Independence-based Service Delivery in Midland County

Final Report

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Table of Contents

Executive Summary	4
Background	6
Impact in Michigan	7
Midland County	8
Methodology	10
Identification of Quality of Life Indicators	10
Consumer Focus Groups	11
Provider Surveys	11
Program Stakeholder Interviews	11
Outcome and Financial Data Research	12
Findings	12
Quality of Life Indicators	12
Consumer Focus Groups	13
Provider Surveys	17
Stakeholder Interviews	23
Outcome and Financial Data	31
Areas for Action	33
Attract and Retain Talent	33
Reduce Regulatory Burden	34
Invest Capital in Innovation	34
Coordinate Staff Training	35
Increase Integrated Employment and Volunteer Opportunities	35
Improve Transportation Options	36
Maintain a Repository of Available Services	36
Create a Community Quality of Life Measure	37
Appendix A	38
Appendix B	40
Annendix C	41

Executive Summary

During the past 40 years, care for adults with intellectual and/or developmental disabilities (I/DD) has shifted immensely from large institutions to a person-based approach, expanding independence within community settings. A recent report reviewed studies published during the last decade that examined numerous outcomes for people with I/DD living in different residential settings. The review found that across all outcome areas, a community-based approach, on average, produces better quality-of-life outcomes for people with I/DD.

The movement toward de-institutionalization coupled with person-based care at the community level for individuals has provided both opportunities and challenges for serving individuals with I/DD in Michigan. For example, the shift has created the need for more housing and community living support options for individuals with I/DD. Within local communities, services to clients vary widely. This is due to several factors, including availability of community resources, local nonprofit capacity, local philanthropic interests, family supports, health access, and financial resources across health and human service systems. As a result, the ability of local providers to affect the quality of life for their clients vary.

In collaboration with the United Way of Midland County, Public Sector Consultants (PSC) led a project to determine whether available community supports and services meet the needs of adults with I/DD and of the broader community in Midland County. As a community, Midland County has embraced independence through person-centered care in its service delivery. With its wide array of services and supports, Midland County is uniquely positioned to use its experience in independence-based care to build a model to showcase the community benefit it derives not only from its health and human service providers, but also to the individuals utilizing those services. Through this evaluation, PSC's goal was to provide a foundational understanding of the effectiveness and efficiency of services and supports for people with I/DD in Midland County as well as ascertain their potential for having a good quality of life.

PSC performed several key activities to engage local stakeholders for input and guidance to identify the quality of services from the point of view of people with I/DD and those working with them. We also asked them to provide feedback on the value of these services to the broader community. The project included the following actions:

- Conducting research scans of existing studies to address quality standards
- Overseeing consumer focus groups

¹ American Association on Intellectual and Developmental Disabilities. July 24, 2015. <u>Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us.</u> Accessed October 9, 2017. http://www.aucd.org/docs/publications/2015_0723_aucd_aaidd_community_living3.pdf

- Performing provider surveys
- Conducting program stakeholder interviews
- Identifying outcomes and financial data

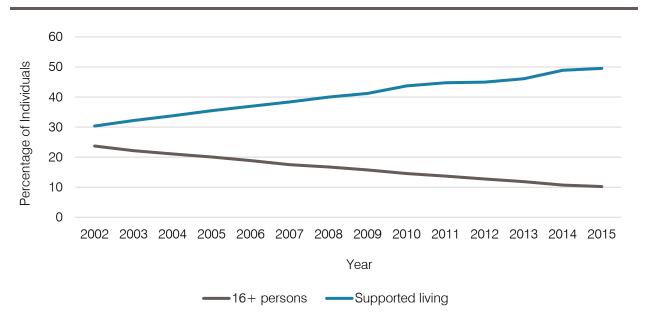
The research yielded a number of findings regarding services in Midland County. Many stakeholders indicated that Midland is advanced in terms of the quality of services offered and overall culture of acceptance. However, many also identified barriers that limit individuals with I/DD from achieving full quality of life. Some major barriers cited include direct care workforce shortages, a high volume of paperwork limiting staff time with consumers, few vocational opportunities, insufficient transportation options, and little coordination across providers and services. Based on the research findings, PSC recommends the following actions, which can be embraced by all stakeholders in the community to further the quality of life for individuals with I/DD:

- Attract and retain talent
- Reduce regulatory burden
- Invest capital in innovation
- Coordinate staff training
- Increase integrated employment and volunteer opportunities
- Improve transportation options
- Maintain a repository of available services
- Create a community quality of life measure

Background

Care for many adults with I/DD has shifted immensely in the last 40 years from large institutions to a person-based approach, which has expanded independence within community settings. Among individuals with I/DD in the United States who receive some form of public funding, those living in an arrangement with 16 or more individuals decreased from approximately 24 percent in 2002 to only 10 percent in 2015. During the same time period, those receiving public funding who were served via a person-based supported living setting increased from approximately 30 percent in 2002 to 50 percent of all persons served in 2015 (Exhibit 1).² A recent report by the American Association on Intellectual and Developmental Disabilities (AAIDD) reviewed studies published during the last decade that examined numerous outcomes for people with I/DD living in different residential settings.³ The review found that across all outcome areas, a community-based approach, on average, produced better quality-of-life outcomes for people with I/DD.

Exhibit 1. Percentage of Individuals with I/DD Who Receive Public Funding Living in 16+ Person Settings Versus Person-based Supported Living Settings in the United States, 2002–2015



Source: Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. *The State of the States in Intellectual Disabilities:* 2017. http://stateofthestates.org/documents/UnitedStates.pdf

² Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. *The State of the States in Intellectual Disabilities: 2017.* http://stateofthestates.org/documents/UnitedStates.pdf

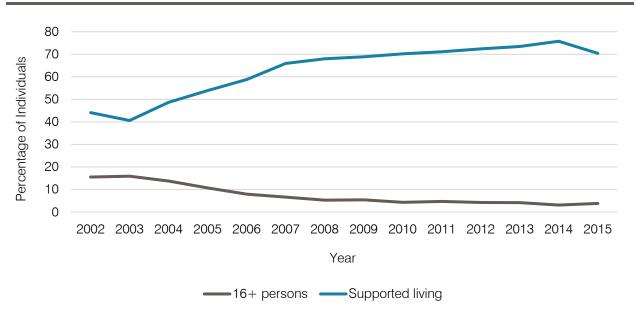
³ American Association on Intellectual and Developmental Disabilities. July 24, 2015. <u>Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us.</u> Accessed October 9, 2017. http://www.aucd.org/docs/publications/2015_0723_aucd_aaidd_community_living3.pdf

Impact in Michigan

The movement toward de-institutionalization coupled with person-based care at the community level has provided opportunities as well as challenges for consumers being served in Michigan. Similar to trends witnessed throughout the United States, Michigan has experienced an overall shift toward supported, independent-based living in recent years. More than 70 percent of individuals with I/DD who receive some form of public assistance were in supported living arrangements in 2015, an increase from 44 percent of individuals in 2002. During that same time period, those living in facilities with 16 or more individuals decreased from approximately 16 percent in 2002 to 4 percent in 2015 (Exhibit 2).

The shift means that individuals with I/DD have more opportunities to live a more independent and fulfilled lifestyle, with a focus on choice in housing, work, and social activities. However, challenges arise in ensuring communities have a culture of acceptance and understanding of the needs of individuals with I/DD and that they make the necessary accommodations. For example, communities must make more considerations for independent housing options for individuals with I/DD under supported living arrangements. Further, alternative housing arrangements must allow individuals access to the necessary supports, work or volunteer opportunities, and social interaction to maintain a fulfilled life. Many communities have struggled to maintain a workforce of care providers to meet the needs of individuals with I/DD living independently and to provide all necessary services, particularly to those who do not have a strong network of family advocates or support.

Exhibit 2. Percentage of Individuals with I/DD Who Receive Public Funding Living in 16+ Person Settings Versus Person-based Supported Living Settings in Michigan, 2002–2015



Source: Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. <u>The State of the States in Intellectual Disabilities</u>: 2017. http://stateofthestates.org/documents/Michigan.pdf

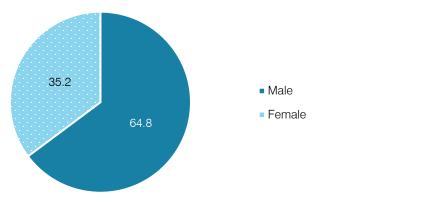
Midland County

Within local communities in Michigan, services to clients vary widely. Several factors may contribute to this, including availability of community resources, local nonprofit capacity, local philanthropic interests, family supports, health access, and financial resources across health and human service systems. As a result, the ability of local providers to affect the quality of life for their clients varies widely. In terms of measuring quality of life, many communities provide services but lack the mechanisms to fully understand how the services they are providing are improving quality of life. An evaluation of the services that a local community offers across provider agencies could be instrumental in determining the outcome measures to be defined to create a more widespread value model. This report begins to make those connections.

Midland County, as a community, has embraced independence through person-centered care in its service delivery. PSC interviewed one provider who commented that "the number of individuals who are able to live on their own in Midland is extremely unique." Other interviewees noted that many individuals with I/DD have moved to Midland because of the "phenomenal" resources, with neighboring counties "about 20 years behind Midland" in how the community and mental health agencies support choice for individuals with I/DD. Midland is served by the Community Mental Health for Central Michigan (CMHCM), which oversees six counties in total, namely Clare, Gladwin, Isabella, Mecosta, Midland, and Osceola. One consistent measure of services across counties is the state performance indicators. In 2018, CMHCM met or exceeded each of its state performance indicators, demonstrating its commitment to individuals with I/DD.

As it relates to population, CMHCM served 489 individuals with I/DD in Midland County in 2017. Of those, the majority were male (65 percent), a proportion that is similar to other research on gender in the I/DD population (Exhibit 3).



