Uses of Assessment Data

to Inform Services and Supports for Individuals with Intellectual and Developmental Disabilities

tbdSolutions

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Summary

This paper is both a summary of feedback regarding the use of data from the *Supports Intensity Scale (SIS®)* and a white paper endorsing potential uses of the information in practice. The content is a compilation of feedback from various **contributors**, including statewide focus groups, respondents to an online survey, and review by the Michigan Department of Health and Human Services Behavioral Health and Developmental Disabilities Administration (MDHHS-BHDDA).

As the completion of the initial round of SIS® assessment draws near, questions remain about the opportunities for use of this information in practice. This detailed dataset has applications for people in a number of different roles: *the Person receiving services, Supports Coordinator, Program Director, Assessor Supervisor, SIS Assessor or Quality Lead, Advocate, Utilization Management, Community Living Supports, HSW Manager, and more*. Furthermore, each of these roles may have a different set of uses for the information.

Several broad areas for use of the data were identified:

- in **Person-Centered Planning**
- in **Benefit Management**
- to **Assure Service Access and Equity**
- to **Understand Population-level Needs**
- in **Advocacy efforts**

While the specific application of the data should not fall into any of the **specific ways in which SIS® data cannot be used** (*identified by MDHHS-BHDDA in published guidance*), the department endorses the use of assessment data to inform each of the areas outlined here.

Contributors also identified additional issues that impact the implementation of this data in practice. These issues include **communication**, **aspects of the tool and related data**, the **timeline** for completion, and **collaboration between groups**. Each of these issues has some bearing on how the data is interpreted and implemented as part of decision-making processes.

While the deadline for completion of the initial round of SIS® assessments is quickly approaching, the use of the resulting information is still in its early development. This paper is offered as a basic foundation on which multiple positive uses can be built.

Context and Purpose

The Supports Intensity Scale (SIS®) is a standardized assessment tool required by the Michigan Department of Health and Human Services (MDHHS-BHDDA) for all Medicaid-eligible persons 18 and older who have intellectual or developmental disabilities (IDD) and who are currently receiving case management or supports coordination or respite-only services through the public behavioral health system. Use of the tool began in June of 2014, with the PIHP contractual requirement to have all eligible individuals assessed by September 30th, 2017.

In anticipation of the completion of this initial implementation phase, MDHHS-BHDDA sought feedback from people receiving services and supports, their family members, advocates, Prepaid Inpatient Health Plan (PIHP) employees, Community Mental Health (CMH) agencies and service providers regarding individuals' experience with the SIS® assessment as well as current and potential uses of the data from the tool.

This document is intended to accomplish two objectives:

- Provide a summary of feedback from individuals who participated in the survey and/or focus groups.
- Provide guidance regarding potential uses of the data from the SIS® assessment tool by stakeholders in multiple roles throughout Michigan's behavioral health system.

Contributors

The guidance and thinking presented here is the result of substantial input from across the behavioral health system. Contributions were made in the following ways...

Focus Groups

A series of focus groups were scheduled throughout the state for individuals with intellectual and/or developmental disabilities, their family members, and their Supports Coordinators/Case Managers. The purpose of these focus groups was to understand people's current use of data from the SIS® and to understand how information gathered during the assessment might be used to inform the Person-Centered Planning process, ensuring that individuals receive supports and services according to their needs.

Four focus groups were offered at locations throughout the state (*in Detroit, Petoskey, Kalamazoo, and Mount Pleasant*) in order to reach a broad audience while minimizing travel time for attendees. **Focus group feedback** was captured in notes taken during the groups and subsequently grouped into related themes to inform this paper. Participants in the Winter 2017 Self Determination Conference were also engaged in a focus group session and their responses are included here as well.

A total of 133 people attended these focus groups.[i] Attendees included individuals receiving services, family members, advocates, peer mentors, supports coordinators, program directors, PIHP employees, SIS assessors, and others.[ii]

Survey

An electronic survey was developed and sent by MDHHS-BHDDA staff via e-mail to each of the following groups on February 1, 2017:

- Advocates and Advocacy Organizations

- Habilitation Support Waiver Leads
- SIS® Assessors and Quality Leads
- CEOs of CMHSPs and PIHPs (*for distribution to IDD staff*)

A reminder e-mail was distributed on March 14, 2017 in advance of the closing of the survey on March 17, 2017.

The survey gathered feedback from users in various roles regarding their experience with the tool and its implementation in Michigan as well as their current and potential future uses of the SIS® assessment data.[iii].

345 people responded to the survey from 127 locations across the state of Michigan. When asked which role best described their involvement in services for individuals with intellectual and developmental disabilities in Michigan, the respondents identified as follows:
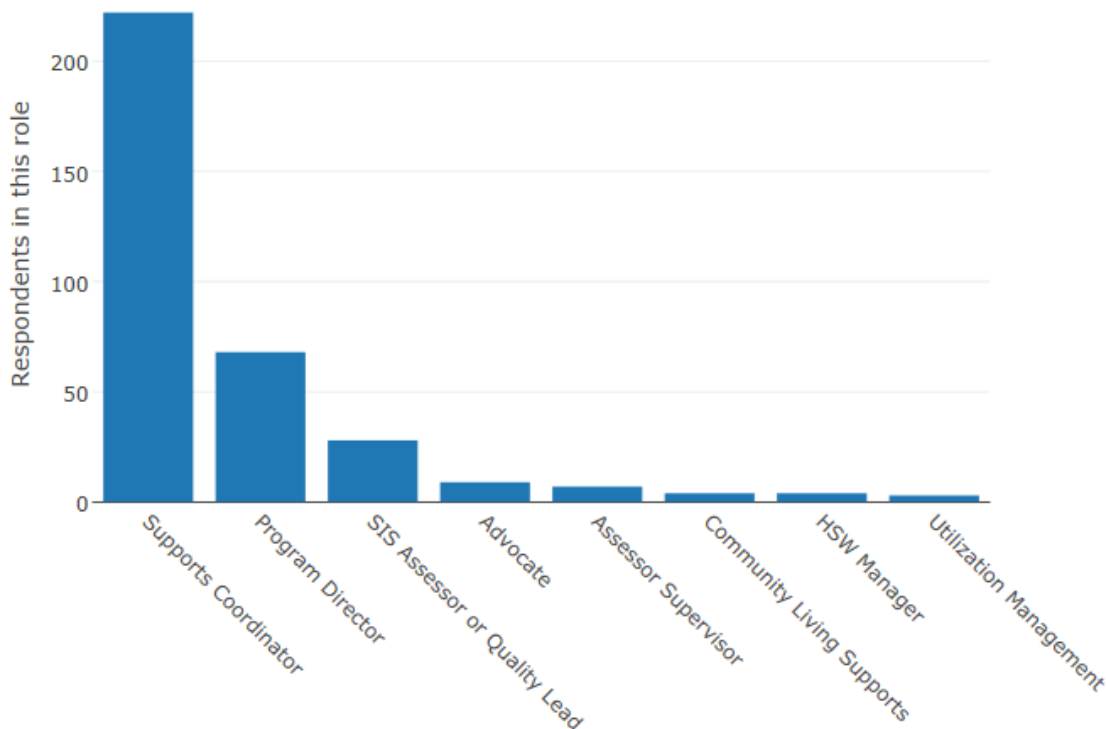
By far, the largest role represented in the responses is Supports Coordinator (n = 222), followed by directors of programs for IDD (n = 68) and SIS® assessors (n = 28). All other roles had fewer than 10 responses.

