

Research

The COVID-19 Pandemic and Quality of Life
Outcomes of People with Intellectual and
Developmental Disabilities



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COVID-19 AND QUALITY OF LIFE OF PEOPLE WITH IDD

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Developmental Disabilities**

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Carli Friedman, PhD
Director of Research
CQL | The Council on Quality and Leadership
100 West Road, Suite 300
Towson, MD 21204
cfriedman@thecouncil.org

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Abstract

Background. People with intellectual and developmental disabilities (PWIDD) are contracting and dying of COVID-19 at significantly greater rates than nondisabled people and people with other disabilities. Despite the increased risk of COVID-19 for the IDD community, there has been less attention drawn to the impact of the pandemic on people with IDD, especially beyond their health and safety. Yet, PWIDD also face unique challenges as a result of the pandemic compared to other populations.

Objective. The purpose of this study was to explore the impact of the COVID-19 pandemic on the quality of life outcomes of PWIDD.

Methods. We conducted a secondary analysis of Personal Outcome Measures[®] interviews from 2019 and 2020 ($n = 2,284$).

Results. There were significant differences in the following quality of life outcomes of PWIDD between 2019 and 2020: continuity and security; interact with other members of the community; participate in the life of the community; intimate relationships; and, choose goals.

Conclusions. Our findings suggest the COVID-19 pandemic has negatively hindered the quality of life outcomes of PWIDD in a number of different areas. While the pandemic has been undoubtably hard on the IDD community, in many ways it has simply intensified an underfunded and fractured IDD service system. However the IDD service system evolves during and after the pandemic, it must be done in a way that prioritizes the quality of life of PWIDD and what is most important to them.

The COVID-19 Pandemic and Quality of Life Outcomes of People with Intellectual and Developmental Disabilities

People with intellectual and developmental disabilities (PWIDD) are contracting and dying of COVID-19 at significantly greater rates than nondisabled people and people with other disabilities.¹⁻⁵ While IDD itself puts people at more risk, PWIDD are also more likely to have co-morbidities that increase their risk for contracting and dying of COVID-19.¹ Many PWIDD also experience greater risks because they live in congregate settings where they not only live with many other people, but also may not be able to isolate because of the presence of housemates, the need for personal care, and/or a rotation of support staff coming into the house.^{2, 6-8} For example, in one intermediate care facility for persons with developmental disabilities (ICFDD) in Illinois, 310 out of 344 PWIDD tested positive for COVID-19.⁹ In fact, estimates suggest more than 40% of all COVID-19 deaths in the United States were people with disabilities who lived in congregate settings.¹⁰

In addition to the increased risk PWIDD face, living during the pandemic has changed PWIDD's lives. Like all people,¹¹ many PWIDD are more stressed, isolated, and traumatized from the pandemic.^{5, 12, 13} Yet, PWIDD also face unique challenges as a result of the pandemic compared to other populations. For example, COVID-19 has radically disrupted Home- and Community-Based Services (HCBS) service provision,⁷ which most PWIDD rely on for their health, safety, and quality of life (QOL).¹⁴ Many IDD service providers are struggling to function and provide services to PWIDD because of a lack of resources and funding, and increased staffing shortages.¹⁵ For example, Avalere Health¹⁵ found 68% of IDD service providers were required to close IDD service lines due to government order, resulting in a 32% loss in revenue which further increased instability.

Despite the increased risk of COVID-19, there has been less attention drawn to the impact of the pandemic on PWIDD. For example, there is a lack of data about COVID-19 trends among PWIDD and the federal government is not tracking outbreaks in institutions and group homes.^{1,9,16} A lack of pandemic data about PWIDD makes it more difficult to monitor the impact of COVID-19 on this community and identify risk factors; it also results in PWIDD's needs being undiscovered, and as a result, ignored and unmet.^{1,9,16}

While research has been working to fill in the gaps about COVID-19 and PWIDD, thus far most research has focused on the impact of COVID-19 on the health and safety of PWIDD. We hope to add to this knowledge by exploring how living through the pandemic impacted PWIDD's QOL. For these reasons, the purpose of this study was to explore the impact of the COVID-19 pandemic on the QOL outcomes of PWIDD. We had the following research question: How did PWIDD's QOL outcomes change during the COVID-19 pandemic? To explore this research question, we conducted an analysis of secondary Personal Outcome Measures[®] (POM) QOL interviews from 2,284 PWIDD.

Methods

Measure

We utilized POM¹⁷ data for this study. (IRB determined it was exempt from review.) The POM is a person-centered QOL tool which was developed 30 years ago based on focus groups with people with disabilities, their families, and other key stakeholders about what really mattered in people with disabilities' lives. The POM has gone through a number of revisions based on pilot testing, a Delphi survey, feedback from advisor groups, commission of research and content experts, and validity testing.¹⁸ The most recent edition is comprised of 21 different QOL areas (see Table 1 for outcomes).

POM administration occurs in 3 stages. During the first stage, a trained and certified interviewer has an in-depth conversation with the PWIDD following open-ended prompts (see POM manual¹⁷ for prompts). During the second stage, the interviewer discusses individualized supports with someone who knows about the organizational supports the PWIDD receives. During the final stage, the interviewer completes decision-trees (decision-trees for each outcome are available at The Council on Quality and Leadership¹⁷) about the 21 QOL outcomes based on the information gathered to determine if each outcome is present (1) or not (0).

Data

All participants were IDD service recipients. Human service providers, and state and local governments conduct POM with PWIDD for person-centered planning discovery – to determine what is important to the person, as well as where the provider needs to target supports.

Organizations also use POM as part of their quality improvement efforts – to determine where they are excelling and where there are opportunities for improvement. For example, they may aggregate POM across their entire organization, and/or compare aggregate POM scores of each

residential setting or different service lines. Organizations implement POM in a range of ways, depending on their purpose, size, and capacity. For example, some organizations interview everyone they support at regular interviews (e.g., every few years) for person-centered discovery and planning, others conduct a random sample to represent their organization in aggregate, while others conduct a convenience sample. Organizations have the option of sharing POM data, including demographic data, with The Council on Quality and Leadership for additional analyses; this is how we obtained the POM data for this study.

Participants

Between 2018 and 2020 there were POM for 2,284 PWIDD from 30 different states. Most participants were men (57.1%), White (69.4%), and primarily communicated through verbal/spoken language (82.5%; Table 2). The mean age was 43.8 ($SD = 15.7$). The most common residence type was provider owned/operated home (47.2%), followed by family home (21.8%), and own home (18.5%). The most common disabilities were: autism spectrum (15.8%), seizure disorder (14.5%), and cerebral palsy (13.0%). 12.1% of PWIDD had complex medical support needs (skilled nursing care 12+ hours/day), and 19.9% had comprehensive behavior support needs (24-hour supervision due to risk of dangerous behavior).

Analysis

We conducted a series of binary logistic regressions to examine differences in 2019 and 2020 (independent variable (IV)) in each of the 21 individual outcome areas of the POM (dependent variables (DVs)). We controlled for all participant demographics (covariates (CVs)) and for 2018 (compared to 2019) to minimize yearly variance in 2019.

Results

Differences in Outcomes During the Pandemic

Descriptive statistics are presented in Table 3. There were significant differences in 2019 and 2020 in the following outcomes (Table 4): experience continuity and security; interact with other members of the community; participate in the life of the community; intimate relationships; and, choose personal goals. Controlling for all other variables, PWIDD were 1.54 times less likely to experience continuity and security in 2020 compared to 2019 (Odds ratio (OR; confidence interval (CI))=0.65(0.45-0.94); Figure 1). PWIDD were 1.62 times less likely to interact with other members of the community in 2020 compared to 2019 (OR(CI)=0.62(0.43-0.89)). PWIDD were 1.73 times less likely to participate in the life of the community in 2020 compared to 2019 (OR(CI)=0.58(0.40-0.84)). PWIDD were 1.49 times less likely to have intimate relationships in 2020 compared to 2019 (OR(CI)=0.67(0.46-0.98)). PWIDD were 2.22 times more likely to choose their goals in 2020 compared to 2019 (OR(CI)=2.22(1.51-3.27)).

