

Accommodating Developmental Disabilities in the Social Determinants of Health:

A Brief Inquiry into the Applicability of Metrics to the Lives of Individuals with Developmental Disabilities in Delaware

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Abstract

This commentary outlines the methods and findings of a preliminary study examining the fitness of the Social Determinants of Health in their current conceptualizations for accommodating the specific and general experiences of individuals with developmental disabilities and suggests recommendations for both additional research and policy interventions. The study is based on research conducted with individuals with intellectual and developmental disabilities living in Delaware and other stakeholders working in this community. There is currently extensive literature concerning the validity and importance of including the social determinants of health in healthcare decision-making, but very little research exists around the intersection of developmental disabilities and these determinants. This commentary provides additional detail and added emphasis to calls previously made in this Journal to align social determinants with developmental disabilities and the importance of considering the SDOH in policy measures aimed at supporting this population. The ultimate aim of the work presented here is to explore how the State's interest in putting the SDOH to work generally can be aligned to accommodate the needs and interests of individuals with I/DD and to identify future research and policy interventions in support of these efforts.

Background

The Social Determinants of Health

The connection between health equity and the social determinants of health has been demonstrated through multiple studies. The U.S Department of Health and Human Services (HHS), in its report, *Healthy People 2020*, defines the social determinants of health (SDOH) as “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.” The five key determinants include: economic stability, education, social and community context, health and healthcare, and neighborhood and built environment.¹

A study by the World Health Organization (WHO) Commission on Social Determinants of Health (CSDH) found that the social determinants of health contribute (individually and collectively) to many of the health inequities present within countries. A 2010 WHO article compiled and summarized 13 separate studies to analyze the impact of the social determinants on public health programs. The studies found that among other impacts, the SDOH influenced the prevalence of cardiovascular disease, health and nutrition of children, food safety, unintended pregnancy and pregnancy outcomes, and violence and unintentional injury.²

The Developmental Disability Community

For individuals with developmental disabilities, maintaining good health is essential in order to reduce the effect of “impairment on functioning and participation.”³ However, the IDD community is exposed to many barriers to health including a lack of prepared health providers, scarce access to high quality medical care, and a lack of inclusion of people with IDD in public health efforts.⁴ Additionally, people with acquired physical disabilities such as Polio, Rheumatoid Arthritis, and stroke are more likely to acquire a greater number of chronic diseases.⁵ This increased possibility emphasizes the importance of access to adequate health care, in general, and an appreciation for how social determinants of health create or exacerbate these conditions within the population of individuals with IDD. However, the IDD community is not typically discussed in SDOH literature. In the latest report by the CSDH, the word “women” is mentioned 337 times, “gender” 237 times, “the poor” 75 times, “indigenous people” 37 times, “disabled people” 1 time, and “people with disabilities” 3 times.⁶

Healthy People 2020 maintains an objective of “disability and health,” and commits to “[e]xpanding the knowledge base and raising awareness about determinants of health for individuals with disabilities by increasing:

- 1) the inclusion of individuals with disabilities in public health data collection efforts across the lifespan;
- 2) the inclusion of individuals with disabilities in health promotion activities; and
- 3) the expansion of disability and health training opportunities for public health and health care professionals.”¹

There is an acknowledged lack of data already present regarding the application of the SDOH to the general assessment of health within the IDD community. However, we found no studies assessing the *fitness* of application of the SDOH as generally understood and measured to individuals with IDD. Our brief survey, outlined below, is an attempt at taking that first step in assessment and an exploration of what might need to be modified in our general understanding of social determinants of health in order to make them of use – for both policy and clinical practice – supporting individuals with IDD.

Methodology

This project employed a mixed-methods approach to data collection using content gathered from a series of semi-structured interviews (see Appendix A) to inform and shape the structure of a survey distributed to a broader audience of stakeholders receiving services from Delaware’s Division of Developmental Disabilities Services (DDDS). Methods were structured in this way to allow for a quick, scalable snapshot of the broad intersection of the social determinants with experiences of those living with intellectual and/or developmental disabilities while providing an opportunity for future refinement and focus on select areas of interest.

