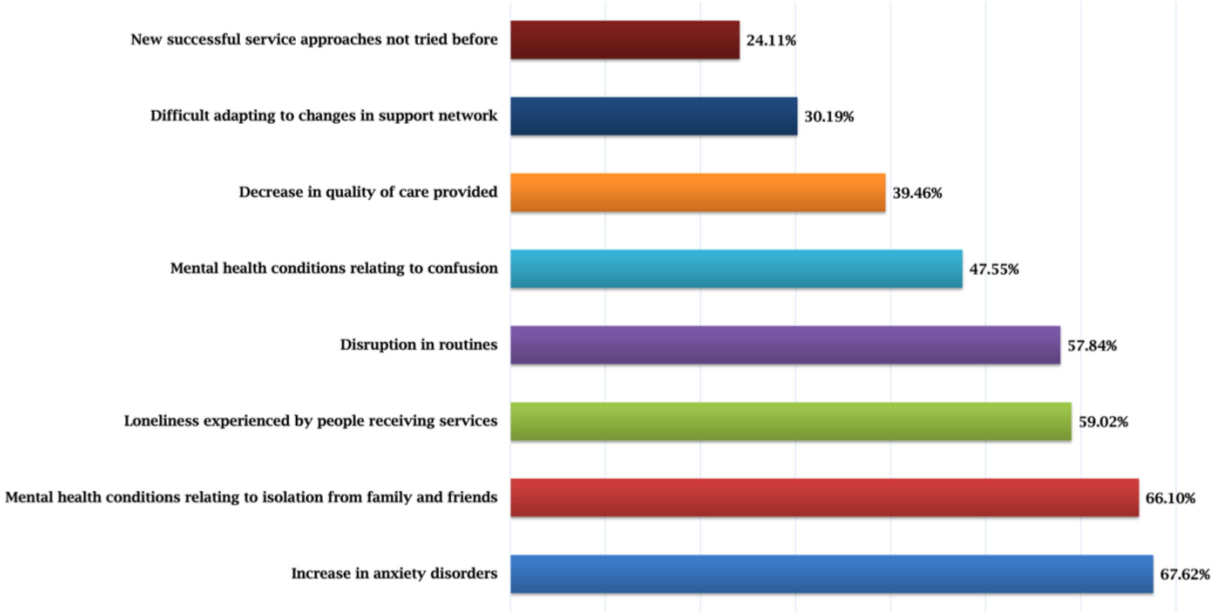
Nearly 90% of participants reported providing in-person support (i.e., office, in-home, or hospital) during the pandemic, while the remaining 10% noted that they had switched to telehealth or remote counseling. Additionally, most respondents (89%) stated that they worked in an urban or suburban setting that catered to a population of 100,000 or more, compared to 11% who noted that their communities were largely rural or semi-rural. As in the pilot study, more than half of the respondents have worked within their respective professions for fewer than five years. No age, gender, or other demographic markers were collected as part of this portion of the study.

Collectively, respondents across all geographic regions noted that the pandemic impacted their ability to provide equitable and effective treatment and care for persons with IDD, resulting in significant increases in anxiety and depression, adverse mental health reactions, feelings of isolation, and disruptions in routines.

Figure *5* provides a detailed representation of these main impacts, as well as additional issues identified by the participants of this study.