Since Supports Coordinators are a crucial part of helping to translate an individual's assessed needs into a dialogue to inform person-centered planning and eventually authorizations for services, it is encouraging to have such a strong response in this area. The high response rate of program directors (n = 68) is also encouraging, especially with regards to potential use of the assessment data to **manage networks of providers** and their programs.

MDHHS Review

The contents of this report have also been reviewed by key staff members within the MDHHS-BHDDA administration and approved for distribution.

Uses of the Data

Most common current uses

The chart below shows the number of respondents who indicated that they were currently using the assessment results to inform their work in a given area (i.e. they responded *"Currently using in my role"* to the specific item) or that they believed the information was potentially useful for their work (i.e. they responded *"Could be useful in my role"* to the specific item). See **here** for a more complete description of each of the survey items.[iv]
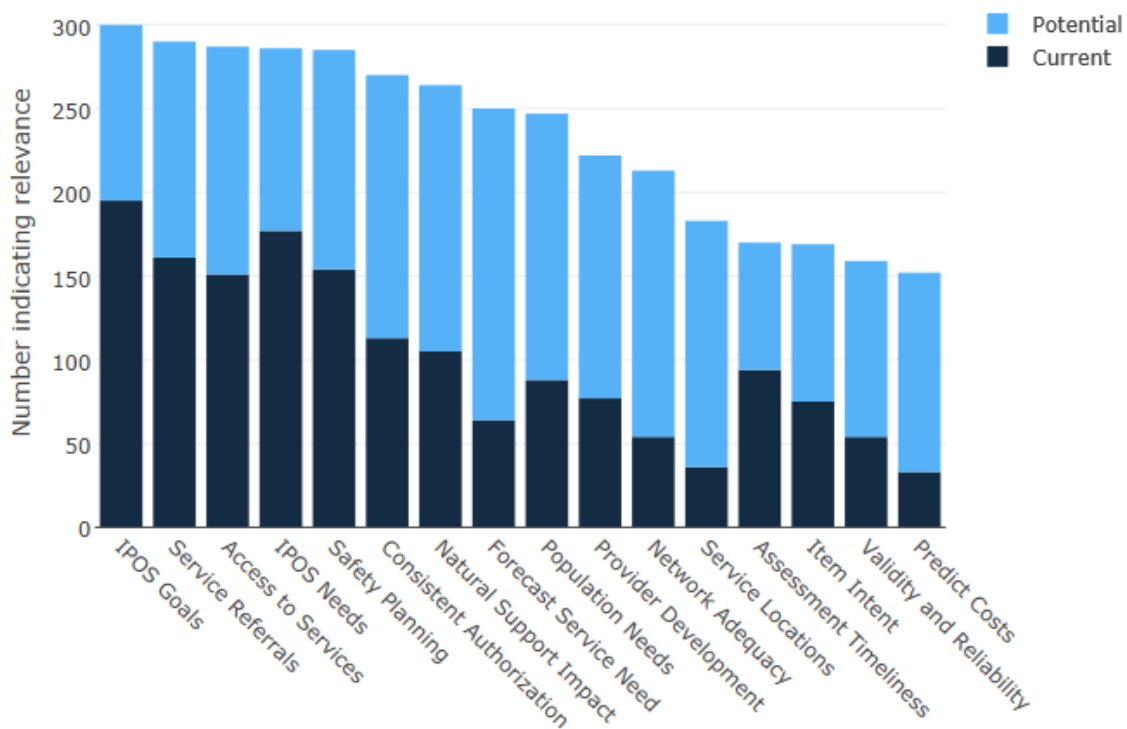
Responses indicate that the most common use of SIS® data is to inform the individual plan of service (IPOS) and related tasks. This is not surprising, given the large number of responses from Supports Coordinators.

Certain uses of the assessment have been engaged more actively in respondents' current practice. For example, the use of the information from the assessment to identify potential goals for person-centered planning had a greater number of respondents indicating *current* use

than *potential* use. On the other hand, many fewer respondents indicated that they were *currently* using the data to identify new locations to make services available, though a number of respondents endorsed this as a *potential* use.

Current uses of data by role

One of the principles informing the questions on the survey was that uses of the data could be meaningfully grouped by the role of the individual using the data. For instance, while it would be inappropriate for a supports coordinator to use solely SIS® data to determine medical necessity for an individual's services, it may be entirely appropriate for a provider network manager to use the data to explore whether there are enough services in a given area to meet the needs of the entire population served. The *role* which is using the data, and the *use* to which it is put, matters.

The visual below provides a summary of how survey respondents in specific roles indicated they were using the data. In the chart, a darker blue means that a higher percent of respondents indicated they were currently using the data for a particular purpose or could potentially use the information for that purpose.[v]
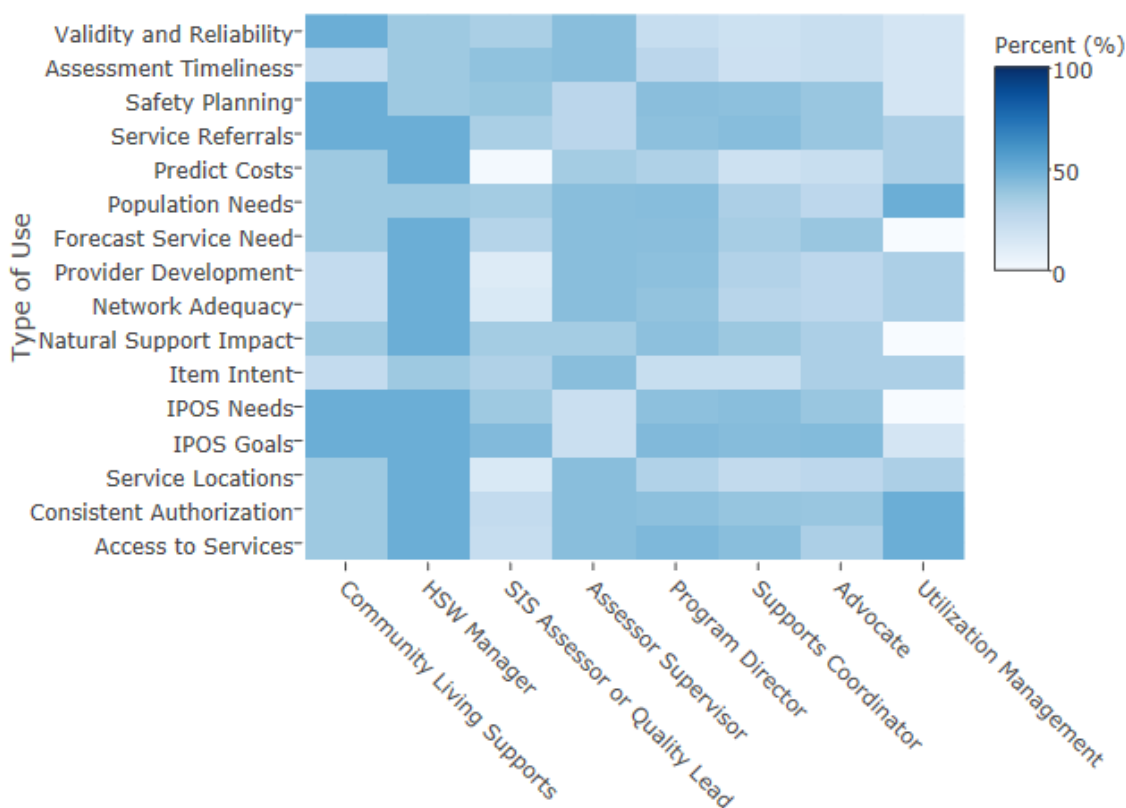
We should note that this summary does not pretend to list all of the potential users or uses of this information. It is likely that many potential uses were not identified in the survey responses. As with any resource, data can be used for ingenious and unpredictable purposes.

