

Research

The Social Determinants of Health Index



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Abstract

Background. Health disparities are avoidable differences which disproportionately impact certain groups. Health equity demands attention to social determinants of health (SDOH), particularly for people with disabilities who often have poorer outcomes and face more health inequities than nondisabled peers.

Objective. The aim of this study was to develop a Social Determinants of Health Index for people with disabilities which utilizes personal outcomes. The Index is aimed at helping disability service providers examine the SDOH of those they support, to arm them with more information to provide targeted services and supports.

Methods. We ran an exploratory factor analysis of Personal Outcome Measures interviews with 1,078 people with disabilities from 2017 to compute composite scores for the factors underlying the model.

Results. Findings revealed the Social Determinants of Health Index had three underlying factors: choice and engagement; person-centeredness; and health and safety. Choice and engagement are often inextricably linked as choice, self-determination, and empowerment play a key role in the social inclusion of people with disabilities. Services being person-centered are not only a right and requirement of home and community-based services, but rights should also be person-centered – each person decides which rights are the most important to them. Finally, the third factor recognizes health and safety as foundational parts of health outcomes.

Conclusions. The creation of the Social Determinants of Health Index for people with disabilities, which utilizes person-centered outcomes, ultimately aims to reduce health disparities. Attention to SDOH can promote good health for all.

Keywords: Social determinants of health; people with disabilities; health equity; health disparities; personal outcomes

Impact

- The manuscript introduces a new measure of social determinants of health for people with disabilities. In doing so, service providers can utilize this tool to measure and then improve the social determinants of health of those they support.
- Health equity demands attention to disparities in social determinants of health of people with disabilities. By targeting the disparities people with disabilities face, we can help facilitate improved quality of life.

The Social Determinants of Health Index

Health disparities are avoidable differences which disproportionately impact certain groups – particularly those who have historically faced discrimination or power imbalances, such as people with disabilities, racial/ethnic minorities, women, LGBTQIA people, etc., due to characteristics of society and/or differences in health care (Abbott & Elliott, 2017; United States Department of Health & Human Services, 2015). People with disabilities have significantly poorer health and shorter life expectancies than nondisabled people (Altman & Bernstein, 2008; Iezzoni, 2011; Krahn, Walker, & Correa-De-Araujo, 2015). For example, people with disabilities are more likely to be obese and to develop heart disease than nondisabled counterparts (Altman & Bernstein, 2008; Iezzoni, 2011). However, these health disparities are not necessarily due to people with disabilities’ impairments or their health behaviors alone, but often because of social determinants of health (Emerson et al., 2011; Frier, Barnett, Devine, & Barker, 2018; Iezzoni, 2011). People with disabilities have poorer outcomes and face more health inequities than nondisabled peers, in part because of “increased risk of exposure to socio-economic disadvantage” (Emerson et al., 2011, p. 146). People with disabilities’ health disparities are particularly impacted by disability employment disparities, high instances of poverty among people with disabilities, a lack of affordable and accessible housing, and a lack of accessible transportation (Frier et al., 2018).

Health equity – “the absence of avoidable, unfair, or remediable differences among groups of people” (World Health Organization, n.d.) – demands much more than simply controlling or preventing disease – poor health cannot be explained by health services alone (Currie et al., 2009; United States Department of Health & Human Services, 2015). Although medical care is important for health, research suggests medical care itself is only responsible for

10% to 15% of preventable mortality in the United States; in fact, health is largely determined by social and physical environments (Braveman & Gottlieb, 2014; Currie et al., 2009). According to the World Health Organization (2010a) “the roots of most health inequalities and of the bulk of human suffering are social: the social determinants of health” (p. 39). To reduce health disparities and promote health equity, attention must be paid to social determinants of health (SDOH). SDOH are “conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (United States Office of Disease Prevention and Health Promotion, n.d., n.p.).

According to decades of research, a large number of social, economic, and environmental factors contribute to health (United States Department of Health & Human Services, 2015). Class, socioeconomic status and poverty all impact peoples’ health and produce and/or reinforce disparities (Abbott & Elliott, 2017; United States Office of Disease Prevention and Health Promotion, n.d.; World Health Organization, 2010b). Poverty in itself is a social determinant, and poverty is also associated with stressful conditions that impact health (United States Office of Disease Prevention and Health Promotion, n.d.). For example, people’s food insecurity and hunger result in health disparities (Larsson, 2013; World Health Organization, 2010b). As such, income inequality, financial in/security, and economic position all impact peoples’ health (Compton & Shim, 2015; Larsson, 2013; Raphael, 2006).

Natural and built environments also serve as SDOH. For example, exposure to toxins and pollution hinder peoples’ health (Compton & Shim, 2015; United States Department of Health & Human Services, 2015; United States Office of Disease Prevention and Health Promotion, n.d.). One’s natural environment, including climate change, green space, and community areas, also

serve as SDOH (Compton & Shim, 2015; United States Department of Health & Human Services, 2015). The built environment, such as buildings, sidewalks, roads, accessibility, aesthetic elements, and neighborhood deprivation, is impacted by social, political, and economic processes and priorities, which in turn impact SDOH (Compton & Shim, 2015; United States Office of Disease Prevention and Health Promotion, n.d.).