Both interviews and surveys focused on *fitness* of current conceptions of the Social Determinants of Health and not on health outcomes associated with those determinants. That is, while there is an acknowledged lack of data examining the social determinants of health and their application to individuals with disabilities, we instead have stepped back to ask whether the language and metrics used to substantiate the determinants themselves adequately accommodate the lived experiences of individuals with developmental disabilities in the first place. The goal of this

specific research was to study the tool itself to examine its applicability to our targeted population. The findings of this research are descriptive level data that do not draw the connection between the determinants and health outcomes, but instead provide perspective on the language and metrics used.

Part A: Semi-Structured Interviews

The semi-structured interviews were conducted with the goal of obtaining experience with and reaction to standard metrics commonly used in each of the five main categories of social determinants. Interviews were conducted through video calls with eight individuals occupying at least one of the following three categories: an individual with an intellectual or developmental disability, a parent of a child with an I/DD, or a professional with experience working with individuals with intellectual and/or developmental disabilities. Interviewees were asked a few short introductory questions before being introduced to the social determinants. Interviewees were asked to draw on personal and professional experiences to reflect on the adequacy of measures used to evaluate the social determinants and to provide feedback for making them more inclusive of their experiences. The interviews were then transcribed, and thematic analysis was conducted with the goal of identifying the most prevalent responses and connections to ideas behind those responses.

Part B: Survey

From the analysis of our semi-structured interviews, we generated a short twenty question survey to be distributed among active DDS service recipients. The survey was sent to all DDS service recipients with cases managed by the Columbus Organization and yielded 171 responses. The survey was designed to collect data in three scales. First, a Likert scale was used to assess what indicators within each determinant were of importance. Participants were then asked to rank-order priorities within each SDOH category, indicating the most important priority within each determinant. Finally, respondents were asked to rank order SDOH categories with regards to immediate needs and priorities for access to a healthy life. The survey also included questions that gauged awareness of SDOH focused initiatives, such as free financial literacy courses.

Results

Part A: Semi-Structured Interview

Figure 1 presents the responses from the semi-structured interview. Each response that is bolded signifies that it was a repeated response, and the parenthesis next to each bolded issue expresses the number of times a response was repeated.

