



A Distance-Delivered Social Skills Program for Young Adults with Williams Syndrome: Evaluating Feasibility and Preliminary Efficacy

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Abstract

Adults with Williams syndrome (WS) display hypersocial behaviors and experience social skills deficits. To improve social outcomes, we evaluated the feasibility, acceptability, and preliminary efficacy of an 8-week distance-delivered social skills program for adults with WS. Sessions were offered twice a week for 90 min. Twenty-four adults with WS were assigned to an intervention or waitlist control group. Outcomes were assessed through interviews and surveys with adults with WS, parents, and facilitators. The intervention was rated as acceptable and feasible by all. Parents rated adults with WS as displaying significant improvements in social skills; yet ratings by adults with WS did not change. Adults also displayed increased social skills knowledge following participation. Implications for practice and future research are discussed.

Keywords Telehealth · Williams syndrome · Social skills · Intellectual disability · Feasibility

Williams syndrome (WS) is a complex neurodevelopmental disability caused by a deletion of about 26 genes on chromosome 7q11.23, affecting an estimated 1 in 7,500 to 20,000 live births each year (Hillier et al., 2003; Pober, 2010). In addition to displaying mild to moderate levels of intellectual disability (estimated mean IQ of 50–60; Martens et al., 2008), individuals with WS are often characterized as overly friendly, socially disinhibited (Davies et al., 1998; Jones et al., 2000), and demonstrating extreme interest in interacting with others (Klein-Tasman et al., 2011; Mervis et al., 2003). Despite this sociable nature, they also exhibit poor social skills across the lifespan that can lead to negative social

outcomes (e.g., Fisher et al., 2020a, b; Jawaid et al., 2012; Sullivan et al., 2003).

Indeed, individuals with WS appear to (a) be highly motivated to interact with others, (b) have a strong desire to make friends and to please others, (c) be too trusting of other people, and (d) have a pervasive and difficult-to-inhibit desire to approach and engage known and unknown individuals (Doyle et al., 2004; Järvinen et al., 2013; Jawaid et al., 2012; Jones et al., 2000). Despite this heightened social motivation, individuals with WS display considerable deficits in social communication (e.g., expressive social communication), social awareness (e.g., ability to notice social cues), and social cognition (e.g., ability to accurately interpret social cues) (Fisher & Morin, 2017; Järvinen et al., 2015; Klein-Tasman et al., 2011; Lough et al., 2016; Van der Fluit et al., 2012). Individuals with WS may also display excessive chatter, make socially inappropriate statements, and engage in self-talk (Davies et al., 1998), and studies suggest that difficulties conversing with peers may impact their ability to establish and maintain friendships (Mervis & Klein-Tasman, 2000).

The juxtaposition of hypersociability and social skills deficits for individuals with WS has been demonstrated across the lifespan and persists into adulthood (Fisher & Morin, 2017; Järvinen et al., 2013). For many individuals with intellectual disabilities, including WS, social skills

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deficits can result in difficulty developing and maintaining relationships, leading to social isolation, loneliness, depression, and suicidal ideation (Davies et al., 1998; Elison et al., 2010; Emerson et al., 2021; Fisher, Josol, et al., 2020; Fisher & Morin 2017; Gilmore & Cuskelly, 2014; Gosch & Pankau, 1997; Petroutsou et al., 2018; Scott & Haverkamp, 2014; Stancliffe et al., 2014). Parents of adults with WS highlight specific deficits with initiating and maintaining conversations and both parents and adults report trouble navigating social relationships and peer interactions (Fisher et al., 2017; Fisher, Shivers, et al., 2020; Fisher & Morin 2017) which may lead to social isolation and feelings of loneliness (Davies et al., 1998; Petroutsou et al., 2018; Sullivan et al., 2003; Thurman & Fisher, 2015). In fact, adults with WS have expressed a desire to have more friends with whom to hang out and from whom they could receive emotional support (Fisher & Morin, 2017). Finally, as they age, the excessive hypersocial behaviors displayed by adults with WS could also lead to increased social vulnerability and risk for exploitation (Doyle et al., 2004; Fisher et al., 2013; Jawaid et al., 2012; Thurman & Fisher, 2015). Without explicit social skills instruction, adults with WS are at heightened risk of being taken advantage of, especially by strangers or individuals who may befriend them in an effort to later exploit them (Fisher et al., 2013; Fisher, Shivers, et al., 2020).

Despite longstanding evidence of the social skills deficits displayed by those with WS and the related poor social outcomes, there is very little intervention research that examines outcomes for people with Williams syndrome (Klein-Tasman et al., 2021). To our knowledge, Fisher and Morin (2017) have conducted the only evaluation of a social skills intervention for this unique population. Their small pilot study evaluated the impact of brief social skills lessons on improving conversational and relationship knowledge and found that after intervention individuals with WS improved in their social skills knowledge (Fisher & Morin, 2017). Given the effectiveness of these preliminary lessons, it is vital that social skills training programs for adults with WS are developed and evaluated in a more systematic way. Further, given the unique behavioral phenotype of individuals with WS, there is a need to develop a disability-specific intervention that accounts for their specific strengths and challenges, while addressing their specific social skills training needs (Thurman & Fisher, 2015).

