My Home

Using the National Core Indicator and state data to understand the living arrangments and the experience of persons with intellectual/developmental disabilities served by the 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 35 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. There are NCI indicators in key areas of concern including: employment, rights, service planning, living arrangements, community inclusion, choice and health and safety.

In January 2013, Michigan convened an NCI Advisory Group, which worked in collaboration with the Developmental Disabilities Practice Improvement Team and the Quality Improvement Council to analyze Michigan data and to make recommendations. Several priority areas were identified: person-centered planning, health, relationships, living arrangements and employment. This brief addresses housing.

The Indicators summarize the surveyed results from personal interviews with persons with I/DD and present 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 identification of several areas of opportunity for improvement.

These include:

- Loneliness. Increasing individual's connections in their community and supporting their relationships with friends and family (decreasing feelings of loneliness)
- 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 feel safe in their home
- Health/Wellness. Increasing physical activity and preventive and routine healthcare to improve health
- Person-Centered Planning. Improving the person-centered planning process, which in turn supports all of the above desired outcomes and experiences to help individuals have the life they want

Five briefs are planned to summarize NCI findings in the areas of: employment, living arrangements, person-centered planning, health/wellness and connecting with friends/family/community. The briefs are intended to generate discussion, as well as provide guidance and suggestions for activities that support improved outcomes and experiences for the individuals supported by the public mental health system. It is our hope that this information will be used to guide quality improvement initiatives and ultimately result in improved outcomes.

Living Arrangements Introduction

Being a part of a community and living as independently as possible, with family or with friends of one's choosing, is a goal for all adults, not just those with I/DD. Michigan has historically been at the forefront of promoting independent community living, beginning with de-institutionalization initiatives and moving on to widespread use of Medicaid waivers to support individuals living in their own homes in the community and fully participating in typical community life.

In addition to Michigan's promotion of community living, the Centers for Medicare and Medicaid Services (CMS) is also promoting/requiring maximum opportunities in the community for individuals receiving Medicaid waiver services. CMS issued final rules in 2014 that define "home and community-based" settings.

These rules are intended to maximize opportunities for people to have access to the benefits of community living, including living in the most integrated setting possible. The rules describe home and community based settings as being integrated in community and supporting full access to it, including opportunities to:

- Seek employment
- Work in competitive integrated settings
- Engage in community life
- Control personal resources
- Receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS
- The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting.

Settings should:

- Ensure individual rights of privacy, dignity and respect and freedom from coercion and restraint
- Optimize, but not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to daily activities, physical environment, and with whom to interact
- Facilitate personal choice regarding services and supports and who provides them

The Mental Health and Wellness Commission Report of 2013 takes its title from this same focus: "Improving Quality of Life by Supporting Independence and Self-Determination," and it provides recommendations for advancing opportunities for independence, self-determination, and addresses issues such as availability of housing and revisiting relationships with residential providers.

The brief summarizes the data on residential status, preferences and service statistics of individuals surveyed and served by the public mental health system. The work group identified, and the report includes, a list of the barriers and difficulties to improving reported experiences and choices for community living arrangements. Recommendations for activities to support community living as independently as possible are targeted at multiple stakeholder groups. Change requires local analysis, targeting relevant barriers and acting on the best information. Success occurs when the community mental health system works with multiple engaged stakeholders and the broader community.

Keys to improving experience and community living options for people with I/DD:

- Plan for and involve multiple stakeholders (individual, family, service providers, employers, community partners, housing specialists/resources)
- Support the dreams of individuals with I/DD to live in their own homes, providing examples and therefore hope and pathways to these dreams
- Use benchmarks and data driven decisions to improve outcomes
- Develop partnerships with non-profit housing organizations to support and encourage the development of safe, accessible and affordable housing

Additional and more detailed information about best practices can be found later in the report. Each of us (the individual, family and friends, supports coordinators, business owners and associations, CMHSP/PIHP leadership, staff at the MI Department of Community Health (MDCH), and legislators) has a role to play and there are opportunities and actions that each can take to help create communities that provide for housing, transportation, employment and welcoming environments for persons with I/DD.

The Data Story

Choice, safety, and experience related to residential status results from the NCI surveys and related data from MDCH are provided in the following tables. Additional results from the NCI survey on employment and for other domains including health, relationships, and living arrangements can be found at www.nationalcoreindicators.org.

Table 1: Demographic Characteristics (NCI respondents)

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: Choice Making and Satisfaction (NCI respondents)

Variable	State (%)	National (%)
Chose Home	52	48
Chose Home Staff	58	56
Chose Roommate	40	38
Likes Home	88	90
Likes Neighborhood	85	88
Wants to Live Somewhere Else	34	27

This data tells us that individuals with I/DD report they have little say in where they live (52% choose their home). Individuals also report they have little say with whom they live with (40% choose roommates) or who provides their care (58% choose home staff).

