Special Communication

Advancing Health Policy and Outcomes for People With Intellectual or Developmental Disabilities
A Community-Led Agenda

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Abstract

**IMPORTANCE** At least 10 million people in the United States have an intellectual and/or developmental disability (IDD). People with IDD experience considerably higher rates of poor overall health, chronic conditions including diabetes, mental health challenges, maternal mortality, and preventable deaths. This Special Communication proposes national goals based on a community-led consensus model that advances priority health outcomes for people with IDD and their caregivers/partners and identifies critical policy opportunities and challenges in achieving these goals. A community-led consensus agenda offers a foundation for focusing research, improving data collection and quality measurement, enhancing coverage and payment for services, and investing in a prepared clinical workforce and infrastructure in ways that align with lived experiences and perspectives of community members.

**OBSERVATIONS** People with IDD prioritize holistic health outcomes and tailored supports and services, driven by personalized health goals, which shift over their life course. Caregivers/partners need support for their own well-being, and easy access to resources to optimize how they support loved ones with IDD. Development of an adequately prepared clinical workforce to serve people with IDD requires national and regional policy changes that incentivize and structure training and continuing education. Ensuring effective and high-value coverage, payment, and clinical decisions requires investments in new data repositories and data-sharing infrastructure, shared learning across public and private payers, and development of new technologies and tools to empower people with IDD to actively participate in their own health care.

**CONCLUSIONS AND RELEVANCE** Consensus health priorities identified in this project and centered on IDD community members’ perspectives are generalizable to many other patient populations. Public and private payers and regulators setting standards for health information technology have an opportunity to promote clinical data collection that focuses on individuals’ needs, quality measurement that emphasizes person-centered goals rather than primarily clinical guidelines, and direct involvement of community members in the design of payment policies. Clinical education leaders, accrediting bodies, and investors/entrepreneurs have an opportunity to innovate a better prepared health care workforce and shared data infrastructure to support value-based care programs.


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Introduction

Prevalence of intellectual and/or developmental disabilities (IDDs), such as autism spectrum disorder, intellectual disability, Down syndrome, and Williams syndrome, now equals 20 to 30 per 1000 and continues to rise, according to the US Centers for Disease Control and Prevention and surveys. People with IDD have different and varying levels of support needs related to communication, learning, self-care, social interactions, and other life skills across circumstances and life stages. They have unique strengths and are able to contribute and enjoy a high quality of life when provided appropriate supports.

Yet people with IDD experience higher rates of poor overall health, long-term co-occurring conditions such as diabetes, mental illness, maternal mortality, addiction and violence, and preventable deaths. Factors contributing to these disparities include poor access to appropriate health care and other services, and lack of training in IDD among the health care workforce, which feeds widespread misunderstanding of IDD among clinicians. Current clinical models and standards do not adequately support, and often conflict with, the needs of people with IDD.

The US lacks a framework for setting health priorities for people with IDD and supporting efforts to measure, improve, and hold clinical organizations and health care professionals, payers, and policymakers accountable for the well-being of the IDD population. Understanding which health outcomes matter most to people with IDD and their caregivers/partners serves as the first, essential step toward creating more effective insurance benefits; financing and payment for services; empowering the health care workforce to have accountability for priority outcomes; and developing tailored care models for people with IDD.

Methods

Over 2022 to 2023, the IIDDEAL (Individuals with IDD Engaged, Aligned, and Leading) project convened more than 180 contributors including people with intellectual and/or developmental disability (IDD), caregivers/partners (family members or others who support someone with IDD), clinicians, payers, and regulators to discover what outcomes should be prioritized, and how system leaders can best support those outcomes. The IIDDEAL Core Team and Advisory Council included 1 and 2 to 3 representatives, respectively, from each of the major partner categories (people with IDD, caregivers/partners, clinical leaders, payers/regulators), most of whom held national or regional leadership positions. Focus group contributors were recruited through outreach to national and regional disability organizations for IDD and caregivers/partners, through national professional societies for clinicians, and by iterative purposive outreach to payers/regulators.

Through collaborative rounds of review and decision-making including people with IDD as codEVERS of this work, we designed and applied specific methods, such as use of graphic facilitation, accommodation of communication needs, and office hours, for collective learning, sharing, and consensus building. Authentic engagement ensured that all involved could contribute to their fullest ability and that norms for inclusive, respectful, and accessible interactions (such as avoiding jargon and use of professional titles) were consistently practiced in all discussions. These strategies were critical to centering decisions on community members’ priorities and lived experience. They allowed people from different backgrounds to better understand each other’s perspectives and roles in identifying solutions.