For this reason, it is important that there be principles to guide the use of this data across the system.

These principles will be embodied in various specific uses, and various stakeholders noted the need for specific uses to be identified to support their implementation of the the information in practice. The request by this focus group participant was echoed multiple times:

> *"Will you publish other ways it can be used? One of reasons I'm here is to look at ways across the board. We're looking for innovation in how we can use the information."*

The specific uses outlined in the next several sections identify promising areas for use of this information across various roles and areas of the behavioral health system in Michigan.

Use in Person-Centered Planning

Specific Types of Use

Since person-centered planning (PCP) is central to the entire system of services and supports, it has multiple steps and participants involved. Thus, there are a number of distinct uses for assessment data within the person-centered planning process.

Assessment data might be used in the following ways to support person-centered planning:

- Recommend individual support needs to inform an individualized plan of service (IPOS)
- Identify potential goals and objectives for inclusion in the IPOS
- Identify potential referrals for additional assessments or relevant services
- Help guide safety planning by identifying areas of risk
- Design an individualized menu of services to support an individual to live independently in the community
- Identify individual strengths for inclusion in the IPOS
- Provide guidance regarding supports which may provide alternatives to guardianship
- Identify areas of specific personal interest or areas on which the individual wishes to focus

Current and Potential Usage

The chart below shows the number of respondents who indicated that the data from the assessment could be relevant for them in their current roles (i.e. they responded either *"Currently using in my role"* or *"Could be useful in my role"* to the specific item).
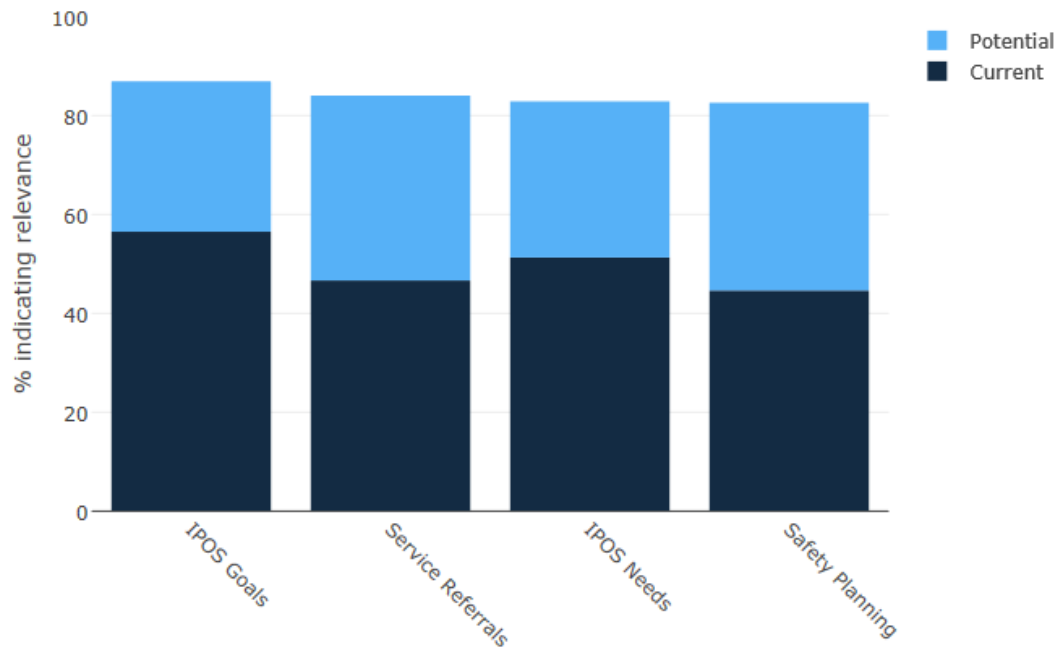
The majority of survey respondents endorsed the SIS® assessment as having usefulness as a part of the PCP process (*either current or potential*) across each of the areas indicated, from identifying needs and related goals to recommending potential services for supporting those goals.

The chart above indicates that there is already some use of this assessment data to support the PCP process, but that this is not yet widespread even among respondents who indicated that the data could be useful in this regard. These findings from the survey were echoed in the focus group dialogues, where responses ranged from *"SIS doesn't come up in person-centered planning."* to *"I can readily access it... review it [and] use it in the PCP process"*.

The chart below shows responses specifically from supports coordinators regarding their use of information from the assessment during the PCP process.
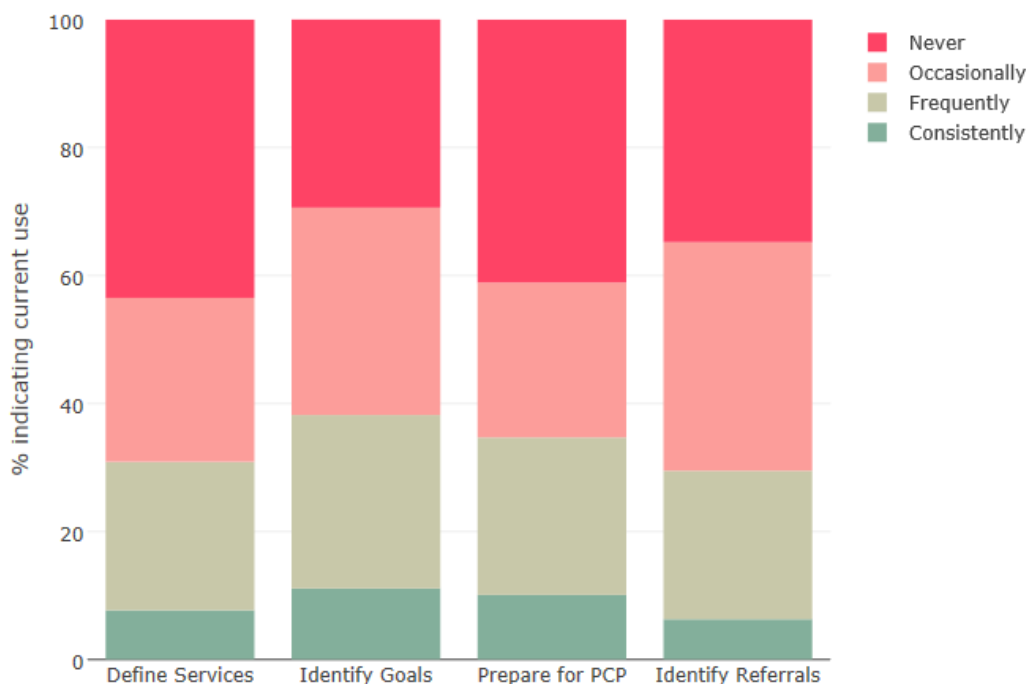
Here we see that over 60% of supports coordinators responding to the survey use the SIS® either *Never* or only *Occasionally* for any of the activities indicated here. When asked why they did not use it more frequently, these respondents articulated a number of issues related to the usefulness of the tool and its integration into the existing PCP process which should prompt a thoughtful reconsideration of current practice.