A number of outcomes' differences between 2019 and 2020 were also reaching significance. Although they failed to reach significance, controlling for all other variables, compared to 2019, in 2020 PWIDD were 1.39 times less likely to have best possible health (OR(CI)=0.72(0.50-1.04), $p=0.08$), 1.39 times less likely to exercise rights (OR(CI)=0.72(0.50-1.04), $p=0.08$), and 1.42 times less likely to have natural supports (OR(CI)=0.70(0.48-1.03), $p=0.07$).

Correlates of Outcomes (Regardless of Year)

Several CVs were also correlated with outcomes. Controlling for all other variables (including year), increased age was associated with increased odds of having the following outcomes present: safe (OR(CI)=1.01(1.00-1.02)); free from abuse/neglect (OR(CI)=1.01(1.01-1.02));

continuity and security (OR(CI)=1.01(1.00-1.02)); exercise rights (OR(CI)=1.01(1.00-1.02)); treated fairly (OR(CI) =1.01(1.00-1.02)); respect (OR(CI)=1.01(1.00-1.02)); use their environments (OR(CI) =1.01(1.00-1.02)); interact with other members of the community (OR(CI)=1.01(1.00-1.02)); participate in the life of the community (OR(CI)=1.01(1.00-1.02)); natural supports (OR(CI) = 1.01(1.00-1.02)); friends (OR(CI)=1.02(1.01-1.02)); social roles (OR(CI)=1.02(1.01-1.2)); and choose where to work (OR(CI)=1.01(1.00-1.02)). People with increased age were less likely to realize goals (OR(CI)=0.98(0.98-0.99)).

Compared to men, women were less likely to have the following present: free from abuse/neglect (OR(CI)=0.70(0.56-0.87)); best possible health (OR(CI)=0.77(0.62-0.96)); continuity and security (OR(CI)=0.74(0.59-0.91)); treated fairly (OR(CI)=0.75(0.61-0.94)); respect (OR(CI)=0.79(0.64-0.98)); use their environments (OR(CI)=0.74(0.59-0.92)); live in integrated environments (OR(CI)=0.73(0.58-0.93)); and natural supports (OR(CI)=0.78(0.63-1.06)). Compared to men, women were more likely to have intimate relationships (OR(CI)=1.27(1.02-1.58)).

Compared to White people, Black people were more likely to have the following present: free from abuse/neglect (OR(CI)=1.29(1.00-1.66)); live in integrated environments (OR(CI)=1.50(1.13-1.98)); participate in the life of the community (OR(CI)=1.30(1.01-1.66)); and, choose services (OR(CI)=1.52(1.18-1.96)). Compared to White people, people from 'other' races were less likely to have the following present: exercise rights (OR(CI)=0.48(0.32-0.73)); treated fairly (OR(CI) = 0.39(0.26-0.59)); use their environments (OR(CI)=0.40(0.27-0.61)); live in integrated environments (OR(CI)=0.49(0.31-0.79)); natural supports (OR(CI)=0.60(0.38-0.93)); intimate relationships (OR(CI)=0.55(0.35-0.88)); decide when to share personal

information (OR(CI)=0.64(0.43-0.97)); social roles (OR(CI)=0.45(0.28-0.73)); and, choose personal goals (OR(CI)=0.50(0.33-0.76)).

People with complex medical support needs were more likely to be safe than people without these support needs (OR(CI)=1.77(1.09-2.86)). People with comprehensive behavior support needs were less likely to have natural supports than people without these support needs (OR(CI)=0.72(0.53-0.93)).

In terms of residence, the following outcomes significantly differed compared to people who lived in provider owned/operated homes (OR(CI)):

- Safe: own home (0.68(0.47-0.98));
- Free from abuse/neglect: own home (0.68(0.50-0.91)), family home (1.53(1.14-2.06));
- Continuity and security: family home (1.94(1.45-2.59));
- Exercise rights: family home (1.77(1.32-2.38)), ICFDD (0.26(0.09-0.74));
- Treated fairly: family home (1.88(1.39-2.54)), ICFDD (0.33(0.13-0.84));
- Respect: family home (1.95(1.45-2.62)), state HCBS group home (2.22(1.00-4.92));
- Use their environments: own home (1.64(1.19-2.25)), family home (1.57(1.16-2.13)), host family/family foster care (2.16(1.23-3.79));
- Live in integrated environments: own home (7.44(5.27-10.50)), family home (7.53(5.40-10.51)), host family/family foster care (3.29(1.97-5.50)), other (2.97(1.60-5.52));
- Interact with other members of community: own home (1.99(1.47-2.69)), family home (1.86(1.39-2.49)), host family/family foster care (2.17(1.30-3.64));
- Participate in life of community: own home (1.50(1.12-2.01)), family home (1.66(1.24-2.21));
- Natural supports: family home (3.49(2.59-4.70));

- Intimate relationships: own home (1.49(1.11-2.01)), family home (2.32(1.73-3.11));
- Decide when to share personal information: family home (1.39(1.04-1.86)), state HCBS group home (2.39(1.07-5.31));
- Social roles: own home (2.10(1.56-2.84)), family home (2.27(1.68-3.05)), host family/family foster care (1.83(1.10-3.06));
- Choose where/with whom to live: own home (4.39(3.18-6.07)), family home (5.49(3.95-7.64)), host family/family foster care (2.62(1.53-4.49)), state HCBS group home (2.26(1.02-5.02));
- Choose where to work: own home (2.69(1.99-3.65)), family home (3.18(2.34-4.31)), host family/family foster care (2.18(1.31-3.61));
- Choose services: own home (2.01(1.48-2.73)), family home (3.18(2.34-4.25)), host family/family foster care (1.79(1.08-2.99)), state HCBS group home (3.86(1.87-7.99));
- Choose personal goals: own home (1.43(1.06-1.93)), family home (1.40(1.05-1.87)), state HCBS group home (2.38(1.11-5.08)).

People with anxiety were less likely to choose where/with whom to live than people without anxiety (OR(CI)=0.61(0.40-0.91)). Autistic people were more likely to have best possible health (OR(CI)=1.48(1.07-2.04)) and, live in integrated environments (OR(CI)=1.47(1.05-2.05)) than non-autistic people. People with behavior challenges were more likely to have social roles (OR(CI)=1.52(1.01-2.29)) than people without behavior challenges. People with hearing loss were more likely to use their environments (OR(CI)=2.56(1.04-6.27)) and less likely to choose where/with whom to live (OR(CI)=0.34(0.13-0.87)) than people without hearing loss. People with mood disorder were more likely to have continuity and security (OR(CI)=1.45(1.05-2.02)) than people without mood disorder. People with

personality/psychotic disorder were less likely to be free from abuse/neglect (OR(CI)=0.59(0.38-0.93)) and have continuity and security (OR(CI)=0.60(0.38-0.96)) than people without this disability. Compared to people without physical disabilities, people with physical disabilities were more likely to choose where/with whom to live (OR(CI)=1.84(1.02-3.32)). People with seizure disorder were less likely to have best possible health (OR(CI)=0.73(0.54-0.99)) and treated fairly (OR(CI)=0.71(0.53-0.96)).