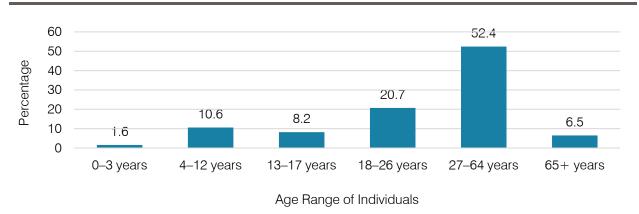


Source: March 2018 email from CMHCM.

⁴ Michigan Department of Health and Human Services. July 30, 2018. <u>Michigan Mission-Based Performance Indicator System: Final Report.</u> https://www.michigan.gov/documents/mdhhs/FY18_Q2_CMHSP_FinalReport_629767_7.pdf

Additionally, more than 70 percent of individuals served by CMHCM in Midland in 2017 were between the ages of 18 to 64, with approximately one-half of them being between the ages of 27 to 64 and another 20 percent between the ages of 18 to 26 (Exhibit 4).

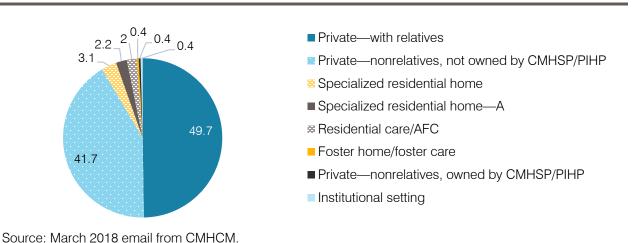
Exhibit 4. Age of Individuals with I/DD in Midland County, 2017



Source: March 2018 email from CMHCM.

Lastly, more than 90 percent of those served by CMHCM in Midland County in 2017 had private residence status. This is consistent with the percentage of individuals who had private residence status in 2015 in the state of Michigan (91 percent) and higher than the national average (82 percent).⁵ Approximately one-half of those with private residence status in Midland County indicated they lived in a private residence with relatives, while another 42 percent lived in a private residence without relatives but not owned by CMHCM or a prepaid inpatient health plan (PIHP) (Exhibit 5).

Exhibit 5. Resident Status of Individuals with I/DD in Midland County, 2017



⁵ Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. <u>The State of the States in Intellectual Disabilities</u>: 2017. http://stateofthestates.org/documents/Michigan.pdf

With its wide array of services and supports, Midland County is uniquely positioned to use its experience in independence-based care to build a value model to showcase the community benefit it derives not only from its health and human service providers, but also to the individuals utilizing those services. By focusing on Midland County, PSC evaluated whether available community supports and services met the needs of adults with I/DD and the broader community. Through focus groups, surveys, interviews, and research on financial data, PSC defined quality of life and identified overall themes to explain a community's return on investment from the services provided by local agencies. This report includes the results and analysis of those findings, as well as recommendations for future improvements for Midland County and the broader system.

Methodology

PSC employed a number of methods within the Midland County community to develop a better understanding of the vision for service delivery and to explore opportunities to expand upon the commitment to individuals with I/DD.

Identification of Quality of Life Indicators

Having a set of common indicators is critical to defining what quality of life is and how it can be measured. In conducting research and talking with stakeholders, PSC identified several broad categories with 38 quality of life indicators (Appendix A). The indicators are offered as measures of quality of life for people with I/DD in Midland County.

The selected indicators are primarily based upon the Association of University Centers on Disabilities (AUCD) and the AAIDD 2015 research paper, Community Living and Participation for People with Intellectual and Developmental Disabilities. The report highlights key components of high-quality community living for those with I/DD, based on more than 50 years of research. The key components are:

- 1. Where and with whom a person lives;
- 2. Where a person works and how he or she earns money;
- 3. What a person does during the day;
- 4. The quality of relationships developed with others during daily activities;
- 5. What and with whom a person does activities of personal interest;
- 6. An individual's health, both physical and emotional;
- 7. If, where, and with whom they worship;
- 8. Their interest and opportunities to engage in learning and personal growth; and
- 9. Their ability to make informed decisions about their lives.

Additionally, the National Core Indicators (NCI) is a set of measures (or indicators) that assess the outcomes of services for individuals with I/DD and their families. The survey is administered voluntarily by state developmental disability agencies across the country. The state of Michigan has participated in this survey previously and is moving toward implementing these indicators statewide for quality of life and service analysis for those with I/DD.

The 38 indicators have been selected for two reasons: 1) Each of them can be clearly connected to at least one of the nine components of high-quality community living identified by AUCD and AAIDD, and 2) they are broadly representative of NCI topics, encompassing those that are more granular or duplicative. PSC utilized the quality of life indicators throughout each portion of its discussions with stakeholders to gather feedback during its research.

Consumer Focus Groups

PSC conducted three focus groups with individuals with I/DD, their family members, and staff who were willing to share their personal experiences with service delivery in the community. Each session lasted 90 minutes and took place on April 30, 2018, and May 2, 2018. PSC collaborated with the CMHCM, Midland Regional Educational Service Agency, and the Arc of Midland to identify participants. Sixteen individuals with I/DD, family members, or staff ultimately participated in the discussions.

Provider Surveys

PSC generated an online survey instrument to gather information and gain additional insight into programs in the community. PSC created two different surveys, one for I/DD provider agencies in Midland County and another for additional support agencies through the Michigan 2-1-1 service listings, an agency that connects individuals with non-profit and government resources in the area. The surveys, which were open between August 2018 and January 2019, generated responses from 19 providers who directly serve individuals with I/DD in Midland County and 22 additional support agencies in Midland County. After gathering the survey data, PSC reviewed the information to ensure that all relevant program information within the community had been collected.

Program Stakeholder Interviews

PSC conducted 11 in-depth key informant interviews with individuals and representatives from organizations that provide programming and other support services to individuals with I/DD in Midland County. Each interview lasted approximately 60 minutes and took place during January and February of 2019. PSC used the results to clarify any information generated within the survey; to further understand each participant's perspectives on their program, mission, and priorities; and to gain insight into community perspectives and expectations.

Outcome and Financial Data Research

PSC assessed the value of the services delivered based on existing state and local reports already generated, including outcome reports, funding analysis, budgets, encounter data, and administrative costs. PSC worked closely with the local community mental health services programs (CMHSP) and other health and human service providers to gather other relevant information to assist in the review. These information points were aligned with earlier programmatic research to understand how the services align with the stated goals. The research also assisted in developing a model to demonstrate the benefits independence-based care can bring to the quality of life of those served and to the community.

Findings

Informed by both qualitative and quantitative data, PSC evaluated the findings from the research, which are included in the following sections.

Quality of Life Indicators

Most stakeholders agreed that the 38 identified indicators were important quality of life measures. In fact, many suggested the indicators were important measures of quality of life for any individual, not only those with I/DD. Some tools providers currently use to assess the impact of their services on quality of life include surveys and in-person interviews with clients and their guardians/families. However, some stakeholders expressed concerns about the method with which the surveys are conducted, particularly whether the feedback reflects the individual's views or someone else's, such as their guardian. It is difficult to determine whether a survey truly captures whether a person is achieving quality of life. This may be further complicated by the fact that many funding streams are based on output (number of services), but not necessarily outcomes. The current fee-for-service-based structure creates an incentive for providers to track services, but not necessarily the impact of those services on overall quality of life.

Across provider agencies, there is not a simple measure that is used consistently to gauge quality of life. While the stakeholders narrowed their initial list to 38 indicators, this is likely too many indicators to measure quality of life without being a burden to administer. The CMHCM shared its internal measure that identifies six overarching categories based on outcomes, rather than outputs. The majority of the 38 indicators PSC identified align with these six measures.

The CMHCM outcome-based measures are:

- 1. I like the staff that helps me
- 2. I chose my place of work or day activity
- 3. I choose how to spend my free time
- 4. I visit friends or people I am close with
- 5. I like where I live
- 6. I have enough privacy at home

Overall, through stakeholder feedback, PSC determined that the single most important indicator is how satisfied individuals are with their life. This is often directly related to the voice of the individual, in having a choice on where to live, who to interact with, or how to spend free time. If that can be answered in a positive way, quality of life is likely being achieved. The 38 indicators identified by PSC and the six CMHCM outcome-based measures can serve as a guide to help answer this main question measuring overall quality of life.

Consumer Focus Groups

Those who participated in the focus groups, including individuals with I/DD, family members, and staff, discussed quality of life support options in Midland County. These discussions helped identify strengths in the community as well as areas for improvement. Strengths included a culture of self-determination, acceptance in the community, and housing options. Areas for improvement included paperwork reduction, staff engagement, staff turnover, improved healthy lifestyles, more social experiences, workforce opportunities, transportation, and long-term support and safety. Many of the suggested improvements are not necessarily exclusive to Midland County but may reflect broader issues within the system.

What Is Working Well

Self-determination

Focus groups participants indicated that Midland County is viewed as a leader in developing and implementing best practices for self-determination. Consumers indicated it is important for them to participate in discussions related to their care plans, services, and budgets so that they can maintain their voice. Many recognized the efforts made within Midland County, compared with those in surrounding counties. In fact, participants noted that many have moved to Midland County so that they can make more decisions regarding the types of services they receive.

Community Acceptance

Community inclusion is an important measure of quality of life that is working well in Midland County. Each individual with I/DD in the focus groups identified different aspects of their life that represent satisfaction to them, such as where they live, the types of services and support they receive, and the activities they do. Some said having their own home was important, while others identified having friends to meet or a job as important to their overall life satisfaction. One family participant said that community inclusion is very important to an individual's quality of life and suggested Midland as a community has a culture of acceptance. Participants identified restaurants and businesses within the community where they felt welcome and included. One example highlighted the level of acceptance, when employees at a local grocer defended the rights of an individual with I/DD to shop independently in their store after a customer made uncompassionate comments about the individual. By coming to the defense of the individual with I/DD, they showed that they appreciated the individual coming to their store on a regular basis and supported the person's right to independently carry out a daily activity.

