The Importance of Relationships

Using the National Core Indicator and state data to understand the importance of relationships for people with intellectual/developmentaldisabilities served by the Michigan public mental health system

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Background

This brief is one in a series of reports on findings from consumer interviews conducted in Michigan during 2012 as part of the National Core Indicator (NCI) Program. In 2011, Michigan joined the NCI program, which began in 1997 and is now used in over 41 states to provide a standardized way to measure and track indicators for persons with intellectual/ developmental disabilities (I/DD) who are served by the public mental health system.

In January 2013, Michigan convened an NCI Advisory Group, which worked in collaboration with the Developmental Disabilities Practice Improvement Team (DDPIT) and the Quality Improvement Council (QIC) to analyze Michigan data and to make recommendations. Five priority areas were identified, which are also NCI indicators: person-centered planning, health, relationships, living arrangements and employment.

This brief addresses the importance of relationships and community connectedness in decreasing loneliness and isolation. The indicators summarize the surveyed results from personal interviews with individuals with I/DD and the background information provided by the community mental health system. Information from these interviews is used to understand the experiences and outcomes and to compare Michigan's outcomes to other states. The information is also used to identify areas for continued improvement in the delivery of public mental health services.

Analysis of the NCI resulted in the identification of several areas of opportunity for improvement. These include:

- **Employment**- Improving employment outcomes.
- **Living Arrangements**- Increasing the number of individuals who have and who exercise choice over where and with whom they live, who have privacy and control over their home environment, and who feel safe in their home.
- **Health/Wellness**- Increasing physical activity and preventive and routine health care to improve health.
- **Person-Centered Planning** - Improving the Person Centered Planning process and measurement of personal outcomes, which in turn supports all of the above desired outcomes and experiences.
- **Relationships** - Decreasing loneliness and increasing people's connections in their community and supporting relationships with friends and family.

Introduction

Isolation, and subsequent loneliness, can be one of the most challenging aspects of providing service and supports for individuals with I/DD. This brief addresses the experience of loneliness by individuals with I/DD and explores opportunities to support individuals to develop and nourish relationships, friendships and community/social connections.

Isolation inherently comes with being perceived as "different" and is exacerbated by the systematic segregation of people with I/DD beginning in childhood. People with I/DD who go to different (segregated) schools and different (segregated) programs have historically faced low social expectations, isolation and stigmatization. Therefore, typical friendships and relationships that others enjoy are more difficult to realize. This also results in a lack of opportunity for individuals with disabilities to be part of a typical community, as well as limits the community's ability to support/include individuals with disabilities. Without naturally occurring experiences, people with I/DD who are separated may develop idosyncratic social skills which could lead to further isolation and stigma.

Friendships, relationships and community belonging are critical aspects, if not the most universally valued condition, of quality of life. Connections with other people improve well-being, happiness, and positive health outcomes. Relationships are also positively correlated with valued community inclusion, access to housing, and employment. People make friends where they live and work. People get involved in activities because they are invited by their friends and family, they get jobs through people they know. Similarly, people make friends through work and shared interests, activities, and hobbies. All these aspects of a good life reinforce one another.

A strong predictor of well-being and enjoying a good life (the pursuit of happiness) for people with I/DD is the amount or number of unpaid people in their lives. These friends and family (described as "natural supports") not only ensure a person has a safety net; they provide the connections and experience that bring all people contentment, happiness, and meaning. These are universal human aspirations. A primary goal of the public mental health system should be to support people to establish and nurture these aspirations via friendships and social networks, as this is a key variable for increasing well-being in all other parts of life (good health, employment, safety, independence, etc.)

The analysis and recommendations provided in this briefing support existing efforts and offer ideas for improvements that have positive outcomes for people in decreasing loneliness and in establishing and maintaining relationships.

The briefing includes a summary of the NCI data on individual's experiences connecting with people in the community-especially establishing and maintaining relationships with friends and family. The workgroup identified, and the report includes, a list of the barriers and difficulties to supporting people in developing and maintaining relationships within their communities, according to their interests and preferences. It also includes recommendations for best practice resources and identifies links to additional resources.

