

UNITED WAY RESEARCH

“DISABILITY”

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INTRODUCTION: DEFINING DISABILITY

Disability is a complex issue. With a multitude of definitions, a struggle for many organizations may be the application or pertinence of the defining source. The goal of this project was to capture a definition of “disability” to standardize reporting. Unfortunately, there is no set definition, so we turned to United Way partners to provide insight. Here is what we learned during a literature review and in-person interviews with six community partners encompassing services for developmentally disabled, chemical dependent/ mentally ill, child protection, and a daycare organization with a family resource center.

In this review, the definition of “disability” was originally planned to be derived from four sources.

SOURCE ONE: MERRIAM WEBSTER

A physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions.

This definition focuses on a person's *ability* but does not provide any thresholds or definitions as to what is considered typical activities and interactions. At base, it is focused on difference from a socially constructed norm.

https://www.merriam-webster.com/dictionary/disability?utm_campaign=sd&utm_medium=serp&utm_source=jsonld

SOURCE TWO: TABERS MEDICAL DICTIONARY

Any physical, mental, or functional impairment that limits a major activity. It may be partial or complete. The definition of disability is controversial. To some experts it refers to any restriction or inability to perform socially defined roles or tasks that are expected of an individual in specific social contexts. Another concept of disability is that it is any restriction or

lack of ability to perform tasks or roles in the manner previously considered normal for an individual.

Contemporary beliefs of disability recognize that characteristics of the environment interact with an individual's abilities to determine functional performance. In this view, the presence of disability is not entirely determined by bodily function or impairment.

According to Tabers, there are 8 types of disabilities;

- developmental disability
- excess disability
- intellectual disability
- learning disability
- mobility disability
- nonverbal learning disability
- phonological disability
- reading disability

This definition is similarly focused on difference from a socially constructed norm but provides more granular detail on types of difference than does the lay definition provided by Merriam-Webster. This definition suggests that disability may be context-specific, without providing any benchmarks or thresholds.

<https://www.tabers.com/tabersonline/>

<https://www.tabers.com/tabersonline/search?st=OSS&q=disability> (239 results)

SOURCE THREE: STATE OF MINNESOTA

The difficulty with finding a universal definition of "disability" for the State of Minnesota was the creation of "Welcome to Disability Minnesota!" - a website to provide a single entry point to over 100 Minnesota state agency programs, products, and services that are devoted to the range of disability issues. The site also provides access to laws, statutes, and regulations in pertinent disability-related areas.

State definitions of disability have a great degree of overlap with Tabers medical dictionary in that they focus on context-specific definitions of disability (by-and-large, educational, employment, and built-environment contexts) while also providing a number of ways to describe disability (physical, learning, etc.)

<https://mn.gov/disability-mn/>

SOURCE FOUR: FEDERAL SOCIAL SECURITY

To meet our definition of disability, you must not be able to engage in any substantial gainful activity (SGA) because of a medically-determinable physical or mental impairment(s):

That is expected to result in death, or that has lasted or is expected to last for a continuous period of at least 12 months.

NOTE: There is a separate definition of disability for children (under age 18) who are applying for the Supplemental Security Income (SSI) program.

As opposed to other sources, the federal definition of disability is highly context-specific (employment) without providing any description other than duration.

<https://www.ssa.gov/redbook/eng/definedisability.htm>

KEY TAKEAWAY: THERE'S NO CONSENSUS

Within the complexity of understanding the “definition” of “disability”, we posed the question of “Are Olmsted County United Way funded organizations collecting a client’s disability status?” We created a multi-question survey with various questions based on a 34-Item Disability Screening Questionnaire (DSQ-34) for use in Low and Middle Income Countries Epidemiological and Development Surveys. As the interviews progressed, we expanded our interviewee pool to include programs and agencies not currently funded by United Way of Olmsted County.

