BARRIERS TO CARE:

A Comprehensive Analysis of Health System Challenges for People with Intellectual and Developmental Disabilities in Pennsylvania

THE SOCIAL IMPACT STUDIO | Special Olympics Pennsylvania | The Arc Pennsylvania

Introduction

In principle, healthcare should be compassionate, competent, and universally accessible. However, substantial gaps remain for many individuals, particularly those in vulnerable populations. This report focuses on one group that often faces these challenges: people in Pennsylvania with intellectual and developmental disabilities (IDD).

Despite representing a significant portion of the population, individuals with IDD face substantial health disparities. For example, people with IDD in Pennsylvania experience higher rates of asthma (10.5%), yet the state does not routinely collect data on how such conditions specifically affect this population. While 99% of adults with IDD have health insurance, barriers like delayed care, denied services, and lack of coordinated support continue to affect outcomes. Their needs are often invisible in health planning, and systems don't always include people with IDD in decisions that affect their care.

We are a collaborative team of researchers, advocates, and community partners working through the Rosemary Collaboratory Initiative, which brings together Special Olympics Pennsylvania, The Arc of Pennsylvania, and other disability advocacy organizations. The Rosemary Collaboratory is a global initiative focused on documenting and addressing health barriers faced by people with intellectual and developmental disabilities worldwide.

This Pennsylvania report is part of a coordinated effort across multiple states and countries to build a comprehensive understanding of health challenges and solutions for people with IDD. This coordinated effort began with a health systems-level assessment (SLA), a comprehensive evaluation tool that examines how well health systems serve people with IDD, developed collaboratively by Special Olympics International and the Missing Billion Initiative (MBI), a global effort to address the lack of health data and services for people with disabilities.

Through this partnership, we have reviewed policies, conducted desk research, and gathered stories and insights from many sources: people with IDD, their families and caregivers, healthcare professionals, and experts in the field. By combining findings from our Pennsylvania surveys, personal stories, and expert recommendations, we hope to give a full and honest picture of what's working, what isn't, and what needs to change. Our findings will contribute to a broader global dialogue and inform both local and international policy recommendations for improving healthcare access and quality for people with IDD.

This report goes beyond quantitative data and policy analysis to center the lived experiences of individuals with IDD: their challenges, resilience, and aspirations. We want to share their experiences, highlight the obstacles they face, and show why it's so important to rethink how our health system serves people with IDD.

Ensuring equitable and accessible health for individuals with IDD requires collaboration among policymakers, healthcare providers, advocates, and the broader community. This report is meant to help us understand the issues more deeply and inspire us to take action.

Ultimately, the way we care for our most vulnerable community members reflects the values and integrity of our society. It is our collective responsibility to ensure that all individuals receive the dignity, respect, and quality care they deserve.

Executive Summary

Across Pennsylvania, people with intellectual and developmental disabilities (IDD) face significant barriers when seeking access to supports, services, and systems that impact health outcomes. Through extensive surveys, interviews, and case studies, we've uncovered a complex web of challenges affecting both individuals with IDD and the healthcare professionals who serve them. The voices represented in this report reflect more than just data; they convey lived experiences, including the frustration of seeking appropriate care, meaningful encounters with compassionate providers, and the everyday resilience of individuals with IDD as they navigate a health system that often falls short of addressing their unique needs.

Our findings highlight critical gaps in healthcare worker training, communication barriers during medical appointments, and systemic issues like inadequate insurance coverage and fragmented care coordination. Yet amidst these challenges, we also discovered promising practices and innovative programs that offer pathways toward more inclusive health.

This report aims to identify problems as well as present actionable recommendations developed through collaborative efforts with disability advocates, healthcare providers, and most importantly, people with IDD themselves. By centering their lived experiences and expertise, we aim to catalyze meaningful change across Pennsylvania's healthcare landscape.

Executive Summary (Plain Language)

This report is about the health outcomes of people with intellectual and developmental disabilities (IDD) in Pennsylvania.

We talked to many people with IDD, their families, and healthcare workers. We learned that getting good healthcare can be hard for people with IDD.

Here are some of the main things we found:

- Many healthcare providers say they did not get training about talking to and caring for people with IDD.
- Sometimes, people with IDD do not understand what their doctor says.
- Some people cannot afford care when needed, and others don't have insurance.
- Getting to the doctor or finding the right care can be confusing or take a long time.
- People with IDD want to be treated with respect and to be included in decisions about their health.

But we also found some good things:

- Some programs and doctors are making healthcare better for people with IDD.
- There are ideas and plans to help make things easier and more fair, like better training for doctors, starting a group of people with IDD to share their opinions with government, and collecting more data about health needs.

What can you do next?

- Share your opinions about how healthcare can better serve people with IDD.
- Participate in programs that support people with IDD to lead healthcare conversations and health opportunities in your communities.
- Visit the [Special Olympics Pennsylvania Rosemary Collaboratory webpage,](https://specialolympicspa.org/rosemary-collaboratory) (https://specialolympicspa.org/rosemary-collaboratory) share it on social media, and sign up to receive updates and participate in activities

This report shares these stories and ideas. We hope it helps make healthcare better for everyone with IDD in Pennsylvania.

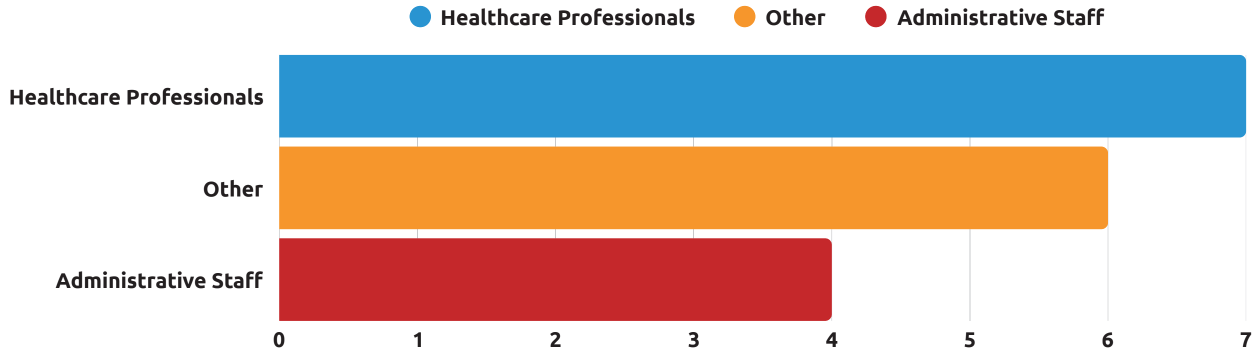
1. The Current Status of Health Services – Demographics and Perceived Challenges

