

Research

The Impact of Organizational Supports on
the Person-Centered Health of People with
Intellectual and Developmental Disabilities



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People with Intellectual and Developmental Disabilities**

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Abstract

Background. People with intellectual and developmental disabilities (IDD) have significantly poorer health than the general population. A key threat to health programs for people with IDD is commitment from stakeholders, especially service organizations.

Specific Aims. The aim of this study was to explore the role disability service organizations play in promoting the best possible physical and mental health of people with IDD.

Method. To do so, this study analyzed secondary Personal Outcome Measures® data from 1,341 people with IDD in the United States using binary logistic regressions.

Findings. Our findings revealed organizational supports can play a key role in promoting the health of people with IDD.

Discussion. By paying attention to all of these aspects of health and supports, especially discrepancies in supports, service organizations can work to counteract health disparities in those they support.

Background

People with intellectual and developmental disabilities (IDD) have significantly poorer health and shorter life expectancies than the general population (O'Leary, Cooper, & Hughes-McCormack, 2017; Ouellette-Kuntz, 2005). This includes increased prevalence of cardiovascular disease, obesity, hypertension, osteoporosis, and poor oral health compared to nondisabled people (Haveman et al., 2010). People with IDD also tend to experience age related health conditions earlier and more rapidly than nondisabled people (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Glasson, Dye, & Bittles, 2014; Nochajski, 2000; World Health Organization, 2001). Their higher rates of chronic health conditions are due to genetics, social circumstances, environmental conditions, and access to health care services (Bittles et al., 2002; Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz, 2005; Taggart & Cousins, 2014). Moreover, people with IDD's health disparities are often exacerbated by social determinants of health, such as poverty and social exclusion (Ouellette-Kuntz, 2005).

Targeted health initiatives have been found to improve the health, quality of life, and community participation of people with IDD (Heller, McCubbin, Drum, & Peterson, 2011; Mann, Zhou, McDermott, & Poston, 2006; Marks, Sisirak, & Heller, 2010; Marks & Heller, 2003). However, a key threat to health programs for people with IDD is commitment from stakeholders, especially service organizations and their staff (Marks et al., 2010). Despite being a primary source of support for community living via the direct services and other resources they provide, organizations typically struggle to implement community based health programs (Spassiani, 2015). Common barriers include a lack of resources and structure to create and sustain initiatives, lack of motivation, and lack of support staff stability (Lynnes, Nichols, & Temple, 2009; Spassiani, 2015).

Specific Aims

Because of the crucial impact organizations can have in reducing disparities and increasing health outcomes, the aim of this study is to explore the role organizations play in promoting the best possible health of people with IDD. As defined by The Council on Quality and Leadership (2017a), best possible health is person-centered and depends “on the current health status of a person and the possibility of health interventions to restore lost capacity, stabilize a condition or minimize further loss of function. Best possible health is defined in terms that are satisfactory for the person” (p. 21). Best possible health also includes the person with IDD’s personal definition regarding what makes them feel healthy (physically and mentally) and helps them achieve their goals in life. To explore this relationship, we had two main research questions: 1) who is most/least likely to have best possible health organizational supports in place?; and, 2) how does having organizational supports in place impact health? To do so, this study analyzed secondary Personal Outcome Measures[®] surveys data from 1,341 people with IDD in the United States.

Methods

Participants

The secondary survey data utilized in this survey were transferred to the researchers with no identifiers; as such the author’s institutional research board (IRB) determined it was exempt from full review. Participants were originally recruited over approximately two years (January 2015 – December 2016) through organizations in the United States that provide services to people with disabilities, including: service coordination; case management; family and individual supports; behavioral health care; employment and other work services (including day habilitation services); residential services; non-traditional supports (micro-boards and co-ops); and, human

services systems. 1,341 people with IDD consented to participate. The majority of participants were White (74.4%), used verbal/spoken language as their primary communication method (82.2%), and lived in provider owned or operated homes (50.5%). The distribution of age, gender, and guardianship status were more evenly distributed (see Table 1).

[Table 1 approximately here]

Since clinical information was not included in the data set, average daily support needs was used as a proxy for severity of impairment. Average daily support needs was defined as the average number of hours the person needed support and/or received support services per day, presumably those with the most support – around the clock (24/7) – have more severe impairments than those with less support needs. 64.1% of participants in the sample had high support needs, needing 24/7 around the clock support (Table 1).