Social, political, and cultural institutions and structures also impact the health of people (Kim, Chen, & Spencer, 2012; United States Department of Health & Human Services, 2015). For example, social structures, such as social exclusion, segregation, and social stratification impact health (Larsson, 2013; Raphael, 2006; World Health Organization, 2006, 2010b). Kim et al. (2012) explain,

social stratification emerges as a consequence of persistently biased social and economic policies that favor a majority group holding power. As a result, social stratification puts those with less power and fewer resources at risk for differential exposure and vulnerability to health and mental health problems, as well as the consequences of these problems. (p. 346)

Social structures often result in an unequal opportunities; those groups with more advantages (e.g., income, education, social class, etc.) have better health (Compton & Shim, 2015). Race, class, gender, disability, and sexual orientation not only are SDOH in and of themselves, they are also markers of power in/equities that influence health (Raphael, 2006). Discrimination is also a SDOH; racial and ethnic discrimination, sexism, ableism, and other forms of prejudice, even unconscious forms, contribute to health inequities, particularly because they are linked to structures, policies, and attitudes (Braveman & Gottlieb, 2014; Compton & Shim, 2015; Kim et al., 2012; World Health Organization, 2010b).

Governance – the ideology of the current government – as well as policies also impact peoples’ lives and, as a result, their health (Raphael, 2006; World Health Organization, 2010b). Macroeconomic policies, public policies, and social policies all have a downstream effect that result in health disparities and, as such, are all SDOH (Compton & Shim, 2015; World Health Organization, 2010b). For example, these policies impact the labor market, housing, education, healthcare, and many more areas, all of which are SDOH in and of themselves (World Health Organization, 2010b). For example, factors such as the availability of preventative care and access to medicines, both of which depend on policy and funding, impact people’s health and result in health inequities (Kim et al., 2012; United States Department of Health & Human Services, 2015). When there are stronger social protections, there is better population health because social protections serve as safety nets (Raphael, 2006; United States Department of Health & Human Services, 2015). Neoliberalism, the most dominant political ideology of the United States, is also problematic for health disparities as it emphasizes individualism, thereby ignoring structural understandings and determinants of health, and supports unequal resource allocation and the weakening of social structures and protections (Raphael, 2006).

Education also plays an important role in health (Abbott & Elliott, 2017; World Health Organization, 2010b). Educational opportunities, as well as the quality of education, impact peoples’ health (United States Office of Disease Prevention and Health Promotion, n.d.). In fact, the links between education and health may be bi-direction in that people with greater educational opportunities are healthier, and people who are healthier have greater educational opportunities (Braveman & Gottlieb, 2014). The link between education and other social determinants, such as employment, exacerbate health disparities.

A number of factors related to employment are also SDOH (Abbott & Elliott, 2017; Frier et al., 2018; World Health Organization, 2010b) and may also be bi-directional. Unemployment can result in health inequities and health inequities also cause unemployment (Compton & Shim, 2015; Raphael, 2006). Job insecurity as well as underemployment both contribute to health outcomes (Compton & Shim, 2015; Raphael, 2006). Once people are employed, the training they receive, the working conditions of their job, the demands of their employment, and their job dis/satisfaction all play a factor in health (World Health Organization, 2006, 2010b). Factors such as work stress, effort-reward imbalance, low control over work, and decision latitude and authority also impact health (Braveman & Gottlieb, 2014; Lauder, Kroll, & Jones, 2007). Unsupportive workplaces, including those without social supports or with poor treatment by supervisors, negatively impact health (Compton & Shim, 2015; Lauder et al., 2007). Finally, both having a living wage, and the prestige of the occupation – how society regards the occupation – impact health (Janßen, Sauter, & Kowalski, 2012).

Housing is yet another factor that impacts peoples' health (Kim et al., 2012; Raphael, 2006; World Health Organization, 2006). Housing stability, insecurity, and homelessness create health disparities (Compton & Shim, 2015; Lauder et al., 2007). The affordability of housing as well as its quality are also SDOH (United States Office of Disease Prevention and Health Promotion, n.d.). Residential segregation produces health inequities (United States Office of Disease Prevention and Health Promotion, n.d.). Moreover, the physical and social neighborhood and communities in which people inhabit are SDOH (Kim et al., 2012; Raphael, 2006). Neighborhood conditions either facilitate or hinder opportunities, mental health, health behaviors, risk behaviors, and physical activity (Currie et al., 2009). While the availability of community-based resources for community living, and recreational and leisure promote health,

exposure to violence and crime in neighborhoods and communities hinders health (Compton & Shim, 2015; United States Office of Disease Prevention and Health Promotion, n.d.). Moreover, community access to healthy food also plays a role in determining health; those that live in food deserts have not only poorer nutrition but also poorer physical activity (Braveman & Gottlieb, 2014). Transportation plays an important role in health, in large part because it is interconnected with other social determinants (Abbott & Elliott, 2017; Compton & Shim, 2015; Frier et al., 2018). A lack of reliable and affordable transportation in one's neighborhood or community hinders access to education, employment, healthcare, healthy food, and many more opportunities that promote health.

Relationships promote health and reduce health inequities (Lauder et al., 2007; United States Department of Health & Human Services, 2015). For youth, peer relationships can be crucial to development, long-term social skills, and self-efficacy (Currie et al., 2009). While a lack of social support and loneliness hinder health, social capital can facilitate it (Larsson, 2013; Lauder et al., 2007; World Health Organization, 2006, 2010b). Finally, access to technology is a SDOH. Peoples' access to mass media, information technologies (e.g., cell phones, internet), and other technologies, such as social media, all impact health (United States Office of Disease Prevention and Health Promotion, n.d.).

