Individuals with IDD Engaged, Aligned, and Leading – IIDDEAL Project

12 QUALITY MEASURES

IIDDEAL
Individuals with IDD Engaged, Aligned, and Leading

Statement of purpose for sharing IIDDEAL

We want healthcare to understand how to measure the things that are most important to people with IDD so that they can support better health and wellness.

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12 Quality Measures

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What is a quality measure?

A quality measure is a tool that we use to find out how well healthcare is working for us.

Quality measures tell us about healthcare for a population.

This includes healthcare workers, settings, and insurance.

Quality measurement is important for all aspects of our healthcare experience.

- What happens before, during, and after a health care visit
- How I feel physically or emotionally
- How long I wait to get what I need

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Why do we need quality measures?

- Healthcare groups use the results of quality measures to see how well they are doing their jobs.
- Healthcare groups can make better decisions when we measure their quality of care.

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Top Themes for Measure Changes

- Most measures should use simpler words that are easier to understand.
- Age ranges should match real life, like when young people move to adult services or when women may have children.
- Measures should include people with IDD, not leave them out.
- Surveys should let a caregiver or proxy help answer only when needed.
- Measures should address the mental health challenges many people with IDD face.
- The best measures focus on each person's goals and support care that fits their needs.

Glossary

- **Advance Care Planning** - Making plans now for future health care, support, and living needs.
- **Claims data** - Information from insurance records and bills.
- **Continuity of care** - Getting the care you need without gaps or delays.
- **Payer** - An organization that pays for health care, such as an insurance company.
- **Proxy** - A trusted person who answers questions for someone else when needed.
- **Psychosocial care** - Support that helps with feelings, behavior, relationships, and daily life.
- **Transcranial Magnetic Stimulation (TMS)** - A treatment that uses magnets to help certain brain conditions.

12 Quality Measures

- Person-Centered Outcome Measure
- Connection to Community Service Providers
- Child and Adolescent Major Depressive Disorder (MDD) Suicide Risk Assessment
- Person-Centered Primary Care Measure (PRO-PM)
- Person-Centered Contraceptive Counseling
- Children with Special Healthcare Needs (CSHCN) Who Receive Services Needed for Transition to Adult Healthcare
- Adolescent Assessment of Preparation for Transition (ADAPT) to Adult Focused Care
- Follow-Up After Emergency Department Visit for Mental Illness
- Consumer Assessment of Healthcare Providers and Systems (CAHPS), Home and Community Based Services Measures
- Follow-Up after Hospitalization for Mental Illness
- Use of First-Line Psychosocial Care for Children and Adolescents on Anti-Psychotics
- Advanced Care Plan

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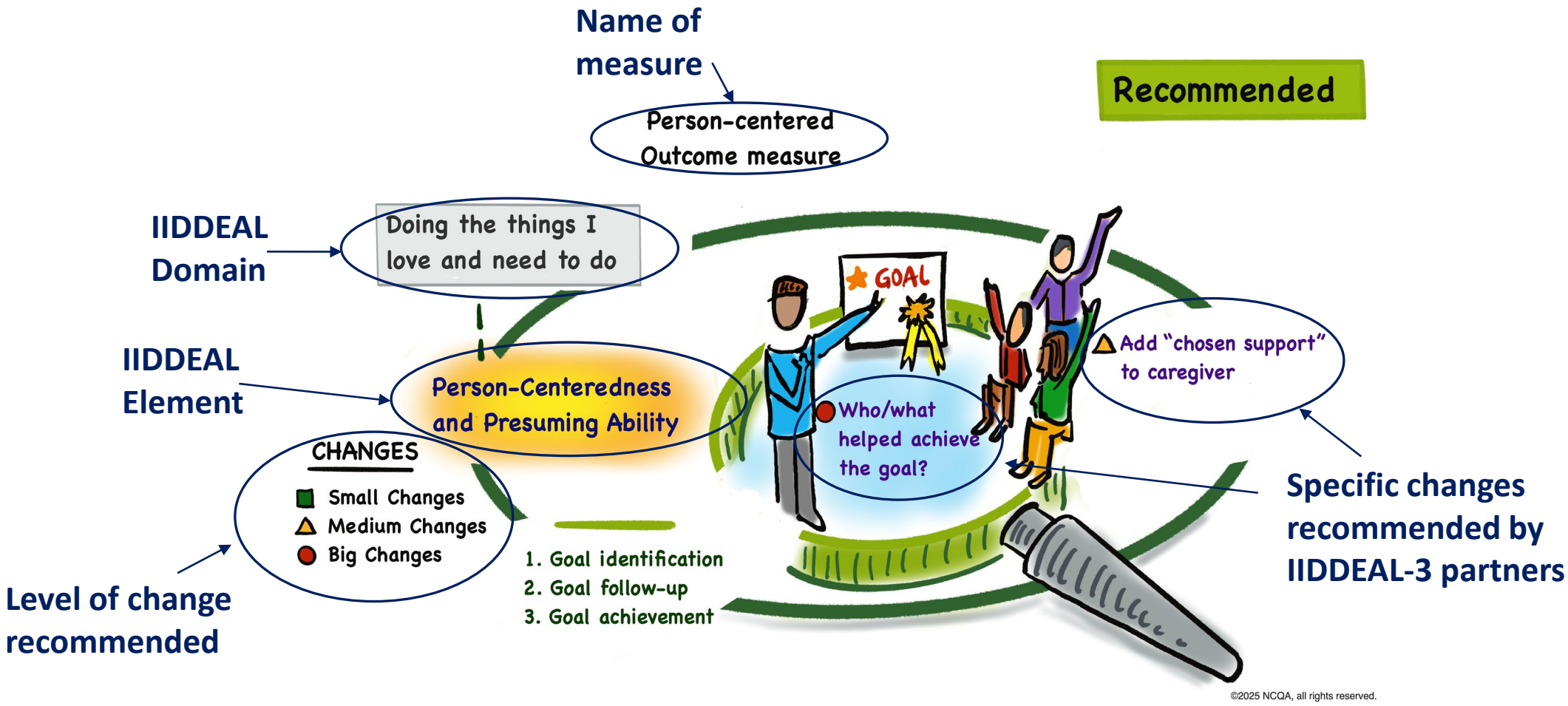
Parts of the Quality Measure Drawing



Recommended

Person-centered
Outcome measure

Doing the things I
love and need to do

Person-Centeredness
and Presuming Ability

Add "chosen support"
to caregiver

Who/what
helped achieve
the goal?

CHANGES

- Small Changes
- Medium Changes
- Big Changes

1. Goal identification
2. Goal follow-up
3. Goal achievement

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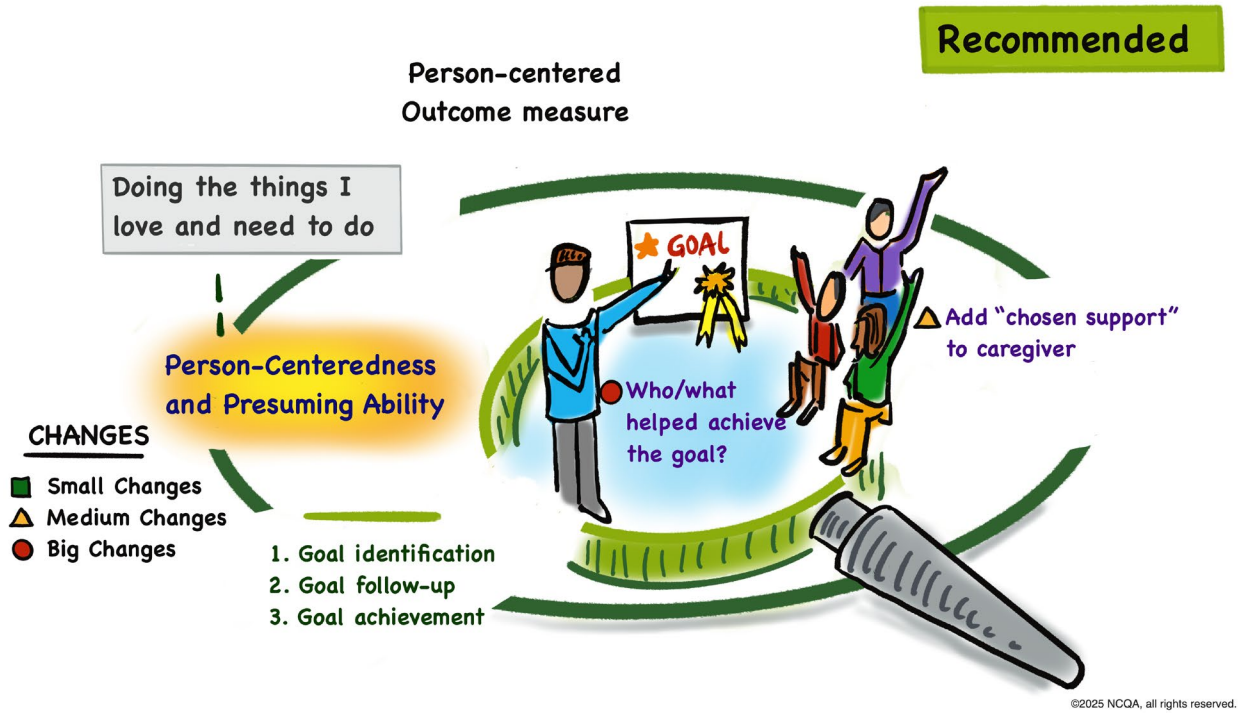

Pros:

- Can be used with care givers/partners as proxies.
- Already being used in Medicaid.
- Highly valued by people with IDD because it asks about their goals and presumes they are able.
- Key to changing clinicians' mindsets because it centers on patients' goals.
- Can use data in electronic health records.
- Clinical groups prefer this 5-point scale over other tools that measure goals.
- Can use this in many different care settings.
- Can use this to hold clinical groups and payers accountable if used widely.