Housing

Many focus group participants indicated that access to housing is working well in Midland County, saying that they own their own home or are living with roommates who are a good fit. Having a staff person who was a good fit was also noted as being important in ensuring respect and helping individuals feel comfortable in their home. One family member of an individual who has received services for 26 years noted that high quality support for staff was important to "encourage people to be long-time staff members, which greatly enhances the quality of life for individuals." While many consumers noted positive aspects of housing in Midland County, other stakeholders have noted limitations, including waiting lists for affordable housing or issues with roommates. A recent study found that 40 percent of Midland County's renters earn less than \$20,000, a category that individuals who are employed full-time at minimum wage fall into, including many individuals with I/DD.6 Of those low-income renters, 90 percent pay for more expensive housing than they can afford due a shortage of affordable options.⁷ This indicates there are still some housing areas that may need to be further addressed.

Areas for Improvement

Paperwork Reduction

For areas needing improvement, focus group participants noted that paperwork to obtain or continue services has increased and has created system inefficiencies. For example, one family participant said that even when she makes sure her child's paperwork is completed and submitted to the agency ahead of deadlines, service providers have reported that it wasn't submitted. This has resulted in services ending and paperwork having to be redone. In addition, some participants felt that keeping up with the paperwork took away from time spent with the individual receiving services. One commented that "care and daily activities are more important than completing paperwork," while another noted that staff should "interact with people" while

⁶ United Way of Midland County. 2018. Midland County Housing Analysis 2018: Housing Analysis for Midland County. Michigan. Accessed April 22, 2019. https://midlandhabitat.org/wpcontent/uploads/sites/39/2018/03/czb Midland March 2018.pdf

⁷ Ibid.

they are with them, rather than focus on paperwork. While many understand a certain level of paperwork needs to be completed due to funding requirements, the volume and complexity is burdensome. Several participants mentioned the same information was collected multiple times by different organizations, as well as the same agencies.

Staff Engagement

While many expressed positive experiences with staff, several also noted challenges around staff engagement. Focus group participants described the relationship with staff as being "like family," so it was important to them that the staff person be a good fit and be willing to build a relationship with the individual. A positive relationship helps staff to understand what the individual with I/DD likes and dislikes, as well as their preferences for how tasks are done within their home. However, not all participant experiences with staff were positive. For example, one individual said some staff spent too much time on their phones instead of interacting with them. Another individual noted that not all staff followed the person-centered plan and goals put in place to help maintain their lifestyle, which may include how staffing support should help with meals, laundry, grocery shopping, and cleaning.

Staff Turnover

Individuals with I/DD and their families commented on the challenges of staff turnover. It is difficult when individuals do not know who will be spending the day with them. They preferred a longer-term staff person with whom they are familiar. Some family members suggested that the staff turnover rate could be high because their pay is low. Staff who participated in the focus groups reiterated that low pay caused problems with keeping good staff in the community. Staff provides great value to individuals with I/DD, yet they do not always feel that others see that value. One staffer noted that they work a lot of hours and "would like to feel more appreciated" for the work they do.

Healthy Lifestyles

Another challenge identified was around healthy lifestyles. Some focus group participants said having good healthcare and no disruptions with Medicaid services was important to their quality of life. Individuals with I/DD discussed their overall desire to generally be active, including being out in the community with friends and taking part in physical activity. Examples included walking at the mall, going to dances, and gardening. Some individuals with I/DD in the focus groups also participate in the Special Olympics. Family members said that some staff could benefit from additional training for activities related to healthy living. For example, staff could help individuals take part in exercise or in preparing meals and snacks with fresh foods.

Social Experiences

Although individuals with I/DD identified several activities and social experiences, they would like more social opportunities. The individuals with I/DD participating in the focus groups noted relationships and activities they participate in within the community other than with staff and family. Participants mentioned relationships with coworkers, friends, and significant others and said they enjoy meeting friends at the mall or a local coffee shop to play board games. Participants also commented that an annual dance was a place to be with friends. One participant had therapy animals (cats) in her home to enrich her quality of life. However, some previously available community services, such as facilitated "circle meetings" to help individuals build a network of friends, had not been done recently. One participant said it is difficult to know about all the opportunities and suggested creating a calendar or directory of social opportunities in the community.

Workforce Opportunities

Individuals with I/DD said they would also like more opportunities for paid employment. Several said they volunteer at a variety of businesses or organizations in the community, but they cannot improve their financial situation by earning money. Some participants work or have worked at the Arnold Center but would like to know of other opportunities in the community. One individual participated in Job Club and learned how to fill out employment applications and go on interviews. However, that person has not secured a job yet. A few of the individuals with I/DD participating in the focus groups said that they enjoy working at their paid and unpaid jobs. One participant held numerous jobs, paid and unpaid combined. She indicated she worked at multiple locations in very short blocks of hours, but she said she would prefer employment that provided ample job hours on a regular basis. Given the numerous positions, it was difficult to find transportation between positions.

Transportation

All focus group participants acknowledged that transportation is an important quality of life indicator that is available in Midland County. However, participants identified challenges to the systems of transportation available in the community, especially in underserved rural areas. Participants discussed the different services or opportunities available to them in the community, including Dial-a-Ride and County Connection. However, there were some barriers, such as needing to call 24 hours in advance to arrange transportation instead of being able to make same-day transportation requests or not having transportation available in the evening. Participants said transportation services end at 10:00 p.m., which does not allow an individual to accept a job with an evening shift.

Long-term Support and Safety

As supports have improved, individuals with I/DD are living longer—longer than many key caregivers and family members. A few family members voiced concerns about long-term funding for community supports, such as planning, financial assistance, staffing, and housing. Parents and staff feel there is a threat looming over the system of community support as dollars shrink for community mental health (CMH) services and Medicaid, which leaves individuals who need the most support in difficult situations. Any cuts to these funding streams affect how providers can maintain services. Another parent noted that she has had to advocate more for her child's staff person to attend an event or to meet with her child, particularly with recent funding cuts. She noted that she is "always trying to prove the medical necessity of services and supports" so that they can be provided. In addition, family members participating in the focus groups said that individuals who do not have family members in the community may not have the same supports as individuals who do. These family members recognized that without family support, some individuals' experiences vary greatly from others with more engaged family. As one participant noted, just because an individual has support staff, "that doesn't mean they have an advocate" who realizes all of the supports the individual could have for a better quality of life.

Safety concerns and how to address them were also raised by family members in the focus groups, particularly for I/DD individuals who outlive their family. Family participants said they are trying to teach their child and their friends about personal safety issues and how to have healthy relationships. In addition, participants identified the Arc of Midland as a valuable community resource that holds classes with law enforcement and the fire department on safety in the home. Safety is also discussed in care team meetings.

Provider Surveys

I/DD Provider Survey

The providers who responded to the survey deliver a variety of services to those with I/DD in Midland County. More than one-half of the respondents indicated that they provide personal care and community living supports. Additionally, more than one-third of respondents provide transportation, skill building and training, and respite care services. Among these top five services available in Midland County, the majority of providers delivering the services indicated that consumers had a choice in selecting them. Other services available to individuals, identified by more than 20 percent of responding I/DD providers, include individual therapy; adaptive behavior treatment; supported employment; residential room and board; and music, art, and recreation.8

⁸ See Appendix B for a listing of all services included in the survey.

Quality of Life Indicators

To better understand how the services delivered in Midland County affect quality of life, providers were asked to indicate which quality improvement indicators most closely aligned with the services provided to those with I/DD. The choices were narrowed to the 38 quality of life indicators identified by PSC. Of those, approximately one-half of all respondents who provide services to those with I/DD in Midland County suggested the 13 indicators in Exhibit 6 most closely align with their services offered.

Exhibit 6. Quality of Life Indicators that Most Align with I/DD Provider Services Offered in Midland County

Category	Quality of Life Indicator
Choice and Decision Making	Decides or has input in deciding daily schedule
Work	Opportunities to engage in learning or personal growth activities
Community Inclusion	 Able to go out and do the things he/she likes to do in the community Able to go out and do the things he/she likes to do in the community as often as wants to
Relationships	 Has friends other than staff and family Has friends (may be staff or family) and can see friends when they want Can see and communicate with their family whenever they want Has someone to confide in
Satisfaction	Services and supports help person live a good lifeIs satisfied with daily life
Service Coordination	Person was able to choose services they get as part of service plan
Access	Staff have the right training to meet the person's needs
Wellness	Engages in physical activity

Source: PSC survey of I/DD providers in Midland County.

There were several quality of life indicators that few providers indicated as closely aligning with the services they provide. Those indicators, cited by 15 percent or fewer providers, are listed in Exhibit 7.

Exhibit 7. Quality of Life Indicators that Least Align with I/DD Provider Services Offered in Midland County

Category	Quality of Life Indicator
Self-determination	Can make changes to budget/services if needed
Relationships	Feels lonely
Health	In poor health
Wellness	Uses nicotine or tobacco productsUses alcohol and/or marijuana
Respect and Rights	 Has a place to be alone at home Has ever voted in local, state, or federal election or had the opportunity and chose not to

Source: PSC survey of I/DD providers in Midland County.

In terms of tracking quality of life indicators, the most common method cited by providers is conducting surveys. Surveys may go to individuals with I/DD who are receiving services, as well as family members, guardians, or CMH case managers. Additionally, several respondents noted that they monitor quality of life indicators by adhering to person-centered plans, reviewing progress notes (from physicians, staff, etc.), and conducting in-person meetings with consumers, family, and staff. Some also noted that they do not track indicators.

Barriers

Provider respondents who deliver services to those with I/DD in Midland County noted a number of barriers in providing services to individuals. The most common barrier cited was related to funding issues, particularly low reimbursement rates, which make it difficult to attract quality staff and compete with other organizations offering higher wages with less training. One provider also noted that funding sources in general are limited. Additionally, other providers noted barriers due to federal and state regulations. For example, one respondent felt that there were simply too many rules. In an effort to efficiently implement the rules, the local CMH agency worked to streamline forms and payment across providers; while this is helpful for some, the complexity of the rules can make it difficult for different types of providers to adapt them to their specific services. Another provider noted that they were prevented access to training tools needed to offer certain types of care. Some also noted issues with consumers, when they are not home to receive services or are not aware of the options that may be available to them.