Compared to people who primarily communicated through verbal/spoken language, people who communicated through other means were less likely to have the following present: safe (OR(CI)=0.63(0.43-0.94)); treated fairly (OR(CI)=0.75(0.57-1.00)); and, decide when to share personal information (OR(CI)=0.69(0.52-0.92)). They were more likely to have the following present: social roles (OR(CI)=1.41(1.05-1.88)); choose where/with whom to live (OR(CI)=1.89(1.35-2.65)); choose where to work (OR(CI)=2.03(1.49-2.75)); choose personal goals (OR(CI)=1.69(1.28-2.22)); and, realize personal goals (OR(CI)=1.55(1.18-2.04)).

Discussion

The pandemic negatively hindered the health and safety of PWIDD as they were more susceptible to contracting COVID-19 and dying from it. The purpose of this study was to explore the impact of the pandemic on the QOL outcomes of PWIDD. Our analysis of 2019 and 2020 POM revealed significant differences in the following QOL outcomes: people experience continuity and security; people interact with other members of the community; people participate in the life of the community; people have intimate relationships; and, people choose goals.

Continuity and Security

In our study, there was a significant decrease in continuity and security between 2019 and 2020, with only 37% of PWIDD having the outcome present in 2020. Continuity and security is fundamental; without stability one is not likely to have a high QOL, regardless of the presence of other outcomes. COVID-19 impacted all people's lives and most people felt less secure as a result of the pandemic.¹¹ However, PWIDD may have been particularly impacted by the pandemic as they have less economic security and are more likely to live in poverty.¹² For example, one survey found 90% of people with disabilities had increased expenses during the pandemic.¹⁹

In addition, PWIDD's health and QOL are largely dependent on the government services they receive.²⁰ The pandemic dramatically shifted how disability service providers operate.²¹ Most providers were required to close services due to government orders, which hindered the continuity and security of PWIDD, and increased provider instability due to loss of revenue.^{15, 22-}
²⁴ Many IDD service providers were struggling because of a lack of resources and funding, with some ultimately having to close,¹⁵ hindering the continuity and security of PWIDD. Direct support professional (DSP) turnover, which was already problematic prior to the pandemic, also

rose in the pandemic because of increased workload, DSPs leaving work to take care of children or family members, and DSPs' increased fears of being infected.^{21, 24, 25} Because of being short staffed during the pandemic, overtime is costing the average provider 1 million dollars a year,²⁴ which places providers even more at risk of total collapse. Ultimately, provider instability and DSP turnover trickle down to the QOL of PWIDD.²⁶ Not only do PWIDD have less control over their lives than ever before, they have also seen their services and routines disrupted, decreased quality of support, and a rotating door of support staff, if they were lucky enough to not lose support altogether.^{5, 7, 12, 22, 24, 27}

Community

In 2020, PWIDD in our sample were less likely to interact with other members of the community and participate in the community compared to 2019. In addition to lockdown restrictions that applied to all populations, many PWIDD were forced to isolate because of the increased threat COVID-19 represented to them,^{13, 25, 27} and/or because they lived in settings that required them to stay home.²² DSP turnover and shortages,²⁵ in combination with providers prioritizing health and safety above all else,²³ also meant PWIDD had fewer opportunities to participate in the community, even in ways that complied with social distancing. Health anxiety could have also lead PWIDD to stay home more and avoid certain community activities.²⁷ In addition to fewer opportunities to participate in the community, there was less variety of community activities to participate in.²⁷

Intimate Relationships

PWIDD in our study were less likely to have intimate relationships in 2020 compared to 2019. PWIDD were more isolated as a result of the pandemic,^{13, 24} which is especially problematic as PWIDD already had smaller social networks and were at risk for social isolation prior to the

pandemic.²⁷⁻²⁹ Many congregate settings required sheltering-in-place and prohibited all visitors, resulting in PWIDD being cut off from family, friends, and partners, and with some PWIDD not even understanding why.^{21, 25, 27} While many PWIDD turned to technology to connect with partners, friends, and family to compensate, many still miss social contact.²⁷ PWIDD also frequently lack privacy, including for romantic relationships and sex;³⁰ they likely had even fewer opportunities for privacy and sex if they were required to shelter-in-place with other housemates and/or were denied visitors. Given the high mortality among PWIDD and in congregate settings during the pandemic,¹⁻⁵ PWIDD may have also lost partners to COVID-19. The decrease in intimate relationships among PWIDD is especially problematic as social and intimate relationships, benefit mental health, community engagement, and QOL.³¹⁻³⁴

Choosing Goals

The only outcome that increased in 2020 compared to 2019 was “people choose personal goals.” While this increase seems counterintuitive given the restrictions placed on PWIDD’s lives, as a result of the closing of service lines, such as day programs, and people being home all the time, many providers needed to come up with creative ways to engage PWIDD, including by helping them learn new things.²² This creativity led many providers to consider shifting to individualized person-centered supports moving forward.²² Many PWIDD also received more personal attention from staff during this time,²² which likely meant PWIDD were more often consulted about their preferences. The chance to engage in new and different activities may have also exposed PWIDD to new opportunities and skills, which changed their preferences and future goals. In addition, the pandemic has allowed PWIDD to have the space and time to think about what they want in the future when the pandemic is over and to prioritize what is important to them. Given the counterintuitive nature of this finding, we recommend future research explore choosing goals

in more depth; for example, did it increase because of providers' improvisation and creativity, or were there other factors that resulted in increased goal choice in 2020?

Implications

Although many QOL outcomes failed to be significantly different in 2019 and 2020 in our study, it is important to note PWIDD's QOL outcomes were not particularly good in 2020 *or* 2019 – even in 2019, a large proportion of PWIDD in the sample did not have many of the outcome areas present. Furthermore, those QOL areas that were least present in 2020 were also least present in 2019. For example, only about one-third of PWIDD chose where/with whom to live, or chose services in either year. Less than 45% of PWIDD had friends, intimate relationships, or natural supports even *before* the pandemic. There were also many disparities in outcomes in our study across years; for example, women, people of color, and people in provider owned/operated homes were less likely to have many of the outcomes present regardless of year.

While the pandemic has been undoubtably hard on the IDD community, in many ways it has simply intensified an underfunded and fractured service system,²⁴ upon which PWIDD depend.¹⁴ Most people with disabilities live in poverty.¹² The DSP crisis has been going on for decades.^{15, 24} Many service providers were already dangerously unstable, with the average provider having only a single month's "cash on hand to maintain operations" (p. 6) prior to the pandemic.²⁴ Many PWIDD, even those who physically live in the community, were not and are not integrated into their communities and are isolated with fewer relationships.^{28, 29, 35, 36}

Compounding these issues is the fact that the majority of states have seen a significant decrease in tax revenue and will need to make substantial budget cuts to compensate.³⁷ During the Great Recession this led to a reduction in the proportion of total federal Medicaid spending going towards PWIDD.³⁸ There are concerns COVID-19 could lead to a roll back of the progress

that has been made regarding community integration, self-determination, and QOL of PWIDD prior to the pandemic.^{22, 23} American Network of Community Options and Resources Foundation and United Cerebral Palsy²⁴ warn, the

new challenges wrought by COVID-19 are exacerbating preexisting cracks in the system that threaten the longterm viability of community-based disability services. In turn, the ability of people with IDD to be included in the community is in jeopardy—if providers go out of business, the people they support will have fewer options and resources to live, work and thrive in the community of their choosing. (p. 8)²⁴

As DSP turnover hinders the QOL of PWIDD,²⁶ during and in wake of recovery from the pandemic, efforts must also be made to increase the stability and tenure of DSPs. For example, there have been calls for professionalization of the workforce, and for the Department of Labor to recognize the profession as a standard occupation classification, which would help promote increased reimbursement rates and wages, and make it easier to identify trends and unmet needs of DSPs.^{39, 40}