Social Skills Training Programs

Social skills training programs (SSTPs) are a frequently used strategy for improving the social success of individuals with autism spectrum disorder (ASD), but have also

been used with individuals with other intellectual and neurodevelopmental disability conditions (e.g., Gresham et al., 2001). SSTPs often involve direct training approaches in group settings, in which individuals are explicitly taught (through observations, modeling, rehearsal, and feedback) specific skills needed for social success. Although findings with individuals with ASD report moderate to high effect sizes for both in-person and computer-based SSTPs (Soares et al., 2021), specific factors should be considered when implementing SSTPs with adults with WS.

First, the topics within commercially available SSTPs for adults with disabilities (e.g., Laugeson 2017; Walker-Hirsch et al., 2020) may not holistically address the unique social difficulties experienced by adults with WS who might benefit from a combined approach, incorporating concepts and topics from various curricula. For example, given the social approach behaviors of individuals with WS, their tendency to trust strangers, and the potential social vulnerability that could result from these behaviors (Doyle et al., 2004; Fisher et al., 2013; Järvinen et al., 2015; Jawaid et al., 2012; Jones et al., 2000; Lough et al., 2016; Thurman & Fisher, 2015), adults with WS may benefit from a SSTP that first teaches them to understand the different relationships in their lives and about social boundaries, such as with lessons from the *Circles*® curriculum (Walker-Hirsch et al., 2020). Once adults with WS are able to understand the social circles, they might then benefit from instruction on how to interact with different people in their lives and how to maintain conversations, such as with instructions from certain lessons within the *PEERS*® curriculum (Laugeson, 2017). Finally, adults with WS might benefit from ending training with an explicit discussion about boundaries and socially appropriate and inappropriate behaviors, such as through lessons from the *A 5 Is Again the Law!* Program (Buron, 2007). Thus, rather than attending a single SSTP that might only address one aspect of their social skills deficits, a new training that incorporates specific components from different programs will better meet the needs of adults with WS. Second, individuals with WS may struggle to follow and comprehend the material in existing SSTPs (e.g., the *PEERS*® curriculum is evidence-based for those with ASD without co-occurring intellectual disability). Thus, these lessons need to be adapted to meet the learning needs of this population.

Third, because WS is a rare condition, few individuals with WS live in close proximity. Therefore, they may have to attend a SSTP with individuals with different diagnoses and social skills needs, or they may have to travel long distances to attend weekly SSTP lessons with others with WS. Additionally, there are relatively few providers with expertise in WS, so it may be difficult to find a SSTP provider who understands the needs of those with WS. Or

these providers may only have knowledge of interventions that have been developed for individuals without disabilities or with other disability conditions (Klein-Tasman et al., 2021). The recent movement toward synchronous and

asynchronous telehealth intervention delivery for individuals with intellectual and neurodevelopmental disabilities (Rispoli & Machalicek, 2020; Soares et al., 2021), however, may address this gap in services for adults with WS.

Table 1 Title, Example Content, and Homework Assignment Topic for Each of the SSTP-WS Intervention Lessons