Cons:

- Designed for use only with adults.
- Does not capture if the person's living environment presents barriers to their goals.
- Some clinical groups may just "go through the motions" and not take this seriously.

Recommended Uses:

- Program management but not linked to incentives.
- Quality improvement.
- Public or private quality reporting.

Key considerations:

- ***Partners considered this measure the top priority for promoting adoption.***
- Critical that goals capture what the person with IDD wants; not what others want for them.
- Consider ways to expand use of this measure for people with IDD who are in jail, mental hospitals, or nursing homes.
- Patients with IDD may need help narrowing down to a specific goal. Clinical groups need training in how to have conversations with patients with IDD about their goals.

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NAME of the MEASURE:	Person-centered outcome measure
Goal:	People can do the things they love and need to do
How to achieve this:	Ask people about their goals and help them reach them.
Why this matters:	People with IDD want to be asked about their goals.
Why people liked this measure:	• This tool works in all IIDDEAL domains because it can be matched to a person's goal and presumes ability. For example, a mental health goal would fit under "Improving My Emotional or Mental Health." • Can be used with caregivers/partners as proxies. • Already being used in Medicaid.
Specific changes recommended to improve the measure:	• Choose one caregiver to be the main supporter. • Add information on who or what helped the patient achieve their goal.

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Adolescent Assessment of Preparation for Transition (ADAPT) to adult focused care

Recommended

Improving physical health, reduced pain, and improved energy

Supported and Shared Decision-Making

- Translate into other languages
- Expand to ages 16-27
- Add questions about actions, not just decisions
- Lower reading level
- Update choices for race/gender

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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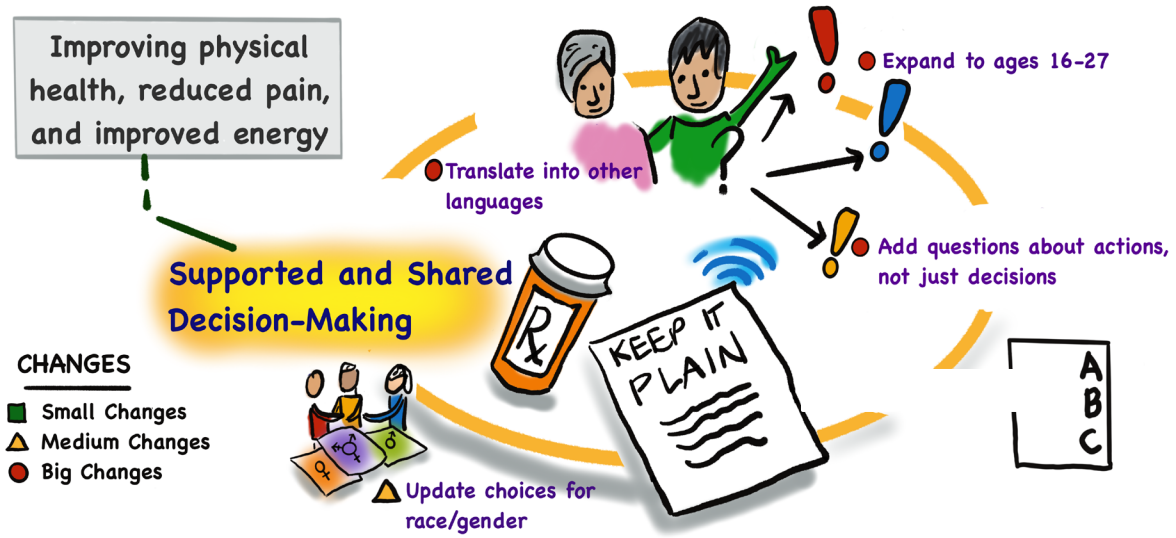
Adolescent Assessment of Preparation for Transition (ADAPT) to adult focused care

Recommended



Recommended Uses:

- Quality improvement.
- Accountability at the system level.

Key considerations:

- While this is a valuable measure, it leaves an important gap for measures that reflect how successfully a youth with IDD transitions to adult services. Consider combining this measure with other measures on transitions.
- Care givers/partners need to support the youth with IDD but also need to give the youth the chance to lead decision-making.
- The system of adult services is poorly prepared to serve maturing youth with IDD. It needs more resources to meet their needs.
- Clinical groups may need guidance on how to use the results of this measure for quality improvement.
- Payers can offer pediatric clinical groups an "episode of care" payment to motivate them to focus on preparing youth for transitions.

Pros:

- Can be used with care givers/partners as proxies.
- Addresses an important life stage of transitioning from youth to adult services, where many youth with IDD "fall off a cliff."
- Respectful of a youth's ability to make decisions.
- Questions about youth being able to discuss transition with a doctor without their parent in the room are especially respectful.

Cons:

- Most questions focus on youth making decisions. Only one question focuses on youth taking action (to fill drug prescriptions).

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NAME of the MEASURE:	Adolescent Assessment of Preparation for Transition to Adult Focused Care (ADAPT)
Goal:	Improve physical health, reduce pain and improve energy
How to achieve this:	Supported and shared decision making
Why this matters:	Many young people with IDD lose services when they become adults.
Why people liked this measure:	• Can be used with caregivers/partners as proxies. • Focuses on the important change from youth services to adult services, a time when many young people with IDD lose support. • Respectful of a youth's ability to make decisions. • Questions that let young people talk with their doctor without a parent in the room show respect for their independence.
Specific changes recommended to improve the measure:	• Lower reading level • Add questions about actions not just decisions • Expand to ages 16-27 • Translate into other languages • Update choices for race/gender

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Recommended

Connection to Community Service Providers

Doing the things I love and need to do

Add "... got reliable, ongoing help..."

Expand to all ages

Help Clinicians Address Social Drivers of Health

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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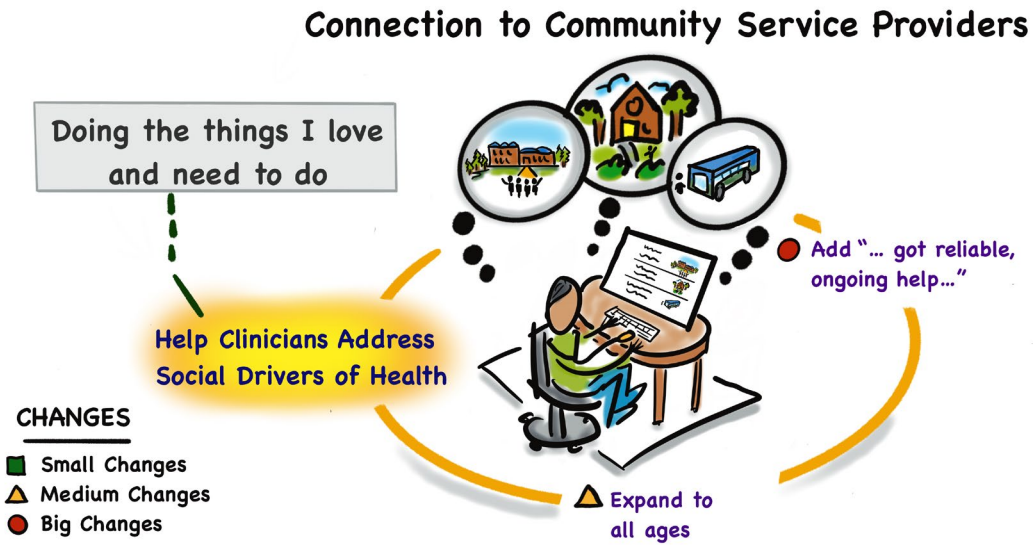
Recommended



Pros:

- Already being used in Medicare payment programs for doctors and hospitals.
- Culturally sensitive.
- Respectful in how questions are worded.
- Critical to adopt because people with IDD have many social needs.

Cons:

- Designed for use only with adults.

- **Recommended Uses:**
  - Program management but not linked to incentives.
  - Quality improvement.
  - Public or private quality reporting.
  - Accountability at the system level.
- **Key considerations:**
  - Clinical groups may interpret "social needs" too narrowly. That could also include environmental factors, and cultural/spiritual needs. On the other hand, starting with basic needs like housing, transportation, and food can help focus efforts by clinical groups. They may not be able to address every need.
  - Reliable transportation to get to clinical services should be included.
  - Clinical groups need meaningful incentives to address patients' social needs, but they can do so.
  - Using this measure in real situations will also help people with IDD learn about what social services are available in their community, which would be helpful in future situations.
  - This measure should not be limited to primary care settings. Clinical specialists should also routinely address social needs.
  - People with IDD can share this measure with their clinical teams to make them aware of social needs.

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NAME of the MEASURE:	Connection To Community Service Providers
Goal:	People can do the things they love and need to do
How to achieve this:	Help clinicians address social drivers of health
Why this matters:	Many things affect a person's health, like where they live, what they eat, if it is easy or hard to get to appointments, etc.
Why people liked this measure:	• Medicare already uses this in programs that support payments to doctors and hospitals. • Culturally sensitive. • Respectful in how questions are worded. • Critical to adopt because people with IDD have many social needs.
Specific changes recommended to improve the measure:	• Expand to people of all ages • Change language to "…got reliable, ongoing help…" instead of stopping at 2 months.

