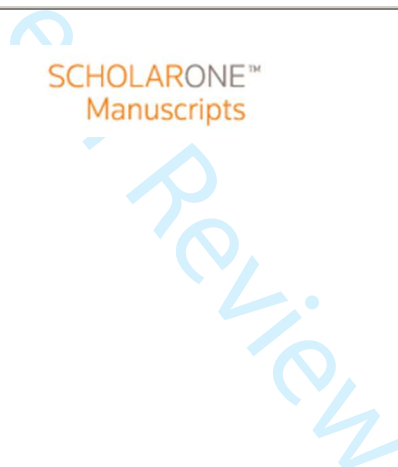




The Impact of Organizational Supports on the Health of People with Intellectual and Developmental Disabilities

Journal:	<i>Journal of Policy and Practice in Intellectual Disabilities</i>
Manuscript ID	JPPID-18-0030
Manuscript Type:	Original manuscript
Keywords:	disability service organizations, health disparities, long term services and supports, people with intellectual and developmental disabilities



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Running head: ORGANIZATIONAL HEALTH SUPPORTS

**The Impact of Organizational Supports on the Health of
People with Intellectual and Developmental Disabilities**

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people with intellectual and developmental disabilities

ORGANIZATIONAL HEALTH SUPPORTS

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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 health of people with IDD.

Method. To do so, this study analyzed secondary Personal Outcome Measures[®] data from approximately 1,300 people with IDD in the United States.

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.

ORGANIZATIONAL HEALTH SUPPORTS

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Introduction

People with intellectual and developmental disabilities (IDD) have significantly poorer health and shorter life expectancies than the general population (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 et al., 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 other key social determinates 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 et al., 2011; Mann et al., 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 (Citation removed for review). Common barriers include a lack of resources and structure to create and sustain initiatives, lack of motivation, and lack of willingness by staff to assist people with IDD with health promotion (Citation removed for review; Lynnes, Nichols, & Temple, 2009).

ORGANIZATIONAL HEALTH SUPPORTS

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3 Because of the crucial impact organizations can have in reducing disparities and
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5 increasing health outcomes, the aim of this study is to explore the role organizations play in
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7 promoting the best possible health of people with IDD. Best possible health is person-centered
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9 and depends “on the current health status of a person and the possibility of health interventions to
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11 restore lost capacity, stabilize a condition or minimize further loss of function. Best possible
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13 health is defined in terms that are satisfactory for the person” (The Council on Quality and
14
15 Leadership, 2017a, p. 21). Best possible health also includes the person with IDD’s personal
16
17 definition regarding what makes them feel healthy and helps them achieve their goals in life. To
18
19 explore this relationship, we had two main research questions: 1) who is most/least likely to have
20
21 best possible health organizational supports in place?; and, 2) how does having organizational
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23 supports in place impact health? To do so, this study analyzed secondary Personal Outcome
24
25 Measures[®] surveys data from approximately 1,300 people with IDD in the United States.
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Methods**Participants**

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35 The secondary survey data utilized in this survey were transferred to the researchers with
36
37 no identifiers; as such the author’s institutional research board (IRB) determined it was exempt
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39 from full review. Participants were originally recruited over approximately two years (January
40
41 2015 – December 2016) through organizations in the United States that provide services to
42
43 people with disabilities, including: service coordination; case management; family and individual
44
45 supports; behavioral health care; employment and other work services; residential services; non-
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47 traditional supports (micro-boards and co-ops); and, human services systems. 1,341 people with
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49 IDD consented to participate. The majority of participants were White (74.4%), used
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51 verbal/spoken language as their primary communication method, had 24/7 around the clock daily
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ORGANIZATIONAL HEALTH SUPPORTS

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3 support (61.1%), and lived in provider owned or operated homes (50.5%). The distribution of
4
5 age, gender, and guardianship status were more evenly distributed (see Table 1).
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7 [Table 1 approximately here]
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Measure