Social Determinants of Health and People with Disabilities

While all of the aforementioned SDOH impact people with disabilities alongside their nondisabled peers, people with disabilities also face a number of social determinants that are specific to their status as people with disabilities. Ableism¹ in healthcare systems, social support, social exclusion and isolation, and living conditions negatively contribute to people with

¹ Discrimination in favor of the nondisabled.

disabilities' mental and physical health (Emerson et al., 2011). In fact, the ableist focus on preventing and curing disability, and conflating disability with illness can result in broader inequities being ignored (Emerson et al., 2011). Emerson et al. (2011) explain to promote health equity for people with disabilities, systems must

address the drivers of social stratification (e.g. by ensuring that disabled children access effective education, regulate labour markets to ensure that disabled adults can access rewarding and secure employment); address differential exposure to adversity (e.g. social marketing to combat disablist attitudes); address differential vulnerability (e.g. by promoting the resilience of disabled people); and address differential consequences (e.g. by ensuring that all disabled people have equal access to effective healthcare). (p. 146)

Purpose

According to the United States Department of Health & Human Services (2015), “the availability of high-quality data for all communities is ultimately a health equity issue” (n.p.). For this reason, as well as because people with disabilities face a number of health inequities and disparities, the aim of this study was to develop a Social Determinants of Health Index for people with disabilities which utilizes personal outcomes. To do so, we selected indicators from the Personal Outcome Measures[®], a person-centered quality of life measure for people with disabilities, based on literature about SDOH and then ran an exploratory factor analysis (EFA) of Personal Outcome Measures[®] interviews with 1,078 people with disabilities to compute composite scores for the factors underlying the model.

Methods

Participants

As this study involved secondary data, it was exempt from review by our Institutional Review Board (IRB). Our secondary data were originally collected over a one-year period (January 2017 to December 2017) from organizations that provide human services to people with disabilities. The sample included 1,078 people with disabilities; participant demographics are presented in Table 1. Age, gender, and guardianship status were relatively even distributed across the participants. However, the majority of participants (71.0%, $n = 741$) had intellectual and developmental disabilities, and were White (78.0%, $n = 743$). Most participants lived in provider owned or operated homes (50.3%, $n = 462$), with fewer living in their own homes or apartments (23.6%, $n = 217$), family homes (15.6%, $n = 143$), and other settings. The majority of participants (61.6%) received 24/7 around the clock supports, with the remaining participants receiving less daily support.

Instrument

The instrument used in this study was the Personal Outcome Measures[®] (The Council on Quality and Leadership, 2017). The Personal Outcome Measures[®] determines people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports, in a person-centered manner. The Personal Outcome Measures[®] includes 21 indicators divided into five factors (Table 2). Each of the 21 indicators are multidimensional constructs, which contain over 400 probes in total. Over 25 years of administration, the Personal Outcome Measures[®] has been continuously refined via pilot testing, feedback from content experts and advisory groups, a Delphi survey, and validation analyses (The Council on Quality and Leadership, 2017). The Personal Outcome Measures[®] has construct validity; moreover, only data from certified reliable interviewers (those who pass a 85% reliability test) was utilized (Friedman, 2018c).

In the first stage of administration, a trained Personal Outcome Measures[®] interviewer has an in-depth conversation(s) with the participant with disabilities about each of the indicators. During this first stage, the interviewer has an open-ended conversation with the person while following specific prompts. Afterwards, the interviewer speaks to someone who not only knows the person with disabilities well but also knows about the organizational supports they receive (e.g., case manager, direct support professional, etc.). During this second interview, the interviewer asks the person about outcomes as well as individualized supports. Finally, during the third stage, if necessary, the interviewer may observe the participant in various settings and/or conduct individual record reviews. Utilizing decision trees, the interviewer then completes the indicator questions about personal outcomes and individualized supports based on all of the data compiled throughout the various stages. As the measure is person-centered, if there are any discrepancies across stages – differences between people with disabilities opinions and those given by the person who knows the participant with disabilities best – the person with disabilities' answers are the ones used.

Procedure

Indicators were selected for the Social Determinants of Health Index based on a review of literature on SDOH, including the *Healthy People 2020* SDOH framework (United States Office of Disease Prevention and Health Promotion, n.d.). The following Personal Outcome Measures[®] indicators were selected as variables for the EFA: people are respected; people are safe; people are treated fairly; people choose where and with whom to live; people choose where they work; people exercise rights; people experience continuity and security; people have the best possible health; people interact with other members of the community; people participate in the life of the community; and, people perform different social roles. (Please see The Council on Quality and

Leadership (2017) for more information regarding each indicator.) These indicators were selected because they comprised different areas of SDOH.

Data Screening and Analysis

To develop the Social Determinants of Health Index, Personal Outcome Measures[®] data from 2017 were collected from approximately 1,078 interviews. SPSS 23 was used for analysis. The data were screened for administrative errors and missing data, which were removed resulting in a total $n = 1,043$. The minimum amount of data for factor analysis was satisfied, providing a ratio of over 95 cases per variable (Garson, 2008). We then ran an EFA with the indicators described above in the procedure section to compute composite scores for the factors underlying the model.

Results

An EFA using a promax rotation was utilized to compute composite scores for the factors underlying the model. Sampling adequacy using the Kaiser-Meyer-Olkin measure was 0.86 and Bartlett's test of sphericity was found to be significant ($\chi^2(55)=2659.75, p < 0.001$). EFA results revealed the indicators loaded into three factors with eigenvalues that exceeded 1.00; the three-factor solution explained a cumulative variance of 39.2% for the 11 items' scores (Table 3). The first factor explained 29.8% of the variance, the second 6.2%, and the third 3.2% (Figure 1).