The data also indicates that while most individuals like their home (88%), one-third of individuals would choose to live elsewhere (34%).

Table 3: Personal Freedom and Safety (NCI respondents)

Variable	State (%)	National (%)
Home is Never Entered Without Permission	**86**	--
Bedroom is Never Entered Without Permission	80	84
Can Be Alone at Home With Visitors	79	80
Has Enough Privacy at Home	89	90
Feels Safe at Home	77	82
Feels Safe in Neighborhood	83	85
Has Someone to go to for Help if Afraid	90	90

This data tells us that 23% of individuals with I/DD do not feel safe in their home.

Table 4: Relationships by type of residence (NCI respondents)

Residence	Community-Based	Individual Home	Parent's Home
Have friends who are not staff or family members	62%	74%	67%
Feel lonely at least half the time	42%	50%	37%

This data tells us, that individuals feel lonely a great deal of the time, and this is highest for individuals who live in their own homes.

Table 5: Living Arrangement by Disability

Living Arrangement	DD only (%)	DD/MI (%)	Total Number
Private w/Relatives	61%	44%	24,372
Private, non-relatives	15%	19%	7,151
Foster Care	1%	1%	434
General Residential	4%	6%	1,868
Specialized Residential	15%	23%	7,846
Institution	1%	2%	554
Supported Independent Program	1%	3%	724
Other (Includes Homeless and Unreported)	2%	3%	951

Data Source: MDCH, 2013.

Barriers and Challenges to finding the home you prefer:

Systemic

- This represents a paradigm shift, moving from group homes to independent living
- There is a lack of safe, affordable, and accessible housing
- Level of support needs drive living arrangement (many supports "bundled" into specialized residential)
- It is perceived that it is "easier" for individuals to be "placed" into AFC/group home, it is less work for supports coordinators and case managers
- There is a lack of strong vision and message that the system is moving away from segregated living arrangements
- Independent living narrowly defined as applying only to individuals living without supports, broad definition of living on one's own home is not consistently used
- Coordination, collaboration and resource sharing between funding agencies, providers, fiscal intermediary, community housing groups is not fully leveraged

Knowledge

- A new business model for providers is not broadly developed or known (staffing agent, staff back-up, emergency response team, other supports)
- There is a lack of knowledge about safe, affordable (subsidized) accessible housing that does exist
- There is a lack of awareness/skills for self-advocacy
- There are varying perceptions of choice: not everyone has the ability to live where they want and that they can change their mind

Access

- Transportation not consistently available, affordable or accessible throughout communities
- Some legacy models of service delivery tie transportation access to group home living
- There is a lack of employment or other daily community based activity (What will I do with my day if I live on my own?)
- Housing assistance not uniformly available due to conservative interpretation of the Medicaid service of housing assistance

Financial

- Looking at cost factors individually rather than collectively (it will be more expensive for some people to live independently, but not the collective)
- Provider investment in bricks and mortar, along with lack of resources to change business model

Social

- Perceived safety issue among individuals and families is raised as reason for preferring group home living
- The lack of social networks for individuals (who do I want to live with/ spend time with?)
- Family influence regarding fears, perceived safety issues and lack of experience with different independent living options

Suggested Best Practices

A series of meetings with stakeholders (individuals served, family and friends, supports coordinators, provider organizations, CMHSP/PIHP leadership, staff at MDCH) and review of evidence based practices produced the following suggestions:

...for CMHSP/PHIP/Providers

- Broadly share and publicize success stories for individuals with disabilities who are succesfully living in their own homes
- Focus on improving person-centered planning process, ensuring that living in one's own home is fully explored
- Develop relationships with local non-profit housing organizations, promoting the inclusion of people with disabilities in planning
- Establish best practice guidelines for use of specialized residential settings and best practices/ guidelines for supporting individuals to transition to their own homes from these settings as desired
- Assure a competent, well-trained and fairly compensated direct support workforce is available
- Establish benchmarks for increasing number of adults living in their own homes in communities
- Promote and support networking for individuals with disabilities, broadening their community networks and circle of friends (potential housemates)
- Develop expertise in the use of various assistive technologies to support independence
- Examine rate setting methodologies, provide models on how to set rates so that community living in one's own home is supported (pay for performance, outcome based or incentive models)

Story of Independence: 1

Jimmy is an outgoing, energetic, happy person with a full life. He loves going to the mall and all things related to sports. He recently went to a hockey game. He lives an apartment with a roommate, has a job, friends and a girlfriend. Jimmy says he is, "getting my life straight".

