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Addressing social skills deficits in adults with Williams syndrome



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ABSTRACT

Background: Individuals with Williams syndrome (WS) are hypersocial; yet, they experience social difficulties and trouble with relationships. This report summarizes findings from three studies examining the social functioning of adults with WS and the feasibility of a social skills training program for adults with WS (SSTP-WS) through the examination of performance on initial lesson plans.

Method: Study 1: 114 parents of adults with WS completed the Social Responsiveness Scale-2. Study 2: 10 adults with WS and 12 of their parents participated in focus groups to further describe the deficits identified in Study 1 and to discuss a SSTP-WS. Study 3: 30 adults with WS were randomly assigned to 2 lessons on either conversations or relationships and pre-post change in social skills knowledge was assessed.

Results: Study 1 indicates adults with WS experience severe social impairments in social cognition, and mild-moderate impairments in social awareness and social communication. Qualitative results in Study 2 indicate a SSTP-WS should address conversation skills and relationships. In Study 3, participants showed gains in social skills knowledge following completion of lessons.

Implications: A SSTP-WS may be beneficial for adults with WS. Future research should describe the social needs of individuals with WS at different ages and should further develop a SSTP-WS.

What this paper adds?

Although there is a large amount of research examining the social behaviors of individuals with Williams syndrome (WS), the findings have not been extended to the development of interventions designed to directly address their social skills deficits. This paper presents the iterative process to develop a social skills training program that meets the unique needs of adults with WS. This paper adds to the literature in three ways. First, this paper extends previous research on children with WS by assessing the social skills deficits of a large sample of adults with WS. We provide data that indicate that, similar to children with WS, adults with WS continue to experience the most impairments related to social cognition and least impairments related to social motivation. Second, this paper uses the results of the social skills survey to talk with parents and adults with WS about their social needs and the needs on which they feel a social skills training program should focus. Finally, this paper is the first to develop a social skills intervention for individuals with WS. Borrowing from the methods and curricula for social skills training programs for individuals with autism, this paper reports on how lesson plans were adapted to meet the unique needs of individuals with WS. We present results from an initial pilot of four lesson plans developed for an intervention specific for adults with WS. These lesson plans meet a critical need to address the social skills deficits of adults with WS.

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1. Introduction

Williams syndrome (WS) is a complex neurodevelopmental disability caused by a deletion of ~26 genes on chromosome 7q11.23 (Hillier et al., 2003). One of the most salient features of the WS behavioral phenotype is the extremely social personality (Klein-Tasman & Mervis, 2003; Mervis et al., 2003; Klein-Tasman, Li-Barber, & Magargee, 2011). Indeed, individuals with WS are often characterized as gregarious (Gosch & Pankau, 1997), charming (Fryns, Borghgraef, Volcke, & Van den Berghe, 1991), and disinhibited in their social approach behavior towards both familiar and unfamiliar people (Järvinen, Korenberg, & Bellugi, 2013). Despite their hypersociability, individuals with WS experience a number of social difficulties, including trouble establishing and maintaining peer relationships (e.g., Davies, Udwin, & Howlin, 1998; Sullivan, Winner, & Tager-Flusberg, 2003). Such difficulties result in nearly 75% of adults with WS reporting feelings of social isolation (Davies et al., 1998), 30% reporting difficulty forming friendships, and 49% reporting a poor understanding of the concept of friendship (Elison, Stinton, & Howlin, 2010).

While research has speculated that specific aspects of social skills impairments contribute to the social difficulties and isolation experienced by individuals with WS (Davies et al., 1998; Fisher, Moskowitz, & Hodapp, 2013; Jawaid et al., 2012; Mervis & Klein-Tasman, 2000), there is a dire need for systematic research to examine and address the social skills deficits experienced by adults with WS. Thus, this report describes the iterative approach to describe the social skills deficits and social needs of adults with WS and to use those findings to develop a social skills training program (SSTP) addressing those needs. Findings from three studies were used to (1) describe the most salient social skills deficits experienced by adults with WS; (2) identify the social needs and best approach to address these needs for adults with WS; and (3) pilot lessons developed for a SSTP to improve the social functioning and knowledge of adults with WS. Before describing these three studies, we first discuss the previous research related to social functioning of individuals with WS and describe why a SSTP might be an appropriate intervention for this population. We then briefly present the methods and results of the three studies.

1.1. Social functioning of individuals with WS

Before effective interventions can be developed to support the social needs of adults with WS, it is necessary to understand the paradox between hypersociability and the social isolation experienced by these individuals (Thurman & Fisher, 2015). Although no empirical studies have explicitly examined the link between social skills deficits and friendship difficulties among individuals with WS, certain deficits are hypothesized to relate to their friendship problems. For example, the tendency to display excessive chatter, make socially inappropriate statements, and engage in self-talk could be related to the high rates of peer rejection experienced by individuals with WS (Davies et al., 1998). Other studies suggest that difficulties conversing with peers lead to trouble establishing and maintaining friendships (Mervis & Klein-Tasman, 2000). Such speculation is further supported by research indicating that similar social skills deficits displayed by individuals with autism spectrum disorder (ASD) lead to problems with friendships, romantic relationships, social participation, and vocational success (Barnhill, 2007).

