



Pediatric Neurology Part I: Chapter 4. Health outcomes measurement: concepts, guidelines and opportunities (Handbook of Clinical Neurology)

Gabriel M. Ronen, Peter L. Rosenbaum

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In this chapter we argue that modern thinking about chronic neurological and developmental conditions requires that we recognize all aspects of functioning and quality of life in addition to the biomedical dimensions of these disorders. We find the International Classification of Functioning, Disability, and Health (ICF) a useful framework by which to think about and understand the many dimensions of health; and we appreciate its heuristic value as a stimulus to consider a range of outcomes of these individuals. Quality of Life (QOL) and Health-Related Quality of Life (HRQL) cover the additional perceived dimensions that are so important to patients' personal valuations, aspirations, and satisfaction about health throughout their lifespan, of which we see QOL being the broader construct. In order to measure outcomes at either the individual clinical or research level it is essential to ask clear and specific questions as a prelude to selecting measures that are appropriate in terms of both their content and their measurement properties. We provide some brief guidelines that we hope will be helpful to readers who wish to expand their activities in measuring clinical outcomes

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