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12 The instrument used in this study was the Personal Outcome Measures[®] (The Council on
13
14 Quality and Leadership, 2017a), developed by the international non-profit disability organization
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16 The Council on Quality and Leadership (CQL). The Personal Outcome Measures[®] is designed to
17
18 determine people with disabilities' quality of life, including self-determination, choice, self-
19
20 advocacy, and supports. The Personal Outcome Measures[®] includes 21 indicators divided into
21
22 five factors: my human security; my community; my relationships; my choices; and, my goals.
23
24 *My human security* includes the following indicators: people are safe; people are free from abuse
25
26 and neglect; people have the best possible health; people experience continuity and security;
27
28 people exercise rights; people are treated fairly; and, people are respected. *My community*
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30 includes the following indicators: people use their environments; people live in integrated
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32 environments; people interact with other members of the community; and, people participate the
33
34 life of the community. *My relationships* includes the following indicators: people are connected
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36 to natural support networks; people have friends; people have intimate relationships; people
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38 decide when to share personal information; and, people perform different social roles. *My*
39
40 *choices* includes the following indicators: people choose where and with whom to live; people
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42 choose where they work; and, people choose services. *My goals* includes the following
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44 indicators: people choose personal goals; and, people realize personal goals.
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51 Personal Outcome Measures[®] administration occurs in three stages. In the first stage, a
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ORGANIZATIONAL HEALTH SUPPORTS

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3 trained Personal Outcome Measures[®] interviewer has in-depth conversations with the participant
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5 with disabilities about each of the indicators. For these conversations, the interviewer follows
6
7 specific open-ended prompts. During the second stage of the Personal Outcome Measures[®]
8
9 interview, the interviewer speaks with someone who knows the participant with disabilities and
10
11 their organizational supports best, such as a direct support professional, and asks them questions
12
13 about individualized supports and outcomes to fill in any gaps. During the final stage, if
14
15 necessary, the interviewer observes the participant in various settings and then completes the
16
17 indicator questions about personal outcomes and individualized supports based on the
18
19 information gathered in the three stages. Individual record reviews are also conducted as needed.
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24 The Personal Outcome Measures[®] was developed over 25 years ago based on findings
25
26 from focus groups with people with disabilities, their family members, and other key
27
28 stakeholders about what really mattered in their lives. The Personal Outcome Measures[®] tool has
29
30 been continuously refined over the past two decades through pilot testing, 25 years of
31
32 administration, commission of research and content experts, a Delphi survey, and feedback from
33
34 advisory groups (The Council on Quality and Leadership, 2017a). The Personal Outcome
35
36 Measures[®] has inter-rater reliability and construct validity (Citation removed for review; The
37
38 Council on Quality and Leadership, 2017b).
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Variables and Analysis

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

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place”. 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

ORGANIZATIONAL HEALTH SUPPORTS

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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.

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

ORGANIZATIONAL HEALTH SUPPORTS

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3 issues and their impact; and, (6.) support the person to self-manage their health? (The Council on
4 Quality and Leadership, 2017a). All of five of these features must be in place for the support to be
5 considered in place.
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10 Utilizing these data, our first research question was: who is most likely to have
11 organizational supports in place for health? For this question, we utilized binary logistic
12 regression models with best possible health organizational supports in place as the dependent
13 variable (DV) and demographic factors as independent variables (IVs). Univariate analyses were
14 run to determine odds ratios.
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21 Our second question was: how does having organizational supports in place impact
22 health? This was explored in two ways. In the first, in order to examine how specific supports
23 impact best possible health – the outcome being present – we ran binary logistic regressions with
24 the DV of ‘best possible health - outcome present,’ and each of the different types of support as
25 IVs (Table 2); we also controlled for average daily support needs as a proxy for impairment
26 level. We also wanted to examine how having best possible health organizational supports in
27 place impacts different areas of health. To do so, controlling for hourly support needs, we
28 examined how having ‘best possible health - organizational supports in place’ (IV) impacted
29 different areas of health which each served as the DV in different models. Univariate analyses
30 were run to determine odds ratios.
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44 [Table 2 approximately here]

45 46 47 **Results**

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49 According to descriptive statistics, the overwhelming majority of organizations
50 supporting participants knew the person’s definition of best possible health, provided supports
51 for the person to promote and maintain best possible health if needed or requested, assured the
52 person had support to obtain regular medical and health services, responded to the person’s
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ORGANIZATIONAL HEALTH SUPPORTS

