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IIDDEAL
Individuals with IDD Engaged, Aligned, and Leading

Recommendations for Quality Measures To Promote Outcomes That Matter for People With Intellectual And/or Developmental Disabilities

PHASE 3 REPORT | MAY 2026

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INDIVIDUALS WITH IDD ENGAGED, ALIGNED, AND LEADING (IIDDEAL) PHASE 3: RECOMMENDATIONS FOR QUALITY MEASURES TO PROMOTE OUTCOMES THAT MATTER FOR PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

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EXECUTIVE SUMMARY

Individuals with IDD Engaged, Aligned, and Leading (IIDDEAL) is a national, multi-phase initiative to build consensus on ways to measure and promote the health outcomes that matter most to people with intellectual and/or developmental disabilities (IDD).

The first two phases of IIDDEAL identified 9 priority health outcome domains and 29 priority healthcare elements that support those outcomes. Phase 3 of IIDDEAL engaged 38 partners to identify, review, and recommend existing quality measures that align with IIDDEAL priority domains and elements. Phase 3 also considered strategies for addressing many gaps where no current measures align.

IIDDEAL partners recommend that clinical organizations, payers, regulators, policymakers, and researchers begin using the following 12 quality measures. While IIDDEAL partners identified many modifications that would improve the measures, they consider it important to begin looking at data about people with IDD using these measures now. All 12 have been endorsed by reputable organizations and used in major public- and private sector quality improvement, reporting, and payment programs.

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

However, IIDDEAL partners identified shortcomings in many of the measures when applied to people with IDD. However, IIDDEAL partners identified shortcomings in many of the measures when applied to people with IDD. For example, many patient-reported

instruments are written at a reading level that may be too advanced for this population. Understanding why small, medium, or big changes to these measures are important helps those using them to design programs that better support patients with IDD.

Gaps persist for most priority elements in IIDDEAL where no current quality measures align well. IIDDEAL partners recognize that many gaps may be best addressed through policy advocacy, and/or by creating quality standards for clinical providers and health plans. Other gaps, especially those relating to symptoms and function (for example, quality of sleep, level of energy), could be addressed with existing patient-reported outcome measures. Lastly, some gaps may require modifying existing quality measures and/or developing new quality measures, which will take more time and resources.

Quality measure developers and researchers should consider changing their approaches to improve the chances that measures are appropriate for as many people as possible. Specifically:

- ***Quality measures need to consider the communication preferences and needs of people with IDD***. Surveys and patient-reported measures should be written at the fifth or sixth grade reading level, with visual cues such as icons to help people understand and respond. They should also allow a support person to help the person with IDD to respond and/or serve as a proxy.
- ***Many quality measures explicitly exclude people with IDD***. This is an especially serious problem for measures that focus on healthcare issues of particular importance to, or that pose greater risks for, people with IDD, such as antipsychotic medications, mental health, sexual/reproductive/gender health, safety issues, and respectful shared decision-making.
- ***Researchers should include people with IDD in clinical research studies***. Some quality measures that exclude people with IDD sometimes do so because they rely on data from research studies that did not include people with IDD. For example, research on the use of psychosocial therapy or anti-psychotic medications that exclude people with IDD make it difficult to build quality measures on those topics that can include people with IDD.

Healthcare leaders should begin looking at quality measure data that is separated for people with IDD vs. people without IDD. This is important to do even before we have perfect measures. This is a critical first step in drawing attention from clinicians, payers, and regulators to the needs of people with IDD, and building programs and policies to help them achieve the outcomes that matter most.

BACKGROUND

History of IIDDEAL Phases 1 and 2

Individuals with IDD Engaged, Aligned, and Leading (IIDDEAL) is a long-term project. It aims to build agreement on how to measure the quality of healthcare that people with intellectual and/or developmental disabilities (IDD) receive. Using a consensus approach to measurement can help clinicians, insurers, researchers, and policymakers support people with IDD to achieve the health and life goals that are most important to them.

IIDDEAL is coordinated by Augusta University, Institute for Exceptional Care (IEC), the National Committee on Quality Assurance (NCQA), and Brandeis University.

In Phases 1 and 2 of IIDDEAL, we learned what good health and bad health mean to people with IDD. First, we spoke with individual adults with IDD. Then we had different group conversations with people with IDD, family members, clinicians, and payers and regulators. The groups identified nine priority Outcome Domains, and over 80 Elements in healthcare that support the Outcome Domains. Finally, these partners selected a Consensus Working Group that met several times to come to agreement on the most important 29 Elements to measure. (**Table 1**) For more information on Phases 1 and 2, see Benevides et al., and Nicholson et al.

We held two Policy Summits with leaders of state and federal agencies for Medicaid, Medicare, and home-and-community-based services (HCBS), insurance leaders, and clinical leaders. Summit participants gave feedback on the opportunities and barriers for promoting priority health Outcome Domains and Elements. This feedback led to an article, co-authored by many IIDDEAL contributors, that sets out bold national goals to promote priorities identified in IIDDEAL, and strategies to achieve them by 2030.

Table 1. IIDDEAL Outcome Domains and Priority Healthcare Elements

Domain	**Priority Elements**
Making Healthy Choices	• Provider checks with me about my goals and supports decision making • Peer supports and education across lifespan • Access to dental and vision care across the lifespan

Physical Health, Reduced Pain, Improved Energy	• Care coordination • Supported or shared decision-making • Understanding and measuring pain and energy through each person's form of communication
Emotional and Mental Health	• Self-advocacy/self-determination and accommodations • Referral to counselor who knows about IDD • Adapted and tailored mental health interventions • Trauma informed care
Sexual, Gender, Reproductive Health & Parenting	• Access to sexual/reproductive healthcare • Parenting classes – relevant, appropriate to parents with IDD • Connecting people with IDD experiencing sexual assault with mental health resources
Doing the Things I Love and Need to Do	• Person-centeredness & presuming ability • Resources to live somewhere safe & accessible • Help clinicians address social drivers of health
Family Care Giver/Partner Wellness & Support	• Long-term planning • Respite care services • Resources for caregivers/partners
Healthcare Workforce Development	• Teach all clinicians life-course development of people with IDD • Train clinicians with standardized patients, simulated scenarios, and practical tools to work with people with IDD • Require clinical exposure to people with IDD • Include IDD elements in accreditation requirements
System Supports	• Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs • Continuity of services, co-location of services as a solution, navigation supports between sectors (e.g., community services and healthcare) • Increased payment for providers to spend sufficient time with people in care settings
Payer & Regulator Needs	• Metrics for the health outcomes that matter • Innovative tools, models of care, data, & technology • Data on value of different services

Goals of Phase 3

Phase 3 of IIDDEAL began in July 2024 and finished in December 2025. The goals of this phase were to:

1. Identify existing quality measures that could align to each of the 29 priority Elements identified in Phases 1 and 2.
2. Review each candidate quality measure and recommend those that are most relevant for and inclusive of, people with IDD.
3. Review gaps where no current quality measures align to an IIDDEAL Element and identify potential strategies for filling those gaps.
4. Finalize recommendations on a set of key quality measures that are most important to adopt as soon as possible, how they should be used, and on next steps for filling in measure gaps.
5. Begin engaging state and federal leaders, payer leaders, clinical leaders, and disability leaders to promote adoption of recommended measures and investment in filling measure gaps.

Engagement Approach

IIDDEAL places people with IDD at the center of its work. In each phase, adults with IDD and family members who support adults and/or children with IDD contribute key perspectives that drive the group's decision-making.

Over 18 months, we met regularly with three teams comprised of people with IDD, care partners/givers, clinicians, national clinical leaders, payers, policy leaders, IDD researchers, and quality measure experts:

- Monthly meetings with the IIDDEAL Core Team comprised of eight members representing diverse perspectives. Most Core Team members had dual identities (for example, a clinician who was also a family member supporting someone with IDD).
- Quarterly meetings with the IIDDEAL Advisory Council comprised of 13 similarly diverse members.
- Five prep meetings and an all-day in-person meeting with the Consensus Working Group (CWG). CWG members were nominated and selected by the Core Team and Advisory Council. Twenty-six CWG members included IDD self-advocates, family members, clinicians treating patients, national clinical leaders, policy leaders, payers, IDD researchers, and quality measurement experts.

To ensure a collaborative and supportive setting for discussion and decisions, IIDDEAL applied IEC's principles on authentic engagement, and adheres to the engagement guide created by the AASET project and refined by IIDDEAL participants.

In practice, this approach included:

- Paying IDD self-advocates and family members for their time and input.
- Sharing pre-meeting videos and offering Office Hours to help people prepare for meetings.
- Partnering with Tim Corey of Colibri Facilitation to draw illustrations during meetings and to summarize decisions after meetings.
- Using Plain Language, welcoming different communication preferences, and giving people plenty of time to ask questions, form their thoughts, and share them.
- Setting group norms for each meeting to set rules for respectful discussion.
- Using only people's first names, and valuing all kinds of expertise, including professional knowledge and lived experience.
- Setting a process for voting and building consensus. The voting approach included options for people to express a range of opinions and feel respected and safe in disagreeing. If any partner chose the last option, the group continued discussions until they came to consensus.
    - I like this option and want to move forward.
    - I don't like this option but am fine with moving forward if others like it.
    - I don't have a strong opinion about this option and am fine moving forward if others like it.
    - I don't like this option and am not comfortable moving forward with it. Can we discuss it further?

Building consensus often requires multiple cycles of discussion. Typically, the Advisory Council weighed in on a given measure first, followed by Core Team and then Consensus Working Group. However, we held several follow-up discussions to share feedback from one group with the others, especially when there were differences of opinion across the groups. This allowed us to get more refined insights from each group, and for iterative review.

PHASE 3 METHODS

Understanding Quality Measures

There are many ways to measure quality. We make the distinction between:

- Quality measures that can be used to compare how well different parts of the healthcare system perform in supporting patients. These measures have usually been reviewed ("endorsed") by a respected national organization. They have also been tested to make sure that comparisons of performance are fair.
- Outcome measures that reflect health results for a given patient or population. Some outcome measures can support comparisons of performance.
- Patient-reported outcome measures (PROMs) that use data provided by patients (with or without help from others). These measures are especially important because they focus on patients' experience and perspectives. Some PROMs can support comparisons of performance and could also considered quality measures.

In IIDDEAL Phase 3, we prioritized quality measures because our focus was on tools to use in holding healthcare professionals and groups accountable for providing good healthcare to people with IDD. However, in future phases of IIDDEAL, we plan to address which outcome measures and PROMs could also align with IIDDEAL priorities, especially for the many gap areas where we could not find existing quality measures that align.

Measuring quality of care can be technical and complicated. To support clear decision-making, we created the Quality Measures Basics presentation and reviewed it at the first meeting with each group of partners. Quality Measures Basics uses analogies to food and restaurants to explain the role of quality measures in improving healthcare, their building blocks, what makes a quality measure strong or weak, and how they are used in clinical or payment programs.

Process for Selecting Quality Measures

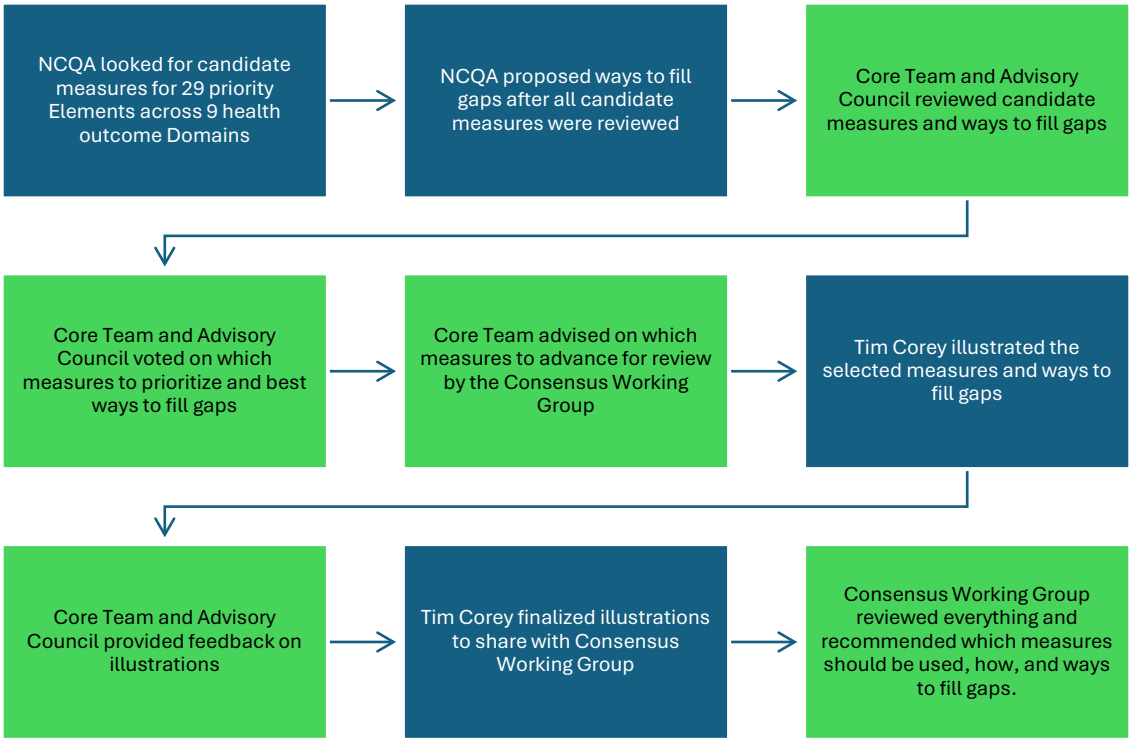


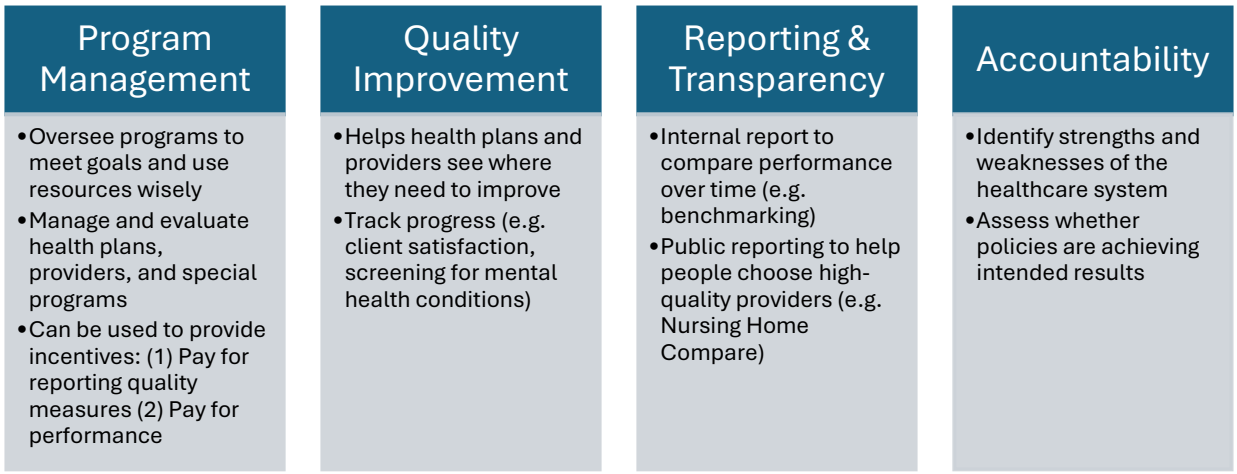
Figure 1: Process for Selecting Quality Measures to Recommend