Lesson	Content	Homework Topic
1: Introduction to Social Skills	<ul style="list-style-type: none"> • Basic definition of social skills • Expectations for online social behavior • Things people with great social skills usually do 	Identifying Social Skills
2: Social Circles – Introducing the 3 Ts of Social Boundaries (adapted from Walker-Hirsch et al., 2020)	<ul style="list-style-type: none"> • How people you know fit into different types of Social Circles • The 3 Ts of social boundaries: Talk, Touch, and Trust • How to use each Social Circle to understand your relationships with other people 	Know Your Social Circles
3: More About Social Circles	<ul style="list-style-type: none"> • Appropriate ways to greet the people in each of your Social Circles • Ways to tell the difference between a friend and an acquaintance • Ways to tell the difference between a friend and a professional 	Revise Your Social Circles
4: Conversation Basics – Part 1	<ul style="list-style-type: none"> • Different parts of a conversation • A conversation recipe for making a strong, quality conversation • How to use the letters T.A.L.K. to remember some basic conversation skills 	Practice Details in Conversation
5: Conversation Basics – Part 2	<ul style="list-style-type: none"> • “WH” and other question words that help keep a conversation flowing • To use the Topic Hand to help you remember to ask on-topic questions • Recipe for strong conversations 	Practice WH Questions in Conversation
6: Balanced and Equal Conversations	<ul style="list-style-type: none"> • How to tell the difference between balanced and unbalanced conversations • How to keep a conversation flowing back and forth 	Practice Making Comments and Questions
7: Types of Talk in Your Social Circles	<ul style="list-style-type: none"> • Appropriate topics of conversation to have with the people in each Social Circle • The difference between small talk, personal talk, and professional talk • Review the 3 Ts of talk, touch, and trust 	Practice Types of Talk with Different People
8: Conversation Crashers – Part 1 (adapted from Laugeson et al., 2017)	<ul style="list-style-type: none"> • The definition of a conversation crasher • The Interrogator and Conversation Hog • How conversation crashers can make people feel in social situations 	Conversation Record- Keep Track of Your Questions and Comments
9: Conversation Crashers – Part 2	<ul style="list-style-type: none"> • Examples of how conversation crashers can derail a conversation • The TMI: Too Much Information conversation crasher • How conversation crashers can make people feel in social situations 	Conversation Record- Keep Track of Your Questions and Comments
10: Getting to Know Others – Part 1	<ul style="list-style-type: none"> • Why asking others about themselves is a helpful social skill • How asking others about themselves also helps them get to know you better • Examples of safe and neutral topic questions to get to know others 	Record a Conversation
11: Getting to Know Others – Part 2	<ul style="list-style-type: none"> • A review of the levels of trust and talk in each Social Circle • A review of topics of conversation in each Social Circle • A review of having quality and balanced conversations 	Conversation Self-Monitoring
12: Acquaintance to Friend	<ul style="list-style-type: none"> • Ways to know when someone belongs in your acquaintance circle rather than your friend circle • 5 Steps to help you decide if someone is a good candidate to be your friend • Example situations that help you practice using a checklist with the 5 Steps to Friendship 	Acquaintance to Friend Checklist
13: Planning a Get-Together	<ul style="list-style-type: none"> • Reasons for having get-togethers • Examples of different get-togethers • 6 Steps for planning a get-together 	Plan a Get-Together
14: Boundaries – Part 1 (adapted from Buron 2007)	<ul style="list-style-type: none"> • Expectations for adult social behavior • Using a 5-Point Scale to understand adult social behavior • Levels 1, 2, & 3 on the 5-Point Scale for Social Boundaries 	Labeling Your Social Behaviors
15: Boundaries – Part 2	<ul style="list-style-type: none"> • Expectations for adult social behavior • Using a 5-Point Scale to understand adult social behavior • Levels 4 & 5 on the 5-Point Scale for Social Boundaries 	My Social Skills Journey
16: Closing and Reflection	<ul style="list-style-type: none"> • Appropriate ways to say goodbye • Program wrap-up and reminders • Sharing social skills journeys 	

Although most research includes the parent or teacher as the primary participant (Sutherland et al., 2018), some studies have demonstrated the effectiveness of telehealth interventions working directly with individuals with ASD (e.g., Hepburn et al., 2016) and show promise that such a strategy might effectively meet the needs of adults with WS.

The Current Study

To address barriers to accessing effective SSTPs for adults with WS and to meet the unique needs of this population, the current study was designed to assess the feasibility, acceptability, and preliminary efficacy of a distance-delivered SSTP designed to improve social skills behaviors and knowledge of adults with WS (SSTP-WS). The primary objective was to assess the feasibility and acceptability of the SSTP-WS. The secondary objective was to evaluate the initial efficacy of the SSTP-WS, as evidenced by improvement in social skills as rated by adults with WS and a parent and by performance on a social skills knowledge assessment. The research questions were: (1) What is the perceived feasibility and acceptability of the distance-delivered SSTP-WS intervention among the group facilitators, adults with WS, and parents? And (2) What is the preliminary efficacy of the SSTP-WS in improving social skills behaviors and increasing social skills knowledge?

Method

SSTP-WS Intervention

The SSTP-WS was developed through an iterative development process, involving input and feedback from community stakeholders, including adults with WS and their parents, experts in WS, experts in social skills interventions, and community-service providers (see Fisher et al., in preparation for a more detailed description of the development process). Lessons were either developed by the research team or adapted from currently existing programs (e.g., Buron 2007; Laugeson, 2017; Walker-Hirsch et al., 2020) and revised with input from community stakeholders. The SSTP-WS was delivered through synchronous virtual sessions using Zoom, an online platform for video conferencing. Homework assignments, lesson slides, lesson review videos, and other program materials were housed in a Google Classroom. A packet containing the homework assignments and other program materials was also mailed to each participant before the start of the SSTP-WS. Several activities used Breakout Rooms in Zoom, allowing for

participants to receive more time practicing social skills with individualized feedback.

Two facilitators delivered the SSTP-WS. Because these facilitators were part of the research team and assisted in the development of the SSTP-WS and the facilitator manual, they were not provided with specific training at the start of the program. However, they were supervised by a licensed Marriage and Family Therapist; also, the lead facilitator was a Certified Rehabilitation Counselor, and the assistant facilitator had a bachelor's degree from a teacher preparation program. All sessions were recorded and reviewed by all members of the research team and the team met weekly to discuss successes and areas for improvement.

The SSTP-WS consisted of 16 lessons offered for 90-minutes two times per week for eight weeks in groups of 6 participants. All lessons followed the same general format. The first 30–40 min consisted of a welcome and check-in, review of the homework and previous lessons' content, a few questions to check for understanding, and a warm-up activity to introduce the day's lesson content. A short (~5 min) movement break was then provided before spending the last 45 min of the lesson on content instruction and rehearsal, assigning the homework for the lesson, and self-reflection on social skills progress.