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3 changing health needs and preferences, and supported the person to be aware of their medical
4 issues and their impact (see Table 2). Only slightly less than half of participants, however, were
5 supported to self-manage their health however. Moreover, only 63.9% participants had best
6 possible health supports in place – organizations completed all of the aforementioned activities.
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12 A binary logistic regression model was performed with the DV ‘best possible health –
13 supports in place’ and the demographic IVs to determine who was most/least likely to be
14 supported; the model was significant, $-2LL = 1428.48$, $\chi^2(31) = 105.62$, $p < .005$. The model,
15 which correctly classified 68.6% of cases, explained 11.8% (Nagelkerke R^2) of variance. See
16 Table 3 for odds ratios. According to univariate statistics, older adults (age 75 and older) were
17 4.25 times more likely than people age 18 to 24 to have health organizational supports in place.
18 Native American or Indigenous people were 2.41 times more likely to have organizational
19 supports in place than White people. People whose primary communication method was
20 body/facial expressions and ‘other’ were 1.48 and 2.75 times, respectively more likely than
21 people who primarily used verbal communication to have organizational supports around health
22 in place. People with independent decision making were 1.64 times more likely to have
23 organizational supports in place than people with assisted decision making. People who lived in
24 provider owned or operated homes and state operated Home and Community Based Services
25 (HCBS) group homes were 2.18 and 2.17 times more likely than people who lived in their own
26 home or apartments to have organizational supports in place. Finally, compared to people with
27 support as needed (on call), people who have 3 to 6 hours of daily support were 4.55 times less
28 likely to have organizational supports, people with 24/7 around the clock support were 6.25
29 times less likely, and ‘other’ daily support 6.67 times less likely.
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ORGANIZATIONAL HEALTH SUPPORTS

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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. When people have best possible health organizational supports in place, regardless of impairment level, they are 4.41 times more likely to have annual physicals, and 2.16 times more likely to have annual dental exams. When people have best possible health organizational supports in place, they are 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. When best possible health organizational supports are in place, people are 3.36 times more likely to select health intervention services in consultation with their health care professionals. When people have best possible health organizational supports in place, their health intervention services are 5.47 times more likely to be effective. People that have best possible health organizational supports in place are 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 are 13.16 times more likely to have best possible health outcomes present.

[Table 4 approximately here]

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 know the person’s definition of best possible

ORGANIZATIONAL HEALTH SUPPORTS

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3 health people with disabilities were 3.57 times more likely to have best possible health
4 (outcomes present) than when organizations did not know their definition (Figure 1). When
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6 organizational supports are provided for the person to promote and maintain best possible health
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8 people with disabilities are 2.31 times more likely to have health outcomes present than when
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10 organizational supports are not provided. When organizations respond to the person's changing
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12 health needs and preferences, the person they support is 2.08 times more likely to have health
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14 outcomes present than when they do not provide this support. When the organization supporting
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16 the person supports them to be aware of their medical issues and their impact, people are 2.12
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18 times more likely to have best possible health (outcomes present). Finally, people supported to
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20 self-manage their health are 1.81 times more likely to have best possible health outcomes
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22 present.
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28 [Figure 1 approximately here]
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30 Discussion

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33 People with IDD have significantly higher risk of developing chronic health conditions
34 compared to the general population as a result of genetics, social circumstances, environmental
35 conditions, and access to health care services (Bittles et al., 2002; Krahn et al., 2006; Ouellette-
36 Kuntz, 2005; Taggart & Cousins, 2014). Our findings reveal individualized organizational
37 supports can play a key role in promoting the health of people with IDD. People with IDD are
38 approximately 13 times more likely to have best possible health outcomes present when
39 organizational supports are in place. In particular, organizational supports positively impact the
40 likelihood of almost all aspects of health examined.
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51 Although there is not a significant difference in the likelihood of people with IDD having
52 a primary care doctor, or seeing health care professionals, when organizational supports are in
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ORGANIZATIONAL HEALTH SUPPORTS