Staff from several agencies in our community agreed to an interview to provide their experiences and perspectives:

Listed below are the questions included in the interview, meant to explore the agency’s current perspective on measuring and assessing disability, as well as some additional aspects of the service landscape experienced by agencies in Rochester. The questions focused on measuring and assessing disability were:

1. Within the complexity of understanding the “definition” of “disability, is your program attempting to collect a client’s disability status? Has this been what you consider to be “successful”?
2. Within the complexity of understanding the “definition” of “disability, is your program attempting to assess a client’s disability status? Has this been what you consider to be “successful”?
3. Is there a particular mechanism (tool) is used by your program to gather disability information?

4. Does your program define “disability” in a context of “any restriction or inability to perform socially defined roles or tasks that are expected of an individual in a specific social context?”
5. Does your program define “disability” in a context of “any restriction or inability to perform tasks or roles in the manner previously considered normal for an individual?”
6. Can you speak to your program or agency’s beliefs around how disability should be defined and perceived? Such as environmental, physical, social considerations that define “disability”?
7. Has your program tried to “measure” a client’s disability to understand the outcome of your program and identify service gaps?

Summarized below are response to each of the interview questions. Full responses can be found quoted underneath the summary. Names and agencies identifying information has been removed.

WITHIN THE COMPLEXITY OF UNDERSTANDING THE “DEFINITION” OF “DISABILITY, IS YOUR PROGRAM ATTEMPTING TO COLLECT A CLIENT’S DISABILITY STATUS? HAS THIS BEEN WHAT YOU CONSIDER TO BE “SUCCESSFUL”?

In general, agencies specifically developed to serve individuals with disabilities are collecting disability status as a requirement of their work – these statuses are aligned with various medical diagnoses and state/federal disability definitions. Other agencies may collect disability status to varying degrees, with some documenting the information only if it is offered by program participants and other requesting this information from all program participants. In most instances, programs will request information that is highly context specific. Some examples include a preschool asking for IEP information, or a program focusing on rehabilitation doing monthly checks on sobriety and mental illness.

1. *All referrals come from County social workers with accompanying medical documentation. Clients served are from SE MN. Region. Referrals are necessary for program to receive funding. Staff member felt attempt to collect disability status was overall successful. Although gathering this type of information was harder for individuals over the age of 18. DD waiver is necessary for age 18 and over. There can be service overlaps for clients age 18 to 21.*
2. *Yes, successful. Required to have documentation for whatever disability a client is diagnosed. Ex. Autism, Down Syndrome, etc. This information does help in the*

decision-making process. Funding sources require individual meets "disability" definition. Able to take private pay.

3. *No. Use Adverse Childhood Experience (ACE) tool score based on childhood trauma.*
4. *Yes. On intake, ask if collecting any SSI or disability income, does client have needs? Can review at monthly visits. Document in care plan. Ability to intervene at times, if needed.*
5. *No. People may offer this type of information.*
6. *Yes. For children, licensing requires this information. Ex. If Individualized Education Plan (IEP) exist, needs to be on file. Direction comes from School District. "Success" is being defined/ refined. Working on a tool to use in the Family Resource Center.*

WITHIN THE COMPLEXITY OF UNDERSTANDING THE "DEFINITION" OF "DISABILITY, IS YOUR PROGRAM ATTEMPTING TO ASSESS A CLIENT'S DISABILITY STATUS? HAS THIS BEEN WHAT YOU CONSIDER TO BE "SUCCESSFUL?"

The two agencies developed to serve individuals with disabilities do assessments on occasion, but in most cases program participants will already have been assessed prior to their referral being made.

Other agencies uniformly responded that they do not assess a program participant's disability status, while at the same time doing assessments on dimensions of functioning such as trauma, chemical dependency, mental health/illness, and early childhood development. Any one of these assessments may reveal disability status or be viewed as assessing context-specific disability status in and of themselves.

1. *Yes, successful when implemented correctly. Staff training/ team training can be a hinderance to this success.*
2. *County caseworker does assessment and determines needs. "MN. Choices" possible name of program caseworker may utilize. At later time, may do functional assessment.*
3. *No.*
4. *Don't necessarily assess. Depends on staff's licensure. Ability to refer, if needed. Does client have County "ARMS" worker?*
5. *No.*
6. *No, not disability focused. Program does collect information ongoing.*

IS THERE A PARTICULAR MECHANISM (TOOL) IS USED BY YOUR PROGRAM TO GATHER DISABILITY INFORMATION?