Figure 5

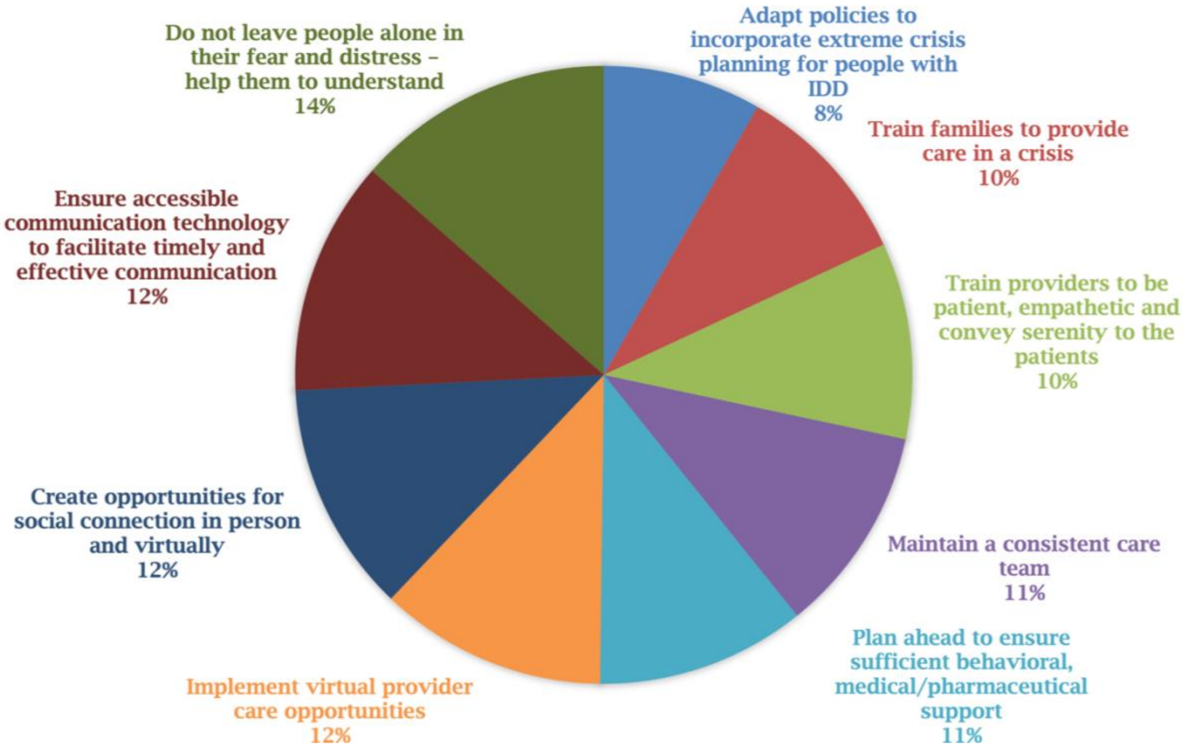
The Pandemic's Impact on Persons with IDD



Additionally, respondents provided their perspectives on major strategies that, if implemented, would improve the treatment and care of people with IDD and co-occuring mental health conditions during future pandemic events. As shown in **Figure** *6*, most of these suggestions center around introducing adaptive services, avoiding isolation, ensuring access to support and care, creating opportunities for continued social interactions, and incorporating telehealth options for all, regardless of community size.

Figure 6

Strategies to Improve Outcomes for Persons with IDD



Discussion of Findings

Partcipants were asked to provide their top four examples regarding how the pandemic influenced their specific circumstances within the following topics: (1) developing successful strategies that improved services or care, (2) exposure to new and existing barriers to care, (3) impact on persons with IDD, and (4) opportunities for changes in the future. The following sections provide detailed information on the prominent themes that emerged from the study and the related suggestions provided by study participants.