Measure

The instrument used in this study was the Personal Outcome Measures® (The Council on Quality and Leadership, 2017a), developed by the international non-profit disability organization The Council on Quality and Leadership (CQL). The Personal Outcome Measures® is designed to determine people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports. The Personal Outcome Measures® includes 21 indicators divided into five factors: my human security; my community; my relationships; my choices; and, my goals. *My human security* includes the following 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; and, people are respected. *My community* includes the following indicators: people use their environments; people live in integrated environments; people interact with other members of the community; and, people participate the

life of the community. *My relationships* includes the following indicators: people are connected to natural support networks; people have friends; people have intimate relationships; people decide when to share personal information; and, people perform different social roles. *My choices* includes the following indicators: people choose where and with whom to live; people choose where they work; and, people choose services. *My goals* includes the following indicators: people choose personal goals; and people realize personal goals.

Personal Outcome Measures[®] administration occurs in three stages. In the first stage, a trained Personal Outcome Measures[®] interviewer has in-depth conversations with the participant with disabilities about each of the indicators. For these conversations, the interviewer follows specific open-ended prompts. During the second stage of the Personal Outcome Measures[®] interview, the interviewer speaks with someone who knows the participant with disabilities and their organizational supports best, such as a direct support professional or case manager, and asks them questions about individualized supports and outcomes to fill in any gaps. During the final stage, if necessary, the interviewer observes the participant in various settings and then completes the indicator questions about personal outcomes and individualized supports based on the information gathered in the three stages. Individual record reviews are also conducted as needed.

The Personal Outcome Measures[®] was developed over 25 years ago based on findings from focus groups with people with disabilities, their family members, and other key stakeholders about what really mattered in their lives. The Personal Outcome Measures[®] tool has been continuously refined over the past two decades through pilot testing, 25 years of administration, commission of research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership, 2017a). The Personal Outcome

Measures[®] has inter-rater reliability and construct validity (Friedman, 2018 The Council on Quality and Leadership, 2017b). Only interviews from certified interviewers, who must score at least 85% agreement with expert CQL staff, were utilized in this study.

Variables and Analysis

This study particularly focused on the Personal Outcome Measures[®] indicator “best possible health.” Best possible health “is defined in terms that are satisfactory for the person” (The Council on Quality and Leadership, 2017a, p. 21). The main variables of this study were “best possible health outcomes present” and “best possible health organizational supports in place”.

Best Possible Health: Outcomes Present. Following the above procedure, suggested questions for the information gathering discussion with the participant for “best possible health outcomes present” included:

- Do you feel healthy? If no, what bothers you?
- What do you do to stay healthy?
- What health concerns (physical and mental) do you have?
- Do you discuss your health concerns with anyone? How are your questions or concerns addressed?
- Are you seeing a doctor, dentist, and other health care professionals?
- Do you receive regular exams? What kind?
- Do you take any medication? If so, what is it and how does it help?
- What advice has your health care professional given you? Are you following it? If yes, is it working? If no, what do you think the problem is?

- If you think the medications, treatments, or interventions are not working, what is being done? (The Council on Quality and Leadership, 2017a, p. 22)

Then to determine if the “best possible health” outcome was present, based on the conversation: (1.) the participant must see health care professionals; (2.) health care professionals must have identified the person’s current best possible health situation, addressing any health care issues or concerns, and interventions; (3). health intervention must have been selected by the person in consultation with the health care professional; (4.) health interventions, as desired by the person, must be effective; (5.) if the person needs devices or equipment such as glasses, hearing aids or dentures, these must be available and in good repair; and, (6.) the person must receive health care as recommended for their sex, age and health risks (The Council on Quality and Leadership, 2017a). The participant must have all six of these items for the outcome to be considered present; if they do not have all six, it is considered not present unless it is because of personal choice.

Best Possible Health: Organizational Supports. To decide if the best possible health individualized organizational supports were in place, the interviewer was provided the following suggested question to guide the discussion with the participants’ staff:

- How has the person defined best possible health?
- What preventive health care measures are in place for the person?
- How is the person involved in his or her own health care?
- Is the person following the health care professional’s recommendations? If no, why do you think that is?
- Do you think the person feels health interventions are working? If not, what is being done about it?