The 11 factors loaded onto three factors (Table 3). Labels for these factors are: choice and engagement; person-centeredness; and, health and safety. *Choice and Engagement* includes: people interact with other members of the community; people participate in the life of the community; people perform different social roles; people choose where they work; and, people choose where and with whom to live. *Person-Centeredness* includes: people exercise rights; people are treated fairly; people are respected; and, people experience continuity and security.

Health and Safety includes: people have the best possible health; and, people are safe.

Cronbach's alpha was used to determine internal consistency for each of the components: choice and engagement (0.71), person-centeredness (0.76), and health and safety (0.47). While health and safety did not have a high Cronbach's alpha, Cronbach's alpha is impacted by the number of items on the scale (Field, 2013; Graham, 2006) and health and safety only had two indicators.

Despite low Cronbach's alpha, the analysis met both Kaiser's (1960) and Cattell's (1966) criterion for factor retention had reliable loadings (Stevens, 2002), and had a 'meritorious' Kaiser-Meyer-Olkin value according to Hutcheson and Sofroniou (1999).

Table 4 provides descriptive data for the Index. The mean score of participants suggest they are more likely to have health and safety ($M = 0.69$, $SD = 0.35$), than person-centeredness ($M = 0.50$, $SD = 0.38$) or choice and engagement ($M = 0.40$, $SD = 0.33$). A means analysis conducted to examine the differences among the components for the different demographic groups revealed few differences across the factors based on age or gender; however, there were wider differences in terms of race/ethnicity, guardianship status, residence type, daily support needs, and disability type (Table 5). People with assisted decision making or full/plenary guardianship had lower choice and engagement, as well as person-centeredness scores than people with independent decision making; differences were not as large for health and safety. people with disabilities with assisted decision making or full plenary guardianship should receive person-centered services and have choice and engagement.

People with more daily support, especially those with 6-24 hours, typically had lower choice and engagement scores, and person-centeredness scores than people with less daily support, such as those with support as needed (on call).

People with disabilities in provider owned or operated homes, state-operated home and community-based services (HCBS) group homes, and intermediate care facilities had lower choice and engagement scores than people with disabilities in their own homes, host family/family foster care, and family homes. People in state-operated HCBS group homes also had the lowest person-centeredness scores compared to the other settings.

People with behavioral challenges, Down syndrome, limited vision or who were legally blind, and/or physical disabilities had the lowest scores for choice and engagement. People with brain injury and/or personality/psychotic disorders had the lowest scores for person-centeredness. People with other mental illness/psychiatric diagnoses had the lowest score for health and safety.

Discussion

People with disabilities face a number of health inequities and disparities compared to nondisabled people. One of the first steps in remedying these disparities and maximizing the quality of life of people with disabilities is to measure peoples' social determinants of health. Therefore, the purpose of the study was to develop and validate the Social Determinants of Health Index. The Index is aimed at helping disability service providers examine the SDOH of those they support, to arm them with more information to provide targeted services and supports. An EFA revealed the Social Determinants of Health Index had three underlying themes: choice and engagement; person-centeredness; and health and safety.

Choice and Engagement

Choice and engagement are important aspects of SDOH. Choice includes ones' ability to make decisions about ones' life and community. Choice necessitates self-determination, participation, and autonomy. Ones' right to choose where to work and where to live are

reinforced by the Medicaid HCBS settings rule (CMS 2249-F/2296-F) (Centers for Medicare and Medicaid Services, 2014). Choice and engagement are often inextricably linked as choice, self-determination, and empowerment play a key role in the social inclusion of people with disabilities, including their right to be in the community and to access and interact with the world around them according to the Americans with Disabilities Act (ADA; 1990), *Olmstead v LC* (1999), and the HCBS settings rule. Gidley, Hampson, Wheeler, and Bereded-Samuel (2010) explain, according to social inclusion theory, “the narrowest interpretation [of social inclusion] pertains to the neoliberal notion of social inclusion as access” (p. 7). Access in this instance is about social capital, not necessarily about quality. “A broader interpretation regards the social justice idea of social inclusion as participation or engagement” (Gidley et al., 2010, p. 7), particularly human rights, opportunity, and fairness. Finally, “the widest interpretation [of social inclusion] involves the human potential lens of social inclusion as success through empowerment” (Gidley et al., 2010, p. 7)

Person-Centeredness

Factor two, person-centeredness, was comprised of four outcomes: people exercise rights, people are treated fairly (due process for rights), people are respected, and people experience continuity and security. Services being person-centered are not only a right and requirement of HCBS (Centers for Medicare and Medicaid Services, 2014), but rights should also be person-centered – each person decides which rights are the most important to them. Moreover, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as well as the ADA (1990) reinforce people with disabilities are entitled to the same rights as nondisabled people, including the right to be respected (United Nations, 2006). Moreover, elements of

respectful practice include supporting the person to control their life and recognizing complexity regarding choice, judgements, wellbeing, and dignity (Bigby, Frawley, & Phillips, 2014).