Change requires local analysis, targeting relevant barriers and acting on the best information. Best practice models identified in Michigan, and the country, show that rates of isolation and loneliness can be decreased. Success occurs when the community mental health system works with multiple engaged stakeholders and the broader community and are led by individuals with I/DD.

Keys to decreasing loneliness and increasing relationships and friendships for persons with I/DD:

- Prioritize relationships, friendships and full citizenship.
- Plan for community connections that lead to relationships and involve multiple stakeholders (individual, family, service providers, employers, state agencies, local community) while upholding leadership of individuals with I/DD.
- Develop partnerships in the broader community with peopl who share the vision of full and supported community inclusion.
- Support community efforts and organizations promoting full inclusion for all, regardless of race, gender, national origin, religion, sexual orientation, age and disability.
- Use benchmarks and data driven decisions to sustain focus/effort and to improve outcomes.

Each of us (the individual, family and friends, supports coordinators, business owners and associations, Community Mental Health Services Programs (CMHSP) and Pre-paid Inpatient Health Plans (PIHP) leadership, staff at the Michigan Department of Health and Human Services (MDHHS), and elected officials have a role to play and there are opportunities and actions that each can take to contribute to decreasing loneliness and emphasizing the importance of relationships for all individuals with I/DD.

The Data Story

The results from the NCI surveys and related data from MDHHS are provided in the following tables. The data included here are the best proxy measures available for measuring community connections. Information provided individuals surveyed using the NCI tool reports on loneliness, friends (including having a best friend or a friend who is not paid staff) and reporting on the ability of individuals to do activities typical of people who do not have I/DD. Additional results from the NCI survey domains including health, employment, living arrangements, and feelings of not being safe can be found at www.nationalcoreindicators.org.

Table 1: Demographic characteristics (%)

Variable	State N=407	National N=8,000
Age (mean)	44	44
Gender (male)	60	56
Race		
White	75	72
Black	19	19
Severity of Disability		
Mild	40	35
Moderate	22	29
Severe/Profound	32	27
Dual Diagnosis	45	33
Means of Expression (spoken)	72	76
Mobility		
Independence	71	77
With Assistance	15	14
Non-Ambulatory	13	9
Overall Health Excellent	34	40
Residence		
Family Home	32	33
Independent	21	14
Group Home	32	32
Behavior		
Self-Injurious Behavior	26	21
Disruptive Behavior	38	38
Destructive Behavior	24	25
Uses Self Directed Supports	16	7

Table 2: Proportion of people who reported they have friends who are not staff or family members ("yes, not staff or family" only)

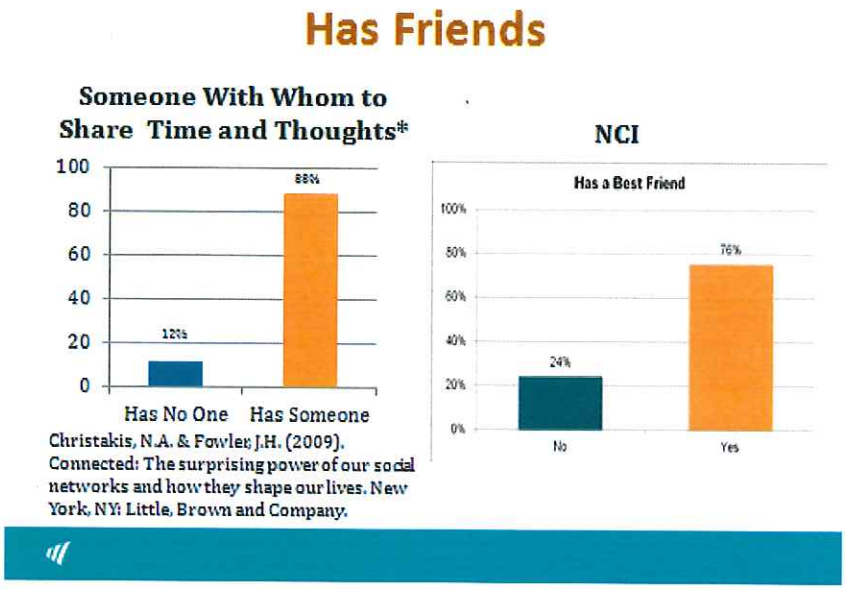
State	Overall In State	N	Institution	Community -Based	Individual's Home	Parent's Home
Significantly Above Average						
MEORC	83%	308	n/a	84%	84%	81%
AL	82%	247	n/a	72%	85%	93%
ME	80%	240	n/a	77%	86%	n/a
GA	79%	380	n/a	76%	92%	79%
NC	77%	538	n/a	75%	80%	79%
NJ	76%	360	n/a	76%	n/a	78%
Within Average Range						
PA	75%	893	n/a	69%	84%	76%
HI	75%	224	n/a	n/a	n/a	78%
MA	74%	401	n/a	70%	82%	70%
AR	74%	254	91%	72%	72%	69%
IL	74%	244	n/a	71%	86%	74%
MO	73%	347	n/a	71%	75%	n/a
CT	71%	263	n/a	64%	72%	78%
OH	71%	376	n/a	61%	81%	74%
LA	71%	282	n/a	75%	65%	70%
NY	70%	1,769	n/a	67%	79%	70%
MI	68%	272	n/a	62%	74%	67%