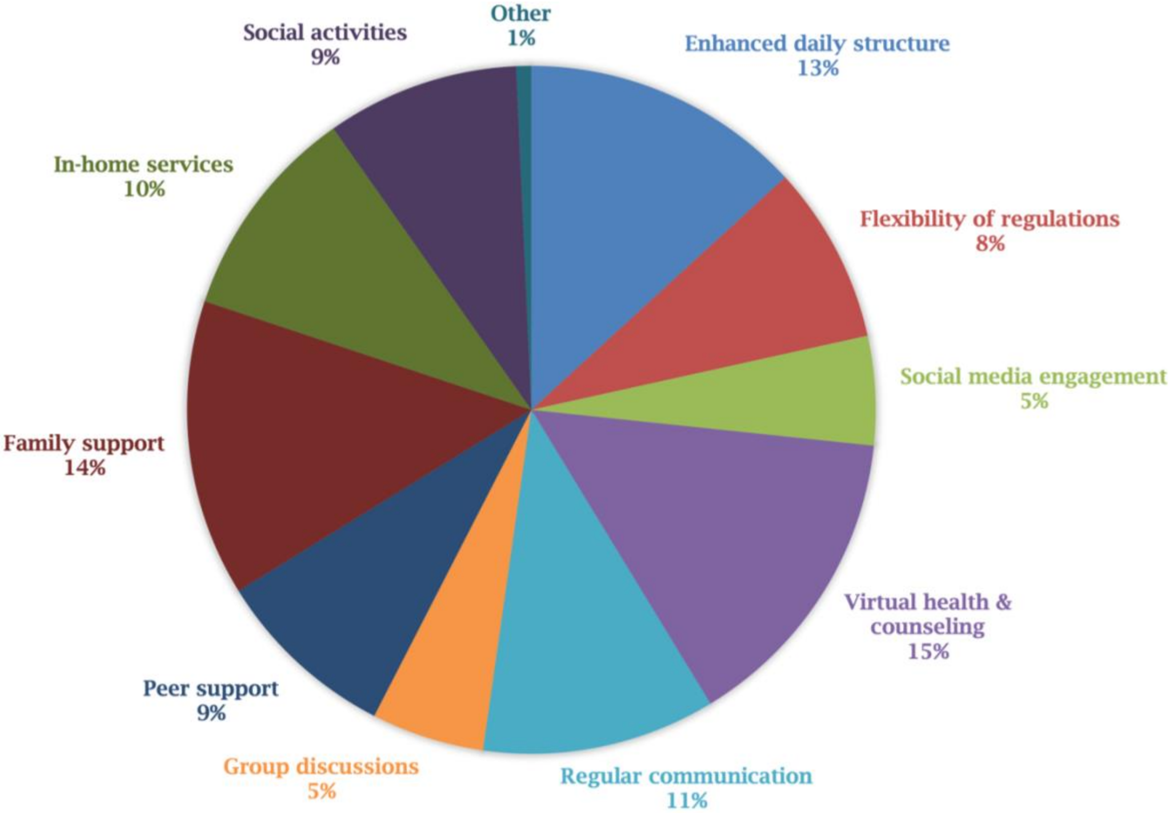
Successful Service Strategies Provided During the Pandemic

When asked about the most successful strategies implemented during the pandemic that resulted in improvements in the systems of care and support for persons with IDD, respondents identified access to telehealth and virtual counseling (59.7%), increased family support (56.8%), enhanced daily structure (53.8%), regular communications between patient and provider (44.7%), and in-home services (41.3%).

Many positive factors that contributed to these successful strategies centered around increased social interactions and improved direct communications, as shown in **Figure** *7*.

Figure 7

Successful Strategies Provided During COVID-19



Note: Responses classified as "Other" varied from relocation for safer environments and proper referrals to providing personal protective equipment and maintaining previous routines.

Culturally, English-speaking respondents (i.e., those from the United States, Canada, Australia, and New Zealand) replicated this sentiment and order of impact. At the same time, non-English-speaking participants identified in-home care and enhanced daily structure as more of a significant benefit to their clients than regular communication. Geographically, providers and caregivers working and residing in rural communities (i.e., countryside or regions located outside of a city or town) noted that family support (61.4%) was the primary successful strategy, with telehealth and tele-counseling services coming in a close second (58.6%).

Clinical providers, including psychiatrists, therapists, counselors, behavioral analysts, and psychologists, shared the same views as most participants. However, they generally noted that regulatory flexibility provided more options for improved care and service than in-home services alone. Similarly, social workers, case managers, family caregivers, and direct support professionals felt that telehealth and virtual counseling provided the best option to accommodate persons with IDD who were forced into isolation due to the various state and federal regulations in place.

Minor variations among the profession types related to successful strategies were noted; generally, all respondents expressed the need for expanded care options. These included adding more family support and improving communication as the core concepts to successfully treating, caring for, and supporting persons with IDD during a global health crisis.