The foundation of understanding any health system lies in its demographics and the initial perceptions of those it serves. Our inquiry into healthcare for individuals with IDD in Pennsylvania begins with a landscape analysis of the current health system, incorporating two pivotal surveys: one designed to obtain the perspective of healthcare professionals and the other directly engaging individuals with IDD. While each survey offers a unique perspective, together with additional background research, they paint a clear picture of a health landscape filled with significant challenges but also rich with opportunities for meaningful change and improvement.

1.1 The Health Workforce Perspective: Insights from Professionals

The "Health Workforce Survey on Barriers to Caring for People with IDD Preliminary Data Pennsylvania" provides initial insights from a small but diverse group of healthcare professionals (27 respondents) regarding perceived obstacles to delivering effective care. While this sample size limits the generalizability of findings, combined with additional research and data, it offers valuable preliminary perspectives from experienced and highly educated individuals.

Professions of Healthcare Workforce Survey Respondents



When asked how often they provide care to people with IDD, 15% indicated they ‘Never’ provide care to people with IDD, with 48% of providers delivering care to people with IDD at least monthly.

When healthcare professionals were asked to identify and rate key barriers on a scale of 1 (not a challenge) to 5 (key challenge), they highlighted challenges across both systemic and service-delivery dimensions. Regarding broader systemic barriers, healthcare professionals identified several key concerns:

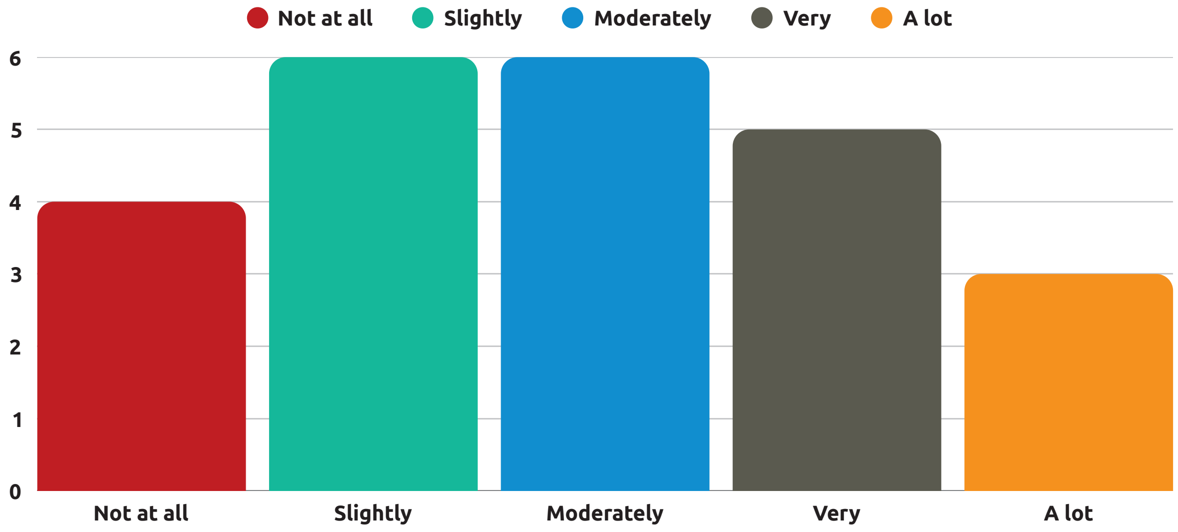
Health financing challenges topped the list (mean rating 4.29 out of 5), showing providers feel they lack adequate financial incentives to care for people with IDD. Pennsylvania Medicaid offers targeted reimbursement adjustments, most notably dental benefit-limit exceptions to cover extra sedation or assistive devices, but these are limited to specific services and are rarely matched by commercial insurers. As a result, many IDD-related services remain underfunded.

Another major concern was the **unclear understanding of the health needs** of people with IDD, including the absence of clear clinical care standards (average rating of 4.00). This highlights the urgent need for consistent, standardized guidelines.

Representation was also a problem, with people pointing out the lack of formal involvement of individuals with IDD in health decision-making (average rating of 3.86). Similarly, in terms of **governance**, the needs of people with IDD are often left out of state and local health policies and plans (average rating of 3.67). These findings show that people with IDD are often systematically excluded from key health conversations and decisions. Missing Billion systems-level assessment (SLA) data for Pennsylvania scored just 0.625 out of 1.0 on cross- department coordination, noting that while the independent Pennsylvania Developmental Disabilities Council (PDDC), a federally-mandated state council that advocates for people with developmental disabilities, includes self-advocates and caregivers, no formal interagency taskforce exists within state government to embed IDD voices in health policy-making.

Specialized IDD training should be provided to care providers periodically (mean 4.75), and **more time should be allocated for consultations with IDD patients** (mean 4.75). These top-ranked priorities echo findings from the SLA, which similarly called for routine, structured training programs and adjusted appointment lengths to ensure high-quality care for people with IDD.

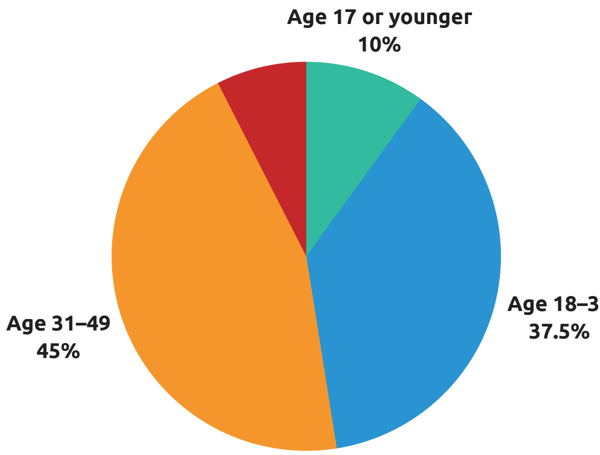
These responses send a strong message: the current healthcare system isn't fully prepared to meet the needs of people with IDD. Key problems include lack of financial support, insufficient specialized training, lack of clear standards, and systemic exclusion of IDD voices.