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3 place, people with IDD are more likely to have annual physicals and annual dental exams, both
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5 of which are important to help prevent secondary conditions (American Dental Association,
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7 2006; Kaye, 2007; Owens et al., 2006). When organizational supports are in place health care
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9 professionals are more likely to identify the person's best possible health situation and, address
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11 any health care issues or concerns, and interventions. When organizational supports are in place
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13 health intervention services were more likely to be selected by the person in consultation with
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15 health care professionals and health intervention services were more likely to be effective. By
16
17 paying attention to all of these aspects of health and supports, especially discrepancies in
18
19 supports being offered, service organizations can work to counteract health disparities in those
20
21 they support. In addition to the benefits to health itself, doing so also fosters collaboration with
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23 the person with IDD, allowing them to be consulted more and have more choice.
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29 Not only is every area of best possible health impacted by organizational supports being
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31 in place, every type of organizational support promotes the best possible health of people with
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33 IDD. People with IDD are more likely to have best possible health outcomes present when
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35 organizations support people to self-manage their health, support the person to be aware of their
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37 medical issues and their impact, assure that the person has support to obtain regular medical and
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39 health services, know the person's definition of best possible health, provide supports to promote
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41 and maintain best possible health, and respond to the person's changing health needs and
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43 preferences.
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48 As found, individualized organizational health supports facilitate the best possible health
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50 of people with IDD; to ensure all people with IDD benefit from organizational supports, there are
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52 a number of support disparities that need to be addressed. For example, while overall those with
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54 higher support needs were less likely to have supports in place, there was a mix of odds across
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ORGANIZATIONAL HEALTH SUPPORTS

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3 the daily support categories suggesting the level of support needed – impairment severity – is not
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5 necessarily the only factor impacting if people have best possible health organizational supports
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7 in place.
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10 People who live in provider-owned or operated group homes, or state-operated group
11
12 homes are less likely to have health supports in place than people who live in their own homes or
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14 apartments. This finding may be particularly problematic given that past research has found that
15
16 people with IDD who live independently are more likely to be unhealthy, overweight, and obese
17
18 because they eat less nutritious foods, and participate less in physical activity because they are
19
20 not educated on health behaviors (Rimmer & Yamaki, 2006; Yamaki, 2005).
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24 Those who had assisted decision making, rather than independent decision making, were
25
26 approximately two times less likely to have organization supports in place for best possible
27
28 health. Meanwhile full/plenary guardianship was not significant. More research is needed to
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30 explore why people with assisted decision making in particular were less likely to have supports
31
32 in place; it may be because this model is relatively new than independent decision making or full
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34 guardianship and therefore the roles of people with disabilities and their supporters are less clear
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36 cut. In fact, supported decision making (SDM) and its parallels are relatively new guardianship
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38 models in the United States (Citation removed for review). While SDM is considered “a
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40 pragmatic approach to legal determinations concerning personhood” which honors self-
41
42 determination and empowerment, there are serious concerns from both supporters and critics
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44 about the lack of evidence and guidelines for SDM (Citation removed for review; Gooding,
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46 2013; Kohn, Blumenthal, & Campbell, 2012).
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51 In terms of likelihood to receive organizational supports, there are also a number of
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53 findings that may seem counterintuitive. For example, our models revealed people 75 and older
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ORGANIZATIONAL HEALTH SUPPORTS

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3 are more likely to have health supports in place than those 18 to 24. People whose primary
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5 communication method is body/facial expressions are also more likely to have organizational
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7 supports than people who primarily used verbal communication. Moreover, Native American
8
9 and Indigenous people are also more likely to have supports in place than White people. Perhaps
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11 organizations are cognizant of the health disparities and are culturally sensitive to the unique
12
13 needs of these groups, and therefore go out of their way to put supports in place for them.
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15 However, these findings may also be related to the unequal distribution of our sample; for
16
17 example, only 39 participants were 75 and older, and only 54 people were Native
18
19 American/Indigenous. Future research should examine if these findings were sample specific; if
20
21 they are replicable, more research is needed to explore why organizations are focusing on these
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23 groups in particular.
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29 When interpreting our results, a number of limitations should be noted. Our data was not
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31 representative of people with IDD in the United States as a whole; while 22 states were
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33 represented in the sample, the majority of data came from three states. Most of our participants
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35 were White and had high support needs. Additionally, participants were recruited through
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37 organizations that provide long term services and supports, particularly those organizations who
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39 partner with the Council on Quality and Leadership to conduct Personal Outcome Measures[®]
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41 interviews; therefore, this sample may not be representative of all people with IDD, or all service
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43 providers. Finally, as this was a secondary data analysis, the researcher did not have the ability to
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45 ask additional questions or add additional research variables.
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Conclusion

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51 Organizations play an important role in facilitating the health of people with IDD. Yet,
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53 agencies' attitudes can determine if health initiatives are sustained (Citation removed for review).
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ORGANIZATIONAL HEALTH SUPPORTS