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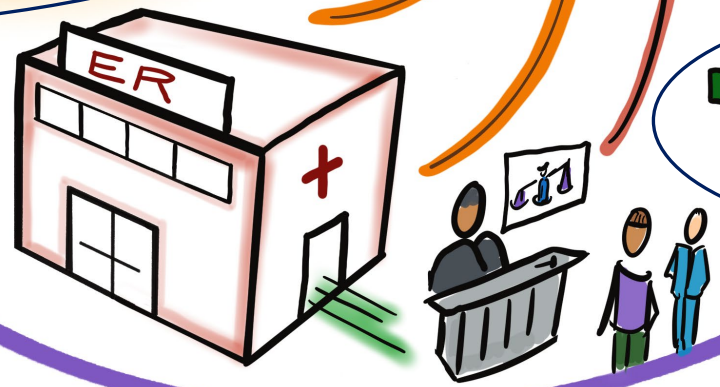
Recommended

System Supports

Follow-Up After Emergency Department Visit for Mental Illness

Informed consent

Continuity of services, co-location of services as a solution, navigation supports between sectors



Add TMS (Transcranial Magnetic Stimulation)

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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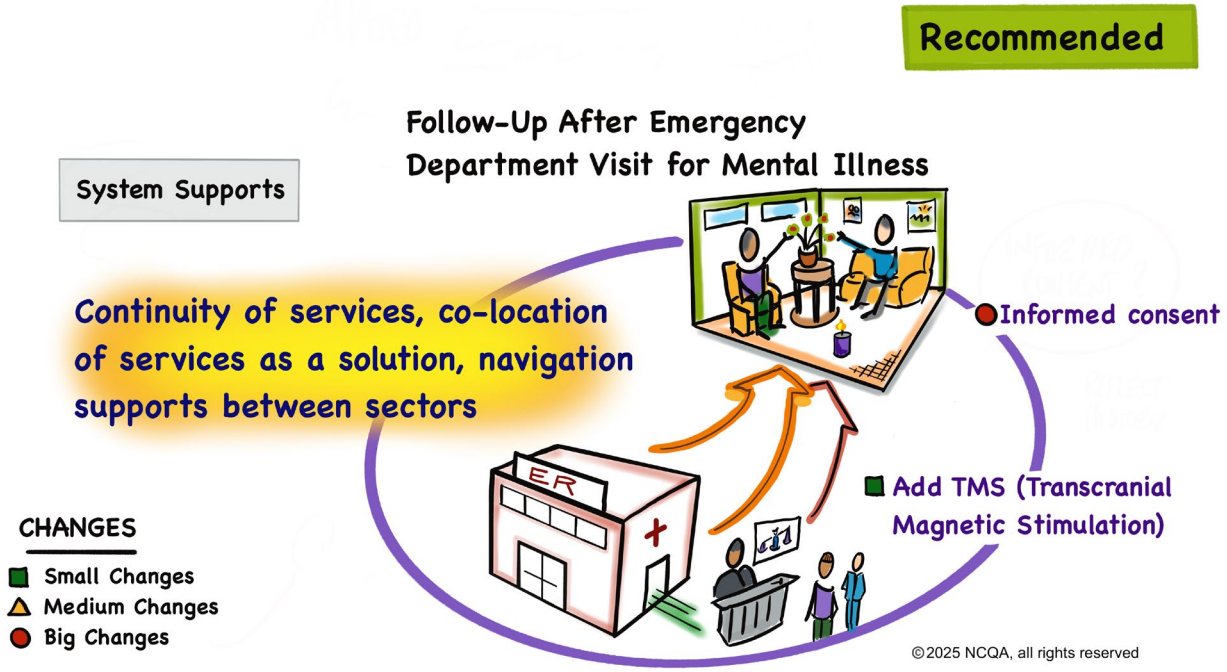

Pros:

- Highly relevant for continuity of care.
- The measure is widely used, and based on claims data, which reduces burden on providers.

Cons:

- Requiring the principal diagnosis to be mental illness could exclude people with IDD who present with other principal diagnosis, but who also need mental health follow-up. For example, a person with IDD with a behavioral outbreak could have that listed as a diagnosis, instead of mental illness, and they could especially need a follow-up visit.
- The measure is specifically for mental illness, which is important, but is narrow and doesn't address the entire intent of this Element, which is about continuity of care broadly across the system.

Recommended Uses:

- Program management without incentives.
- Quality improvement.

Key considerations:

- Disagreement about the inclusion of electroconvulsive therapy (ECT) as an appropriate type of follow-up service in this measure. Some IIDDEAL partners were concerned that people with IDD have been harmed by shock therapy and other traumatic physical treatments. Other IIDDEAL partners noted that ECT should not be the first-line treatment for most patients but can be an important treatment for some people. Some IIDDEAL partners recommended including transcranial magnetic stimulation (TMS) as a more updated treatment option because it has been shown to be effective for people with IDD and is not invasive.
- Informed consent should follow state laws related to informed consent.
- ED visits are not scheduled but may be great opportunities for clinical teams to provide support to a person with IDD to connect with providers in the community.
- This measure could support comparisons between people with IDD versus people without IDD, to see if people with IDD are less likely to have continuity of care.
- Getting a person with IDD the right kind of mental health follow-up care depends on the clinician knowing important things about them, like their living situation and clinical history. Clinicians in the emergency department also need access to important documents related to the person with IDD (such as guardianship forms or care plans) to make the right decisions.

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NAME of the MEASURE:	Follow-Up After Emergency Department Visit For Mental Illness
Goal:	System Supports
How to achieve this:	Providers hand off care between settings, people can have an opportunity to access services in one place, and people get help moving through different service systems.
Why this matters:	Reduces the burden on the patient to coordinate care.
Why people liked this measure:	• Highly relevant for continuity of care. • The measure is widely used, and based on claims data, which reduces burden on providers.
Specific changes recommended to improve the measure:	• Informed consent should follow state laws related to informed consent • IIDDEAL partners had different opinions about including electroconvulsive therapy (ECT). Some expressed concerns about past harms. Others felt it may be appropriate for certain patients. Partners also suggested considering transcranial magnetic stimulation (TMS) as another treatment option.

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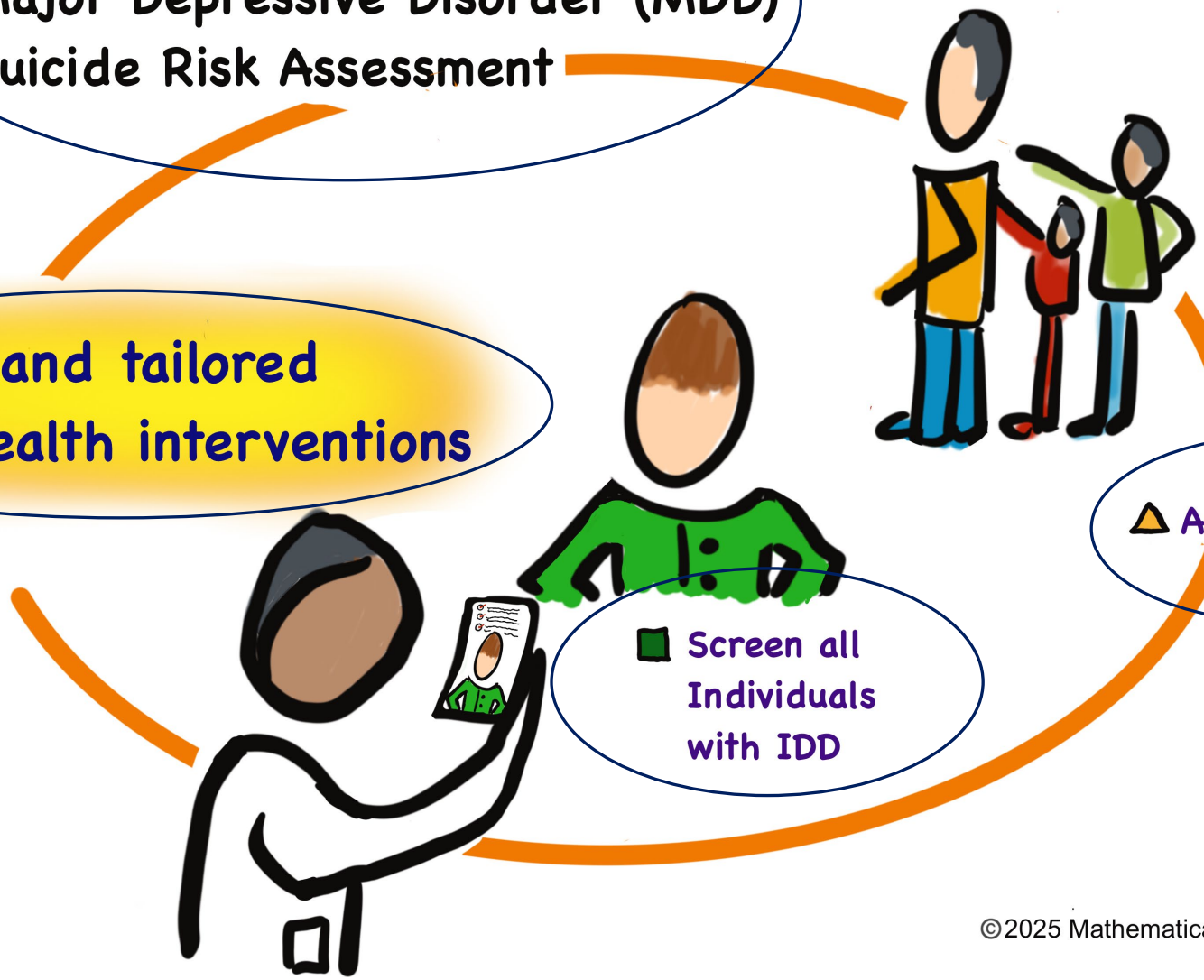
Recommended