- How have you explored health issues with the person?
- What supports does the person need to achieve or maintain best possible health?
- Who provides the support?
- How was this decided?
- How do you assist the person to overcome barriers to this outcome?
- What organizational practices, values, and activities support this outcome for the person?

(The Council on Quality and Leadership, 2017a, p. 22)

Then to determine if the “best possible health” supports were in place based on the conversation, the organization must: (1.) know the person’s definition of best possible health; (2.) provide supports for the person to promote and maintain best possible health if needed and requested; (3.) assure that the person has support to obtain regular medical and health services; (4.) respond to the person’s changing health needs and preferences; (5.) support the person to be aware of their medical issues and their impact; and, (6.) support the person to self-manage their health? (The Council on Quality and Leadership, 2017a). All of six of these features must be in place for the support to be considered in place.

Analyses. Utilizing these data, our first research question was: who is most likely to have organizational supports in place for health? For this question, we utilized binary logistic regression models with best possible health organizational supports in place as the dependent variable (DV) and demographic factors as independent variables (IVs). Univariate analyses were run to determine odds ratios.

Our second question was: how does having organizational supports in place impact health? This was explored in two ways. In the first, in order to examine how having best possible health organizational supports in place impacts different areas of health. To do so, controlling for

hourly support needs, we examined how having ‘best possible health – organizational supports in place’ (IV) impacted different areas of health which each served as the DV in different models. Univariate analyses were run to determine odds ratios. We also wanted to examine how specific supports impact best possible health – the outcome being present. To do so, we ran binary logistic regressions with the DV of ‘best possible health - outcome present,’ and each of the different types of support as IVs (Table 2); we also controlled for average daily support needs as a proxy for impairment level.

Findings

[Table 2 approximately here]

According to descriptive statistics, the overwhelming majority of organizations supporting participants knew the person’s definition of best possible health (79.0%), provided supports for the person to promote and maintain best possible health if needed or requested (82.5%), assured the person had support to obtain regular medical and health services (85.5%), responded to the person’s changing health needs and preferences (85.3%), and supported the person to be aware of their medical issues and their impact (72.7%) (see Table 2). Only slightly less than half of participants (49.4%), however, were supported to self-manage their health. Moreover, only 63.9% participants had best possible health supports in place, which is when organizations completed all of the aforementioned activities.

Likelihood to Receive Organizational Supports for Health

A binary logistic regression model was performed with the DV ‘best possible health – supports in place’ and the demographic IVs to determine who was most/least likely to be supported; the model was significant, $-2LL = 1428.48$, $\chi^2(31) = 105.62$, $p < .005$. The model, which correctly classified 68.6% of cases, explained 11.8% (Nagelkerke R^2) of variance. See

Table 3 for odds ratios. According to univariate statistics, older adults (age 75 and older) were 4.25 times more likely than people age 18 to 24 to have health organizational supports in place. Native American or Indigenous people were 2.41 times more likely to have organizational supports in place than White people. People whose primary communication method was body/facial expressions and ‘other’ were 1.48 and 2.75 times, respectively more likely than people who primarily used verbal communication to have organizational supports around health in place. People with independent decision making were 1.64 times more likely to have organizational supports in place than people with assisted decision making. People who lived in provider owned or operated homes and state operated Home and Community Based Services (HCBS) group homes were 2.18 and 2.17 times more likely than people who lived in their own home or apartments to have organizational supports in place. Finally, compared to people with support as needed (on call), people who have 3 to 6 hours of daily support were 4.55 times less likely to have organizational supports, people with 24/7 around the clock support were 6.25 times less likely, and ‘other’ daily support 6.67 times less likely.