Despite agencies saying they do not assess for disability status, five of the six agencies were able to identify the tool that they used to assess program participants' context-specific behaviors, and which could be used for person-centered planning, such as to develop a treatment or intervention plan for that individual. The agency which does not have a such a tool relies on outside assessments from Olmsted County.

1. *Utilize a "one-page snapshot". Focus on person-centered planning. Believe can't keep person in a bubble. Struggle with getting State and Federal lawmakers to understand that. Coming down the pipeline for a change is the Olmstead Act (federal law, like Massachusetts State in yr. 1999.) (WIOA- Federal Plan Remove Sub-Minimum Act.)*
2. *No.*
3. *ACE score. Agency views participants as "resilient".*
4. *Utilization of Intake and Care Plan. Ex. Do track for TBI (traumatic brain injury). There is a "Head Trauma and Brain Injury" questionnaire.*
5. *There is some data collection. Ministry leader may collect some data and share nationally. Helps identify issues.*
6. *Teaching Strategies Gold are completed which may lead to a referral re: disability.*

DOES YOUR PROGRAM DEFINE "DISABILITY" IN A CONTEXT OF "ANY RESTRICTION OR INABILITY TO PERFORM SOCIALLY DEFINED ROLES OR TASKS THAT ARE EXPECTED OF AN INDIVIDUAL IN A SPECIFIC SOCIAL CONTEXT?"

Five of the six agencies interviewed could identify within their programming an assessment that focused on context-specific performance. This was typically tied to the agency's focus – such as early childhood development, sobriety, and recovery from trauma. When responding to this question, the interviewee would often respond that they do this but they don't use the label 'disability' due to the stigma.

1. *Yes, overall. No, for TBI clients (exception of possibly impulse control).*
2. *Yes, along with need to take care of Activities of Daily Living (ADL's).*
3. *Yes, but do not use the word "disability". "Disability" has such a negative context.*

4. *Not necessarily. Labels can cause guilt and shaming. Instead, ask, "How is your mental or physical health going?" Provide monthly social opportunities for adults, no children.*
5. *No.*
6. *If child not meeting developmental milestones, this may be a "red flag". (Ex. lunchtime)*

DOES YOUR PROGRAM DEFINE "DISABILITY" IN A CONTEXT OF "ANY RESTRICTION OR INABILITY TO PERFORM TASKS OR ROLES IN THE MANNER PREVIOUSLY CONSIDERED NORMAL FOR AN INDIVIDUAL?"

This question generated similar responses to the previous question. Two agencies reiterated the importance of language when discussing disability and individual abilities.

1. *Yes, use "unique abilities" instead of "disability".*
2. *There is difficulty in this agency answering cognitive or intellectual disability occurring before age 21. TBI does not have to occur before the age of 21. At times clients may "float" to different programs depending on funding.*
3. *Yes, but don't label as "disability". Think of traits and being successful.*
4. *Not necessarily. Labels can cause guilt and shaming. Goal is to be non-discriminatory.*
5. *No. Provide literature and someone may self-identify.*
6. *Conversational summary may lead to a referral at some point. Have not had a child with a physical disability yet.*

CAN YOU SPEAK TO YOUR PROGRAM OR AGENCY'S BELIEFS AROUND HOW DISABILITY SHOULD BE DEFINED AND PERCEIVED? SUCH AS ENVIRONMENTAL, PHYSICAL, SOCIAL CONSIDERATIONS THAT DEFINE "DISABILITY"?

Each respondent spoke of the importance to be person-centered, and that defining, measuring, and assessing an individual's disability status was only important in terms of implementing the work or providing services. Agencies designed to support adults with disabilities tended to acknowledge that diagnoses and the term 'disabled' were necessary to getting the work done, especially in an environment where eligibility, vouchers, and reimbursements are based off such assessments. Other programs focused on the pragmatic – whether a behavior or characteristic is considered or labelled a disability is secondary to the fact that it may be a vulnerability or barrier to a program participant's success.

