

# research snapshot

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## Separating Disability From Disease: A Constructive Approach For Health Services And Policy

### What is this research about?

Disability is often conflated with disease - in popular discourse, in the terminology used by health professionals, and in how we approach the organization and delivery of health care services. Health conditions are things people *have*, whereas disability is defined in terms of how an individual *functions*, according to the World Health Organization's International Classification of Functioning, Disability and Health (ICF). Functioning occurs at various levels, including bodily processes, daily activities, and in social contexts, where a person's environment influences their experience of disability. In the absence of a clear distinction between disease and disability, a disease-based lens predominates, with its focus on diagnosis and treatment. The need for careful attention to optimizing functioning through rehabilitation and supports aimed at the person and his or her environment, a cornerstone of the disability perspective, may be neglected.

### What did the researchers do?

The authors critically reviewed and synthesized information from a wide variety of sources, including the ICF, philosophical sources that describe how different kinds of knowledge inform our thinking and our perspectives, and clinical and scientific evidence from topics as diverse as the neuroscience of specific neurodevelopmental conditions (such as autism), to the impact that functional impairments may have

### What you need to know:

Distinct disease and disability perspectives may affect thinking and actions in dealing with health needs of children and adults with chronic health conditions without our even realizing it. There are possible harms in neglecting a disability perspective for children with neurodevelopmental impairment; the authors argue the importance of explicitly and consistently considering both perspectives.

on families, regardless of the child's diagnosed condition.

### What did the researchers find?

- The disease perspective is concerned with the diagnosis, treatment and cure of health conditions based on a sound understanding of their biological underpinnings.
- The disability perspective is concerned with formulating a detailed picture of an individual's functioning, the factors that promote or hinder functioning (including carrying out daily activities and social participation), and a range of measures that fall under the banner of (re)habilitation. These include therapies, specialized equipment or technology, and supports, all of which aim to optimize functioning and the person's environment.
- A biomedical approach of 'diagnose-and-treat' is less appropriate for childhood neurodevelopmental disorders. Diagnoses are seldom informative as

to underlying brain processes that treatments can specifically target. Furthermore, children who share a diagnosis differ greatly in terms of their symptoms, and in their functional strengths and limitations. Under a disability perspective, interventions and supports are tailored to the characteristics, and hence needs, of the child and family.

- Clinical services, research efforts and policy-making often remain oriented to a disease perspective: clinics, research programs, and criteria for eligibility for (re)habilitative service and supports may all hinge on the presence or absence of a particular diagnosed health condition.

### How can you use this research?

Analysis from this research will equip clinicians, policy-makers, educators and members of the public to advance an agenda for children and adults with chronic health conditions associated with disability that is progressive and appropriate to current concepts and emerging evidence. Stakeholders can turn to our recommendations for ways to recalibrate the disease and disability perspectives within clinical service delivery (clinics and data gathering that emphasize functioning), policy-making (access to services and supports based on functional need), research (studies of child functional characteristics and impact on families and family need across conditions), and health education.

### About the Researchers

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### Keywords

Childhood Neurodisability, Health Conditions, Disability, Functioning, International Classification of Functioning, Disability and Health.

### Knowledge Translation at Kids Brain Health Network (KBHN, formerly NeuroDevNet)

This is a KBHN product. KBHN is a Network of Centres of Excellence dedicated to helping children with neurodevelopmental disorders. The Knowledge Translation Core at KBHN helps to maximize the impact of research and training in neurodevelopmental disorders. The KT Core serves KBHN researchers, students and their partners by providing services such as: knowledge brokering, support for KT events, support for KT products, KT capacity building, KT evaluation and support for KT planning.

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