- Experts from the National Committee on Quality Assurance (NCQA) searched public and private sources such as the National Quality Forum, Partnership for Quality Measurement (PQM) Battelle, health plan accreditation organizations, Centers for Medicare & Medicaid Services (CMS) reporting programs and CMS measures under consideration (MUC) list, Agency for Healthcare Research and Quality (AHRQ), Human Services Research Institute (HRSI), Centers for Disease Control and Prevention (CDC), as well as measure by academic institutions, national initiatives, and state reporting programs to find quality measures related to the 9 outcome domains and 29 healthcare elements prioritized in IIDDEAL. This search identified **71 measures**.
- NCQA then excluded **52 measures** that had not been endorsed by a national organization, were not used in current quality improvement or payment programs, or that did not closely align with IIDDEAL elements. This resulted in NCQA recommending **22 measures** to progress for the Core Team and Advisory Council to review.

- The Core Team and Advisory Council discussed each of the 22 measures. They considered issues such as whether the measure (1) could apply to people with IDD across the lifespan; (2) was inclusive of people with IDD; (3) used respectful language; and (4) could be adapted to be more appropriate for people with IDD. Core Team and Advisory Council dropped some measures because they explicitly excluded people with IDD or reflected outdated assumptions about people with IDD (such as that people with IDD are not parents). These discussions resulted in lists of "pros" and "cons" for each measure.
- The Core Team and Advisory Council also identified ways that each measure should be adapted to be more appropriate for people with IDD. For example, a measure on rates of screening for suicide risk should not be limited to people who have a diagnosis of depression, because many people with IDD can feel suicidal without having a diagnosis of depression. Based on these discussions, Core Team and Advisory Council recommended that **19 measures** progress for the Consensus Working Group to review.
- NCQA assessed whether proposed changes to a given measure would be "minor," "medium," or "major" changes.
    - A small change would be expected to take less than a year and minimal cost. Small changes would not affect how the measure is defined.
    - A medium change would be expected to take 1-2 years and moderate cost. Medium changes could affect some data collected by using the measure or slightly change the population targeted by the measure.
    - A big change would be expected to take several years and be expensive. Big changes could affect how the measure is defined, how data for the measure is collected and compared across providers, and/or big changes in the population targeted by the measure.
- The CWG discussed each of the 19 measures. They considered the same factors that the Core Team and Advisory Council had. However, the CWG also considered which measures were: (1) likely to be relevant for the largest number of people with IDD; (2) addressed the largest number of IIDDEAL domains and elements; (3) easiest to collect valid data for; and (4) could be adopted with the fewest major changes. This resulted in CWG's final recommendation of **12 quality measures** for healthcare groups to prioritize in the short term.
- **Appendix A** lists the 71 measures identified by NCQA and which measures were not prioritized by the Advisory Council, Core Team, and CWG.
- The CWG also discussed how each of the 12 quality measures should be used by healthcare groups now. They considered (1) how commonly the measure has already been used with people with IDD so that data are already available; (2) how

much is known about how scores on the measure would vary across healthcare professionals and groups; (3) how difficult it would be to collect data for the measure on an ongoing basis; and (4) how much education healthcare users would need about IDD and the measure to effectively use it. **Figure 2** summarizes the main ways to use quality measures considered by the CWG.

- At the all-day Summit in November 2025, the CWG reviewed each of the 12 recommended measures, and voted on four measures to prioritize for promotion and early adoption.



Process for Building Recommendations on How to Fill Measure Gaps

Many gaps remained where no current quality measures aligned well with domains and elements in IIDDEAL. This happened for several reasons:

- **Of the quality measures identified many were survey-based measures.** Of the 22 measures reviewed, 11 required the collection of a survey, assessment or a PROM. Several of these surveys are lengthy (60+ questions) that require significant time to respond to. These place a high burden on both the person receiving care as well as an administrative burden on the providers collecting the data.
- **Very few quality measures identified were designed for and tested on the IDD population.** NCQA identified only two quality measure sets that were developed and tested with individuals with IDD. Both quality measure sets were based on surveys: 1) National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD) and 2) Consumer Assessment of Healthcare Providers and Systems Home and Community-Based (HCBS CAHPS®).

- Some elements are **difficult to capture in a quality measure**. For example, the Element of "Increased payment for providers to spend sufficient time with people in care settings" in the Domain of System Supports can be measured by tracking whether and how much government programs and private payers pay extra for clinical teams to spend time with patients with IDD. However, a quality measure cannot reflect this concept.
- Some elements **reflect concepts that are new** and less familiar to healthcare leaders. This results in less attention being paid to creating quality measures to capture them. For example, the element of "Understanding and measuring pain and energy through each person's form of communication" in the Domain of Physical Health, Reduced Pain, and Improved Energy is different from how clinicians usually assess pain. Little research has been done on how to reliably and validly capture an individual patient's way of expressing pain, such as through changes in body movements or the sounds that a person makes.
- Some elements **reflect the need for entire programs or policies to change**, rather than changing the behaviors of individual clinicians or clinical groups. For example, the element of "Teach all clinicians life-course development of people with IDD," in the Domain of Healthcare Workforce Development, requires that medical and nursing schools and hospital training programs change how they teach about IDD. Such changes can be tracked with surveys of training programs, but not with quality measures.
- Some elements could be reflected by quality measures, **but existing measures are not appropriate to use with people with IDD** or would need to undergo major changes. For example, quality measures do exist that reflect the element of "Long Term Planning" in the Domain of Family Care Giver/Partner Wellness & Support. But those measures currently focus on patients nearing the end of life, or the elderly. This excludes the large need for long-term planning for people with IDD to begin much earlier in life, such as in early adulthood. This is because parents often serve as the primary care givers/partners for people with IDD, and long-term planning needs to begin years before parents pass away.

It is also important to note that **gaps can exist even when Phase 3 partners recommended an aligned quality measure for that element**. That reflects partners' sense that the available quality measure does not fully capture the concept in the element. For example, Phase 3 partners recommended a measure on post-partum health risk screening to address the element of "Access to Sexual/Reproductive Healthcare," but noted that a basic part of the element's concept is that clinicians assume all persons with IDD may want and can have a sexual life and/or have children, not just offer reproductive

services to people once they become pregnant. Thus, there remains a gap for a measure to capture whether clinicians address sexual/reproductive health for all patients with IDD.

NCQA developed initial suggestions of strategies to fill gaps. These strategies fell into five categories, each with pros and cons. (**Table 2**)

Table 2. Strategies for Addressing Measure Gaps

Gap-Filling Strategy	**Pros**	**Cons**
Create new quality measures	• Can ensure that an Element's concept is fully captured • Ensures the measure is appropriate for and includes people with IDD • Could lead to a "report card" on care for people with IDD	• Expensive • Will take years to finish • Providers and health plans think there are already too many quality measures
Adapt existing quality measures	• Ensures the measure is appropriate for and includes people with IDD • Many quality measures are already in use for payment and public reporting • Does not expand the number of quality measures • Not starting from scratch since this phase of IIDDEAL has identified what needs to change • Could take less time than creating new measures • Could lead to a "report card" on care for people with IDD	• Can be expensive • Can take years to finish • Measure stewards that "own" a given measure may not be willing to make changes
Target clinicians and clinical groups with practice standards	• Direct influence on clinical activity across multiple IIDDEAL Domains and Elements	• Could be as burdensome for clinicians as reporting quality measures • Will take time to implement

	• Can address many Domains and Elements in IIDDEAL • Can leverage other existing resources such as training pathways developed by IEC and other groups • Could happen in a phased approach (for example, start with training requirements, then include standards for how practices should be set up)	• Providers may need incentives or regulations to adopt standards
Set quality standards for health plans	• Potential for large-scale, national change • Could be less burdensome than collecting data for quality measures	• Health plans will push some or much of the reporting burden to clinical groups • Not all people with IDD have health insurance • Standards that don't address access challenges will have less impact • Will take time to implement • Health plans may need incentives or regulations to adopt standards • Need more research on what leads to better outcomes for people with IDD
Advocate for changes in federal or state policies	• Potential for large-scale change • Successful states could be role models and add to peer pressure for other states to act • States have huge influence on Medicaid and HCBS services	• Requires time, resources, and allies • Policies that vary from state to state can make it harder for health plans to comply • May create inequity across states

NCQA created a mapping of which strategies might be most suited for filling each gap. **Appendix B**. Using a process like the one for selecting measures to recommend, The Advisory Council, Core Team, and CWG discussed ways to fill each gap and additional pros and cons of different approaches.

At an all-day Summit in November 2025, the CWG voted on which gaps to prioritize for promoting solutions. However, partners did not make final recommendations on specific strategies to fill gaps because of the large number of gaps, and because availability of funding will also influence the choice of strategies to fill gaps. Addressing gaps will continue in future phases of IIDDEAL.

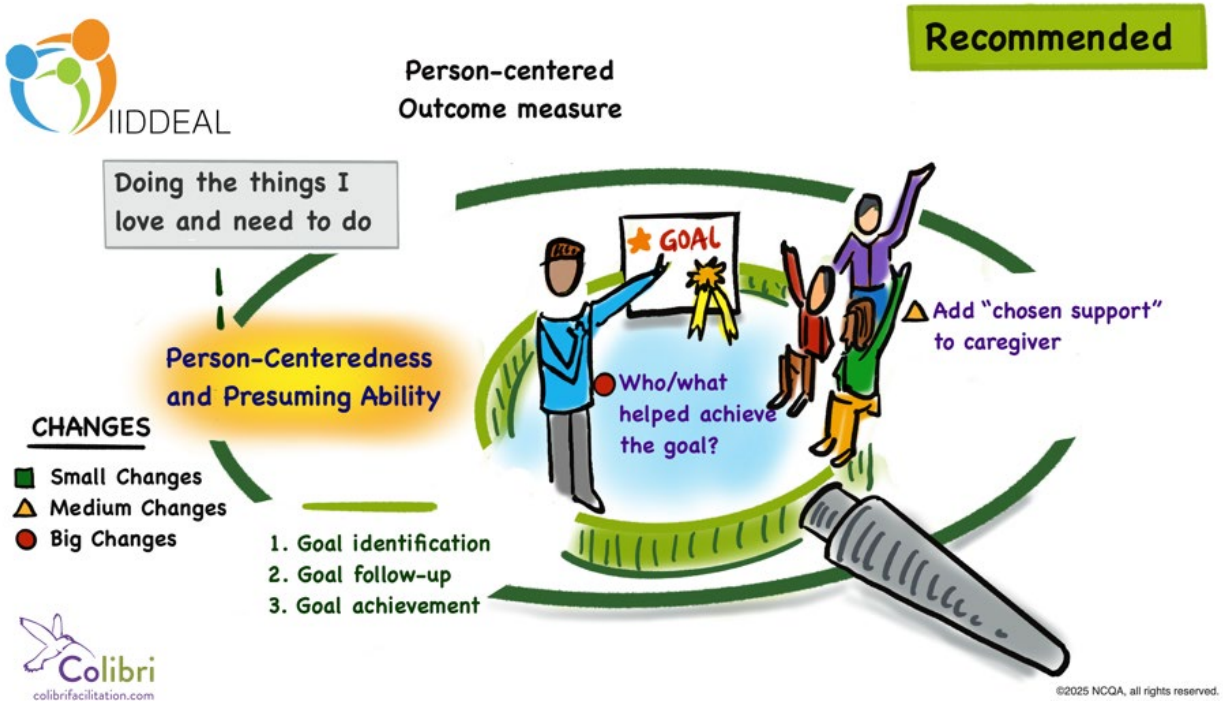
QUALITY MEASURE RECOMMENDATIONS

This section details the 12 quality measures recommended by the CWG, including:

- An illustration of the measure.
- How the measure is defined.
- A link to specifications for the measure.
- Which IIDDEAL Domains and Elements the measure addresses.
- The measure's pros and cons.
- How, if at all, the measure should be adapted for people with IDD, and whether these are small, medium, or big changes.
- How the CWG recommends the measure be used.
- Key considerations in using the measure.