Some lessons had more time dedicated to instructional content, whereas others focused more on practicing the social skills discussed during the lesson. Activities were designed to provide opportunities to learn about and practice various social skills in an environment with constructive feedback. For example, participants practiced having a back-and-forth conversation while the facilitators and other group members observed and provided immediate feedback on their performance. The curriculum was developed such that each lesson built upon the previous one; key vocabulary words and concepts were presented and reviewed throughout the program to promote understanding of concepts and skills. See Table 1 for the title, content, and homework assignment related to each lesson.

Participant Eligibility

Any individual with WS between the ages of 18–30 years who lived in the United States, spoke English, and had internet access and a computer/tablet was eligible to participate. Because the SSTP-WS was developed to meet a community need and we wanted to determine for whom the program would be most successful, no exclusion criteria (e.g., intellectual functioning, comorbid diagnoses) were applied during this pilot of the SSTP-WS.

Although they were not required to attend sessions, a parent was asked to complete surveys before and after

the intervention. Participants were also asked to identify a “trusted companion” who would be available to help them with internet connectivity or other computer problems, who could help them complete their homework assignments between each session, and who would complete behavioral practice and observations each week, as well as surveys before and after the intervention.

Design

A two-group pre-post-test design with intervention and waitlist control conditions was conducted. Once the intervention group completed the SSTP-WS, the waitlist control group was enrolled in the SSTP-WS. The intervention group completed the measures at two points in time, at pre (time 1)- and post (time 2)-SSTP-WS. The waitlist control group completed measures at three time points, pre-intervention (time 1), post-waitlist (time 2), and post-SSTP-WS (time 3).

Measures

Participant Characteristic Measures

Demographics. Parents and adults with WS completed a demographic questionnaire, including information about their age, gender, living situation, and family income.

Intellectual Functioning. The *Kaufman Brief Intelligence Test, 2nd Edition* (KBIT-2; Kaufman & Kaufman 2004) is a psychometric measure used to assess verbal, non-verbal, and full-scale IQ. It can be used with individuals aged 4–90 years, and has been used in several previous studies with adults with WS (Fisher et al., 2016). See Table 2 for mean KBIT-2 scores.

Functional Abilities. The Activities of Daily Living (ADL; Seltzer & Li 1996) scale was completed by the parent to assess the functional abilities (e.g., degree to which the individual is able to walk, read, participate in leisure activities, and work) of the participants with WS. The ADL contains 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. See Table 2 for the mean total ADL scores.

Feasibility and Acceptability Measures

Facilitator Acceptability and Feasibility. To examine perceptions of acceptability, understanding, and feasibility of the SSTP-WS from the viewpoint of the facilitators, both facilitators completed the Usage Rating Profile-Intervention,

Table 2 Demographic Information at Pre-intervention for Participants (n = 24) Assigned to the SSTP-WS Intervention or Waitlist Control Group

Variable	Intervention M(SD) or n (%)	Waitlist Control M(SD) or n (%)	<i>t</i> / χ^2
Participant with WS			
Age	23.83 (3.19)	24.25 (3.98)	−0.283
Sex			0.168
Male	5 (41.7%)	6 (50.0%)	
Female	7 (58.3%)	6 (50.0%)	
Race			^a
White	9 (75.0%)	12 (100%)	
Latino	2 (16.7%)	0 (0%)	
Mixed Race	1 (8.3%)		
Ethnicity			3.43
Hispanic	3 (25.0%)	0 (0%)	
Not Hispanic	9 (75.0%)	12 (100%)	
KBIT-2			
Total	62.58 (12.60)	64.75 (12.72)	−0.419
Verbal	70.92 (9.94)	71.08 (9.26)	−0.043
Non-Verbal	61.67 (17.98)	66.58 (14.94)	−0.729
ADL	44.42 (5.42)	44.92 (10.17)	−0.150
Current living situation			
With parent	12 (100%)	11 (91.7%)	
Apartment with support	0 (0%)	1 (8.3%)	
Parent Participant and Parental Information			
Sex of Parent Participant			
Female	11 (91.7%)	10 (83.3%)	0.381
Male	1 (8.3%)	2 (16.7%)	
Mother age	54.58 (6.62)	56.50 (6.08)	−0.738
Father age	57.42 (7.51)	60.60 (8.97)	−0.906
Family Income			
\$15,000-\$29,000	1 (9.1%)	0 (0%)	
\$30,000-\$49,000	1 (9.1%)	0 (0%)	
\$50,000-\$69,000	0 (0%)	1 (9.1%)	
\$70,000-\$99,000	3 (27.3%)	3 (27.3%)	
Over \$100,000	6 (54.5%)	7 (65.6%)	
Maternal Education			
High school degree	1 (9.1%)	1 (8.3%)	
2-year degree	4 (36.4%)	2 (16.7%)	
4-year degree	2 (18.2%)	3 (25.0%)	
Graduate or professional degree	4 (33.3%)	6 (50.0%)	

Note. ^asample size too small to calculate. WS=Williams syndrome; M=mean; SD=standard deviation; KBIT-2=Kaufman Brief Intelligence Test-2; ADL=Activities of Daily Living

Revised (URP-IR; Chafouleas et al., 2011) after implementation of the SSTP-WS with the intervention group. The URP-IR consists of 29 items rated on a 6 point scale (1 = strongly disagree to 6 = strongly agree). Total scores from three subscales of the URP-IR were used (18 items total), including acceptability (9 items), understanding (3 items), and feasibility (6 items). Interviews were also conducted to gather

the facilitators' perceptions of the program's strengths and weaknesses, modes of delivery, impact and applicability, feasibility, and their role as the facilitator. Facilitators also took extensive field notes and engaged in weekly meetings with the research team to discuss any issues, questions, or concerns with delivering the program.