While it may not be immediately apparent why continuity and security fits in person-centeredness, included alongside rights and treated fairly, research has found a lack of continuity and security, particularly the high direct support professional (DSP) turnover rate, hinders peoples' quality of life. For example, people with disabilities who do *not* experience DSP turnover are twice as likely to exercise rights, be treated fairly, and be respected than people with disabilities who experience turnover; they are also less likely to receive organizational supports to facilitate these outcomes (Friedman, 2018b). In addition to impacting the growth and sustainability of community services, workforce stability can be an indicator of the quality of people with disabilities' lives (McLaughlin, Sedlezky, Belcher, Marquand, & Hewitt, 2015). Workforce issues greatly hinder the ability to make services person-centered and significantly limit the potential of services and supports (Friedman, 2018a).

Health and Safety

Factor three was comprised of two indicators: people have the best possible health; and people are safe. Health and safety are more traditional metrics but nonetheless important aspects of SDOH. Service organizations have long been required to track and report basic health quality metrics, such as evacuation drills, or incidences of abuse and neglect, to the states in which they operate. As these procedures are traditional forms of accountability, it is not necessarily surprising it outscored the other two factors. However, with new research about the benefits of SDOH, as well as legislation and litigation such as the ADA and *Olmstead v LC*, and advocacy by people with disabilities, has come a recognition that health and safety, although important, are not the only determinants of health and quality of life.

Differences Across Groups

Our findings also unearthed a number of differences across the groups in terms of social determinant factors. People with assisted decision making or full/plenary guardianship had lower choice and engagement and person-centeredness scores than people with independent decision making. People with disabilities with assisted decision making or full plenary guardianship should receive person-centered services and have choice and engagement. Currently, in the United States, guardians are typically given broad sweeping powers, rather than roles in the specific areas where the person with disabilities could use assistance (Salzman, 2011, pp. 174-175). In fact, Salzman (2011) even suggests this sweeping guardianship system violates the ADA and *Olmstead* because it not only is not the least restrictive option, it also limits peoples' rights. As such, Salzman (2011) recommends utilizing less sweeping restrictions, such as by utilizing supported decision making, a least-restrictive guardianship model which creates assisted opportunities for people with disabilities to exercise legal decision-making capacity. More research is needed to explore the relationship between guardianship and SDOH, including to determine any moderating effect guardianship may have.

People with more daily support often had lower choice and engagement and person-centeredness scores than people with less daily support. These factors include indicators related to choices, opportunities to participate in and interact with the community, exercise rights, and be respected. People with more significant disabilities are often denied choice-making opportunities based on well-intended protections. The limiting of people with disabilities' choices have often been entrenched in paternalism and based on conceptualizations that people with disabilities are incapable, low ability, and incompetent (Barnes & Mercer, 2003; Harris & Fiske, 2007; Reid, Stoughton, & Smith, 2006; Susman, 1994). Moreover, historically policy

designed to protect people with disabilities has been a source of disability oppression and actually taken away some of their rights (Carey, 2009; Quinn & Degener, 2002). For example, institutionalization, which originally aimed at protecting and caring for people with disabilities, frequently violates people with disabilities' rights to liberty and freedom (Braddock et al., 2015; Quinn & Degener, 2002; Trent, 1994). Through both formal policies and everyday acts, avoidance of risk is often built into the physical and social environments of many people with disabilities (Perske, 1972). However, "it is difficult to learn how to make decisions and handle risk if the chance to undertake either of these activities is denied" (Hudson, 2003, p. 261). If people with disabilities are to have equal opportunities, this includes the opportunity to take risks. Rather than over support people, the best supports involve balancing the duty of care and dignity of risk. It is the service organization's responsibility to support the person to understand the risks to reduce risk, rather than take away their choices altogether or deny their rights.

We also found differences in terms of choice and engagement scores and person-centeredness scores across settings, with people with disabilities in provider owned or operated homes, state-operated HCBS group homes, and intermediate care facilities having lower choice and engagement scores, and people in state-operated HCBS group homes having lower person-centeredness scores. These findings regarding choice and engagement, and person-centeredness are consistent with previous research which has found individual and family homes continue to be the gold standard in terms of quality of life outcomes (Friedman, 2019). Unfortunately, many provider "services today have become standardized, inflexible and unaccountable to those they serve" (Spagnuolo, 2016, n.p.). As such, to facilitate SDOH outcomes it is necessary for organizations to move beyond compliance and custodial models of care; they can begin to do so by not only attending to their culture to one that is accountable to the people with disabilities

they serve, including by reexamining norms and removing assumptions, but also by introducing evidenced based person-centered practices.

White people with disabilities in this study had higher choice and engagement scores on average than people of color with disabilities in this study. In particular, the largest gap in terms of choice and engagement scores was between White people and Latinx people, with Latinx people having choice and engagement present 14% less often than White people. When it came to person-centeredness, the differences were mixed – while people from ‘other’ races and Black people had the lowest scores, Indigenous Americans, Asian people, and Latinx people all scored higher than White people. Finally, when it came to health and safety, although there were slight differences by race, most of the racial groups had relatively close scores, with the exception of people from ‘other’ races. Given widespread and systemic racism, especially for people of color with disabilities, some of these disparities are perhaps not surprising (Bhopal, 1998; Blair et al., 2013; Erevelles & Minear, 2010; Goodman et al., 2017). However, there were a number of instances where people of color scored higher on factors than White people. As this is antithetical to existing research about discrimination, more research is needed to determine if these differences are statistically significant, and if so, if there are interactions causing these effects.

People with behavioral challenges, Down syndrome, limited vision or who were legally blind, and/or physical disabilities had the lowest scores for choice and engagement. People with brain injury and/or personality/psychotic disorders had the lowest scores for person-centeredness. People with other mental illness/psychiatric diagnoses had the lowest score for health and safety. People with these disabilities may have lower factor scores because of attitudes regarding their abilities, or because of interactions with other factors such as

impairment severity. More research is needed to determine why these disabilities resulted in lower factor scores; future research should examine if they can be replicated as these findings may be sample specific.