The quality measures are ordered with highest priority measures first, and lowest priority measures last.

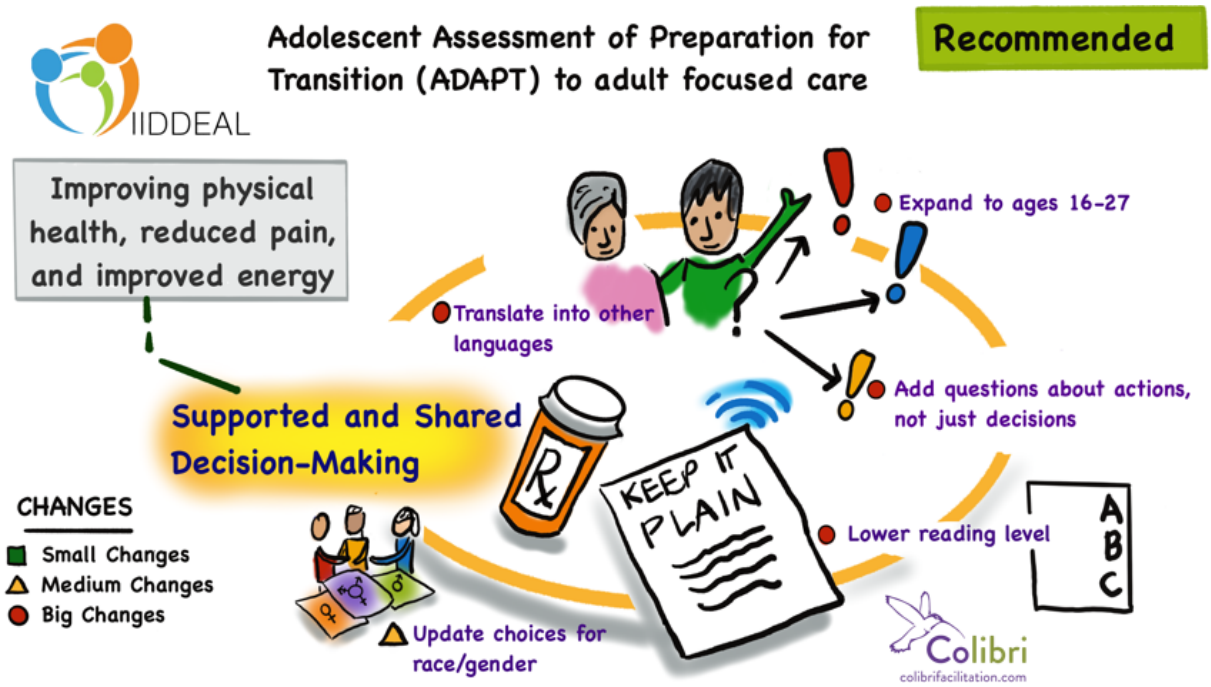
Person-Centered Outcome Measure



- **Definition**: A three-part measure that documents (1) a specific 3- to 6-month goal identified by the patient; (2) progress during the follow-up period measured on a 5-point scale; and (3) whether the goal was achieved.
- **Specifications**: https://www.ncqa.org/hedis/reports-and-research/pco-measures/
- **IIDDEAL Domains**:
    - Doing the Things I Love and Need to Do
    - Making Healthy Choices
    - Physical Health, Reducing Pain and Increasing Energy
    - System Supports
    - Payer and Regulator Priorities
- **IIDDEAL Elements**:
    - Person-centeredness and presuming ability
    - Provider checks with me about my goals and supports decision making
    - Supported or shared decision-making (in partnership with the person with IDD and their caregivers. Some people with IDD may not be able to express their preferences and may rely more on caregivers to communicate on their behalf.)
    - Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs
    - Metrics for health outcomes that matter

- **Pros:**
    - Can be applied across all IIDDEAL Domains depending on the individual's goal (i.e. an individual's goal related to mental health care could fit under the domain improving my emotional or mental health).
    - 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.
- **Medium change**: Add "chosen support" when mentioning caregivers.
- **Big change**: Add information on who or what helped the patient achieve their goal.
- **Recommended Uses:**
    - Program management but not linked to incentives.
    - Quality improvement.
    - Public or private quality reporting.
- **Key considerations:**
    - ***The CWG 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.

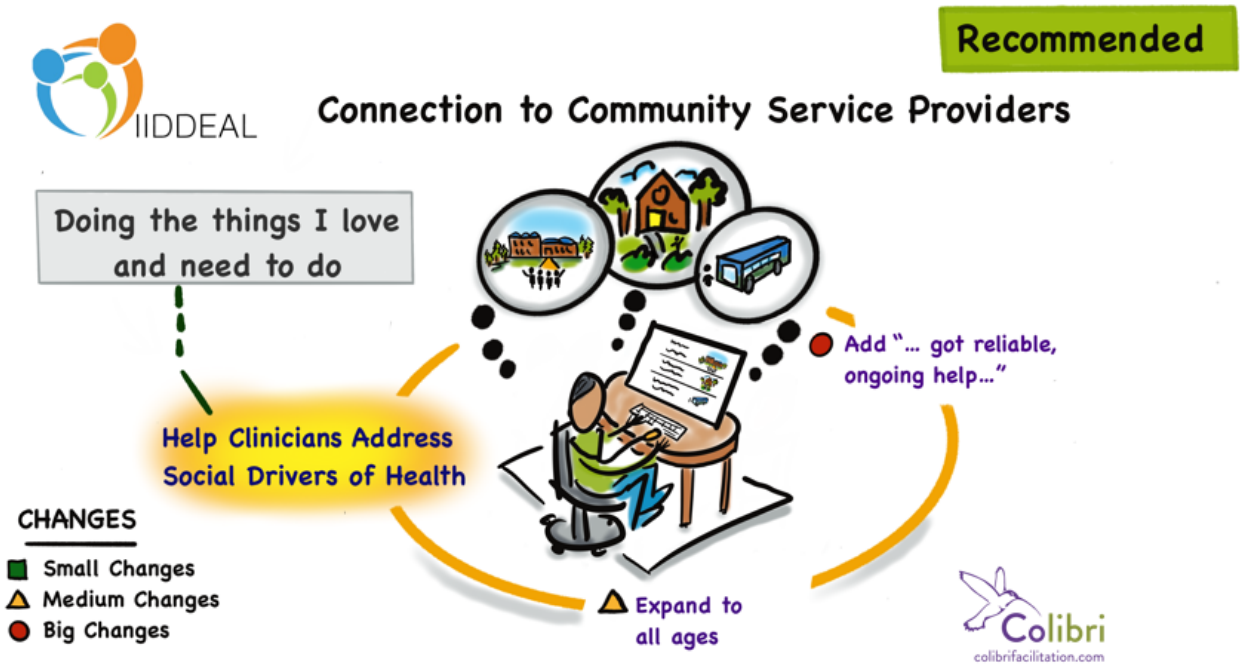
Adolescent Assessment of Preparation for Transition (ADAPT) to Adult Focused Care



- **Definition**: How well youth ages 16-17 years old with a chronic health condition were prepared to move to providers who mostly treat adults. The ADAPT survey has measures for 4 areas:
    - Counseling on Transition
    - Self-Management
    - Counseling on Prescription Medication
    - Transfer Planning
- **Specifications**: https://p4qm.org/measures/2789
- **IIDDEAL Domain**: Improving Physical Health, Reduced Pain, Increased Energy
- **IIDDEAL Element**: Supported and shared decision-making (in partnership with the person with IDD and their caregivers. Some people with IDD may not be able to express their preferences and may rely more on caregivers to communicate on their behalf.)
- **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).
    - The survey's reading level (~8th grade) is too high. One IIDDEAL partner commented that most youth with IDD would need support to answer the questions.
- **Small change**: Update response options on race/ethnicity and gender to include more categories.
- **Big changes**:
    - Lower reading level to 5th or 6th grade.
    - Expand the eligible population to ages 16-26. This reflects updated best clinical practice of starting transition planning at a younger age, and that many youth can remain on their parents' health insurance until age 26.
    - Add more questions about youth taking action to prepare for transition.
- **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.

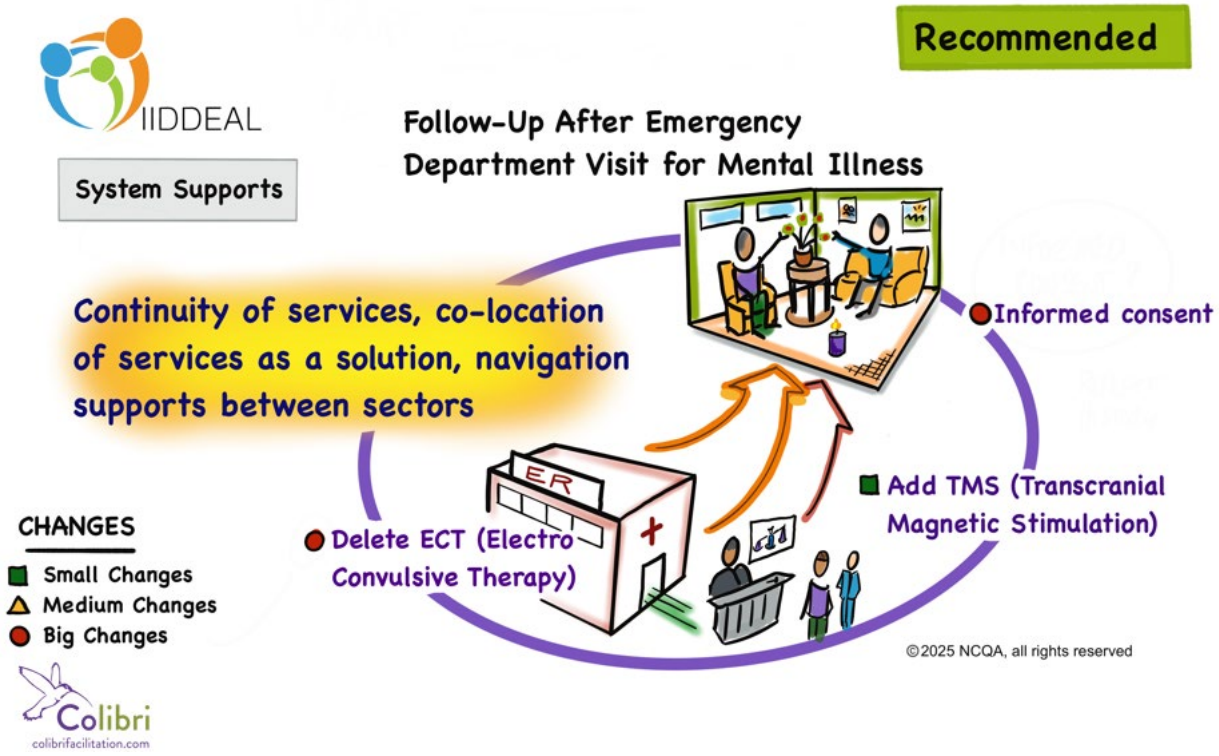
Connection To Community Service Providers



- **Definition**: Percent of adults who have social needs (food, housing, transportation, house utilities, or safety); AND got help for at least one of their needs within 2 months.
- **Specifications**: https://cmit.cms.gov/cmit/#/MeasureView?variantId=11704&sectionNumber=1
- **IIDDEAL Domain**: Doing the Things I Love and Need to Do
- **IIDDEAL Element**: Help clinicians address social drivers of health.
- **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.
- **Medium change**: Expand to people of all ages.
- **Big change**: Change language to "...got reliable, ongoing help..." instead of stopping at 2 months.
- **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.

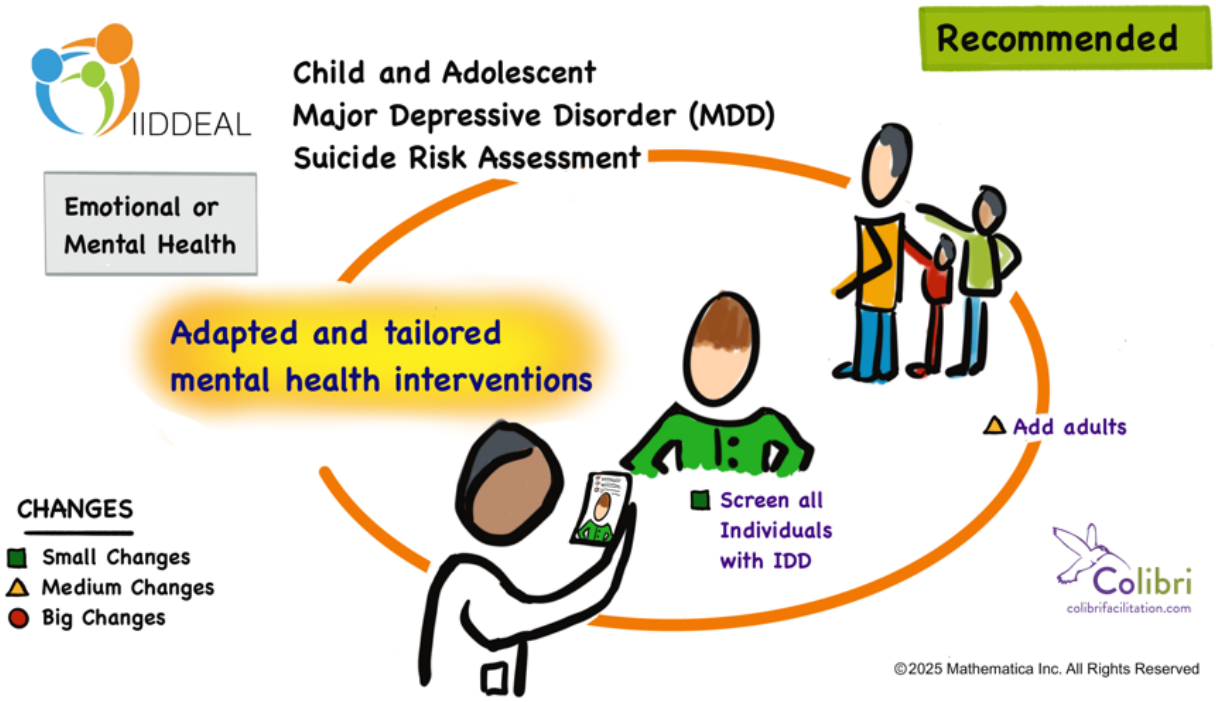
Follow-Up After Emergency Department Visit For Mental Illness



- **Definition**: Annual emergency department (ED) visits for members with a principal diagnosis of mental illness or intentional self-harm.
    - The percentage of ED visits with follow-up within 7 days of the ED visit; and
    - The percentage of ED visits with follow-up within 30 days of the ED visit.
- **Specifications**: https://p4qm.org/measures/3489
- **IIDDEAL Domain**: System Supports
- **IIDDEAL Element**: Continuity of services, co-location of services as a solution, navigation supports between service sectors.
- **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:**
    - 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.
    - Some IIDDEAL partners also recommended including transcranial magnetic stimulation (TMS) as a new 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.