This data tells us that:

- Two-thirds of individuals with I/DD report that they have friends, while one-third report that they do not have friends (outside of paid staff or family).

- Individuals who live in their own home report more friendships than those living in group homes or parent's home.

Table 3: National comparison of general population who report having friends and individuals with I/DD who report having friends



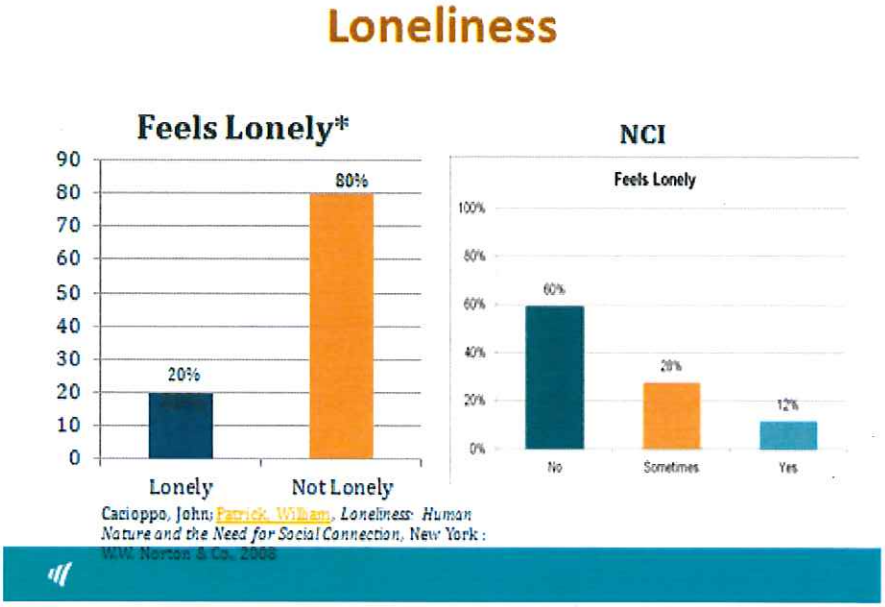
Although the questions were phrased differently, the comparison can still be made that individuals with I/DD report having a best friend/someone to share time and thoughts with, half as often as the general population.

Table 4: Proportion of people who reported they feel lonely at least half the time ("yes" and "sometimes" responses)

State	Overall In State	N	Institution	Community-Based	Individual Home	Parent's Home
Significantly Above Average						
KY	72%	326	n/a	67%	90%	74%
SC	51%	312	n/a	59%	47%	45%
Within Average Range						
AR	45%	245	33%	46%	44%	50%
NC	44%	516	n/a	54%	32%	42%
MI	44%	258	n/a	42%	50%	37%

This data tells us that a significant portion of individuals with I/DD feel lonely. Individuals with I/DD who live in their own home report this at a higher rate than individuals living in group homes or parent's home.

