



Measuring Up

Know when a support-needs
assessment meets
the standards





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Measuring Up | Know when a support needs assessment meets the standards

States and other entities are increasingly using support needs assessments—sometimes referred to as functional needs assessments—for a variety of purposes, including eligibility for Home and Community-Based Services (HCBS), prioritizing needs for waiver services, service planning, and for allocating resources. In fact, a 2018 review of 1915(c) waivers showed that at least 31 states were using support needs assessments for individual budgets.¹ Given the newly proposed Ensuring Access to Medicaid Services rules,² the trend of using support needs assessment for HCBS services is likely to continue and expand. Support needs assessments measure the pattern and intensity of supports that are necessary for a person to participate in activities like people without disabilities.³ They measure support needs across different areas (e.g., medical needs, daily needs) and vary in how and why they are developed. For example, some assessments were developed without a specific state or use in mind, but strictly to establish a valid and reliable measure of support needs. (e.g., Supports Intensity Scale,⁴ InterRAI,⁵ Inventory for Client and Agency Planning⁶). Other assessments were developed by states to serve their own unique circumstances and purposes (e.g., Minnesota’s MnCHOICES,⁷ Florida’s Questionnaire for Situational Information,⁸ Oregon’s Needs Assessment⁹).



¹ https://www.hsri.org/files/uploads/publications/HSRI_White_Paper_Individualized_Services_FINAL.pdf

² <https://www.regulations.gov/document/CMS-2023-0070-0001>

³ Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., Wehmeyer, M. L., & Borthwick-Duffy, S., Coulter, D. L., Craig, E. M., Gomez, S. C., Lachapelle, Y., Luckasson, R. A., Reeve, A., Spreat, S., Tassé, M. J., Verdugo, M. A., & Yeager, M. H. (Collaborators). (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, 47(2), 135-146. <https://doi.org/10.1352/1934-9556-47.2.135>

⁴ <https://www.aaid.org/sis>

⁵ <https://interrai.org/>

⁶ Bruininks, R. H., Hill, B. K., Weatherman, R. F., & Woodcock, R. W. (1986). Examiner’s manual. ICAP: Inventory for Client and Agency Planning. Allen, TX: DLM Teaching Resources.

⁷ https://www.dhs.state.mn.us/main/idcplg?ldcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=DHS16_180264

⁸ <https://apd.myflorida.com/waiver/qsil/>

⁹ <https://www.oregon.gov/dhs/Compass-Project/Pages/ONA.aspx>

Regardless of who creates the assessment or why, it must meet specific standards for use. These standards—ranging from scientific (e.g., validity) to practical (e.g., collecting background information on people who receive services)—are even more important when states are using the assessment to determine access to services or funding. A high-quality assessment is needed to support robust service planning, allocate resources defensibly, determine who needs services the most, and aid in understanding people’s needs to provide supports. Whether you are a state staff member exploring potential assessments for use in your state or an advocate wanting to enhance your understanding of assessments, this resource is meant to provide a starting point to learn about what makes a good quality support needs assessment and important standards states should have when they use them.

How does it measure up?

If your state is going to use a support needs assessment that could impact peoples' lives, then that assessment needs to have some standards!



Remember, assessment development is a science. Support needs assessments should be informed by the science of measure development.	
Set your boundaries. Make sure that the assessment is feasible to administer both in cost and other resources.	Show me the validity and reliability. Show the validity and reliability of the support needs assessment, especially when its being used to decide who can access the waiver, which services they get, or how much.
Show respect. Show respect to the people who take the support needs assessment by focusing on what they can do, rather than what they cannot do.	Train your assessors. Assessments are only as good as the assessor. For this reason, assessors should undergo rigorous training.
Ask the right questions. Ask questions that will ensure you gather information about different types of support needs, like daily living, medical, and behavioral needs.	Get your tech together. Make certain that the support needs assessment can be used for planning and other purposes, and inform policy.
Ask questions in the right way. Ask questions in the right way to make sure that the support needs assessment can inform individual supports and explain supports needed across the entire population.	Get the word out. Ensure everyone knows what the support needs assessment is for and what will be expected of them.

Remember, assessment development is a science.

Support needs assessment is a type of test or screening tool. There is a whole field of science dedicated to the study of the development of what are called psychological measures, like support needs assessments. States should not take on the task of developing an assessment without including or learning from people who specialize in measure development. Being knowledgeable about the overall processes and steps in measure development can help you to critically evaluate a support needs assessment.