Not so long ago, Jimmy's life was much different. Between 2001 and 2013, most of Jimmy's time was spent receiving treatment in various psychiatric hospitals. After being released from Kalamazoo Psychiatric Hospital (KPH) in January 2013, Jimmy moved into his own apartment with a roommate, where he receives support and staffing from Residential Opportunities, Inc (ROI). Previously, Jimmy had tried living in group home settings, but was unsuccessful. He says it "wasn't the right fit". Once he moved into his own apartment, Jimmy decided he had a goal: to stay "out" (of the hospital) for two years. To assist with this goal, Jimmy and his staff, Allisha, started attending Dialectical Behavioral Therapy (DBT). Jimmy feels DBT has helped him stay out of the hospital by teaching him how to "check my surroundings, check my body, my emotions and urges". The support of Jimmy's person-centered planning team has also contributed greatly to his success: JoAnne (gentle teaching); Diane and Joyce (positive behavioral support); Steve (support coordination); Allisha (ROI Staff) – the entire team provides ongoing support that helps Jimmy be the success he is today.

Once living independently, Jimmy also decided he wanted to find a job. He worked with supported employment staff, learning job skills and what it would take to find paid employment.

In October 2013, Jimmy was hired at Burger King, where he works one day per week with his job coach, Brad, maintaining the lobby. About making money Jimmy said, "I love it! It's my spending money. I can do things. Working makes me feel excited." While his goal is to work more days and hours, Jimmy is happy to have a paid job.

Jimmy's goal is to keep being more and more independent. For the first time in years, Jimmy was able to spend Christmas with his family, and had a Yankee's themed birthday party. He is the assistant coach for an adult softball team. Allisha commented, "We're very proud of how he's made it out and stayed out. He keeps finding new ways to be independent and have his own life." When asked how he feels about life now, Jimmy replied "I'm happy. Real happy. Excellent!"

...for families

- Encourage and support individuals with disabilities with developing friendships and other community relationships and networks
- Provide opportunities for typical community activities for individuals with disabilities
- Focus on improving person-centered planning process, ensuring that living in one's own home is fully explored

...for individuals with disabilities

- Be active in the community, getting involved in clubs, sports, etc.
- Support and nurture friendships, providing support and being supported
- Learn how to budget money and live within a budget
- Learn about assistive technologies available to support independence

Story of Independence: 2

"They are like three peas in a pod!" said Jon. "My brother Tony and his housemates, Derek and Michael have lived in this beautiful, accessible home and just love it! It gives them the freedom they want and need."

Jon is referring to a home the three guys live in that was made possible through a partnership between Community Living Services (CLS) and Community Housing Network (CHN). "This home was built with accessibility in mind," said Jon. "We were so fortunate to find it nestled in a quiet community. It has large door frames because my brother and one of his housemates use wheelchairs, an accessible bathroom, three car garage for vans with wheelchair lifts. It's just perfect for these three guys."

The young men have lived in their home for about a year and enjoy each other's company and have fun together. Through self-determination arrangements, all three of them have their own individual budgets and have freedom and choice in their lives. "My brother is very pleased with this living arrangement. It's the perfect bachelor pad!" said Jon.

For more information about CLS, log on to www.comlivserv.com. For more information about Community Housing Network, www.communityhousingnetwork.org.

...for communities

- Develop housing standards that promote full inclusion of people with disabilities in all aspects of community life. Consider doing so as part of broad community diversity initiatives
- Support housing coalitions whose mission is to improve availability of safe, affordable and accessible housing for everyone in the community, which includes people with disabilities
- Embrace planning that supports standards for housing that include visitability, use Universal Design and have readily accessible transportation

...for State Policy Leaders

- Use NCI and other existing data to drive decision making regarding quality improvement activities related to living arrangements
- Develop measures to support systemic readiness for CMS requirements (cf. 441.301(c)(5)(v)) and address the recommendations of the Mental Health and Wellness Commission 2013 report
- Increased efforts at state departmental levels between DCH and DOT to improve access to transportation for people with disabilities
- Increased efforts at state departmental levels between DCH and DOE to improve transition to successful community living for students with disabilities
- Increased efforts at state departmental levels between DCH and MSHDA to improve access to affordable and accessible housing. Community Housing Network (CHN) and other local initiatives
- Develop transition plan for compliance with CMS regulations for "home and community settings". Specifically address congregate settings to ensure full opportunity for personal autonomy, community integration and choice
- Identify DDPIT promising practices across the state for replication. Provide one-time funding to support/train on these models/practices