Figure 1. SDOH, Key Issues (Identified by HHS), and Proposed Key Issues

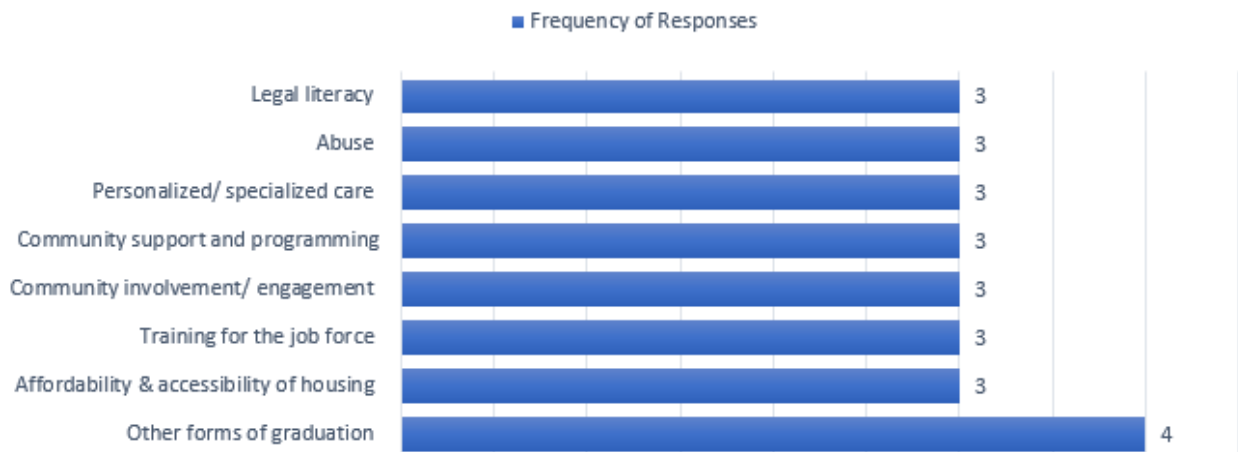
| Determinant | Economic Stability | Education | Social and Community Context | Health and Healthcare | Neighborhood & Built Environment |
|--|---|--|--|--|--|
| Key Issues (as identified by HHS)¹ | <ul style="list-style-type: none"> Poverty Employment Food Insecurity Housing instability | <ul style="list-style-type: none"> High school graduation Enrollment in higher education Language and literacy Early childhood education and development | <ul style="list-style-type: none"> Social cohesion Civic participation Discrimination Incarceration | <ul style="list-style-type: none"> Access to healthcare Access to primary care Health literacy | <ul style="list-style-type: none"> Access to foods that support healthy eating patterns Quality of housing Crime and violence Environmental conditions |
| Proposed Key Issues² | <ul style="list-style-type: none"> → Accessibility, affordability, and availability of housing (3) → Training for employers on inclusivity (2) → Support in the employment role (2) → Long Term caregivers (2) <ul style="list-style-type: none"> ○ Access to med supply companies for food security ○ Registering with support services ○ Guardianship/finance controls ○ State services ○ Retirement ○ Home dynamic ○ Financial literacy ○ Disability income | <ul style="list-style-type: none"> → Other forms of graduation (4) → Training for the job force (3) → Utilization of IEPs (2) → Integration in schools (2) → Early intervention (2) → Specialized service and support (2) → Accommodations in higher ed (2) <ul style="list-style-type: none"> ○ Post high school job support training ○ Support for communication ○ Special Education ○ Paraprofessionals | <ul style="list-style-type: none"> → Community involvement/engagement (3) → Community support and programming (3) → Communication support (2) → Family support (2) → Socialization (coworkers, friends) (2) <ul style="list-style-type: none"> ○ Racial and ethnic discrimination and the intersection with disability discrimination ○ Modalities of learning ○ Entrepreneurship/ hobbies/activities/ skills ○ Social support | <ul style="list-style-type: none"> → Personalized/specialized care (3) → Access to behavior support services (2) → Home visits (2) → Insurance (2) → Quality of provider (education, social competence) (2) → Health technology (updated technologies, tests etc) (2) <ul style="list-style-type: none"> ○ Access to speech therapy ○ Pharmaceuticals ○ Caregivers' health ○ Cognitive ability to function ○ Plain language medical literature | <ul style="list-style-type: none"> → Abuse (3) → Legal literacy (3) → Social work rather than police intervention (2) → Educating the IDD community about crime and victimization (2) <ul style="list-style-type: none"> ○ Workplace environment |

[1] The already established key issues from the U.S. Department of Health and Human Services.

[2] The key issues identified from the survey, grouped by key determinant

Part A of the survey identified key issues and underlying causes that are the strongest indicators of the five determinants for the developmental disability community. Figure 2 indicates the most frequently identified priorities and the frequency of responses.

Figure 2. Top Indicators for Determinants by Frequency of Responses



Part B: Survey

Part B surveyed 171 individuals receiving services from DDDS and identified the order of key issues and underlying causes that are important to the developmental disabilities community when considering the five key determinants.