IIDDEAL began by learning the health stories of individuals with IDD, then facilitating serial group discussions: first with people with IDD, then family caregivers/partners, then clinicians, and lastly with payers and regulators. This approach generated 9 priority health outcome domains (making healthy choices, physical health/reduced pain/improved energy, emotional or mental health, sexual/gender/reproductive health and parenting, doing the things I love and need to do, family caregiver/partner wellness and support, healthcare workforce development, system supports, and payer/regulator needs) and 51 system elements that support these domains.
IIDDEAL then convened a Consensus Working Group comprising 35 representatives nominated by other IIDDEAL contributors and selected through voting by the IIDDEAL Core Team, based on nominees’ relevant experience and professional standing to influence development and application of quality measures related to IDD, and to maximize diversity. The Consensus Working Group included people with IDD, caregivers/partners, IDD clinical experts, general clinical leaders, public and private payers, federal and state regulators/policymakers, IDD researchers, and quality measurement experts. They voted on 3 to 4 supportive elements to prioritize within each health outcome domain that had the greatest potential for action. The group then met in-person to draft national goals for 2035 that would advance the 9 outcome domains and prioritized supportive elements.

IIDDEAL subsequently convened a policy summit with 27 leaders from the Centers for Medicare & Medicaid Services (CMS), Agency for Healthcare Research and Quality (AHRQ), Administration on Community Living, Office of the Assistant Secretary for Planning and Evaluation, Health Resources and Services Administration, the Centers for Disease Control and Prevention, several state Medicaid and/or developmental disabilities service agencies, the AARP, the National Quality Forum, the National Committee on Quality Assurance, private health plans, and research funding organizations. Policy Summit attendees contributed perspectives on (1) the degree to which proposed national goals are aligned with current programmatic and policy initiatives at their organizations; and (2) challenges and opportunities in achieving national goals.

**Health Priorities and How Clinicians, Payers, and Regulators Can Support Them**

Of the 9 outcome domains, 6 holistically capture different dimensions of well-being for people with IDD or their caregivers/partners, such as strategies for optimizing their everyday life experiences, rather than on clinical outcomes related to the underlying IDD condition or co-occurring clinical conditions. The remaining 3 outcome domains capture dimensions of clinical workforce development, system supports that shape benefit design and payment policy, and the data, clinical, and technology infrastructure that payers and regulators need to make decisions affecting people with IDD. Although some IIDDEAL outcome domains and supportive elements overlap with those in CMS’ National Core Indicators for IDD, IIDDEAL focuses on roles that clinical teams, payers, and regulators play in advancing health outcomes, rather than on home- and community-based services (HCBS), while acknowledging that different sectors need to coordinate how they serve people with IDD. Although IIDDEAL centers on perspectives of the IDD community, its priority health outcome domains and supportive elements have broad applicability to other populations with complex needs, such as mental illness or dementia.

**National Goals to Advance IDD Health Outcomes That Matter**

Box 1, Box 2, and Box 3 summarize 43 ambitious national goals to achieve by 2035 that present concrete milestones to improve outcomes that matter. The goals address 3 major areas for improvement to disrupt current practices in data collection and quality measurement, coverage and payment for services, and development of the clinical workforce and shared infrastructure. Some goals apply to multiple policy areas but were grouped based on the outcome domain or element that motivated the goal.

Improving quality measurement to support IIDDEAL priorities (Box 1) entails pivoting away from clinical guideline–based metrics, which commonly focus on specific medical diagnoses and therapies, toward greater reliance on patient-reported outcome measures and measures of person-specific goal attainment. Meaningful measures will require collecting new data through electronic health records (EHRs) or other tools, capturing information on priorities such as how a person expresses pain, their health goals, and caregiving in standardized and searchable formats. This could be accelerated by payers incentivizing clinical organizations to collect and extract such data for quality reporting and accountability. Common patient/caregiver experience surveys would need to modify or add questions to capture supported/shared decision-making, elements of care coordination, and
dimensions of care relationships particularly important to the IDD community, such as respect and presumption of ability.