Developing an assessment typically involves a process like this:

- 1. Plan** the assessment (purpose, content areas or domains, how it will be used, audience/population).
- 2. Draft** potential questions asked in the assessment targeted to each of the identified content areas.
- 3. Perform** pilot test with the draft assessment.
- 4. Analyze** results of the pilot to revise if needed.
- 5. Perform** pilot test with the revised draft assessment.
- 6. Analyze** results of the second pilot test to make any additional changes.
- 7. Finalize** the assessment and conduct ongoing testing.

Measure development is strengthened when the community impacted by the assessment is involved in the entire development process. Documentation

of the measure development process, testing, and results is critical and can provide evidence of the quality of the support needs assessment.

Set your boundaries.

While finding an assessment that has a strong development process is important, so too is using an assessment that is feasible in both the short and long-term. No matter how well developed, if the assessment cannot be accurately and efficiently administered, then it won't meet the needs.

Choosing an assessment that is not feasible to administer, may result in unnecessary costs and impacts on people receiving services.

As states decide whether to adopt a support needs assessment, they must consider the different uses that they have for the assessment and make sure that the chosen assessment meets those identified uses. For example, if a state is using an assessment for demonstrating eligibility for enrolling in a waiver program (i.e., level of care assessment) but also hopes to use the results to inform service planning, then care should be taken beforehand to ensure that the assessment can meet both purposes adequately.

Administering assessments is a significant undertaking. The state must consider the resources available to manage use of the assessment including scheduling assessments, conducting assessments, recording results, and sharing results with the person being assessed. To successfully conduct assessments, states may choose to hire their own assessment teams, hire external assessors, or delegate duties to regional entities.

As states already using assessments can attest, the cost of purchasing or developing the assessment can be very high, even before accounting for the ongoing administration and technology costs. For some states, costs have been a major deciding factor in their choice of support needs assessment. However, assessments may be required annually or up to every five years to reflect changes a person may have in their needs. Ongoing, up-to-date assessments for all service recipients carry a cost that must be considered.

Along with costs, states will need to make sure that the assessment can be administered on a timeline that meets its needs. For example, is it feasible to administer the assessment annually if it is critical to support planning? If the state is leading the development of the assessment, then it will also need to consider how long it takes to develop an assessment. The development process, if done right, takes time.

Since assessment may impact a person's budget and/or access to services, the assessment has the capacity to fundamentally alter how a person interacts with the service system. For people new to services, the assessment may be their first introduction into the service system. Therefore, it is important that the state is transparent and thorough in their communications about the support needs assessment and its uses. States must work with people receiving services, family members, advocacy groups, regional staff, providers, legislators, and judges overseeing appeals to make sure people understand and are receptive to using the chosen assessment. Support and backing for the use of the assessment is essential and can help mitigate any miscommunications about the assessment which is typically meant to improve the lives of people receiving services, by better matching their needs to what the service system can provide.

A matter of dignity

Support needs assessments, when done well, are a person-centered way to learn about a person's strengths and the support they need as well as demonstrate respect and care for them.



Show respect.

Support needs assessments have been used for as long as state HCBS Waiver programs have been around. As such, some earlier assessments may have language or concepts that have not stood the test of time. For instance, an assessment may ask about a person's ability to write a check or use a telephone book, both of which are not likely to be used by younger populations causing confusing or misleading results. An assessment may also focus on what a person can't do, rather than what they can do, which is not respectful or person-centered.

Best practices today suggest that assessments should focus on the person's strengths and need for support, so that services can work to build on and bolster existing strengths. Assessments must be person-centered since they will have an impact on whether or how the person receives services. The language in the assessment should be respectful and supportive. The assessment must allow the person and people important to them to answer questions or

demonstrate what they need and can do.

Respondents to the assessment cannot be people who have never seen the person demonstrate their skills in different activities and settings. Likewise, the assessment will prove inadequate for helping the person find the right supports if it only seeks to list diagnoses and deficits.

Every service system supports people and families who represent multiple cultures and use multiple languages. The assessment must reflect such diversity in the terms and content used. It must be tested across different demographics and be shown to measure concepts effectively and respectfully in the same way. The assessment also must be available in the languages commonly spoken in the state and be properly translated and tested with people speaking those languages.

Finally, a respectful assessment can be administered by and/or conducted with a person with lived experience of disability. States should consider whether the assessment is able to be read by screen readers, whether the language is easy to understand, whether any reports are 508 compliant, whether technology platforms are accessible, and other important aspects of document and language accessibility.

Ask the right questions.

Knowing the correct content areas to cover in the assessment depends heavily on the population who will be assessed and why they are being assessed. There are, however, several content areas that all assessments should have. Over time, support needs assessments have been used successfully when they collect the following types of information.