While the pandemic has intensified these cracks in the IDD service system, it also brings forth lessons and opportunities for improvement in the future. For example, social and informational technologies have helped connect PWIDD like never before.^{5, 22} These technologies also enabled providers to get more creative with service provision and help defray DSP shortages.²⁴ During the pandemic, most states also modified their HCBS programs to increase flexibility; it has been suggested this continue post-pandemic, along with increased HCBS funding, especially for individual settings rather than congregate ones.^{24, 37} As a result of

this increased flexibility, as well as because of the increase in people choosing goals in our study, we hope there will be an increase in individualized services and self-direction moving forward.²²

Limitations

When interpreting the findings from this study, a number of limitations should be noted. While we controlled for demographics and 2018 for yearly variance, this was not a longitudinal design. This was a convenience sample and there is a chance of selection bias. All participants were also service recipients, which may have altered their QOL during the pandemic since they would have been more likely to be served by providers than people without formal services. This was an analysis of secondary data. As such, we did not have the ability to add additional variables or questions. For example, we did not have information on if members of the sample contracted COVID-19. We also did not have information about funding and waiver access, which could have impacted the results. We did not explore interactions. Given the impact of the pandemic, some of the 2020 interviews in the dataset may have been conducted virtually instead of in-person, which could have impacted the results. There were also fewer interviews conducted in 2020 as a result of the pandemic, compared to other years. In addition, although demographics were controlled, there were some differences in demographics across the years. For example, residence type, which plays a role in outcomes, shifted slightly over the years. These limitations all represent opportunities for future study.

Conclusion

However the IDD service system evolves during and after the pandemic, it must be done in a way that prioritizes the QOL of PWIDD, and, based on the findings from our study, in a way that draws particular attention to the continuity and security, relationships, and community participation of PWIDD, and the disparities unearthed in our study. To promote the QOL of PWIDD, there must be a service system that “deemphasizes cost savings in favor of meeting people’s unique needs, regardless of the severity of their disability or the complexity of their support plans” (p. 5).²⁴ Most importantly, as a community that has been significantly impacted by the pandemic, PWIDD must be consulted in whatever changes are made; as the famous self-advocacy quote goes, “nothing about us, without us.”

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Table 1

Personal Outcome Measures® Indicators

People are safe

People are free from abuse and neglect

People have the best possible health

People experience continuity and security

People exercise rights

People are treated fairly

People are respected

People use their environments

People live in integrated environments

People interact with other members of the community

People participate in the life of the community

People are connected to natural supports

People have friends

People have intimate relationships

People decide when to share personal information

People perform different social roles

People choose where and with whom to live

People choose where to work

People choose services

People choose personal goals

People realize personal goals

Note. See the POM manual¹⁷ for more information about each outcome, including decision-trees. Data includes if each outcome is present (1) or not (0).

Table 2
Demographics (n = 2,284)

Characteristic	Total (n = 2,284)		2020 (n = 261)		2019 (n = 864)		2018 (n = 1,159)	
	%	n	%	n	%	n	%	n
Age (M (SD))	43.8 (15.7)		44.4 (14.8)		43.8 (15.9)		43.6 (15.8)	
Gender (n = 2,198)								
Man	57.1%	1254	57.5%	142	56.3%	468	57.6%	644
Woman	42.9%	944	42.5%	105	43.8%	364	42.4%	475
Race (n = 2,231)								
White	69.4%	1548	66.1%	166	69.7%	586	70.4%	796
Black	22.6%	504	21.5%	54	20.6%	173	24.5%	277
Other	8.0%	179	12.7%	32	10.2%	86	5.4%	61
Complex medical support needs (n = 1,757)								
No	87.9%	1545	87.4%	180	87.2%	546	88.5%	819
Yes	12.1%	212	12.6%	26	12.8%	80	11.5%	106
Comprehensive behavior support needs (n = 1,757)								
No	80.1%	1408	79.6%	164	76.8%	481	82.5%	763
Yes	19.9%	349	20.4%	42	23.2%	145	17.5%	162
Residence type (n = 2,137)								
Provider owned/operated home	47.2%	1009	43.7%	107	46.0%	376	48.4%	526
Family home	21.8%	466	15.9%	39	21.8%	178	22.9%	249
Host family / family foster care	4.3%	91	3.7%	9	4.6%	38	4.0%	44
Own home	18.5%	395	28.6%	70	17.5%	143	16.7%	182
State HCBS group home	1.9%	40	1.6%	4	2.0%	16	1.8%	20
Other	4.3%	91	3.7%	9	5.1%	42	3.7%	40
ICFDD	2.1%	45	2.9%	7	2.2%	18	1.8%	20
Disability/diagnosis								
Anxiety	10.9%	250	10.0%	26	10.3%	89	11.6%	135
Autism spectrum	15.8%	361	14.2%	37	15.6%	135	16.3%	189
Behavior challenges	8.5%	193	8.4%	22	8.8%	76	8.2%	95
Cerebral Palsy	13.0%	296	16.5%	43	12.0%	104	12.9%	149
Down syndrome	7.8%	179	7.7%	20	8.6%	74	7.3%	85
Hearing loss - severe or profound	2.8%	63	3.8%	10	2.0%	17	3.4%	36
Impulse control disorder	4.6%	106	5.0%	13	5.1%	44	4.2%	49
Vision loss (severe/profound) or Blind	3.3%	75	5.0%	13	2.8%	24	3.3%	38
Mood disorder	12.1%	276	10.7%	28	11.6%	100	12.8%	148
Other mental/psychiatric disability	12.1%	276	6.9%	18	12.3%	106	13.1%	152
Personality/psychotic disorder	6.2%	142	6.1%	16	6.7%	58	5.9%	68
Physical disability	4.6%	104	3.8%	10	4.4%	38	4.8%	56
Seizure disorder	14.5%	332	16.9%	44	13.1%	113	15.1%	175
Primary communication method (n = 2,113)								
Verbal/spoken language	82.5%	1743	89.9%	213	84.9%	665	79.1%	865
Other	17.5%	370	10.1%	24	15.1%	118	20.9%	228

Table 3

Descriptive statistics

Outcome	% present	
	2020	2019
People are safe	81.2%	75.5%
People are free from abuse and neglect	48.7%	45.6%
People have the best possible health	55.0%	60.6%
People experience continuity and security	36.9%	46.8%
People exercise rights	41.9%	46.6%
People are treated fairly	51.5%	53.4%
People are respected	48.5%	53.8%
People use their environments	56.9%	61.6%
People live in integrated environments	50.0%	50.9%
People interact with other members of the community	43.1%	56.7%
People participate in the life of the community	35.4%	46.9%
People are connected to natural supports	35.8%	44.8%
People have friends	35.4%	43.1%
People have intimate relationships	32.3%	42.8%
People decide when to share personal information	43.1%	45.3%
People perform different social roles	37.3%	40.9%
People choose where and with whom to live	35.8%	35.9%
People choose where to work	39.6%	42.6%
People choose services	34.2%	35.5%
People choose personal goals	67.3%	35.5%
People realize personal goals	65.8%	68.4%