Enhancing coverage and payment for services (Box 2) focuses on dental and vision care; colocation of physical health, mental health, and social services (whenever possible); and HCBS services (such as housing or vocational support), which currently are inaccessible to hundreds of thousands of people on states' wait lists.20 IIDDEAL proposes that all clinicians receive higher reimbursement for clinical encounters with patients with IDD because they often need more time to accommodate communication preferences, physical challenges, and/or behavioral support needs during a visit.21 Importantly, coverage and payment policies should be informed through consistent engagement of community members by Medicare, state Medicaid agencies, and health plans, not during a visit.21 Importantly, coverage and payment policies should be informed through consistent engagement of community members by Medicare, state Medicaid agencies, and health plans, not

Box 1. IIDDEAL National Goals for 2035 on Improving Data Collection and Quality Measurement to Track, Improve, and Hold the Health System Accountable for Outcomes

- People with IDD and their caregivers/partners will reach consensus on a definition of social drivers of health that is reflective of their community and set standards for collecting related data in EHRs.
- EHRS will add ways to routinely capture information on:
  - How a person with IDD or support team signals a change in pain or energy
  - Pain and energy assessments based on new standard scales and/or comprehensive evaluation to identify physical causes
  - Tailored guidance for clinical teams to give individual patients with IDD and their caregivers/partners about when to alert the clinical team about changes in pain and energy

A new national standard for EHR is established and the 3 largest EHR companies will include a question in the person’s medical record for answers to the question, “Are you a caregiver?” and capture a range of types of caregiving, such as whether respite care is required.

75% of caregivers/partners will have an identified respite care plan as part of the long-term care plan or complex care plan in the EHR of their person with IDD.

A new national standard for EHRs is established and implemented by the 3 largest EHR companies to include a new structured field to capture patient’s broad goals and what they would like to be accomplished in the encounter. Alternatively, more consistent use of existing “goals” fields in EHRs would capture longer-term priorities than “reason for visit” fields.

At the point of transition to adult care professionals (eg, ages 14-26 y), 50% of people with IDD and their caregiver/partners will document steps they are taking and preferences in their EHR related to: connecting with services, services needed or wanted, other family members involved in care, and crisis/emergency plan, and this plan should be reviewed at a minimum every 5 y.

Abbreviations: EHR, electronic health record; IDD, intellectual and/or developmental disability; IIDDEAL, Individuals with IDD Engaged, Aligned, and Leading.
only on advisory councils but also in positions where they can actively colead the design of programs and policies.

Ensuring an adequately prepared clinical workforce (Box 3) identifies varied strategies, such as formally designating people with IDD as a medically underserved population to bolster incentives for clinicians to serve them,22 certification in IDD competencies for key disciplines of primary care and mental health, and infusing IDD-related competencies in standards at every level of clinical education and accreditation, from prelicensure schooling to continuing education.23,24 IIDDEAL especially emphasizes improving training for clinicians in meeting the sexual/reproductive health needs of people with IDD because of both the disturbing history of forced sterilization in women with IDD25 and the often overlooked needs that people with IDD have for a safe and fulfilling sexual life that may include parenting.26 Dramatically growing the number of clinicians who themselves have IDD27 would give peers positive exposure to people living with IDD as well as more grounded understanding of the malleable challenges that health care presents.

**Box 2. Individuals with IDD Engaged, Aligned, and Leading National Goals for 2035 on Improving Coverage and Payment Policies to Ensure Adequate Access to Necessary Services and Supports**

Medicaid in all states will expand dental coverage for adults with IDD or other disabilities to include extensive coverage27 inclusive of more frequent preventive visits, interventions, and payment for longer visits.

Public and private health insurance companies offer new or enhanced benefits for children and adults with IDD or other disabilities, inclusive of health, vision, and dental coverage (eg, more frequent preventive visits and payment for visits that last more than 1 hour).

In the next 5 y, IDD advocates will identify at least 2 policy levers (eg, mental health parity laws, designations of underserved populations; law enforcement policies) to make integrated mental/physical care available to and effective for people with IDD.

CMS funds 1115 waivers for housing benefits via short-term Medicaid rent assistance in at least 10 states that support people experiencing food insecurity, housing insecurity, or people who are economically and medically vulnerable.

Medicare, Medicaid in 25 states, and the 3 largest insurers2 offer coverage for technology tools to enhance safety and health in the home.

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Medicare, Medicaid in 25 states, and the 3 largest insurers2 offer health care professionals extra payments to address personalized social drivers of health.

CMS or 5 states conduct a demonstration project in Medicare and/or Medicaid that incorporates individualized health and well-being life plans to address social drivers of health.