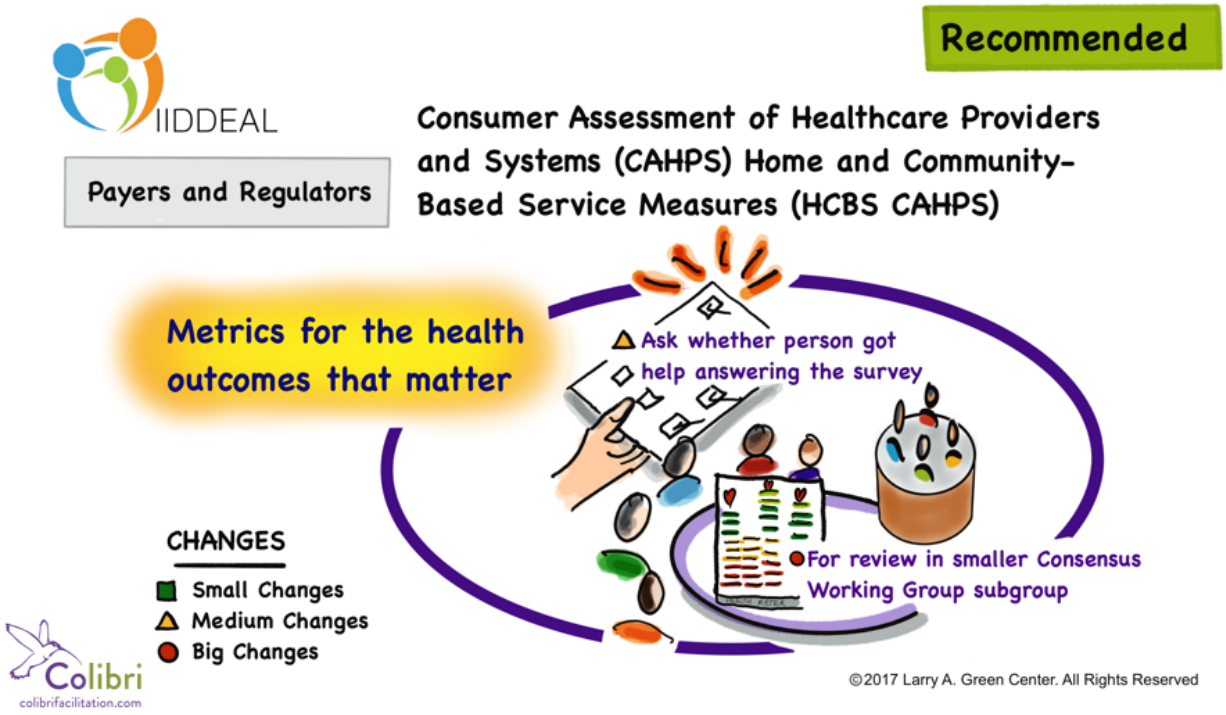
Child and Adolescent Major Depressive Disorder (MDD) Suicide Risk Assessment



- **Definition**: Percentage of patient visits for those patients 6 through 17 years with a diagnosis of major depressive disorder that included assessment for suicide risk. Allows clinicians to decide what suicide assessment tool to use.
- **Specifications**: https://cmit.cms.gov/cmit/#/FamilyView?familyId=122
- **IIDDEAL Domain**: Emotional or Mental Health
- **IIDDEAL Element**: Adapted and tailored mental health interventions.
- **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.
- **Big changes**:
    - Screen all individuals with IDD who can express suicidality (with or without communication support).
- **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.

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



- **Definition**: A 69-item survey that assesses the experiences of adult Medicaid beneficiaries who receive long-term services and supports from state Home and Community Based Services (HCBS) programs. It addresses topics such as:
    - Getting needed services.
    - Communication with providers.
    - Experience with case managers.
    - Choice of services.
    - Access to medical transportation.
    - Personal safety.
    - Community inclusion.
    - Empowerment.
- **Specifications**: https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbscahps-admin-ta-guide.pdf
- **IIDDEAL Domain**: Payer and Regulator Needs
- **IIDDEAL Element**: Metrics for the outcomes that matter.

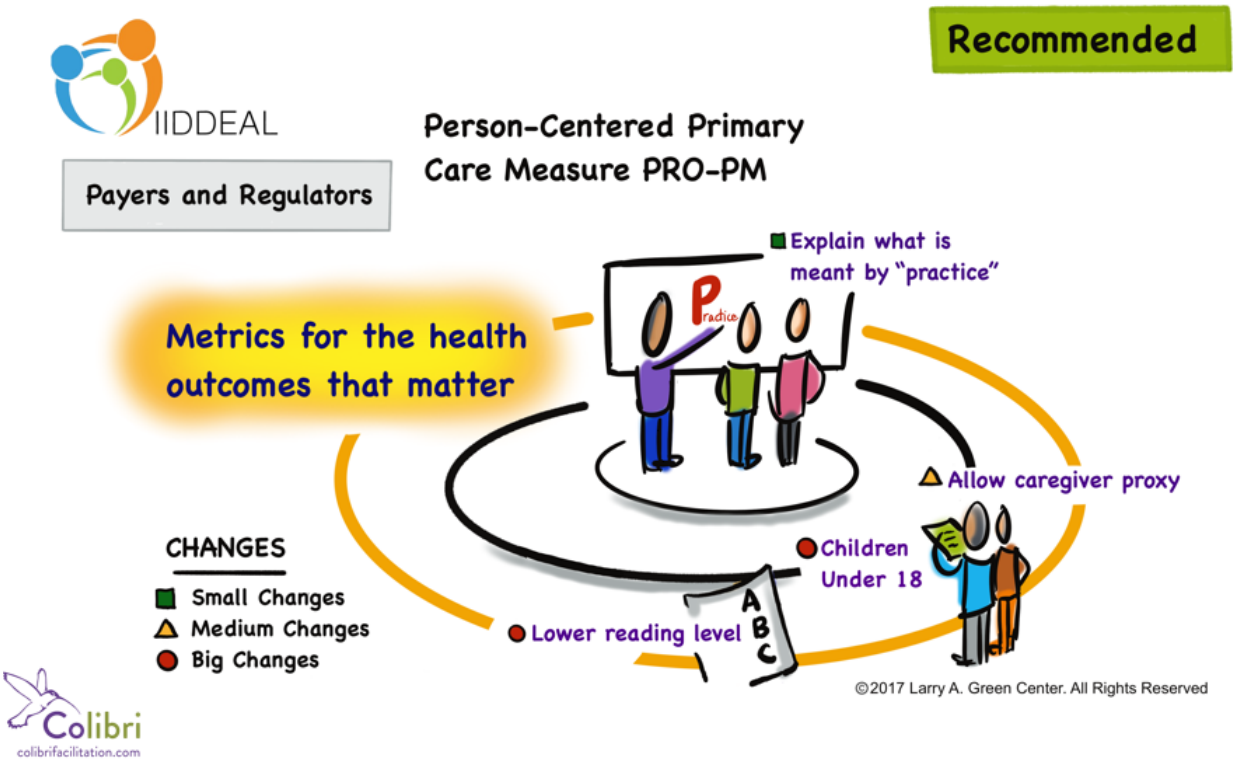
- **Pros:**
    - This measure captures people's experiences with a wide range of issues in home- and community-based services.
    - It is already being used in some states.
    - The survey can be used across population groups and to compare facilities.
    - Data collected using CAHPS can be easily accessed by individual provider groups to look at their own performance.
- **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.
- **Medium Changes:**
    - Create a version that allows a care giver/partner to complete the survey, ONLY if it is absolutely necessary.
    - Add a question about whether a person with IDD got help answering the survey.
- **Big Changes:**
    - Expand the eligible age range to include families with children.
    - Reduce language to 5th or 6th grade reading level.
- **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 requires a small fee to access. Costs to collect the data using the NCI are likely similar to costs for collecting data using CAHPS.

- 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.

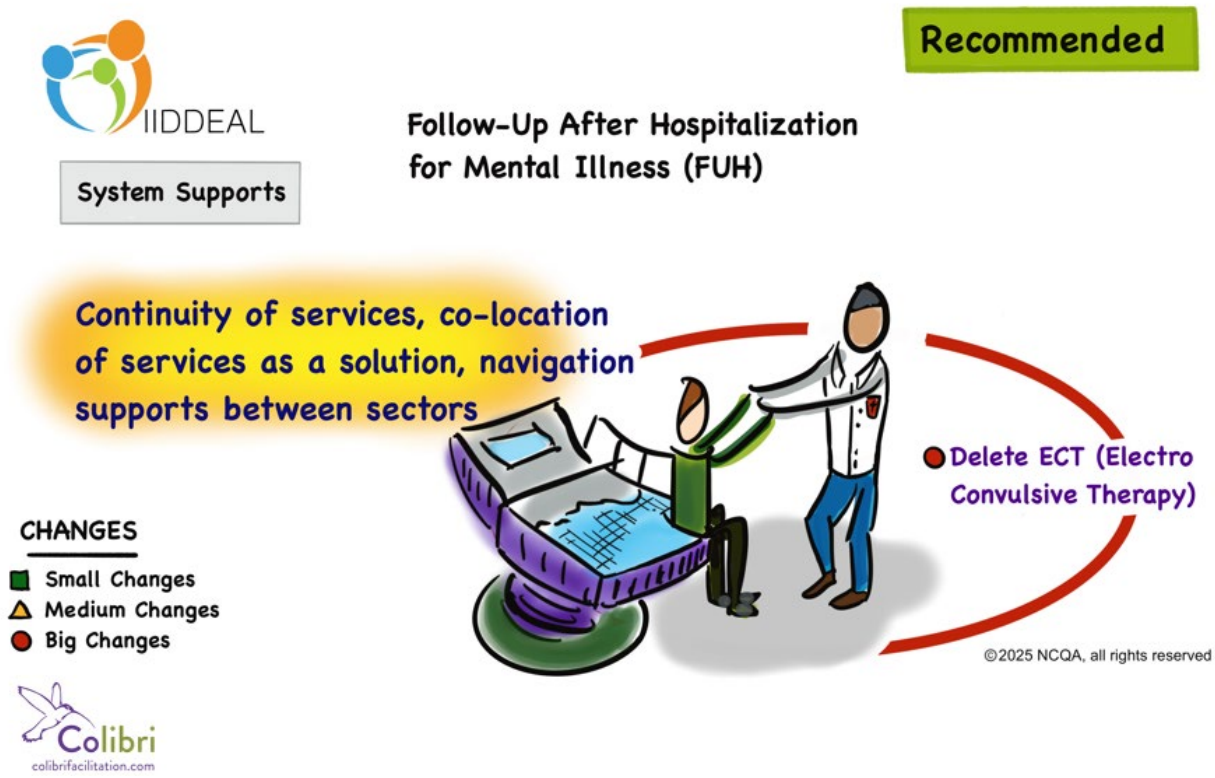
Person-Centered Primary Care Measure (PRO-PM)



- **Definition**: An 11-item survey that assesses primary care aspects rarely captured yet thought responsible for effects on population health, equity, quality, and sustainable expenditures.
- **Specifications**: https://p4qm.org/measures/3568
- **IIDDEAL Domains**:
    - Payer and Regulator Needs
    - Doing the Things I Love and Need To Do
- **IIDDEAL Element**:
    - Metrics for the outcomes that matter.
    - Person-centeredness & presuming ability.
- **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.
    - Only available to adults (18 and older); the measure would also be beneficial for families with children.
    - The reading level is too high.
    - It is not clear who gets to define what "person-centered" planning is.
- **Small Change:**
    - Add an explanation of what a "practice" is.
- **Medium Changes:**
    - Create a version that allows a care giver/partner to complete the survey, ONLY if it is absolutely necessary.
    - Add a question about whether a person with IDD got help answering the survey.
- **Big Changes:**
    - Expand the eligible age range to include families with children.
    - Reduce language to 5th or 6th grade reading level.
- **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.

