

## Developing IDD Competent Healthcare Systems

### Introduction

People with intellectual and developmental disabilities (IDD) face significant barriers in accessing quality healthcare, which is associated with poorer health outcomes and reduced quality of life. These disparities stem from systemic ableism, inadequate training, payment constraints, and environmental barriers, among other factors. The current U.S. healthcare system often fails to recognize and accommodate the unique needs of people with IDD, resulting in missed diagnoses, inadequate treatment, and compromised care quality (St. John et al, 2018; Krahn & Fox, 2014).

Within the population of people with IDD, there are well documented racial and ethnic health disparities that compound the impact of these inequities (Gilela & Perkins, 2022; National Academies of Sciences, Engineering, and Medicine, 2018). Eliminating health care disparities experienced by people with IDD must acknowledge that within the broader community are individuals with their own unique needs and preferences. A comprehensive approach will require examining and improving the entire American healthcare system. Critical to this transformation is the active partnership of people with IDD, their families, and professionals in gaining new knowledge through research, training healthcare providers, and developing and implementing policies that determine how services are funded and managed. By addressing major systemic drivers of care and strengthening the connection between research, policy, and practice, we can create meaningful change.

### Recommendations for Education and Training

Comprehensive changes in training for the current and future medical and allied healthcare

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### Plain Language Summary

People with intellectual and developmental disabilities (IDD) often have trouble getting good healthcare. This leads to poorer health and a lower quality of life. The problem is even worse for people with IDD from minority racial and ethnic backgrounds.

There are three main ways we can fix this:

1. Doctors and other healthcare workers need better training. They should learn about IDD while they're in school and keep learning about it every year after that. This will help them give better care to all their patients.
2. We need more research. This means studying what makes it hard for people with IDD to get healthcare and finding ways to make it better. It's really important that people with IDD to be a part of planning and doing this research.
3. We need to change how healthcare is paid for. Doctors should get paid fairly for the extra time they spend helping patients with IDD. Insurance companies should make sure their rules help people with IDD get the care they need.

When we make these changes, we expect to see:

- Better health for people with IDD
- Healthcare providers who know more about helping people with IDD
- Fewer problems getting healthcare
- Better information about what works and what doesn't

It is important to make these changes now. Every day we wait means people with IDD aren't getting the healthcare they deserve.

workforce is essential. Healthcare providers must be prepared with the knowledge and skills to competently care for all patients, including people with IDD, across diverse racial, ethnic, cultural, linguistic, and other identity groups. To improve health care for people with IDD, we recommend that all medical and allied health:

- Pre-service educational standards require the inclusion of IDD content. Undergraduate and graduate training programs must prepare their graduates with the knowledge and skills to provide high-quality, competent healthcare for people with IDD across the lifespan, instilling a clear understanding that all patients—with or without IDD—must receive information in ways they can understand and make decisions using.
- Continuing education and licensure standards require a minimum of one hour annually on IDD-focused healthcare training.
- The long-term impact of such training must be evaluated to assess its effectiveness in improving health access, experience, and outcomes for people with IDD.

Ensuring individuals with IDD are actively involved in their healthcare decisions is vital for fostering autonomy and inclusion. Their voices must lead individual care planning and systemic policymaking to address long-standing inequities. Quality healthcare for people with IDD needs to be a priority to create healthcare systems that can genuinely address their unique needs and preferences. Clear and explicit policy development and implementation strategies are necessary to dismantle systemic barriers and promote equity particularly for those from marginalized communities.

### Recommendations for Research

Research to reduce healthcare disparities in the IDD population is essential. We recommend that research be designed and implemented to:

- Adopt a set of IDD status code-identifiers for national surveys, healthcare documentation systems, and other research uses.
- Improve the coding of patient health data so that IDD status is accurately represented in health datasets.
- Identify factors that affect access and care quality and identify strategies that improve healthcare access and quality for patients with IDD.
- Evaluate the implementation, effectiveness, and outcomes of interventions for those with IDD.
- Examine data that characterizes health status and service gaps for people with IDD across racial, ethnic, linguistic, cultural, and other identity groups.

### Recommendations for Health and Finance Policy

Private and public health insurance reform and oversight are critical to support the necessary and appropriate coverage and reimbursement rates for the healthcare of people with IDD. Payment reform is crucial for sustainable improvement to healthcare access and quality for patients with IDD. We recommend that:

- Healthcare providers be equitably compensated for the additional time and resources needed to provide quality healthcare for people with IDD. This compensation should be linked to health outcomes achievement to ensure quality care delivery.

In addition, healthcare organizations, health systems, and insurers of health, mental health,

dental, and vision services must:

- Regularly review their policies and practices to ensure the optimal delivery of care and health outcomes for people with IDD.
- Maintain strict compliance with all applicable federal and state regulations
- Ensure that their patient health data records accurately capture IDD status to support analysis and evaluation.

### Conclusion

Implementing the above recommendations will require a coordinated effort across and among healthcare organizations, educational institutions, policy makers, and researchers in partnership with people with IDD and their families. When these recommendations are successfully implemented, however, the outcomes will be substantial, including: 1) improved health outcomes for people with IDD, 2) enhanced IDD competency of the medical and allied healthcare workforce, 3) enhanced quality of healthcare for people with IDD, 4) reduced barriers to healthcare access for people with IDD, and 5) enhanced data collection and research practices to support the generation of new knowledge about improving the health outcomes of people with IDD. These steps will build a more equitable and robust healthcare system for everyone. The time for action is now – any delay perpetuates existing disparities and denies people with IDD their right to competent, quality healthcare.

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