- Focus on improving person-centered planning process, ensuring that living in one's own home is fully explored
- Discuss SSI rate structure with DHS, particularly discrepancy in funding for individuals who live on their own compared with living in AFC
- Continue to promote paradigm shift, including anti-stigma efforts, for professionals

Housing Resources and other resources that support living in your own home

- "Keeping the Promise: Self Advocates Defining the Meaning of Community Living" (http://autisticadvocacy.org/wpcontent/uploads/2012/02/KeepingthePromise-SelfAdvocates DefiningtheMeaningofCommunity.pdf)
- "Getting My Own Address"-Community Housing Network -www.communityhousingnetwork.org
- Local Centers for Independent Living
- Local Continuum of Care networks
- MI-TOP (Michigan Transition Outcomes Project)

Supporting individuals to live in their own home

- "Possibilities Video Series" showing examples of people with disabilities living successful lives in their communities (http://ddi.wayne.edu/possibilities.php)
- Leaders in Policy Advocacy (LIPA)-DD Council- www.michigan.gov/ddcouncil
- RICC (Regional Inclusive Community Coalitions)-DD Council-www.michigan.gov/ddcouncil
- MI SIBS (http://www.misibs.org/)

Are we making a difference?

The environments in which we live have a significant impact on the quality of our lives, from our health to our relationships and beyond. We are committed to making a tangible difference in the lives of people with developmental disabilities through thoughtful planning and data-driven decisions. Our goals include ensuring living situations that are:

- Safe
- Satisfying
- Respectful of privacy
- Chosen by people's own decisions

We propose to measure our performance by examining the following areas:

Experience of People We Serve

To measure this area, the workgroup recommends converting groupings of related NCI questions into composite scores using the top box scoring method.[1] This method refers to the percentage of people served whose responses indicate excellent performance for a given set of questions.[2]

- Satisfaction with Living Situation (NCI Composite Score)
- Perceived Safety at Home (NCI Composite Score)
- Privacy in Living Situation (NCI Composite Score)
- Choice of Living Situation (NCI Composite Score)

Conformance with Standards

Increase in percentage of settings that meet the CMS Home and Community Based Services (HCBS) Final Rule 1915(i). While the method of measurement and auditing of settings for compliant with the HCBS final rule has not yet been determined, required characteristics of living situations are available for reference at the Medicaid.gov website and include:

- integration and full access to community
- choice in living situation and services
- assurance of privacy, dignity and respect, and freedom from coercion and restraint

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[1]The sets of questions were selected based on their relevance to persons served and their coherence with individual characteristics of settings compliant with HCBS Final Rule 1915(i).
[2]This method is currently being used for similar measures by CMS, including the HCAHPS survey data used in its Patient Experience of Care Domain of its Hospital Value-Based Purchasing initiative.

Endnotes

[i]This composite score will look at the percentage of "top box" responses across multiple questions related to Satisfaction with Living Situation. Denominator: All responses to the NCI Survey. Exclusions: Responses in which numerator items were coded as "Don't know, no response, unclear response" (9) or "Not applicable" (8). Numerator: Responses in which the answers to the following questions were as follows: "Do you like your home or where you live?" = Yes (2), "Would you like to live somewhere else?" = No (0), "Do you like your neighborhood?" = Yes (2).

[ii]This composite score will look at the percentage of "top box" responses across multiple questions related to perceived safety in a person's living situation. Denominator & Exclusions: Same as above. Numerator: Responses in which the answers to the following questions were as follows: "Are you ever afraid or scared when you are at home?" = No - rarely (0), "Are you ever afraid or scared when you are out in your neighborhood?" = No - rarely (0), "If you ever feel afraid, is there someone you can go to for help?" = Yes (2).

[iii]This composite score will look at the percentage of "top box" responses across multiple questions related to privacy in a person's living situation. Denominator & Exclusions: Same as above. Numerator: Responses in which the answers to the following questions were as follows: "Do people let you know before they come into your home?" = Yes (2), "Do people let you know before coming into your bedroom?" = Yes (2), "Do you have enough privacy at home?" = Yes, has enough privacy (2).

[iv]This composite score will look at the percentage of "top box" responses across multiple questions related to a person's perceived choice in living situation. Denominator & Exclusions: Same as above. Numerator: Responses in which the answers to the following questions were as follows: "Who chose (or picked) the place where you live?" = Person made the choice (2), "Did you choose (or pick) the people you live with (or did you choose to live by yourself)?" = Yes, chose people s/he lives with, or chose to live alone (2), "Do you choose (or pick) who helps you at home? " = Yes, person chooses staff (2), "Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?" = Person decides (2).