Table 5: Comparison of general population(U.S.) who report feeling lonely and individuals with I/DD in Michigan(NCI) who report feeling lonely



The chart to the left tells us that individuals with I/DD report feeling lonely at a rate that is almost two times higher than the general population.

The chart to the right tells us that individuals with I/DD sometimes/often feel lonely 40% of the time—close to half of the time, and higher than the national average. It also indicates that individuals with I/DD do not feel they are able to see friends (sometimes/often) at a rate higher than the national average.

Barriers and Challenges to Important Relationships

Systemic

- Low expectations of a regular life of connection for individuals with I/DD.
- Historical practices of segregating individuals with I/DD, in special education, day programs, sheltered workshops, congregate settings. Disability-only activities have the consequence of limiting opportunities for individuals to make and nurture friendships and develop social connections.
- Programs and services designed around "health and safety" and "skill acquisition" without similar/greater emphasis on friendships, relationships and belonging.
- Lack of support choices – staff hired by agency without shared interests, generational concerns or cultural background similar to those they are employed to support.
- Perception of individuals with I/DD as vulnerable and needing "protection", coupled with limited opportunities to develop personal networks through supported, typical community experiences.
- Perception that people with I/DD need public supervision or guardians surrounded by staff or para-professionals and must experience community as tourists or in groups as "outings".
- Historical practices of spending money, purchasing clothes and paying bills are made without the persons consent or knowledge.

Experience/Social Etiquette

- Individuals who are segregated/isolated in special settings do not have opportunities to develop social etiquette or typical, reciprocal relationships.
- The non-disabled community has stigmatized individuals with I/DD, resulting in limited experience with positive interactions with individuals with I/DD. Additionaly, the non-disabled community has not yet fully embraced a community where people with I/DD are valued and belong as equal citizens.
- Limited opportunity to explore and develop shared interests due to lower expectations of belonging and participation.
- Reliance on government programs (SSI, SSDI) for income and low rates of employment limit financial resources for discretionary spending.

Access

- Affordable housing is limited to those that are separated from the mainstream of community life.
- Lack of employment.
- Reliable, affordable, easy-to-use transportation is not always available. Public transportation is often limited, or non-existent in all but the largest metropolitan areas.
- Imposed poverty due to limited financial resources to truly engage in the community.
- Reliance on government programs (SSI, SSDI) for income and low rates of employment which limit financial resources for discretionary spending.
- Job selection is limited due to income restraints.

Recommendations and Best Practices

Recommendations are organized by stakeholder groups. Each stakeholder is invited to identify and work toward changes in the area where they can have the most impact. MDHHS and workgroups in the Behavioral Health and Developmetnal Disabilities Adminstration (BHDDA) can assist you to plan for and implement recommendations. Change in a single area will result in improvement. Efforts in multiple areas and will support a more robust change process and greater improvements in outcomes.

...CMHSP/PIHP

- Provide guidance and training on person-centered planning processes exploring and expanding individuals' interests to deepen or develop meaningful relationships; and on using supports to establish and nurture friendships.
- Confirm framework for services and support that presumes that each of us lives our own life, under our own control but as part of interlocking and diverse communities of family, friends, colleagues, members and peers.
- Uphold new Home and Community-Based Services (HCBS) rule requiring service delivery in the most integrated setting possible and in the same degree/manner as individuals not receiving services.