Table 4
Differences in outcomes in 2019 and 2020

Variable	Odds ratio [95% confidence interval]			
	Safe	Free from abuse/ neglect	Best possible health	Continuity and security
Model				
-2LL	1355.33	1960.01	1843.94	1977.17
χ^2 (df = 28 for all models)	67.27***	82.29***	51.97**	88.41***
R ²	0.07	0.07	0.05	0.08
2020 (ref: 2019)	1.16 [0.76-1.77]	0.77 [0.54-1.11]	0.72 [0.50-1.04]	0.65* [0.45-0.94]
Covariates				
2018 (ref: 2019)	1.93*** [1.44-2.59]	1.14 [0.90-1.44]	1.51*** [1.18-1.92]	1.35* [1.07-1.70]*
Age	1.01* [1.00-1.02]	1.01*** [1.01-1.02]	1.00 [1.00-1.01]	1.01* [1.00-1.02]
Woman (ref: man)	1.02 [0.77-1.35]	0.70** [0.56-0.87]	0.77* [0.62-0.96]	0.74** [0.59-0.91]
Race (ref: White)				
Black	1.20 [0.86-1.67]	1.29* [1.00-1.66]	1.15 [0.88-1.51]	1.21 [0.94-1.56]
Other	0.76 [0.47-1.22]	1.00 [0.67-1.50]	0.77 [0.51-1.16]	0.86 [0.58-1.29]
Complex medical support needs (ref: no)	1.77* [1.09-2.86]	1.40 [0.99-1.97]	1.16 [0.81-1.66]	0.92 [0.65-1.29]
Comprehensive behavior support needs (ref: no)	0.73 [0.51-1.05]	1.02 [0.76-1.36]	1.00 [0.74-1.36]	1.00 [0.75-1.34]
Residence type (ref: provider owned/operated home)				
Own home	0.68* [0.47-0.98]	0.68** [0.50-0.91]	0.80 [0.59-1.09]	0.79 [0.59-1.06]
Family home	0.94 [0.65-1.37]	1.53** [1.14-2.06]	0.84 [0.62-1.14]	1.94*** [1.45-2.59]
Host family / family foster care	1.02 [0.53-1.96]	0.84 [0.51-1.38]	1.20 [0.70-2.04]	1.59 [0.97-2.61]
State HCBS group home	0.88 [0.34-2.25]	0.92 [0.44-1.90]	1.12 [0.50-2.49]	0.97 [0.47-2.00]
ICFDD	2.30 [0.51-10.34]	0.83 [0.34-2.00]	1.05 [0.41-2.68]	1.37 [0.57-3.31]
Other	0.53 [0.27-1.05]	0.61 [0.33-1.13]	0.67 [0.36-1.24]	1.43 [0.78-2.62]
Disability/diagnosis				
Anxiety (ref: no)	1.09 [0.69-1.70]	1.30 [0.93-1.84]	0.93 [0.66-1.32]	0.91 [0.65-1.27]
Autism spectrum (ref: no)	0.80 [0.55-1.16]	0.92 [0.68-1.24]	1.48* [1.07-2.04]	1.30 [0.96-1.75]
Behavior challenges (ref: no)	1.43 [0.83-2.49]	1.35 [0.89-2.05]	1.15 [0.75-1.77]	0.92 [0.61-1.38]
Cerebral Palsy (ref: no)	0.80 [0.53-1.22]	0.95 [0.68-1.32]	1.39 [0.98-1.97]	0.90 [0.65-1.26]
Down syndrome (ref: no)	0.78 [0.47-1.31]	1.29 [0.84-1.98]	1.21 [0.78-1.88]	1.09 [0.72-1.66]
Hearing loss - severe or profound (ref: no)	1.10 [0.44-2.73]	0.99 [0.50-1.96]	0.83 [0.41-1.65]	1.03 [0.52-2.01]
Impulse control disorder (ref: no)	0.58 [0.32-1.07]	0.70 [0.41-1.18]	1.06 [0.61-1.83]	0.98 [0.58-1.64]
Vision loss (severe/profound) or Blind (ref: no)	0.86 [0.42-1.76]	1.13 [0.63-2.00]	1.02 [0.57-1.83]	1.24 [0.71-2.17]
Mood disorder (ref: no)	1.44 [0.92-2.25]	1.17 [0.84-1.62]	0.87 [0.62-1.21]	1.45* [1.05-2.02]
Other psychiatric disability (ref: no)	1.09 [0.71-1.66]	1.15 [0.83-1.60]	1.04 [0.74-1.46]	0.90 [0.65-1.24]
Personality/psychotic disorder (ref: no)	1.13 [0.62-2.04]	0.59* [0.38-0.93]	1.06 [0.66-1.71]	0.60* [0.38-0.96]
Physical disability (ref: no)	1.32 [0.62-2.83]	1.28 [0.73-2.23]	1.04 [0.59-1.85]	1.30 [0.75-2.24]
Seizure disorder (ref: no)	0.85 [0.58-1.24]	0.78 [0.58-1.06]	0.73* [0.54-0.99]	0.84 [0.62-1.14]
Communication: verbal/spoken language (ref: other)	0.63* [0.43-0.94]	0.77 [0.58-1.01]	1.20 [0.91-1.60]	0.93 [0.71-1.22]

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table 4 (continued)
Differences in outcomes in 2019 and 2020

Variable	Odds ratio [95% confidence interval]			
	Exercise rights	Treated fairly (due process)	Respect	Use their environments
Model				
-2LL	1977.17	1925.18	1971.51	1836.50
χ^2 (df = 28)	88.41***	84.39***	74.63***	80.02***
R ²	0.08	0.07	0.07	0.07
2020 (ref: 2019)	0.72 [0.50-1.04]	0.88 [0.61-1.27]	0.84 [0.59-1.21]	0.76 [0.52-1.10]
Covariates				
2018 (ref: 2019)	1.22 [0.97-1.54]	1.04 [0.82-1.31]	1.27* [1.01-1.26]	1.19 [0.94-1.52]
Age	1.01* [1.00-1.02]	1.01* [1.00-1.02]	1.01** [1.00-1.02]	1.01** [1.00-1.02]
Woman (ref: man)	0.97 [0.78-1.20]	0.75* [0.61-0.94]	0.79* [0.64-0.98]	0.74** [0.59-0.92]
Race (ref: White)				
Black	1.28 [1.00-1.65]	1.25 [0.96-1.61]	1.27 [0.99-1.64]	1.05 [0.80-1.36]
Other	0.48*** [0.32-0.73]	0.39*** [0.26-0.59]	0.72 [0.48-1.08]	0.40*** [0.27-0.61]
Complex medical support needs (ref: no)	0.90 [0.64-1.27]	1.14 [0.81-1.61]	1.11 [0.79-1.56]	0.90 [0.63-1.28]
Comprehensive behavior support needs (ref: no)	1.07 [0.80-1.44]	1.07 [0.80-1.44]	1.02 [0.76-1.36]	1.16 [0.85-1.58]
Residence type (ref: provider owned/operated home)				
Own home	0.98 [0.73-1.32]	1.16 [0.86-1.55]	0.81 [0.61-1.09]	1.64** [1.19-2.25]
Family home	1.77*** [1.32-2.38]	1.88*** [1.39-2.54]	1.95*** [1.45-2.62]	1.57** [1.16-2.13]
Host family / family foster care	0.96 [0.59-1.59]	1.03 [0.63-1.70]	1.31 [0.80-2.15]	2.16** [1.23-3.79]
State HCBS group home	1.65 [0.78-3.47]	1.51 [0.70-3.24]	2.22* [1.00-4.92]	1.26 [0.59-2.71]
ICFDD	0.26* [0.09-0.74]	0.33* [0.13-0.84]	0.88 [0.37-2.12]	1.01 [0.41-2.49]
Other	1.36 [0.74-2.51]	1.68 [0.89-3.17]	1.49 [0.81-2.76]	0.87 [0.47-1.61]
Disability/diagnosis				
Anxiety (ref: no)	0.96 [0.69-1.35]	1.10 [0.78-1.55]	0.97 [0.69-1.36]	0.74 [0.53-1.05]
Autism spectrum (ref: no)	1.16 [0.86-1.56]	0.97 [0.72-1.32]	1.03 [0.76-1.36]	1.03 [0.75-1.41]
Behavior challenges (ref: no)	1.09 [0.73-1.64]	0.90 [0.60-1.35]	0.70 [0.47-1.04]	1.26 [0.81-1.96]
Cerebral Palsy (ref: no)	0.98 [0.71-1.37]	0.97 [0.69-1.35]	0.86 [0.62-1.19]	1.02 [0.72-1.43]
Down syndrome (ref: no)	1.50 [0.97-2.30]	1.04 [0.67-1.60]	0.91 [0.60-1.39]	1.10 [0.70-1.71]
Hearing loss - severe or profound (ref: no)	0.77 [0.40-1.50]	1.22 [0.61-2.45]	1.04 [0.53-2.05]	2.56* [1.04-6.27]
Impulse control disorder (ref: no)	0.80 [0.47-1.34]	1.13 [0.66-1.92]	1.00 [0.60-1.68]	1.78 [0.97-3.27]
Vision loss (severe/profound) or Blind (ref: no)	1.07 [0.61-1.86]	0.95 [0.54-1.68]	1.41 [0.79-2.51]	1.29 [0.70-2.39]
Mood disorder (ref: no)	0.98 [0.71-1.35]	0.99 [0.71-1.37]	1.10 [0.79-1.52]	0.85 [0.60-1.19]
Other psychiatric disability (ref: no)	1.16 [0.83-1.60]	1.31 [0.94-1.83]	1.20 [0.86-1.66]	1.16 [0.82-1.64]
Personality/psychotic disorder (ref: no)	0.66 [0.42-1.04]	0.86 [0.54-1.36]	0.83 [0.53-1.31]	1.16 [0.71-1.90]
Physical disability (ref: no)	1.92 [1.09-3.37]	1.12 [0.64-1.97]	0.97 [0.56-1.67]	0.82 [0.47-1.44]
Seizure disorder (ref: no)	0.60 [0.44-0.81]	0.71* [0.53-0.96]	0.82 [0.61-1.10]	1.05 [0.76-1.44]
Communication: verbal/spoken language (ref: other)	0.97 [0.74-1.28]	0.75* [0.57-1.00]	0.86 [0.66-1.14]	0.97 [0.73-1.29]