Participant and Parent Acceptability and Feasibility Rating Scale. To assess participant and parent perceptions of the utility of the intervention, we used an adapted version of the URP-IR (see Sung et al., 2019) to be completed post-SSTP-WS. The URP-SSTP-WS consisted of 17 items exploring the participant's overall experience, acceptability, understanding, feasibility, motivation and satisfaction, and likelihood to participate in a similar group rated on a 5-point scale (1 = strongly disagree to 5 = strongly agree). Reliability coefficients of the current sample were Cronbach's alpha = 0.935 for adults with WS and 0.943 for parents. To examine end-user acceptability of the SSTP-WS, participants and their parents were also provided an open-ended question on the survey stating, "Please let us know if you have anything else you want to share about this program."

Participant Interviews. Follow-up interviews or focus groups were also conducted with participants with WS within 1–3 weeks after they completed the SSTP-WS. Depending on the participant's availability, either a focus group with 2–4 participants or an individual interview was conducted. To examine feasibility participants were asked: (1) how did you feel about the length of the program? (2) how did you feel about the length of each session? and (3) what was easy/difficult about the homework assignments and what can we do to make them better? To examine acceptability participants were asked: (1) what motivated you to join the group? (2) what topics did you find useful/important/interesting? (3) what was the most important thing you learned in the program? (4) do you feel more comfortable or confident in your social skills after being in the program? (5) what did you like most/least about the program? (6) was the group worth your time? and (7) was the group enjoyable?

Treatment Fidelity. To ensure treatment fidelity, the assistant facilitator completed a fidelity checklist during each session. There was a total of eleven checklist items for each session, determining if the lead facilitator was prepared for group, reviewed content as necessary, taught new content as necessary, and provided opportunities for engagement, practice, and feedback. Across all lessons and both groups, procedural fidelity was 95%.

Initial Efficacy Measures

Social Skills. The *Social Skills Improvement System (SSIS;* Gresham & Elliot 2008) parent and student forms were used to assess change in social skills. Although the SSIS assesses

two domains, only the social skills domain (communication, cooperation, assertion, empathy, responsibility, engagement, self-control) was used in the current study. Items are rated on a 3-point Likert scale (0 = "never occurs", 1 = "sometimes occurs", 2 = "very often occurs"). Raw scores on the social skills domain were used to evaluate change in social skills from pre- to post-intervention. All scales had strong reliability; Cronbach's alpha for adults with WS was 0.962 for social skills pre-intervention and 0.956 post-intervention. Alpha for parents was 0.916 pre-intervention and 0.932 post-intervention. Although the SSIS has not been previously used with individuals with WS, it has been successfully used to assess social skills of children and adults with other neurodevelopmental disabilities (Cheung et al., 2017; Walsh et al., 2019).

Social Skills Knowledge. A 25-question multiple-choice assessment was designed to assess participants' social skills knowledge. Questions were developed based on the content covered in the SSTP-WS. The format was modeled from the *Test of Adolescent Social Skills Knowledge* (Laugeson et al., 2009) and piloted in a previous study (Fisher & Morin, 2017). An example of a question is "What is one way you can show someone you are listening to them when you are having a conversation? (a) Turn away from the person and look at someone else; (b) Ask a question about a new topic that interests you; or (c) Face the person and look at them." Answers to questions were randomized. Participants completed the assessment in Google Classroom one week prior to the start of intervention and one week post-intervention.

Procedure

After institutional review board approval, participants were initially recruited through the Williams Syndrome Association (WSA) Research Registry. A promotional email with a link to sign up to receive more information about the study was sent to all individuals on the research registry who were between the ages of 18 and 30 years. Those who signed up for more information were sent an introductory email and a link to book an initial meeting to discuss the purpose of the study, expectations, time commitment, scheduling, and waitlist condition. After the initial meeting, those who were still interested in participating were emailed a link to the informed consent and pre-surveys for the adults with WS and their parents to complete. Similar to other online surveys for adults with WS (Fisher, Josol, et al., 2020), parents were asked to assist the adult with WS in completing the survey (e.g., reading questions aloud, clicking responses) if necessary, but to not provide the adult with responses.

After initial meetings were held with 40 potential participants, the first groups were scheduled to begin. To

determine group assignment, individuals indicated the times they were available during the week and these times were matched with the facilitators' availability. Two meeting times in which the most participants were available were determined (to allow for two groups of 6 participants to run concurrently, 12 participants total). If more than six individuals were available for a meeting time, a random number generator was used to assign participants.