Child and Adolescent
Major Depressive Disorder (MDD)
Suicide Risk Assessment

Emotional or
Mental Health

Adapted and tailored
mental health interventions



Add adults

Screen all
Individuals
with IDD

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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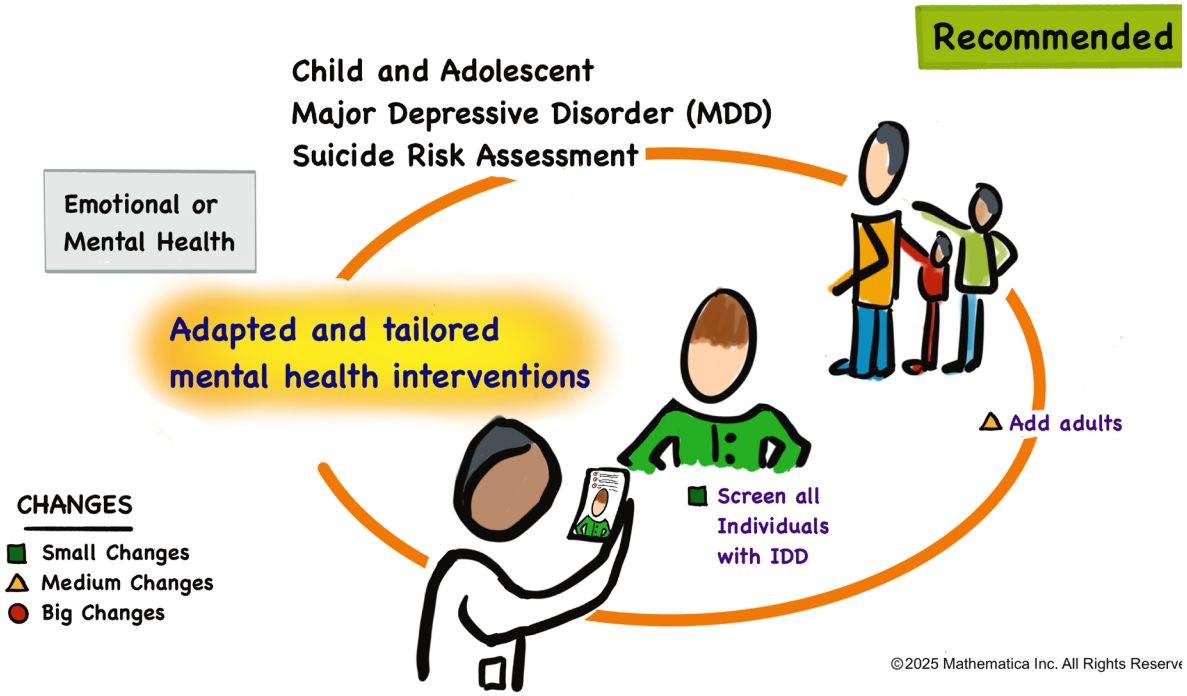

Recommended Uses:

- Program management with incentives.
- Quality improvement.
- Accountability at the system level.

Key considerations:

- This measure needs to be paired with an outcome measure that reflects treatment if a child or youth was suicidal.
- Requiring a diagnosis of depression to qualify for the measure will exclude children and youth who could not access diagnostic services.
- It is important to identify or develop suicide risk assessment tools that are tailored for children and youth with IDD.

Pros:

- Addresses higher suicide risk in children and youth with IDD than among other children.
- Does not exclude children and youth with IDD.
- Flexibility for clinicians to choose the suicide risk assessment tool means they can use a tool adapted for children with IDD.
- This is a valuable process measure that captures an important first step in preventing suicide.

Cons:

- The measure does not reflect "Adapted and tailored mental health interventions," which IIDDEAL partners described as including non-traditional approaches such as art or pet therapy, tailored to the individual child's needs.
- The measure does not capture what actions the clinician took after assessing suicide risk.
- Focusing only on children with a diagnosis of depression is too limiting. Other conditions such as high anxiety or panic attacks can also lead to suicide among children and youth with IDD.
- Since clinicians can choose the risk assessment tool, they will use different tools. That may make it hard to compare which tools are most effective.
- The age span is limited.
- The measure is not consistent with other guidelines on pediatric suicide screening, which promotes screening all children.
- The measure excludes adults with IDD, who also have increased risk of suicide.
- The measure does not capture whether the suicide risk assessment was done in a respectful or culturally appropriate way.

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NAME of the MEASURE:	Child and Adolescent Major Depressive Disorder (MDD) Suicide Risk Assessment
Goal:	Emotional or Mental Health
How to achieve this:	Adapted and tailored mental health interventions
Why this matters:	Children and youth with IDD have a higher risk for suicide than other children.
Why people liked this measure:	• Addresses higher suicide risk in children and youth with IDD than among other children. • Does not exclude children and youth with IDD. • Doctors have the flexibility to use a suicide risk assessment tool that fits the needs of people with IDD. • This is an important measure because it tracks early actions that can help prevent suicide.
Specific changes recommended to improve the measure:	• Screen everyone with IDD, including those who use communication support. • Add adults

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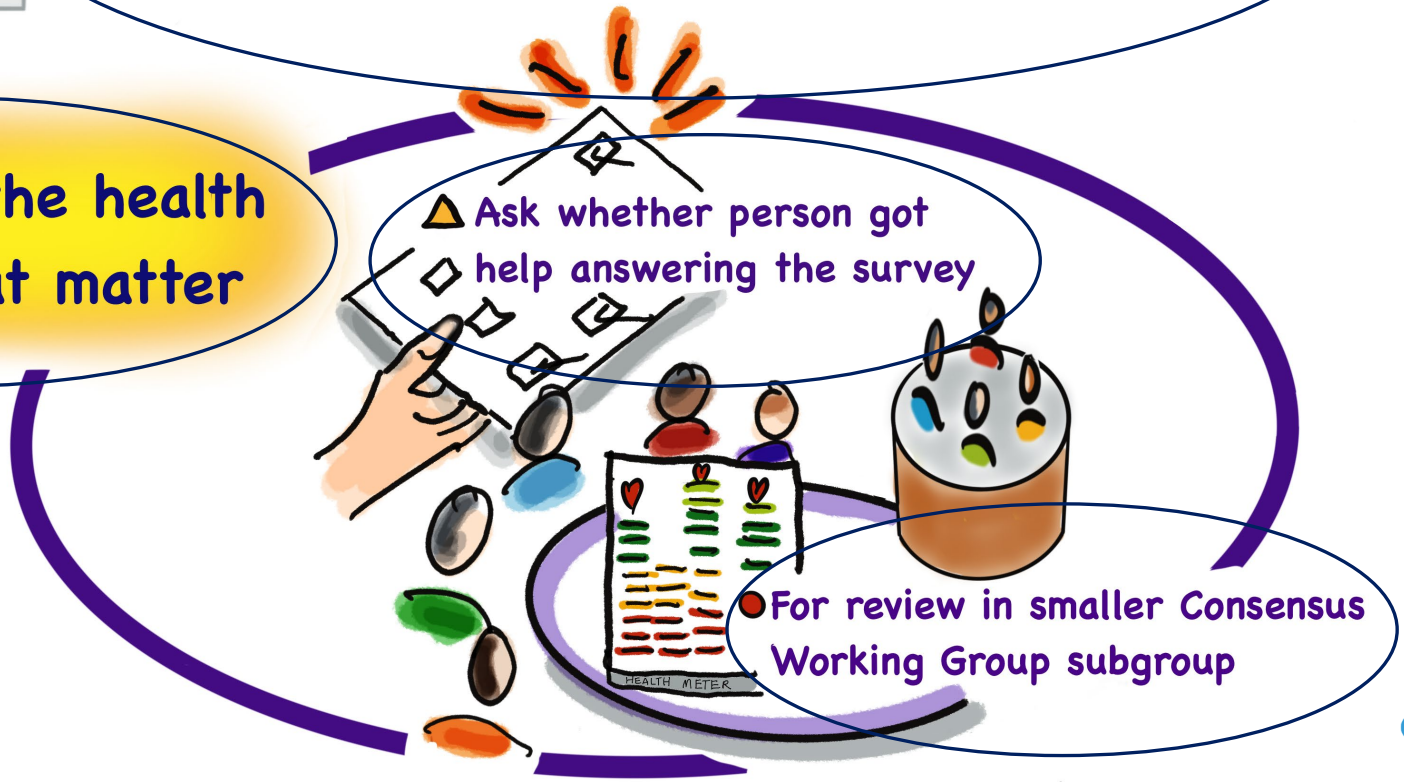
Recommended

Payers and Regulators

Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community-Based Service Measures (HCBS CAHPS)

Metrics for the health outcomes that matter



CHANGES

- Small Changes
- Medium Changes
- Big Changes

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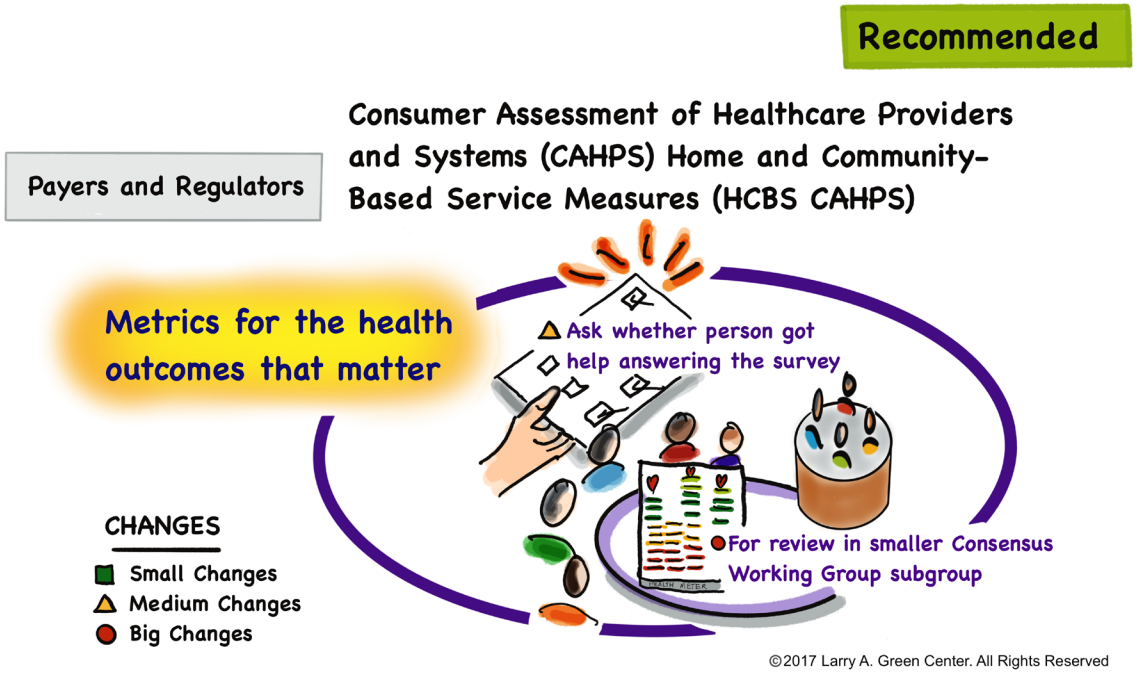

Pros:

- This measure captures people's experiences with a wide range of issues in home- and community-based services.
- It is already being used in some states.
- The survey can be used across population groups and to compare facilities.
- Data collected using CAHPS can be easily accessed by provider groups.