I. Economic stability

1. Access to employment or vocational training
2. Registration with state-based services
3. Accommodations in employment

II. Education

1. Utilization and quality of IEPs
2. Access to alternate degrees
3. Access to accommodations in higher education

III. Social and Community Context

1. Access to appropriate communication
2. Support of community
3. Involvement in community

IV. Health and Healthcare

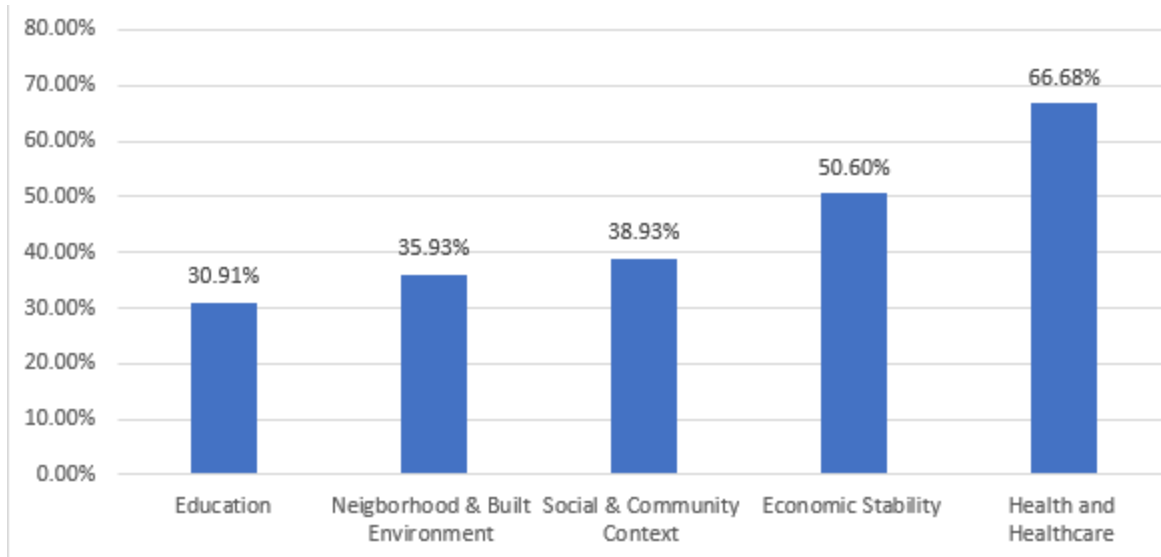
1. Access to quality medical care
2. Plain language medical literature
3. Behavioral supports

V. Neighborhood and Built Environment

1. Affordable, accessible housing
2. Affordable, readily available transportation
3. Comfort in law enforcement interactions.

The respondents were then asked to rank the determinants according to what they felt was a top priority for indicating their health outcomes. Respondents could indicate more than one determinant as a top priority. Figure 3 depicts the ranking of determinants based on respondents' top priority.

Figure 3. Percent of Respondents who Indicated Top Priority



A small number of additional questions regarding awareness of resources to address some of these priorities were also asked. When asked about S.T.A.N.D., abuse training in DE, only 18% were aware of this resource. When asked about awareness of financial literacy courses through DE Money School, 30% knew about this service.

Policy Options, Opportunities, & Further Research

Additional research is needed to systematically understand what role the social determinants of health can and should have in accounting for the health and livelihoods of individuals with intellectual and developmental disabilities, and what additions or modifications would need to be made to those determinants to make them applicable and inclusive of this population. Based on this preliminary work, however, there is plenty of data to suggest at least a few immediate, trackable policy interventions that can be made.

Policy Options – Short-Term

1. Resources available to the developmental disability community regarding education, economic stability, community, health, and environment should be easy to access and easy to navigate.

Through the semi-structured interviews conducted, it was found that while many programs in place aim to address the inequities in the SDOH for the developmental disability community, often they are not known because of the lack of accessible advertisement or display of these resources. Further, in the surveys, it was found that many people were not aware of free, community-based initiatives such as free financial literacy classes. In the survey, individuals indicated that they would like help finding a job. Comments like these provide an opportunity for resource creation, such as an inclusive employers list. Through improving how programs and recourses are marketed and advertised to individuals, the full potential of the programs increases.

2. Access to plain language medical literature and opportunities to improve health literacy are critical for ensuring equal access to healthcare. The State and Delaware-based healthcare communities must come together to remove these barriers.

In the semi-structured interview portion of the study, access to plain language medical literature was flagged as a priority. Further, during the survey, it was ranked either number one or number

two in health and healthcare by over 53% of respondents. Providing plain language medical literature is a short-term goal that can be implemented in healthcare settings such as clinics, doctors' offices, and hospitals. This could also mean ensuring that language or ability to read are not barriers in understanding medical options. The U.S. Department of Health and Human Services (HHS) maintains a health literacy [webpage](#) that provides tools that can be utilized to improve the usability of different health tools.