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3 Research has indicated it is critical for organizations to have clear guidelines and procedures
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5 regarding health supports and programs, particularly for direct support staff (Citation removed
6
7 for review; Hewitt et al., 2004; Jansson et al., 2010). Success of organizational health supports
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9 also depends on the programs being internally monitored, and encouraged by management
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11 (Elsworth & Astbury, 2004; Savaya, Spiro, & Elran-Barak, 2008). We recognize most disability
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13 organizations are facing an increased burden due to statewide budget cuts and the direct support
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15 professional crisis (American Network of Community Options and Resources, 2014); however,
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17 everyone is entitled to quality health care (Office of the United Nations High Commissioner for
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19 Human Rights & World Health Organization, 2008; United Nations, 1948; World Health
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21 Organization, 2015). Thus, LTSS funding must reflect and recognize the vital role organizations
22
23 play in facilitating optimal health of people with IDD. In the meantime, organizations can
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25 implement cost-effective and simple programs, such as supporting people to self-manage their
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27 health (Citation removed for review), in order to improve the health and quality of life of people
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29 with IDD.
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References

- American Dental Association. (2006). Healthy mouth, healthy body. *Journal of the American Dental Association*, 137(4), 563.
- American Network of Community Options and Resources. (2014). *Ensuring a sustainable work force for people with disabilities: Minimum wage increases can not leave direct support professionals behind*. Alexandria, VA: Author.
- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57(7), M470-M472.
- Citation removed for review.
- Elsworth, G., & Astbury, B. (2004). *Evaluating the sustainability of pilot projects in health promotion*. Paper presented at the European Evaluation Society Conference, Berlin, Germany.
- Evenhuis, H. M., Hermans, H., Hilgenkamp, T. I., Bastiaanse, L. P., & Echteld, M. A. (2012). Frailty and disability in older adults with intellectual disabilities: results from the healthy ageing and intellectual disability study. *Journal of the American Geriatrics Society*, 60(5), 934-938.
- Glasson, E., Dye, D., & Bittles, A. H. (2014). The triple challenges associated with age-related comorbidities in Down syndrome. *Journal of Intellectual Disability Research*, 58(4), 393-398.
- Gooding, P. (2013). Supported decision-making: a rights-based disability concept and its implications for mental health law. *Psychiatry, Psychology and Law*, 20(3), 431-451.

ORGANIZATIONAL HEALTH SUPPORTS

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3 Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., & Strydom, A. (2010). Major
4
5 health risks in aging persons with intellectual disabilities: an overview of recent studies.
6
7 *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 59-69.
8
9
- 10 Heller, T., McCubbin, J. A., Drum, C., & Peterson, J. (2011). Physical activity and nutrition
11
12 health promotion interventions: what is working for people with intellectual disabilities?
13
14 *Intellectual and Developmental Disabilities*, 49(1), 26-36.
15
16
- 17 Hewitt, A. S., Larson, S. A., Lakin, K. C., Sauer, J., O'Neill, S., & Sedlezky, L. (2004). Role and
18
19 essential competencies of the frontline supervisors of direct support professionals in
20
21 community services. *Mental Retardation*, 42(2), 122-135.
22
23
- 24 Jansson, S. M., Benoit, C., Casey, L., Phillips, R., & Burns, D. (2010). In for the long haul:
25
26 knowledge translation between academic and nonprofit organizations. *Qualitative Health*
27
28 *Research*, 20(1), 131-143.
29
30
- 31 Kaye, E. K. (2007). Bone health and oral health. *The Journal of the American Dental*
32
33 *Association*, 138(5), 616-619.
34
35
- 36 Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2012). Supported decision-making: A viable
37
38 alternative to guardianship. *Penn St. L. Rev.*, 117, 1111.
39
40
- 41 Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health
42
43 care access for people with intellectual disabilities. *Mental Retardation and*
44
45 *Developmental Disabilities Research Review*, 12(1), 70-82.
46
47
- 48 Lynnes, M. D., Nichols, D., & Temple, V. A. (2009). Fostering independence in health-
49
50 promoting exercise. *Journal of intellectual Disabilities*, 13(2), 143-159.
51
52
53
54
55
56
57
58
59
60