Cons:

- The survey is long, which creates burden for both the person conducting the survey and the person responding to it.
- The reading level may be too high.
- CAHPS is not a true assessment of needs being met.
- People taking the survey may not know what HCBS services are available.
- It isn't clear if proxies can respond to the survey.
- The survey is done by telephone. Other methods may be more inclusive, such as by video, or on a computer with assistance for people who have speech disabilities.
- It isn't clear whether the survey gets high response rates.

Recommended Uses:

- Program management with incentives.
- Quality improvement.
- Public or private quality reporting.
- Accountability at the system level.

Key considerations:

- IIDDEAL partners discussed at length the pros and cons of this CAHPS survey versus the National Core Indicators (NCI) about people's experience with HCBS services. Partners felt both surveys were valuable and especially appreciated the NCI's holistic approach to measuring a person's health and life needs and how well they have been supported. 48 states use the NCI, while fewer than 10 states use CAHPS. This is a sign that states prefer the NCI. Partners also noted that:
  - The National Core Indicators survey has over 180 questions. This means it captures much more information than CAHPS but also makes it harder to respond to.
  - However, data from the NCI survey cannot be easily accessed by clinical groups and is not designed to be analyzed at the level of a single organization.
  - The NCI survey is also more expensive to use.
- Overall, IIDDEAL partners recommended starting with adoption of the CAHPS HCBS survey. But they also strongly encourage stewards of the NCI survey to consider ways to make the data easier to access and analyze at the level of a single organization.

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NAME of the MEASURE:	Consumer Assessment of Healthcare Providers and Systems (CAHPS), Home and Community-Based Service Measures
Goal:	Payer and Regulator Needs
How to achieve this:	Metrics for the outcomes that matter
Why this matters:	We need more data to check how well doctors treat patients with IDD.
Why people liked this measure:	• This measure looks at how people feel about the services they receive at home and in their community. • It is already being used in some states. • This survey works for many groups of people and can be used to compare facilities. • CAHPS data helps provider groups see what they are doing well and where they can improve.
Specific changes recommended to improve the measure:	• Use a caregiver- or proxy-completed survey only when there is no other option • Add a question asking if the person with IDD received help completing the survey. • Expand the eligible age range to include families with children • Reduce language to 5th or 6th grade reading level.

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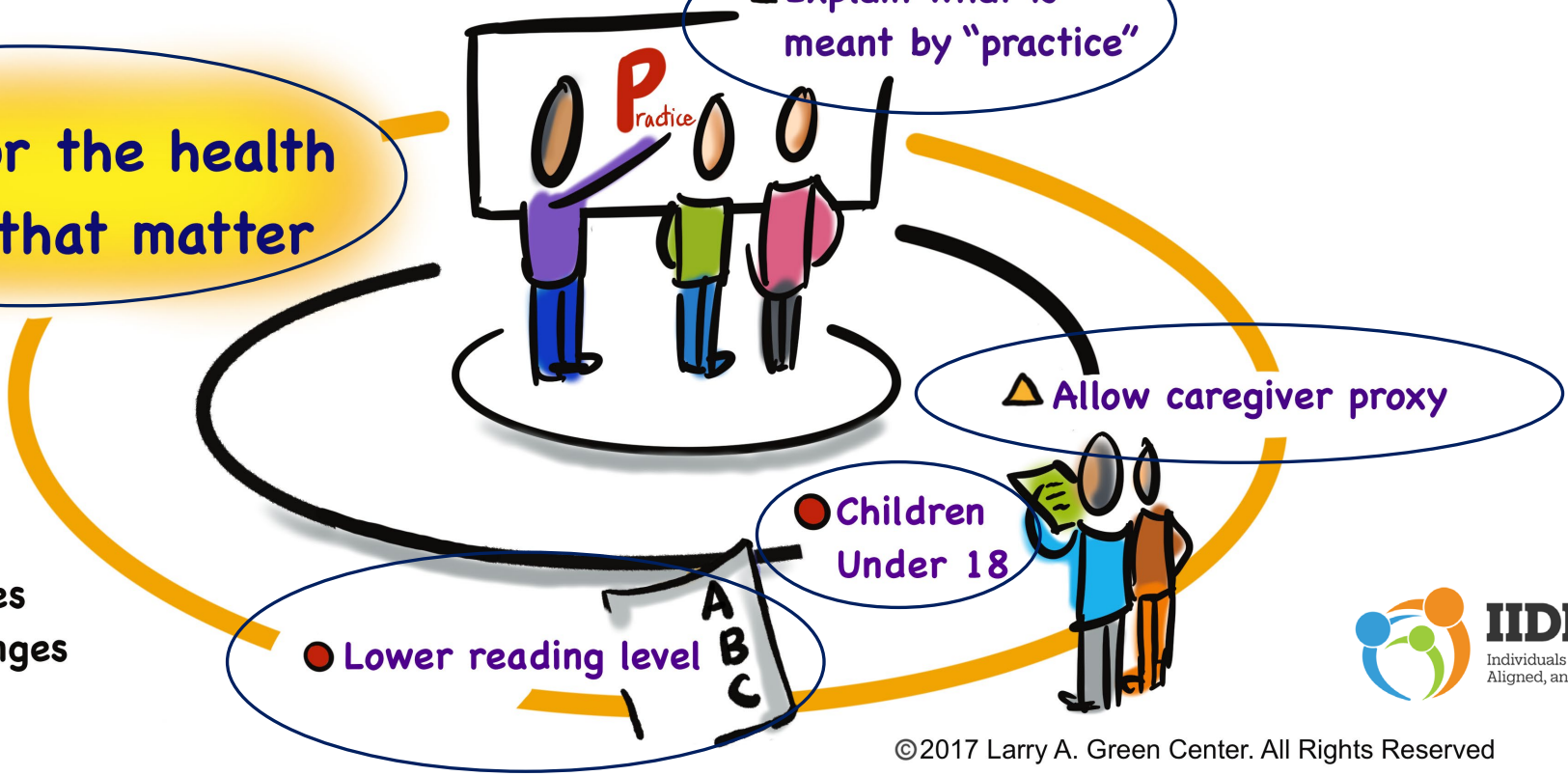
Recommended

Person-Centered Primary Care Measure PRO-PM

Payers and Regulators

Metrics for the health outcomes that matter



CHANGES

- Small Changes
- Medium Changes
- Big Changes

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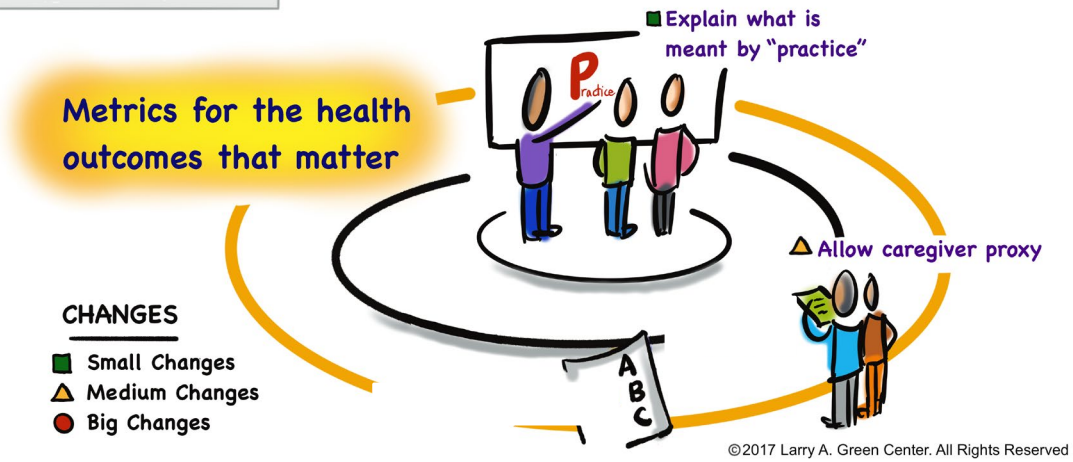
Recommended

Payers and Regulators

Person-Centered Primary Care Measure PRO-PM



Pros:

- This measure captures a wide array of otherwise lost elements of primary care.

Cons:

- It is not clear if there is an option for a person with IDD to get support in answering the survey, or if there is a way to track if they got help.
- It is not clear who gets to define what "person-centered" planning is.

Recommended Uses:

- Program management without incentives.
- Quality improvement.
- Accountability at the system level.