Respondents also noted that staff shortages caused significant barriers to individuals with I/DD in receiving services. When there are not enough staff to cover support hours, individuals end up not receiving the care needed. Additionally, several providers cited income as a barrier for individuals in receiving services, as well as transportation issues, lack of awareness of services or benefits of receiving services, and difficulty with regulations leading to delays in care.

Budget

Approximately one-half of provider respondents who deliver services to those with I/DD in Midland County have not experienced changes in budget during the past five years (Exhibit 8). However, approximately one-third noted that they have faced decreases in government support and reductions in services (number of visits, length of services, or fewer service options). None of the respondents indicated that they have experienced reductions in extracurricular or social activities for individuals with an I/DD. Others noted that they have had to decrease the amount of work funded by government programs due to low reimbursements, as well as having large increases in overhead expenses for mandatory training and technology requirements.

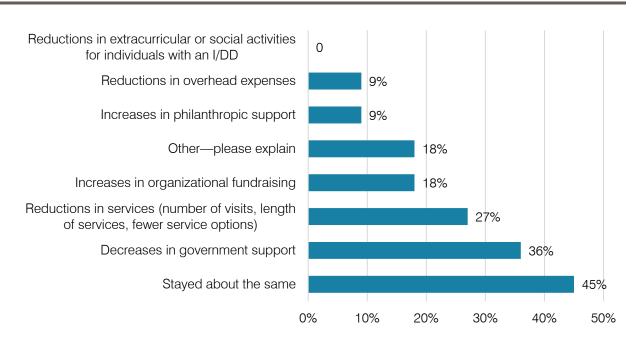


Exhibit 8. Changes to I/DD Provider Budgets in the Past Five Years

Source: PSC survey of I/DD providers in Midland County (N=11). Respondents could choose more than one response, so percentages total more than 100 percent.

General Community Service Provider Survey

The general community service providers who responded to the survey deliver a variety of services to those with I/DD in Midland County. Services range from counseling and assessments to in-kind donations of clothing, small appliances, food, and personal care items. Additional services include independent living support, nursing home transition services, financial aid, transportation, housing, care coordination, dental and medication services, volunteer and work experience opportunities, and skill-building (how to use computers, obtain a library account, etc.).

Quality of Life Indicators

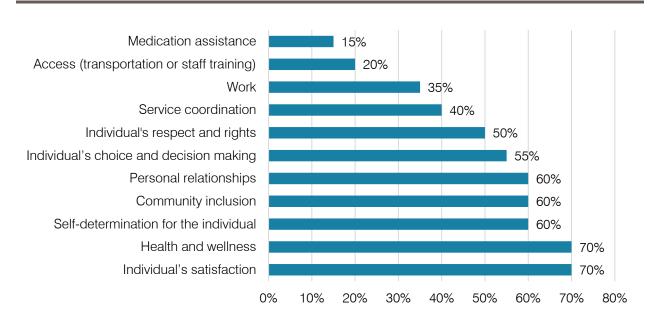
Many community service providers indicated that the services they provide help individuals with I/DD achieve important quality of life measures. Among respondents, 70 percent provide services that support satisfaction and health and wellness for individuals with I/DD (Exhibit 9). Some of the services offered by community service providers to support these measures include working with individuals to build their cognitive, emotional, and behavioral skills; creating a welcoming environment; and ensuring safety.

Additionally, more than one-half of respondents indicated that their services support those with I/DD in choice and decision making, personal relationships, community inclusion, and selfdetermination. The services offered to help individuals achieve these quality of life measures include adhering to an individual's person-centered plans, educating them on available resources, and empowering individuals to make decisions about their lives.

Only one-third or fewer respondents indicated that they provide medication assistance, access via transportation or staff training, or work supports to individuals with I/DD. Among those that do offer services to support these categories, the services provided include linking individuals with community organizations to find work placement, skills training, resume building, prepping for an interview, bus passes, and transportation programs.

While many providers indicated they do not track many quality-of-life indicators, common methods for those who do include surveys or progress reports over time.

Exhibit 9. Quality of Life Categories that Community Service Provider Organizations Support for Individuals with I/DD



Source: PSC survey of general service providers in Midland County (N=20). Respondents could choose more than one response, so percentages total more than 100 percent.

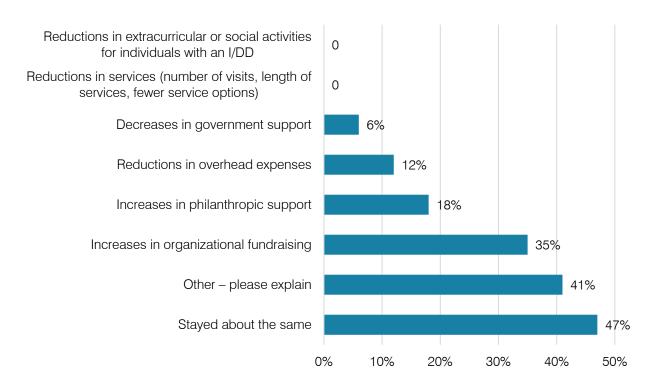
Barriers

Survey respondents identified a number of barriers that they, as a general community service provider organization, have experienced in delivering services to those with an I/DD. Several noted that they have faced issues with caregivers, including those who provide insufficient information about an individual to conduct an accurate needs-assessment or do not fully respect the desires of the individuals (for example, in exercising certain spiritual beliefs). Additionally, one respondent indicated that caregivers possess limited time and training to assist individuals, which may be the result of low reimbursement rates preventing providers from adequately scheduling and training staff. Some community service providers have experienced barriers in offering services when families or guardians do not agree with the need for services or who provide insufficient or incorrect information regarding an individual's health history. Other barriers noted by community service providers include inadequate transportation, lack of family involvement, or clients who do not meet program guidelines or are under- or uninsured. One provider of social supports also commented that they do not offer staff to assist individuals, so those with I/DD must have the appropriate staff available to assist them in participating in the social activities, which can be a barrier. It is worth noting that a few community service providers indicated they have not experienced any barriers in providing services to individuals with I/DD.

Additionally, community service provider respondents have witnessed barriers for individuals in receiving the services offered. Financial burden and transportation were cited by several community service providers as barriers for clients. Respondents also noted barriers in terms of quardians who are not able to complete the appropriate paperwork before services and who lack knowledge of availability of services and accessibility issues (for example, outdated elevators or unsuitable reading levels). Some community service providers indicated that there were no barriers for individuals with I/DD in obtaining their services.

Budget

In terms of budget, approximately one-half of the community service provider respondents indicated that their budget revenue has stayed about the same during the past five years(Exhibit 10). Despite the stagnation, many stakeholders have suggested that expenses are increasing. One-third of respondents noted that they have experienced increases in organizational fundraising during the past five years. None of the community service provider respondents indicated a reduction in services, extracurricular activities, or social opportunities for individuals with an I/DD. Approximately 40 percent of community service providers noted other changes to their budgets during the past five years, including decreases in foundation support, as well as increases in overhead expenses, patient volume, donated items, and services overall. Some noted that they do not receive any outside funding or that they have not experienced any budget changes during the past five years.



Source: PSC survey of general service providers in Midland County (N=17). Respondents could choose more than one response, so percentages total more than 100 percent.

Stakeholder Interviews

PSC conducted interviews with 11 different stakeholders in Midland County. The organizations provide a variety of services in the community, with seven of the organizations providing community living supports, as well as housing, advocacy, work, and social service supports.

Defining Quality of Life

Stakeholders defined quality of life in a number of different ways. The two quality of life categories most cited by interviewees were choice and community. Many stakeholders felt that it was important for individuals to have a choice in the services they receive, their living environment, and the goals they would like to work toward achieving. Additionally, many stakeholders indicated that helping individuals have a level of community participation and engagement was critical to quality of life. Several providers also mentioned that maintaining a safe environment, having access to services to match their needs, and receiving the same opportunities and independence as those without I/DD were important to quality of life.

Every interviewed stakeholder agreed that there was alignment between the quality of life indicators their organization measures and those identified by PSC. Several providers suggested that the 38 quality of life indicators are essential to any person's quality of life, whether they are a person with I/DD or not. One stakeholder commented that the indicators should be the foundation of any human services agency.

In terms of measuring quality of life indicators, stakeholders employ various methods to track success. Eight of the 11 stakeholders identified surveys as a key tool, which was the most commonly cited method. Some conduct surveys monthly while others conduct them annually. Survey respondents may include individuals with I/DD, as well as family, friends, guardians, or outside organizations. Additionally, several provider organizations indicated that they track quality of life based upon whether their care plan follows a client's person-centered plan, used to develop an individual plan of service, and they measure progress through notes. Other methods cited include conducting in-person meetings with clients to solicit direct input, adhering to government standards that mandate personal choice and community inclusion, and evaluating based upon key metrics, such as living environment, whether an individual earns income, and opportunities to engage in a variety of relationships. Many stakeholders indicated that they make changes to their services based upon the feedback. While the feedback indicated there are several methods for providers to assess quality of life, many are not captured in measures that would demonstrate improved quality of life.

When discussing how the community could best measure and communicate its impact on quality of life for individuals with I/DD, many stakeholders identified community inclusion as being essential. It could be assessed by evaluating whether businesses are providing job opportunities for individuals with I/DD or observing whether people interact with different groups at community events. Education could be conducted so that the community is aware of the benefits not only to those with I/DD who are receiving services, but also to the community as a whole when individuals with I/DD can obtain needed support so that they can contribute to the public good, as well. Other outcomes that could be measured include the percentage of homeowners among those with I/DD, whether the I/DD population has an employment rate consistent with the broader community, or the level of attendance at general community events.