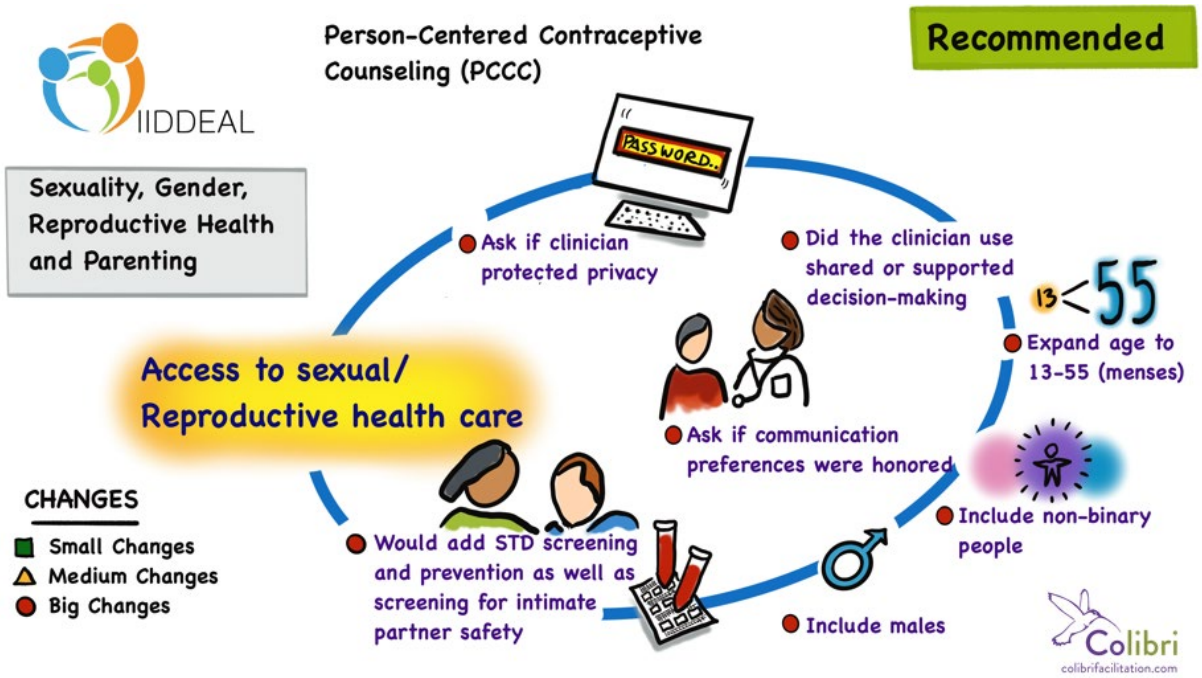
Follow-Up After Hospitalization for Mental Illness



- **Definition**: The percentage of discharges for members who were hospitalized for treatment of selected mental illness or intentional self-harm diagnoses and who had a follow-up visit with a mental health provider.
    - The percentage of discharges with follow-up within 7 days; and
    - The percentage of discharges with follow-up within 30 days.
- **Specifications**: https://p4qm.org/measures/0576
- **IIDDEAL Domain**: System Supports
- **IIDDEAL Element**: Continuity of services, co-location of services as a solution, navigation supports between service sectors.
- **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.

Person-Centered Contraceptive Counseling

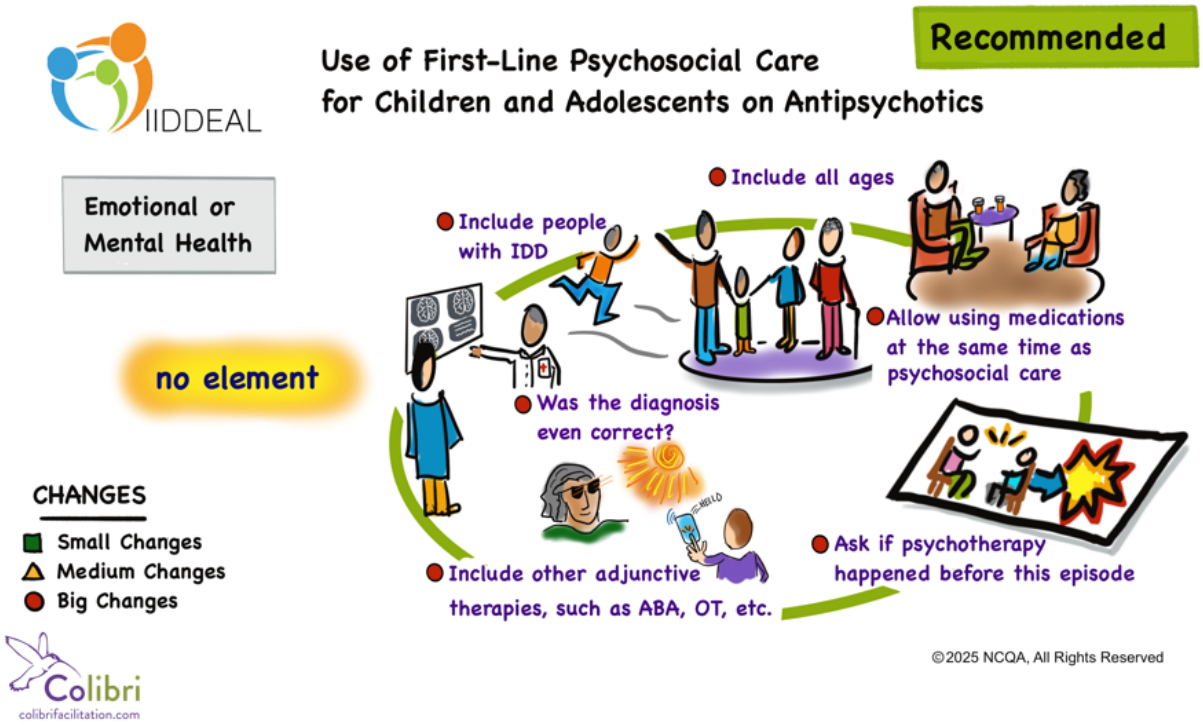


- **Definition**: A 4-item survey specifically designed to capture key domains of birth control care quality for patients who are not pregnant:
    - Respecting me as a patient.
    - Letting me say what matters to me about my birth control.
    - Taking my preferences about my birth control seriously.
    - Giving me enough information to make the best decision about my birth control method
- **Specifications**: https://p4qm.org/measures/3543
- **IIDDEAL Domain**: Sexual, Gender, Reproductive Health & Parenting
- **IIDDEAL Element**: Access to sexual/reproductive healthcare
- **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.
- **Medium changes:**
    - Add questions about screening for sexually transmitted diseases and intimate partner safety risks.
    - Allow for a proxy to respond to the survey.
- **Big changes**:
    - Expand to include others beyond individuals assigned female at birth as males should also be involved in family planning and sexual health.
    - Expand age range to anyone who has started menstruating to 50 years old.
    - Add questions about whether communication preferences and privacy were respected by the clinician.
- **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.

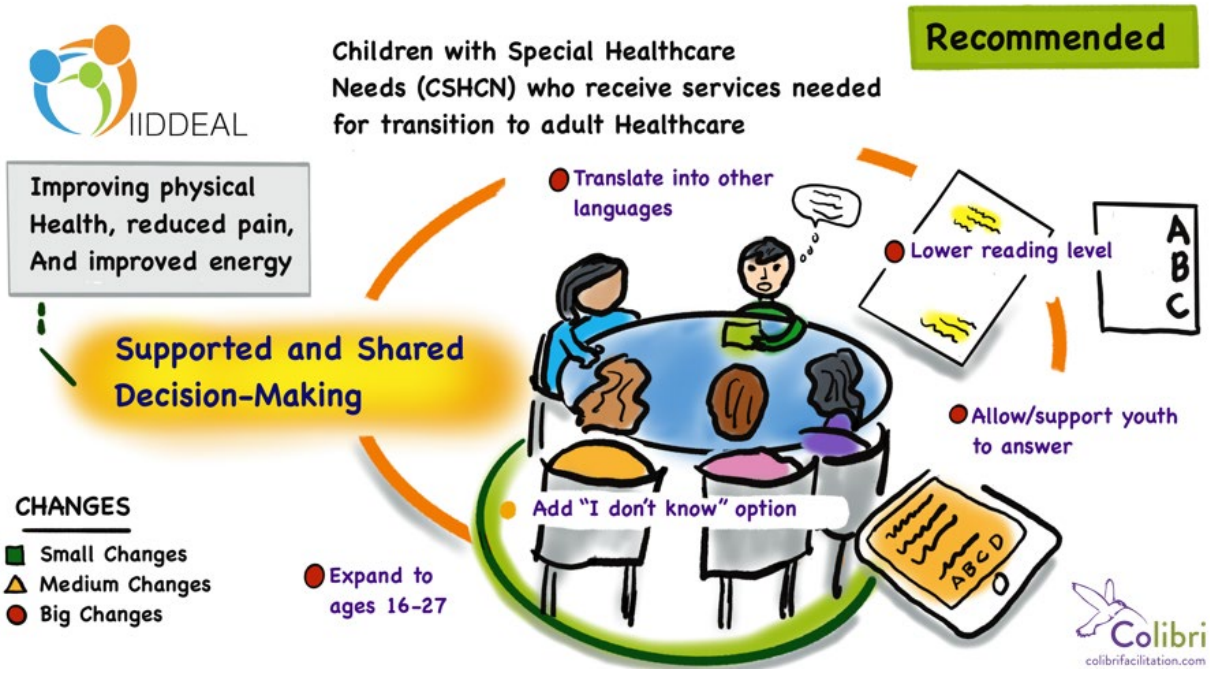
Use of First-Line Psychosocial Care for Children and Adolescents on Anti-Psychotics



- **Definition**: Percentage of children and adolescents 1-17 years of age who had a record of getting psychosocial care first BEFORE getting a prescription for antipsychotic medication even though they didn't have a diagnosis for which the drug was approved by the FDA.
- **Specifications**: ps://p4qm.org/measures/2801
- **IIDDEAL Domain**: Emotional or Mental Health
- **IIDDEAL Element**: This measure does not align to a specific Element but rather to the entire Domain.
- **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.
- **Big changes**:
    - Include children and adults with IDD of all ages.
    - Allow for exceptions if the patient needs psychosocial care and anti-psychotic drugs at the same time.
    - Allow for other types of therapy, such as occupational therapy or applied behavioral analysis, to qualify as psychosocial care.
    - Assess whether the patient received psychosocial care in a previous episode of using anti-psychotic drugs.
- **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.

Children With Special Healthcare Needs (CSHCN) Who Receive Services Needed for Transition to Adult Healthcare



- **Definition**: Whether children (12-17) with complex needs have doctors who usually/always encourage responsibility for self-care, AND have discussed transitioning to adult health care, changing needs, and how to keep insurance coverage.
- **Specifications**: https://p4qm.org/measures/1340
- **IIDDEAL Domain**: Improving Physical Health, Reduced Pain, Increased Energy
- **IIDDEAL Element**: Supported and shared decision-making.
- **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.
- **Small change**: Add an "I don't know" response option to all questions.
- **Big changes**:
    - 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.
- **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.

Advanced Care Plan

- **Definition**: The percentage of persons 66–80 years of age with advanced illness, an indication of frailty or who are receiving palliative care, and persons 81 years of age and older who had advance care planning during the measurement period.
- **Specifications**: https://cmit.cms.gov/cmit/#/FamilyView?familyId=37
- **IIDDEAL Domain**: Family Care Giver/Partner Wellness and Support
- **IIDDEAL Element**: Long-term planning
- **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.

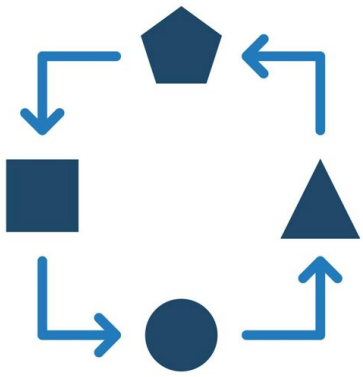
    - The measure is too narrowly focused on medical care and end of life issues. It does not address advance planning for other needs such as housing or daily supports.
    - The measure does not assess the quality of advance care plans and what they include.
    - A good advance care plan should take a person's health status into account.
    - The measure does not reflect whether for care givers/partners would receive support in the advance care plan.
- **Big changes**:
    - Expand eligibility age range to 14 and older, with regular updates made to advance plans at least every two years.
    - Define advance care planning to include plans for whole life care, so they address issues such as housing, legal guardianship, disability benefits, and health insurance coverage.
- **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.

RECOMMENDATIONS ON STRATEGIES TO FILL MEASURE GAPS

Many gaps remain across IIDDEAL Domains and Elements where existing quality measures do not align well and/or are not appropriate for people with IDD. This section explains five main strategies that could be used for filling gaps and maps each type of strategy to the IIDDEAL Domains and Elements they could best address. IIDDEAL partners identified important considerations in applying these strategies.

Adapting Existing Quality Measures

	What this means
Adapting existing quality measures	Taking an existing measure updating it to include more people, improve accessible language, age, and tools for people with IDD. Includes stratification. This would be like updating an existing recipe and making some adjustments (i.e. add more salt, cook at a higher temperature, use only vegan ingredients). Example: Adapting the depression screening and referral measure to ensure it includes a depression screening tool appropriate for individuals with IDD.



IIDDEAL partners support adapting existing quality measures as an important gap-filling strategy. They place emphasis on changing existing measures to make them ***more inclusive*** of people with IDD, rather than customizing measures for people with IDD. They note the opportunity for government or a national quality measurement organization to encourage ***all measure developers*** to review their quality measures and make changes to:

- Ensure the reading level in surveys is at the 5th or 6th grade level.
- Allow people with IDD to be included in the measure whenever possible.
- Ensure the measure is defined in a way that is appropriate for people with IDD. For example, suicide risk assessment shouldn't be limited to people who have a formal diagnosis of depression, because it is not uncommon for people with IDD to feel suicidal but not have a depression diagnosis.

Pros:

- Existing measures that already apply to other populations, if adapted, could allow comparisons of quality of care for people with IDD to care for other people.
- Does not expand the already large number of quality measures.
- The hard work of getting stakeholder input on measure concepts is already being done in this phase of IIDDEAL.
- Adapting measures could be less expensive and time consuming than creating new measures.
- Adapted measures could lead to a "report card" on quality of care for people with IDD.