How much did your degree specialize in IDD?

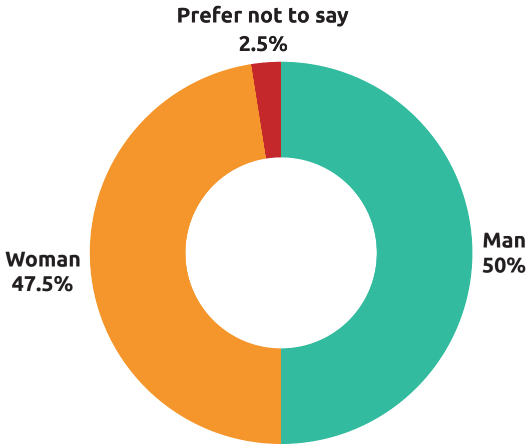
1.2 The Patient Perspective: Voices from the Community

The "Barriers to Care for People with IDD – Pennsylvania – December 2024" survey provides invaluable direct insights from individuals with IDD themselves, or those completing the survey with caregiver support. With a sample size of 40 participants, this group is larger than the health worker survey, though it still represents a relatively small cohort. Additional data gathering and research has been utilized to support its use for broad generalizability.

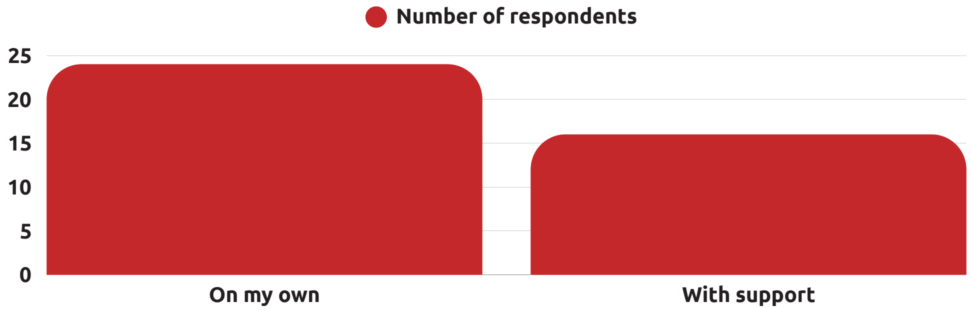
Age of Survey Respondents



Gender of Survey Respondents



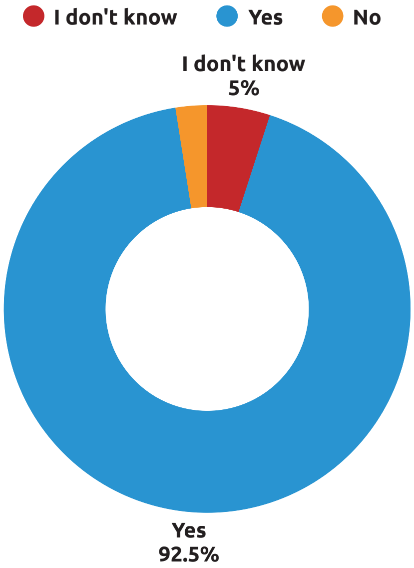
How Respondents Completed the Survey



Most survey respondents, 93%, reported having a person or place they go to for care or healing. The 'Doctor's office' was the primary location for 49% (18 respondents), followed by 'Hospital' at 25% (9 respondents) and 'Local clinic' at 23% (8 respondents).

This aligns with the 2023 National Core Indicators report for Pennsylvania (a national survey that tracks outcomes for people with IDD), which found that 91% of adults with IDD had received a routine preventive check-up in the previous 12 months[1].

Do you have a person or place you go to for care or healing?



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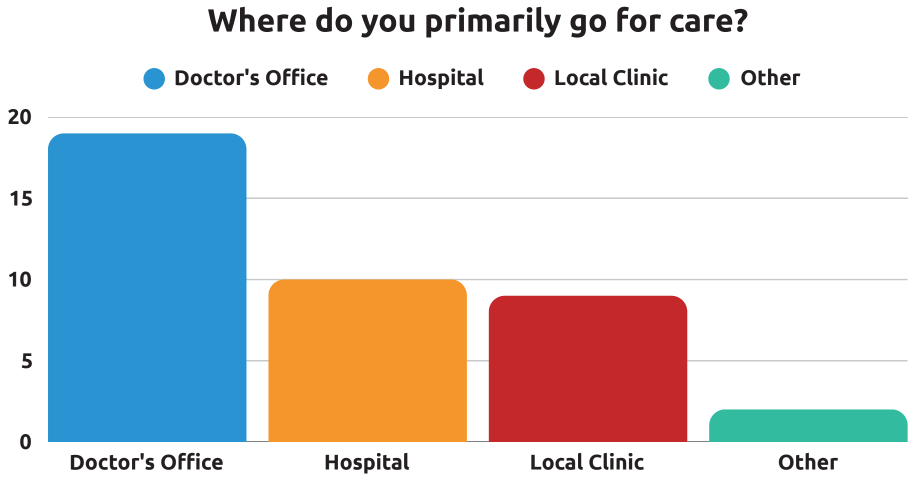
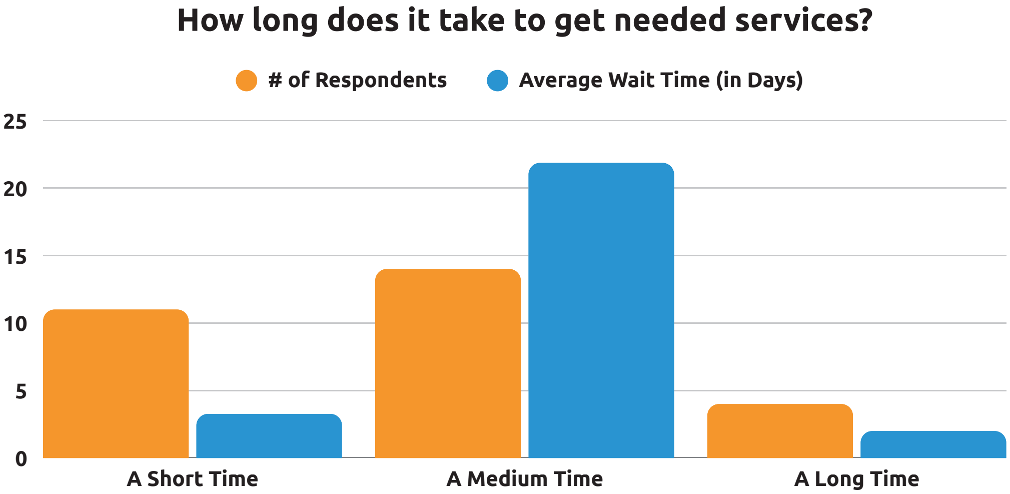
[1] National Core Indicators - Pennsylvania State Data (2023). Retrieved from: https://legacy.nationalcoreindicators.org/state-data/pennsylvania