What Is Working Well

Quality of Services

Midland County offers a variety of services that help individuals with I/DD attain a high quality of life. Several essential organizations identified by stakeholders include CMHCM, the Arc of Midland, and the Arnold Center. Each of these organizations plays a unique and critical role in helping individuals access services by offering funding, advocating for improved policies, and providing individuals with vocational skills training. One provider noted that surrounding counties that are larger may have more services, but they often do not compare with the level of support offered in Midland. That level of support is recognized by people who moved to Midland

specifically so that an individual with I/DD could obtain needed services. As one respondent noted, Midland is "ahead of the curve in thinking differently and trying to really provide different options for folks." Additionally, many stakeholders indicated that the community living support services available in Midland County are important, as they help individuals with I/DD achieve their goals and carry out their desired quality of life. There are a number of different providers offering these services in Midland, allowing those with I/DD to choose an option that best suits their needs.

Culture

Midland is unique in its culture of acceptance, as well as having a large number of individuals with I/DD living independently or semi-independently. Many respondents indicated that the level of support provided in Midland is stronger than in other counties. It has employers willing to hire people, as well as foundations and organization in the area that demonstrate that they value all citizens. For example, one stakeholder cited Dow Chemical as a global leader in inclusion, not just in terms of physical or ethnic differences, but also for those with I/DD. By working to find ways to integrate individuals with I/DD into the company through internships and training, the company gives a sense of purpose to the individuals and helps to create a more inclusive environment in the overall community. This is critical to quality of life, as many people make friends where they live and work. According to the Michigan Department of Health and Human Services, "a strong predictor of well-being for people with I/DD is the number of unpaid people in their lives (natural supports)" to help prevent social isolation and loneliness. Several stakeholders credited Dow, along with several other benefactors in the region, as the reason why Midland is ahead of the curve in having an accepting community.

Areas for Improvement

Reimbursement Levels

Nearly every stakeholder indicated that they have faced funding difficulties in recent years. Many discussed the low Medicaid reimbursement levels and the direct impact it has had on quality of life for individuals with I/DD. According to stakeholders, reimbursement rates are currently \$13.50 per hour for Adult Home Help and between \$17-\$19 per hour for community living support, depending upon the service. In the past, CMHCM would reimburse the difference between Adult Home Help and community living support hours, but it was mandated by the state to stop providing that extra funding in recent years. Some stakeholders also noted regional differences in payments, where reimbursement rates vary by county. Due to these funding

⁹ Michigan Department of Health and Human Services. n.d. "Inclusive Community." Michigan Department of Health and Human Services. Accessed March 20, 2019. https://www.michigan.gov/mdhhs/0,5885,7-339-71550 2941 4868 4897 90348---,00.html

shortages, many indicated that some providers have not been able to accept individuals who need a large number of Adult Home Help hours, because they lose money on those clients from the low reimbursement rate for those types of services. This means that some individuals who need services the most are not able to obtain them.

Some organizations mentioned the need to be more creative and innovative with how to use the funding that does exist, including interpreting regulations in a way that maximizes benefits to individuals with I/DD. For example, some counties have interpreted Medicaid regulations to include overnight support for individuals who need it, but Midland County does not allow reimbursement for that service; it can be challenging for CMH agencies to push back on the rules, as they are at risk for paybacks, as well. Another example of innovative use of funding is looking to tools embedded in smaller initiatives and broadening them to a wider population to receive the services. Currently, providers offering services to individuals with I/DD for selfdetermination work under the Habilitation Supports Waiver and are able to reimburse for goods and services, such as a class. This model could be expanded to those not receiving services under that waiver.

Others stressed the difficulty with "having to do more with less" when the budget is simply not there. Many providers operate as non-profit organizations and have experienced a number of other financial challenges in keeping up with mandated client reporting, staff training requirements, and health insurance and benefits for employees. The reimbursement rates simply do not cover the costs for all of the expenses required to operate their business, which in turn affects quality of life for individuals with I/DD. For example, if an individual with I/DD wants to go to a movie or out to eat at a restaurant, a staff person cannot attend unless they or their employer is willing to pay for those types of activities, as they are not reimbursable. Additionally, one provider noted that the reimbursement rate for mileage to take an individual to a doctor's appointment is so low that they do not even bother processing the paperwork to claim the funds. Due to these constraints, individuals with I/DD can be limited in their ability to be out in the community or obtain needed medical care. Finally, one stakeholder noted that those who are not eligible for Medicaid are not able to receive financial support for services under the current system, which can cost hundreds of thousands of dollars a year. This means that some individuals with I/DD may not be able to access services at all.

Direct Care Workforce Shortage

Low reimbursement rates have also had an impact on the ability for providers to recruit and retain quality staff, which every stakeholder who was interviewed has experienced or witnessed. Due to low reimbursement rates, many providers are only able to pay employees minimum wage, after accounting for additional costs such as employee benefits and overhead. This means they are competing with other minimum wage organizations, such as fast food

restaurants, grocery stores, and moving companies. Many providers are losing direct care workers to those types of jobs, as average pay is the same, but those working with individuals with I/DD are required to obtain more training than most other minimum wage workers and are not always valued—financially or culturally—for the challenging work (Exhibit 11).

Exhibit 11. Select State Occupational Employment and Wage Estimates in Michigan

Occupation	Number Employed	Median Hourly Wage	Mean Hourly Wage	Annual Mean Wage
Childcare Workers	17,510	\$10.65	\$11.38	\$23,670
Food Preparation and Serving	392,990	\$10.09	\$11.70	\$24,340
Home Health Aides	26,580	\$11.18	\$11.91	\$24,770
Personal Care Aides	39,740	\$11.06	\$11.65	\$24,230

Source: Bureau of Labor Statistics, United States Department of Labor. May 2018. Occupational Employment Statistics. Accessed April 22, 2019. https://www.bls.gov/oes/current/oes_mi.htm

Some respondents cited a recent legislative proposal to keep support staff wages at least \$2.00 above minimum wage to help retain staff as a potential solution, but they noted it has not yet been passed by the legislature and will likely require a high level of advocacy to succeed. Many direct support workers are on Medicaid themselves, working to support their families. This strain creates a high level of turnover, cited between 40-60 percent by stakeholders, making it difficult for providers to maintain quality staff who are able to fully meet the needs of the job. The impact on quality of life for individuals with I/DD is noticeable. Some indicated that it is difficult to provide services to individuals with I/DD who only need help for short periods of time, rather than large blocks, as staff are not willing or able to commute back and forth. For individuals with I/DD who can obtain services, they do not always know who will be showing up to their house to provide very personal care. As one provider noted, "We are only as good as the staff person who is scheduled to work at the client's house." Without quality staff, services for individuals with I/DD suffer as a result.

Employee Training

Several stakeholders discussed the difficulty in keeping up with staff training requirements. Respondents indicated that there has been an increase in specialized training requirements in recent years, but no funding or coordinated effort to provide the training. Some providers mentioned that the training that is required is not only burdensome, but often not useful, as many providers cannot afford better options. It frequently requires staff to read a document online and sign off on it, without actually gaining substantial knowledge. Further, due to the high levels of staff turnover, providers are continually having to spend time and resources training new staff. One provider mentioned how training from one mental health agency is often not recognized in another county. If staff need to cross county lines, they may not be considered

certified even though they received the same training as the staff in that county. One provider suggested that certification be recognized statewide from one mental health board to the next, so that there is state reciprocity on training. This could help to minimize the amount of time providers have to spend tracking and coordinating training for staff.

Regulatory Burden

Stakeholders indicated that a high level of federal and state oversight has created a large amount of paperwork that takes away time spent providing services to individuals with I/DD. There are different programs that serve the Medicaid population for behavioral health, including Adult Home Help, Community Living Support (CLS), and MI Choice Waiver. Each has a different set of rules and regulations, creating a tremendous amount of overhead for providers. Some stakeholders noted increases in reporting and training requirements without additional funds to make the changes. Additionally, several stakeholders felt there have been increases in the number of audits. One provider noted that the amount of time spent on paperwork has been so burdensome, it doubles the workload of some staff. Others have had to employ full-time staff just to review paperwork to ensure they are meeting the reporting requirements to get reimbursed for the time spent delivering services. Another indicated that there have been instances when they have not submitted reimbursements or other claims because it is not worth the administrative cost to complete the paperwork.

Many stakeholders also noted that federal and state regulations have limited the availability of certain services for those with I/DD. For example, due to complex rules, providers expressed confusion as to whether they are able to obtain reimbursement for individuals receiving their services across county lines. Many suggested they were not able to do so, precluding an individual with I/DD's ability to attend a sports game or show in another county. However, one stakeholder indicated that the Michigan Department of Health and Human Services (MDHHS) clarified that mileage reimbursement and use of CLS staff is allowed in other counties. Despite the clarification, the confusion around the issue has limited services for some individuals based on provider knowledge of the issue. Additionally, stakeholders indicated that many individuals with I/DD have experienced decreased service hours due to Medicaid restrictions mandating that services are limited to those that are medically necessary, defined as a service that is clinically appropriate to meet a person's mental health needs. 10 For example, some individuals who are higher needs who have chosen to move out of a nursing home and into an independent living arrangement have not been able to obtain the proper overnight support to ensure safety due to these regulatory restrictions. One provider shared a story where a diabetic patient experienced a decrease in service hours because of regulations limiting what qualifies for services. The provider was told that, even though the patient didn't know how to use their insulin, they could not be reimbursed for additional hours of care because it was a physical

¹⁰ Michigan Department of Health and Human Services. October 1, 2018. MDHHS/CMHSP Managed Mental Health Supports and Services Contract: FY19. Accessed March 6, 2019. https://www.michigan.gov/documents/mdch/FY09-10 CMHSP Contract Boilerplatewithattachments 312216 7.pdf

medical issue, which would be outside of the scope of behavioral health services. The client passed away within 30 days of the change in service hours. This type of situation often occurs at hospitals, doctor's offices, and other instances where there are medical and behavioral overlaps in services, forcing a provider to either deliver care to an individual without reimbursement or forego needed care for an individual.