Implications for Practice, Research, and Policy

The Social Determinants of Health Index has many uses and can be utilized for varying scopes. Providers can utilize the Index to examine an individual person's score in order to determine where to target supports and services to facilitate the person's SDOH and their quality of life. For example, if a person scored high in terms of health and safety, but low in terms of person-centeredness, the provider could be intentional about implementing services that supported the person to exercise rights, be respected, have continuity and security, and so on. For example, in order to attend to rights, organizations must ensure they solicit the person's preferences and desires about the exercise of rights, identify the rights that are important to the person and learn about their preferences regarding their rights, provide the person with the support needed to exercise their rights, particularly those most important to them, and have adequate due process procedures for any rights limitations or restrictions (The Council on Quality and Leadership, 2017) (Additional suggestions regarding person-centered organizational supports can be found at The Council on Quality and Leadership (2017)). Providers can also aggregate Index scores for all the people they support to determine where they are excelling as an agency and where they need to make a concerted effort to improve their services in order to facilitate the SDOH outcomes of those they support. Moreover, by aggregating Index scores, providers can also look at disparities that may exist across the people they support. For example, the agency may discover that on average the older adults with disabilities they support have disparities in one of the areas of the Index, or across the entire Index compared to younger

adults, and utilize this information to design programs and services to help address these disparities. Similarly, aggregate provider-wide Index scores can be utilized to compare the quality of different providers or could even be used by states to determine the quality of the services in their state as a whole, especially in comparison to national benchmarks.

The Index can also be used by researchers to further explore the SDOH of people with disabilities. Health disparities are an indicator of a nation's health; as such, health disparities research is key for health equity (Abbott & Elliott, 2017). Not only can the Index be utilized to examine disparities in SDOH amongst people with disabilities, it can also be utilized to explore differences in SDOH across various sub-populations or factors (e.g., setting, service lines, etc.). Index scores can also be used to examine the relationships between SDOH and people with disabilities' quality of life as a whole, or different areas of their quality of life. For example, how does having friends facilitate people with disabilities' SDOH outcomes? How do organizational supports facilitate the presence of SDOH outcomes? Do people with higher Index scores get sick less or use emergency care less often? What's the relationship between Index scores and service expenditures? As the long-term services and supports system for people with disabilities moves away from fee-for-service and towards value-based payments and managed care, SDOH data and research is critical to help determine which areas should be prioritized as performance measures. Index data can be utilized to help show that by focusing on choice, engagement, person-centeredness, and health and safety, quality will not only increase, but expenditures may also decrease because attention to SDOH can improve people's health.

Limitations

When interpreting our findings, a number of limitations should be noted. First, our sample was not representative of people with disabilities as a whole as most participants had

intellectual and developmental disabilities and were White. This was a secondary analysis, so we did not have the ability to add variables or ask additional questions. The aim of this study was to develop the Social Determinants of Health Index; for this reason, although we examined descriptive differences across groups, we did not run statistical tests to compare findings across groups or to examine interactions between the groups. We believe these limitations represent opportunities for future research.

Conclusion

Health disparities are avoidable differences which disproportionately impact certain groups. Navarro (2009) notes, “it is not *inequalities* that kill, but those *who benefit from the inequalities* that kill” (p. 15). Health equity demands attention to SDOH, particularly for people with disabilities who often have poorer outcomes and face more health inequities than their nondisabled peers. The creation of the Social Determinants of Health Index for people with disabilities, which utilizes person-centered outcomes, is one strategy to work towards ultimately reducing health disparities. The United States Department of Health & Human Services (2015) notes, “This nation has within reach the ability to assure that all residents have equal access to quality public health, health care, and essential community services that preserve and protect health” (n.p.). Attention to SDOH can promote good health and quality of life for all.

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Table 1
Demographics (n = 1078)

Characteristics	<i>n</i>	%
Age range (n = 948)		
18 to 24	106	11.2%
25 to 34	214	22.6%
35 to 44	165	17.4%
45 to 54	165	17.4%
55 to 64	171	18.0%
65 to 74	91	9.6%
75+	36	3.8%
Disability		
Intellectual/developmental disability	741	71.0%
Mood disorder	179	17.2%
Seizure disorder/neurological problems	173	16.6%
Anxiety disorders	142	13.6%
Behavioral challenges	133	12.8%
Cerebral palsy	119	11.4%
Other mental illness/psychiatric diagnosis	114	10.9%
Autism spectrum disorder	108	10.4%
Personality/psychotic disorder	93	8.9%
Impulse-control disorder	79	7.6%
Down syndrome	49	4.7%
Physical disability	47	4.5%
Limited or no vision - legally blind	38	3.6%
Hearing loss - severe or profound	30	2.9%
Brain injury	23	2.2%
Alzheimer's disease or other dementia	19	1.8%
Other disabilities not listed	41	3.9%
Gender (n = 1010)		
Man	549	54.4%
Woman	461	45.6%
Race (n = 952)		
White	743	78.0%
Black	142	14.9%
Indigenous American	22	2.3%
Latinx	24	2.5%
Asian	6	0.6%
Other	15	1.6%
Primary method of communication (n = 966)		