Cons:

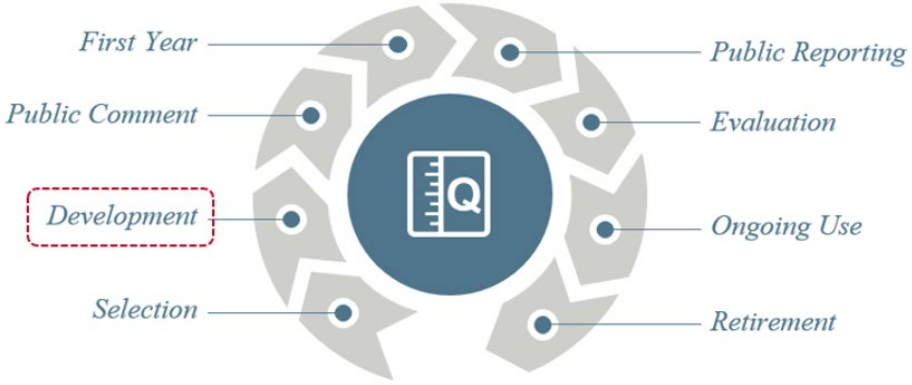
- Adapting existing quality measures could be just as complicated and expensive as creating new measures.
- Measure stewards who "own" current measures may not be willing to make changes.

Considerations in Adapting Existing Quality Measures for Specific IIDDEAL Elements
Provider checks with me about my goals and supports my decision-making • We must acknowledge that many people with IDD are not receiving basic care, such as preventive screenings, as recommended by clinical guidelines. • Some existing measures on patient empowerment may also be appropriate here, because people with IDD need skills to raise their concerns with providers.
Supported and shared decision-making • If existing frameworks for shared decision-making can be adapted to be more inclusive of people with IDD, these measures could be more accessible to other patients too, such as patients with brain injuries.
Adapted and tailored mental health interventions • We must acknowledge that many people have challenges accessing mental health care.

Resources for care givers/partners
Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs • Measures are especially important for setting clear expectations on what services and outcomes providers are billing for, and payers are paying for.

New Quality Measure Development

	What this means
New quality measure development	Developing a new measure from scratch. Measure development is an iterative process and includes stakeholder consensus throughout: • Draft specifications (outline measure components) • Discuss with expert panels • Test assess scientific soundness, feasibility, meaningfulness • Seek approval from healthcare experts to post draft measure for public comment If we think about quality measures as a recipe, this would be like inventing a new dish and new recipe tailored for the IIDDEAL framework with lots of taste testers throughout making sure the recipe is perfect. Example: Develop a new quality measure for caregiver support.



IIDDEAL partners support development of new quality measures only under certain circumstances:

- If it would be prohibitively expensive and time-consuming to adapt existing quality measures.
- If no other measures, such as patient-reported outcome measures, could be adapted to be appropriate for people with IDD.

- If the new quality measure could be useful for broader populations beyond people with IDD. Being able to apply a new measure broadly would better justify the time and resources to create it. Developing new measures that focus only on the IDD population may result in healthcare groups segregating people with IDD and treating them differently from other patients.
- If there was strong investment from government or a government-funded group to support measure development.
- If new measures are created ***with*** and for people with IDD, to ensure inclusive language and relevance.

Pros:

- New measures could become part of a "report card" on quality of care for people with IDD.

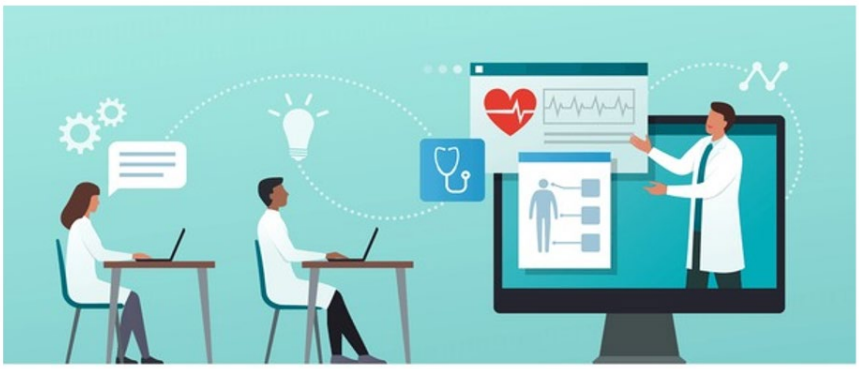
Cons:

- Creating new measures is an expensive and complicated process.
- Clinical groups and payers think there are already too many quality measures.

Considerations in Creating New Quality Measures for Specific IIDDEAL Elements
Provider checks with me about my goals and supports my decision-making • We must acknowledge that many people with IDD are not receiving basic care, such as preventive screenings, as recommended by clinical guidelines.
Care coordination
Respite services (for care givers/partners)
Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs • Measures are especially important for setting clear expectations on what services and outcomes providers are billing for, and payers are paying for.

Targeting Clinical Providers

	What this means
Targeting Clinical Providers	A provider recognition program includes training and care standards that ensure a provider is educated in and provides high-quality care to people with IDD. Payers can use the recognition program to pay more to practices that qualify. This is like giving an award to a really good chef or restaurant that they can display for customers to see that they make great food. Example: Development of a recognition program that certifies primary care practices that provide high-quality care for individuals with IDD.



IIDDEAL partners believe that targeting clinical providers with recognition programs can be a more direct way to encourage them to learn about IDD and how best to serve people with IDD. Providers can make changes to how they deliver care ***and then*** measure how quality of care changes. IIDDEAL partners believe training clinicians about DDD is the first critical step in any recognition program. Training should involve exposure to people with IDD, to underscore the importance of their lived experience.

Pros:

- A recognition program can include many IIDDEAL Elements, such as training, or approaches that are respectful and inclusive of individuals with IDD that cannot be captured by quality measures.
- IEC and other groups have already built materials that could be used, such as training pathways for clinicians.
- A recognition program could be built in a phased approach (e.g., start with training standards, then add standards for how a practice is set up)

Cons:

- Recognition programs take time to design and implement.
- Providers will need incentives or regulations to seek recognition. Incentives could include higher payment rates for practices that achieve recognition (especially from Medicare and Medicaid), a bonus for completing recognition, and/or higher payments for practices that serve patients with more complex needs and achieve better outcomes. One example of using regulation is the Commission on Dental Accreditation, which requires that all U.S. dental schools train students to treat patients with IDD. Other influential groups such as Association of American Medical Colleges and the Accrediting Council on Graduate Medical Education have issued guidelines about disability training. Medicare and Medicaid could also require providers to seek recognition. These regulations help set expectations for providers to build IDD-related skills and knowledge.
- Without incentives, recognition programs might only attract providers who are already committed to serving people with IDD.

Targeting Clinical Providers for Specific IIDDEAL Elements
Peer supports and education across the lifespan
Care coordination
Understanding and measuring pain and energy through each person's form of communication
Self-advocacy/self-determination and accommodations
Referral to counselor who knows about IDD
Trauma informed care
Access to sexual/reproductive health care
Parenting classes – relevant, appropriate to parents with IDD
Connecting people with IDD experiencing sexual assault with mental health resources
Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs
Continuity of services, co-location of services as a solution, navigation supports between sectors (e.g., community services and healthcare)
Include IDD elements in accreditation requirements
Train clinicians with standardized patients, simulated scenarios, and practical tools to work with people with IDD
Teach all clinicians life course development of people with IDD

Creating Quality Standards for Health Plans

	What this means
Creating standards for health plans	Quality standards are the rules and guidelines to make sure health plans are doing a good job at providing care. Quality standards are like food safety standards for restaurants to ensure that all the employees wash their hands, the fridge can keep the food cold, the oven works, food is cooked properly, etc. The restaurant then gets a grade on how well they do. Example: Programs such as NCQA's Health Equity Accreditation, or Health Equity Accreditation Plus that help health plans improve care for underserved populations. NCQA is currently working to add requirements for health plans to identify members with disabilities. This strategy could potentially support broad adoption of quality metrics for people with IDD.

IIDDEAL partners are supportive of creating quality standards for health plans to address measure gaps. Health plans touch many lives and can be highly influential with providers. But it's critical that people with IDD and care givers/partners are involved in all major decisions about what these standards include. Standards that don't reflect perspectives of people with lived experience are less likely to be effective and may do harm.

Pros:

- Potential to have national impact.
- Setting standards for health plans could take some burden off providers and health plans for data collection.

Cons:

- Quality standards for health plans will take time to design and implement.
- Standards for health plans will not capture people with IDD who are in traditional (fee-for-service) Medicare or Medicaid.
- It's not clear how eager health plans will be to make changes.
- We may need more evidence on what leads to better outcomes for people with IDD before health plans will believe in new quality standards.
- Health plans may need incentives or to be required to adopt quality standards.

Considerations in Creating Quality Standards for Health Plans, Related to Specific IIDDEAL Elements
Peer supports and education across the lifespan
Care coordination • Effective care coordination needs to involve those who support the person with IDD, such as family members, direct support personnel. • But care coordination has to be centered on what the person with IDD wants.
Access to sexual/reproductive health care • It's important that quality standards hold health plans accountable for supporting people's access to services, not just for sexual/reproductive health, but all the services they need.
Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs • Quality standards should also address how easy it is for patients to use the health plan's grievance process, if they are experiencing barriers to accessing services or other challenges.
Continuity of services, co-location of services as a solution, navigation supports between sectors (e.g., community services and healthcare)
Include IDD elements in accreditation requirements • Quality standards for health plans could include that the plan must make sure the providers they contract with have received training about IDD. Plans can partner with clinical training programs and groups that govern training programs to get providers trained. • Quality standards could also be a key part of a ***health plan*** getting accreditation.

Advocating for Changes in State or Federal Policy

	What this means
Advocating for changes in state or federal policy	This activity includes working with state Medicaid agencies or the Centers for Medicare and Medicaid Services to improve health insurance coverage to pay for needed healthcare for individuals with IDD. This would be like partnering with the U.S. Food and Drug Administration (FDA) to improve food safety and nutrition. Example: Advocating for states to include coverage for sensory-friendly dental procedures for individual with IDD in their Medicaid plans.

IIDDEAL partners recognize that changes in federal and state policies may be the most appropriate strategy to address IIDDEAL gaps related to access to services, clinical workforce development, improving data that can be shared by many healthcare groups, and payment for services. These are not gaps that can be easily addressed by individual clinical groups or health plans. However, advocacy efforts must include people with IDD and care givers/partners, as they can best represent what policy changes are most important to them and why.

Pros:

- Advocacy could result in meaningful changes in health care coverage and quality for individuals with IDD
- States who are successful and really advance IIDDEAL priorities could put pressure on lagging states to follow.
- Policy change is an opportunity to make person-centered care truly person-centered, and not just a buzzword.
- Advocacy offers a path to influencing Medicaid and Medicare.

Cons:

- Policy changes take time.
- Changes may be difficult to accomplish for all 50 states.
- Different policies across states cause inherent inequity.

Considerations in Advocating for Federal and State Policy Changes, for Specific IIDDEAL Elements
Dental and vision care across the lifespan • Dental societies can play a part in advocacy for better insurance coverage for dental services. • Access to adequate dental and vision care not only improves physical health but enables people with IDD to live their lives more fully and achieving economic security.
Increased payment to spend sufficient time with people in care settings • Medicare and Medicaid should offer higher payment rates for visits with people with complex needs. Some dental insurance plans are already doing this and can offer lessons learned.
Innovative tools, models of care, data & technology
Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs • If there is a way to include qualitative data as well as quantitative data in feedback to clinical groups, that would help humanize people with IDD and motivate change. • The Food and Drug Administration should also consider adopting IIDDEAL measures in drug trials. • State waivers in Medicaid and for HCBS offers a testing ground for new payment approaches. • Better payment for services requires better financing. Advocates need to also promote where the money should come from.
Continuity of services, co-location of services as a solution, navigation supports between sectors (e.g., community services and healthcare) • Innovative approaches to bundling services for people with IDD and data on their effectiveness would be particularly valuable.
Data on the value of different services • Innovative approaches to bundling services for people with IDD and data on their effectiveness would be particularly valuable.

KEY LEARNINGS FROM IIDDEAL PHASE 3

Phase 3 generated many important themes about measuring what matters for people with IDD.

- ***Quality measures need to consider the communication and cognitive preferences and needs that people with IDD experience***. Surveys and PROMs should be written at the fifth or sixth grade reading level. Use of icons, graphics, captions, and alt+text in documents would also support people in understanding and responding to surveys and PROMs. Use of patient-reported measures would benefit from options for a support person to help the person with IDD to respond and/or serve as a proxy.
- ***Too many quality measures explicitly exclude people with IDD***. This is an especially serious problem for measures that focus on healthcare issues of particular importance to, or that pose greater risks for, people with IDD. These include topics such as use of antipsychotic medications, mental health, sexual/reproductive/gender health, risk assessment for safety issues, and respectful shared decision-making.
- ***Most priority Elements in IIDDEAL are things that nearly everyone wants and needs*** – whether that is supported decision-making or having a clinical team that prioritizes your personal goals. Adopting measures and addressing gaps in IIDDEAL would benefit all patients.
- All 12 of the recommended measures in IIDDEAL are already being widely used. Efforts to make them more relevant and powerful in helping people with IDD reach better health outcomes can start by looking at the measure ***data stratified by IDD status***. This would call attention to the experience of people with IDD.
- It is ***critical to immediately begin looking at data from these measures for people with IDD***, even as we promote efforts to adapt them as recommended in IIDDEAL.
- IIDDEAL's emphasis on holistic, person-centered approaches aligns closely with the federal government's current focus on ***wellness, prevention, and supporting people to live as independently as possible***.
- ***Traditional quality measurement to hold clinical groups and payers accountable is not the answer to everything*** that is important to people with IDD in healthcare. Many priorities can be better addressed through advocacy, policy changes, better clinical training, and/or collecting patients' reports on their health in specific circumstances.