[Table 3 approximately here]

Impact of Organizational Supports on Different Areas of Health

To determine the impact of having ‘best possible health – supports in place’ (IV) on different areas of health (DVs), binary logistic models were performed, controlling for daily support needs as a proxy for impairment severity. Table 4 details results of each of the models, including odds ratios. Compared to people who do not have supports in place, when people had best possible health organizational supports in place, regardless of impairment level, they were 4.41 times more likely to have annual physicals, and 2.16 times more likely to have annual dental exams. When people had best possible health organizational supports in place, they were

12.63 times more likely to have health care professionals identify their best possible health situation, and address any health care issues, concerns, or interventions compared to people who did not have supports in place. Compared to people who did not have supports in place, when best possible health organizational supports were in place, people were 3.36 times more likely to select health intervention services in consultation with their health care professionals. When people had best possible health organizational supports in place, their health intervention services were 5.47 times more likely to be effective compared to people who did not have supports in place. People that had best possible health organizational supports in place were 5.45 times more likely to have devices or equipment (e.g., eyeglasses, dentures, etc.) available and in good repair than people without supports in place. Finally, people with best possible health organizational supports in place were 13.16 times more likely to have best possible health outcomes present compared to people without supports in place.

[Table 4 approximately here]

Impact of Different Types of Supports on Health

To determine the impact of organizational support on health, each type of organizational support (IVs) was run in a binary logistic regression model with the DV ‘best possible health – outcome present,’ controlling for daily support needs; the model was significant, $-2LL = 1083.91$, $\chi^2(12) = 226.99$, $p < .005$. The model, which correctly classified 77.6% of cases, explained 26.7% (Nagelkerke R^2) of variance. According to univariate statistics, regardless of the person’s impairment level, when organizations knew the person’s definition of best possible health people with disabilities were 3.57 times more likely to have best possible health (outcomes present) than when organizations did not know their definition (Figure 1). When organizational supports were provided for the person to promote and maintain best possible

health people with disabilities were 2.31 times more likely to have health outcomes present than when organizational supports were not provided. When organizations responded to the person's changing health needs and preferences, the person they support was 2.08 times more likely to have health outcomes present than when they did not provide this support. When the organization supporting the person supported them to be aware of their medical issues and their impact, people were 2.12 times more likely to have best possible health (outcomes present) compared to when organizations did not provide this support. Finally, people supported to self-manage their health were 1.81 times more likely to have best possible health outcomes present compared to people not supported to self-manage their health.

[Figure 1 approximately here]

Discussion

People with IDD have significantly higher risk of developing chronic health conditions compared to the general population as a result of genetics, social circumstances, environmental conditions, and access to health care services (Bittles et al., 2002; Krahn et al., 2006; Ouellette-Kuntz, 2005; Taggart & Cousins, 2014). Our findings reveal individualized organizational supports can play a key role in promoting the health of people with IDD. People with IDD were approximately 13 times more likely to have best possible health outcomes present when organizational supports were in place. In particular, according to our findings, organizational supports can positively impact the likelihood of almost all aspects of health examined.

Although there was not a significant difference in the likelihood of people with IDD having a primary care doctor, or seeing health care professionals, according to our findings, when organizational supports were in place, people with IDD were more likely to have annual physicals and annual dental exams, both of which are important to help prevent secondary

conditions (American Dental Association, 2006; Kaye, 2007; Owens, Kerker, Zigler, & Horwitz, 2006). Based on this sample, when organizational supports were in place health care professionals were more likely to identify the person's best possible health situation and, address any health care issues or concerns, and interventions. According to our findings, when organizational supports were in place health intervention services were more likely to be selected by the person in consultation with health care professionals and health intervention services were more likely to be effective. By paying attention to all of these aspects of health and supports, especially discrepancies in supports being offered, service organizations can work to counteract health disparities in those they support. In addition to the benefits to health itself, doing so also fosters collaboration with the person with IDD, allowing them to be consulted more and have more choice.

Not only is every area of best possible health impacted by organizational supports being in place, according to our findings, almost every type of organizational support promoted the best possible health of people with IDD. People with IDD were more likely to have best possible health outcomes present when organizations supported people to self-manage their health, supported the person to be aware of their medical issues and their impact, knew the person's definition of best possible health, provided supports to promote and maintain best possible health, and responded to the person's changing health needs and preferences.