Verbal/spoken language	189	19.6%
Face/body expression	136	14.1%
Communication device	14	1.4%
Sign language	11	1.1%
Other	16	1.7%
Guardianship status (n = 929)		
Independent decision making	285	30.7%
Assisted decision making	267	28.7%
Full/plenary guardianship	352	37.9%
Other	25	2.7%
Residence type (n = 919)		
Own home/apartment	217	23.6%
Family's house	143	15.6%
Host family/family foster care	27	2.9%
Provider operated house or apartment	462	50.3%
State operated HCBS group home	21	2.3%
ICFDD (state-operated or private)	20	2.2%
Other	29	3.2%
Daily support (n = 873)		
On call - support as needed	13	1.5%
0 to 3 hours/day	46	5.3%
3 to 6 hours/day	90	10.3%
6 to 12 hours/day	93	10.7%
12 to 23 hours/day	57	6.5%
24/7 - around the clock	538	61.6%
Other	36	4.1%

Note. People could have more than one disability. HCBS=Home and Community Based Services. ICFDD=Intermediate Care Facilities for People with Developmental Disabilities.

Table 2

Personal Outcome Measures factors and indicators

My human security	My community	My relationships	My choices	My goals
People are safe	People use their environments	People are connected to natural support networks	People choose where and with whom to live	People choose personal goals
People are free from abuse and neglect	People live in integrated environments	People have friends	People choose where to work	People realize personal goals
People have the best possible health	People interact with other members of the community	People have intimate relationships	People choose services	
People experience continuity and security	People participate in the life of the community	People decide when to share personal information		
People exercise rights		People perform different social roles		
People are treated fairly				
People are respected				

Table 3

Factor Loadings and Communalities

Item	Factor			Communality (h ²)
	Choice and engagement	Person- centeredness	Health and safety	
Interact with other members of the community	0.67			0.42
Participate in the life of the community	0.66			0.44
Perform different social roles	0.63			0.40
Choose where to work	0.50			0.29
Choose where and with whom to live	0.34			0.21
Exercise rights		0.83		0.59
Treated fairly		0.79		0.62
Respected		0.36		0.44
Continuity and security		0.30		0.28
Best possible health			0.59	0.36
People are safe			0.55	0.26

Table 4

Descriptive Statistics of the Social Determinant of Health Index

Indicator	<i>M</i>	<i>SD</i>
Factor 1: Choice and engagement	0.40	0.33
Interact with other members of the community	0.60	0.49
Participate in the life of the community	0.46	0.50
Perform different social roles	0.36	0.48
Choose where to work	0.34	0.47
Choose where and with whom to live	0.26	0.44
Factor 2: Person-centeredness	0.50	0.38
Exercise rights	0.45	0.50
Treated fairly	0.54	0.50
Respected	0.52	0.50
Continuity and security	0.49	0.50
Factor 3: Health and safety	0.69	0.35
Best possible health	0.66	0.47
People are safe	0.77	0.42

Table 5
Demographic Characteristics by Average Factor Score

Description	Choice and engagement		Person-centeredness		Health and safety	
	M	SD	M	SD	M	SD
Age range						
18 to 24	0.30	0.31	0.45	0.37	0.55	0.38
25 to 34	0.41	0.34	0.54	0.38	0.75	0.33
35 to 44	0.41	0.33	0.53	0.38	0.69	0.35
45 to 54	0.43	0.31	0.47	0.38	0.72	0.33
55 to 64	0.42	0.31	0.59	0.36	0.76	0.33
65 to 74	0.45	0.34	0.57	0.39	0.79	0.27
75+	0.47	0.34	0.65	0.36	0.73	0.33
Disability						
Alzheimer's disease or other dementia	0.36	0.32	0.47	0.41	0.79	0.30
Anxiety disorders	0.40	0.32	0.61	0.36	0.76	0.33
Autism spectrum disorder	0.44	0.33	0.51	0.39	0.67	0.35
Behavioral challenges	0.32	0.27	0.59	0.39	0.74	0.33
Brain injury	0.36	0.35	0.41	0.42	0.78	0.31
Cerebral palsy	0.37	0.32	0.50	0.37	0.78	0.33
Down syndrome	0.34	0.33	0.47	0.40	0.70	0.36
Hearing loss - severe or profound	0.41	0.30	0.65	0.34	0.77	0.32
Impulse-control disorder	0.36	0.29	0.51	0.37	0.71	0.34
Intellectual/developmental disability	0.40	0.32	0.51	0.38	0.71	0.34
Limited or no vision - legally blind	0.34	0.35	0.56	0.37	0.80	0.30
Mood disorder	0.38	0.32	0.50	0.37	0.71	0.35
Other mental illness/psychiatric diagnosis	0.43	0.32	0.53	0.38	0.64	0.38
Personality/psychotic disorder	0.35	0.29	0.42	0.38	0.68	0.35
Physical disability	0.30	0.32	0.50	0.36	0.75	0.33
Seizure disorder/neurological problems	0.37	0.29	0.48	0.39	0.74	0.31
Other disabilities not listed	0.43	0.36	0.57	0.42	0.68	0.37
Gender						
Man	0.42	0.33	0.54	0.38	0.75	0.33
Woman	0.39	0.32	0.50	0.39	0.68	0.35
Race						
Indigenous American	0.36	0.24	0.69	0.27	0.69	0.35
Asian	0.33	0.31	0.58	0.52	0.67	0.29
Black	0.41	0.32	0.50	0.37	0.71	0.36
Latinx	0.28	0.31	0.60	0.38	0.75	0.35
White	0.42	0.33	0.52	0.38	0.72	0.33
Other	0.32	0.40	0.38	0.41	0.60	0.46
Primary method of communication						