Indeed, a growing body of research has clearly highlighted that individuals with WS do have impairments in social skills. For example, compared to children with other genetic forms of intellectual disability, children with WS had poor social competence (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004) and, compared to children without disabilities, delayed social skills development (Mervis, Klein-Tasman, & Mastin, 2001). Klein-Tasman et al. (2011), van der Fluit, Gaffrey, and Klein-Tasman (2012) reported that while children and adolescents with WS had less difficulty with the prosocial aspects of social functioning, such as social motivation (e.g., desire to engage in social interpersonal behavior) and social awareness (e.g., ability to pick up on social cues), they had considerable deficits in the social cognitive aspects of social functioning, including social communication (e.g., expressive social communication) and social cognition (e.g., ability to accurately interpret social cues). Similarly, Lough, Flynn, and Riby, (2015, 2016) reported impaired social skills in all domains of social reciprocity, as well as poor personal space regulation, for children and adolescents with WS.

Although there have been fewer systematic examinations of the social functioning of adults with WS, there is some evidence indicating that the social behaviors of the majority of adults with WS continue to fall within the clinically significant range of social skills deficits (Järvinen, Ng, & Bellugi, 2015; Riby et al., 2014). Similar to children and adolescents with WS, Järvinen and colleagues reported that adults with WS continued to display deficits related to social cognition and social communication. Overall, previous research indicates that although individuals with WS are friendly and motivated to interact with others, they also demonstrate difficulties with interpersonal and social communication skills.

1.2. Social skills training programs

Given the link between social difficulties and poor social outcomes, it is vital that researchers move beyond describing the social skills deficits of individuals with WS to designing interventions to address these issues. SSTPs are an evidence-based practice implemented to improve social success in individuals with ASD and other developmental disability populations (e.g., Gresham, Sugai, & Horner, 2001). Most SSTPs involve direct training approaches, in which social skills are directly taught to the individual in either group settings or one-on-one. Although empirical support for the success of SSTPs exists for individuals at all stages of development and intellectual functioning (e.g., Bellini, Peters, Benner, & Hopfm, 2007; Gantman, Kapp, Orenski, & Laugeson, 2012), fewer programs have been developed for adults with disabilities. Further, programs for adults generally focus on those with ASD without co-occurring intellectual disability (e.g., Gantman et al. 2012). As such, it is unclear if the topics and training methods of currently existing SSTPs for adults with ASD would be effective for adults with WS.

Although the efficacy of a SSTP for individuals with WS has not been examined, the similarities to the social skills deficits of those with ASD indicate that this could be an impactful intervention. As such, this report (1) identifies the most salient social skills deficits of adults with WS; (2) summarizes the social needs discussed by parents and adults with WS and their suggestions for how to address those needs; and (3) provides an overview of the development of a selection of lessons for a SSTP specifically for adults with WS (SSTP-WS) and a summary of outcomes from an initial pilot of the lessons.

2. Study 1

To design effective interventions, it is important to first determine the most salient issues to be addressed. While there is a growing body of research related to the social difficulties of children and adolescents with WS (e.g., see [Mervis & Klein-Tasman, 2000](#)), less research exists examining the social impairments of adults with WS. Therefore, Study 1 was designed to identify and describe the social skills deficits of a sample of adults with WS. The research questions were: (1) Do adults with WS experience social skills deficits? And if adults with WS experience social skills deficits, (2) do these deficits differ by gender, age, or functional ability? and (3) do they display more difficulty in certain areas of social functioning compared to others?

2.1. Method

2.1.1. Participants

Participants were 114 parents/caregivers of adults with WS. Overall, 105 (92%) were mothers to the individual with WS, 6 (5.3%) were fathers, and 3 (2.7%) were other relatives. The majority of respondents were female (93.8%). Parents reported on the social skills of 114 adults with WS (59 male, 55 female), whose mean age was 27.99 years ($SD = 7.55$; range = 18–52).

2.1.2. Procedure

Social skills were assessed as part of a larger study examining the social experiences of adults with WS. A targeted recruitment email was sent to parents from previous research projects and to all members of the Williams Syndrome Association who had a child with WS who was 18 years of age or older. The recruitment email included a description of the study and asked interested parents/caregivers to email the first author for a link to the parent survey. Once the parent survey was completed, the parent was directed to a page containing a link to a survey for adults with WS to complete. To address the research questions for this report, only the results from the parent measures related to social skills and functional abilities were included in the analyses. If the parent and the individual surveys were both completed, participants were mailed a \$10 gift card to thank them for their participation.

