



# Long-Term Functioning and Participation Across the Life Course for Preterm Neonatal Intensive Care Unit Graduates

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## KEYWORDS

- NICU graduates • Academic performance • Learning disorders • Survival rates
- Neurodevelopmental disorders • Functional outcomes
- Lifecourse health development

## KEY POINTS

- There is increased recognition that the major functional sequelae of preterm birth is a spectrum of cognitive, executive function, coordination, learning, social and adaptive behavior disorders.
- Key outcomes include literacy, numeracy, and social skills.
- Proactively providing support to families and developmental and educational supports to children can optimize academic functioning and participation in adult learning, physical and behavioral health activities, community living, relationships, and employment.

Two frameworks inform assessing the complexity of children's risk and resilience after prematurity. The first is the *International Classification of Functioning, Disability and Health for Children and Youth* (ICF-CY).<sup>1</sup> The ICF-CY is derived from, and compatible with, the *International Classification of Functioning, Disability and Health* (ICF).<sup>2</sup> The

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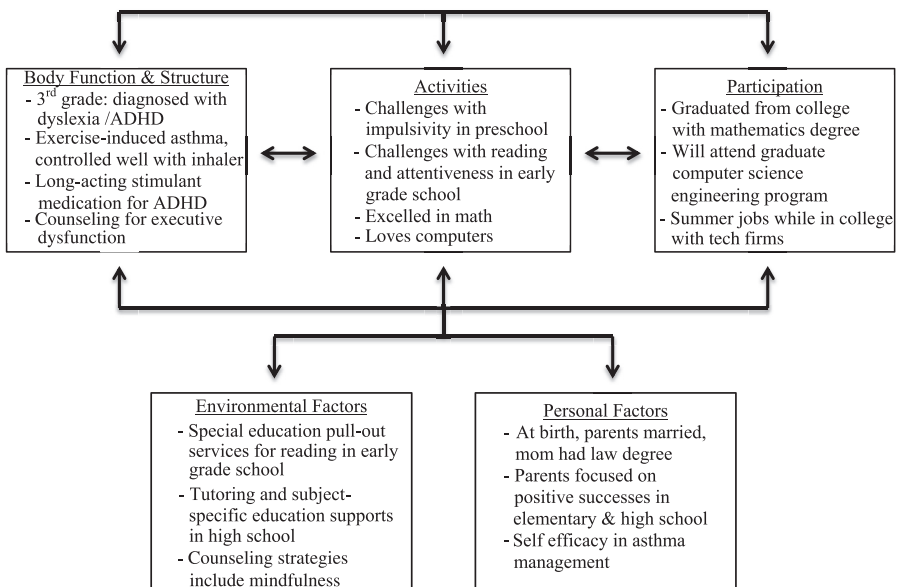
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components of the ICF in the context of health include *body function and body structure impairments; activity and activity limitations; participation and participation restrictions; and environmental factors*. Environmental factors make up the physical, social and attitudinal contextual settings in which children and adolescents live and conduct their lives. This framework goes behind dichotomous classification of impairments (eg, cerebral palsy (CP), yes or no; intellectual disability, yes or no) and instead describes a spectrum of functioning at body structure and body function levels; for example, activities in whole-person tasks like running, reading, and dancing, and participation in roles with peers like being on a team, participating in church, temple, or mosque, or meeting friends for a movie. This ICF model is illustrated in **Fig. 1** for a child who was born late preterm.

Historically, functional measures in childhood included basic daily skills of feeding, dressing, toileting, and bathing; however, adaptive behaviors in daily living also include conceptual skills (literacy, numeracy, keyboarding, and written language), social skills (self-direction, maintaining relationships), and community-living skills (household chores, cooking, shopping, using transportation, and employment). These composite adaptive outcome skills impact on both becoming an independent adult and participation in community life and are illustrated in **Fig. 2** for a child who survived extreme prematurity.

The second framework, the *Life Course Health Development Model (LCHD)*, holds that the trajectories of children are influenced by the dynamic interactions of multiple risks, protective factors, and promoting factors, especially during sensitive periods of health development.<sup>3</sup> From the standpoint of premature infants, due to critical human brain development in the second and third trimesters, this must consider complex maternal, placental, and fetal dynamic interactions. Likewise, infant, toddler, and childhood periods of development are indelibly influenced by multilevel, multidirectional, transactional, and long-lasting interactions, and critically emphasize the



**Fig. 1.** ICF Case 1: 34 weeks' gestational age, maternal preeclampsia, behavior, educational, and stressors: resilience at age 22 years.

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