100% of individuals with IDD who have experienced sexual assault or trauma, regardless of disability, are supported and provided accommodations to access all appropriate mental health and other services.

Medicare, Medicaid, and the 3 largest insurers2 will provide universal coverage for sexual assault treatment, including reproductive, physical/dental, and mental health sequelae to people with IDD.

Medicare, Medicaid in 25 states, and the 3 largest private insurers2 all include people with IDD on advisory councils, workgroups, and other stakeholder meetings, and support them to meaningfully lead or colead the design of payer’s programs and policies serving people with IDD.

To enhance payment on the actual experience of care, the major patient experience surveys must include design, outreach, and analytic elements that make the surveys meaningfully accessible to, and private for, people with IDD (eg, people who use assistive devices, plain language, use of graphics and illustrations, audio).

Medicare, Medicaid in 25 states, and the 3 largest insurers2 will offer coverage for colocation of key services (eg, mental health imbedded into primary care; dental and primary care).

Medicare, Medicaid in 25 states, and the 3 largest insurers2 will offer coverage for an independent system navigator imbedded into the care setting, addressing needs across medical and community sectors, and across different lifespan transitions.

Medicare, Medicaid in 25 states, and the 3 largest private insurers2 offer higher payment to clinicians to have longer visits with people with IDD, which may be inclusive of spending time with caregivers/partners when they attend visits.

Federal agencies or other national organizations, in collaboration with community members, will develop a framework for an online, searchable database with community resources organized by areas of need, including emergency services.

Abbreviations: CMS, Centers for Medicare & Medicaid Services; EHR, electronic health record; IDD, intellectual and/or developmental disability.

* The 3 largest insurers were defined as those having the greatest total enrollment across insurance products.
Lastly, the IIDDEAL model calls for investments in new tools and shared infrastructure (Box 3). This includes ways to share data across service sectors; directories of local social and community resources such as housing and vocational support; a repository of analyses on the relative effectiveness and return on investment of different tools, service models, and payment strategies; and new technologies that improve health and well-being for people with IDD, such as digital tools that enhance safety at home and generate early alerts of emerging clinical problems.

### Box 3. Individuals With IDD Engaged, Aligned, and Leading National Goals for 2035 on Development of an Adequately Prepared Clinical Workforce and Other Shared Infrastructure to Address Priority Supportive Elements

The federal government designates people with IDD as a medically underserved population and offers incentives for clinicians to serve this community. At least 25 states require a certification/continuing education program for primary care and mental health professionals on how to serve people with IDD with co-occurring mental health and substance use disorders based on their preferred way of receiving help, emphasizing the value of self-determination. 25 States identify resources for and support the development of a qualified workforce through the implementation of a psychiatric/mental health consultation or colocaction model, especially for primary care professionals (eg, ECHO model). General principles of accessible, empowering, nonstigmatizing, and trauma-informed care are integrated into training curricula for health care and other service professionals, including via direct experience with people with IDD and caregivers/partners. Create an incentive-based clinician certification on person-centeredness, respect for persons and presumption of ability/assent/consent, that rewards clinicians for investing in learning how to support these concepts in practice. The accrediting and licensing boards in all health care professions will include IDD content across the lifespan in at least 10% of competency requirements, some of which may be IDD focused, and some which may address common conditions that people with IDD have, in the learning continuum from training into practice. Health professional students and trainees in all prelicensure programs will receive mandatory training in areas of importance to people with IDD and caregivers/partners, through existing models that partner with community experts as part of the training teams and interactive patient training experiences with people with IDD, and practice using tools that support better care for people with IDD (eg, augmentative and alternative communication devices, telehealth).

Increase 10-fold the number of health care and dental practitioners who have IDD. 50% of primary care clinicians and reproductive health clinicians routinely screen and provide developmentally appropriate resources and/or education about basic sexual, reproductive, gender, and parenting support across the lifespan to people with IDD. 100% of public high-school youth with IDD are required as nondisabled students to be included in the standard health curriculum. Each state establishes and maintains a directory of in-person and/or online self-advocate peer support groups that qualify to receive payment by payers and regulators, including in rural and urban areas. Directories are accelerated through state-to-state learning networks. Development of a technology solution to address data sharing across sectors of care including but not limited to educational, medical, dental, and community care for promoting continuity and coordination of services.