As found, individualized organizational health supports can facilitate the best possible health of people with IDD; to ensure all people with IDD benefit from organizational supports, there are a number of support disparities that need to be addressed. For example, while, overall those with higher support needs were less likely to have supports in place, there was a mix of odds across the daily support categories suggesting the level of support needed – impairment

severity – is not necessarily the only factor impacting if people have best possible health organizational supports in place. Ideas about people with more severe impairments' abilities may impact if and how people with more severe impairments are supported to participate in health decisions about their lives. Wehmeyer and Bolding (2001) remind us,

the prevalent assumption is that these individuals [with more severe disabilities] cannot or do not become self-determined, an opinion formed almost exclusively on assumptions about individual capacity or the limitations thereof... However, by addressing issues pertaining to environment and opportunity, and by providing adequate supports and accommodations, people with [disabilities] can enhance their self-determination and assume greater control of their lives. (p. 374)

As demonstrated by this study's results, people who live in provider-owned or operated group homes, or state-operated group homes were more likely to have health supports in place than people who lived in their own homes or apartments. This finding parallels with other evidence that has found that people with IDD who live independently are more likely to be unhealthy, overweight, and obese because they eat less nutritious foods, and participate less in physical activity because they are not educated on health behaviors (Rimmer & Yamaki, 2006; Yamaki, 2005).

Those who had assisted decision making in our sample, rather than independent decision making, were approximately two times less likely to have organization supports in place for best possible health. Meanwhile full/plenary guardianship was not significant. More research is needed to explore why people with assisted decision making in particular were less likely to have supports in place; it may be because this model is relatively newer than independent decision making or full guardianship and therefore the roles of people with disabilities and their

supporters are less clear cut. In fact, supported decision making (SDM) and its parallels are relatively new guardianship models in the United States (VanPuymbrouck, 2017). While SDM is considered “a pragmatic approach to legal determinations concerning personhood” which honors self-determination and empowerment, there are serious concerns from both supporters and critics about the lack of evidence and guidelines for SDM (Gooding, 2013; Kohn, Blumenthal, & Campbell, 2012; VanPuymbrouck, 2017).

In terms of likelihood to receive organizational supports, there were also a number of groups which were more likely to receive supports. For example, our models revealed people 75 and older were more likely to have health supports in place than those 18 to 24. People whose primary communication method is body/facial expressions were also more likely to have organizational supports than people who primarily used verbal communication. Moreover, according to our findings, Native American and Indigenous people were also more likely to have supports in place than White people. Perhaps organizations are cognizant of the health disparities that exist among minority groups and/or are culturally sensitive to the unique needs of these groups, and therefore go out of their way to put supports in place for them. However, these findings may also be related to the unequal distribution of our sample; for example, only 39 participants were 75 and older, and only 54 people were Native American/Indigenous. Future research should examine if these findings were sample specific; if they are replicable, more research is needed to explore why organizations are focusing on these groups in particular.

When interpreting our results, a number of limitations should be noted. Our data was not representative of people with IDD in the United States as a whole; while 22 states were represented in the sample, the majority of data came from three states. Most of our participants were White and had high support needs. Additionally, participants were recruited through

organizations that provide services and supports, particularly those organizations who partner with the Council on Quality and Leadership to conduct Personal Outcome Measures[®] interviews; therefore, this sample may not be representative of all people with IDD, or all service providers. Finally, as this was a secondary data analysis, the researcher did not have the ability to ask additional questions or add additional research variables. For example, we did not access to information about organization type, which may impact the types and levels of health supports provided. Moreover, there may have been additional factors which impacted the supports people received, such as relationships with family members or friends, which we did not have access to, and could not control for.

Conclusion

Organizations play an important role in facilitating the health of people with IDD. Yet, agencies' attitudes towards health and their organizational culture can determine if health initiatives are sustained (Spassiani, 2015). Research has indicated it is critical for organizations to have clear guidelines and procedures regarding health supports and programs, particularly for direct support staff (Hewitt et al., 2004; Jansson, Benoit, Casey, Phillips, & Burns, 2010; Spassiani, 2015). Success of organizational health supports also depends on the programs being internally monitored, and encouraged by management (Elsworth & Astbury, 2004; Savaya, Spiro, & Elran-Barak, 2008). We recognize most disability organizations are facing an increased burden due to statewide budget cuts and the direct support professional crisis (American Network of Community Options and Resources, 2014); however, everyone is entitled to quality health care (Office of the United Nations High Commissioner for Human Rights & World Health Organization, 2008; United Nations, 1948; World Health Organization, 2015). Thus, long term services and supports funding must reflect and recognize the vital role organizations play in

facilitating optimal health of people with IDD. In the meantime, organizations can implement cost-effective and simple programs, such as supporting people to self-manage their health (Friedman, Rizzolo, & Spassiani, in press), in order to improve the health and quality of life of people with IDD.