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table 4 (continued)
Differences in outcomes in 2019 and 2020

Variable	Odds ratio [95% confidence interval]			
	Live in integrated environments	Interact with other members of community	Participate in life of community	Natural supports
Model				
-2LL	1701.09	1966.62	1987.62	1912.86
χ^2 (df = 28 for all models)	353.82***	75.95***	57.35***	119.01***
R ²	0.28	0.07	0.05	0.10
2020 (ref: 2019)	0.82 [0.55-1.22]	0.62** [0.43-0.89]	0.58** [0.40-0.84]	0.70 [0.48-1.03]
Covariates				
2018 (ref: 2019)	1.09 [0.84-1.40]	1.13 [0.90-1.43]	0.89 [0.71-1.12]	1.05 [0.83-1.33]
Age	1.01 [1.00-1.01]	1.01* [1.00-1.02]	1.01* [1.00-1.02]	1.01** [1.00-1.02]
Woman (ref: man)	0.73* [0.58-0.93]	0.91 [0.73-1.13]	0.85 [0.69-1.06]	0.78* [0.63-0.97]
Race (ref: White)				
Black	1.50** [1.13-1.98]	1.07 [0.83-1.38]	1.30* [1.01-1.66]	1.18 [0.92-1.53]
Other	0.49** [0.31-0.79]	0.80 [0.53-1.20]	0.68 [0.45-1.04]	0.60* [0.38-0.93]
Complex medical support needs (ref: no)	0.90 [0.62-1.30]	1.16 [0.82-1.63]	0.96 [0.69-1.35]	1.27 [0.90-1.79]
Comprehensive behavior support needs (ref: no)	0.94 [0.68-1.29]	0.85 [0.63-1.13]	0.97 [0.73-1.30]	0.72* [0.53-0.97]
Residence type (ref: provider owned/operated home)				
Own home	7.44*** [5.27-10.50]	1.99*** [1.47-2.69]	1.50** [1.12-2.01]	1.34 [0.99-1.80]
Family home	7.53*** [5.40-10.51]	1.86*** [1.39-2.49]	1.66*** [1.24-2.21]	3.49*** [2.59-4.70]
Host family / family foster care	3.29*** [1.97-5.50]	2.17** [1.30-3.64]	1.52 [0.93-2.48]	1.41 [0.85-2.33]
State HCBS group home	1.37 [0.66-2.86]	1.46 [0.70-3.02]	1.31 [0.64-2.68]	0.73 [0.33-1.58]
ICFDD	0.35 [0.10-1.21]	0.60 [0.24-1.47]	0.44 [0.16-1.23]	0.87 [0.34-2.22]
Other	2.97*** [1.60-5.52]	0.87 [0.47-1.59]	1.12 [0.61-2.05]	1.17 [0.63-2.17]
Disability/diagnosis				
Anxiety (ref: no)	0.79 [0.54-1.15]	1.00 [0.71-1.40]	0.89 [0.63-1.24]	1.21 [0.86-1.70]
Autism spectrum (ref: no)	1.47* [1.05-2.05]	1.18 [0.88-1.60]	1.26 [0.94-1.70]	1.09 [0.80-1.48]
Behavior challenges (ref: no)	1.17 [0.75-1.83]	1.31 [0.87-1.98]	1.07 [0.72-1.60]	1.42 [0.94-2.15]
Cerebral Palsy (ref: no)	0.90 [0.63-1.30]	0.84 [0.61-1.17]	1.03 [0.74-1.43]	0.94 [0.67-1.32]
Down syndrome (ref: no)	0.70 [0.44-1.12]	1.04 [0.68-1.58]	1.04 [0.68-1.58]	1.08 [0.70-1.67]
Hearing loss - severe or profound (ref: no)	1.02 [0.48-2.16]	1.20 [0.61-2.38]	1.67 [0.85-3.27]	0.74 [0.37-1.50]
Impulse control disorder (ref: no)	1.34 [0.75-2.39]	1.07 [0.63-1.82]	1.18 [0.70-1.98]	0.94 [0.55-1.61]
Vision loss (severe/profound) or Blind (ref: no)	1.49 [0.79-2.81]	0.91 [0.52-1.59]	1.48 [0.85-2.58]	1.13 [0.64-1.99]
Mood disorder (ref: no)	1.11 [0.78-1.60]	0.83 [0.60-1.15]	0.91 [0.66-1.25]	0.88 [0.63-1.23]
Other psychiatric disability (ref: no)	1.15 [0.80-1.65]	1.43 [1.03-2.00]	1.05 [0.76-1.44]	1.17 [0.84-1.63]
Personality/psychotic disorder (ref: no)	0.79 [0.48-1.30]	1.39 [0.87-2.22]	1.04 [0.66-1.63]	1.03 [0.62-1.64]
Physical disability (ref: no)	0.98 [0.54-1.79]	1.52 [0.87-2.66]	1.52 [0.88-2.60]	0.90 [0.52-1.58]
Seizure disorder (ref: no)	0.95 [0.68-1.32]	0.79 [0.59-1.07]	0.78 [0.57-1.05]	1.02 [0.75-1.38]
Communication: verbal/spoken language (ref: other)	1.76 [1.30-2.37]	1.19 [0.91-1.56]	1.04 [0.79-1.36]	0.84 [0.64-1.11]

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table 4 (continued)
Differences in outcomes in 2019 and 2020