Work Supports

Several stakeholders noted that individuals with I/DD are able to go to school until they are 26 in Michigan, compared to age 22 under federal law. This was identified as an important policy so that those with I/DD can continue their education beyond the age of 18, helping them to further mature and access services to help them past graduation. In Midland County, 20 percent of individuals with I/DD served by CMHCM in 2017 completed some form of K-11 education, with 54.6 percent of individuals reaching grade 12 or a GED. 11 However, only two percent received any form of college or vocational school education. Further, stakeholders indicated that there is limited availability in the number of employment-training programs and microenterprise opportunities for individuals with I/DD for after they leave school. According to the Michigan Developmental Disabilities Council, the unemployment rate for individuals with I/DD in Michigan is extremely high, at 81 percent, compared to a 9 percent unemployment rate for people without I/DD.¹² In Midland County, 11 percent of individuals with I/DD receiving services from CMHCM in 2017 had part-time employment; one person had full-time employment; the rest were either unemployed, not in the competitive integrated labor force (student, retired, sheltered workshop, prevented from working due to I/DD), or under 16 years of age. 13 While some companies, such as Dow Chemical, have begun hiring individuals with I/DD with certificates into the company to complete internships and train to grow into new positions, several stakeholders suggested there are not enough employers who are offering these types of opportunities for those with I/DD. Many stakeholders noted the importance of having employment and volunteer opportunities available, not only for individuals to support themselves financially, but also to help emotionally. Most individuals go from spending most of their day in school to adulthood where their day may not be as structured. Having the proper transitional services and opportunities to fill their day and stay engaged and productive is essential to quality of life.

Transportation

While Dial-a-Ride and public transportation are available, many respondents noted the need for better transportation options. Some cited experiences where individuals with I/DD have had to wait up to two hours for Dial-a-Ride service or buses. One provider tested Dial-a-Ride and reported that his typical commute to work takes 10 minutes; however, with Dial-a-Ride, it took nearly an hour. This creates issues, not only for those who have work or volunteer positions, but

¹¹ March 2018 email to PSC from CMHCM.

¹² Michigan Protection and Advocacy Services, Inc. September 2014. *Employment First in Michigan*. Accessed March 6, 2019. https://www.michigan.gov/documents/mdch/Employment+First+in+Michigan 469682 7.pdf

¹³ March 2018 email to PSC from CMHCM.

also for those needing to get to a doctor's appointment or other scheduled meetings, as well as daily activities and community events. One provider noted that staff is only able to transport individuals certain places based upon their person centered plan. It can be particularly difficult to obtain service during evenings and weekends, creating the need for more service during extended hours.

Coordination

There are a lot of providers accompanying the large volume of services offered in Midland. Several stakeholders noted that coordination could be improved. In the past, there was a coordinator position that oversaw the budget, support staff training, housing, and other services available to individuals with I/DD. Due to a Medicaid funding shift, that position was absorbed by other billable service codes and functions. Today, case managers at CMHCM must fulfill those responsibilities in addition to having larger caseloads and higher amounts of paperwork. Case managers also must make clinical decisions about the types of services and supports individuals with I/DD receive, based upon a monthly meeting that typically lasts only 15 minutes. One stakeholder noted that one case manager recently had 58 people on their caseload. With resources stretched so tight, case managers cannot fully develop relationships with the individuals they serve or function to the fullest extent for each person. The case manager role could be supplemented by a coordinator position or adjusted to have fewer caseloads, which would provide total coordination for all services across providers for a single individual.

Collaboration

Several stakeholders suggested the community could improve communications across organizations to determine what resources are available and how stakeholders could work together to fill gaps in services. Some providers were interested in expanding into additional service areas but faced challenges in obtaining funding from local foundations if another organization was providing similar services. However, it may not be possible for one organization to singlehandedly provide all needed services in one area. Additionally, some stakeholders mentioned the need for better collaboration with partners outside the traditional I/DD community, such as medical professionals. While they are not at the front line of care, they could become better partners in treating individuals with I/DD. By increasing collaboration across all groups, stakeholders may be able to better understand where needs exist in the community, how they can differentiate themselves, and how they can work together to foster better quality of life for individuals with I/DD.

Outcome and Financial Data

Cost and Utilization Trends

According to data from the State of the States in Developmental Disabilities Project, In Michigan, approximately \$1.56 billion public dollars were spent on I/DD services in 2015.14 Of that, approximately one-third is state or local spending. The rest is federal funding, with the largest share (\$740.9 million) from the Medicaid Home and Community-based Waiver program.

The number of individuals receiving public funding for services more than doubled between 2000 and 2015, from 12,752 to 31,020 respectively. 15 The majority of the increase has been among those obtaining supported living funding, from 1,712 individuals in 2000 to nearly 22,000 individuals in 2015. However, during the same timeframe there has been a nearly 50 percent decline in the number of individuals living in settings with 16 or more persons, from 2,453 in 2000 to only 1,188 in 2015. There are several factors that may be contributing to this shift. First, the baby boomer population is aging, where one in every five U.S. residents will be older than 65 in 2030.16 This not only means that the caregivers in that generation are reaching retirement age, but it also shows that more caregivers will be needed to serve the expanded population. Additionally, more people are seeking services: the older generation is living longer and the younger generation is seeking supports and services much earlier as fewer people enter facilities with more than 16 people and parents are not able to take care of their adult children. Finally, medical and technological advances have allowed for better and earlier screening and diagnosis, which may also contribute to the increase in individuals obtaining services. 17

Recent data suggests that supported living costs less than care for individuals in a group setting. The average annual cost of care for supported living in Michigan in 2015 was approximately \$20,000, whereas the average annual cost of care for those living in a group setting of seven or more individuals was nearly \$35,000.18

¹⁴ Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. The State of the States in Intellectual Disabilities: 2017. http://stateofthestates.org/documents/Michigan.pdf

¹⁵ Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. *The State of the States in Intellectual Disabilities: 2017.* http://stateofthestates.org/documents/Michigan.pdf

¹⁶ United States Census Bureau. March 13, 2018. "Older People Projected to Outnumber Children for the First Time in U.S. History." Newsroom. Accessed March 20, 2019. https://www.census.gov/newsroom/press-releases/2018/cb18-41population-projections.html

¹⁷ National Institutes of Health. June 30, 2018. "Intellectual and Developmental Disabilities." Research Portfolio Online Reporting Tools. Accessed March 20, 2019. https://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=100

¹⁸ Braddock, D., R. Hemp, E.S. Tanis, et al. 2017. The State of the States in Intellectual Disabilities: 2017. http://stateofthestates.org/documents/Michigan.pdf

Program Administration Spending

Program administration is a necessary component of any organizational structure. While it may be difficult to determine the layers of administration when subcontracting is involved, Medical Loss Ratio (MLR) is one measure that may allow for comparisons across administrative rates. The Affordable Care Act (ACA) includes several provisions to assess MLR. The MLR limits the portion of dollars a health insurer may spend on administration (including executive salaries), marketing, and profits. If an insurer does not meet the standard set by the state, that insurer must pay back premiums in the form of rebates to customers.

Compared to standards set by MDHHS for health plans, Michigan mental health organizations maintain very high ratios, meaning a higher rate of resources are used for medical purposes. rather than administrative. On average, Michigan health plans need to maintain an MLR of 82.9 percent.¹⁹ In 2017, all of Michigan's PIHPs exceeded a rate of 90 percent for their specialty services populations, which includes individuals with I/DD. While lower MLR rates raise a question about whether recipients are receiving an appropriate level of value from their provider, a higher rate may raise concerns about the efficiency or sustainability of an organization. It's difficult to determine what potential causes are affecting the high MLR rates for PIHPs. There may be several factors contributing to elevated rates, including:

- Costs continue to be driven largely by fee-for service for organizations in initial stages of managed care implementation;
- Higher unit payment to providers;
- Inefficient care management activity; or
- Appropriate level of medical services with capitation rates set too low.

Studies of MLRs have noted that health plans in states who have carved out difficult to manage costs such as mental health are able to manage and stabilize their MLR rates. This may be the case for PIHPs in Michigan, as they are solely managing difficult costs. In addition, information provided throughout the interviews conducted with providers suggests the high MLR may be affected by low capitation rates for services provided as well as a continued fee-for-service environment.

In addition to the high MLR rate for specialty services, the MLR rates for the Healthy Michigan population indicate that PIHPs in many places have rates in excess of 100 percent, meaning they are spending much more than they are receiving in payment for services. These high MLRs confirm that the shift of Healthy Michigan resources (from general fund to Healthy Michigan) have made service delivery more difficult for PIHPs. As a result, many PIHPs are relying on reserves to support operations, making it more difficult to pursue innovative solutions as they try to stabilize their budgets.

¹⁹ Goldsmith, J., Mosley, D., Jacobs, A. May 3, 2018. "Medicaid Managed Care: Lots of Unanswered Questions (Part 1)." Health Affairs. Accessed March 27, 2019. https://www.healthaffairs.org/do/10.1377/hblog20180430.387981/full/

Areas for Action

There are many challenges that providers face in delivering services to individuals with I/DD, particularly when it comes to costs, staffing issues, and regulatory burdens. At the same time, the shift toward independent living arrangements among the I/DD population has created different service and delivery needs, such as more housing and transportation options. Based on the research, the following are improvements that all stakeholders can embrace to improve the quality of life for individuals with I/DD.