2.1.3. Measures

2.1.3.1. Social Responsiveness Scale-Second Edition (SRS-2; Constantino & Gruber, 2005) assesses the presence and severity of social impairment. Parents rate 65 items on a 4-point Likert scale. The SRS-2 yields five subscales, including: social awareness, social cognition, social communication, social motivation, and autistic mannerisms. Higher scores on each subscale indicate greater severity of social impairment. Cronbach's alphas for this sample indicate moderate to high levels of internal consistency, with the total scale level $\alpha = 0.85$; social awareness = 0.48, social cognition = 0.81, social communication = 0.88, social motivation = 0.77, and autistic mannerisms = 0.81. The weaker reliability of social awareness is similar to that reported by [Klein-Tasman et al. \(2011\)](#) and is still considered broadly acceptable.

While the SRS-2 was originally developed as an autism screener and a way to detect milder traits of autism, this tool has since been used for a range of disability populations and several studies have used the SRS/SRS-2 as a measure of social impairment in WS (e.g., [Järvinen et al., 2015](#); [Klein-Tasman et al., 2011](#); [Lough et al., 2015](#); , 2016; [Riby et al., 2014](#)). The t-scores of the SRS-2 were examined to determine the percent of adults with WS to fall within the clinically significant range of social difficulties. Specifically, t-scores below 60 indicate no clinically significant social impairments, t-scores between 60 and 75 indicate mild to moderate social impairments, and t-scores 76 and above represent severe social skills deficits.

2.1.3.2. Activities of Daily Living (ADL; Seltzer & Li, 1996) assesses the functional abilities (e.g., degree to which the individual is able to walk, read, participate in leisure activities, and work) of individuals with intellectual and developmental disabilities through 14 items rated on a 5-point scale (1 = *not at all* to 5 = *very well*). Variables are summed into a single, cumulative score ranging from 14 to 70, with higher scores indicating greater functional independence. This scale has been reliably used in previous research of individuals with intellectual disability and WS (e.g., [Lough & Fisher, 2016](#); [Seltzer & Li, 1996](#)). Cronbach's alpha for this sample indicates a high level of internal consistency (total scale $\alpha = 0.80$). Mean total ADL score for this sample was 46.70 (7.22; range 25–62).

2.1.4. Data analysis

Preliminary data analysis procedures included: checking the distribution of the variables, imputation for missing values, and conducting Cronbach alphas to verify the reliability of the scales. Then, descriptive analyses (e.g., frequencies and multivariate analysis of co-variance [MANCOVA] using ADL score as a covariate) were conducted to determine the extent of social skills deficits experienced by individuals with WS.

2.2. Results

Over half (51.8%, $n = 59$) of parents of adults with WS reported clinically significant social skills impairments on the SRS-2. The

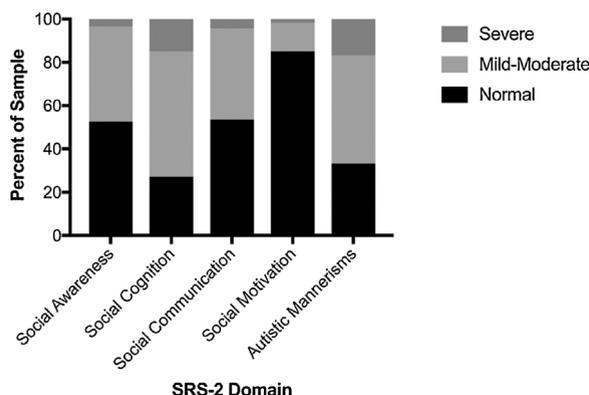


Fig. 1. Percent of participants falling in the average (t-scores below 60), mild/moderate (t-scores between 60 and 75), and severe ranges (t-scores 76 and above) on the Social Responsiveness Scale-2 (SRS-2), as rated by parents or caregivers.

percent of young adults falling within the normal, mild-moderate, and severe ranges at the domain level is presented in Fig. 1. The majority of the young adults with WS were rated to have clinically significant social difficulties related to social cognition (72.8%, $n = 83$) and autistic mannerisms (66.7%, $n = 76$). Nearly half of participants were also rated to have at least mild to moderate difficulties in the domains of social awareness (47.4%, $n = 54$) and social communication (46.5%, $n = 53$). Fewer participants (15%, $n = 17$) were reported to have clinically significant difficulties in the domain of social motivation.

Next, neither age nor gender were significantly related to total score on the SRS-2 or to any domain scores. Scores on the ADL, however, were significantly negatively correlated with total SRS-2 t-score ($r(114) = -0.59$) and with all domain t-scores (r 's range from -0.56 to -0.42 , all p 's < 0.001), indicating that individuals with lower independent functioning abilities were rated to have more significant social skills deficits.

Third, a MANCOVA with the t-scores of the five factors of the SRS-2 as the dependent variables indicated there was a significant effect for domain, Wilk's $\Delta = 0.65$, $F(5, 108) = 11.79$, $p < 0.001$, multivariate $\eta^2 = 0.353$. Follow-up t -test comparisons with Bonferroni correction of alpha level 0.01 indicated that social cognition and autistic mannerisms were the most problematic and were rated significantly higher than the remaining three domains. Social awareness and social communication were rated as significantly more impaired than social motivation. Overall, parents reported the most impairment in social cognition and autistic mannerisms and the least difficulties associated with social motivation (see Table 1).