ORGANIZATIONAL HEALTH SUPPORTS

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- 1
2
3 Mann, J., Zhou, H., McDermott, S., & Poston, M. B. (2006). Healthy behavior change of adults
4 with mental retardation: Attendance in a health promotion program. *American Journal on*
5 *Mental Retardation*, 111(1), 62-73.
6
7
8
9
10 Marks, B., Sisirak, J., & Heller, T. (2010). *Health matters: The exercise and nutrition health*
11 *education curriculum for people with developmental disabilities*. Baltimore: Brookes
12 Publishing Company.
13
14
15
16
17 Marks, B. A., & Heller, T. (2003). Bridging the equity gap: Health promotion for adults with
18 intellectual and developmental disabilities. *Nursing Clinics of North America*, 38(2), 205-
19 228.
20
21
22
23
24 Nochajski, S. M. (2000). The impact of age-related changes on the functioning of older adults
25 with developmental disabilities. *Physical & Occupational Therapy in Geriatrics*, 18(1),
26 5-21.
27
28
29
30
31 Office of the United Nations High Commissioner for Human Rights, & World Health
32 Organization. (2008). *The right to health: Fact sheet no. 31*. Geneva: United Nations.
33
34
35 Ouellette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals
36 with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*,
37 18(2), 113-121.
38
39
40
41
42 Owens, P. L., Kerker, B. D., Zigler, E., & Horwitz, S. M. (2006). Vision and oral health needs of
43 individuals with intellectual disability. *Mental Retardation and Developmental*
44 *Disabilities Research Review*, 12(1), 28-40.
45
46
47
48
49 Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Developmental*
50 *Disabilities Research Reviews*, 12(1), 22-27.
51
52
53
54
55
56
57
58
59
60

ORGANIZATIONAL HEALTH SUPPORTS

20

- 1
2
3 Savaya, R., Spiro, S., & Elran-Barak, R. (2008). Sustainability of social programs: A
4 comparative case study analysis. *American Journal of Evaluation*, 29(4), 478-493.
5
6
7 Taggart, L., & Cousins, W. (2014). *Health promotion for people with intellectual and*
8 *developmental disabilities*. London: McGraw-Hill Education (UK).
9
10
11
12 The Council on Quality and Leadership. (2017a). *Personal Outcome Measures: Measuring*
13 *personal quality of life* (3rd ed.). Towson, MD: Author.
14
15
16
17 The Council on Quality and Leadership. (2017b). *The Personal Outcome Measures® 2017:*
18 *Measuring outcomes now and into the future*. Towson, MD: The Council on Quality and
19 Leadership.
20
21
22
23
24 United Nations. (1948). *Universal declaration of human rights (217 [III] A)*. Paris: Author.
25
26
27 World Health Organization. (2001). Healthy ageing – adults with intellectual disabilities:
28 Summative report. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 256–
29 275. doi:10.1046/j.1468-3148.2001.00071.x
30
31
32
33 World Health Organization. (2015). Health and human rights (fact sheet N°323). Retrieved
34 from <http://www.who.int/mediacentre/factsheets/fs323/en/>
35
36
37
38 Yamaki, K. (2005). Body weight status among adults with intellectual disability in the
39 community. *Mental Retardation*, 43(1), 1-10.
40
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ORGANIZATIONAL HEALTH SUPPORTS

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		
Man	719	53.6%
Woman	613	45.7%
No response	9	0.7%
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	###	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		
Independent decision making	370	27.6%
Assisted decision making (supported and limited guardianship)	494	36.8%
Full/plenary guardianship	423	31.5%
Other	35	2.6%
No response	19	1.4%
Residence type		
Own home/apartment	284	21.2%

ORGANIZATIONAL HEALTH SUPPORTS

22

Family's house	213	15.9%
Host family/family foster care	24	1.8%
Provider-operated house or apartment	677	50.5%
Private ICFDD	22	1.6%
State-operated HCBS group home	43	3.2%
State-operated ICFDD	25	1.9%
Other	22	1.6%
No response	31	2.3%
Average daily support		
On call - support as needed	28	2.1%
0 to 3 hours/day	60	4.5%
3 to 6 hours/day	94	7.0%
6 to 12 hours/day	155	11.6%
12 to 23 hours/day	76	5.7%
24/7 - around the clock	819	61.1%
Other	46	3.4%
No response	63	4.7%

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

Review

ORGANIZATIONAL HEALTH SUPPORTS

23

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%

ORGANIZATIONAL HEALTH SUPPORTS

24

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

ORGANIZATIONAL HEALTH SUPPORTS

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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.