1. *Always put person first before disabilities. Person centered approach. Ex. If a person in a wheelchair wants to go skydiving, how can we make that happen? There is a very joint effort within Olmsted County (workplace, family home, medical).*
2. *Prefer not defined at all. Obviously a need. Philosophically, we all have a disability. We try not to categorize. We will always have to find ways to help each other.*
3. *Strongly stressed the System is disabled.*
4. *Referred to Program brochure. See enclosed.*
5. *Not necessarily a perception. Program is there as a supportive mechanism. Ex. social delays are a disability if it causes a vulnerability.*
6. *Provide family atmosphere. Relationships are important. Purposeful in knowing who parents are. All of the children "disabled" wouldn't be able to pick out in classroom.*

HAS YOUR PROGRAM TRIED TO "MEASURE" A CLIENT'S DISABILITY TO UNDERSTAND THE OUTCOME OF YOUR PROGRAM AND IDENTIFY SERVICE GAPS?

Two agencies responded yes to this question. Both track the disability status of participants upon intake and use state/federal definitions of disability.

1. *Yes, specific to client and what they want to achieve. This allows independence. Dignity vs. risk.*
2. *No. Might measure if change in environment has created positive change. Person-centered. Support for people around the person, too. People with developmental disabilities are not children. We make determination based on need. We're all vulnerable. Ex. Uber or Lyft. Change in environment is key. Having the "right" environment is key.*
3. ***missed question***
4. *No. At intake, one year, discharge, use "ASAME's".*
5. *Yes. Would like to meet the needs of those coming through the doors.*
6. *No, this is a new program. Open eight months at time of interview (open- October 2018).*

QUESTIONS ABOUT WORKFORCE AND SERVICES ENVIRONMENT

Interviewees were also asked additional questions about their program staff, workforce considerations, and the services environment in Rochester. The results of these questions can be found in the appendix. These responses are anticipated to be used in the United Way Learning Cohorts in 2019-2020.

1. How is your program supporting positive change for disabled staff?
2. Can you speak to the diversity of your staff?
3. Does your program promote the idea of staff serving as role-models for disabled clients?
4. How are staff members serving as role models to your clients?
5. Has your program created any surveys to gauge participants' satisfaction?
6. Is your program currently experiencing a workforce shortage?
7. How would you describe your program's relationship with Olmsted County Human Services?
8. Are there any suggestions your program may have to improve communication with other community programs or Olmsted County Programs?

NEXT STEPS

The results of the questions related to the definition of disability will be used in the following ways:

- Funded program partners will be invited to answer a narrative question around the disability status of the program participants
- Propose including a disability-focused activity (or activities) in the 2020 Advocacy Agenda for United Way of Olmsted County
- Propose developing an allies and advocate training for UWOC staff focused on disability

Future questions that may be proposed to the learning cohorts are:

- Are United Way funded organizations adequately serving the disabled populations utilizing their assistance?
- How are United Way programs supporting positive change for disabled program participants?
- How do we serve all our program participants?
- How are caregivers supported?

APPENDIX: WORKFORCE AND SERVICES ENVIRONMENT RESPONSES

How is your program supporting positive change for disabled staff?

1. Focus on unique abilities. Interviewee is supervisor of eleven staff (two with MI/MH issues, one with autism, one visually impaired, one with TBI, one with PTSD, other self-disclosed.)
2. Probably have disabled staff. Would make any necessary changes to accommodate needs. We don't go out to recruit disabled staff.
3. Asking question, "Is there anything that would prohibit you from doing your job?" Maternity leave is an example. Person-centered approach.
4. Not a discussion we talk about. Only have resume. Talk with each other.
5. There are staff with disabilities. We have a mentoring partnership.
6. Director has an "open-door" policy. Staff able to talk with supervisor. This is a small non-profit. Director feels the staff "feel" supported.

Can you speak to the diversity of your staff?