Key considerations:

- This measure covers important concepts but asks them in a way that makes it difficult for providers and systems to know what to do to improve.
- Primary care practices and patients may need education to understand what person-centered care is.

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NAME of the MEASURE:	Person-Centered Primary Care Measure (PRO-PM)
Goal:	Payer and Regulator Needs
How to achieve this:	Metrics for the outcomes that matter
Why this matters:	Primary care doctors take care of patients with IDD
Why people liked this measure:	• This measures important patient experiences in primary care that are often missed.
Specific changes recommended to improve the measure:	• Add an explanation of what a “practice” is. • Use a caregiver- or proxy-completed survey only when there is no other option • Add a question asking if the person with IDD got help completing the survey. • Expand the eligible age range to include families with children. • Reduce language to 5th or 6th grade reading level.

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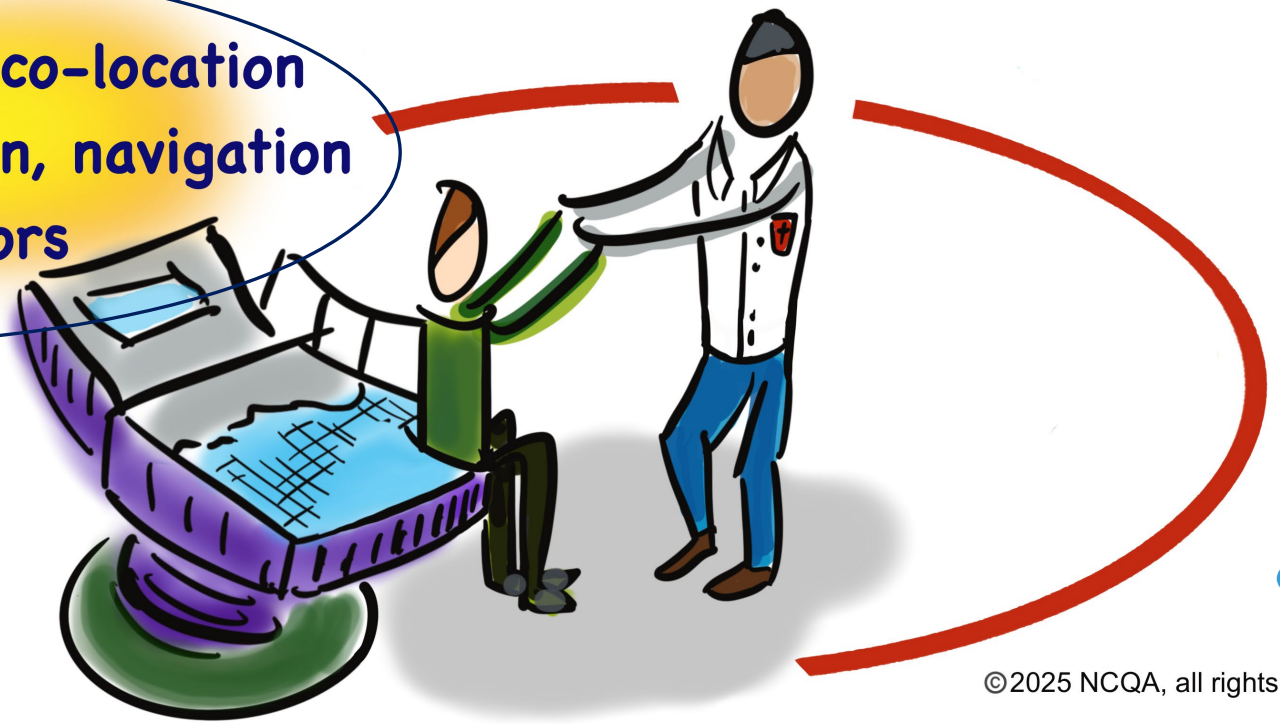
Recommended

Follow-Up After Hospitalization for Mental Illness (FUH)

System Supports

Continuity of services, co-location of services as a solution, navigation supports between sectors



CHANGES

- Small Changes
- Medium Changes
- Big Changes

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Recommended

Follow-Up After Hospitalization for Mental Illness (FUH)

System Supports

Pros:

- This measure captures patients at high risk who most need follow-up.
- It encourages continuity of care.
- It is widely used and based on insurance claims, which reduces burden on providers.

Cons:

- The measure is specifically for mental illness, which is important, but is narrow and doesn't address the entire intent of this Element, which is about continuity of care broadly across the system.

Recommended Uses:

- Program management without incentives.
- Quality improvement.

Key considerations:

- IIDDEAL partners felt continuity of care is especially important for people with IDD who have mental illness. It is easy for them to fall through the cracks if they do not get help to make follow-up appointments and get to the visit.
- There was a great deal of discussion about the inclusion of electroconvulsive therapy (ECT) as an appropriate type of follow-up service in this measure. Some IIDDEAL partners were concerned that people with IDD have been harmed by shock therapy and other traumatic physical treatments. Other IIDDEAL partners noted that ECT should not be the first-line treatment for most patients but can be an important treatment for some people.
- IIDDEAL partners also discussed the importance of getting informed consent before sending a patient with IDD for ECT or residential treatment. This means following the informed consent laws of the state the patient lives in.
- Some IIDDEAL partners recommended including transcranial magnetic stimulation (TMS) as a more updated treatment option because it has been shown to be effective for people with IDD and is not invasive.

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NAME of the MEASURE:	Follow-Up After Hospitalization for Mental Illness
Goal:	System Supports
Why this matters:	Risk of suicide is higher among people with IDD.
How to achieve this:	Providers hand off care between settings, people can have an opportunity to access services in one place, and people get help moving through different service systems.
Why people liked this measure:	• This measure captures patients at high risk who most need follow-up. • It encourages continuity of care. • Because this measure uses insurance records, providers do not have to spend as much time collecting information.
Specific changes recommended to improve the measure:	• Consider transcranial magnetic stimulation (TMS) as a follow-up treatment option.

IIDDEAL
Individuals with IDD Engaged, Aligned, and Leading

Recommended

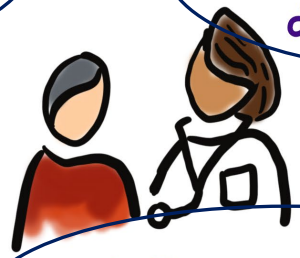
Person-Centered Contraceptive Counseling (PCCC)

Ask if clinician protected privacy

Did the clinician use shared or supported decision-making

13<55

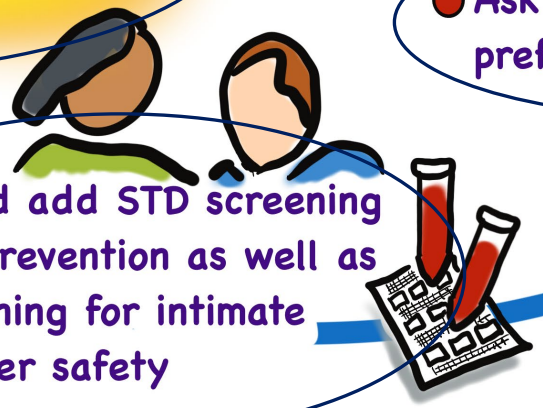
Expand age to 13-55 (menses)



Ask if communication preferences were honored

Include non-binary people

Include males



Would add STD screening and prevention as well as screening for intimate partner safety

Sexuality, Gender, Reproductive Health and Parenting

Access to sexual/ Reproductive health care

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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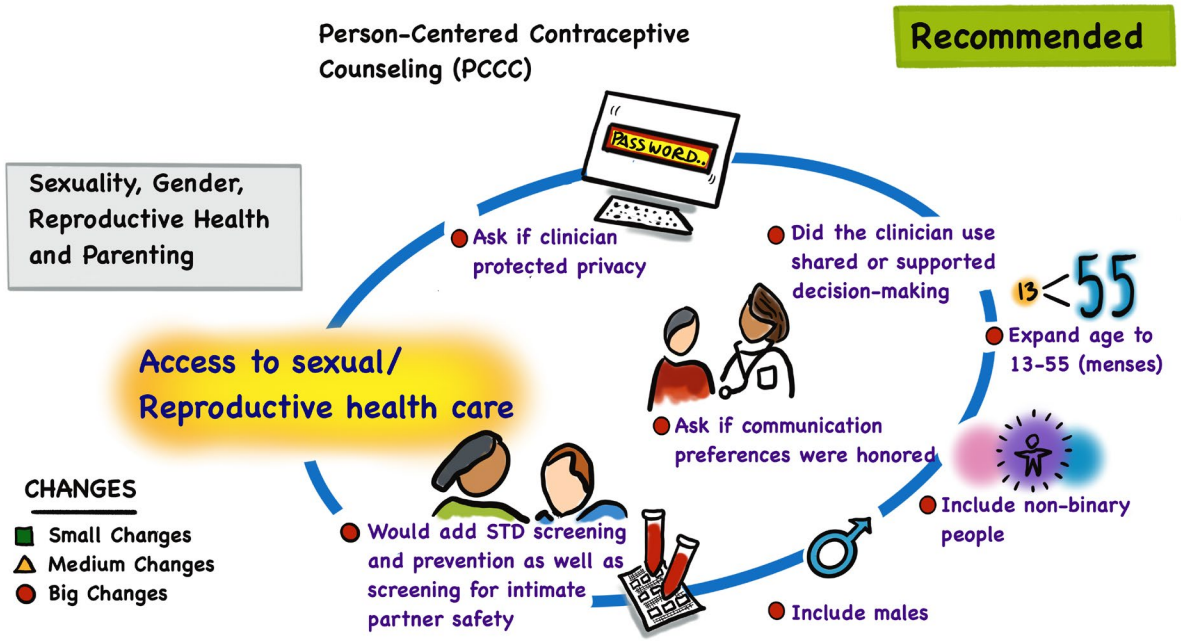

Recommended Uses:

- Quality improvement.