Intervention Group

Twelve individuals in groups of six participants each were enrolled to participate in the intervention. Emails were sent to all individuals assigned to the intervention group with the dates and times of the SSTP-WS. If an individual was no longer available to participate, the next individual on the list was contacted. A one-hour orientation meeting was scheduled with each participant and their parent and/or trusted companion to review the group expectations, Zoom technology, and Google Classroom interface. The two groups began the SSTP-WS the following week, participating two times per week for 8 weeks.

One week following completion of the SSTP-WS, all participants in the intervention group completed the post-assessments, as well as the URP-SSTP-WS. Between one and three weeks post-intervention all participants with WS were invited to participate in focus groups or individual interviews (depending on availability) to discuss their experiences with the program.

Waitlist Control Group

Prior to the intervention group beginning the SSTP-WS, ten individuals with WS and their parent had completed the pre-assessments (time 1). These individuals did not receive any treatment while the intervention group participated in the SSTP-WS. Once the intervention group completed intervention, the waitlist control group was sent the surveys to complete again (time 2). One month later, the individuals in the waitlist control group (plus two others who signed up for the study after intervention began) were contacted to obtain updated availability. Individuals were placed into groups similarly to those who received the first round of intervention. They participated in a one-hour group orientation meeting the week prior to the start of the group and then two groups of 6 participants attended sessions two times per week for 8 weeks. One week following completion of the SSTP-WS, all participants and parents completed the post-assessments (time 3), the URP-SSTP-WS, and a focus group or individual interview.

Following the first round of intervention, the facilitators completed the URP-IR and participated in an interview with

a member of the research team. Following both rounds of intervention, the research team met to discuss the program, to review the acceptability and feasibility data, and to make minor revisions to the SSTP-WS.

Data Analysis for Preliminary Efficacy Results

Due to the small sample size and preliminary development stage of the SSTP-WS program, quantitative analyses were not intended to validate the efficacy of the SSTP-WS intervention. Rather, analyses were conducted to explore preliminary efficacy of this pilot study in improving social skills behaviors and increasing social skills knowledge. We first evaluated preliminary efficacy by testing the effect of time; we hypothesized that the intervention group would improve in social skills over time (intervention was conducted in between the time points) and the waitlist control group would not improve in social skills between the time points. To test this, we used a repeated measures factorial ANOVA, with a within-subjects variable (time) interacting with a between-subjects variable (intervention). We compared the waitlist control group with the intervention group, on the change in adult with WS and parent social skills domain scores on the SSIS from time 1 (pre-intervention) to time 2 (post-intervention). Change in the intervention group and no change in the waitlist control group provided evidence to preliminary efficacy.

To further test the effect of the intervention, we combined all the adult with WS and parent pre-intervention scores on the social skills domain of the SSIS for the intervention (time 1) and waitlist control groups (average of time 1 and time 2) and compared these scores with the post-intervention measures (time 2 or time 3) for both the adult with WS and parent-reports. An advantage of using this approach is that we can use all available pre-intervention data from the waitlist control group by either averaging the first two time points or using the one time point that was collected for each participant. We used a paired t-test to compare pre-intervention to post-intervention scores on the SSIS and the social skills knowledge assessment. Analyses were computed using R statistical software (R Core Team, 2021) and type I error was set at 5%.

Results

Demographic Information and Participants

Figure 1 depicts the flowchart of enrollment and group allocation. In total, 61 individuals completed the sign-up form;