For Peer Review

ORGANIZATIONAL HEALTH SUPPORTS

26

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.

ORGANIZATIONAL HEALTH SUPPORTS

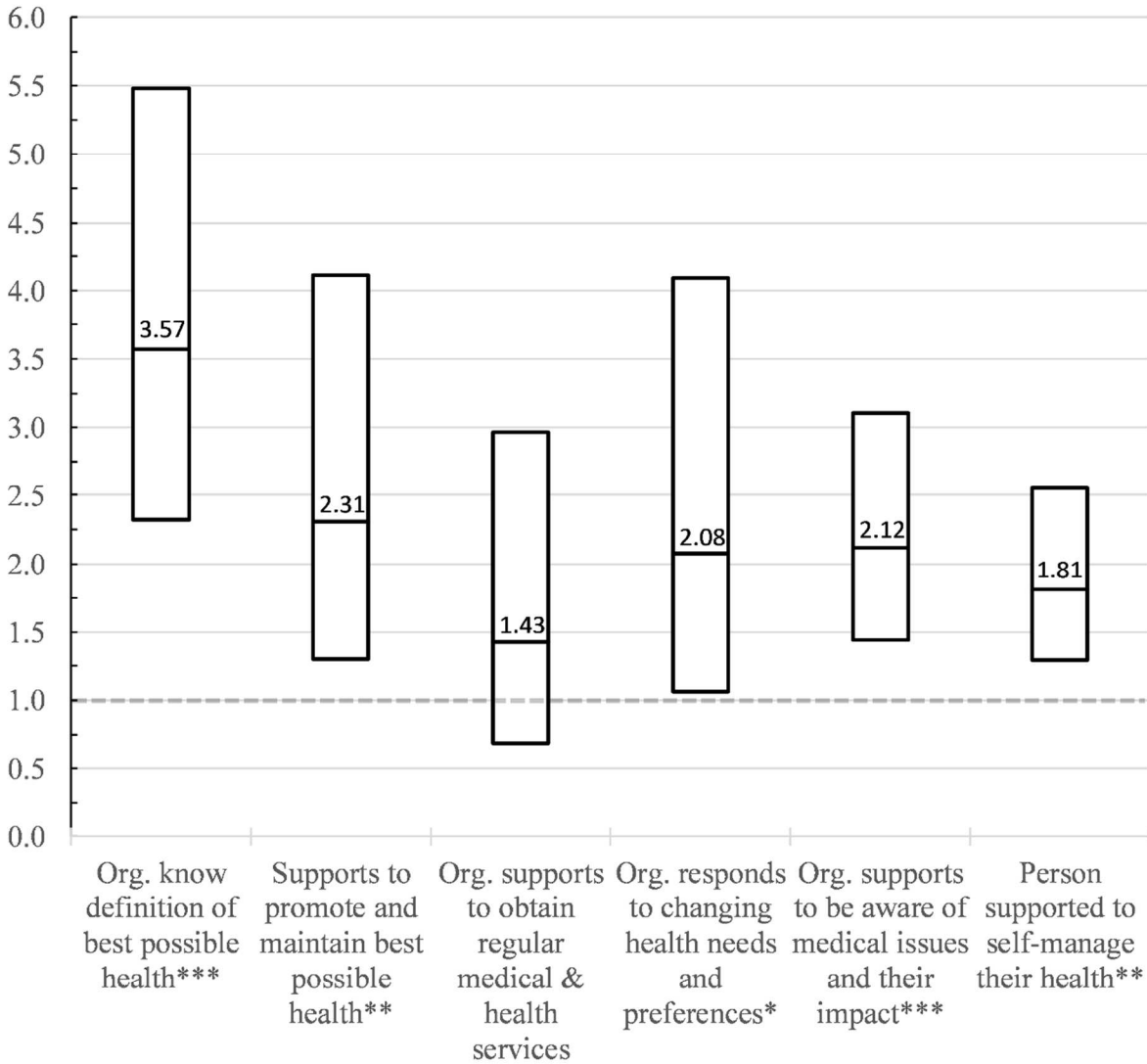


Figure 1. Odds of best possible health depending on organizational support type. *p<.05. **p<.01. ***p<.001. Org. = Organization.