Attract and Retain Talent

The number one issue heard from providers was the need for higher reimbursement rates, which many felt was needed to attract and retain talent. An evaluation by the CMHCM found that behavioral health and I/DD Medicaid rates have not kept up with average Medicaid rate increases across the country or average commercial health insurance rate increases across the country.²⁰ Some stakeholders suggested advocating for a reimbursement rate that is high enough to allow providers sufficient funding to provide a starting wage that is at least \$2.00 per hour above minimum wage, a proposal created by a workgroup mandated by the Michigan Legislature, the Workgroup on the Direct Support Workforce.²¹ By keeping reimbursement rates at a level where direct care staff wages were above minimum wage, providers would be better positioned to offer more competitive wages and benefits, compared with other companies offering minimum wage, to recruit and retain quality workers. One barrier that impacts talent retention by providers is the limited flexibility that is created by the fee for service structure administered by local CMH service providers that incentivizes a system based on delivering services, but not necessarily quality. Medicaid funds are paid on a per Medicaid-eligible capitated basis, with CMHs acquiring funding per member per month. The American Network of Community Options and Resources identified several payment reform principles for consideration.²² By modernizing payment structures to better align with long-term support needs, rather than a medical model, providers could focus more on quality of life for individuals with I/DD, rather than working to provide a service in a certain amount of time to receive a designated amount of funding.

²⁰ CMHCM. March 2017. Bending the Healthcare Cost Curve: The Success of Michigan's Public Mental Health System in Achieving Sustainable Cost Control. Accessed March 6, 2019. https://cmham.org/wp-content/uploads/2019/03/CHI2bending-the-cost-curve-final.pdf

²¹ The Arc of Michigan. 2016. Section 1009 Report: Recruitment and Retention Challenges for the Workforce Delivering the Most Frequently Used Supports and Services. Accessed March 6, 2019. https://arcmi.org/content/uploads/sites/15/2016/05/FINAL-report-section-1009-on-direct-support-workforce-3-26-2016.pdf

²² American Network of Community Options and Resources. January 2019. Advancing Value & Quality in Medicaid Service Delivery for Individuals with Intellectual & Developmental Disabilities. https://ancor.org/sites/default/files/advancing value quality in medicaid service delivery for individuals with idd.pdf

Reduce Regulatory Burden

Providers of I/DD services must comply with both the state Medicaid program and federal Home and Community-based Services rules. The immense reporting requirements from these programs tie up dollars that are not getting to individuals. Under the current system, there are situations where a single individual receives care under two different funding streams—Adult Home Help and CLS. This means that direct care workers not only have to track incremental activities, but also keep track of which timesheet they are working on based on the payer. Many providers also noted the difficulty in keeping track of various training and reporting requirements, and the need to hire additional staff to handle the overhead. The complexities unnecessarily impact quality of life for individuals with I/DD, as time is taken away from providing services to fill out paperwork due to the various funding streams and immense oversight, for example, from verifying a service was actually provided. While it is important to have some level of documentation to help prevent fraud, a more streamlined process could help to reduce the time commitment and overall burden. Several stakeholders discussed the need for one funding stream to help reduce the regulatory burden, so that there is consistent billing, standards, and deliverables across services and for the individuals receiving them. Should separate funding streams continue, other actions should be taken to better align regulatory requirements and reduce the amount of paperwork required by staff.

Invest Capital in Innovation

Modern technology has allowed for different ways to deliver care. However, due to regulatory barriers, it can be difficult for providers to invest in innovations. Under the current system, providers are only able to obtain reimbursement when a staffer is physically with a consumer. However, if the system were modernized to allow for innovations, consumer safety could be improved through technology. For example, higher need individuals who require overnight care but have difficulty obtaining it due to Medicaid restrictions could receive overnight monitoring via telehealth, or a service line could be created for overnight emergency response. Studies have shown that telemonitoring is both feasible and beneficial for moderate- to high-functioning individuals with I/DD and it contributes to more independence, confidence in carrying out daily activities, and knowledge.²³ The study also found enhanced satisfaction among caregivers, as they could better understand patient needs and coordinate care delivery via telehealth technology. Better incentives should be expanded to the behavioral health system to allow for these types of innovations.

²³ Nambisan, Priya, Donna Lamkin, and Carrie DeLong. October 16, 2014. "Feasibility, Benefits and Challenges of Using Telemonitoring for the Aging with Developmental Disabilities (DD): An Exploratory Study." Online Journal of Public Health Informatics. Accessed March 6, 2019. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4235325/

Coordinate Staff Training

Another recommendation that could help to alleviate the direct care workforce shortage issue is coordinated training for direct care staff. While some training is available online through the local CMH organization, many stakeholders indicated that this training is not comprehensive or beneficial. Further, many staff have to pay their employer up front to receive their mandatory training, until the training fee is reimbursed and refunded. A more centralized system could help reduce the need for staff to obtain training if they switch between providers, including those in different counties. By investing in appropriate and well-coordinated training for direct care workforce staff, time, effort, and administrative costs in tracking, offering, and maintaining classes for employees could be saved. This would also help achieve quality of life for individuals with I/DD by potentially increasing provider resources to be spent on improved services and ensuring safety through properly-trained staff.

Increase Integrated Employment and Volunteer Opportunities

Many stakeholders identified the need for additional transitional services and integrated work or volunteer opportunities for individuals with I/DD. In particular, several stakeholders commented on the lack of advanced education or transition supports for individuals after they age out of the traditional school setting. A more concentrated effort to provide information about services and supports available after school to individuals with I/DD who are between the ages of 24 and 26 and their families could help prepare them for their future. In Midland County, fewer than 15 percent of individuals surveyed by CMHCM had full- or part-time employment. According to the Michigan Developmental Disabilities Council, only 19 percent of individuals with I/DD were employed in Michigan in 2017.²⁴ However, 60 percent of individuals with I/DD in Michigan indicated that they want a job.²⁵ The importance of having a daily activity was stressed by many stakeholders, not only to give a sense of purpose to individual with I/DD, but also to give back to the community. Studies have shown that businesses and taxpayers benefit from integrated employment opportunities, due to lower staff turnover and reduced individual dependency on financial supports.²⁶ More could be done to connect individuals with I/DD to training and integrated work opportunities, benefiting both businesses and individuals seeking employment.

²⁴ Michigan Department of Health and Human Services. March 19, 2019. Open Up: Michigan Launches "Inclusion" Campaign During Developmental Disabilities Awareness Month. Accessed March 19, 2019. https://www.michigan.gov/som/0,4669,7-192-47796-492359--,00.html

²⁵ Michigan Protection and Advocacy Services, Inc. September 2014. *Employment First in Michigan*. https://www.michigan.gov/documents/mdch/Employment+First+in+Michigan 469682 7.pdf

²⁶ Rall, Jaime, James Reed, and Amanda Essex. February 15, 2016. "Employing People with Disabilities." National Conference of State Legislatures. Accessed March 20, 2019. http://www.ncsl.org/research/labor-andemployment/employing-people-with-disabilities.aspx

For example, Washington state has implemented an Employment First policy, in which adults with I/DD entering the system focus their first nine months on finding a job, a model that could be considered to increase employment among the I/DD population in Michigan.²⁷

Improve Transportation Options

Another major barrier cited by the different stakeholder groups include transportation issues. Studies have estimated that approximately 30 percent of individuals with I/DD experience transportation problems, compared with only three percent of those without I/DD.²⁸ With more individuals with I/DD living independently in a home, rather than a group setting, it means there are not doctors and staff on site. Rather, individuals must travel to doctor's appointments and daily activities, such as grocery shopping or social events. While some transportation options were identified by stakeholders, such as public buses or Dial-a-Ride, many indicated the services available are insufficient in meeting the needs of individuals with I/DD, as they are not always timely, reliable, or available at the hours needed.

Maintain a Repository of Available Services

Many stakeholders suggested that there was a knowledge gap in information about services. Some noted that families are in the dark on what supports are available once their child becomes an adult. Others indicated that those with family support fared better than those who do not have this type of backing. More information could be collected and shared about all of the available supports and services in the region. Several providers also expressed a desire to increase service array; more awareness of the other organizations in the region and what services they are providing could help agencies to differentiate themselves or create partnerships.

²⁷ United Cerebral Palsy and the ANCOR Foundation. 2019. *The Case for Inclusion Report*. http://caseforinclusion.org/application/files/5715/5534/1836/UCP_Case_for_Inclusion_Report_2019_Final_Single_Page_ 041519.pdf

²⁸ Rizzolo, Mary Kay. December 8, 2016. "The State of Transportation for People with Disabilities." *The Council on Quality* and Leadership. Accessed March 20, 2019. https://c-q-l.org/resource-library/resource-library/all-resources/the-state-oftransportation-for-people-with-disabilities

Create a Community Quality of Life Measure

Communities should have one measure that is used consistently across providers to gauge quality of life. Most commonly, consumers, providers, and other stakeholders cited surveys as the tool they used for this task. While some questions arose as to whether a survey can truly capture the voice of an individual with I/DD, rather than a caretaker or guardian, it is the most efficient tool that is already being implemented by a variety of stakeholders. It should be simple in content and easy to administer. To help create a common measure that is capturing the impact of services on quality of life, survey questions should be based on outcomes, rather than outputs.

Appendix A

Quality of Life Indicators

These 38 indicators are offered as measures of quality of life for people with I/DD in Midland County. These have been selected for two reasons: 1) Each of them can be clearly connected to at least one of the nine components of high-quality community living identified by AUCD and AAIDD, and 2) they are broadly representative of NCI topics, encompassing those that are more granular or duplicative. The numbers in parentheses indicate which of the AUCD/AAIDD components the indicator supports.

