Access, Communication, and Belonging in Healthcare and Public Health Core Framework

Disability Justice in Public Health

Based on the webinar of the same name, this resource highlights the key ways that we explored making health care and public health more accessible, especially for the IDD and Deaf communities. Check out the full webinar, and the broader webinar series on APHA NOW.

Disability justice centers on access, communication, dignity, trust and belonging, enabling people to fully participate in their communities and lives.

- It's intersectional, acknowledging how disability intersects with race, culture, language, gender, identity, sexuality, socio-economic status and immigration experiences.
- Accessibility and inclusion must be foundational to system design, not afterthoughts.

Nine Priority Health Outcomes for the IDD Community

People with intellectual and/or developmental disabilities (IDD) identified the following as priority outcomes for their health (IIDDEAL, IEC). The IDD community prioritizes areas such as quality of life, social participation and caregiver support, not just traditional clinical outcomes.

1. **Emotional/Mental Health:** Self-advocacy, role models, meaningful work, ability to express feelings
2. **Improved Physical Health:** Reduced pain and increased energy (quality of life, not just clinical metrics)
3. **Sexual, Gender, Reproductive Health and Parenting**: Appropriate care and support for those who want to parent
4. **Doing Things I Love/Need to Do:** Transportation, social connections, employment support
5. **Family Caregiver Wellness:** Caregiver health, resources and well-being
6. **Workforce Development:** Training healthcare providers on IDD and disability competency
7. **System Supports:** Easy access to community services and professional navigation assistance
8. **Organizational Tools:** Measures, data and interventions to track progress
9. **Payers and Regulators:** Health care, health departments and insurance companies need better tools and data to support people with disabilities

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Critical Health Equity Gaps

Healthcare System Failures

- Lack of provider training on IDD and disability competency
- Communication access is not prioritized in clinical settings, including lack of qualified ASL interpreters
- Video Relay Interpretation (VRI) devices are insufficient and place responsibility on patients, not healthcare providers (PubMed)
- The intersection of disability with race and culture is often ignored
- Caregivers are not adequately supported as essential partners

Actionable Strategies for Healthcare and Public Health Programs

1. Design with Intersectionality

- Acknowledge how disability intersects with race, class, immigration status, language and culture
- Partner with culturally-specific disability organizations
- Use universal, inclusive design that addresses systemic barriers

Resources

Pan-Asian Disability and Neurodiversity Resources • *The Black Deaf Project* • *Combatting Misinformation: Understanding the Facts About Disability*

2. Co-Create Solutions with the IDD Community

- Engage people with disabilities directly in program design as central stakeholders
- Compensate community advisors for their expertise
- Assume competence and offer support to enable contribution
- Design for the entire spectrum (whole person), not individual accommodations

Resources

Engagement to Identify Health Priorities of People With IDD • *Principles for Authentic Community Engagement; Making Disability a Priority in Health Equity*

3. Prioritize Communication Access in Healthcare Settings

- Provide in-person, qualified ASL interpreters for medical situations (not VRI devices)
- Implement ASL kiosks with deaf staff for check-in and initial communication
- Offer multiple communication options: Augmentative and Alternative Communication (AAC) devices, written notes, choice boards, gestures
- Engage with people, not at them

Resources

Position Statement On Health Care Access For Deaf Patients (NAD) • *The Black Deaf Project* • *Positive Discourse: Communication Disabilities 101* • *NAC — Sebat Lab* • *Otto Lana's AAC work (LinguaBridge)* • *https://www.floetyc.com/*

4. Build Provider and Workforce Competency

- Train healthcare providers on IDD-specific health needs and communication strategies
- Speak in plain language with age-appropriate vocabulary
- Address people with IDD directly using their names, even when there's a caregiver present; allow time for response
- Be curious, ask questions and build trust; expect variation in needs

Resources

Action to Build Clinical Confidence and Culture (ABC3) • *Disability Fundamentals Trainings for Managers* • *National Roadmap for Disability Inclusive Healthcare* • *Resource Guide for Emergency Departments* • *Docs With Disabilities*

5. Support Family Caregivers as Essential Partners

- Recognize caregiver wellness as critical to system success
- Provide resources, respite care and health support for caregivers
- Include caregivers in care planning and decisionmaking
- Build systems that work across the lifespan, not just for children

6. Use Community-Defined Metrics

- Track outcomes that matter to the IDD community (quality of life, social participation, employment)
- Move beyond clinical metrics to holistic measures of health and well-being
- Develop organizational tools for accountability and continuous improvement

Resources

Understanding the IDD Community: Essential Data and Insights • *Engagement to Identify Health Priorities of People With IDD*

7. Embed Accessibility into Organizational Culture

- Make accessibility foundational to all public health programs, not an add-on
- Budget for accommodations as standard practice
- Build capacity through ongoing training and mentorship

Resources

10 Tips to Increase Disability Inclusion in the Workplace • *Employer Quick Guide* • *APHA's Disability Section Mentoring Program*

Vision for the Future

Disability justice looks like disabled people in leadership positions, medical schools, Congress and decisionmaking roles, fully represented across healthcare and public health systems as providers, advocates and voices shaping policy and practice.

Public health must shift from designing **for** people with IDD to designing **with** them, centering their priorities, investing in communication access, supporting caregivers and building truly inclusive systems from the ground up.