

Parent/caregiver perspectives of functioning in autism spectrum disorders: A comparative study in Sweden and South Africa

Marisa Viljoen, Soheil Mahdi, David Griessel, Sven Bölte and Petrus J de Vries

Where we live can have a significant influence on our functioning in daily life. Little research has, however, directly compared how parents/caregivers from very different countries felt about the everyday functioning of their children with autism spectrum disorder (ASD). One of the tools for measuring functioning is the International Classification of Functioning (ICF), which measures categories and subcategories of body functions (e.g., attention functions, cognitive functions), activities & participation (e.g., dressing, interpersonal interactions, carrying out daily routine), and environmental factors (e.g., immediate family, health professionals, transportation services, systems and policies). We wanted to find out if parents/caregivers from Sweden and South Africa felt their children struggled with similar or different everyday tasks. We therefore used data from a large international study on the ICF for ASD where South African and Swedish families were asked identical questions about their children's functioning. We expected that body functions and activities & participation would be mentioned in both countries, but that environmental factors would mainly be talked about in low-resource South Africa. We found that only four categories were mentioned many times in both countries (three activities & participation categories, and one environmental factor). One environmental factors category (health professionals), six body functions categories (e.g. attention functions, basic cognitive functions), and three activities and participation categories (undertaking a single task, managing one's own behaviour and speaking) were mentioned many times in the one country, but almost never in the other. We also wanted to see if the same categories were mentioned as positives (facilitators) or negatives (barriers). Only three ICF categories (immediate family, attention functions, products and technology for personal use) differed in this regard. The fact that we found so many similarities between South African and Swedish parent/caregivers' perspectives suggest that the ICF is relevant across the globe. We recommend more studies comparing functioning in ASD and other conditions, internationally.