Likewise, the 2022 National Health Interview Survey shows that 88% of adults with reported cognitive disability had visited a healthcare provider in the past year[2]. These data underscore that individuals with IDD in Pennsylvania engage regularly with formal healthcare services.

However, the journey to care is often fraught with delays. When asked about the time it takes to get needed services, 50% reported "A medium time," and 6% "A long time." For "a short time," the mean wait was 3.27 days; for "a medium time," it stretched to 21.86 days; and for "a long time," it was 2.00 days.

The "a long time" category showed an unexpectedly short average of 2 days, which may reflect a data anomaly or a very small subset of respondents. This discrepancy suggests significant variability and potential for prolonged waits for critical services.



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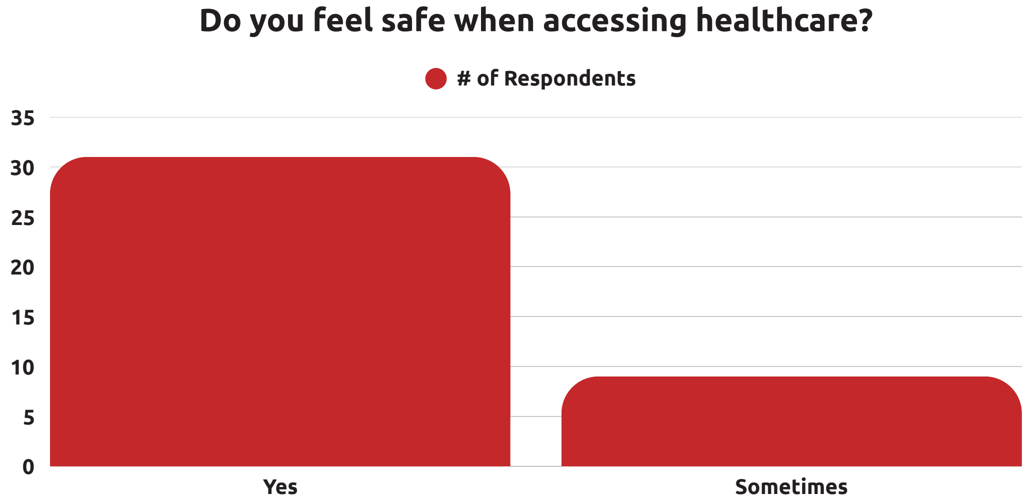
[2] U.S. Centers for Disease Control and Prevention (CDC) (2023). Retrieved from: https://www.cdc.gov/nchs/nhis/documentation/2022-nhis.html?CDC_AAref_Val=https://www.cdc.gov/nchs/nhis/2022nhis.htm

Safety, a fundamental aspect of care, generally fares well, with 77% feeling safe in healthcare settings or seeking health services. However, 23% sometimes do not, indicating areas for improvement in creating truly safe environments. A substantial 67% (27 of 40) reported needing assistance for appointments, including 15 needing help throughout the entire journey, 9 needing directions upon arrival, and 7 needing assistance with the check-in process. This highlights a critical need for enhanced navigation and logistical support. Travel times to appointments also varied, with 62% reporting a "short time" (mean 18.93 minutes), 34% a "medium time" (mean 29.44 minutes), and 3% a "long time" (mean 80 minutes).



Waiting times at the facility itself before seeing a provider were generally "short" for 70% (mean 18.00 minutes), but 22% waited a "medium time" (mean 26.67 minutes), and 7% a "long time" (mean 110.00 minutes). A wait of nearly two hours (110 minutes) is unacceptable and clearly poses a significant barrier.

When asked what would help individuals with IDD receive better healthcare, the top responses were:

- "Getting to visit more easily" (8 respondents)
- "More information" (7 respondents)
- "Feeling more comfortable and welcome at a healthcare provider's office" (6 respondents)
- Receiving more financial and/or government support to pay for healthcare (6 respondents)**

**According to a 2025 analysis by the Medicaid and CHIP Payment and Access Commission (MACPAC) of the 2021–2024 National Survey on Health and Disability, among U.S. adults aged 18–64 with intellectual and developmental disabilities (IDD), 54.7% had some form of Medicaid coverage (including those with dual Medicaid/Medicare and Medicaid with private insurance)[3].

Participants also received an opportunity to list additional themes related to accessing health services. These "Other" included long specialist wait times (3-6 months) for one individual, a desire for providers versed in rare disorders or IDD, need for care coordinators, and insurance denials. These qualitative responses provide deeply personal insights into the systemic frustrations experienced by individuals with IDD.

2. Weaving the Narrative: Challenges and Best Practices in Healthcare Delivery

The quantitative data provides a basic outline, but it is the lived experiences and personal stories of individuals with IDD and healthcare professionals working in the system that bring the full picture of the healthcare experience to life. When we combine the data with these lived experiences, we begin to truly understand what healthcare feels like for this community. This chapter explores the real challenges people face, the promising practices already in place, and creative ideas for making things better, turning statistics into a meaningful story of what is and what could be.

