



# Self concept in people with Williams syndrome and Prader–Willi syndrome

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## Abstract

This study explored self concepts in matched groups of adolescents and adults with Williams syndrome (WS) and Prader–Willi syndrome (PWS), using Damon and Hart's [Self-understanding in Childhood and Adolescence, Cambridge University Press, New York, 1988] semi-structured interview. The main findings were that the WS participants were more productive in their responses to the interview, providing more self characteristics. The WS group also used more social and psychological categories in describing their self concept, and their responses were in general at a higher level than the responses for the PWS group. There were significant age-group differences, with the adolescents offering more self descriptions that were coded as physical and active, whereas the adults gave more social and psychological responses. Different themes were emphasized in the interviews from the two groups. These themes reflected the distinct phenotypes associated with these disorders, the participants life experiences, and their overall attitudes toward their syndrome.

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## 1. Introduction

Although the development of self understanding has captured the interest of psychologists for many years (Damon & Hart, 1982, 1988; Erickson, 1968; Harter, 1983, 1990; Kagan, 1982; Livesly & Bromley, 1973; Montemayor & Eisen, 1977; Secord & Peevers, 1974), only recently have researchers begun to

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examine how people with developmental disorders conceptualize themselves. The goal of this study was to explore self concepts in adolescents and adults with two genetically-based neurodevelopmental disorders, each with distinct cognitive and behavioral characteristics: Williams syndrome (WS) and Prader–Willi syndrome (PWS). Similarities and differences in how people with these syndromes reflect on their lives and view themselves, and changes in self concept in these populations between adolescence and adulthood were the focus of our investigation.

The notion of self concept represents a multifaceted construct comprising several dimensions that define a person's view of his or her 'personhood' or individuality. These typically include physical attributes, cognitive and psychological features, as well as interpersonal and social dimensions that ensure a connection to society, integration into a social-cultural world, and especially differentiation from others. Damon and Hart's model of self understanding (1982, 1988) provides a comprehensive framework for studying both the structural organization and developmental changes along multiple, interacting dimensions of the self concept. The basis of this model is the multidimensional self theory of James (1892), who first distinguished between the "me"-aspect (i.e., the set of self attributes that one can objectively know, that are organized into a hierarchical structure of material, social, and spiritual constituents), and the "I"-aspect (i.e., the person's subjective experience of individual identity reflected in an awareness of one's own distinctness, continuity over time, volition and reflective ability) of the self concept. Damon and Hart (1982, 1988) utilized this scheme as a theoretical starting point for devising their semi-structured self-understanding interview. Responses to interview questions are classified according to a coding scheme consisting of four self-as-object (the "me" in James' theory) *categories*—physical descriptors, activities, social and psychological aspects of self description—and three self-as-subject (the "I" in James' theory) *categories*—self continuity, distinctness, and agency. Categories are further classified into four *levels*, reflecting an increase in the complexity of self description, from defining the self in concrete terms of "surface", observable characteristics, to a concept of self as perceived in reference to the reactions of others and to one's life philosophy.

Besides its use in developmental studies of the self concepts of typical children and adolescents, this approach has also been proven sensitive to capturing the specificity of atypical developments in self understanding related to mental health difficulties, or neurodevelopmental disorders (e.g., studies of anorexic adolescent girls, see Schorin, 1985, adolescents with conduct disorder, see Melcher, 1986, children and adolescents with autism, see Lee & Hobson, 1998).

Investigations of self concepts among people with mental retardation or developmental disorders (Fine & Caldwell, 1967; Gowans & Hulbert, 1983; Shurr, Joiner, & Towne, 1970; Widaman, Macmillan, Hemsley, Little, & Balow, 1992; Zeitlin & Turner, 1988) have been sporadic and focused primarily on global self-worth or on academic self-perceptions. In many of these studies the nature of the participants' disabilities was often left unspecified, and it appears that

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