

Framework to Improve the Quality of Care for Individuals with Intellectual and Developmental Disabilities

Executive Summary

Individuals with intellectual and developmental disabilities (IDD) deserve high-quality, compassionate, and person-centered care. However, disparities in the quality of care remain a significant challenge due to a lack of awareness about the unique needs and rights of this community, as well as insufficient training for healthcare aides. This federal policy paper outlines a comprehensive approach to enhance the quality of care for individuals with IDD by raising awareness, advocating for their rights, and implementing specialized training programs for caregivers. The framework aims to ensure that individuals with IDD receive the dignified, informed, and compassionate care they deserve.

Problem Statement

Despite progress in disability rights and inclusion, individuals with IDD continue to face significant barriers to receiving quality care. Many healthcare aides lack the necessary training to understand and address the complex needs of people with IDD, leading to disparities in health outcomes and quality of life. Furthermore, the voices of individuals with IDD are often overlooked in decision-making processes that affect their care. There is a pressing need for systemic changes to improve the quality of care, empower caregivers with specialized knowledge, and ensure that the rights and needs of individuals with IDD are recognized and prioritized.

Goals of the Policy

1. **Enhance the quality of care** for individuals with IDD by implementing specialized training programs for healthcare aides.
2. **Raise awareness about the unique needs and rights** of the IDD community to foster a more inclusive and compassionate society.
3. **Empower individuals with IDD** by amplifying their voices and ensuring their active participation in decisions regarding their care.
4. **Promote person-centered care practices** that prioritize dignity, autonomy, and the holistic well-being of individuals with IDD.

I. Specialized Training Programs for Healthcare Aides

1. **Develop a Comprehensive National Training Program**
 - **Goal:** Equip healthcare aides with the skills and knowledge needed to provide high-quality, compassionate care for individuals with IDD.
 - **Action Items:**



- Design a federally endorsed training curriculum covering essential topics such as communication strategies, behavioral health, medical considerations, and person-centered care approaches for individuals with IDD.
- Ensure the training includes both theoretical and practical components, with opportunities for hands-on learning through simulations, mentorship programs, and clinical placements.
- Make the training program accessible through online and in-person formats to reach healthcare aides across the country, including those in rural and underserved areas.

2. **Require Certification for Healthcare Aides Working with Individuals with IDD**

- **Goal:** Establish a standardized certification process to ensure that all healthcare aides meet minimum competency standards in IDD care.
- **Action Items:**
 - Introduce a national certification requirement for healthcare aides who provide care to individuals with IDD, with periodic recertification to keep skills up to date.
 - Partner with state licensing boards to integrate the certification into existing healthcare aide licensing requirements.
 - Provide financial assistance for healthcare aides to cover the costs of certification, including scholarships, grants, or employer reimbursement programs.

3. **Incorporate Ongoing Professional Development Requirements**

- **Goal:** Keep healthcare aides informed of the latest best practices, research, and technologies in IDD care.
- **Action Items:**
 - Mandate continuing education requirements for healthcare aides, focusing on emerging topics such as assistive technology, positive behavioral supports, and trauma-informed care.
 - Establish a federal funding program to support ongoing professional development opportunities, including workshops, conferences, and online courses.
 - Create incentives for employers who invest in the continuous training of their healthcare staff, such as tax credits or federal grants.

II. Raising Awareness About the Needs and Rights of Individuals with IDD

1. **Launch a National Awareness Campaign**

- **Goal:** Educate the public, healthcare professionals, and policymakers about the unique needs and rights of individuals with IDD.
- **Action Items:**



- Partner with advocacy organizations, celebrities, and influencers to create a nationwide media campaign that highlights the challenges faced by individuals with IDD and promotes their rights to dignified and person-centered care.
- Develop educational materials for schools, healthcare institutions, and community organizations that emphasize the importance of inclusion, accessibility, and respect for individuals with IDD.
- Designate an annual "IDD Awareness Month" to host events, forums, and advocacy activities that foster dialogue and engagement around the issues affecting the IDD community.

2. **Promote the Use of Person-First Language and Practices in All Federal Programs**

- **Goal:** Ensure that federal policies and programs use language and practices that prioritize the dignity and humanity of individuals with IDD.
- **Action Items:**
 - Update federal guidelines and official documents to use person-first language (e.g., "individuals with IDD" instead of "the disabled") and require contractors and grantees to do the same.
 - Offer training on person-first language and inclusive practices to federal employees, healthcare providers, and educators.
 - Include person-first language as a criterion in federal grants and contracts related to healthcare and social services.

III. Empowering Individuals with IDD and Amplifying Their Voices

1. **Establish a Federal Advisory Council on IDD Care**

- **Goal:** Involve individuals with IDD and their families in shaping policies and programs that affect their lives.
- **Action Items:**
 - Create an advisory council composed of individuals with IDD, family members, caregivers, and disability advocates who provide input on federal policies, programs, and services.
 - Ensure the council meets regularly and that its recommendations are reported to relevant federal agencies and Congress.
 - Fund programs that support self-advocacy training for individuals with IDD to help them engage more effectively in policy discussions.

2. **Support Self-Advocacy and Peer Support Networks**

- **Goal:** Empower individuals with IDD to advocate for their needs and share their experiences.
- **Action Items:**
 - Provide federal grants to organizations that offer self-advocacy training, leadership development, and peer support for individuals with IDD.



- Develop resources and toolkits that help individuals with IDD and their families understand their rights and navigate the healthcare system.
- Promote the inclusion of self-advocates in decision-making roles within healthcare facilities, educational institutions, and community organizations.

IV. Promoting Person-Centered Care Practices

1. Establish National Standards for Person-Centered Planning

- **Goal:** Ensure that all care plans for individuals with IDD prioritize their preferences, goals, and overall well-being.
- **Action Items:**
 - Implement federal guidelines that require person-centered care planning in all programs that provide healthcare and support services to individuals with IDD.
 - Monitor and evaluate the quality of care plans to ensure they meet person-centered standards, with regular reviews and updates as needed.
 - Offer training to healthcare aides, case managers, and other providers on how to conduct person-centered planning that genuinely involves individuals with IDD in the decision-making process.

2. Expand Access to Integrated, Holistic Healthcare Services

- **Goal:** Address the physical, mental, and social health needs of individuals with IDD through a coordinated approach to care.
- **Action Items:**
 - Integrate primary care, mental health services, and disability supports into a seamless care model that addresses the full spectrum of health needs.
 - Provide funding for interdisciplinary care teams that include healthcare aides, social workers, behavioral health specialists, and other professionals.
 - Encourage the use of health information technology, such as electronic health records, to facilitate communication and coordination among providers.

Implementation Strategy

1. **Establish a Federal Task Force on IDD Care Improvement:** This task force will oversee the implementation of the proposed policies, ensure collaboration across agencies, and report progress to Congress.



2. **Provide Funding Through Grants and Incentives:** Allocate federal funding to states, healthcare facilities, and training providers to support the implementation of training programs, awareness initiatives, and person-centered care practices.
3. **Monitor Progress and Adapt the Policy as Needed:** Implement a data-driven approach to evaluate the effectiveness of the initiatives, with regular feedback from individuals with IDD, caregivers, and advocates.

Conclusion

This federal policy framework aims to improve the quality of care for individuals with intellectual and developmental disabilities by addressing training gaps, raising awareness, and promoting person-centered care practices. By equipping healthcare aides with the necessary skills and fostering a society that recognizes the unique needs and rights of the IDD community, the policy seeks to ensure that all individuals receive the compassionate and dignified care they deserve.