[3] MACPAC Issue Brief (2025). Retrieved from: https://www.macpac.gov/wp-content/uploads/2025/06/Access-in-Brief-Differences-in-Demographics-and-Access-for-Adults-with-IDD.pdf

2.1 The Intersecting Challenges: A Deeper Dive

The Crux of Compensation and Time Constraints

One of the strongest concerns shared by healthcare professionals is the lack of proper financial support in the system. Many pointed to the insufficient incentives for caring for people with IDD (average rating of 4.29 out of 5), along with the pressure of limited time during appointments, as major barriers to quality care.

An optometrist noted that eye exams for individuals with IDD routinely take two to three times longer than standard appointments, yet reimbursement rates do not reflect this extra time. Still, providers are expected to deliver care in the same short window, without additional support.

This creates a system that prioritizes productivity over people. One physician described it as being pushed into a "transactional rather than human" model, where providers are constantly rushed, and patients are left feeling like an afterthought.

The impact is real and personal. John, a Special Olympics athlete with Autism Spectrum Disorder (ASD) based in Philadelphia, shared that he often feels "rushed and anxious" during appointments and doesn't get enough time to fully understand what's being said. This goes directly against what patients say they need most: more time for explanations and a calm, simple approach to care.

The Training and Knowledge Gap

Both surveys unequivocally highlight the deficiency in healthcare worker training. "Inadequate healthcare worker training" received a mean of 4.38 from professionals, and a majority (73%) of professionals admitted to having completed "None" of the Special Olympics online courses.

In our clinician focus-group discussions, participants noted the lack of 'correct training in graduate school' for specialists. This translates into a lack of confidence and sometimes even "fear, dread, concern" among providers when faced with patients they "do not often see or understand," leading to a "we're going to fall behind" mindset that impedes quality care.

The consequence for patients is a perception that not all providers "understand and support their specific needs," and difficulty finding doctors specializing in IDD.

Communication – The Unseen Barrier

When asked if they understood their provider, 46% of individuals with IDD responded "Yes," 50% responded "Sometimes," and 4% responded "No”. This communication gap is profound, leading to confusion about instructions for 69% of respondents. Clinicians acknowledge this, with a registered dietitian noting, "Teaching nutrition is very hard because of [the] communication process for people with IDD, people not trained in communicating respectfully and in plain language and creative ways." Patients' expressed needs for "clearer instructions" and "help making decisions" (as reported in the survey priorities) speaks volumes about this unmet need.

Accessibility Beyond the Ramp

Physical accessibility (“poor accessibility of health facilities”) remains a challenge, but the surveys highlight a broader definition of accessibility. Transportation is a major hurdle for 67% of individuals with IDD, who need “help throughout the whole journey from home to the healthcare provider”. “Getting to visits more easily” was a top patient priority. Beyond physical access, the “welcoming” nature of waiting rooms, clear signage, the initial interaction with administrative staff, plain language communication, additional time for appointments, and alternative forms of communication are all identified by clinicians as critical, yet often overlooked, elements of accessibility that can cause anxiety for patients with IDD.

Stigma, Attitudes, and Equitable Treatment

The prevalence of "negative attitudes and stigma within health services" is a deeply concerning finding. Individuals with IDD report that only 52% feel they are "treated the same as other patients, without IDD". Jesse, an individual with Attention Deficit/Hyperactivity Disorder (ADHD) and autism, experiences misunderstandings and negative attitudes about his disabilities from both strangers and people he knows, which can leave him emotionally closed.

Fragmentation and Lack of Coordination
The healthcare system is described by clinicians as "very fragmented, very siloed". The absence of a "hub to coordinate all these pieces" means that information flow is poor, leading to issues like under- or over-medication. Marisa and her mother highlight the constant need for her mother to act as a “main advocate” scheduling appointments, updating records, and ensuring all specialists are aware of her full medical history because “this coordination doesn’t just happen by chance”. This burden on caregivers is immense and points to a system not built for integrated, holistic care.

Policy and Systemic Barriers (Beyond Training)
Beyond training and funding, policies themselves create challenges. The "lack of clarity about the health-related needs of people with IDD, like clinical care standards" is a major structural flaw. Reimbursement policies that don't account for the extra time needed for IDD care, limits on prescribed medical aids (e.g., "one pair of glasses per year makes it hard for parents when kids may break them all the time"), and fragmented data systems that prevent a holistic view of the patient are all cited. The absence of a "statewide, interagency, government-led vehicle for providing people with IDD and their caregivers with information and support for making healthcare decisions" is a glaring policy gap.

2.2 Glimmers of Hope: Best Practices and Innovative Solutions

Despite the significant challenges, the report also unearths a number of existing best practices and innovative approaches that offer pathways forward, demonstrating that effective IDD care is not only possible but already being implemented in pockets across Pennsylvania.

Exemplary Models: The FAB Center and IM4Q Programs

Pennsylvania is home to several such innovative programs; two leading examples are the FAB Center and the Independent Monitoring for Quality (IM4Q) program.

The Jefferson University FAB Center

Operating under the Department of Family and Community Medicine at Jefferson University in Philadelphia, Pennsylvania, the FAB Center provides comprehensive healthcare for adults with IDD.

Overview of Services and Supports Provided: The program accepts most major insurance carriers and addresses critical gaps in adult complex care by offering services such as extended visit times, team-based care, and coordinated services across medical specialties, ensuring well-rounded and person-centered support. To qualify for services, an individual must have had a complex, childhood-onset condition prior to the age of 22, which may include other complex diagnoses not exclusively IDD.

Key interventions focus on supporting patients as they transition from pediatric to adult care, navigating complex healthcare systems, and addressing challenges like diagnostic diagnostic overshadowing (when health problems are incorrectly attributed to a person's disability rather than being properly diagnosed) and inadequate reimbursement models.

The program collaborates with state agencies such as the Office of Developmental Programs (ODP) and partners with local organizations and healthcare providers to advocate for policy reforms. The FAB Center is part of an ongoing effort to develop sustainable models for adult IDD care, building on years of experience in family medicine. By focusing on advocacy, care coordination, and patient-centered practices, the center is setting a standard for inclusive healthcare systems.

