



# MEDICAL HEALTH HOMES

*Promoting Integrated, Person-Centered Care for  
People with Intellectual & Developmental Disabilities*

## **DISABILITY-INFORMED HEALTH CARE NAVIGATION**

*Guiding people with intellectual and developmental disabilities (I/DD)  
through the complexities of health care and disability service systems*

### **The Critical Issue**

Health care and disability service systems are complex and fragmented. It can be difficult for an individual and family to know how to enter the system, choose the best services, and use these services effectively. Historically, the health care system has focused on acute, episodic care with disjointed communication between providers and limited experience coordinating care with long-term disability services and supports. People with intellectual and developmental disabilities (I/DD) often have complex health care needs that require more intensive medical services coordinated across different providers in multiple settings, as well as a wide range of disability and social supports. As the individual's needs become more complicated, the system is less capable of providing quality care that promotes health and functioning.

Disability-informed health care navigation is needed to address a critical gap identified by multiple stakeholders: access to knowledgeable professionals able to facilitate seamless and comprehensive services for persons with disabilities within the healthcare, disability, and related service systems. The intent is not to duplicate existing services, but to address an unmet need and persistent gap in people's lives.

People with I/DD need a system that cares for the whole person and coordinates care across sectors, addresses long term service and support needs, promotes shared decision-making, and pays for valued outcomes that matter to the person, family, provider, and system. Disability-informed health care navigation is applicable to our current healthcare and disability services infrastructure, and evolving models and systems of care.

### **Medical Health Home Recommendation**

*Establish a system of "care navigation" designed to benefit individuals with an I/DD, their caregivers and multiple service systems by providing direct assistance in connecting to and moving between services and systems. Emphases: access to, continuity, and coordination of health care, Medicaid services and long-term supports.*

## Goals of Health Care Navigation

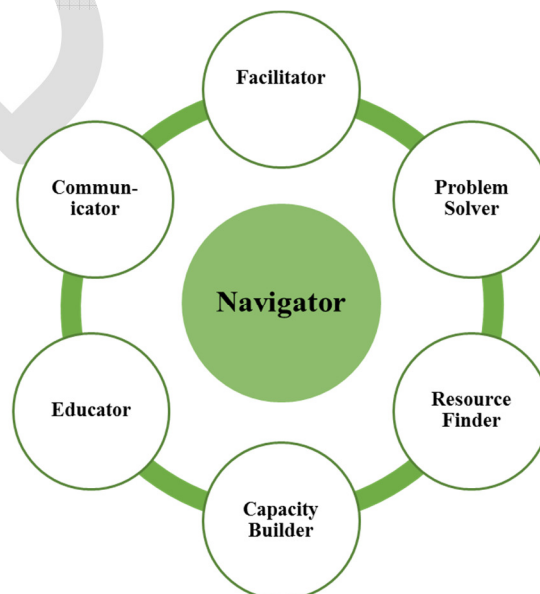
Navigation is intended to help individuals eliminate barriers to access to care, diagnosis, treatment, timely and recommended screenings, and supportive services.

1. Enhance the individual's ability to access and successfully interact with health care professionals and make informed decisions.
2. Increase health care professionals' abilities to communicate with individuals with I/DD and support shared decision-making.
3. Ensure that health services are synchronized with long-term services and supports to maximize health outcomes.
4. Promote self-determination and informed choice in health care decisions.

## Functions of Health Care Navigation



## Health Care Navigation Roles



## Health Care Navigation Examples

**Effective navigation services are determined by individual need and location:**

Complexity	Disability	Medical	Disability & Medical	Disability, Medical & Mental Health	Intermittent Life Transitions
<b>Need</b> ↑ High need ↓ Low need ↑↓ Intermittent	↑ Disability ↓ Physical Health ↓ Mental Health	↓ Disability ↑ Physical Health ↓ Mental Health	↑ Disability ↑ Physical Health ↓ Mental Health	↑ Disability ↑ Physical Health ↑ Mental Health	↑↓ Disability ↑↓ Physical Health ↑↓ Mental Health
<b>Navigation Accountability</b>	Disability System	Medical System	Medical System	Disability System	Disability System
<b>Where</b>	Disability MCO or Provider	Specialty Medical Practice	Patient Centered Medical Home	Disability MCO or Provider	Disability MCO or Provider
<b>Who</b>	Disability Navigator	Nurse Navigator	Nurse or Social Work Navigator	Disability Navigator	Disability Navigator
<b>Example Beneficiaries</b>	School age child Autism Limited speech & language Seizures Self-harming behaviors Poor Sleep Gastro-intestinal issues Lives with family	Young child Genetic disorder Significant ID & delays Sensory issues Cardiac abnormalities Muscle pain Seizures Pulmonary issues Nutritional challenges Lives with family	Young adult Cerebral Palsy Mobility limitations Learning disability Vision impairment Seizures Attends college Primary care provider not in college town Lives away from family in apt with supports	Middle aged man Mild ID Autism Aggressive behaviors Frequent ED visits Diabetes Hypertension Multiple medications Needs psychiatric evaluation Lives in group home: family in another county	Older woman Down syndrome Seizures Gum disease Gastro-intestinal issues Lived with mother who recently died
<b>Current Services</b>	Primary Care Medications GI specialist Innovations Waiver Autism services Special Education & related services (OT, SLP)	Pediatric care Specialty Clinic Emergency Dept. In-patient care DME PT, OT, Speech Medications Medical supplies Innovations Waiver	Primary Care Personal Care S Medications Dental Innovations Waiver	NC START State funded services (residential) Primary care Emergency Dept. Medications	No formal futures plan in place

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For additional information contact **Karen Luken** at [karenluken@gmail.com](mailto:karenluken@gmail.com)