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Table 1

Demographics (n = 1,341)

Characteristic	<i>n</i>	%
Age range		
18 to 24	95	7.1%
25 to 34	250	18.6%
35 to 44	223	16.6%
45 to 54	279	20.8%
55 to 64	252	18.8%
65 to 74	122	9.1%
75+	39	2.9%
No response	81	6.0%
Gender (<i>n</i> = 1,332)		
Man	719	54.0%
Woman	613	46.0%
Race		
White	998	74.4%
Black or African American	246	18.3%
American Indian or Indigenous	54	4.0%
Hispanic, Latinx, or Spanish Origin	29	2.2%
Other (Asian, Native Hawaiian, other Pacific Islander, or other)	16	1.2%
Primary method of communication		
Verbal/spoken language	1102	82.2%
Face/body expression	169	12.6%
Sign language	16	1.2%
Communication device	14	1.0%
Other	33	2.5%
No response	7	0.5%
Guardianship status (<i>n</i> = 1,322)		
Independent decision making ^a	370	28.0%
Assisted decision making (supported and limited guardianship) ^b	494	37.4%
Full/plenary guardianship ^c	423	32.0%
Other	35	2.6%
Residence type (<i>n</i> = 1,310)		
Own home/apartment	284	21.7%
Family's house	213	16.3%
Host family/family foster care ^d	24	1.8%
Provider-operated house or apartment ^e	677	51.7%
Private ICFDD ^f	22	1.7%
State-operated HCBS group home ^g	43	3.3%

State-operated ICFDD ^f	25	1.9%
Other	22	1.7%
Average daily support (<i>n</i> = 1,278)		
On call - support as needed	28	2.2%
0 to 3 hours/day	60	4.7%
3 to 6 hours/day	94	7.4%
6 to 12 hours/day	155	12.1%
12 to 23 hours/day	76	5.9%
24/7 - around the clock	819	64.1%
Other	46	3.6%

Note. ICFDD = Intermediate care facility for people with developmental disabilities. HCBS = Home and Community Based Services.

^aPeople with no legal restrictions of their decision making

^bLess sweeping guardianship wherein people with disabilities are supported with decision making but still maintain control of decision making capabilities; legal status differs by state.

^cLegal rights and decision making are transferred to a guardian who exercises them on behalf of the person with disabilities.

^dCommunity residential settings, typically an individual home, that mirror child foster care but are designed for adults with IDD that do not need skilled nursing. These "single-family residences offer 24-hour care in a home-like setting that is safe and secure...Adult foster home providers provide meals, transportation to appointments and other activities, medication management, assistance with activities of daily living, personal care, mobility, and household activities...The goal is to provide necessary care while emphasizing the individual's independence" (Oregon Department of Human Services, n.d., n.p.)

^eResidential setting and a specific "physical place that is owned, co-owned, and/or operated by a provider...[where an] individual resides" (Indiana Family & Social Services Administration, 2016, p. 7). These settings are often also licensed by the state. Group homes are an example of provider owned or operated homes.

^fAn institutional "facility which primarily provides health-related care and services above the level of custodial care to [IDD] individuals but does not provide the level of care available in a hospital or skilled nursing facility" (Centers for Medicare and Medicaid Services, n.d.-a., n.p.). "Institutions' (4 or more beds) for individuals with intellectual disabilities... must provide 'active treatment'...in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services" (Centers for Medicare and Medicaid Services, n.d.-b, p. 1-2) ICFDD can be public (state run) or private.

^gA community based "residence, with shared living areas, where clients receive supervision and other services such as social and/or behavioral services, custodial service, and minimal services (e.g., medication administration)" (Centers for Medicare and Medicaid Services, 2016, n.p.). Although group homes size regulations can vary by state, most are smaller than ICFDD.