Variable	Odds ratio [95% confidence interval]			
	Friends	Intimate relationships	Decide when to share personal information	Social roles
Model				
-2LL	1913.45	1920.50	1963.92	1868.88
χ^2 (df = 28 for all models)	60.28***	80.78***	88.54***	109.86***
R ²	0.05	0.07	0.08	0.10
2020 (ref: 2019)	0.77 [0.53-1.13]	0.67* [0.46-0.98]	0.99 [0.69-1.42]	0.87 [0.60-1.28]
Covariates				
2018 (ref: 2019)	0.86 [0.68-1.09]	0.89 [0.71-1.13]	1.68*** [1.33-2.12]	0.95 [0.75-1.21]
Age	1.02*** [1.01-1.02]	1.01 [1.00-1.01]	1.00 [0.99-1.00]	1.02*** [1.01-1.02]
Woman (ref: man)	0.93 [0.75-1.16]	1.27* [1.02-1.58]	1.01 [0.82-1.26]	0.90 [0.72-1.13]
Race (ref: White)				
Black	1.37 [1.07-1.76]	1.17 [0.91-1.50]	1.06 [0.82-1.36]	1.15 [0.89-1.48]
Other	0.64 [0.41-1.00]	0.55* [0.35-0.88]	0.64* [0.43-0.97]	0.45** [0.28-0.73]
Complex medical support needs (ref: no)	0.94 [0.67-1.33]	1.13 [0.80-1.60]	0.89 [0.64-1.25]	0.82 [0.57-1.18]
Comprehensive behavior support needs (ref: no)	0.81 [0.60-1.09]	0.98 [0.73-1.32]	1.03 [0.77-1.38]	0.93 [0.69-1.26]
Residence type (ref: provider owned/operated home)				
Own home	1.32 [0.98-1.78]	1.49** [1.11-2.01]	0.78 [0.58-1.04]	2.10*** [1.56-2.84]
Family home	1.21 [0.90-1.63]	2.32*** [1.73-3.11]	1.39* [1.04-1.86]	2.27*** [1.68-3.05]
Host family / family foster care	1.42 [0.86-2.34]	0.95 [0.56-1.60]	1.22 [0.74-2.01]	1.83* [1.10-3.06]
State HCBS group home	1.02 [0.48-2.15]	1.44 [0.70-2.97]	2.39* [1.07-5.31]	1.21 [0.57-2.55]
ICFDD	0.88 [0.34-2.24]	0.33 [0.09-1.13]	0.48 [0.19-1.19]	0.23 [0.05-1.03]
Other	1.13 [0.61-2.10]	1.60 [0.87-2.93]	1.09 [0.59-1.99]	1.42 [0.76-2.66]
Disability/diagnosis				
Anxiety (ref: no)	1.37 [0.98-1.92]	1.16 [0.83-1.63]	0.87 [0.62-1.22]	1.14 [0.81-1.62]
Autism spectrum (ref: no)	0.78 [0.57-1.07]	1.15 [0.85-1.55]	1.18 [0.87-1.60]	1.31 [0.97-1.77]
Behavior challenges (ref: no)	1.20 [0.80-1.81]	1.17 [0.78-1.75]	1.17 [0.78-1.75]	1.52* [1.01-2.29]
Cerebral Palsy (ref: no)	0.95 [0.68-1.33]	0.78 [0.55-1.10]	0.79 [0.57-1.10]	0.73 [0.51-1.04]
Down syndrome (ref: no)	1.67 [1.10-2.54]	1.23 [0.80-1.89]	0.98 [0.64-1.50]	0.89 [0.57-1.38]
Hearing loss - severe or profound (ref: no)	1.35 [0.69-2.63]	1.08 [0.55-2.13]	0.81 [0.41-1.58]	1.01 [0.51-2.01]
Impulse control disorder (ref: no)	1.00 [0.59-1.70]	0.88 [0.52-1.50]	0.84 [0.50-1.41]	0.73 [0.42-1.26]
Vision loss (severe/profound) or Blind (ref: no)	1.45 [0.83-2.52]	0.95 [0.54-1.68]	1.33 [0.75-2.34]	0.95 [0.53-1.69]
Mood disorder (ref: no)	0.76 [0.54-1.07]	0.87 [0.63-1.22]	0.83 [0.60-1.15]	1.36 [0.98-1.90]
Other psychiatric disability (ref: no)	0.93 [0.67-1.29]	0.99 [0.72-1.38]	1.01 [0.73-1.40]	0.95 [0.68-1.33]
Personality/psychotic disorder (ref: no)	1.14 [0.72-1.81]	0.93 [0.58-1.47]	0.76 [0.48-1.20]	0.63 [0.39-1.02]
Physical disability (ref: no)	1.69 [0.98-2.90]	1.24 [0.71-2.15]	1.18 [0.68-2.04]	1.42 [0.81-2.50]
Seizure disorder (ref: no)	1.06 [0.78-1.44]	1.01 [0.74-1.37]	0.75 [0.56-1.01]	0.84 [0.62-1.15]
Communication: verbal/spoken language (ref: other)	1.06 [0.80-1.40]	0.92 [0.70-1.22]	0.69* [0.52-0.92]	1.41* [1.05-1.88]

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table 4 (continued)
Differences in outcomes in 2019 and 2020

Variable	Odds ratio [95% confidence interval]			
	Choose where/with whom to live	Choose where to work	Choose services	Choose personal goals
Model				
-2LL	1615.96	1842.13	1818.93	1917.77
χ^2 (df = 28 for all models)	230.71***	143.27***	133.70***	81.92***
R ²	0.20	0.13	0.12	0.07
2020 (ref: 2019)	1.17 [0.79-1.74]	0.87 [0.60-1.27]	1.10 [0.75-1.62]	2.22*** [1.51-3.27]
Covariates				
2018 (ref: 2019)	0.68** [0.52-0.88]	0.67** [0.53-0.86]	1.14 [0.89-1.46]	0.91 [0.72-1.15]
Age	1.01 [1.00-1.01]	1.01** [1.00-1.02]	1.00 [0.99-1.01]	1.00 [0.99-1.00]
Woman (ref: man)	1.22 [0.96-1.56]	0.92 [0.74-1.16]	1.03 [0.82-1.29]	1.00 [0.81-1.25]
Race (ref: White)				
Black	1.18 [0.90-1.55]	1.20 [0.92-1.55]	1.52** [1.18-1.96]	1.19 [0.93-1.53]
Other	0.65 [0.39-1.08]	0.67 [0.72-1.04]	0.78 [0.49-1.23]	0.50** [0.33-0.76]
Complex medical support needs (ref: no)	0.94 [0.64-1.39]	0.79 [0.55-1.14]	0.93 [0.65-1.33]	1.27 [0.90-1.79]
Comprehensive behavior support needs (ref: no)	0.97 [0.70-1.35]	1.01 [0.75-1.37]	1.17 [0.86-1.58]	0.78 [0.59-1.05]
Residence type (ref: provider owned/operated home)				
Own home	4.39*** [3.18-6.07]	2.69*** [1.99-3.65]	2.01*** [1.48-2.73]	1.43* [1.06-1.93]
Family home	5.49*** [3.95-7.64]	3.18*** [2.34-4.31]	3.15*** [2.33-4.25]	1.40* [1.05-1.87]
Host family / family foster care	2.62*** [1.53-4.49]	2.18** [1.31-3.61]	1.79* [1.08-2.99]	1.03 [0.63-1.70]
State HCBS group home	2.26* [1.02-5.02]	1.38 [0.65-2.95]	3.86*** [1.87-7.99]	2.38* [1.11-5.08]
ICFDD	0.00 [0.00-0.00]	0.44 [0.13-1.53]	0.13 [0.02-1.01]	0.82 [0.34-2.02]
Other	1.49 [0.75-2.96]	1.81 [0.98-3.33]	1.66 [0.89-3.10]	0.95 [0.52-1.73]
Disability/diagnosis				
Anxiety (ref: no)	0.61* [0.40-0.91]	0.75 [0.52-1.08]	0.65 [0.45-0.95]	0.98 [0.70-1.37]
Autism spectrum (ref: no)	0.94 [0.67-1.32]	1.10 [0.81-1.50]	1.11 [0.81-1.51]	1.14 [0.84-1.54]
Behavior challenges (ref: no)	0.92 [0.58-1.46]	1.23 [0.81-1.86]	0.94 [0.62-1.44]	1.51 [1.00-2.27]
Cerebral Palsy (ref: no)	0.80 [0.55-1.18]	0.90 [0.64-1.28]	0.82 [0.58-1.18]	0.94 [0.68-1.31]
Down syndrome (ref: no)	1.18 [0.73-1.90]	0.71 [0.45-1.13]	1.12 [0.72-1.75]	1.03 [0.67-1.57]
Hearing loss - severe or profound (ref: no)	0.34* [0.13-0.87]	0.82 [0.40-1.68]	0.81 [0.39-1.67]	0.84 [0.43-1.65]
Impulse control disorder (ref: no)	1.19 [0.66-2.15]	1.15 [0.67-1.99]	0.97 [0.55-1.69]	0.80 [0.47-1.34]
Vision loss (severe/profound) or Blind (ref: no)	0.95 [0.51-1.78]	0.67 [0.36-1.23]	0.87 [0.48-1.58]	1.00 [0.57-1.76]
Mood disorder (ref: no)	0.80 [0.55-1.16]	0.79 [0.56-1.11]	0.98 [0.69-1.38]	1.02 [0.74-1.41]
Other psychiatric disability (ref: no)	0.86 [0.59-1.24]	0.80 [0.57-1.13]	1.06 [0.76-1.49]	0.98 [0.71-1.35]
Personality/psychotic disorder (ref: no)	1.02 [0.62-1.70]	0.80 [0.50-1.29]	1.03 [0.64-1.66]	1.18 [0.75-1.87]
Physical disability (ref: no)	1.84* [1.02-3.32]	1.25 [0.71-2.21]	1.52 [0.87-2.68]	0.85 [0.49-1.46]
Seizure disorder (ref: no)	0.84 [0.60-1.19]	0.96 [0.70-1.31]	0.75 [0.55-1.04]	0.99 [0.73-1.34]
Communication: verbal/spoken language (ref: other)	1.89*** [1.35-2.65]	2.03*** [1.49-2.75]	1.07 [0.80-1.43]	1.69*** [1.28-2.22]