Background information

The assessment must provide identifying information and demographics on the person that are useful and useable. For example, the identifier type (e.g., first and last name, Medicaid ID) must align with what is used in other data sources that may need to be linked to assessment data in the future. Assessments must ask questions about demographic information that are important (e.g., the living situation of the person if that impacts individual budgeting) as well as exploring how well the HCBS system is working (e.g., identifying whether disparities exist in who is found eligible for services by assessor, race, or gender collected in the assessment). While diagnosis may be necessary to collect in some circumstances (e.g., when services are dependent on a person having a particular diagnosis), diagnosis should not be used to measure support need.

Some or all of the background information collected may be accessible from other sources. These sources can help to decide which personal background questions to include on the assessment and determine the best way to link data sources to ensure all vital information is captured.

Daily living needs

The assessment must ask about the needs a person has to complete day-to-day activities. These have been referred to as activities of daily living and instrumental activities of daily living. Some examples include supports needed for bathing, dressing, maintaining personal hygiene, eating, preparing foods, performing housework, managing finances, managing medications, shopping, maintaining employment, and getting around in the community. The questions should

probe at the amount, type, frequency, and/or duration of the support needed for each type of daily living need.

Medical needs

Many assessments include indications of the medical conditions or diagnoses that a person may have, but—more importantly—an assessment must ask about the support needed because of those conditions or diagnoses. Common categories may include the intensity and amount of support needed for heart disease, respiratory disease, seizures, and neurological conditions, skin conditions, and indicating any needs that should only be performed by medical professionals. Medical needs may account for a substantial amount of highly trained staff time for many people, so collecting information on what support is needed and the amount of time dedicated to those needs is crucial to understanding how to support the person more holistically.

Behavioral needs

Like medical needs, support for challenging behaviors can account for a sizable proportion of the supports and services a person may need. Therefore, it is important to understand the needs related to a person's behaviors. The serious behaviors that should be asked about include self-injury, injury to others, destruction of property, or behaviors that impede the person's safety. This category of questions may also involve understanding the needs of people due to mental health (e.g., increased support for general daily living needs during periods of depression). Across all behavioral needs, the emphasis of the questions should not be on diagnosis or behaviors but on the support needed



to avoid, mitigate, and/or lessen behaviors that are harmful to the person or others. The important characteristics of these supports should include the frequency, duration, and type of the support needed. It is also helpful to know if specialized supports, such as behavior technicians, will best meet the person's needs.

Other support needs

Depending on the use of the assessment, it may also be important to understand and include contextual factors about the person. This may include questions that help support coordinators determine whether any tangible resources or referrals are needed, or whether additional services or supports are necessary to compensate for challenges at home such as an aging primary caregiver.

Depending on the population being assessed, the assessment may include needs such as memory, cognition, communication, or other relevant needs. It might also be used to understand the frequency or rhythm of needs. For example, the cyclical nature of supports needed for behavioral and/or mental health needs could provide invaluable information for service planning. Aside from asking the right questions, asking questions in different ways may help complete the picture of a person's support needs. For example, the time frames used in the assessment may provide valuable parameters for understanding how consistently the person needs support (e.g., in the past three days versus in the past three months), definitions of terms used in the assessment can help respondent to answer accurately (e.g., what constitutes prompting versus cueing), and the framing of the content can help the person feel comfortable responding (e.g., strengths-based versus deficits-based).

Ask questions in the right way.

Just as important as covering the necessary content areas, the assessment must ask questions in a format that aligns with how the assessment will be used.



Questions can take on formats such as open-ended, scale, ranking, or multiple choice. The appeal of an open-ended question for allowing people to use their own voice to describe needs should be weighed with the practicality of using such data across the population.

Certain questions in the assessment may be more useful for service planning or to help providers understand the unique needs of each person, and for these types of questions, it might be helpful to ask open-ended questions that allow the person to explain their needs. When assigning individual supports budgets or prioritizing for the waiver, however, questions with response options, like multiple choice questions, enable the state to adopt an approach that can be applied fairly across the entire population. Since the questions do not require analysis or interpretation and can be aggregated.

Additionally, the response options for the questions in the assessment must match the kinds of information that should be captured in each area. That is, most assessments ask about daily living activities. There is, however, wide variability in the wording of questions for each daily activity. An open-ended question may ask for a broad description of the support that is needed for performing a particular activity. Scaled questions may ask about the types of support for each activity (e.g., prompting, some physical assistance,

complete physical assistance), frequency of support (e.g., throughout the day, once a day, a few times a week, weekly, monthly), duration of support (e.g., less than 5 minutes, 5 to 30 minutes, 30 minutes to 1 hour, 2-3 hours), or some combination of these categories (e.g., prompting throughout the day on most days). Before picking an assessment, a state must consider whether the questions allow for collecting the kind of information that the state needs for its intended purposes.