If one thinks of supports coordinators who are already using the assessment in the PCP process (i.e. those responding *Current*) as early adopters, the question for the broader system becomes how to spread the learning of that group to the rest of those who see the potential relevance of the tool (i.e. those responding *Potential*) and ultimately to demonstrate the usefulness of the assessment for those who did not originally see its potential (i.e. those who did not endorse either *Current* or *Potential* use).[vi]

Considerations

A number of helpful considerations related to this use of the data were identified by focus group attendees during their dialogues. These themes are summarized below.

Integration into Process

While the information from the assessment may have potential, making it useful in reality will require a purposeful integration of the information into the PCP process for individuals receiving services.

An integrated process would be one that:

- *Summarizes relevant results*: Distills information from the assessment which is relevant to the individual person, rather than merely providing an abstract score (*too little information*) or a list of all question responses (*too much information*).
- *Makes results available*: The information should be easily available to those involved in the PCP process in a timely manner.
- *Honors individual choice*: The use of the information from the assessment should provide a meaningful set of options without automating the decision-making process or taking away individual control.

Feedback from focus groups consistently stressed that this integration was crucial, but was far from being the standard of practice in current person-centered planning. The excerpted feedback below attests to this:

> *"It has aspects that can improve the PCP process. On the state level, we [as advocates] wanted to focus more on improving PCP process. Instead of just saying we have in law that PCP is how we drive services, if there could be a merging [of assessment data into a more consistent PCP process] that could be a beautiful thing."*

> *"SIS doesn't come up in person-centered planning. We're not told as supports coordinators that we need to integrate it into the process... Only when you start talking about authorizations does the SIS come up."*

> *"We sat down for 90 minutes with a CM to make that connection. She's the only one... that uses the SIS and aligns it with PCP. She's tried to show new CM's, and they're like... well there's just a lot that they have to do."*

For this integration to become a reality, several related logistical issues will need to be resolved:

1. Consistent Integration into PCP Process
2. Consistent Integration into EMR Workflow supporting PCP Process
3. Scheduling of Assessments to Align with PCP
4. Consistent Training of Facilitators
5. Guidance Regarding Use of Data in 2nd and 3rd Year after Initial Assessment

Benefits of Use

A number of distinct benefits were identified related to the use of assessment data in the person-centered planning process:

- Insight into individual needs and strengths for all treatment team members
- The assessment was felt to be well aligned with the content of other assessments, and to provide support for these
- The consistent identification of health and safety needs
- In addition to relatively stable needs, the assessment also allows for a focus on more dynamic needs which may change over time (e.g. behavioral needs)

- Overcoming preconceptions of family members

Feedback from respondents included the following:

> *"It took 7 times of hearing my client say the same thing, the assessor acknowledged it, and then it clicked for me that it was a necessary goal. [I had spent] 13 years of working with that person without having that realization."*

> *"We're having the SIS and all this stuff is coming out about what she can do. By the time we have the PCP, the sister and consumer was able to come in and realize... if she has aspirations to do her own thing, she's going towards that."*

> *"A person who lives with their parent currently, being able to say 'It's not that I can't cook, it's that you don't allow me to do things.' ...Not what's happening right now, but what could happen."*

Caveats for Use

In addition to the benefits noted above, several important cautions were communicated by respondents:

- *Personal priorities change*: While the SIS® assessment allows a person to tag specific support areas as *"important to"* them, focus group participants cautioned that these items should not be interpreted as accurate indicators of a person's current priorities, since these will naturally change with time.
- *Mismatch between needs and preference*: While the assessment identifies both support needs and individual preferences (*in the form of "important to" items tagged in the assessment*), the relationship between these is not always straightforward to interpret. For instance, a person may "need" a high level of supports in employment, but this would not be relevant for individual planning if the person was not interested in pursuing employment. On the other hand, essential safety-related items (*eating, for example*) may need to be incorporated into the person-centered planning process even if they are not explicitly endorsed by the person.

As one focus group member summarized:

> *"We need to remember that the value of the information from the assessment is not a substitute for getting to know a person. There is nothing that replaces investing in other people and caring about them. To think that a tool is going to do that...it's just not."*

Use in Benefit Management

Specific Types of Use

Tailoring services to the needs of a specific individual is a hallmark of person-centered planning, but there is an additional level of complexity required to support the design of provider networks to meet the precise needs of the populations they serve. Assessment data

from the SIS® has been identified as having potential applications for the following activities related to benefit management:

- Inform the development of provider network service offerings.
- Evaluate provider network adequacy relative to the specific needs of the population in a given area.
- Identify locations to make services available for individuals within an accessible distance from their homes.
- Forecast needs for services not yet available.
- Provide consistently-formatted guidance to service providers related to the scope, duration and intensity of services authorized by the IPOS.
- Assist providers to develop an enhanced array of services to support compliance with the HCBS Final Rule.

Current and Potential Usage

The chart below shows the number of survey respondents who indicated that the data from the assessment could be relevant for them in their current roles (i.e. they responded either *"Currently using in my role"* or *"Could be useful in my role"* to the specific item).
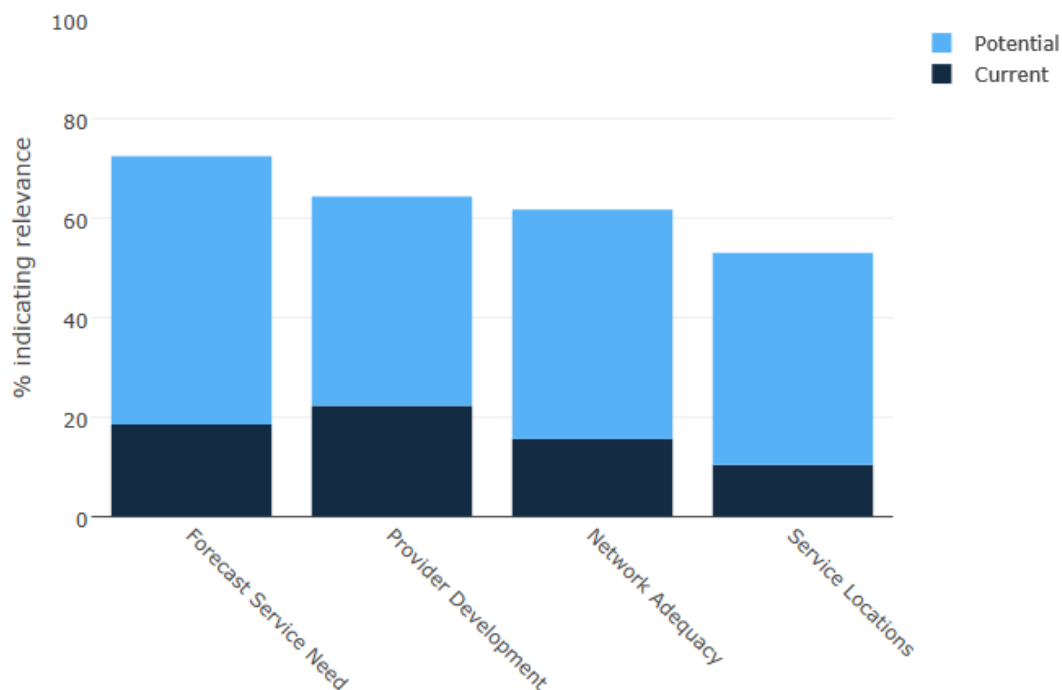
While the majority of survey respondents endorsed the assessment as having usefulness in managing and developing a full array of benefits (*either current or potential*) across each of the areas indicated, a higher proportion marked these as *potential* uses, indicating that these applications of the data are not yet developed.