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table 4 (continued)
Differences in outcomes in 2019 and 2020

Variable	Realize personal goals
Model	
-2LL	1837.76
χ^2 (df = 28 for all models)	53.72**
R ²	0.05
2020 (ref: 2019)	0.85 [0.58-1.25]
Covariates	
2018 (ref: 2019)	0.76* [0.59-0.97]
Age	0.98*** [0.98-0.99]
Woman (ref: man)	1.15 [0.91-1.44]
Race (ref: White)	
Black	1.03 [0.79-1.34]
Other	0.81 [0.53-1.23]
Complex medical support needs (ref: no)	0.89 [0.63-1.27]
Comprehensive behavior support needs (ref: no)	0.91 [0.67-1.23]
Residence type (ref: provider owned/operated home)	
Own home	1.07 [0.78-1.46]
Family home	1.00 [0.73-1.36]
Host family / family foster care	0.70 [0.42-1.16]
State HCBS group home	1.65 [0.74-3.67]
ICFDD	0.59 [0.25-1.40]
Other	0.97 [0.51-1.85]
Disability/diagnosis	
Anxiety (ref: no)	0.78 [0.55-1.10]
Autism spectrum (ref: no)	1.06 [0.77-1.45]
Behavior challenges (ref: no)	1.36 [0.88-2.11]
Cerebral Palsy (ref: no)	0.83 [0.59-1.17]
Down syndrome (ref: no)	1.06 [0.68-1.65]
Hearing loss - severe or profound (ref: no)	0.58 [0.30-1.15]
Impulse control disorder (ref: no)	0.72 [0.42-1.24]
Vision loss (severe/profound) or Blind (ref: no)	1.41 [0.76-2.59]
Mood disorder (ref: no)	1.33 [0.94-1.90]
Other psychiatric disability (ref: no)	0.90 [0.64-1.26]
Personality/psychotic disorder (ref: no)	1.11 [0.68-1.80]
Physical disability (ref: no)	1.24 [0.69-2.23]
Seizure disorder (ref: no)	1.15 [0.84-1.58]
Communication: verbal/spoken language (ref: other)	1.55** [1.18-2.04]

Note. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

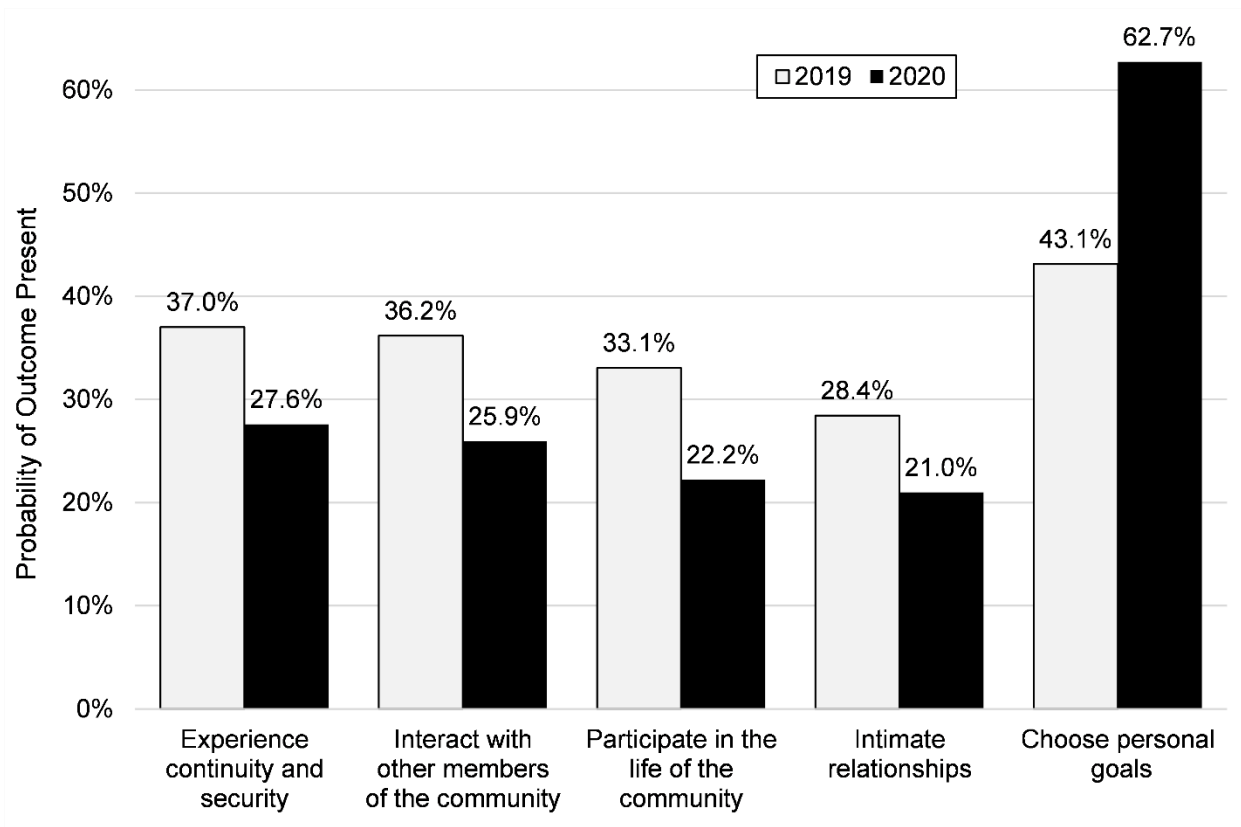


Figure 1. Probability of outcomes present in 2019 and 2020. Only significant outcomes shown; all other variables are controlled.