Table 2
Descriptive Statistics

Variable	Yes		No	
	<i>n</i>	%	<i>n</i>	%
Participant sees health care professionals	1228	91.6%	11	0.8%
Participant has a primary care doctor	1228	91.6%	3	0.2%
Person has annual physical	1135	84.6%	26	1.9%
Person has annual dental exam	1045	77.9%	58	4.3%
Health care professionals identified the person's best possible health situation, addressing any health care issues or concerns, and interventions	1154	86.1%	63	4.7%
Health intervention services have been selected by the person in consultation with health care professional	889	66.3%	325	24.2%
Health intervention services, as desired by the person, have been effective	1027	76.6%	187	13.9%
If the person needs devices or equipment such as glasses, hearing aids, or dentures, these are available and in good repair	841	62.7%	54	4.0%
Best possible health - Outcome Present	939	70.0%	384	28.6%
Organization knows person's definition of best possible health	1059	79.0%	158	11.8%
Supports provided for the person to promote and maintain best possible health if needed/requested	1106	82.5%	106	7.9%
Organization assures that the person has support to obtain regular medical and health services	1147	85.5%	61	4.5%
Organization responds to the person's changing health needs and preferences	1144	85.3%	74	5.5%
Organization supports person to be aware of their medical issues and their impact	975	72.7%	235	17.5%
Person is supported to self-manage their personal health	663	49.4%	538	40.1%
Best possible health - Support in place	857	63.9%	468	34.9%

Table 3

Likelihood to have Organizational Supports in Place: Results of the Binary Logistic Regression

Model	O.R.	95% C.I.	
Age (ref: 18 to 24)			
25 to 34	0.68	0.39	1.18
35 to 44	0.92	0.53	1.62
45 to 54	0.90	0.53	1.56
55 to 64	1.33	0.76	2.35
64 to 74	1.38	0.73	2.63
75+	4.25**	1.43	12.59
Women (ref: men)	1.19	0.92	1.53
Race (ref: White)			
Black or African American	0.93	0.67	1.29
Hispanic or Latinx	1.46	0.58	3.66
American Indian or Alaska Native	2.41*	1.07	5.40
Other	0.51	0.16	1.58
Primary communication method (ref: verbal)			
Sign language	0.74	0.23	2.36
Communication device	2.82	0.75	10.60
Body/facial expression	1.48*	1.00	2.18
Other	2.75*	1.08	6.99
Guardianship (ref: independent decision making)			
Assisted decision making	0.61**	0.43	0.85
Full/plenary guardianship	0.93	0.65	1.33
Other	0.74	0.34	1.60
Residence type (ref: Own home/apartment)			
Family's house	1.19	0.73	1.94
Host family/family foster care	1.05	0.42	2.59
Provider-operated house or apartment	2.18***	1.53	3.11
Private ICFDD	0.71	0.27	1.88
State-operated HCBS group home	2.17*	1.03	4.57
State-operated ICFDD	2.74	0.99	7.58
Other	1.32	0.48	3.63
Daily support (ref: as needed - on call)			
0 to 3 hours/day	0.75	0.21	2.72
3 to 6 hours/day	0.22*	0.07	0.72
6 to 12 hours/day	0.32	0.10	1.01
12 to 23 hours/day	0.32	0.10	1.10
24/7 - around the clock	0.16**	0.05	0.49

Other	0.15**	0.04	0.52
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Note. * $p < .05$, ** $p < .01$, *** $p < .001$. O.R. = Odds ratio. C.I. = Confidence interval.

ICFDD = Intermediate care facility for people with developmental disabilities.

HCBS = Home and Community Based Services.

Table 4

Impact of Supports on Different Areas of Health: Binary Logistic Regression Models

Model	-2LL	df	χ^2	O.R.	95% C. I.	
Person sees health care professionals	113.92	7	11.28	3.95*	1.09	14.25
Person has a primary care doctor	36.26	7	5.67	1.13	0.10	13.15
Person has annual physical***	208.58	7	39.05	4.41**	1.87	10.38
Person has annual dental exam***	427.06		24.65	2.16**	1.25	3.74
Health care professionals identified best possible health situation, including addressing any health care issues or concerns and interventions***	394.15	7	80.53	12.63***	6.06	26.33
Health intervention services selected by the person in consultation with health care professional***	1269.1	7	112.14	3.36***	2.56	4.41
Health intervention services have been effective***	887.73	7	127.38	5.47***	3.84	7.80
Devices or equipment available and in good repair (if applicable)***	359.86	7	39.45	5.45***	2.88	10.31
Best Possible Health - Outcome Present***	1154.16	7	370.23	13.16***	9.79	17.68

Note. * $p < .05$, ** $p < .01$, *** $p < .001$. O.R. = Odds ratio. C.I. = Confidence interval. The independent variable (IV) for each model was "best possible health - supports in place." Average hourly support needs were also controlled.