Identify 5 key outcomes from this framework that community members say have the biggest gap in effective interventions and make investments to develop new interventions as solutions. The size of investments should be proportionate to the size of the need to people with IDD, families, payers, clinicians due to the gaps. Interventions and tools should be developed in partnership with people with IDD families, universities, payers, clinicians, and government, and leverage crowdsourced platforms that include personal experiences. Creation of centralized, accessible databases that house information on the value (ROI) of different payment approaches, care models/services (eg, comprehensive primary care models), and interventions/tools. Value/ROI may be defined differently for each stakeholder group. Production of at least 30 national press stories, television shows, movies, national social media campaigns, advertisements by national companies, foster/adoptive agencies, and/or other major media releases that positively demonstrate people with IDD as parents, and promote influencers with IDD. Expansion of existing curricula on parenting for people with IDD by a coalition that includes public agencies, community members that include peer mentors who are IDD parents, birthing service professionals, and community-based organizations. The enhanced curriculum is implemented by at least 25% of all birthing centers, hospitals, pregnancy-care practices, independent professionals who support birthing, and state agencies that offer parenting resources.

**Abbreviations:** IDD, intellectual and/or developmental disability; ROI, return on investment.
Challenges and Opportunities for Improving Data Collection and Quality Measurement

The generalizability of priority health outcomes in IIDDEAL, and the alignment of proposed patient experience elements with current efforts at CMS28 and other federal agencies, presents several opportunities for policymakers. These include investing in developing new patient experience metrics relevant for broad populations and adapting existing goal attainment metrics for the IDD population. Additional measure development would be necessary before CMS and other payers could address certain clinical priorities identified in IIDDEAL,29 such as the need for pain detection and management or sexual/reproductive health. Sponsors of patient experience surveys will need to address undersampling of people with IDD, improving survey accessibility with graphical or other accommodations, and strategies for sharing results with respondents, which is key to building and maintaining trust. Because the Consumer Assessment of Healthcare Providers and Systems survey (CAHPS) has broad industry uptake and produces national benchmarks, it is particularly important for CAHPS to adapt29 by modifying or removing some current questions to accommodate new ones aligned with community priorities.30

Optimal measurement requires reliable and structured data collection. Payers would need to offer clinicians sufficient incentives to shift their mindset from checklists of guideline-based processes to one that prioritizes capturing a person's goals and engaging in shared or supported decision-making as recommended by AHRQ. More generally, payers could consider novel data collection methods (eg, via email, apps, direct messaging) that conform with data standards such as Fast Healthcare Interoperability Resources (FHIR), Health Level Seven (HL7), and United States Core Data for Interoperability (USCDI),30,31 understanding that non–EHR-based data sources would necessitate mechanisms for sharing results with clinical teams and payers in actionable formats.

Fundamentally, meaningful measurement and accountability cannot occur without accurate, representative data on the IDD population, which currently does not exist. In the short-term, measure development and quality measurement may need to rely on data describing subpopulations such as those in Medicaid, Medicare, or a specific clinical institution.

Critical next steps thus include:
• Building a standardized dataset on people with IDD.
• Creating data tools to better identify people with IDD.
• Building coalitions of diverse patient advocacy groups (eg, people with IDD, those who are frail and/or elderly, patients with cancer, ideally of diverse races and cultures) that would benefit from new metrics, to advocate for focused commitment from government and others for funding and policy alignment.
• Reviewing currently available quality performance measures to identify gaps.
• Defining the testing needed to develop and validate new measures.
• Engaging other key policymakers and stakeholders, including the Office of the National Coordinator on Health Information Technology.
• Creating a roadmap for holding health care organizations accountable for outcomes (such as financial incentives or public reporting) once measures are available.

Challenges and Opportunities for Improving Coverage and Payment for Services

Inconsistencies in insurance laws and regulations across public and private payers create barriers to predictable access to needed services for people with IDD, especially because their insurance coverage changes across the lifespan. Medicare, Medicaid, and HCBS waivers place different restrictions on benefits such as dental care, mental health care, or vocational support. Variation in state coverage requirements for Medicaid and commercial plans disincentivize large or sustained investments by national health plans. Policies that shift with political election cycles further disrupt long-term planning by payers and clinical organizations.

Regulators and payers can design new processes to ensure that community members help shape policies. Lawmakers could reexamine restrictions under the Paperwork Reduction Act that
severely limit the degree to which federal agencies and federally funded entities can gather community input. Federal and state agencies, and managed care plans could engage community members in official roles to review Medicare and Medicaid plan bids and evaluate plans’ performance. Doing so would entail accommodating different communication needs in meetings and documents, reassuring community members expressing opinions would not jeopardize their public benefits, and partnering with community advocacy groups to build trust.

