

Who does well – why?

As a graduate psychology student in the early 1960s, I came to the University of Iowa Hospital School with much energy, considerable naivety, and many questions. Do children with cerebral palsy (CP) have difficulties with psychological adjustment, what do their families need, can we really have an effect on their quality of life, do we know anything that really makes a difference in the long term? What do we mean by 'they have to accept their disability', what standard is the baseline from which to best measure improvement, and what is 'normal' adjustment if a child has a physical disability? Over the last three decades, has practice changed for the better for the child with CP? Have our perspectives changed on any of these questions?

As I stated at the 51st meeting of the American Academy for Cerebral Palsy and Developmental Medicine, one's 'perspective, view, and outlook' often dictate what we as clinicians and researchers consider important, and above all, what we devote our time to in research¹. How we see the clinical problem is often a problem in itself. The first studies on adjustment of children with disability, circa 1960, focused on individuals who could not adjust. Such children were characterized with general statements of maladjustment and compared with healthy individuals. The children's experience was assumed to be the same, based upon similar physical problems, and degrees of adjustment were often naively related to degrees of bodily impairment^{2,3}.

Historically, few researchers looked for positive outcomes. This has been noted by one of the founders of the American Academy for Cerebral Palsy & Developmental Medicine, Eric Denhoff. His paper entitled 'The family influence on successful school adjustment of children with cerebral palsy' partly stresses the need to look at who does well and learn from these children and their families⁴. 'Good' families had 'warm and secure' relationships, realistically appraised the developmental strengths of their child, and encouraged opportunities for independence. This progressive view has suggested a positive adaptation to illness and disability. Researchers are now focusing on positive coping strategies (for example, short-term goal setting, compensatory skills, functional adjustment from personal baselines) with the knowledge that individuals cope and adapt in different and evolving ways. Adaptation to changes in disability is the preferred perspective, with emphasis on an evolving view of the child functioning within their particular social environment.

'Who does well' or how children with CP progress has often been the framework of developmental studies performed on children. Studies focusing on a changing picture of children growing and maturing within a normal developmental framework have been used to define who does well. Such a longitudinal perspective with a large group of children with CP may answer many questions and

debunk some myths. What is it that enables some individuals to do well?

Families and friendships, those who implicitly and explicitly care for you, are key in enhancing the life of the person with disabilities. Opportunities for education and degrees of self-sufficiency with both economic and social support from the local community are most important. Perhaps most fundamental is a lifestyle which increases autonomy by encouraging self-decided choices in life and which moves toward a sense of self-actualization. These choices need to be based upon the person's skills and self-sufficiency⁵. Choice is the fundamental characteristic that promotes a sense of control and identity. Many disabilities by definition severely restrict choices for the person.

Children do well when families have access to quality health care. Health care refers to the broad spectrum of services including physical and mental health care. Children also benefit from early treatment services that enable families actively to assist children. Finally, practitioners who encourage family and individual participation in treatment choices find that such involvement increases an individual's motivation and often leads to more functionally positive outcomes.

Disability is part of the human condition. However, perspective has changed; evolving adaptation to one's difference over time is one of the preferred orientations in understanding disabilities. People and needs change. Autonomous decision-making by the person with disabilities within the context of their limitations is part of the journey to independence of an individual with disabilities. Doing well is making your own choices; we need to promote this perspective.

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References

1. Harper DC. (1999) From science to practice: keeping the promise. In: *NEWS, American Academy for Cerebral Palsy and Developmental Medicine*. Rosemont, IL: AACPDM.
2. Harper DC. (1991) Psychosocial aspects of physical differences in children and youth. In: Jaffe K, editor. *Physical Medicine and Rehabilitation Clinics of North America. Volume 2*. p 765–79.
3. Harper DC, Peterson DB. (1999) Psychosocial adaptation in neuromuscular musculo-skeletal disorders in children. In: Elliott T, Frank R, editors. *Handbook of Rehabilitation Psychology*. New York: American Psychological Association. (Forthcoming.)
4. Denhoff E, Holden W. (1954) The family influence on successful school adjustment of children with cerebral palsy. *Exceptional Parent* 20: 5–7.
5. Harper DC. (1999) Social psychology at difference: stigma, spread and stereotypes in childhood. *Rehabilitation Psychology* 44: 133–44.