2.3. Brief discussion

Similar to findings from previous research examining children and adolescents with WS (Klein-Tasman et al., 2011; Lough et al., 2015, 2016; Riby et al., 2014), the majority of adults with WS were reported to have clinically significant social skills deficits, with most displaying clinically significant impairments in social cognition. Akin to the WS social profile, few participants struggled with social motivation. These results confirm that while individuals with WS appear to be highly social and are motivated to interact with others, they still experience impaired social skills and poor social understanding.

These findings extend the research by examining a large sample of adults with WS, indicating that adults (just as with children and adolescents) struggle with social reciprocity. The deficits in social cognition and social communication, or the ability to take another's perspective and impairment in expressive communication, may be particularly relevant to the difficulties with initiating and maintaining conversations and in handling negative peer interactions. These initial results indicate a need for an intervention for adults with WS that addresses social cognition and teaches appropriate social interactions (e.g., conversations).

Table 1
Mean t-score for each domain of the SRS-2 and significantly different domains.

SRS Domain	Mean (SD)	F	Domains Differing
Social Awareness	58.64 (8.93)	24.18**	Cog, Aut > Aw > Mot
Social Cognition	64.67 (10.57)	34.23**	Cog > Aw, Comm, Mot
Social Communication	57.66 (10.04)	52.14**	Aut, Cog > Comm > Mot
Social Motivation	50.68 (8.86)	28.91**	Aut, Cog, Aw, Comm > Mot
Autistic Mannerisms	64.96 (10.64)	38.75**	Aut > Aw, Comm, Mot

Note: Cog = social cognition; Aut = autistic mannerisms; Aw = social awareness; Mot = social motivation; Comm = social communication.

** $p < 0.01$.

3. Study 2

Results from Study 1 confirm that adults with WS do have social skills deficits and, similar to those with ASD, may benefit from a SSTP. Before designing such an intervention, however, it is important to validate these findings by gaining a more in-depth perspective about the social needs of adults with WS and the best way to address these needs. Conducting focus groups about a potential intervention with participants can not only help inform the development of the intervention, but they are also an important source of social validity (Kozleski, 2017). Specifically, including the potential participants' voices in the design will help to ensure the intervention is a socially valid approach to training and to addressing important skills (Kozleski). Study 2, therefore, was designed to validate the results of the survey findings through focus group interviews with adults with WS and with their parents and to gain a better understanding of the social needs of adults with WS and the best way to address those needs.

3.1. Method

3.1.1. Participants

Four focus groups were conducted with 22 participants; 10 adults with WS participated across 2 focus groups and 12 parents (2 fathers, 10 mothers) responding about the 10 adults with WS participated across 2 separate focus groups (e.g., parents and adults were not in the same focus group meetings). The majority (60%) of the parents were married and 70% had the adult with WS living at home with them. While all participants were White, they came from a variety of socioeconomic backgrounds with 65.5% making below \$100,000 and 62.5% earning less than a college degree. The mean age of the adults with WS was 27.1 ($SD = 9.56$; range 17–50). Sixty percent of the adults with WS were male and 40% were female. Half of the adults with WS had attended a post-secondary education program for individuals with disabilities (the others had completed high school with a certificate), and half of the adults had either a paid or unpaid job (the others did not work).

3.1.2. Procedure

Emails were sent to local parents of adults with WS, inviting them and the individual with WS to participate in a focus group about the social needs of adults with WS and the best way to address those needs. To accommodate individuals across the state, two meetings (1 for parents, 1 for adults with WS) were held on the eastern side of the state and two meetings were held on the western side of the state. The focus groups were conducted in private meeting rooms, in buildings with ample parking. Participants were provided with snacks, drinks, and a \$20 gift card to thank them for their participation.

Upon arrival, participants were asked to complete a short demographic questionnaire. Parents were asked to provide information about their own background as well as the background of the individual with WS. Research assistants were available to assist the adults with WS to complete their demographics questionnaire (e.g., reading each question aloud). Responses from adults with WS were verified through comparison with parent responses. If there were discrepancies, the parent's responses were used.

Once all participants arrived, two separate semi-structured focus group protocols were followed, one for parents and one for adults with WS. For the adult participants with WS, the focus group protocol was developed to determine their feelings toward their friendships (did they feel as though they had friends?), what they wanted to change, what they have already done to try to improve their friendships (and was it successful), and what they felt they needed help with. The focus groups were recorded for later transcription, all protocol questions were addressed, and they lasted an average of 41 min.

The primary aim of the parent group was to inform the results of the large-scale survey on social skills deficits (Study 1). A secondary aim was to determine how parents felt pre-existing social skills programs could be adapted to meet the needs of adults with WS. Thus, the interviewer (the first author) first provided a written summary of the findings from Study 1 and reviewed the findings with the parents. Next, the interviewer showed the parents a short video description of a currently existing social skills program for adults with ASD and provided a list of the topics covered within that curriculum. After viewing the video, the interview asked parents to indicate whether they felt the format and curriculum (as described in the video and on the handout) would be appropriate to meet the needs of adults with WS. The remaining discussion then focused on areas of need identified by the parents for teaching social skills to individuals with WS, discussing areas that were already addressed in the currently existing curriculum, and additional areas of focus that were needed. The focus groups were recorded for later transcription, all protocol questions were addressed, and they lasted an average of 60 min.

