



# Who reports it best? A comparison between parent-report, self-report, and the real life social behaviors of adults with Williams syndrome



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## ABSTRACT

Given the reliance on self-report in studies of adults with intellectual disabilities, this study examined individual vs. parental reports concerning the social approach behaviors of adults with Williams syndrome (WS) across a hypothetical and a live behavioral setting. Individuals with WS ( $N = 30$ ) were asked whether they would approach strangers in two hypothetical, laboratory tasks (yes/no questionnaire vs. judging facial stimuli of individuals with different emotional expressions). Similarly, their parents also responded to a rating scale of their child's social approach behavior toward strangers displaying various emotions. Then, in a community setting, behavioral coders recorded actual social approaches of individuals with WS toward strangers. Although self-report ratings were consistent across measures, these measures did not correspond to the individuals' actual behaviors during the community observations. Conversely, parental reports did not correspond to their child's self-report measures, but parents did more accurately predict their child's real-life social approach behaviors. Implications are discussed for both research and practice.

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## 1. Introduction

Due to various methodological issues, the validity and reliability of both parent and self-report questionnaires have recently been questioned. [Finlay and Lyons \(2001\)](#) noted that, for parent reports, researchers usually assume that parents are aware of the individual's behaviors, thoughts, and feelings and are able to accurately report such phenomena. In the emerging area of participatory research, however, researchers have emphasized the importance of obtaining information directly from individuals with disabilities ([Chappell, 2000](#)). But limitations also exist when gathering self-report data from these individuals. Specifically, individuals with intellectual disabilities have difficulty with responding to specific question content, phrasing, and response formats and are prone to inconsistent reporting and acquiescence bias ([Finlay & Lyons, 2001](#); [Heal & Sigelman, 1995](#)). Individuals with intellectual disabilities may also find it difficult to reflect on abstract concepts, including judging their own behaviors or what they would do in hypothetical situations ([Finlay & Lyons](#)).

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Due to these limitations, it remains unclear whether parent or self-report is the most accurate form of measurement related to individuals with intellectual disabilities. While researchers agree that individuals with intellectual disabilities should be given the opportunity to provide their own responses, accommodations are still needed to enhance the accuracy and assess the validity of self-report data. Specifically, [Heal and Sigelman \(1995\)](#) have suggested that multiple formats of self-report data should be collected and compared for response consistency. These self-report data should also be triangulated with reports from other respondents, such as parents, to assess correspondence ([Heal & Sigelman, 1995](#)). [Finlay and Lyons \(2001\)](#) also recommended simplifying the response format from a Likert-type scale to yes/no responses and to provide picture representations with the questions. Finally, in order to determine the most accurate form of measurement, self-report and parent-report data should be supplemented with naturalistic observations ([Schroeder, Cappadocia, Bebko, Pepler, & Weiss, 2014](#)).

In this study, we compared self-report and parent-report data – for both hypothetical, laboratory tasks and for real-life behaviors – of young adults with Williams syndrome. Williams syndrome (WS) is a rare genetic disorder caused by a microdeletion of at least 24 genes on chromosome 7, resulting in borderline to moderate levels of intellectual disability ([Hillier et al., 2003](#); see [Martens, Wilson, & Reutens, 2008](#), for review). These individuals have long been described as having a strong social drive and desire to approach and interact with strangers ([Doyle, Bellugi, Korenberg, & Graham, 2004](#); see [Järvinen, Korenberg, & Bellugi, 2013](#), for review). Statements concerning the social approach behaviors of adults with WS, however, have generally been inferred from parent-report questionnaires and hypothetical self-report tasks ([Fisher, Moskowitz, & Hodapp, 2013](#); [Jones et al., 2000](#); [Riby, Kirk, Hanley, & Riby, 2013](#)).

When results from parent-report are compared to those of self-report, conflicting findings arise as to whether individuals with WS are truly indiscriminate toward approaching strangers. Compared to parents of individuals with other disabilities and individuals without disabilities, parents rate their children with WS as more indiscriminately social (see [Järvinen et al., 2013](#); [Jones et al., 2001](#), for review). But individuals with WS vary in their own reports, with some appearing social and others appearing more socially reserved ([Bellugi, Adolphs, Cassady, & Chiles, 1999](#); [Frigerio et al., 2006](#); [Jones et al., 2000](#); [Martens, Wilson, Dudgeon, & Reutens, 2009](#); [Porter, Coltheart, & Langdon, 2007](#); see [Jones et al., 2001](#), for review).

It is important to note, however, that the self-report data collected from individuals with WS might not be accurate because of the various measurement limitations associated with assessing individuals with intellectual disabilities. For example, individuals with WS are often asked to rate their own social approach behavior in hypothetical situations, such as through viewing photographs of unknown adults and indicating whether they would like to approach and interact with the person (see [Jones et al., 2001](#), for review). These responses should be interpreted with caution, as individuals with intellectual disabilities have a difficult time responding to questions about abstract concepts, such as hypothetical situations ([Heal & Sigelman, 1995](#)). Additionally, participants with WS are typically asked to rate their desire to approach on a 4 to 5-point Likert-scale; yet, individuals with intellectual disabilities have a difficult time providing answers to Likert-type scales ([Finlay & Lyons, 2001](#)). Finally, participants are only administered one assessment of approachability, forfeiting the possibility of checking for consistency across measures ([Heal & Sigelman](#)).

A final limitation is that only one study has directly compared parent-report to self-report and no studies have compared these reports to naturalistic observations of the social behaviors of individuals with WS. When [Järvinen-Pasley et al. \(2010\)](#) directly compared parent-report to self-report within the same sample, they found no correspondence between responses. Thus, it remains unclear whether parents or individuals with WS are more accurate at reporting the social behaviors of adults with WS.

The current study had three aims. First, to assess the consistency of reporting among adults with WS, we compared two forms of self-report data, concerning social approach behavior. To account for a possible effect of social desirability (e.g., participants providing the response they thought we were looking for), one task was administered through a computer program with no researcher interaction, while the other was administered verbally with a research assistant. Additionally, to further comply with the recommendations for self-report assessment with individuals with intellectual disabilities, we simplified the response format from a Likert-scale to yes/no ([Finlay & Lyons, 2001](#)). Second, we assessed the correspondence between parent-report and self-report by comparing both forms of self-report measurements to the parents' responses to similar questions concerning the social approach behaviors of adults with WS. Finally, to determine the most accurate reporter of social approach behaviors, we compared parent-report and self-report to a naturalistic observation of the social behaviors of the sample of adults with WS.

## 2. Method

### 2.1. Participants

Participants consisted of 30 young adults with genetically confirmed WS (15 female, 15 male) and their parents (26 mothers, 4 fathers). All participants were White. Individuals with WS were an average of 26.43 ( $SD = 8.56$ ) years of age (range 16–50). Participants with WS were administered the Kaufman Brief Intelligence Test, 2nd edition (KBIT-2; [Kaufman & Kaufman, 2004](#)), which yields verbal, non-verbal, and full scale IQ scores. Average full scale IQ was 70.43 ( $SD = 13.73$ ); consistent with the WS cognitive profile ([Searcy, Lincoln, Rose, Klima, Bavar, & Korenberg, 2004](#)), the verbal standard score averaged 77.50 ( $SD = 11.51$ ) and the non-verbal standard score averaged 69.80 ( $SD = 16.90$ ). Most individuals with WS lived at home with their parents (90%), while the remaining participants lived independently with support (10%).

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