Communication device	0.37	0.35	0.58	0.42	0.83	0.32
Face/body expression	0.32	0.28	0.53	0.39	0.79	0.29
Sign language	0.38	0.27	0.67	0.33	0.94	0.17
Verbal/spoken language	0.43	0.33	0.52	0.38	0.70	0.35
Other	0.45	0.35	0.52	0.40	0.77	0.26
Guardianship status						
Independent decision making	0.48	0.33	0.56	0.36	0.71	0.34
Assisted decision making	0.38	0.32	0.58	0.39	0.78	0.33
Full/plenary guardianship	0.37	0.32	0.45	0.37	0.69	0.34
Other	0.43	0.32	0.42	0.42	0.57	0.31
Residence type						
Own home/apartment	0.53	0.33	0.57	0.39	0.73	0.33
Family's house	0.41	0.34	0.45	0.37	0.68	0.38
Host family/family foster care	0.50	0.28	0.44	0.37	0.64	0.31
Provider operated house or apartment	0.35	0.30	0.53	0.37	0.74	0.33
State operated HCBS group home	0.26	0.28	0.34	0.35	0.76	0.31
ICFDD (state-operated or private)	0.33	0.31	0.56	0.40	0.62	0.36
Other	0.39	0.33	0.48	0.41	0.67	0.34
Daily support						
On call - support as needed	0.67	0.32	0.58	0.36	0.71	0.40
0 to 3 hours/day	0.63	0.34	0.72	0.35	0.74	0.33
3 to 6 hours/day	0.48	0.36	0.52	0.39	0.66	0.38
6 to 12 hours/day	0.40	0.31	0.53	0.37	0.69	0.36
12 to 23 hours/day	0.40	0.30	0.44	0.39	0.76	0.32
24/7 - around the clock	0.37	0.30	0.51	0.38	0.73	0.33
Other	0.60	0.35	0.61	0.36	0.74	0.34

Note. ICFDD = Intermediate care facility for people with developmental disabilities. HCBS = Home and community based services.

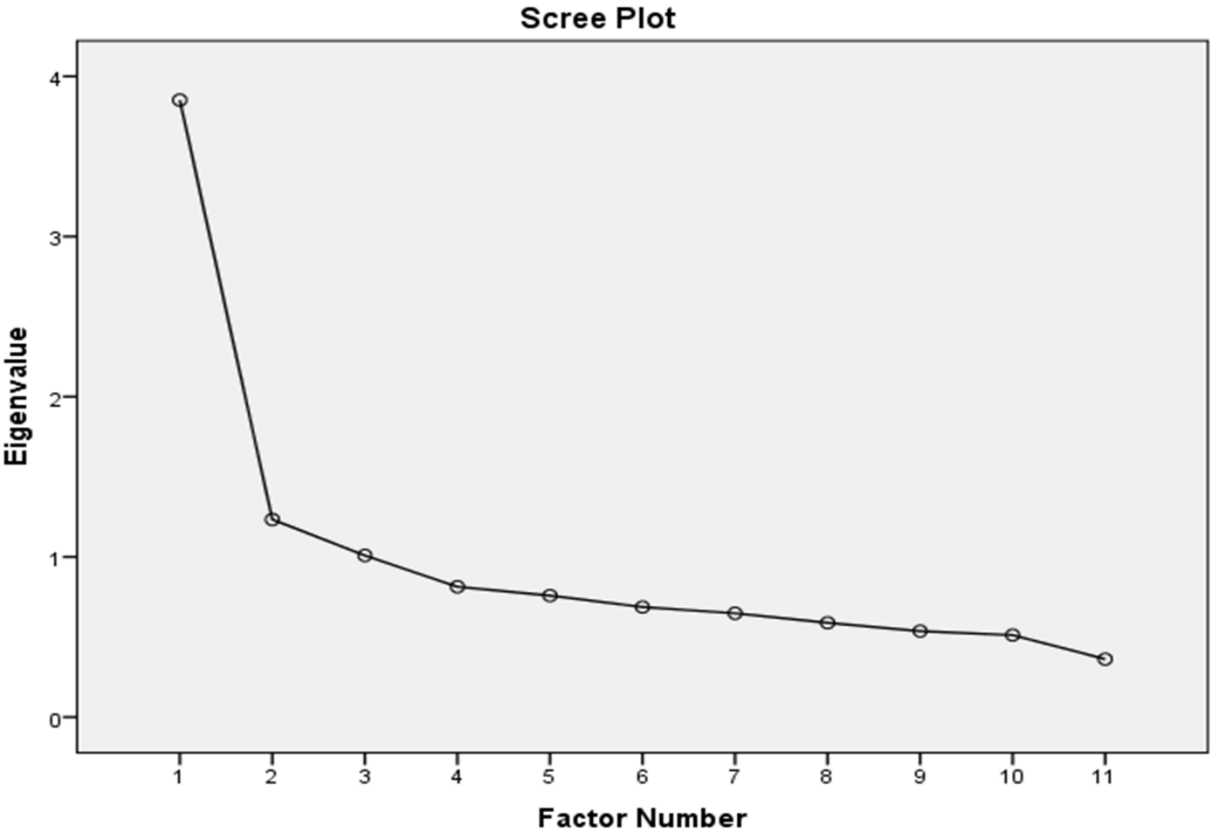


Figure 1. Scree plot.