Results and Achievements: The FAB Center has notably improved healthcare for adults with IDD. Its major successes include:

- **Extended Visit Times:** Allowing providers, trained to work with patients with complex care needs, to better understand and address unique needs, leading to more accurate diagnoses and improved treatment outcomes tailored to specific circumstances.
- **Team-Based Care:** Enabling seamless collaboration between providers, specialists, and support staff to comprehensively address medical, behavioral, and social needs.
- **Smooth Patient Transitions:** Partnering with pediatric providers to create structured approaches, ensuring continuous care during the challenging transition from pediatric to adult care.
- **Systemic Advocacy:** Addressing healthcare system barriers like insurance policies that overlook the time-intensive nature of IDD care, pushing for better reimbursement models, and actively paving the way for sustainable adult complex care systems.
- **Patient Support:** Assisting patients in securing required authorizations for treatments, medical equipment, and obtaining photo IDs for transportation, increasing accessibility. Families and patients consistently report positive outcomes, appreciating the center's efforts to guide them through complex healthcare systems.

Challenges and Opportunities: A primary challenge for the FAB Center has been the **lack of established adult complex care models** for individuals with IDD, leaving providers without a complete framework. **Insurance policies** are another major hurdle; reimbursement models often fail to account for the time and complexity of IDD care, making extended visits difficult to fund. Prior authorization and billing practices often delay access to necessary treatments.

Despite these challenges, the FAB Center continues to provide care, with expanded staffing (social workers, nurses), absorbing administrative burdens and advocating for enhanced payment models for care coordination. Their work highlights the potential for meaningful progress when care systems prioritize inclusivity and person-centered approaches.

Ideas for the Future of Care: The FAB Center emphasizes the critical need for adult healthcare systems to provide the same level of comprehensive, coordinated care for adults with IDD that is more commonly found in pediatric care settings. They stress building structures for adult complex care, improving care coordination, and ensuring seamless transitions. Addressing systemic barriers like reimbursement challenges and misdiagnosed conditions is crucial for accessible and equal care. While immediate costs may seem high, long-term investments in coordinated, person-centered systems can reduce risks, improve outcomes, and create a sustainable healthcare framework for adults with IDD.

The Independent Monitoring for Quality (IM4Q) Program

Implemented in partnership with Temple University's Institute on Disabilities and the Pennsylvania Office of Developmental Programs (ODP), IM4Q is a vital program ensuring that the voices of individuals with IDD are heard. Its goal is to improve the quality of life and services for individuals with IDD by gathering their direct input and using it to propose policy changes, ensuring services genuinely and regularly meet their needs and preferences

Overview of Services and Supports Provided: The IM4Q program conducts about 5,000 interviews each year, engaging directly with individuals receiving services from the Pennsylvania Department of Human Services, their families, and others who know them well. By including people from diverse living situations (family homes, small group settings, larger residential centers), IM4Q captures a broad range of experiences. Temple University's Institute on Disabilities partners closely with ODP to coordinate and analyze the data. Uniquely, local teams include people with disabilities and family members as interviewers. The program receives matching federal and state funds, promoting a more person-centered system by connecting ODP, county IDD offices, supporting coordination organizations, and provider agencies.

Results and Achievements: For over two decades, IM4Q's annual data collection has guided Pennsylvania's efforts to improve health strategies for individuals with IDD. This steady feedback loop allows ODP to track progress, identify immediate needs, and implement reforms. Key successes include:

- **Concrete Policy Changes:** Data has prompted policy changes like ensuring communication devices are more readily available, improving civic participation (e.g., voting registration), and increasing competitive and integrated employment opportunities.
- **Amplifying IDD Voices:** IM4Q ensures individuals with IDD have a direct voice in shaping services to align with personal goals, leading to participants feeling "heard." The engagement process, conducted by trained monitors with personal connections to the disability community, builds trust and yields more accurate data.
- **"Considerations" for Individual Improvement:** Interviewers record individual "considerations" (e.g., getting a job, learning a computer), which are then addressed by county support systems to improve personal lives.
- **Shift in Service Culture:** Continuous quality improvements have fostered a service culture where providers, policymakers, and advocacy groups utilize IM4Q data, highlighting trends and progress against national benchmarks (National Core Indicators®).
- **Adaptability During Crisis:** The program successfully transitioned to virtual interviews during COVID-19, preserving its value as a continuous feedback tool and enabling the state to monitor IDD well-being during a challenging time.

Challenges and Opportunities: One challenge IM4Q faces is capturing a diverse set of voices representing the broad IDD population, expanding beyond certain settings to include individuals with autism and those living with families. This broadening introduced complexity in outreach and interviewing. Survey fatigue has also been identified as a challenge, leading to strategies to streamline the process and broaden sampling. The shift to virtual interviews during COVID-19 was both a challenge (requiring quick adaptation and training) and an opportunity (allowing greater flexibility and choice). Despite ongoing challenges like recruiting diverse monitors and maintaining participant engagement, IM4Q's adaptability has turned obstacles into valuable learning experiences, sustaining trust, relevance, and impact.

Ideas for the Future of Care: The IM4Q team emphasizes that consistently gathering and responding to the voices of individuals with IDD leads to meaningful, long-term improvements in services and policies. It's about ensuring individuals' shared experiences directly inform state and local system decisions, guiding quality enhancements and systemic reforms that shape their future.

These programs demonstrate the tangible benefits of prioritizing the unique needs of individuals with IDD through thoughtful design, dedicated resources, and a commitment to continuous improvement and advocacy.

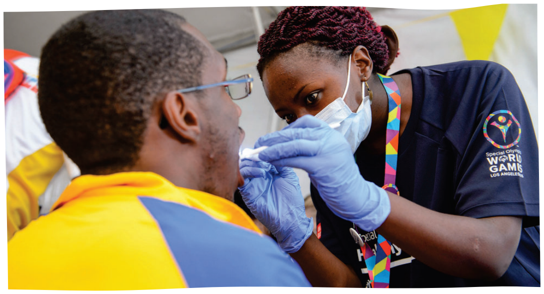
Additional Best Practices and Innovative Solutions

Person-Centered Care, Interdisciplinary Collaboration, and Care Coordination

Effective IDD care rests on truly person-centered approaches that integrate extended appointment times, team-based practice, and dedicated care navigation. Clinicians and individuals with IDD alike emphasize the need for 'extra time with appointments' and 'longer appointments' so providers can better understand and address each patient's unique needs.