To create overall scores that use multiple questions from the assessment in a way that is quantitatively analyzable, questions in each area should be asked with response options that are able to be grouped together. For example, each medical support need question may ask about the extent of need on a scale from 0 – no need, to 5 – complete assistance needed, so that a sum score across all medical need items can be created for a total medical score).

Show me the validity and reliability.

When support needs assessments have a direct impact on whether a person can receive services or how much support they will receive, it is critical that the assessment is valid and reliable. During assessment development and on a periodic basis after assessment implementation, the reliability and validity must be measured and deemed acceptable to have a credible and defensible assessment. These terms are frequently used to describe the quality of assessments, but this standard requires that there be documented (self-published or from an academic journal) evidence of the statistical testing of validity and reliability that supports the

use of the assessment for the population(s) who will be assessed in the state.

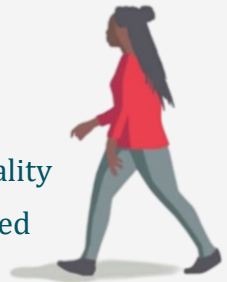
Much like measure development is a science unto itself, psychometric testing is a field dedicated to the statistical testing of assessments. Therefore, it is recommended that experienced professionals are planning and conducting these tests. This testing should be documented so that people outside the field of psychometrics can read and learn about the testing and decide on the quality or thoroughness of the results.

- **Assessment validity** refers to whether an assessment measures what it says it measures. For purposes of this paper, that means whether an assessment truly measures support need.
- **Assessment reliability** refers to how consistent an assessment is.

Both validity and reliability are important to test on support needs assessments, though the testing for

“Valid and reliable”

is a commonly used phrase describing support needs assessments, but a high-quality assessment will have detailed documentation of multiple statistical tests that demonstrate validity and reliability.



each may be done at different times. Validity, for example, is often not tested as frequently as reliability may be tested.

Some of the important types of validity and reliability for an assessment to demonstrate are shown below.

Assessment Validity | Types and Definitions

Content

Assessment content, response options, scoring, and other assessment features are needed to measure support need.

Construct

The assessment measures the actual construct of support need.

Criterion-related

The assessment is related to an expected outcome (predictive) or a similar construct (concurrent) and is not related to constructs that are not similar (discriminant).

Assessment Reliability | Types and Definitions

Test/Retest

The same person gets the same scores on the same assessment when taken again.

Internal consistency

All of the questions in the assessment are measuring the same concept (support need).

Parallel forms/Alternate forms

The same person gets the same scores on two assessments that are conceptually the same (parallel) or close to the same (alternative).

Inter-rater

Different assessors score the same person the same way.

Train your assessors.

While the content, reliability, and validity are critical to a support needs assessment, one sometimes overlooked aspect is whether every assessor is trained and skilled enough to administer the assessment.

Some assessments are available with rigorous training programs in lock step with the assessment. Others, especially those developed by the state for its express use, may need to develop their own rigorous training and/or certification programs.

This training should reflect not only detailed guidance for administering an assessment fairly across all people who will be assessed but should also provide explicit examples of how to score and record responses as well as help assessors navigate challenging issues or incompatible responses. Rigorous trainings will involve weeks of practice testing with feedback to help assessors improve. Assessment developers are helpful in creating training since they are most intimately aware of what questions are measuring and why and how the assessment was developed.

An important measure of whether the training is rigorous is inter-rater reliability, or whether different assessors score an assessment for the same people in the same way. Inter-rater reliability should be tested before the assessment is used, but also should be tested regularly.

Just as the assessment itself should be respectful, the assessors should administer the assessment in a person-centered way that recognizes the person's importance in the assessment and how the assessment will impact them. Assessors must also conduct assessments in culturally appropriate ways, which should be guided by training.

When possible, training for assessors should

include guidance from people with lived experience, or stories about their experience with the assessment. Assessors must have opportunities to practice administering the assessment with people with disabilities—specifically with the population they will be assessing.

Get your tech together.

No matter why the state has elected to use assessment, or how the results of such an assessment will be used (two things a state should determine BEFORE choosing an assessment), having the right technology will allow the state to optimize the administration of and use of the assessment.

First, it is imperative that there is an ability to electronically capture and store results. If there is a need to develop such a system, it will involve time and resources. Some assessments may come with accompanying systems that may be used for this purpose, but others do not, especially if states are leading the development of a new assessment.