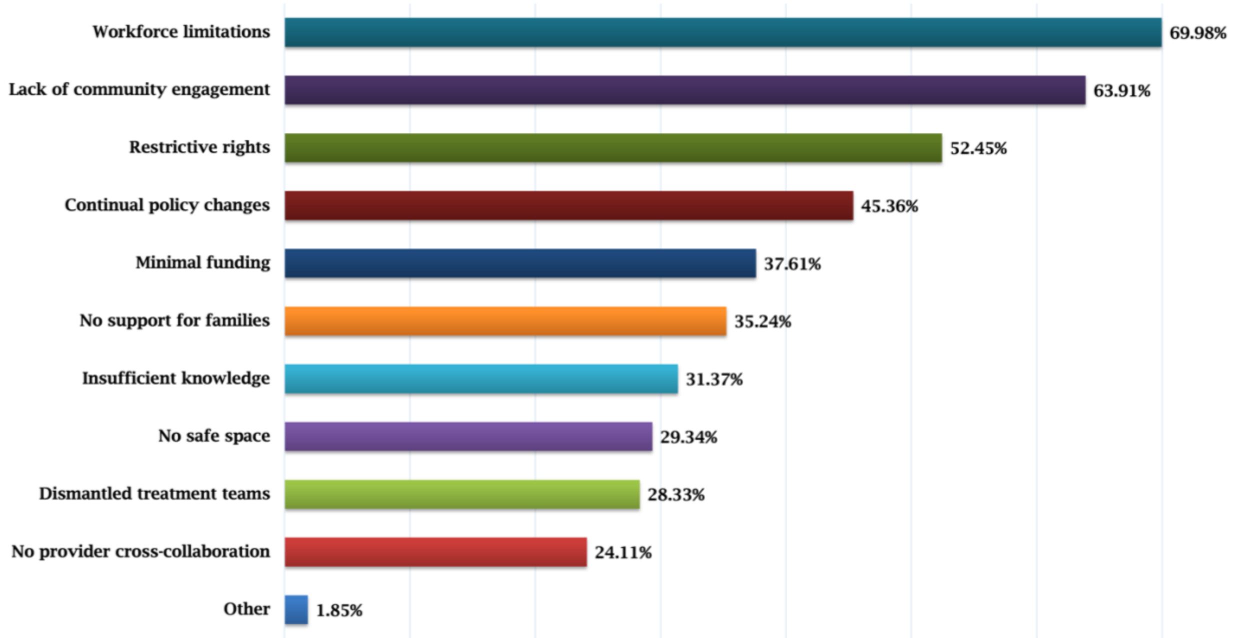
Perceived Barriers Impacting Treatment, Care, and Support Options

All respondents noted that significant barriers were magnified during the pandemic, given the in-person, physical, and geographic limitations many persons with IDD and MI faced. The most significant barrier presented by the participants related to their workforce limitations (70%)--which reduced their capacity to provide equitable and effective care to their patients. Additional barriers included a lack of community resources related to social activities and employment opportunities (64%) and restricted visitations mandated by state and federal regulations and ordinances (52%).

Figure *8* shows all barriers identified by the percentage of respondents to selected them.

Figure 8

Barriers to Care and Service



When comparing the responses from the English language participants to those who completed the non-English survey, it was found that the barriers surrounding access to community resources, employment opportunities, and workforce limitations were significantly higher for the English language respondents (81% and 74%, respectively). This increase may be related to regulatory or policy procedures in place before and during the pandemic that were not adaptable to the disruption in traditional care options. Unsurprisingly, many respondents identified these procedures as being insufficient and ineffective in managing adequate provider-to-client care ratios necessary to sustain proper treatment and support services. However, an increase in policy changes during the pandemic also appeared to reflect a substantial disconnect between effective service and care—of which 58% of the total respondents acknowledged that this disconnect impacted their ability to provide equitable service, support, and treatment options for all of their clients across all demographic markers due to the fact that the policy changes that were implemented were too broad to create a positive impact.