HOW TO GET INVOLVED

Converting the IIDDEAL framework and priorities into concrete improvements in people's health and lives will require more than a single project. Making lasting change in how healthcare groups and payers serve people with IDD depends on many passionate people taking coordinated action at different levels in the healthcare system.

- Clinics serving people with IDD can use recommended measures to start tracking their own performance and look for ways to improve.
- Self-advocates can share recommended measures with their healthcare teams to start the conversation about what's most important to work on together.
- Payers and regulators can adopt recommended measures into payment programs, stratify data from measures by IDD status, and/or share data with clinical groups and the public on where things are going well and where there is opportunity to improve.
- Researchers can adopt recommended measures and routinely include people with IDD in their research studies.
- And public agencies can educate payers and providers about the need to focus on these key measures.

We encourage all groups and advocates interested in advancing health and life outcomes that matter for people with IDD to take action.

You can:

- Share feedback with us on this report by emailing info@ie-care.org with the subject line: IIDDEAL Phase 3.
- Attend future webinars to learn how your organization can apply these recommendations. Sign up for IEC's Email List to receive information about webinars.
- Partner with the IIDDEAL team to promote recommended measures to other organizations and/or funding to support projects that fill measure gaps. We will provide a slide presentation and short summary that you can use to introduce others to IIDDEAL and the recommended measures.
- Share suggestions on how to fill measure gaps at the email address above.

Appendix A. Original 71 candidate Quality Measures from NCQA's environmental scan

Quality Measure Name	Link to specifications
1. Person-Centered Outcome Measure: Goal Achievement, Goal Follow-up, Goal Identification	https://www.ncqa.org/hedis/reports-and-research/pco-measures/
2. Connection To Community Service Providers	https://cmit.cms.gov/cmit/#/MeasureView?variantId=11704&sectionNumber=1
3. Adolescent Assessment of Preparation for Transition (ADAPT) to Adult Care	https://p4qm.org/measures/2789
4. Children With Special Healthcare Needs (CSHCN) Who Receive Services Needed for Transition to Adult Healthcare	https://p4qm.org/measures/1340
5. Use of First-Line Psychosocial Care for Children and Adolescents on Anti-Psychotics	https://p4qm.org/measures/2801

6. Child and Adolescent Major Depressive Disorder (MDD) Suicide Risk Assessment	https://cmit.cms.gov/cmit/#/FamilyView?familyId=122
7. Advanced Care Plan	https://cmit.cms.gov/cmit/#/FamilyView?familyId=37
8. Person-Centered Contraceptive Counseling	https://p4qm.org/measures/3543
9. Follow-Up After Emergency Department Visit for Mental Illness	https://p4qm.org/measures/3489
10. Follow-Up After Hospitalization for Mental Illness	https://p4qm.org/measures/0576
11. Person-Centered Primary Care Measure (PRO-PM)	https://p4qm.org/measures/3568
12. Consumer Assessment of Healthcare Providers and Systems (CAHPS), Home and Community-Based Service Measures	https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbscahps-admin-ta-guide.pdf
13. Identifying Personal Priorities for Functional Assessment Standardized Items (FASI) Needs	https://p4qm.org/measures/3593

14. Comprehensive Assessment for Patients with Complex Needs	https://cmit.cms.gov/cmit/#/FamilyView?familyId=144
15. Children Who Receive Effective Care Coordination of Healthcare Services When Needed	https://p4qm.org/measures/0719
16. Continuity of Primary Care for Children with Medical Complexity	https://p4qm.org/measures/3153
17. Maternity Care: Postpartum Follow-up and Care Coordination	https://cmit.cms.gov/cmit/#/FamilyView?familyId=420
18. Follow-Up After High-Intensity Care for Substance Use Disorder (FUI)	https://www.ncqa.org/report-cards/health-plans/state-of-health-care-quality-report/follow-up-after-high-intensity-care-for-substance-use-disorder-fui/
19. Patient Activation Measure (PAM)	https://cmit.cms.gov/cmit/#/FamilyView?familyId=1212
20. Family Experiences with Coordination of Care (FECC)-1 Has Care Coordinator	https://p4qm.org/measures/2842
21. Family Experiences with Coordination of Care (FECC) -	https://p4qm.org/measures/2843

3: Care coordinator helped to obtain community services	
22. Family Experiences with Coordination of Care (FECC) - 5: Care coordinator asked about concerns and health	**https://p4qm.org/measures/2844**
23. Family Experiences with Coordination of Care (FECC) - 7: Care coordinator assisted with specialist service referrals	**https://p4qm.org/measures/2845**
24. Family Experiences with Coordination of Care (FECC)- 8: Care coordinator was knowledgeable, supportive and advocated for child's needs	**https://p4qm.org/measures/2846**
25. Family Experiences with Coordination of Care (FECC) - 9: Appropriate written visit summary content	**https://p4qm.org/measures/2847**
26. Family Experiences with Coordination of Care (FECC)- 15: Caregiver has access to	**https://p4qm.org/measures/2849**

medical interpreter when needed	
27. Family Experiences with Coordination of Care (FECC)-16: Child has shared care plan	**https://p4qm.org/measures/2850**
28. CollaboRATE Shared Decision Making Score	**https://p4qm.org/measures/3227**
29. Alignment of Person Centered Service Plan (PCSP) with Functional Assessment Standardized items (FASI) needs	**https://p4qm.org/measures/3734**
30. Evaluation of Functional Status (Basic and Instrumental Activities of Daily Living [ADL]) for Home-Based Primary Care and Palliative Care Patients	**https://p4qm.org/measures/3497**
31. Access to Medical Equipment	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=11**
32. Driver of Health Screen Positive Rate	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=1662**

33. Driver of Health Screening Rate	https://cmit.cms.gov/cmit/#/FamilyView?familyId=1664
34. Resolution of At Least 1 Health-Related Social Need	https://mmshub.cms.gov/measure-lifecycle/measure-implementation/pre-rulemaking/lists-and-reports
35. Screen Positive Rate for Social Drivers of Health (SDOH)	https://mmshub.cms.gov/measure-lifecycle/measure-implementation/pre-rulemaking/lists-and-reports
36. Screening for Social Drivers of Health (SDOH)	https://mmshub.cms.gov/measure-lifecycle/measure-implementation/pre-rulemaking/lists-and-reports
37. Pain Assessment and Follow-Up	https://p4qm.org/measures/0420
38. Functional Outcome Assessment	https://cmit.cms.gov/cmit/#/FamilyView?familyId=274
39. Social Need Screening and Intervention (SNS-E)	https://cahmi.org/our-work-in-action/measurement-in-action/compendium/measure-details?id=92
40. Gains in Patient Activation Measure (PAM) Scores at 12 Months	https://mmshub.cms.gov/measure-lifecycle/measure-implementation/pre-rulemaking/lists-and-reports
41. Functional Status Change for Patients with Low Back Impairments	https://p4qm.org/measures/0425
42. Weight Assessment and Counseling for Nutrition and	https://cmit.cms.gov/cmit/#/FamilyView?familyId=760

Physical Activity for Children and Adolescents	
43. Oral Evaluation, Dental Services	**https://p4qm.org/measures/2517**
44. Children Who Received Preventive Dental Care	**https://p4qm.org/measures/1334**
45. Prevention: Topical Fluoride for Children, Dental or Oral Health Services	**https://p4qm.org/measures/3700**
46. Utilization of Services, Dental Services	**https://p4qm.org/measures/2511**
47. Pre-School Vision Screening in the Medical Home	**https://p4qm.org/measures/1412**
48. Children Who Receive Family-Centered Care	**https://p4qm.org/measures/1333**
49. Developmental Screening	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=1003**
50. Healthy Physical Development by 18 Years of Age	**https://p4qm.org/measures/1514**
51. Children Age 6-17 Years who Engage in Weekly Physical Activity	**https://p4qm.org/measures/1348**

52. Depression Screening and Follow-Up for Adolescents and Adults (DSF-E	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=1778**
53. Clinical Depression Screening and Follow-Up	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=672**
54. Preventive Care and Screening: Unhealthy Alcohol Use: Screening & Brief Counseling	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=597**
55. Follow-Up Care for Children Prescribed Attention-Deficit/Hyperactivity Disorder (ADHD) Medication	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=271**
56. Contraceptive Care - Postpartum	**https://p4qm.org/measures/2902**
57. Contraceptive Care – Most & Moderately Effective Methods	**https://p4qm.org/measures/2903**
58. Contraceptive Care - Access to LARC	**https://p4qm.org/measures/2904**
59. Self-identified Need for Contraception (SINC)-Based	**https://p4qm.org/measures/3682e**

Contraceptive Care, Postpartum	
60. Self-identified Need for Contraception SINC-Based Contraceptive Care, Non-Postpartum	**https://p4qm.org/measures/3699e**
61. Prenatal and Postpartum Care: Postpartum Care (PPC)	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=581**
62. Prenatal and Postpartum Care: Timeliness of Prenatal Care	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=582**
63. Follow-Up After Emergency Department Visit for Substance Use (FUA)	**https://p4qm.org/measures/3488**
64. National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures	**https://p4qm.org/measures/3622**
65. Rating of Specialist	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=645**
66. Closing the Referral Loop: Receipt of Specialist Report	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=133**

67. Transitions of Care (TRC)*	***Note: Specifications are not available publicly – information derived from HEDIS Volume 2**
68. Measuring the Value-Functions of Primary Care: Provider Level Continuity of Care Measure	**https://p4qm.org/measures/3617**
69. Provide Patients Electronic Access to Their Health Information	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=616**
70. Support Electronic Referral Loops by Receiving and Incorporating Health Information	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=709**
71. Support Electronic Referral Loops by Sending Health Information	**https://cmit.cms.gov/cmit/#/FamilyView?familyId=710**

Appendix B. Recommendations on Strategies to Fill Measure Gaps, for Each IIDDEAL Priority Element

IIDDEAL Priority Elements	Creating new quality measures	Adapting existing quality measures	Targeting clinical providers	Health plan quality standards	Advocating for changes in the state or federal policy
Provider checks with me about my goals and supports my decision making	X	X			
Peer supports and education across lifespan			X	X	
Dental and vision care across the lifespan					X
Resources to live somewhere safe & accessible		X			

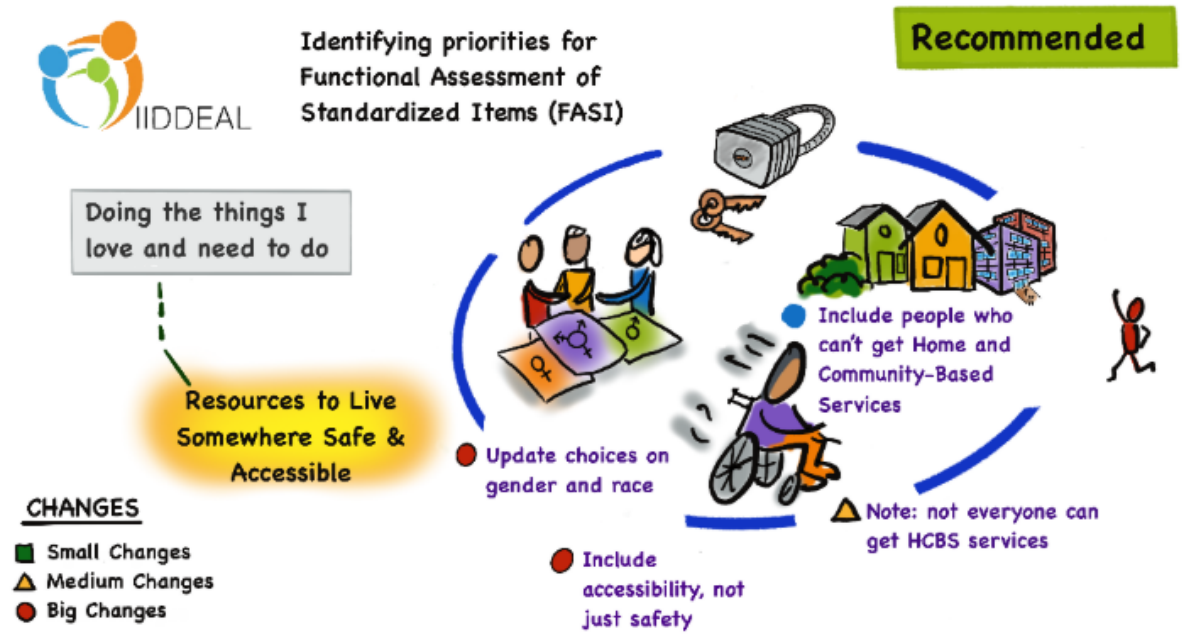
Care coordination	**X**		**X**	**X**	
Supported or shared decision-making		**X**			
Understanding and measuring pain through each person's form of communication			**X**		
Self-advocacy/self-determination and accommodations			**X**		
Referral to counselor who knows about IDD			**X**		
Adapted and Tailored Mental Health Interventions		**X**			
Trauma informed care			**X**		
Respite care services	**X**				
Resources for caregivers/partners		**X**			