The Jefferson University FAB Center & Woods Systems of Care exemplify this model through extended visit times and a team-based care approach, leading to more accurate diagnoses and improved treatment outcomes tailored to individual circumstances.

At the same time, embedding IDD-competent professionals across disciplines, working together in collocated or closely linked clinics, and providing a "tour guide" or care navigator to help patients move from one service to the next ensures that care is seamless rather than siloed. John's wish for a doctor who "takes time to explain things step by step," Marisa's feeling "understood and respected" when physicians review her records and speak clearly, and Jesse's sense of being seen and valued when providers slow down and talk kindly all reflect the power of this integrated, person-centered model.



IDD-Inclusive Training and Experiential Learning

While broadly a challenge, existing efforts to integrate IDD content into mainstream medical and allied-health education are lauded. The Arc of Philadelphia's "Health Outreach Project (HOP) Clinic" provides medical students with opportunities to serve adults with intellectual disabilities, offering vital "awareness and experience." Thomas Jefferson University's training program for medical students on "disability competency" further highlights a commitment to addressing the knowledge gap.

Special Olympics International’s Inclusive Health Fundamentals (IHF) curriculum and Special Olympics Pennsylvania’s Healthy Athletes® program, which offers free, non-invasive health screenings and maintains the Healthy Athletes Provider Directory, a publicly accessible list of healthcare professionals trained in inclusive IDD care, are crucial resources for both training and patient referral. Community-based health screenings, particularly those offered through the Special Olympics Healthy Athletes program in Pennsylvania, are highly effective. John feels "welcomed, understood, and not hurried" in these settings, making him "more likely to seek preventive care."

Community-Based Outreach and Advocacy

Implementing "community outreach programs to raise awareness on IDD related issues including (but not limited to) reducing stigma and discrimination and fostering full inclusion in their communities" is seen as critical. The IM4Q program’s success in engaging directly with individuals receiving services, their families, and local teams (including people with disabilities as interviewers) demonstrates the power of grassroots engagement and person-centered data collection.

Respect for Autonomy and Supported Decision-Making

"Respect of their Autonomy" is a fundamental principle emphasized by healthcare professionals. The Lehigh Valley Center for Independent Living's "Supported Decision Making Pennsylvania" project, which helps transition-aged youth build independent decision-making skills with a "circle of support," exemplifies a best practice in empowering individuals with IDD. Temple University's Institute on Disabilities' work on "Participant Directed Services (PDS)" and collecting stories of self-direction further promotes autonomy and choice. This aligns with patients' desire for "more information and support for making decisions."

Innovative Scheduling and Accommodations

Simple yet effective innovations include one physicians practice of closing "one night per month... to see patients with IDD," creating a welcomed, dedicated space. The recognition of specific needs like "adequate equipment (hoyer lifts, noise canceling headphones, fidgets, weighted blankets, etc.)" and flexible approaches like "short and brief appointments to address small issues separately, rather than longer complex appointments" are vital accommodations. The idea of "pre-visits" to "Introduce IDD to team and treatment rooms prior to scheduling anything" also helps reduce anxiety.

These best practices, though sometimes isolated, offer powerful demonstrations of what is possible when the healthcare system adopts a truly person-centered, flexible, and collaborative approach to individuals with IDD. They provide the practical foundation upon which broader systemic change can be built.

3. Strategic Blueprint for Change: Recommendations for IDD-Inclusive Healthcare

The challenges facing individuals with IDD in accessing equitable healthcare are profound, yet the insights from surveys and interviews also reveal clear pathways for transformative change. The "Rosemary Collaboratory Initiative: Pennsylvania Policy, Systems, and Environmental Change Plan" emerges as a comprehensive blueprint, aiming to accelerate Commonwealth-level research, policy, and practice for IDD-inclusive services and the healthcare system through partnerships and strategic advocacy activities. This chapter details the plan's objectives, strategies, and the underlying rationale for a truly IDD-inclusive healthcare future.

3.1 Overarching Goals and Core Priorities

The initiative's primary goal is an ambitious yet necessary one: to systematically dismantle barriers and foster a healthcare environment that fully embraces and effectively serves individuals with IDD. This comprehensive approach has been developed through strategic partnerships with key advocacy organizations and networks that represent the IDD community across Pennsylvania.

Central to this partnership is activities undertaken by The Arc of Pennsylvania, the state‘s leading advocacy organization for individuals with IDD and their families. They have developed a statewide Disability Health Action Network (DHAN), which brings together disability advocates, healthcare providers, and researchers to address health disparities experienced by people with disabilities.

Key objectives for the DHAN are to promote equitable access to quality healthcare, foster effective communication between stakeholders, and enhance overall health outcomes for people with disabilities through partnerships across healthcare professionals, disability stakeholders, advocacy groups, government agencies, researchers, and community organizations. DHAN’s collaborative approach and focus on policy-level interventions has helped shape the strategic framework for this initiative.

Based on a meticulous identification process that combined insights from the SLA, a priority survey of Special Olympics Pennsylvania athletes, and the DHAN's policy priorities, three core areas of intervention have been identified:

1. **Enhanced Training for Healthcare Workers:** This priority tackles two critical needs: equipping healthcare professionals with stronger skills for caring for people with IDD and ensuring they meet Section 504 medical-accommodation standards.
2. **Providing Individuals with IDD More Information and Support for Healthcare Decision-Making:** This addresses the vital need for autonomy and clarity. Both individually and at the health system level, centering individuals with IDD to actively participate in decisions about their health is paramount.
3. **Increased Data Collection on Health and Insurance Coverage for People with IDD in Pennsylvania:** Accurate, disaggregated data on the health status and insurance coverage of individuals with IDD is essential for evidence-based policy and resource allocation. The current paucity of comprehensive, IDD-specific data hinders the design, targeting, and evaluation of interventions.

These three priorities are mutually reinforcing: progress in any one area amplifies and supports advancements across the others.