Key considerations:

- It's important to realize that people with IDD can want and have sexual lives. That is a part of their humanity. Routinely asking people with IDD about their sexual life is an important step in addressing their reproductive, sexual, and gender health needs.
- People with IDD have also been harmed by forced sterilization and denial of sexual, reproductive, and gender care. This makes it especially important for clinicians to approach these conversations respectfully.

Pros:

- The measure feels relevant and respectful.
- Questions support the connection with providers, choice, and self-determination around making these decisions.
- It highlights that having a good relationship with a provider will help get you to the quality of care desired – and receive the contraceptive care desired.
- The measure is broad-based and could capture a lot of individuals.
- Good because PWIDD are often not respected for their preferences and choices about their birth control and decisions about pregnancy.
- It is easy to complete 4 questions.
- The measure recognizes that people with IDD are sexual beings.

Cons:

- It only includes people assigned female sex at birth. Other people need birth control counseling too.
- Age range of 15-45 years is too narrow. Many people can become pregnant at younger or older ages.
- The questions don't get at if the clinician engaged the person in shared or supported decision making.
- The measure doesn't get at cases where the clinician doesn't even ask the person if they are having sex.
- The measure doesn't ask about whether the clinician supported the person's communication preferences, privacy (for example, if the person had a care giver/partner with them at the visit), or if the information about birth control was in a form that was accessible.
- The measure doesn't ask about consent, sexual safety/sexual assault, and other "intimate partner safety" issues.
- The measure doesn't address sexually transmitted diseases.
- Limited to English and Spanish.

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NAME of the MEASURE:	Person-Centered Contraceptive Counseling
Goal:	Sexual, Gender, Reproductive Health & Parenting
How to achieve this:	Access to sexual/reproductive healthcare
Why this matters:	People with IDD have sex
Why people liked this measure:	• The measure feels relevant and respectful. • These 4 questions support choice, independence, and working with providers to make decisions. • It shows that having a good relationship with your provider can help people get the care they want, including birth control care. • This matters because people with IDD do not always have their preferences respected when making decisions about birth control and pregnancy.
Specific changes recommended to improve the measure:	• Add questions about sexually transmitted disease testing and whether a person feels safe with their partner. • Use a caregiver- or proxy-completed survey only when there is no other option • Broaden this measure to include people of all genders, since family planning and sexual health are important for everyone. • Expand age range to anyone who has started menstruating to 50 years old • Include questions about whether the person felt their communication choices and privacy were respected.

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Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics

Recommended

Emotional or Mental Health

no element

- Include all ages
- Include people with IDD
- Allow using medications at the same time as psychosocial care
- Was the diagnosis even correct?
- Ask if psychotherapy happened before this episode
- Include other adjunctive therapies, such as ABA, OT, etc.

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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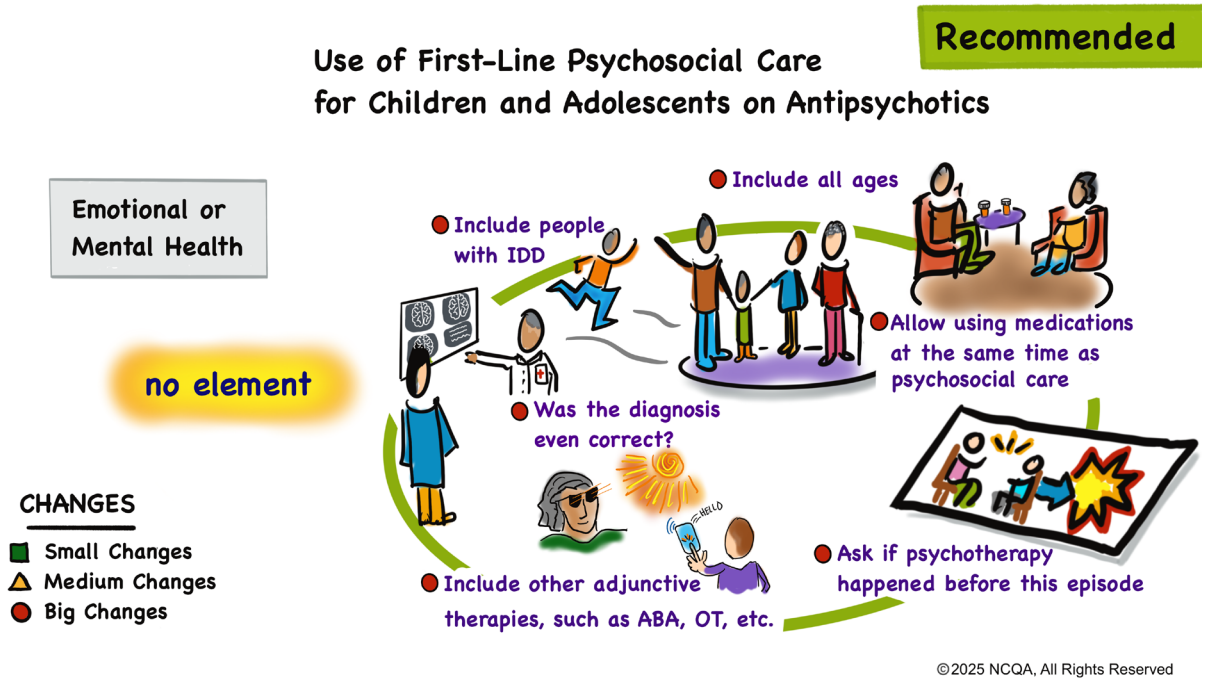

Recommended Uses:

- Quality improvement.
- Accountability at the system level.

Key considerations:

- This measure promotes integrated behavioral health care.
- It is also important to educate care givers/partners about when anti-psychotic drugs are or are not appropriate.
- The ideal treatment for some kids may be to get both anti-psychotic and psychosocial treatment at once.
- There are cases where first line use of drugs is needed if the patient's safety is at risk.
- The measure is focused on prescribers. Other clinicians involved with the patient may have different opinions of what the patient needs.

Pros:

- Addresses the harmful issue of common overuse of anti-psychotic drugs for children with IDD. For most patients, it is better to try other therapies before using drugs.
- The measure uses insurance claims data, so clinical groups don't have to report data.
- The measure is flexible, allowing clinicians to use any suicide risk assessment they think is appropriate.

Cons:

- The measure ***explicitly excludes children with IDD***.
- The measure only applies to first time a person gets an anti-psychotic drug. This may be hard to pinpoint in claims data.
- It may be hard to find this information in claims data.
- The measure only applies to children; adults with IDD are over prescribed anti-psychotic drugs too.
- The measure does not address what happens after the child gets anti-psychotic drugs and what their outcomes are.
- Since clinicians can choose the risk assessment tool, they will use different tools. That may make it hard to compare which tools are most effective.
- The age span is limited.
- Excludes kids that may be most vulnerable to being over-prescribed and under-treated with psychosocial care. For example, younger kids diagnosed with serious mental illness potentially shouldn't be excluded.
- What about cases where there are access barriers causing delays to psychosocial care? The measure does not allow for exceptions if a patient needs antipsychotic medication first before psychosocial care is available.

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NAME of the MEASURE:	Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics
Goal:	Emotional or Mental Health
How to achieve this:	Quality improvement and accountability at the system level
Why this matters:	People with IDD are more likely to be prescribed or overly prescribed antipsychotic medications
Why people liked this measure:	• Addresses the harmful issue of common overuse of anti-psychotic drugs for children with IDD. • This measure uses insurance records, so healthcare groups do not need to send in extra data.
Specific changes recommended to improve the measure:	• Include children and adults with IDD of all ages. • Allow exceptions when a person needs both mental health support and antipsychotic medicine at the same time. • Allow other types of therapy to count as mental health support. • Check whether the person received mental health support the last time they used antipsychotic medicine.

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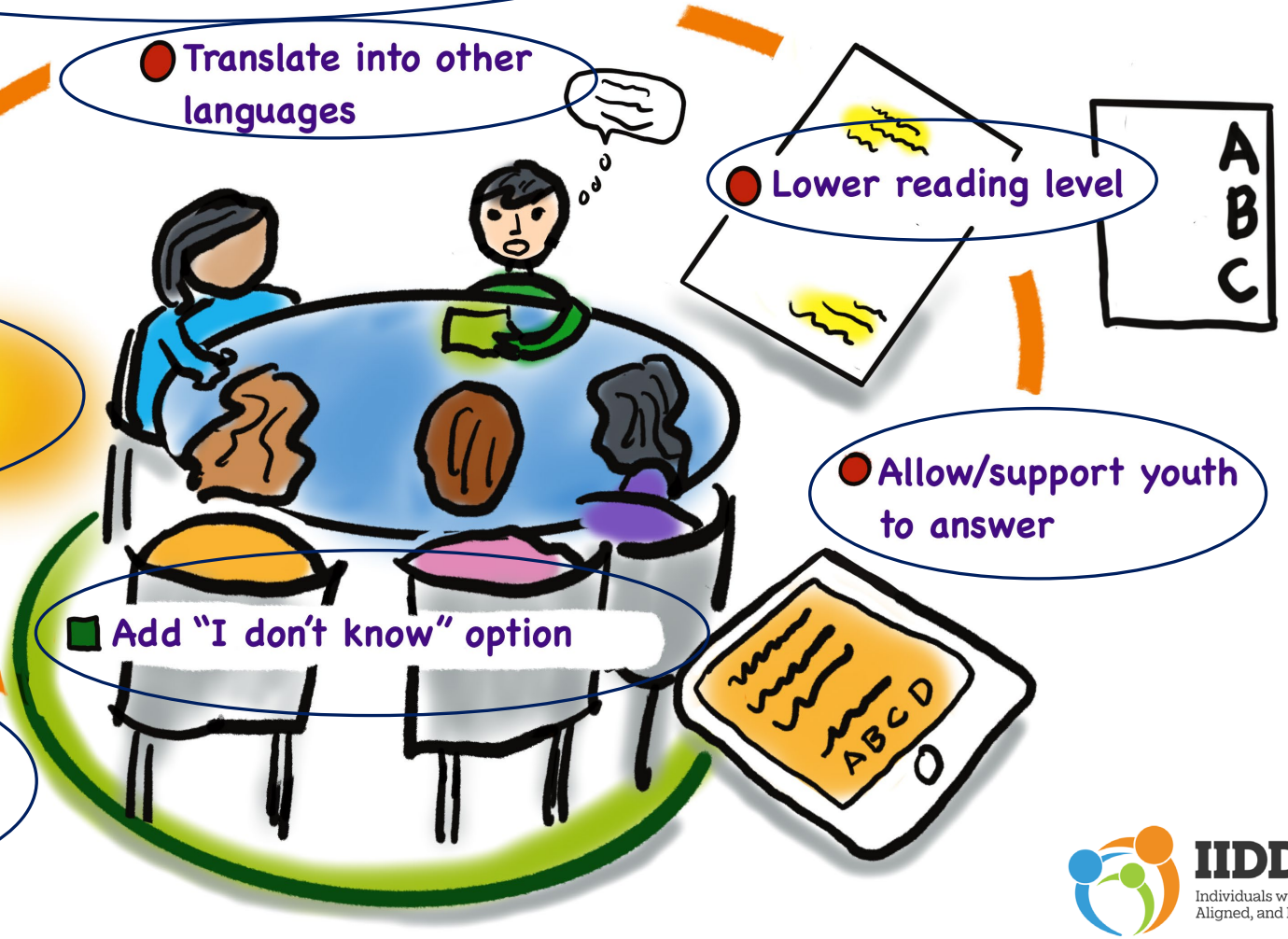
Recommended