This system should be capable of linking the assessment to other systems that house other information that may be relevant for the assessments use. For example, if a state is going to use the support needs assessment for person centered planning, then ideally, the assessment will link to the plan.

To the extent possible, scoring the assessment should be automated to prevent human error. Automation should be built into the technological solution that is used by the state. If the assessment is being used for level of care or being scored for individual budgets, an automatic calculation will allow for quick and accurate use of the assessment information to factor into the person's plan.

Another potential area where automation can be of assistance is in scheduling the assessment, sending notification that an assessment is needed, and providing notices of the assessment's results. Administering the assessment across the population is an undertaking that should be highly organized. Automating processes such as notices indicating when a person needs another assessment may be extremely beneficial to the overall administration of assessments.

Additionally, the assessment should be able to produce usable and helpful reports of the results for the person and their team and the results should be accessible.

Finally, a support needs assessment can offer a wealth of information about the supports of the whole population or a selection of interest. When selecting or developing a technology solution, the state should consider creating or finding streamlined means for storing, retrieving, merging, cleaning, analyzing, and reporting on data. Some states may choose to create reports or dashboards that regularly report on the findings of the assessment across the population. Support needs assessments offer an opportunity for data driven decision making at the state level. States should plan early on for how to make state-wide data most useful.



Get the word out.

The shift to using an assessment of support needs to inform decision making within a service system cannot be understated. One final consideration for using a support needs assessment is making sure that service recipients are well informed about the assessment that will be used and why. States that have successfully implemented support needs

assessments have well-developed communication plans that reach people with disabilities and others so that they are informed about the transition, can raise questions or concerns, and offer constructive feedback to decision makers. Further, it is critical to explain why and how an assessment will be used. People also need to know when changes will take place and how they will affect them and their person-centered plan. Educating all community members helps everyone in the transition. This need not only include direct communication, but also can rely on e-mail blasts, social media posts, videos, and other modes of communication, including outreach to communities that are non-English speaking.

People receiving services also need to know how the assessment is scored and what the results mean for them. This may include providing scoring details and explanations regarding how determinations have been made. Supplementary information can help to explain the assessments uses. For example, when using a support needs assessment to determine an individual budget, there should be publicly available information that explains how the scoring of the assessment relates to the budget. Communications should focus on the information important to people, and not be overwhelming or unnecessary. For example, while the training that assessors are often not publicly available, it is important that people with disabilities understand the assessor's role in the assessment process. A guide outlining what they can expect from the assessment interview should be shared widely with the public.

Lastly, even with the best methods in place, assessments are imperfect. A person may have higher or lower support needs than are indicated on even the most thorough assessments. States should have formal processes in place to support

and remedy the concerns of people who believe that the assessment has not captured their needs adequately. This may include changes to the assessment or a reassessment policy. For example, if a person experiences a medical event

that impacts their support need (e.g., they need more support for ambulating), a policy should be in place that allows them to request a reassessment. These processes should be clearly communicated to people who participate in the assessment

Concluding thoughts

This resource provides a brief overview of high-quality support needs assessments and their requisite standards. While we note the most important qualities of support needs assessments here, this list is not exhaustive, nor does it capture the complexities in judging assessments by each of these standards. The resource alone, should not be used to assess the quality of an assessment for specific purposes. Instead, states should use thorough processes for judging whether a support needs assessment sufficiently determines eligibility or whether an individual budget methodology adequately differentiates support needs and costs.

When undergoing an exploration of the quality of various support needs assessments, it is helpful to develop a process for rating how well assessments fare on each of these standards and others. Perhaps as important as how well assessments excel in these standards is what is important for the state itself. In supporting several states to select a support needs assessment, we have found that a process in which states rank the relative importance of factors and then rate the quality of the assessment on each of the factors can help to judge the assessments applicability and merit. Using these standards from the beginning will help states and other entities to carefully and thoughtfully shift the HCBS system forward, making sure that the support needs assessment aides in the forward momentum. People receiving services and their families should remain central to any decisions made about assessments and be included in all steps of deciding on and implementing a support needs assessment.

If you are unfamiliar with the wide pool of support needs assessments, you may look for existing literature comparing assessments on some of the standards presented here,¹⁰ or reach out to HSRI to support your exploration.

For more information on this work, please contact Colleen at ckidney@hsri.org.

¹⁰ Verdugo MA, Aguayo V, Arias VB, García-Domínguez L. A Systematic Review of the Assessment of Support Needs in People with Intellectual and Developmental Disabilities. Int J Environ Res Public Health. 2020 Dec 18;17(24):9494. doi: 10.3390/ijerph17249494.

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