4. The Road Ahead: Implementation, Collaboration, and a Vision for the Future

The comprehensive analysis presented thus far paints a clear picture: while significant barriers impede equitable health for individuals with IDD in Pennsylvania, there is a clear strategic pathway towards a more inclusive and responsive system. The success of the Rosemary Collaboratory Initiative hinges on meticulous implementation, robust collaboration across diverse stakeholders, and a steadfast commitment to its overarching vision.

5. Implementation: From Plan to Practice

The Pennsylvania Policy, Systems, and Environmental (PSE) Change Plan for the Rosemary Collaboratory outlines specific activities, indicators, responsible parties, resources, timeframes, and monitoring/evaluation mechanisms for each strategic objective. This level of detail is crucial for accountability and progress tracking. The work itself is organized around four interlocking objectives, outlined below:

Objective 1: Grow IDD-focused training for healthcare workers

In Pennsylvania, the Rosemary Collaboratory team will work to identify and catalogue existing IDD training opportunities available in Pennsylvania, from hospital rotations to short online courses. Partnering with medical, dental, and nursing societies, the team will craft clear messages on why this training matters and share them through newsletters, social media, and dedicated web pages. At least five additional hospitals or medical schools will be invited to host hands-on IDD learning experiences, with the goal of securing commitments from interested institutions. Progress will be measured by the number of training sessions logged, societies engaged, outreach metrics, partnership invitations extended, and new partners secured.

Ultimately, change will only happen if it is embedded into the culture and practice of healthcare; where all healthcare providers are trained and competent in serving people with IDD. To this end, the Rosemary Collaboratory team in Pennsylvania plans to work with its partners to develop and implement strategies that can support mandatory training on supporting people with IDD over the long-term.

Objective 2: Re-establish the Governor's Cabinet & Commission on People with Disabilities to improve resource accessibility for people with IDD

This revived Cabinet & Commission will serve as a formal inter-agency coordinating body, aligning state departments, advising on IDD health and support policies, and ensuring regular input from people with IDD and their caregivers. A briefing with the Governor's staff will set out the case for reinstating the commission. In addition, the Rosemary Collaboratory team will develop and disseminate a statewide sign-on letter to the Governor, open to organizations and individuals alike, to demonstrate broad, bipartisan support for the Cabinet & Commission.

Ongoing follow-up with the Governor's Office will keep the issue on the policy agenda until the commission is formally restored. Success will be marked by milestones such as the initial meeting, signatures gathered, and an official commitment to re-establishment.

Objective 3: Build stronger disability data for smarter policy

The Rosemary Collaboratory team will convene researchers, state officials, and self-advocates to identify critical gaps in Pennsylvania's health data. Their findings will shape a Disability Data Action Plan pinpointing which surveys and databases need new questions and a timeline for advocating and adopting changes. The team plans to work with researchers and government officials to pilot test new questions with grassroots advocates to refine them before statewide adoption.

Key indicators include delivery of the action plan, completion of pilot cycles, and formal adoption of the new questions. Ultimately, improved data collection will give critical attention to health disparities experienced by people with IDD in Pennsylvania. By bringing these disparities to light, and regularly measuring them, government officials, advocates, and health professionals will be able to work collaboratively to address systemic challenges across this broad population.

Conclusion

The activities laid out in the Pennsylvania PSE Plan, developed under the Rosemary Collaboratory Initiative, combined with the dedication of countless individuals and organizations, offer a clear pathway toward this transformative future. While the road may be long and fraught with challenges, the compelling evidence of current barriers, coupled with the proven efficacy of existing best practices, provides a powerful impetus for change. By consistently gathering and responding to the voices of individuals with IDD, Pennsylvania can lead the way in creating a healthcare system that truly serves everyone, ensuring that all individuals have the opportunity to live full, healthy, and dignified lives.

This report is an invitation to policymakers, healthcare providers, community leaders, and every citizen to recognize that the health of our society is inextricably linked to the well-being of its most vulnerable members. By investing in compassionate, competent, and accessible healthcare for individuals with IDD, Pennsylvania will not only rectify historical inequities but also strengthen the fabric of its community, ensuring that dignity, opportunity, and health are truly afforded to all. Let us embark on this journey with renewed purpose, guided by empathy and a shared vision of a future in which every individual, regardless of ability, can thrive.

A Call to Action: How You Can Help

What We Learned: People with IDD in Pennsylvania face significant barriers when accessing healthcare. Healthcare providers report lacking adequate training and financial support to serve this population effectively. Individuals with IDD experience communication challenges, long wait times, and often need extensive support navigating the healthcare system.

What's Working: Innovative programs like the Jefferson University FAB Center and the IM4Q initiative show that person-centered, coordinated care can work when systems prioritize extended appointment times, team-based approaches, and truly listen to individuals with IDD.

The Path Forward: Three key areas need attention: enhanced training for healthcare workers, better information and support for healthcare decision-making, and improved data collection on health outcomes for people with IDD.

Community Members: Amplify the voices of individuals with IDD in healthcare conversations and support inclusive health initiatives in your communities.

Get Involved: *Visit the [Special Olympics Pennsylvania Rosemary Collaboratory webpage](https://specialolympicspa.org/rosemary-collaboratory), (https://specialolympicspa.org/rosemary-collaboratory) share about the Rosemary Collaboratory Initiative on social media, and sign up to receive updates and participate in activities.*

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Content Disclaimer:
"These contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services."

For More Information & Partnership Opportunities:

This report is a product of collaborative efforts to illuminate and address health system challenges for people with intellectual and developmental disabilities in Pennsylvania. We invite you to connect with the contributing organizations based on the solutions they offer:

- To explore partnership opportunities related to Special Olympics Pennsylvania's Healthy Athletes programs, health data collection, or data-driven advocacy for systemic change, please contact Chelsea Hammell, VP, Mission Integration, Special Olympics Pennsylvania, at chammell@specialolympicspa.org.

- For engagement in The Arc of Pennsylvania's legislative advocacy initiatives or community-based support and resources for individuals with IDD, please contact Sherri Landis, Executive Director, The Arc of Pennsylvania at slandis@thearcpa.org.

- To discuss the report's research methodology, program evaluation, or applying social impact strategies to disability health challenges, please contact Andrea Lowe, Partner + Collaborator, Social Impact Studio Consulting, at andrea@socialimpact.studio.

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