Further, the HHS Health Literate Care Model (figure 4) should be implemented in Delaware healthcare settings to ensure that health literacy is a central value in DE.⁷

Figure 4. The Health Literate Care Model⁷



The goals of the Health Literate Care Model are:

- Approach all patients as if they are at risk of not understanding health information;
- Employ a range of strategies for clear communication;
- Confirm that patients understand what providers are saying⁷

Ultimately, the Health Literate Care Model outlines the standard of approaching all patients if they may not understand their health conditions or how to manage them. Following this, subsequent confirmation that patients understand is required. This model would create a systemic plan for addressing health literacy.

Policy Options – Long-Term

Delaware-based medical providers should have consistent access to quality continuing education opportunities specific to IDD health and healthcare.

In both the semi-structured interviews and the mass survey, “access to quality medical providers, familiar with developmental disabilities” ranked as a priority. Further, the disparities in physician knowledge around disabilities was demonstrated through a study by Lisa Iezzoni et al. who

found that 35.8% of physicians knew little or nothing about their legal responsibilities under the Americans with Disabilities Act and 68.4% felt that they would be at risk for ADA lawsuits.⁸

To ensure that physicians and health professionals are well versed to treat vulnerable communities, it is important that medical professionals continue learning about developmental disability health. By creating a CME requirement of developmental disability health, the population with disabilities will be provided with the best health treatment possible.

The Medical Society of Delaware (MDS) provides accreditation and training events for medical professionals in Delaware.⁹ There should be a partnership formed with MDS to ensure that medical trainings relating to disability health are incorporated into MDS resources.

Further Research

More evidence-based research should be conducted on the current policy efforts aimed at addressing issues related to the Social Determinants of Health.

Through the literature review, it was found that there is a lack of evidence-based research surrounding the effectiveness of policy interventions on the SDOH. This data collection and policy recommendation serves as a blueprint for further policymaking and policy tracking around the SDOH and disabilities. Producing evidence-based research, specifically targeted at the indicators within the health and healthcare and education determinants, would provide a sound foundation of data that is centered on producing equitable health outcomes. By producing this type of research, the importance and validity of policy in this area will be demonstrated, allowing for the inclusion of the social determinants of health in decision-making.

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References

1. Healthy People. 2020. (n.d.) *Disability and health*. <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>
2. World Health Organization. (1970, Jan 1). *Equity, Social Determinants and public health programmes*. World Health Organization. <https://apps.who.int/iris/handle/10665/44289>
3. Abdullah, N., Horner-Johnson, W., Drum, C. E., Krahn, G. L., Staples, E., Weisser, J., & Hammond, L. (2004). Healthy lifestyles for people with disabilities. *Californian Journal of Health Promotion*, 2(SI), 42–54.
4. Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013, October). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 51(5), 385–398. <https://doi.org/10.1352/1934-9556-51.5.385> PubMed
5. Campbell, M. L., Sheets, D., & Strong, P. S. (1999). Secondary health conditions among middle-aged individuals with chronic physical disabilities: Implications for unmet needs for services. *Assist Technol*, 11(2), 105–122. <https://doi.org/10.1080/10400435.1999.10131995> PubMed
6. Wolbring, G. (2011, July-August). People with disabilities and social determinants of health discourses. *Can J Public Health*, 102(4), 317–319. <https://doi.org/10.1007/BF03404058> PubMed

7. U.S. Department of Health and Human Services. (n.d.). Health literate care model. <https://health.gov/our-work/national-health-initiatives/health-literacy/health-literate-care-model>
8. Iezzoni, L. I., Rao, S. R., Ressler, J., Bolcic-Jankovic, D., Agaronnik, N. D., Lagu, T., . . . Campbell, E. G. (2022, January). US physicians' knowledge about the Americans with disabilities act and accommodation of patients with disability. *Health Affairs (Project Hope)*, 41(1), 96–104. <https://doi.org/10.1377/hlthaff.2021.01136> [PubMed](#)
9. Medical Society of Delaware. (n.d.). CME. https://www.medicalsocietyofdelaware.org/delaware/CMMSD/CME/CMMSD/Nav_Items/CE.aspx