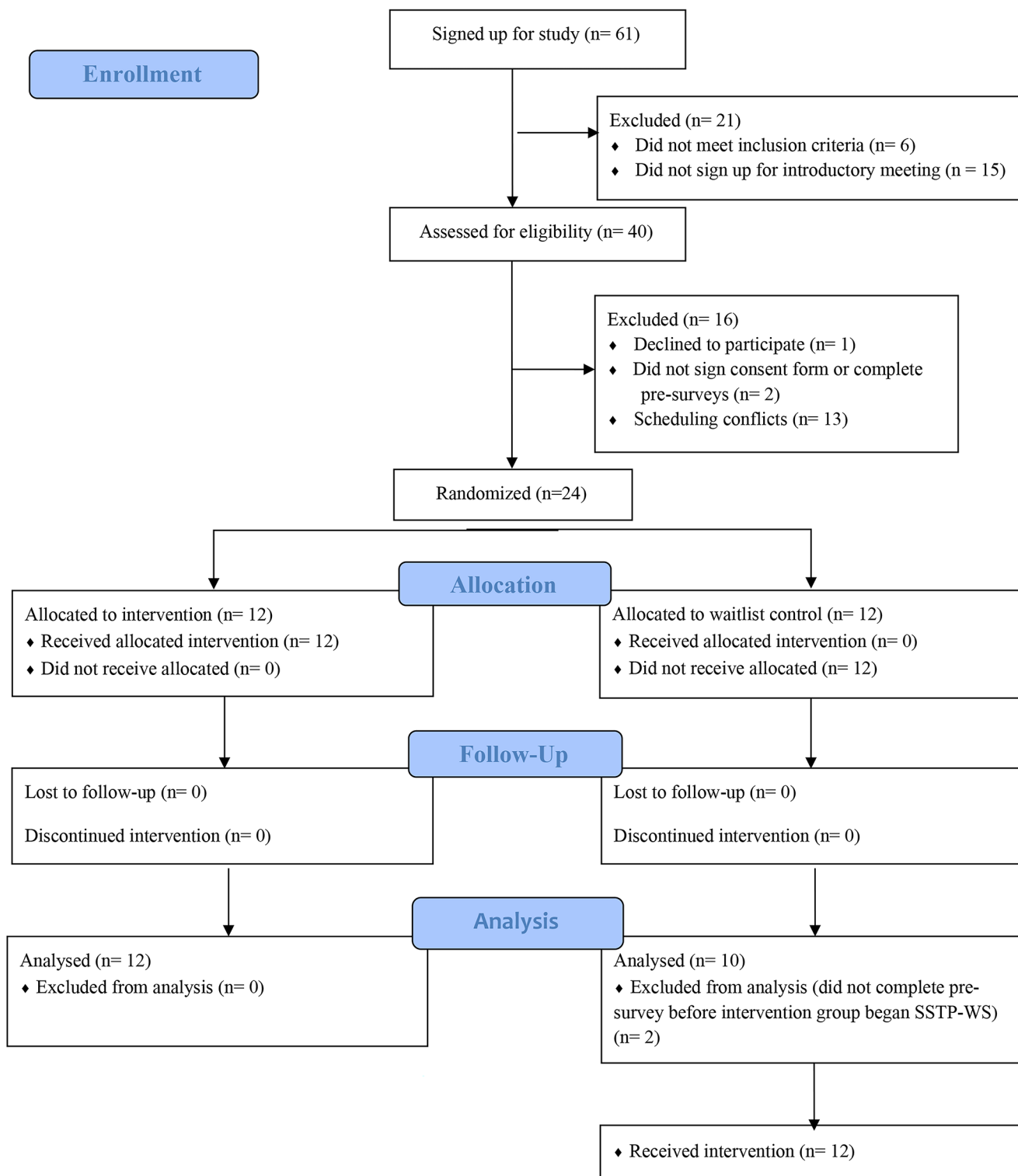


Fig. 1 Flowchart of Enrollment in the SSTP-WS Study and Allocation to Intervention or Waitlist Control Group

49 signed up after receiving the initial email sent through the WS registry; and an additional 12 signed up after hearing a presentation at the WSA convention (during the first week of the intervention). Among those who signed up, six

did not meet the age requirements. The remaining 55 individuals were sent the introductory email and link to sign up for the initial meeting. For the 40 individuals who attended the initial meeting, one parent felt the intervention materials

would be too complex for their child to understand and withdrew; the remaining 39 were sent a link to the consent form and pre-intervention surveys. Two individuals failed to complete the informed consent and pre-intervention surveys, leaving 37 individuals who were eligible and interested in participating in the SSTP-WS. Of those 37, 24 were eventually enrolled in the study (the remaining 13 reported scheduling conflicts). The 24 participants were assigned to intervention or the waitlist control group. Both groups were well matched on demographic variables (see Table 2).

Intervention Group

The intervention group consisted of 12 adults with WS ($n=7$ female, 5 male) and 12 parents ($n=11$ mothers, 1 father) who completed pre- and post-intervention surveys. The participants with WS were assigned to one of two intervention groups, based on availability. Given the COVID-19 pandemic and social distancing orders, only one participant was able to identify a trusted companion (who was not different from the primary parent completing the surveys) with whom to practice social skills and to complete homework. All others completed practices and homework assignments with the parent who completed the research surveys.

Waitlist Control Group

The waitlist control group consisted of 12 adults with WS ($n=6$ female, 6 male) and 12 parents ($n=10$ mothers, 2 fathers) who completed pre-, post-waitlist, and post-intervention surveys. Although more participants in the waitlist control group were able to identify a trusted companion once they received intervention, these companions were either family members ($n=4$ siblings, 1 father) or support/respite providers ($n=4$). Given the inconsistency of the participation of trusted companions, these data are not reported in the current study.

Attrition and Participation

Once enrolled, no participants dropped out of or were removed from the study. Data were taken to monitor both participant attendance at each session ($n=16$ total sessions) and completion of the homework assigned for each session ($n=15$ total homework assignments).

Attendance

The attendance rate for the intervention group was 96.9%, with participants attending an average of 15.50 ($SD=0.80$) sessions and 66.7% attending all 16 sessions. The attendance

rate for the waitlist control group once they began the SSTP-WS was 97.9%, with participants attending an average of 15.67 ($SD=0.49$) sessions and 66.7% attending all 16 sessions.

Overall, participants attended between 14 and 16 sessions, for an average attendance of 15.58 ($SD=0.65$) sessions. The majority of participants ($n=16$; 66.7%) attended all sessions, 6 (25%) missed one session, and 2 (8.3%) missed two sessions. The most frequently missed sessions were session 3, 4, and 15 (each missed by two participants).