Health inequity for people with IDD begins with data inequity, which reflects data inconsistency, incompleteness, and the degree to which people with IDD interact with the health care system. Developing consistent definitions of IDD across federal programs and agencies32 is the first step toward building data tools that comprehensively identify the IDD population. An IDD Data Equity Initiative that coordinates public and private sector activities would help align investments and activities.

Critical next steps include:

• Federal designation of people with IDD as a medically underserved population, to increase access to health care professionals and steer greater resources to clinical organizations serving this population.
• Payment for community-based organizations to become routine members of health care teams.
• Incentives for health care professionals and clinical organizations to close referral loops (getting people with IDD through the “last mile” from referrals to receiving social or other services they need).
• Eliminating wait lists for HCBS and other Medicaid-funded IDD services, and/or making sure that people with the most urgent needs get access first.
• Reducing administrative burden on clinical organizations and health care professionals so they can focus on care relationships and solving problems.
• Ensuring a safety net of services and support for when caregivers/partners age or die.

Challenges and Opportunities for Improving the Clinical Workforce and Building Shared Infrastructure
Driving large-scale culture change among clinicians and preparing them to serve people with IDD requires a broad coalition working for collective impact. Action to Build Clinical Confidence and Culture (ABC3) is an example of such a coalition.23 Members of such coalitions should include groups with influence and/or authority to set standards for training curricula, incentives for training, and clinician credentialing. Clinical training programs focusing on disabilities,33 groups offering peer technical assistance,34,35 and leaders of major training initiatives36 can all partner with public and private funders to promote direct exposure to people with IDD and social media campaigns that target clinicians with positive messages about people with IDD. Lastly, although most of our conversations with partners revolved around licensed clinicians, some goals may be better addressed by community health workers. Future work should aim to identify how community health workers can help grow workforce capacity.

The US needs to invest in new, shared data infrastructure that supports better research, clinical care, and coverage and payment for services. New data infrastructure should be coordinated with the Office of the National Coordinator on Health Information Technology to align with national standards, and with existing efforts to improve data on IDD, including the Administration on Community Living’s I/DD Counts initiative,37 leveraging federal agency strategies for measuring and tracking population-level outcomes.

New technology solutions need to focus on solving problems considered most important by the IDD community and include their perspectives in all aspects of the design and use of new resources. Tool developers could include the IDD community in setting standards to ensure that tools are ethically designed and used, adhering to core disability values. New technology tools would ideally be accessible by all people with IDD and caregivers/partners.
Creating shared knowledge on the relative value and return on investment of different services, payment approaches, technologies, and other tools will require leadership from federal and state policymakers. Organizations that fund IDD research could collect data on outcomes and model what features of different tools/approaches predict higher returns.

Federal and state governments could collaborate to gather and analyze data on approaches that integrate services across sectors, such as clinical and HCBS services.

Critical next steps include:
• Developing and implementing campaigns targeting clinicians in practice and those in training to drive culture change through acquisition of basic skills in serving people with IDD.
• Finalizing a national data definition of IDD for consistent application in research, clinical care, and financing/payment policies.
• Investment in centralized data sources on people with IDD.
• Engagement with the IDD community, technology developers, and other health care stakeholders to identify key gaps in care where new technology solutions could be most valuable and effective.

Conclusions

Achieving the goals identified in IIDDEAL to improve outcomes for people with IDD will require ambitious, multifaceted, and coordinated efforts across public and private sectors. These efforts will require long-term investments and commitment and an openness to questioning and changing current laws and regulations, disrupting current practices in service delivery and reimbursement, and setting high expectations for change.

Similar movements to improve mental health care have encountered significant challenges, including inadequate reimbursement for primary care services that integrate and address the whole person with complex needs, reluctance among clinical organizations to collect patient-reported data, and a national measurement industry that sets standards with the unintended consequence of costly barriers for the adoption of meaningful measures. However, policy and clinical fatigue with traditional measurement approaches and the development of new methodologies for goal attainment metrics offer a new opportunity to press the issue.

The level of health care system transformation that IIDDEAL contributors envision will not happen without leadership that broadly and consistently promotes positive views of people with IDD, focusing on their strengths and capabilities; and illustrates that addressing the needs of people with IDD will create a better health care system for everyone.

ARTICLE INFORMATION

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REFERENCES