3.1.3. Data analysis

The 89 single-spaced pages of data were analyzed using a complementary, sequential mixed-methods design (Greene, 2007). Specifically, the two different research methodologies included results from the survey in Study 1 and the focus groups in Study 2. The purpose for mixing methods was to triangulate data sources (e.g., the survey responses and focus group data). By triangulating data sources, we were able to use multiple sources to establish credibility and confirm our findings for the development of the SSTP-WS.

Verbatim transcripts of each focus group were analyzed for themes. Specifically, a thematic content analysis approach was used to identify themes from both the parent and adult transcripts (Beail & Williams, 2012). Based on the results of Study 1, the authors developed a priori themes which the second author used to initially read all of the transcripts and create a coding framework. The first and second authors then met to discuss and refine the framework. The authors individually coded the text using a line-by-line approach analysis (Creswell, 2003), then met to review their codes and discuss any discrepancies or questions related to an excerpt. The second author then reanalyzed the transcripts to look for any missed codes. By reviewing to see if any additional codes existed,

we explored the full range of data (Lincoln & Guba, 1985) to ensure that we were reflecting all of the themes. This approach was used because while the findings from Study 1 provided some a priori ideas for themes to be identified, the authors also wished to analyze the data for additional concepts that might have arisen (Leech & Onwuegbuzie, 2011).

3.2. Results

3.2.1. Adults with WS focus group

The adults with WS focus group transcripts identified two major themes related to friendships and handling conflict.

3.2.1.1. Friendships. The adults with WS focus group provided insight into the adults' feelings and perceptions of their friendships including the importance of friends, what they like to do with friends or they want to do with friends, and barriers to friendships. Several adults expressed thoughts regarding the importance of having friends in their lives such as, "what's life worth living if you don't have any friends?" and "a friend is someone who spends time with you and if you're having a hard time, they help you and if like you wanta hang out, they'll always try to find time to be with you."

Adults with WS articulated some activities they enjoy doing with friends such as "hanging out", "watching sports and television shows", and "facetiming each other." Others described activities they would like to do with a friend such as, "I kinda want friends who like adventures and like roller coasters" and possibly going to sporting events and concerts. The adults with WS also discussed barriers to friendships, describing their lack of independence and reliance on parents to hang out with friends. For example, one adult stated, "...problem for me is that I don't drive and a lot of my friends don't drive..." and another said, "...the only way that I can get to him is if my mom would drive me down..."

3.2.1.2. Handling conflict. The second major theme that arose from the adult focus groups was the issue with handling conflict. This theme encompassed experiences with bullying and with being left out or ostracized from a group. One adult articulated that others called her names and made it difficult to make friends as she stated,

...called me one of her weirdo friends because I like things that aren't considered normal to like and sometimes if I wanted to do something that she didn't consider normal, she would like freak out on me. And it's kind of awkward to make friends 'cause I'm still worried if I like say I like something that they don't, they'll like leave.

Other adults with WS expressed feelings of being left out of a group or ostracized. One adult stated, "the thing is every time I tried to get a friend in the past, they wouldn't wanta come over. They wouldn't wanta be with me. Everybody I asked would always tell me, 'no, I don't wanta come over.'"

3.2.2. Parent focus group

Overall, the parents agreed that a SSTP would be beneficial for adults with WS and they emphasized a need to focus on conversation skills and relationships. In terms of social skills deficits, two major themes were identified from the parent focus groups: social interactions with others and difficulties with relationships.

3.2.2.1. Social interactions. Parents identified that individuals with WS need support in their social interactions with others, specifically initiating conversations and maintaining a conversation. For example, as parents discussed the difficulty with initiating interactions, one parent stated, "they have no problem walking up to anybody and start talking, but that's sometimes what the problem is, is the way they interrupt conversations." Overall, parents indicated that individuals with WS have difficulty appraising a situation and understanding when it is appropriate to interrupt, join, and initiate a conversation with strangers and those familiar to them. Parents expanded on this, as one stated "the entrance; they'll just walk in and just start talking..." and another said "he might've interrupted and didn't belong there in the first place."

Although parents felt that individuals with WS have a preliminary understanding of conversational skills, they felt these individuals struggle with maintaining the conversation. Some described problems with over-talking, while other described difficulties with moving beyond initial pleasantries. For example, one parent commented that her child would attempt to maintain a conversation if no one else in the group was speaking, "he'll feel like it's his job to keep things going but he doesn't really know how to do that beyond a certain point or even sometimes, he'll give, you know, he'll give a very eloquent sort of impromptu speech but then he loses it because he doesn't know how to end it."