Appendix A

Semi-Structured Interview Guide

DDDS Semi-Structured Interview Survey

Part 1: Background Questions

1. What is your relationship with the IDD community?

Expert Parent Individual with IDD

2. How long have you had this relationship?

_____ years _____ months

3. Are you familiar with the Social Determinants of Health?

yes no

* Share figure 5 (below) on the screen*

Figure 5. Measures of SDOH

| Determinant | <u>Economic Stability</u> | <u>Education</u> | <u>Social and Community Context</u> | <u>Health and Healthcare</u> | <u>Neighborhood and Built Environment</u> |
|--------------------|---|--|---|---|--|
| Measure | <ul style="list-style-type: none"> → Poverty → Employment → Food Insecurity → Housing instability | <ul style="list-style-type: none"> → High school graduation → Enrollment in higher education → Language and literacy → Early childhood education and development | <ul style="list-style-type: none"> → Social cohesion → Civic participation → Discrimination → Incarceration | <ul style="list-style-type: none"> → Access to healthcare → Access to primary care → Health literacy | <ul style="list-style-type: none"> → Access to foods that support healthy eating patterns → Quality of housing → Crime and violence → Environmental conditions |

<https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources>

Read the following aloud:

To provide a general definition, I will read the U.S. Department of Health and Human Services, Healthy People definition. Healthy People defines the Social Determinants of Health as “ the conditions in the environments where 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.”

SDOH can be grouped into 5 domains: Economic Stability, Education, Social and Community Context, Health and Healthcare, and Neighborhood and Built Environment.

Healthy People identify that the goal of SDOH is “ to establish policies that positively influence social and economic conditions and those that support changes in individual behavior, we can improve health for large numbers of people in ways that can be sustained over time. Improving the conditions in which we live, learn, work, and play and the quality of our relationships will create a healthier population, society, and workforce.”

Do you have questions about the role of the social determinants of health before we move forward?

Read the following aloud:

This chart has the 5 key determinants along with key issues that Healthy People have identified as representative of the determinants. I will go through the chart section by section and following each section, I will ask a few follow up questions. Do you have any questions before we move on?

For economic stability, the issues identified were poverty, employment, food insecurity, and housing stability.

1. In your opinion, what if any determinants or measures shown here are not inclusive of the IDD community?

2. What if any measures or determinants should be added to accurately include the IDD community? For example, when thinking about employers, maybe inclusive employers should be added.

For education, high school graduation, enrollment in higher education, language and literacy, and early childhood education and development were identified.

1. In your opinion, what if any determinants or measures shown here are not inclusive of the IDD community? For example, high school graduation may not be applicable to everyone.
2. What if any measures or determinants should be added to accurately include the IDD community? For example, alternative diplomas may need to be added to education to accurately include the IDD population.

For social and community context, the issues identified were social cohesion, civic participation, discrimination, and incarceration.

1. In your opinion, what if any determinants or measures shown here are not inclusive of the IDD community?
2. What if any measures or determinants should be added to accurately include the IDD community? For example, maybe community support should be added?

For health and healthcare, access to healthcare, access to primary care, and health literacy were identified.

1. In your opinion, what if any determinants or measures shown here are not inclusive of the IDD community?
2. What if any measures or determinants should be added to accurately include the IDD community? For example, access to behavioral services?

Finally, the issues identified for neighborhood and built environment were access to foods that support healthy eating patterns, quality of housing, crime and violence, and environmental conditions.

1. In your opinion, what if any determinants or measures shown here are not inclusive of the IDD community? For example, it might be important to note that many of these key issues are drastically different for people living in residential communities and those living alone.
2. What if any measures or determinants should be added to accurately include the IDD community?
3. Do you have any additional comments you would like to share?

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