This was echoed in focus group dialogues, such as the provider network manager who noted that:

"This could be useful when we assess... is our paneled provider [network] sufficient to meet the needs in this area?"

Considerations

A number of helpful considerations were identified by focus group attendees during their dialogues. These themes are summarized below.

Use in Service Coordination and Transitions

The usefulness of a standardized assessment such as the SIS® to serve as a common language for coordination and transitions across providers and settings was raised consistently by focus group participants, who identified several distinct types of applications:

• Transitions between settings and services
• Coordination of concurrent services across multiple providers
• Transitions between supports coordinators (*e.g. due to employee turnover*)

The statements below reinforce a growing body of research and effort surrounding coordination and transitions of care:

"They used to do SIS for all new intakes, and it was extremely helpful for supports coordinators..."

"For new supports coordinators, the SIS would be helpful. When I've known them over 10 years, I can probably help the assessor out."

"If a new case manager comes on, and they have to understand their entire caseload they've been tasked with, they can start to understand them better with access to thorough assessments"

Messaging to People Receiving Services

A number of participants noted that their personal messaging to clients regarding the usefulness of the SIS® assessment included discussions about improving the relevance of services. One participant noted that:

"I framed [the SIS assessment to clients as a tool that] helps us to be able to provide the services you need in the future."

At the current time, however, many provider networks have not yet evolved to incorporate this information into how they develop services and supports, and this can lead to frustration for individuals receiving services:

"People ask, 'How might that help me?' with questions related to job services, for example, when there are no services available"

It will be important to continue to share ways in which individual needs and interests are being considered to shape a more responsive array of services.
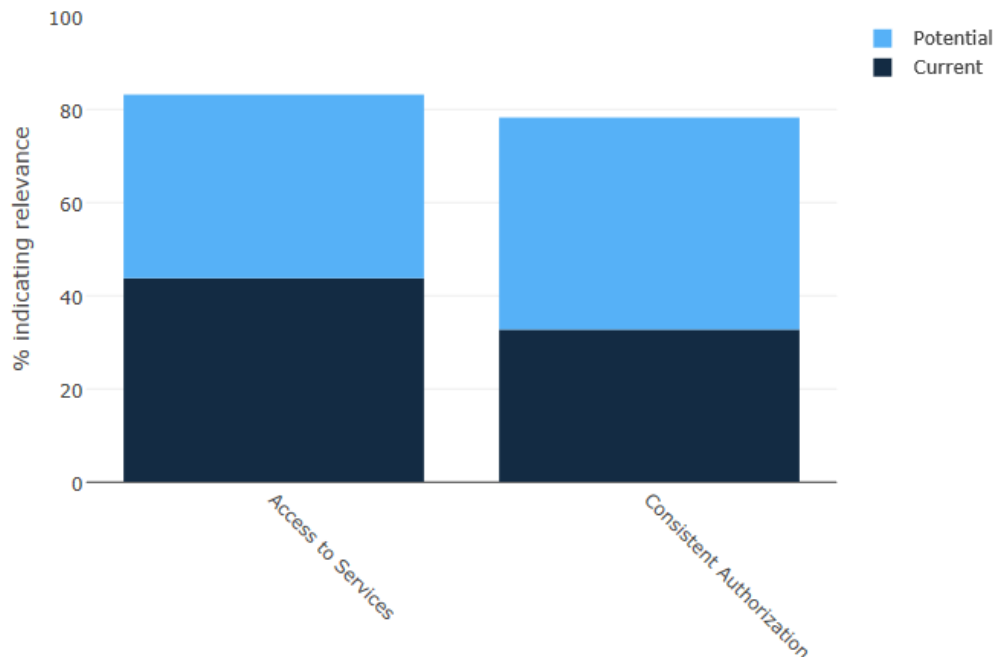
Use in Assuring Access and Equity

Specific Types of Use

Of all the potential uses of data from the SIS® assessment, this was one of the most commonly endorsed during focus group forums. Assessment data from the SIS® has been identified as having potential applications in the following areas related to assuring access to services and ensuring the equity of access for all persons receiving services:

- Ensure people receive the services they need
- Identify services inconsistent with assessed needs
- Inform the prioritization of access to available waiver slots

Current and Potential Usage

The chart below shows the number of respondents who indicated that the data from the assessment could be relevant for them in their current roles (i.e. they responded either *"Currently using in my role"* or *"Could be useful in my role"* to the specific item).

The majority of survey respondents endorsed the SIS® assessment as having usefulness in assuring access and equity (*either current or potential*) across each of the areas indicated. A higher proportion of respondents indicated that they currently used the assessment to ensure

access to services (i.e. *ensure people receive the services they need*) than to identify unnecessary services (i.e. *identify services inconsistent with assessed needs*).

Considerations

A number of helpful considerations were identified by focus group attendees during their dialogues. These themes are summarized below.

A Difficult Balance

While stakeholders consistently endorsed the goal of improving access to services, there was an acknowledged complexity in ensuring that access was distributed equally within budgetary constraints.

Broadly speaking, there were four different types of decisions that participants alluded to in relation to service access:

- Renew access (*Continue access to existing service/benefit*)
- Identify need (*Facilitate access to new service/benefit*)
- Deny request (*Prevent access to new service/benefit*)
- Remove access (*Remove access to existing service/benefit*)

Of these, the latter two types of decisions were of greater concern to participants, whose primary concern is with individual people and not with budgets. However, participants also acknowledged the tension that a disposition toward the first two decision types will tend to use up available resources more quickly.

Respondents from various roles acknowledged this tension when describing their current uses and future hopes for information from the tool to assure access and equity:

> *"I know our SIS assessor always makes it a point to say, this does not decrease services, but could add extra emphasis as to why they do or don't need a service."*

> *"[We] have had people bring up the SIS score when it doesn't jive with the level of services being requested."*

> *"We use [the SIS results] as a talking point to talk about prioritizing our Hab Support Waiver spots. It isn't an end-all, but helps us to prioritize."*

> *"As new people come in, we have a chance to give equality of service for similar level of needs. And wherever they might go, they'll be able to see that they have the tool completed and understand that level of need."*

> *"When I know that the SIS is going to be compiled and go to money-makers... there's people at the local level that can allocate resources in a more independent way..."*

> *"There are conflicting mindsets that are trying to be balanced: We have this pot of money and we need to distribute it vs. we need to provide what is needed to the population."*

The tension between access and equity is common in areas of life where individual use of a limited, shared resource may have unanticipated negative effects on the community as a whole (*i.e. areas which fit the economic description of the **tragedy of the unmanaged commons***). Fortunately, there are well-developed **principles for managing common resources**[vii] and these have been applied to the specific, regulated resources of **healthcare spending**[viii]

## Use in Understanding Populations

Specific Types of Use

In distinction from uses of the data discussed above, such as access and person-centered planning, this section pertains to uses of data which are especially relevant at the state and PIHP level. Assessment data from the SIS® has been identified as having potential applications in the following areas related to population needs:

- Understand different needs across population
- Predict costs
- Identify impact of losing natural supports due to an aging population of parents
- Implement federal and other requirements in a way which optimizes their benefit for the entire population of individuals receiving services