3.2.2.2. Difficulties with relationships. Beyond initiating and maintaining conversations, parents also expressed concerns regarding managing relationships, including dating, handling conflict, and problems connecting with others. In regards to dating, one parent stated "it always seems to me that these kids are very interested in the opposite sex...it's always boyfriend and girlfriend things going on." At the same time, the parents discussed how their children have difficulties truly understanding what it means to date someone.

Parents also described difficulties with handling conflict, especially related to comprehending and processing gossip and disagreements between other individuals. One parent stated, "He doesn't like when people have conflict. And that, sometimes, he doesn't know how to; he'll either get too involved with it or he'll just completely shut them out. He doesn't seem to know when to just kinda let it happen..."

Finally, parents expressed problems with connecting to others. One parent stated,

He had a lot more social connection when he was in elementary/middle school. He had a lot of friends who used to come over... they started growing up mentally and he did not and they didn't wanta keep hanging out with him because he was still back at that, you know, so there, the separating became really big and he doesn't get why they don't want to hang out with him anymore...

Other parents discussed the struggles with initial interactions between the adults with WS and other individuals. They explained that the adult with WS struggles to support the facilitation of friendship building. One parent expressed, "you're almost like stuck in that zone of arranging the play date almost and even these college kids are facilitating that with him, he's doing it more and more independently, but still, it's still that, somebody's still facilitating and sealing the deal."

3.3. Brief discussion

Understanding the social skills deficits and needs of adults with WS are imperative to the development of an effective SSTP-WS. Study 2 was designed to obtain a better perspective of the social impairments of adults with WS and to understand what social needs parents and adults with WS felt should be addressed in a SSTP. Findings from the focus groups provided qualitative details to the impairments identified on the social skills survey. After reviewing the results from Study 1, parents provided specific examples of impairments from the SRS-2 domains of social cognition, social communication, and social awareness. Parents expanded on the findings by specifically discussing the difficulties related to social communication and the adults' struggles with initiating and maintaining conversations. These conversational concerns are similar to those discussed in previous research examining the pragmatic language skills of individuals with WS (e.g., Laws & Bishop, 2004; Philofsky et al., 2007). Other research has directly examined the conversational abilities of individuals with WS, reporting instances of hyper-verbal speech (Udwin & Yule, 1990) and significant perseveration on certain topics (Jones et al., 2000).

Finally, reports from parents and adults with WS confirmed difficulties with social cognition, as both groups spoke about trouble navigating social relationships and peer interactions. Adults with WS expressed a desire to have friends who will not only hang out with them, but who will also be there for them when they need emotional support. Similar to previous research examining the bullying experiences of adults with WS (Fisher, Lough, Griffin, & Lane, 2017; Fisher et al., 2013), these participants discussed the struggles they experience with bullying and being left out. Thus, results highlight the importance of designing a SSTP that not only addresses the basics of social skills (e.g., conversations), but also addresses ways to identify and avoid negative peer relationships.

4. Study 3

Applying the results from Study 1 and Study 2, Study 3 describes a pilot of initial lesson plans developed for a SSTP-WS. SSTPs are typically delivered over 12–14 weeks by a facilitator in small groups of two to eight individuals (e.g., Tse, Strulovitch, Tagalaskis, Meng, & Fombonne, 2007) and most include instruction, modeling, role-play, and feedback on a specific skill each week (Wong et al., 2014). Although several SSTP protocols have been published, few exist for adults with disabilities. One exception is the *UCLA PEERS for Young Adults Program* (Gantman et al., 2012), a 14-week SSTP that was adapted from the evidence-based *UCLA PEERS for Adolescents Program* (Laugeson & Frankel, 2010) to be delivered to young adults with ASD in community settings. The *PEERS for Young Adults Program* has the potential to enhance the social skills of adults with WS, as it addresses two of the identified areas of deficits for adults with WS including, difficulty with conversational skills (Davies et al., 1998; Mervis & Klein-Tasman, 2000) and trouble maintaining friendships and romantic relationships (Davies et al., 1998; Elison et al., 2010). On the other hand, the didactic instruction and specific topics within each lesson do not meet the unique social difficulties of adults with WS, necessitating the adaptation of previously existing SSTPs to develop a specialized SSTP-WS (Thurman & Fisher, 2015).

Study 3 describes the results of four lessons plans designed to address two specific social skills needs that are evident in adults with WS (conversations and healthy relationships). These initial lessons plans were developed and piloted prior to the development of the entire SSTP-WS in an effort to first determine whether the procedures 1) were acceptable to adults with WS, and 2) led to increased social skills knowledge. Data from a brief pre-post assessment are provided, with the acknowledgement that knowledge gain and skill acquisition are different and that direct observation will better inform skill acquisition (e.g., see Fisher, Mello, & Dykens, 2014). The research question was: Following participation in lesson plans on conversations or healthy relationships, do adults with WS increase their social skills knowledge related to the topic in which they received instruction?

4.1. Method

4.1.1. Participants

Thirty adults attending a residential summer camp for individuals with WS participated in this study. Participants were an average of 28.53 (9.62; range 16–57) years old. Half of the participants were male and half were female. Mean IQ was 63.90 (13.61; range 40–91). While no participants in Study 3 overlapped with Study 2, the nature of the anonymous survey precluded the ability to determine if any participants overlapped with Study 1.