1. Yes. Human Resources has this information.
2. Very diverse staff. 62% of staff foreign born or of color.
3. Conscious and intentional about diversity. Need to mirror the population we serve. There are different church backgrounds, genders, skill sets and ethnicity of board members.
4. Not super diverse. No males. Work is with women and children populations.
5. May fluctuate.
6. All female as of time of interview. Has hired first male staff since then. One staff member speaks Mandarin (bi-lingual) and another teacher speaks Spanish (bi-lingual).

Does your program promote the idea of staff serving as role-models for disabled clients?

1. Yes
2. Absolutely.
3. This is a discipleship program. We are participants not recipients. Intentional in hiring people that can relate to participants.
4. Yes. We meet clients "where they're at". Some clients are at a "modeling" stage. We offer a "skills" topic.
5. Yes.
6. Yes, for parents, not just children. Ex. maybe family member can't read.

How are staff members serving as role models to your clients?

1. Working with clients 6 to 8 hours a day. There is awareness of staff and clients disabilities.

2. Demonstrating life skills. This is easier in an Independent Living setting compared to a Group Home setting.
3. As answered above. This is a discipleship program. We are participants not recipients. Intentional in hiring people that can relate to participants.
4. Planning to hire a Peer Support Specialist. Ex. of a question posed to staff is "how are you handling that?"
5. Program is character based. Ex. morality, good listener, greeting newcomers, working your own program.
6. Ex. above. Family member not being able to read.

Has your program created any surveys to gauge participants' satisfaction?

1. Yes. Program willing to share survey.
2. Yes, we do. Survey in Independent Living setting is easier to know of client's views. In a Group Home setting, is it the resident or family / guardian completing the survey?
3. Both pre and post- surveys. Assess Men in Program a minimum of six months. Women and Children there is no maximum length of stay.
4. Yes. Program recently started quarterly and completed during "donation day" and also at discharge.
5. No.
6. Survey will be done at end of Summer of 2019. Licensing requires this survey.

Is your program currently experiencing a workforce shortage?

1. Yes.
2. Yes.
3. "Not in a financial position to have a work shortage." No funds are received by government agencies. No reporting to Department of Human Services. This allows for flexibility in staff being hired.
4. Yes. Caseload in Rochester is forty clients. Caseload in Winona is nineteen clients (which is only allotted funding for the program).
5. No shortage in Rochester. Yes, shortage in Kasson. There is a new ministry leader at Autumn Ridge. Training is offered locally.
6. Currently, no. Early Childhood field is experiencing shortage. Some staff comments are the program is small and allows for chance to get to know families. Family Nights allow staff to see families as they are. Staff members are laying the foundation.

How would you describe your program's relationship with Olmsted County Human Services?

1. Wonderful. Program has a great working relationship with Olmsted County.

2. Good. Olmsted is one of the better Counties in our State. Supportive of innovation. County workers seem to like working for the County.
3. Good. Share the same clientele. Have access to many of the County trainings. Staff attend Family Group Decision Making Conferences. Serve Dodge, Fillmore, and Olmsted (DFO) County probationers.
4. Great. Bi-monthly action team meetings.
5. Program has been offered in Olmsted County Adult Detention Center, not in juvenile detention setting. Program does get court referrals. Relationship with Olmsted County has changed since agency opened in Rochester.
6. Families are on Child Care Assistance through Olmsted County. One family has a County social worker and a release of information is signed to allow communication.

Are there any suggestions your program may have to improve communication with other community programs or Olmsted County Programs?

1. This is tough. Primarily an 8 am. to 4:30 pm. program. There are a lot of activities in the evenings. Need to communicate via the right avenues.
2. Communication is huge. This has been improving over the years. There are collaborative efforts. Ex. Share training efforts, legislative efforts. Olmsted County functions together.
3. Need to work with other agencies. Offer case management services. As a faith-based organization, may be left out of some discussions.
4. Continuing care conferences to look at overall client's services. E-mail with other agencies.
5. Would be great to have a Community Forum, Similar thought as Program #3. Highlight Unity/Diversity/ Structure for Success. There would be more awareness in community.
6. Parents feeling sense of defeat if county paperwork is not filled out. County doesn't treat parent well, yet program staff treating ok.