Participation of children with disabilities across the life course: using socio-ecological perspectives to guide research and practice

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Optimal participation in home, school, and community life is a common goal of parents, especially parents of children with disabilities. Using evidence from the fifth follow-up of the Millennium Cohort Study, Arakelyan et al. describe how the extent of participation differs between children with and without disabilities. They define disability as a biopsychosocial phenomenon, where children with the same health conditions can have different experiences of participation depending on the environmental context. They focus on a broad sample of children aged from 10 to 12 years with and without disabilities, signalling that participation and development is an ongoing process, with this age range being particularly crucial for overall development and well-being.

Overall, Arakelyan et al. conclude that future action must focus on ‘…empowering families and improving parental access… [to services]’. Certainly, family engagement is crucial to equitable and optimal gains in the extent and quality of participation. However, we must also partner with families at every stage to consider how school, community, and policy environments can be maximized to promote long-term positive development and participation.

To more fully understand how child sex, family income, and parental education (determinants identified by the authors) affect the extent and quality of participation of children with disabilities, a socio-ecological approach is useful. Future research and action can combine the International Classification of Functioning, Disability and Health – Children and Youth (https://apps.who.int/iris/handle/10665/43737) and social determinants of health (https://www.who.int/social_determinants/en/) approaches, incorporating life course, racial/ethnic equity, health literacy, intersectional, and family engagement frameworks, among others.2,3

The authors note that children with disabilities have a lower frequency of participation, except when visiting a library. A socio-ecological approach, as defined above, can highlight how such participation might be differently structured.2–4 Is there something about public library operations and policy that drives meaningful participation for all children? Could school-district policies that integrate inclusion opportunities in education, sports, and recreational activities change the extent to which children with disabilities get together with friends? If we do not use such an approach, we miss the opportunity to examine how context structures participation. This in turn perpetuates research and practice that leave out important aspects of children’s participation.

Research and action steps that apply a socio-ecological approach help to keep multilevel determinants (e.g. race/ethnicity and racism, health literacy, family engagement, immigration, transportation, and school-district policy) front and center in designing data collection, analysis models, interpretation of results, program and policy planning, and involving family and professional perspectives.4 Likewise, measuring and designing systems that consider the life course is crucial. Doing so can highlight whether the extent of participation, using multiple determinants at different levels, varies over time (see, for example, Public Health England, Health matters: Prevention – a life course approach) Longitudinal initiatives, such as the Millennium Cohort Study, are uniquely positioned to consider participation of children with and without disabilities.

It is also essential to facilitate action for researchers, practitioners, and families to break down environmental barriers. Children with disabilities and their families can use a socio-ecological approach to navigate systems, partnering with researchers and professionals to identify environmental and systemic barriers that need to be changed.3 Further, trainees and current researchers and professionals should be trained in how to use these approaches to produce practice and research endeavours that can more fully consider participation determinants across the life course.2–4 Certainly, real limitations abound; data sets do not have the variables we desire and there is limited funding and time, among other issues. However, we will perpetuate patterns of lower participation, disengagement, and inequitable opportunities for optimal development and participation among children with disabilities if we fail to frame the solutions from a systems perspective, partnering with families at every stage and level.

REFERENCES