- Include friendships, relationship development and community connectedness as expected priorities in training, planning and outcome measures. Provide concrete suggestions on how to meet and make friends, entertain family and friends, and locate community events.
- Promote and encourage the certification of peer mentors as a means to provide social support and enhance community inclusion and participation for individuals with I/DD.
- Address and minimize stigma, segregation and separateness of services and programs.
- Monitor service provision to ensure that community-based services are used to support (not isolate) friendships and community connections, and that paid services and staff do not replace friendships and community connections.
- Include the individual in the budgeting of their money to increase awareness of cost of living and explore possible choices in the community.
- Provide training and guidance to Supports Coordinators, Direct Support Staff and others on Relationship Mapping, Personal Network Facilitation, Circles of Support, and other tools that encourage and support establishment of relationships and personal and integrated social networks.
- Provide targeted training to Direct Support Staff to support individuals with I/DD to develop and nurture friendships and relationships.
- Engage in Asset Based Community Development and Home ownership (http://www.abcdinstitute.org/).
- Expect, facilitate, encourage, and support self-determination.

...for Individuals with Disabilities

- Expect a full life as active citizens based on a positive vision for a life typical of people without I/DD.
- Include the importance of your relationships in your plans by identifying ways to expand your community connections and relationship development based on your interests and aspirations.
- Seek support and assistance (if necessary) in finding/keeping a job during the person-centered planning process.
- Participate in self-advocacy and peer leadership, if interested.
- Use public transportation when available. Advocate for its existence and extended use.
- Honor the give and take of friendships –invite your friends to do things with you and keep in touch with people who are important to you.

...for Families

- Encourage friendship and social activities from the earliest age, participating through inclusive education.
- Encourage employment and community citizenship for all family members with I/DD.
- Connect with other families of individuals with I/DD to explore current and future range of options for availible services and supports.
- Identify mentors and advocates from which to learn and model connectedness.
- Assure the individuals have numerous friends, family and allies (non-paid individuals) in their life.

...for State Policy Leaders

- Promote policies with inclusive non-segregated foundations.
- Clearly identify natural supports (friendships/relationships) and community connections as priority outcomes of all community-based services.
- Promote integrated, competitive employment as an outcome for all adults.
- Ensure that individuals with I/DD are supported to be active participants in decision making for social service programs in particular schools. Seek input of individuals with I/DD on boards, focus groups, and cascuses.
- Encourage full citizenship and civic engagement for all including accesible voting.

Are we making a difference?

The final section identifies some additional resources to assist you in planning for improvement.

Recommendations for measurement:

- Number of friends and family (unpaid individuals) present/participating in the individual's person-centered planning meeting and subsequent goals of friendship and community connection.
- MDHHS Demographic Indicator of Presence of Natural Supports.
- CMHSP/PIHP to report the number of individuals who hire and employ their own staff to assist in developing community connections.

- Increase control and decision over individual budget. Self-determination trys to include the individual employer model and agency provider of choice.
- Monitor NCI Indicators of having friends and feelings of loneliness.
- This briefing is offered as a resource to CMHSPs, PIHPs, and Providers and other stakeholders. The workgroup welcome suggestions and identification of additional resources or model programs. Please feel free to send suggestion that you want shared with the various workgroups to: HCBSTransition@michigan.gov.

Resources

- Defeating Loneliness (Book by Mary Ellen Copeland) Training by Sherri Rushman
- Arcadia Institute (Kalamazoo, Michigan)-Community Participation Initiative and Community Brokering
- The Importance of Belonging by David Pitonyak, http://www.dimagine.com/
- Community Connections Road Map training by Community Drive, Inc www.communitydrive.org/
- Relationship Mapping—New Paths to Inclusion http://trainingpack.personcentredplanning.eu/index.php/en/communityconnecting/relationships
- The Asset-Based Community Development Institute (ABCD) at the Center for Civic Engagement at Northwestern University http://mn.gov/mnddc/mcKnight/johnMcKnight02.html\
- MI SIBS Network www.misibs.org
- Social Capital" In Control: Practical lessons in supporting isolated people to be part of community http://www.hsapress.co.uk/InCommunity/pdf/287982857.pdf Angela Amado Friends: Connecting people with disabilities and community members.http://rtc.umn.edu/docs/Friends_Connecting_people_with_disabilities_and_community_members.pdf
- "Possibilities" Video Series by the Developmental Disabilities Institute http://ddi.wayne.edu/
- The Arc- http://www.thearc.org/
- Michigan Alliance for Families- http://www.michiganallianceforfamilies.org/