Choice and decision making

- 1. Chose or had input in choosing home (1 and 9)
- 2. Chose or had input in choosing roommates (1 and 9)
- 3. Decides or has input in deciding daily schedule (5, 7, and 9)
- 4. Chooses or has input in choosing how to spend money (9)

Self-determination

- 5. Uses a self-directed supports option (9)
- 6. Hires and/or manages staff (9)
- 7. Can make changes to budget/services if needed (9)

Work

- 8. Has community employment as a goal in service plan (2)
- 9. Takes classes, training, or does something to help get a job or a better job (8)
- 10. Volunteers (8)
- 11. Type of paid employment in the community
- 12. Opportunities to engage in learning or personal growth activities (8)

Community inclusion

- 13. Able to go out and do the things he/she likes to do in the community (3 and 7)
- 14. Able to go out and do the things he/she likes to do in the community as often as wants to (3 and 8)

Relationships

- 15. Has friends other than staff and family (4)
- 16. Has friends (may be staff or family) and can see friends when they want (4 and 5)
- 17. Can see and communicate with their family whenever they want (4 and 5)
- 18. Feels lonely (6)
- 19. Can go on a date or is married or living with partner (4 and 6)
- 20. Has someone to confide in (4)

Satisfaction

- 21. Likes home (1)
- 22. Services and supports help person live a good life (6)
- 23. Is satisfied with daily life²⁹

Service coordination

24. Person was able to choose services they get as part of service plan (9)

Access

- 25. Has a way to get places when wants to go outside of home—like going out to see friends, for entertainment, or to do something fun (7)
- 26. Has a way to get places he/she needs to go (3)
- 27. Staff have the right training to meet the person's needs (9)

Health

- 28. Has a primary care doctor or primary care practitioner (6)
- 29. In poor health (6)
- 30. Had a dental exam in the past year (6)

Medication

- 31. Number of medications taken for at least one of the following: Mood disorders, anxiety, or psychotic disorders (6)
- 32. Has assistance to meet medical needs (6)

Wellness

- 33. Engages in physical activity (6)
- 34. Uses nicotine or tobacco products (6) Uses alcohol and/or marijuana (6)

Respect and rights

- 35. Has a place to be alone at home (1)
- 36. Staff (at home, work, and/or day activity or program) are respectful (4)
- 37. Has ever voted in local, state, or federal election, or had the opportunity and chose not to

Safety

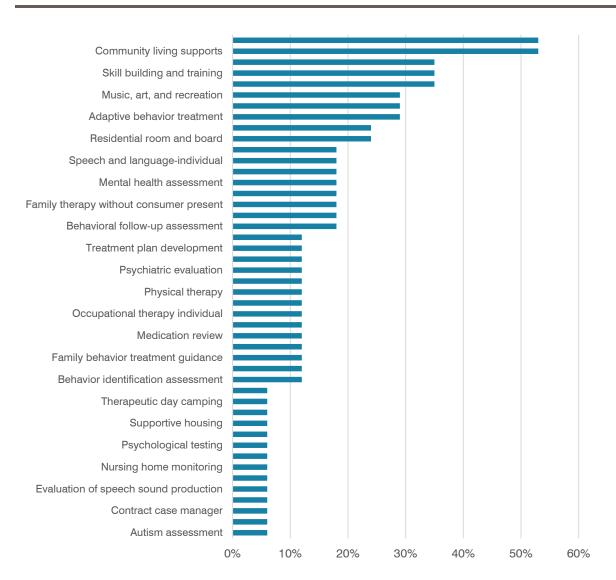
38. Has someone to go to for help if afraid

²⁹ Midland County stakeholders proposed these indicators during a March 2018 meeting and are not a part of the NCI list.

Appendix B

The following chart includes only those services that at least one I/DD provider respondent identified as a service they provide. Those services that no I/DD provider indicated they offer include: autism testing, durable medical equipment, evaluation and management visits, fiscal intermediary services, home modifications, hospital discharge day management, housing assistance provided by grant funding, housing support, inpatient hospital care, inpatient subsequent care by a physician, mental health clubhouse services, parent management training—Oregon model, peer post-booking jail divisions, peer pre-booking jail division, targeted case management, and vehicle modifications.

Appendix B. Services offered by I/DD providers in Midland County

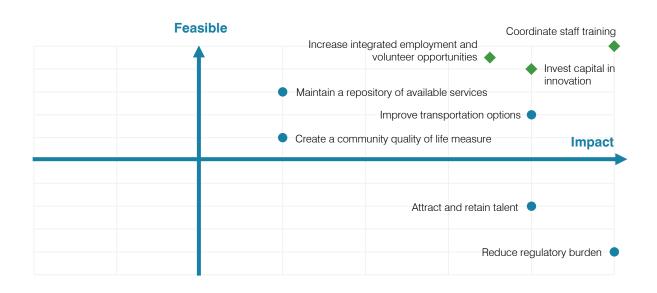


Source: PSC survey of I/DD providers in Midland County (N=17). Respondents could choose more than one response, so percentages total more than 100 percent.

Appendix C

On May 14, 2019, the project steering committee—a group of seven community members representing providers, advocates, and the community mental health agency—reviewed the research findings. They prioritized the action areas identified in the report based upon the potential feasibility and impact each action area would have on improving quality of life for individuals with I/DD. Overall, the steering committee identified coordinate staff training, increase integrated employment and volunteer opportunities, and invest capital in innovation as the most feasible and impactful areas for action. Those that the steering committee felt were feasible but would make a relatively small difference include: maintain a repository of available services as well as create a community quality of life measure. Finally, the group identified improve transportation options, attract and retain talent, and reduce regulatory burden as areas for action that would have a large impact but may be difficult to attain or implement. The steering committee's findings and rationale are summarized below.

Appendix C. Steering Committee Prioritization of Areas for Action



Coordinate Staff Training

Coordinated staff training was rated as the most feasible and impactful area for action by the steering committee. There are two different types of training that the steering committee identified: mandatory direct care worker training and training that could improve care delivery. The steering committee suggested that centralizing mandatory staff training would save a lot of money and reduce burden for staffers and providers who have to take or deliver tests and fill out paperwork each year. Even if only a few of the more expensive and lengthy mandatory trainings, such as CPR, were centralized, it could have a large impact. There are other existing models, such as at Wayne State University, where training is offered for all providers, allowing for common reporting and records that travel with a staff member. Additionally, coordinated care delivery training—for example, on a culture of gentleness—would improve staff skillsets and improve quality of life for individuals with I/DD. The steering committee felt both of these types of training were feasible, as they could be coordinated through a central organization, such as the local community mental health agency.

Increase Integrated Employment and Volunteer Opportunities

The steering committee indicated that in recent years, there has been much momentum in Midland County around increasing integrated employment and volunteer opportunities for individuals with I/DD. One major workforce organization, the Arnold Center, has undergone changes and increased capacity, particularly for volunteer opportunities. Despite the recent momentum, there has still been difficulty finding full- or part-time, integrated employment for individuals with I/DD. The steering committee felt that it would be feasible to build on recent expansions to improve integrated employment opportunities, particularly with small businesses, which may require ongoing support or incentives for good community actions. The steering committee suggested that this would be impactful, as daily activity helps to provide a sense of purpose and is essential to community integration.

Invest Capital in Innovation

The steering committee suggested that telehealth and electronic documentation could have a large impact by increasing access to care. Some systems are already in place, for example, 24/7 audio monitoring; however, monitoring could be expanded to include more services that increase safety while maintaining independence for individuals with I/DD, such as allowing individuals access to their pillbox at certain times of the day or turning off a stove that's left on. There may be some rules in place that need to be changed, such as enabling electronic documentation for activities to be tracked and logged remotely, ensuring compliance with federal rules (e.g., HIPAA), and training staff. However, there is already software being developed to allow for electronic documentation and traction around telehealth more generally, including at the federal regulatory level and with healthcare entities in the region. Thus, the steering committee feels that implementation of telehealth and other electronic systems is both feasible and impactful.

Improve Transportation Options

The steering committee discussed how increasing transportation options for individuals with I/DD would have a large impact, as it would greatly increase the level of community inclusion. However, in terms of feasibility, the committee felt it may be possible, but more challenging to achieve than some of the other areas for action. It is not likely that more money will be allocated to current transportation programs. One alternative option may be to utilize a ride-sharing service, such as Uber, which is entering the Midland County market. A partnership with that type of service, where the cost is underwritten, has potential; however, there would be many logistics to work out, including how to qualify individuals for the service.

Maintain a Repository of Available Services

The steering committee indicated that maintaining a repository of available services is feasible, but not largely impactful. While local organizations could connect with a network such as Michigan 211 to maintain a better system, many felt that this would not greatly affect quality of life for individuals with I/DD, since there are other ways to identify available services.

Create a Community Quality of Life Measure

The steering committee suggested that having a community quality of life measure is an important metric to assess success. However, many felt that it was not largely impactful. Though the results from a common survey could help to direct and prioritize stakeholder choices, many already conduct surveys and having one more would not make a large difference. Further, the committee agreed that having a community survey within Midland County only would not be useful, especially if other communities were not using a similar measure for comparison. Rather, it would need to be broadened to include the entire state. However, it would not be feasible to create a measure that could be implemented statewide.

Attract and Retain Talent

The steering committee discussed whether a change in reimbursement rates was a viable action to attract and retain a broader workforce. Many felt that, even with proposed legislation to increase direct care worker wages by \$2 per hour above minimum wage, it was not a feasible solution, as there is not much traction for that legislation this year. However, if wages could increase to a rate above minimum wage, for example to \$15 dollars per hour, that would have a large impact on a provider's ability to attract and retain quality talent. The steering committee also suggested other ways to attract and retain talent, such as establishing an education program for direct care workers that is on the same level as a certified nursing assistant to

bolster pay and credibility. Many felt that this would be a challenge to implement, but would have a large impact on attracting a better workforce by improving pay, establishing credibility, and potentially creating a pathway to other mental health positions.

Reduce Regulatory Burden

The steering committee agreed that a reduction in regulatory burden would be very impactful, but difficult to achieve. Many felt that a reduction in the numerous requirements and enormous amount of paperwork for each separate funding stream would be beneficial in improving quality of life for both staff and individuals with I/DD. However, while it is possible to advocate on a local level, much of the burden comes from federal or state regulations, which are challenging to alter. It may be possible to make minor changes to more local requirements, for example putting a CPR class together to create efficiencies by training a lot of people at once. However, beyond a granular level, meaningful change is likely not very feasible.



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