

## Key Challenges and Actionable Steps in Financing and Delivery Systems

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### Introduction

People with intellectual and developmental disabilities (IDD) have higher rates of chronic health conditions and reduced access to high-quality healthcare compared to the general population (Havercamp & Bonardi, 2022). These disparities are partly driven by the healthcare financing and delivery systems (Kahonde & Boot, 2024). Achieving health equity for people with IDD will require targeted improvements across these systems.

### Recommendations

#### **Enhance Healthcare Data Collection and Integration**

Lack of comprehensive, integrated data is a significant barrier to addressing healthcare disparities for people with IDD. Existing health-data systems are typically proprietary and exclude key indicators necessary to identify and understand this population's unique health needs. By improving data collection, infrastructure, and integration across the healthcare, social services, and education systems, we can better identify health trends and more effectively track progress in reducing disparities.

#### **Develop Standardized Quality Metrics**

A key challenge in improving healthcare for people with IDD is the lack of standardized quality metrics focused on their health outcomes. Such metrics are necessary to assess healthcare quality across systems and identify disparities. Utilizing standardized quality metrics will ensure a more coordinated approach to healthcare delivery, enabling an enhanced approach to quality measurement, more effective tracking of progress in reducing disparities, and stronger accountability for equitable healthcare.

### Plain Language Summary

People with intellectual and developmental disabilities (IDD) often have more health problems than others. They also have a harder time getting good healthcare. Here are several ideas to fix this:

1. We need better ways to collect information about the health of people with IDD. Right now, we don't know as much as we could about their health problems because schools, doctors, and other services aren't able to share information well.
2. We need better ways to check if doctors and hospitals are giving good care to people with IDD. This would mean creating special ways to measure how well they're doing their jobs.
3. We need to study different ways of providing healthcare to see what works best for people with IDD. This would help to make sure that their treatment plans actually help them.
4. New technologies like artificial intelligence and telehealth could help people with IDD get better care. But right now, many people with IDD can't use these technologies because
  - They might not have good internet.
  - They might need help using computers.
  - Their insurance might not pay for it.
5. Telehealth has become more common, and it could really help people with IDD, especially those who live far from doctors. But we need to make it easier for them to use and give them better internet access.

It's really important for people with IDD and their families to be included in making changes to fix healthcare. This will help make sure that the changes actually work for the people who need them most.

### **Evaluate Healthcare-Delivery Models**

Healthcare-delivery models, such as managed care and value-based payment systems, aim to improve outcomes and reduce costs. However, there is limited evidence on how these models impact people with IDD, particularly in regard to their actual ability to access high-quality healthcare. Research is needed to evaluate the effectiveness of these models for people with IDD. By assessing the impact of different models, we can identify approaches that lead to better outcomes and more efficient care, ensuring that reforms benefit people with IDD without unintentionally exacerbating existing disparities.

### **Finance and Implement Emerging Technologies to Improve Health Outcomes**

Emerging technologies such as artificial intelligence (AI) and precision medicine can potentially improve health outcomes for people with IDD. However, people with IDD are often excluded from research on emerging technologies, resulting in limited data on their effectiveness for this population. In addition, limited internet access, digital-literacy issues, and inadequate insurance coverage often prevent people with IDD from benefiting from these innovations. Including people with IDD in technology research and innovation will be essential to ensuring equitable access.

### **Leverage Telemedicine to Improve Access to Healthcare**

Telemedicine's rapid expansion during the COVID-19 pandemic highlighted its potential to improve healthcare access, particularly for people with IDD in rural or underserved areas. In addition to limited internet access and digital-literacy issues, people with IDD often also need caregiver assistance to access telemedicine. Telemedicine can be made more accessible by improving internet access, increasing digital literacy, and enhancing the usability of telemedicine platforms. Leveraging telemedicine may reduce costs, improve preventive care, and lower healthcare-system expenses for people with IDD.

### **Conclusion**

Improving healthcare for people with IDD will require a comprehensive approach to address gaps in data collection, quality measurement, healthcare delivery, and technology access. Enhancing data systems, developing standardized quality metrics, and evaluating healthcare-delivery models are essential to creating a more equitable healthcare system. Financing and implementing emerging technologies—such as AI, precision medicine, and telehealth—can help to overcome access barriers, increase healthcare access, and improve outcomes. As reform efforts to better meet the needs of people with disabilities progress, new system designs must be informed by input from people with IDD and their families.

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