Current and Potential Usage

The chart below shows the number of respondents who indicated that the data from the assessment could be relevant for them in their current roles (i.e. they responded either *"Currently using in my role"* or *"Could be useful in my role"* to the specific item).
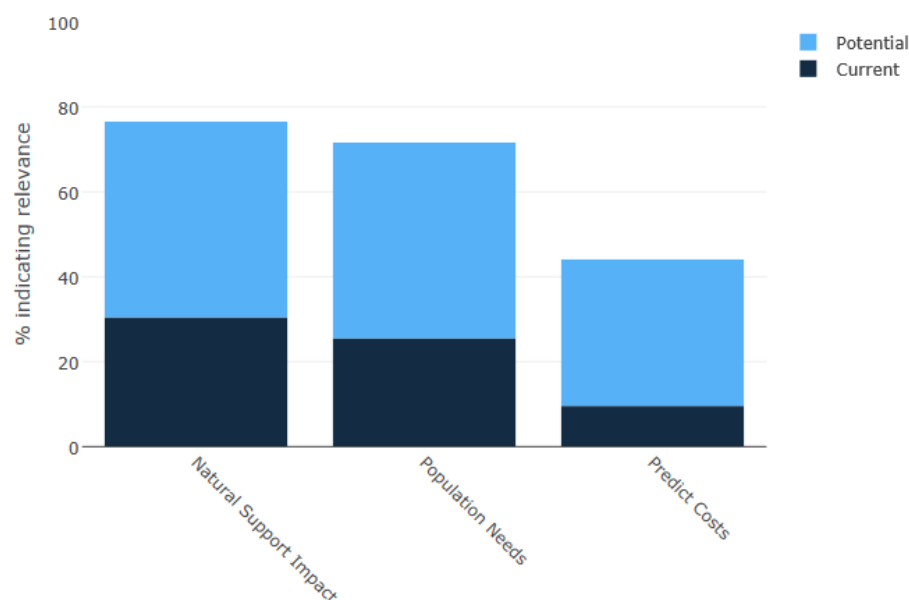
Considerations

Inform Implementation of Federal Requirements

Data regarding individual needs could be particularly relevant in relation to the **Home and Community Based Services (HCBS) Final Rule** and the **Medicaid and CHIP Managed Care Final Rule**.

The dataset could be considered for use related to the following requirements, which are provided as initial examples:

- **supplement time and distance standards for behavior health network adequacy**
- **network adequacy standards, taking into account the characteristics and health needs of the covered population**
- **inclusion of I/DD population-specific measures in a Michigan-specific Quality Rating System**
- **inform the development of needs-based criteria for eligibility for the State plan HCBS benefit**
- recommend relevant community-based services for individuals currently residing in a setting which is not in compliance with the HCBS rule

Use in Advocacy

Specific Types of Use

Advocates perform a role with a broad scope. Since their interest focuses on the individual person's quality of life, they might become interested in any of the uses of the assessment mentioned above, but approach those uses from the specific perspective of their impact on the individual.

- Provide guidance regarding supports which may provide alternatives to guardianship
- Use in fair hearing

Current and Potential Usage

The chart below shows the number of advocates who indicated that the data from the assessment could be relevant for them in their current roles (i.e. they responded either *"Currently using in my role"* or *"Could be useful in my role"* to the specific item).
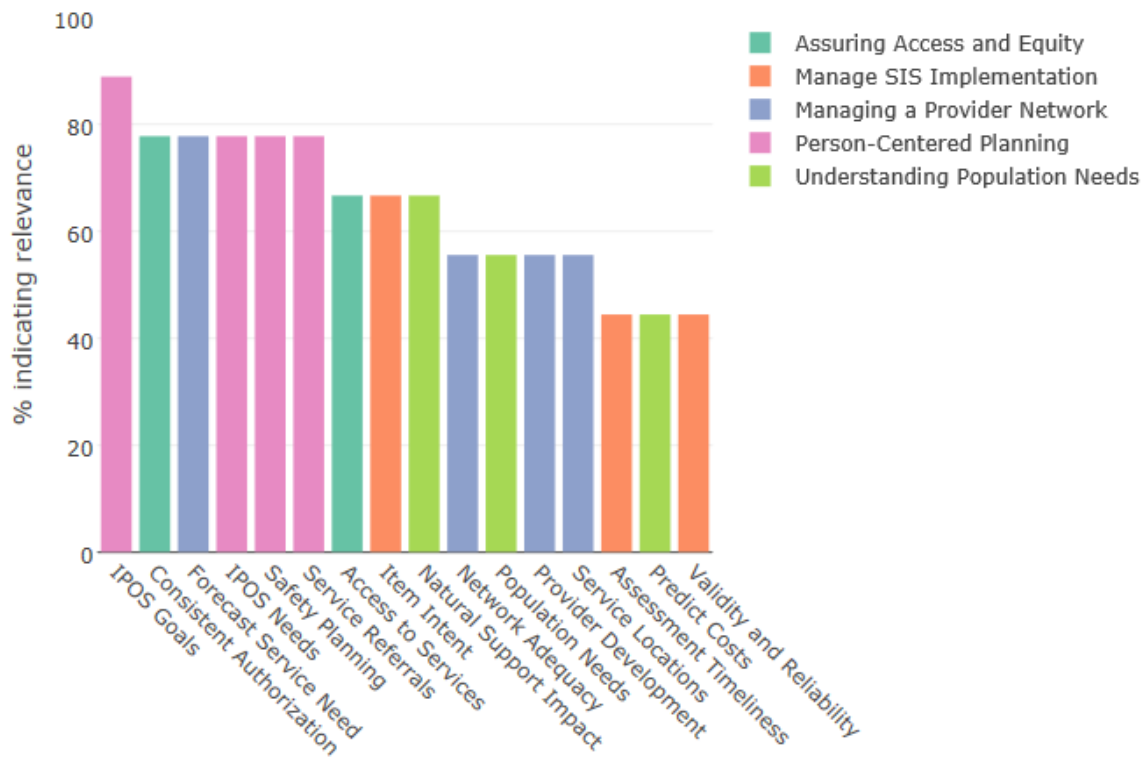
Advocates and others identified an array of potential uses of the data for advocacy purposes, both at the individual level and the population level:

> *"We advocate for individuals with I/DD, [and] while we don't typically sit in on SIS, it helps us to articulate and understand their situation"*

> *"The SIS... was brought up in a Fair Hearing, and it allowed to increase services. That's an advocacy tool use. Went all the way up the chain with it."*

Ways Data Cannot be Used

Since the initial implementation of the SIS® assessment, MDHHS-BHDDA has clarified several uses of the resulting data which are not permitted.[ix] These are:

- As an arbitrary methodology for determining the amount, scope, and duration of community living supports and skill building services implemented outside of a person-centered planning process.
- As a means for achieving budget reductions.
- As a process which supplants use of medical necessity criteria for evaluating the need for community living supports, skill building, and other supports and services.

While these principles have been communicated in MDHHS-BHDDA guidance, focus group participants indicated concern that these inappropriate uses still occurred. The quotes below

indicate how this influences people's perceptions of the data and may even incentivize the presentation of individual needs during assessments.

> *"Because there hasn't been good guidance on what are we supposed to do now that we have the data, which leaves people to interpret it for themselves and develop grids which wrongly link a score to a specific service."*

> *"The fear [of the SIS being used to cut services] sets people up to focus on the deficits. The reality is that some CMHs have used the SIS to cut services and while the department has addressed this, it remains the case."*

> *"Feel like you have to make people sound so bad off or negatively in order to secure the necessary services, when I want to talk positively about the progress that I've made."*

Related Issues

While data is stored in databases and defined in specifications, the *meaning* of the data is influenced by any number of issues which include perceptions of those collecting, analyzing and disseminating the data, and how the data is explained.