4.1.2. Procedure

Stemming from the results of the survey and the focus group interviews, two social skills topics (e.g., conversations and healthy relationships) were selected to develop four lesson plans and pilot at the summer camp. These lesson plans were informed by the

recommendations generated by the parent focus groups and in consultation with two WS experts (a special education teacher and mother of an adult with WS and a post-secondary education teacher for students with disabilities who has worked with several adults with WS in the past 5 years). Specifically, the first author and the two WS experts initially reviewed the results of Study 1 and Study 2 and then explored lesson plans on conversation skills and healthy relationships from various SSTP manuals (e.g., *UCLA PEERs for Adolescents Program* manual (Laugeson & Frankel, 2010); *Health and Family Life Education Common Curriculum* (UNICEF, 2009); *Think Social* (Winner, 2008)). Using these, as well as professional experience as a guide, 4 lesson plans were developed.

Participants were randomly assigned to one of two topics for instruction. *Group 1: Conversations* was comprised of 15 participants, including 9 males and 6 females with an average age of 26.67 (7.88) years. *Group 2: Healthy Relationships* was comprised of 15 participants, 6 males, 9 females with an average age of 30.4 (11.06) years. Groups did not significantly differ in terms of age ($t = -1.07, ns$) or gender ($\chi^2 = 1.20, ns$).

Prior to social skills instruction, all participants completed a pre-test assessment. One day following the pre-test, participants received their first social skills lesson. Following best practice guidelines for SSTP implementation (e.g., Reichow & Volkmar, 2010; Tse et al., 2007), Group 1 was divided into two smaller groups and participated in a lesson titled *How to Have a Conversation*. Behavior skills training (BST) techniques were used to (1) teach the important steps to starting a conversation; (2) model appropriate and inappropriate conversations; and (3) provide feedback during role play with partners. On this same day, Group 2 was divided into two smaller groups and participated in a lesson titled *Healthy and Unhealthy Relationships*. Using BST, the lesson began with instruction differentiating healthy and unhealthy relationships. Next, participants watched role plays and were asked to determine whether each scenario depicted a healthy or an unhealthy relationship with discussion on ways to identify cues for unhealthy relationships. Lessons were delivered by the first author (with a doctorate in special education) and another faculty affiliate of the camp (with a doctorate in developmental psychology) along with two research assistants studying clinical psychology. All individuals were trained in how to deliver the lessons plans and each lesson plan was delivered by the same 2 individuals.

The following day both groups completed a second lesson building on the same topic from the previous day. Thus, Group 1 completed the lesson *How to Have a Two-Way Conversation* and Group 2 completed *Being Taken Advantage Of*. Similar to the first day, lessons were taught through BST including instruction, modeling, role play, and feedback. To encourage reflection and practice, both groups were given homework related to the lesson of each day. All participants completed and returned both homework assignments. One day following completion of the second lesson, all participants completed the post-assessment.

4.1.3. Measures

4.1.3.1. Pre- and post-test assessment. This multiple-choice assessment included 12 questions designed to measure participants' knowledge related to how to have a conversation (6 questions) and how to maintain a healthy relationship (6 questions). Questions were developed based on the content covered in the social skills lesson plans and the format was modeled from the *Test of Adolescent Social Skills Knowledge* (Laugeson, Frankel, Mogil, & Dillon, 2009). An example of a question related to having a conversation is "When starting a conversation with another person you just met, you should: (a) sit back and listen and don't say anything; (b) ask many questions about many different things; (c) find something in common that you both like to talk about." An example of a question related to having a healthy relationship is "How do you know when someone is taking advantage of you? (a) you don't feel respected and you have a bad feeling inside of you; (b) you don't have anything in common with the other person; (c) you don't like to do the same things as the other person." Answers to questions were randomized. Questions were ordered such that Group 1 answered the conversation questions first and Group 2 answered the relationship questions first. Cronbach's alphas for this sample indicate moderate to high levels of internal consistency for the total scale level ($\alpha = 0.77$), the conversation scale ($\alpha = 0.59$), and the relationships scale ($\alpha = 0.65$).

4.1.4. Data analysis

A paired-samples *t*-test was conducted with both groups to examine the change in score from pre-test to post-test on the total score and for each domain.

4.2. Results

As a group, participants made overall gains from pre- to post-assessment ($t(29) = -3.08, p < 0.01$). Additionally, participants

Table 2

Mean scores and *t*-scores for the pre-test and post-test for each group (Conversation vs. Relationship) by type of question.

