

EXECUTIVE SUMMARY

Healthcare for Youth with Neurodevelopmental Disabilities:

A Consensus Statement



The Supporting Access For Everyone (SAFE) Initiative is the first interprofessional consensus statement that describes the standards of care in healthcare settings for youth with neurodevelopmental disabilities.

Background

Approximately 1 in 6 youth has a neurodevelopmental disability (NDD), defined as multifaceted conditions that impact cognition, communication, motor, social, and/or behavior skills. While highly heterogeneous, youth with NDDs are more likely to have substantial medical, mental health, and other support needs.

Youth and adults with NDDs (Autism Spectrum Disorder, Intellectual Disability, Attention-Deficit/Hyperactivity Disorder, etc.) frequently report challenges accessing medical care, and experience more adverse events (including seclusion, restraint, accidents, and injury) leading to poor long-term health outcomes.

These disparities are the result of many factors, including structural ableism (discriminatory practices that undervalue people with disabilities), lack of training for healthcare professionals, and inequitable systems.

SAFE Initiative

In partnership with The Developmental Behavioral Pediatric Research Network (DBPNet) and Association of University Centers on Disability (AUCD), the **Supporting Access For Everyone** (SAFE) Initiative was launched. An interprofessional consensus panel of healthcare experts, adults with NDDs, and caregivers convened. A public forum where 40 presenters provided testimony was followed by a systematic consensus-building process.

The final document identifies 5 critical domains in which healthcare providers, settings, and systems must engage to improve outcomes for youth with NDDs. Within those domains are 10 consensus statements describing specific approaches and priorities. See Weitzman et al. (*Pediatrics*, 2024) and safedbp.org for more information.

Foundational Premises of SAFE Care

SAFE care is:

- Care that individuals understand and want;
- Individualized and evolving with the changing needs of a person;
- Accessible throughout the entire lifespan;
- Equitable and respectful;
- Defined and measured by patient experience, quality of care, and psychological well-being of patients and caregivers, and not solely by narrow interpretations of safety, efficiency, and remuneration.

SAFE care reduces or eliminates:

- Risk of physical and emotional harm to people, including accident, injury, restraint, and seclusion;
- Poor quality, inadequate, and incomplete care;
- Foregone care, which results in untreated healthcare conditions and increased morbidity.

***“Find out what the person in front of you needs...
and build the care and the plan around it.”***

- Patrick Forgey, Advocate

SAFE Consensus Statements

Domain	Consensus Statements
Training	1. All healthcare personnel must be trained in the fundamentals of NDDs, as well as the consequences of non-SAFE healthcare practices that may include trauma.
Communication	2. Communication needs must be consistently accommodated and supported by clinicians, healthcare environments and health settings. 3. Care teams must engage patients with NDDs and their families in mutual, shared, and supported decision-making across the healthcare experience and throughout the lifespan.
Access and Planning	4. Healthcare settings should proactively invite patients and families to collaboratively develop patient-specific accommodation and support plans for use during healthcare encounters to address their complex needs. 5. Healthcare settings must ensure access to interprofessional expertise, materials, and technology, and environmental adaptations needed to support patients with NDDs.
Diversity, Equity, Inclusion, Belonging and Anti-Ableism	6. Healthcare settings must include youth and adults with NDDs in their diversity, equity, inclusion, and belonging efforts. 7. Professionals must recognize the impact of structural or medical ableism on people with NDDs and recognize that there is a higher-than-average prevalence of disability in many marginalized racial, ethnic, gender and sexual identity groups
Policy and Structural Change	8. Healthcare settings must conduct an initial as well as regular needs and readiness assessments to evaluate their current state of practice and existing policies for people with NDDs. Based on identified barriers and facilitators, healthcare systems must develop and execute strategic plans to create sustainable programs and policies specific to their individual contexts. 9. Healthcare settings must engage in continuous quality improvement of their efforts to support care for people with NDDs to ensure timely, equitable, safe, effective, and culturally relevant service provision. 10. Healthcare settings—partnering with individuals with NDD and the public in general—must advocate for changes in reimbursement and payment models, accreditation requirements, and the passage of state and federal laws and regulations that require improvement in care for people with NDD.

Call to Action

Systemic change is required to improve health outcomes for people with NDDs. Shifts in culture and practice must compliment financial investments, allocation of resources, and research to guide dissemination efforts.

This work must proceed in partnership with people with NDDs and their families and engage the entire healthcare community.

All people are entitled to healthcare that is accessible, compassionate, and effective.

*The work of **SAFE** is just beginning!*



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