The following sections outline various issues related to the diffusion and adoption of the SIS® assessment and the use of data derived from the assessment to inform decision-making at the individual, program, and population levels. Implementation of any change is influenced by several factors:[x]

- **communication channels**
- **aspects of the change being implemented**
- **time**
- **relationships between stakeholder groups**

Each of these factors is addressed below, using feedback gathered from both the survey and focus groups.

Communication and Messaging

The use of standard assessment information is an innovation that is being implemented between multiple people and organizations. For this reason, communication is crucially important. This communication includes both official written communication and training from MDHHS-BHDDA as well as informal communication between various individuals and organizations.

It is worth noting that, during the focus groups, respondents did not draw a clear line between the official messaging provided by MDHHS-BHDDA and the informal messaging communicated within their own organizations or teams. The issues with messaging noted here reflect individual perceptions rather than a comprehensive review of formal guidance to date.[xi]

Specific themes related to the ways in which people received and conveyed this messaging included:

- **Mandated requirement**: One of the most consistent messages identified by participants related to the SIS® implementation was some variation of *"The state's making us do it."* While requirements are needed in order to guide a change toward consistent practice around assessment, the communication of this as the primary reason for implementation underscores the need for more champions with a clearly defined message regarding the value of the innovation (*i.e. "This is why the state has prioritized this change..."*). Participants also noted a lack of clarity related to whether the SIS® was required, and the implications for individuals who decline to take the assessment, despite guidance issued from MDHHS-BHDDA.[xii]
- **Use in identifying goals and service planning**: Participants consistently identified **use of the data in person-centered planning** as an intent of SIS® implementation, though they noted various complexities with putting this into practice.
- **Use to support equitable access to services**: Equity was one of the primary purposes identified as a rationale for implementing a standard assessment tool. As noted in the **discussion above**, the interpretation of equity often depends upon how it impacts one's individual experience. Accordingly, many participants stated that their initial exposure to the SIS® tool had been accompanied by a fear that it would be used to decrease their access to services. As one parent put it: *"I would not want it to be used to cut services that are deemed to be necessary for my daughter's support."*

Aspects of the Assessment & Data

Facilitation

One of the primary experiences which impacts the implementation and interpretation of the SIS® assessment data is the experience which they have had with facilitation of the assessment, or what has been communicated to them by others about this experience.[xiii]

240 survey respondents indicated that they had participated in a SIS® assessment and remembered their experience. These individuals were asked to respond to several questions regarding that experience, and their responses are summarized in the chart below:
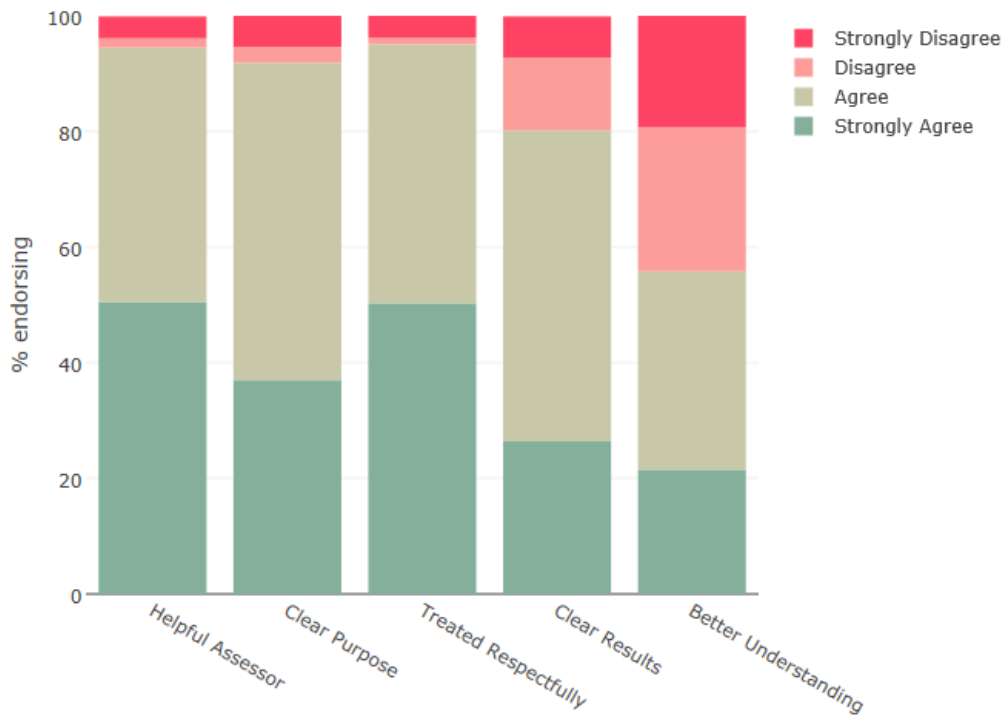
Overall, people's experience of the facilitation of the assessment appeared to be quite positive. The two areas which had less favorable responses had to do with the clarity of the assessment results and the contribution of the assessment process to their overall understanding of the individual being assessed.

That being said, it is worth noting that even in these areas the majority of respondents who had participated in a SIS® assessment indicated that the results of the assessment were clear and that they had a better understanding of the person being assessed as a result.

Format of the tool

Several considerations related to the structure and format of the tool itself were raised repeatedly by participants, specifically regarding the ways in which these impacted their experience of the assessment process and their understanding of the resulting data. Most of the issues noted here were part of a balanced discussion among participants, with some individuals noting difficulties of the format while others acknowledged an understanding of the reasons for these attributes of the assessment.

- **The use of hypothetical questions**: The most common issue noted was the use of a hypothetical scenario to cue survey responses (i.e. *what supports would it take if you lived independently in the community?*). This approach was noted to have the effect of raising discrepancies between individual or family hopes and the reality of the person's current situation. In some instances this was perceived as empowering, while in other instances it was perceived as insulting by family members. The hypothetical format also impacts interpretation of the data, since a high level of need in a particular life area may not be

require allocation of resources if the person is not currently engaging that need *in the community*.

- **Required to answer all questions**: Participants consistently mentioned the considerable length of the assessment, which requires that all questions be answered. The benefits of this approach are that it (*a*) allows for the collection of standardized data across all life areas for each person assessed, and (*b*) prompts discussion regarding life areas where an individual and their supports may have different perceptions. The downside of this approach was that questions were sometimes felt to be irrelevant or uncomfortable and the assessment was not adaptive to observable facts about the person (*e.g. asking about certain medical needs*).

- **Focus on limitations**: While acknowledging the need for an assessment to identify needs in order to support the medical necessity of services, some participants were concerned that a deficit-based approach would increase as use of the data increased. This focus on limitations was compounded by the existence of similar questions on other existing assessments. As one individual noted: *"We already know we can't do stuff, why again with this?"*.

- **Unclear summary/interpretation of output**: Participants noted that the summary output from the assessment was not especially informative at the individual level. One person shared that *"the disconnect was when we got the results back, and said, how do we use these? ...there wasn't a clear score, not sure of next steps."*

Response Burden

Participants indicated that the assessment was challenging to complete based on the following factors:

- **Time to complete each assessment**: Based on the number of questions and other **aspects of the assessment tool**, completion of individual assessments is a time-consuming process. The process includes not only the time period of the assessment interview itself, but time required for scheduling, travel for attendees, documentation and additional work hours needed to supplement productivity requirements for supports coordinators.