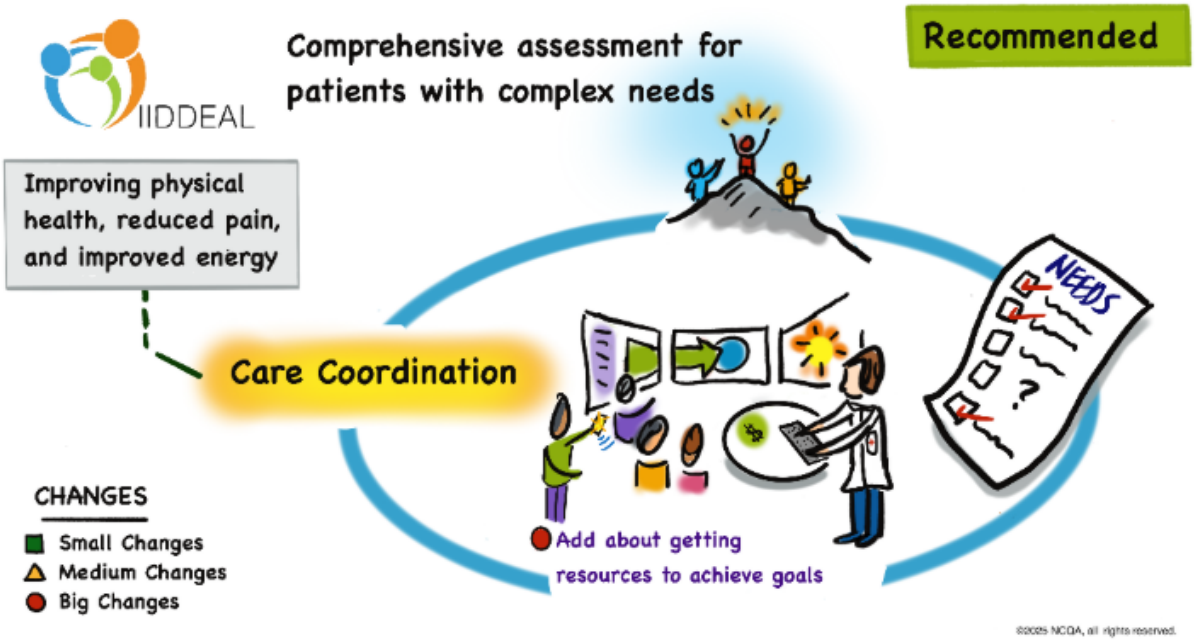
Access to sexual/reproductive health care		**X**	**X**	**X**	
Parenting classes - relevant, appropriate to parents with IDD			**X**		
Connecting people with IDD experiencing sexual assault with mental health resources			**X**		
Payment for priority outcomes, flexible service options, patient-centered quality metrics, effective reimbursement, and resources to build programs	**X**	**X**	**X**	**X**	**X**

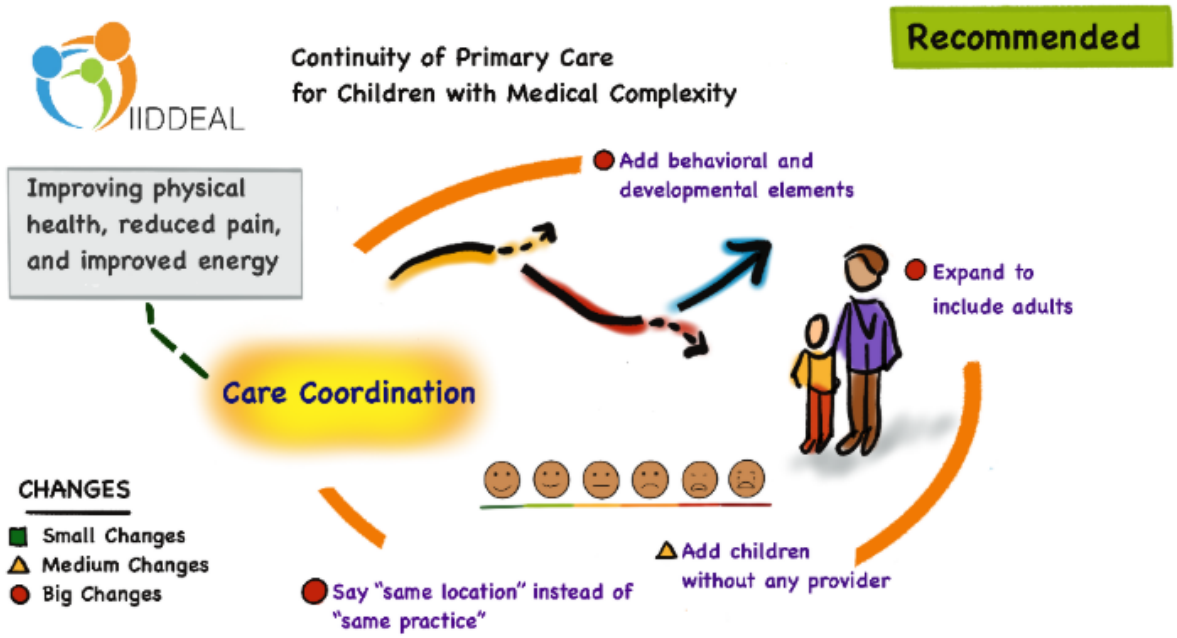
Continuity of services, co-location of services as a solution, navigation supports between sectors (e.g., community services and healthcare)			**X**	**X**	
Increased payment to spend sufficient time with people in care settings					**X**
Innovative tools, models of care, data, & technology					**X**
Data on the value of different services					**X**
Include IDD elements in accreditation requirements			**X**	**X**	

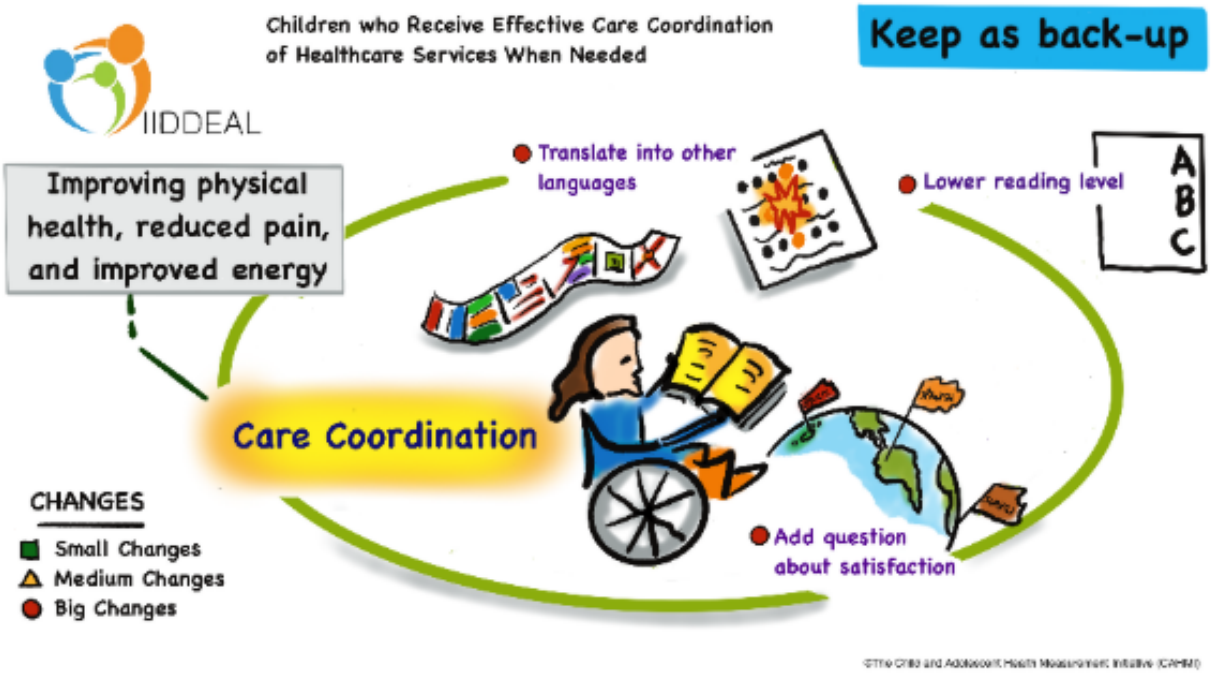
Train clinicians with standardized patients, simulated scenarios, and practical tools to work with people with IDD			**X**		
Teach all clinicians life course development of people with IDD			**X**		

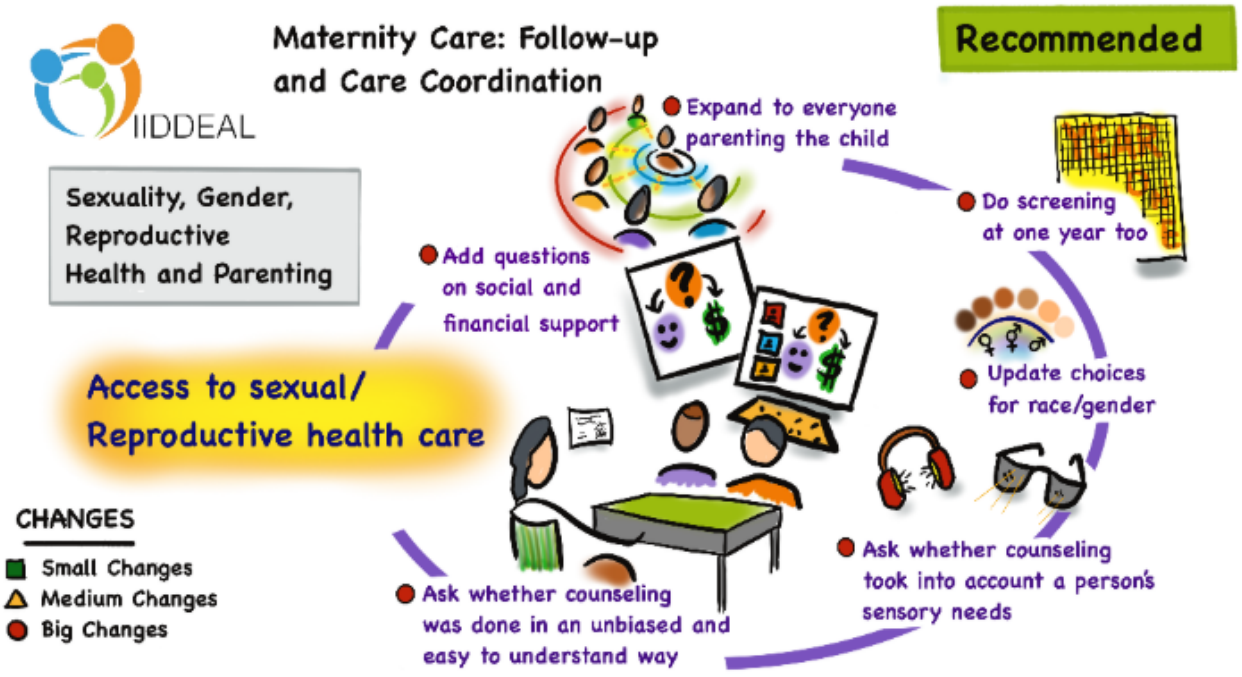
Appendix C. Illustrations and Pros/Cons of measures considered by the Consensus Working Group but not recommended

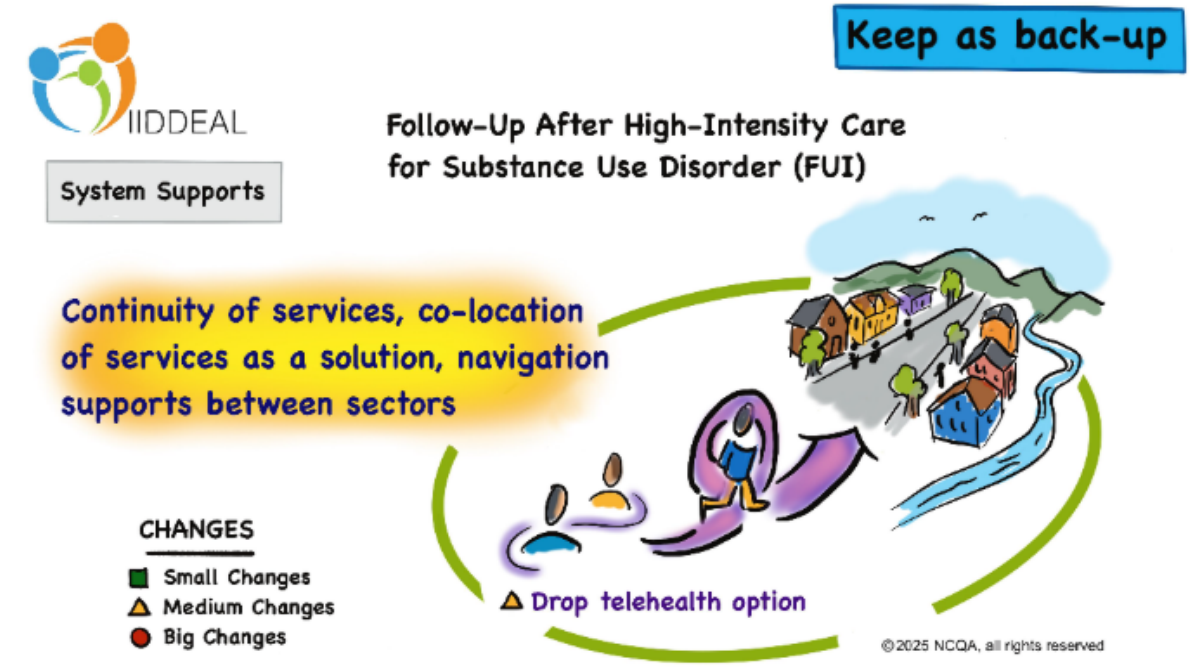









IIDDEAL
Maternity Care: Follow-up and Care Coordination
Recommended
Sexuality, Gender, Reproductive Health and Parenting
Expand to everyone parenting the child
Do screening at one year too
Add questions on social and financial support
Update choices for race/gender
Access to sexual/ Reproductive health care
Ask whether counseling took into account a person's sensory needs
Ask whether counseling was done in an unbiased and easy to understand way
CHANGES
Small Changes
Medium Changes
Big Changes


IIDDEAL
Keep as back-up
Follow-Up After High-Intensity Care for Substance Use Disorder (FUI)
System Supports
Continuity of services, co-location of services as a solution, navigation supports between sectors
Drop telehealth option
CHANGES
Small Changes
Medium Changes
Big Changes
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