Children with Special Healthcare Needs (CSHCN) who receive services needed for transition to adult Healthcare

Improving physical Health, reduced pain, And improved energy

Supported and Shared Decision-Making



CHANGES

- Small Changes
- Medium Changes
- Big Changes

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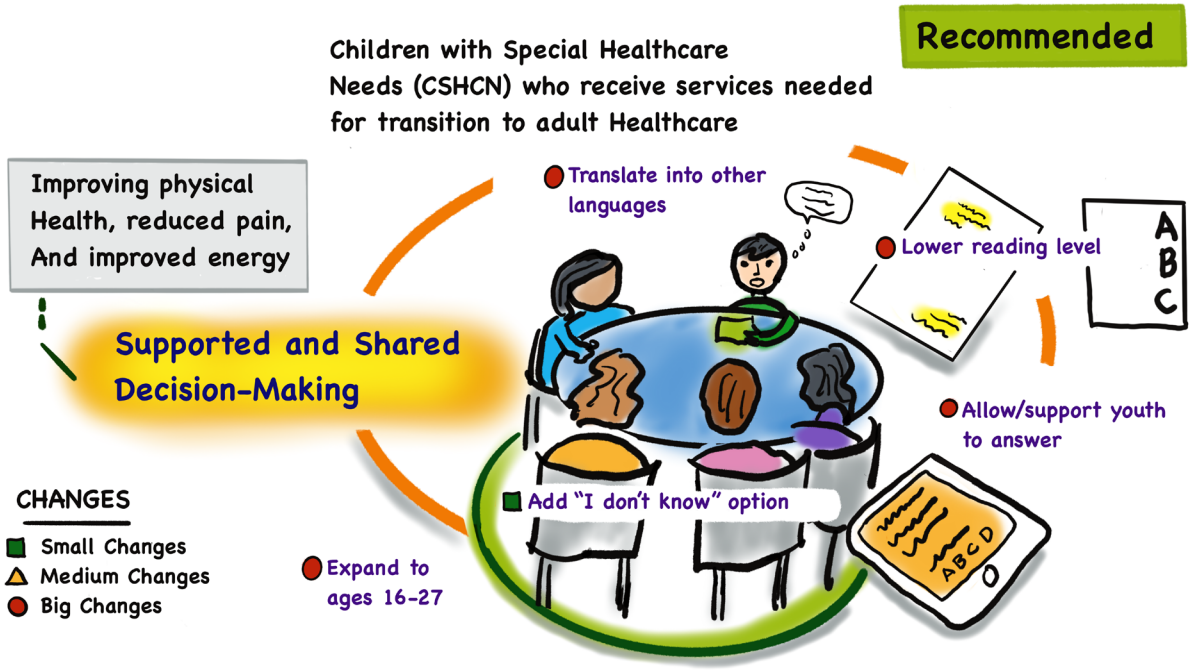

Pros:

- Addresses an important life stage and focuses on children with IDD.
- Designed for use with care givers/partners.
- Highly relevant to supported and shared decision-making.

Cons:

- No option for youth to respond directly (with or without support).
- The age range of 12-17 is too narrow.
- Questions do not reflect the quality of decision-making.
- Questions only have yes/no response options.
- Respondents may not understand what "coverage" means in some questions.
- Reading level is too high.

Recommended Uses:

- Quality improvement.
- Accountability at the system level.

Key considerations:

- This measure used in combination with the ADAPT measure would give a fuller picture of youth transitions.
- The many big changes recommended by IIDDEAL partners would result in a very different measure.
- Clinical groups need to be educated about the harmfulness of making assumptions about a person's "mental age" when planning transitions.

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NAME of the MEASURE:	Children With Special Healthcare Needs (CSHCN) Who Receive Services Needed for Transition to Adult Healthcare
Goal:	Improve physical health, reduce pain and improve energy
How to achieve this:	Supported and shared decision-making
Why this matters:	Many young people lose services when they become adults
Why people liked this measure:	• Addresses an important life stage and focuses on children with IDD. • Designed for use with caregivers/partners. • Highly relevant to supported and shared decision-making.
Specific changes recommended to improve the measure:	• Expand eligibility population to youth 16-26 years old. • Translate into other common languages besides English. • Lower the reading level to 5th or 6th grade. • Create an option for youth to respond directly. • Add an “I don’t’ know” response option to all questions

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Keep as back-up

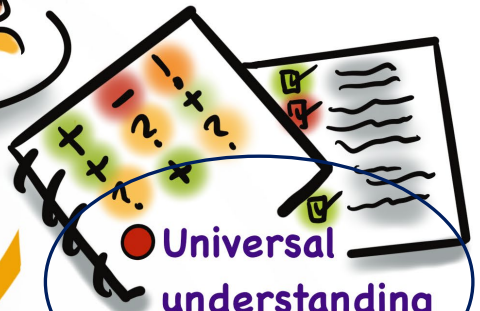
Advanced Care Plan

Family Caregiver/ partner Wellness and Support

Expand to "young adults and older"

Need thorough long-term care planning, starting at age 14, to address multiple areas of need

Long-term planning



Universal understanding of ACP

Need to include plans for whole life care: legal guardianship, SSI application, Medicaid state agency eligibility

CHANGES

- Small Changes
- Medium Changes
- Big Changes

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Pros:

- The measure calls attention to a first step to identify gaps in support.
- A plan is better than no plan.
- The intentionality behind this seems right. The measure prepares families to reduce negative outcomes.
- The measure helps clinical groups and payers to identify who does not have advanced planning and support them.

Cons:

- Starting at age 66 is not "long-term planning" in any meaningful sense for people with IDD.
- The measure is too narrowly focused on medical care and end of life issues. It does not address advance planning for other needs such as housing or daily supports.
- The measure does not assess the quality of advance care plans and what they include.
- A good advance care plan should take a person's health status into account.
- The measure does not reflect whether for care givers/partners would receive support in the advance care plan.

Recommended Uses:

- Quality improvement.

Key considerations:

- People with IDD need to begin advance care planning much earlier in life. Their primary care givers/partners are often their parents, who often die before the person with IDD does. That creates large gaps in their support system that need to be addressed ahead of time.
- Advance care planning for people with IDD also needs to consider the deep grief that often comes from losing a long-term care giver/partner such as a parent.

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NAME of the MEASURE:	Advanced Care Plan
Goal:	Family Caregiver/Partner Wellness and Support
How to achieve this:	Long-term planning
Why this matters:	Many caregivers of people with IDD need help planning for a future time when they are dead.
Why people liked this measure:	• The measure calls attention to a first step to identify gaps in support. • A plan is better than no plan. • The intentionality behind this seems right. The measure prepares families to reduce negative outcomes. • This measure may help healthcare groups and insurance providers find people who do not have an advance care plan and may help them get the support they need.
Specific changes recommended to improve the measure:	• Expand the age range to include people ages 14 and older, and update advance care plans at least every two years. • Define advance care planning to include plans for all parts of life, such as housing, guardianship, disability benefits, and health insurance.

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Learn more about IIDDEAL's Health Outcome Domains and Priority Elements

1. Engagement to Identify Health Priorities of People With Intellectual and/or Developmental Disability: https://journals.sagepub.com/doi/10.1177/15394492251385448
   - Supplementary material: sj-docx-1-otj-10.1177_15394492251385448.docx
2. Advancing Health Policy and Outcomes for People With Intellectual or Developmental Disabilities: A Community-Led Agenda: https://jamanetwork.com/journals/jama-health-forum/fullarticle/2821686
3. Diverse perspectives on supporting the health and wellness of people with intellectual and developmental disabilities: https://pubmed.ncbi.nlm.nih.gov/39818503/

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Learn more about quality measures

1. Download the IIDDEAL Quality Measure Basics guide: https://www.ie-care.org/wp-content/uploads/2026/01/Quality-Measure-Basics_IIDDEAL_Accessibility-check.pdf

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