- **Duplication of items from other assessments**: The time invested in the assessment was compounded by the fact that many organizations have implemented the assessment without eliminating duplicative questions from other assessments, which means that individuals and their families are often asked similar questions multiple times and that data related to their responses exists in both unstructured and structured formats which cannot be easily reconciled.

These issues impact the time needed for implementation of the assessment and use of related data across the entire population.

Timeline

It takes time to implement any change. As mentioned above, the SIS® tool was originally required in June of 2014 with a 3-year window for the completion of an initial assessment for all eligible individuals. This timeframe balances several factors needed for scaling up and implementing the tool:

Operational resources:

- time and resources needed to train and hire assessors
- **time needed to schedule and complete assessments**

Population-level needs:

- Ongoing commitment to **equitable access to services**
- External timelines for projects which **require use of data related to needs**
- Usefulness of the tool at a population level requires completion of current assessments for a representative portion of the population

Relevance of the tool for PCP:

- Interval for reassessment relative to IPOS renewal
- Validity of assessment results over time

Providers consistently noted the current operational challenges related to meeting the required deadline, and voiced a hope that the information would be put to meaningful use:

> *"At some point, it becomes a compliance issue just to get these assessments done, and you don't have the time to do what you want with the info. I'm here to see how we can use the data we get from the system to create something spectacular. Right now it's almost saturation… they don't meet somewhere in between."*

Collaboration Between Groups

One of the most helpful aspects of the focus groups was that they brought individuals who may use the data from multiple vantage points into the same room together. As **mentioned earlier,** different people experience this information differently depending on the role they have in the behavioral health system. This has important implications when it comes to implementing a broad-ranging change such as the use of standardized assessment data for the I/DD population.

While there are notable exceptions, people often choose to interact with others who have similar interests and values.[xiv] It is often easier to interact with individuals with shared perspectives because they share a language and one can assume a similar set of goals. Truly diffusing a change across the broader system, however, requires engaging different groups

and perspectives to introduce new ideas. Without this productive exchange, it is easy for groups of people to become siloed and for the change process to stagnate.

It can also lead to different perceptions regarding the purpose for a change. One example which was raised multiple times during focus groups was the perception by supports coordinators that the standardized assessment indicated a lack of trust in their current assessments.

> *"I feel like the SIS is coming behind me saying Oh, you missed a step. You weren't thorough enough, so we're going to give a stronger intensity scale of need."*

From a skilled supports coordinator's point of view, the system-wide value of having a minimum standard of assessment may not be immediately clear. However, when supports coordinators heard the usefulness of the data to other stakeholders (*e.g. for consistent communication of needs, to inform new supports coordinators, or to support a standard of care*), they voiced a new appreciation of the value of the information.

Continuing to engage a diverse set of stakeholders, from individuals with I/DD to policymakers, regarding the practical implementation of this and other related information will be critical to promoting trust while pursuing positive change. This will require transparency in engaging challenging and often divisive topics to achieve commonly agreed-upon goals.

Supplements

Survey Items

The table below shows more detailed descriptions of the survey items which are referenced in the charts throughout this document. These descriptions can also be seen by hovering over the charts in the web version of the report.

Shortened Descriptions of Assessment Uses

Short Name	Survey Response Detail
Access to Services	Make sure people receive the services they need
Provider Development	Inform development of provider network
Network Adequacy	Evaluate provider network adequacy
Service Locations	Identify locations to make services available
Population Needs	Understand different needs across population
IPOS Needs	Recommend individual needs to inform IPOS
IPOS Goals	Identify potential goals and objectives for IPOS
Service Referrals	Identify potential service referrals
Safety Planning	Help guide safety planning
Predict Costs	Predict costs
Forecast Service Need	Forecast need for services not yet available
Natural Support Impact	Identify impact of losing natural supports
Consistent Authorization	Identify services inconsistent with needs
Item Intent	Align interpretation of items by assessors
Assessment Timeliness	Ensure timely completion of assessments
Validity and Reliability	Review validity and reliability of assessments

Focus Group Comments

There are several pages of Focus Group Comments available for review in the interactive report that can be found at **http://www.tbdsolutions.com/papers-presentations/**

Authors

Endnotes

[i] The attendance by site was as follows: *Detroit = 18, Kalamazoo = 20, Mount Pleasant = 17, Petoskey = 3, Self-Determination Conference = 75*

[ii] While people from multiple roles and areas across the system were in attendance, there was a relatively low turn-out for individuals served and their family members. As the focus groups were intended to be the primary means of gathering personal feedback from persons served and their families, in lieu of the more formal survey, there is substantial value in continuing to engage people receiving services in discussions related to the uses of assessment data.

[iii] The list of potential uses of the data which were included as response options in the survey questions were originally identified by practitioners in the field and subsequently reviewed by MDHHS-BHDDA.

[iv] The labels in the chart shown here are summaries of the text of the question from the survey. To see a more detailed explanation of each, you can hover above the chart or look up the related explanation in the appendix.

[v] While the survey clearly asked respondents "How could the data from the SIS® assessment *help you to perform your role*?", it is not clear that individuals consistently responded with this guidance in mind. Thus, a number of respondents indicated using the assessment for a purpose which clearly falls outside the scope of their role. Furthermore, the feedback from focus groups was not captured as structured data in a way that the specific type of use to be tied to a specific role. For this reason we have not structured the subsequent sections by role.

[vi] This is a common challenge with the implementation and diffusion of any change, which is impacted by aspects of the innovation itself, communication related to the change, time, and a social system which supports use of the innovation.

[vii] Of particular relevance here is the work of the economist Elinor Ostrom, whose work providing practical pointers for managing common resources, such as: *(a) defining clear group boundaries, (b) matching rules governing use of common goods to specific needs and conditions, (c) making sure that those affected by the rules can participate in modifying them where possible, (d) developing a system which allows community members to monitoring other members' behavior, (e) providing accessible, low-cost means for resolving disputes*.

[viii] See, for instance: *Vickery KD, Sauser K, Davis MM. Policy responses to demand for health care access: from the individual to the population. JAMA. 2013;309:665-666.*

[ix] Renwick, T. (2015, October 22). Inappropriate Use of Assessments and Screening Tools (Letter to PIHP Executive Directors).

[x] These factors are adapted from work in the diffusion of innovations. For more information see: *Rogers, Everett (16 August 2003). Diffusion of Innovations, 5th Edition. Simon and Schuster.*

[xi] For instance, people acknowledged that multiple resources had been made available during the initial roll-out of the assessment. One respondent noted that: *"The Department had trainers around the area, so there were presentations...there were quite a few of those"* Nevertheless, a number of individuals were not aware of these resources and therefore noted a lack of clarity in messaging.

[xii] See, for instance: Renwick, T. (2015, April 13). Michigan Supports Intensity Scale (SIS) Implementation (Letter to PIHP Executive Directors). This letter clarified that *"as with all assessments, the SIS is voluntary... Supports and services cannot be denied, reduced or discontinued if a consumer and/or the guardian refuse to cooperate with the assessment process."*

[xiii] Please note that the focus of this paper treats the process of the assessment only to the extent that it impacts the interpretation of the resulting dataset or the willingness of the broader system to use the data. This is not an evaluation of the content of training about how the tool should be implemented, but a summary of feedback from stakeholders about how they have experienced it.

[xiv] In research, these interactions are referred to as *homophilous*, while those with different groups are called *heterophilous*. See: Rogers, Everett (2003). Diffusion of Innovations, 5th Edition. Simon and Schuster. p. 18