Group Assignment		Pre-test	Post-Test	<i>t</i>
1. Conversation	Conversation Qs	5.13 (1.36)	5.47 (0.92)	-2.09*
	Relationship Qs	4.87 (1.41)	4.80 (1.57)	0.32
2. Relationship	Conversation Qs	4.00 (1.51)	4.60 (1.12)	-2.20*
	Relationship Qs	3.80 (1.52)	4.53 (1.72)	-2.44**

Note: * $p \leq 0.05$; ** $p = 0.03$.

made gains on questions related to their assigned group, but not on questions related to the topics for which they did not receive instruction (see Table 2). Specifically, participants in *Group 1: Conversations* significantly increased their score on the post-test on questions related to conversations but not on questions related to relationships. Alternatively, participants in *Group 2: Relationships* significantly increased their score on the post-test on questions related to relationships, and slightly increased their score on questions related to conversations.

4.3. Brief discussion

To address the social skills deficits and needs identified in Studies 1 and 2, Study 3 was conducted to develop the SSTP-WS, to pilot 4 lesson plans, and to assess whether adults with WS could effectively gain social skills knowledge through participation. Participants were engaged in the lessons, demonstrated an understanding of the lesson topics through successful role play, and they completed their homework assignments each night. Following the two lessons, participants significantly increased their knowledge in topics related to their instructional group. Overall, adults with WS learned the strategies of successful conversations or how to recognize and avoid harmful relationships. Based on these initial positive results, the full SSTP-WS will be developed and piloted for use with adults with WS.

5. General discussion

Together, the three studies in this report highlight the social difficulties adults with WS experience in their interpersonal interactions. Findings from the survey were validated through focus group interviews with both adults with WS and their parents. Suggestions for addressing social skills deficits were then incorporated into four lessons plans developed as a part of a SSTP-WS and were piloted during a summer camp for adults with WS. This process of developing the lesson plans for a SSTP-WS directly responds to a call for action for more intervention research for individuals with WS (Thurman & Fisher, 2015). Specifically, this approach allowed for the development of a disability-specific intervention that accounts for the specific strengths and challenges of adults with WS, while addressing their specific needs (Fidler, Philofsky, & Hepburn, 2007).

Despite their highly social personalities, individuals with WS have trouble establishing and maintaining friendships (Mervis & Klein-Tasman, 2000). To our knowledge, no interventions have been developed to specifically address the social skills deficits of individuals with WS. These three studies, then, are the first to systematically examine the social skills deficits of adults with WS and to use the findings to begin to develop the SSTP-WS.

Future research should continue to examine the unique social skills deficits of individuals with WS and should focus on developing social skills interventions that can be implemented with younger children with WS. Similarly, the educational background and level of independence may vary for adults with WS who live outside the US. Future research should compare the social skills of adults with WS living in the US to those living in other parts of the world.

Further, it will be important to conduct a component analysis of a SSTP-WS to determine the most beneficial and effective aspects of the training. For example, Thurman and Fisher (2015) suggested a SSTP that used the combined approach of direct teaching with supplemental peer-mediation; the current lesson plans did not include a peer component but this should be incorporated in the future. Finally, future research must examine the impact of the SSTP-WS beyond a knowledge assessment. As is clear from previous research (e.g., Fisher, 2014; Fisher et al., 2014), the statements of individuals with WS (e.g., responses to a written assessment) do not always correspond with their actions (e.g., behaviors in the community), especially in regards to social interactions. Thus, it is critically important to examine how skills learned in the SSTP-WS generalize to real world social interactions. For example, future research should examine whether conversational abilities improve after intervention, whether participants gain more friendships, and whether individuals participate in more social outings.

While the results of the current studies are promising, certain limitations must be addressed. First, the participants in Study 1 were recruited through an email blast, which might have led to a biased sample of parents looking for support related to the social behaviors of their adult child with WS. Although the study description was kept vague (e.g., did not mention social skills deficits), it is not possible to know if parents of individuals with fewer social skills difficulties chose not to participate. Given the range of social skills in the study sample and similarities to previous research, however, the authors feel this was a representative sample. Second, because WS is a rare genetic condition, it was difficult to recruit a large number of individuals to participate in the focus groups. Although small, several topics were raised and there was a great deal of correspondence between the groups on the east and west sides of the state. Finally, the SSTP-WS is not complete and only four lesson plans were piloted across two days. It was important to pilot these lesson plans before developing the entire curriculum, however, to ensure that participants would benefit from the format and content. Additionally, many evidence-based SSTPs (e.g., PEERS) deliver the lessons across weeks to ensure adequate practice and generalizability of the skills. The lesson plans piloted in this study were delivered on two consecutive days and the pre-post assessments were administered just one day before and after the program. Thus, the results cannot be used to determine whether participants' change in knowledge led to change in behavior. Future research should examine a full SSTP-WS, delivered across 14 weeks, and directly assessing change in behavior in addition to change in knowledge.

In conclusion, adults with WS experience social skills deficits and may benefit from the SSTP-WS, developed to meet their unique social needs. Parents and adults with WS were excited about the potential of the SSTP-WS. The participants in the pilot study enjoyed the training and made significant knowledge gains related to the topics they were taught. Future research should continue to develop interventions to address the social impairments experienced by individuals with WS. Once effective interventions are developed, they can be disseminated into practice and incorporated into the educational curriculum of individuals with WS.

Declaration of interests

None.

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