Direct Impact on Persons with IDD/MI

The mental, physical, and sociological impacts of the pandemic on people with IDD have been the focus of many studies in the last year, putting a spotlight on how traditional, reactive policies and procedures can negatively impact vulnerable populations. In this study, we asked the participants to identify pandemic-related events, experiences, and policies directly impacting their clients, patients, or family members with IDD/MI. A prominent theme in participant responses related to an increase in mental health crisis events, depression, anxiety, loneliness, and disruption in daily routines. Study participants reported that these responses to the pandemic appeared to exacerbate an already delicate balance between health and wellness within IDD populations across the globe. More than half of respondents noted that mental health diagnoses and mental health-related events were among the top examples of the impact the pandemic had (and still has) on persons with IDD. Contextual issues, such as social and community isolation and difficulty adapting to new ways of obtaining treatment and care, further inhibited effective treatment and care. Across provider type, culture, and geography, this trend appeared consistent and suggests that these events and circumstances were experienced to a significant degree by all persons with IDD worldwide.

Improvement Strategies for Future Events

In this study, we asked participants to identify strategies they believed would help ameliorate some of the problems and barriers they faced in providing effective treatment, care, and support to their local IDD community. We believe participant responses provide helpful guidance for future planning and policy development. Some of the prominent improvement strategies cited by participants include:

1. Create adaptable services to respond to changing needs.
2. Include alternatives to isolation in future planning strategies.
3. Expand communication options to utilize when traditional methods are not available.
4. Create opportunities for participation in community and wellness supports.
5. Maintain a consistent and effective cross-collaborative care team.
6. Create and administer applicable training on crisis response.
7. Adapt policies to be responsive to changing crisis circumstances.
8. Ensure that the experiences of persons with IDD and their families inform future pandemic-related planning and procedures.

The insights gained across professional and personal affiliations, geographic locations, cultural views, and workplace settings, demonstrate that there is a universal need and desire to align resources and expand services that will ensure person-centered continuity of care during a global crisis.

Conclusion

This study aimed to examine the perceptions and experiences of providers, caregivers, and family members of persons with IDD/MI during the pandemic to inform the development of effective policies and procedures to improve system responses in the event of a future pandemic. The findings suggest that uniform policy responses to the pandemic created adverse conditions and barriers to providing sufficient care and treatment for persons with IDD. Additionally, support services were hindered by constantly changing policies, limited or ineffective communication, lack of collaboration and outreach, and procedures that did not align with the needs and conditions of those they were meant for. Further, the reduction in the IDD/MI workforce limited how and when support, treatment, and care were provided and made available. This limitation exhausted available resources, creating an imbalance in who got services and how they received them. The significant recommendations that emerged from this study include:

1. Collaboration among provider types and communication pathways between families, patients/clients, and providers must be flexible and adaptable to changes in resources, services, and treatment options.
2. Prioritization of workforce capacity improvements is necessary to ensure sufficient staffing and resources that can accommodate the particular circumstances that universal policies can create for persons with IDD, especially persons with co-occurring mental health disorders.
3. Policy changes should be informed by the needs of service providers and caregivers, enhancing their ability to provide the services and care for their local IDD communities.
4. Socialization and social support are essential interventions to ensure that changes in daily routines or care processes do not adversely affect the mental wellness of persons with IDD.

Suggestions for Future Research

The findings of this study may contribute to the development of more equitable and effective policies that address the needs of persons with IDD, families, caregivers, and service providers. The recommendations contained herein have the potential to benefit all of a community's members in the event of a significant health crisis like the COVID-19 pandemic. A body of existing research addresses the gaps in service, support, and treatment for persons with IDD and co-occurring mental health disorders. The findings of this study suggest that the pandemic intensified these shortcomings but also created an opportunity for future policies and procedures to be more adaptable and effectual. Future researchers should consider the following recommendations to explore the concepts and core themes identified by this study in more depth:

1. No respondents identified working from Asian countries like China, Japan, or Korea. Including these persons in future studies would be beneficial to determine if they experience the same or new barriers or utilize successful strategies.
2. Future studies may benefit from gender or age range demographic markers to determine if these elements factor into how treatment, care, and support are provided or if they play any role in the perceptions of changes needed to improve systems moving forward.
3. Future research should include self-advocates as participants to gauge their views of barriers versus success measures to determine if they align with or differ from the views expressed by providers, caregivers, and family members collected in this study.

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