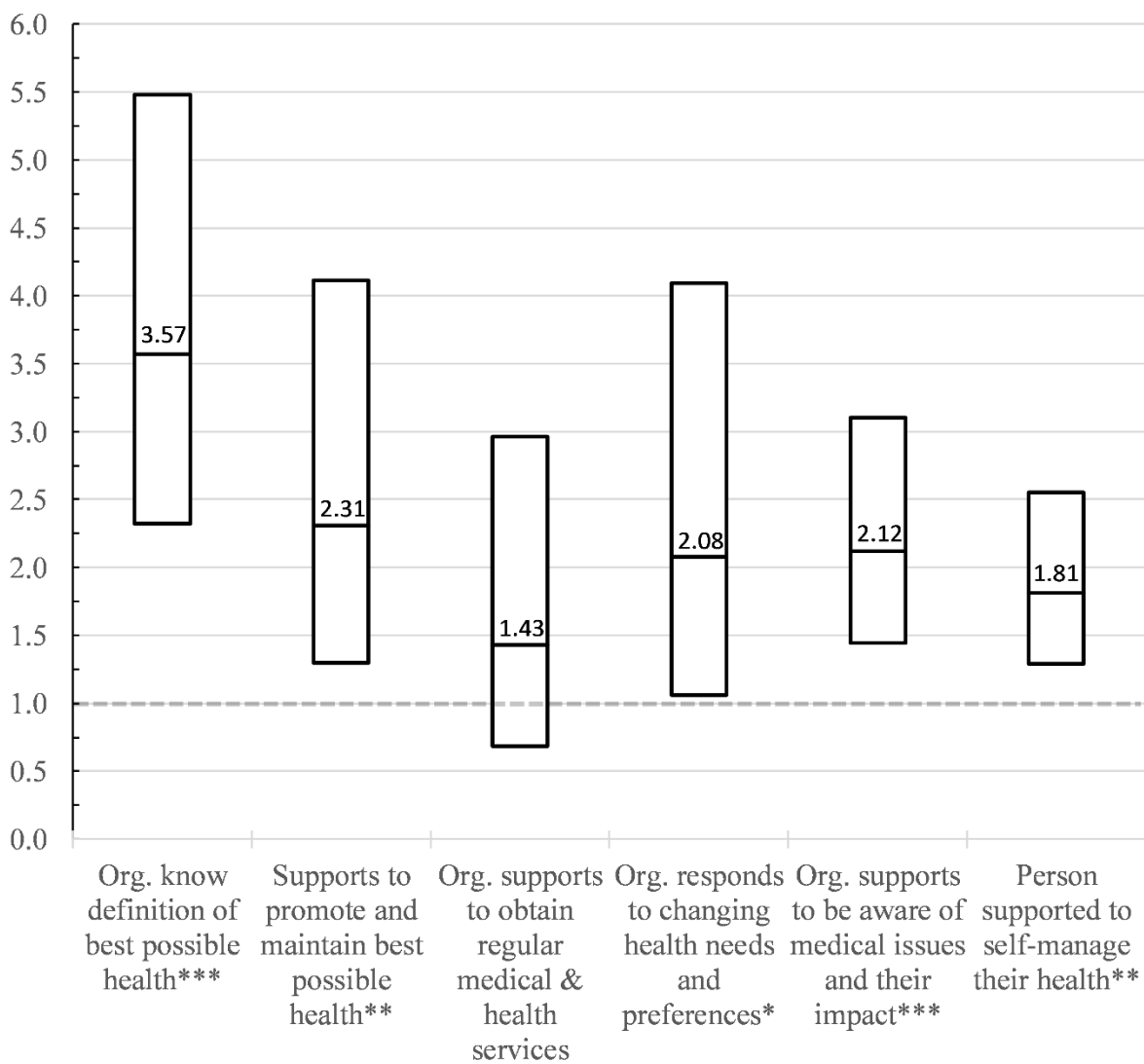


Figure 1. Odds of best possible health depending on organizational support type. * $p < .05$. ** $p < .01$. *** $p < .001$. Org. = Organization.