Homework

The rate of homework completion for the intervention group was 87.8%, with participants completing an average of 13.17 ($SD=2.37$) assignments and 50% completing all 15 homework assignments. The rate of homework completion for the waitlist control group once they began the SSTP-WS was 92.8%, with participants completing an average of 13.92 ($SD=1.44$) assignments and 50% completing all 15 homework assignments.

Overall, participants completed between 8 and 15 homework assignments, for an average of 13.54 ($SD=1.96$) assignments. Half of the participants ($n=12$; 50%) completed all 15 homework assignments, 4 (16.7%) completed 14 assignments, 5 (20.8%) completed 12 assignments, and 1 completed 11 assignments (4.2%), 10 assignments (4.2%), and 8 assignments (4.2%), respectively. The most frequently missed assignment was for session 15, with 8 participants (33.3%) failing to complete the assignment.

Feasibility and Acceptability

Facilitators

Across both facilitators there was an average rating of 5.02 ($SD=0.80$, range 1 to 6), on the URP-IR. The average rating was 5.50 ($SD=0.5$, range 4–6) for the acceptability domain, 5.33 ($SD=0.29$, range 5–6) for the understanding domain, and 4.42 ($SD=0.74$, range 1–6) for the feasibility domain. Information gathered from the facilitator interviews as well as the weekly field notes and meetings with the research team also indicated a high acceptability and feasibility of the program. Facilitators discussed the strengths of delivering the program online, which included the online platform and the ability to connect with people from multiple regional areas. Facilitators also mentioned strengths as the opportunities that participants had to practice skills within the group with other participants, and the ease of following the program.

Despite the overall high levels of acceptability and feasibility of the program from the viewpoint of the facilitators, there are also important areas for improvement. Specifically, the lead facilitator reported that implementation of the SSTP-WS was time intensive. The weekly research team meetings further indicated that the lead facilitator did need to spend extra time preparing the lessons and reviewing the homework assignments. To address this concern, these tasks were divided between the lead and assistant facilitator during implementation of the SSTP-WS with the waitlist control group and the time allocation was then reported to be more feasible.

Adults with WS and Parents

For the entire sample that completed the SSTP-WS, the mean acceptability score on the URP-SSTP-WS for individuals with WS was 4.55 ($SD=0.51$; range 3.24–5.00) and the mean acceptability score on the URP-SSTP-WS for parents was 4.61 ($SD=0.45$; range 3.47–5.00). Individuals with WS in the intervention group ($M=4.75$, $SD=0.31$) rated acceptability slightly higher than did individuals in the waitlist control group after they received intervention ($M=4.33$, $SD=0.61$), $t(22)=2.16$, $p=.042$. Parent acceptability ratings did not significantly differ between the intervention ($M=4.71$, $SD=0.37$) and waitlist control ($M=4.47$, $SD=0.55$) groups, $t(22)=1.24$, ns (see Table 3 for average item ratings on URP-SSTP-WS).

Fourteen adults with WS responded to the open-ended question at the end of the URP-SSTP-WS to share additional thoughts about the program. The adults with WS indicated that the program was enjoyable and helpful. They said they were excited to use their new skills, liked the instructors and content, and enjoyed an opportunity to meet new people with WS through the group. For example, one participant said, “I learned a lot in this program! I hope there will be something else like this in the future!” Another participant said, “I enjoyed learning and being with my friends and meeting new people.”

Twenty-one parents responded to the open-ended question at the end of the URP-SSTP-WS to share additional thoughts about the program. The parents indicated they noticed improvements in the social skills of their adult with WS, and that their adult really enjoyed being able to interact with peers and to learn new skills through the group. One parent said, “I have noticed a lot of progress with [adult participant] in regards to social skills in this short time and am most appreciative of this opportunity!” Another parent said, “I just want to thank you all. [Participant] benefited immensely from this program. I wish I had more quality instructional options for her to attend. It was nice for her to have the connection, quality learning and homework

Table 3 Average Item Ratings on the URP-SSTP-WS for Adults with WS and their Parents

	Adult with WS	Parent with WS
I/My adult with WS was motivated to participate in this program.	4.57 (0.63)	4.39 (0.79)
Each session of the program was implemented within the duration of time as stated.	4.61 (0.50)	4.64 (0.62)
The information and materials covered in this program was appropriate and relevant to social skills for me/adults with WS.	4.54 (0.74)	4.64 (0.56)
The quality of instruction was good.	4.64 (0.69)	4.79 (0.50)
The amount of time required to participate in this program was reasonable.	4.07 (1.12)	4.50 (0.64)
The amount of weekly assignment was reasonable and helpful for my/the adult’s learning.	4.32 (0.98)	4.50 (0.58)
The amount of support I/my adult with WS received was adequate to participate in the program.	4.57 (0.69)	4.57 (0.63)
The expectation of participating in this program was clear.	4.79 (0.42)	4.68 (0.48)
The facilitators made the information in this program as interesting as possible.	4.68 (0.55)	4.75 (0.52)
I/My adult with WS had a positive attitude about participating in this program.	4.68 (0.67)	4.50 (0.58)
I/My adult with WS could easily understand the content covered in this program.	4.39 (0.79)	4.43 (0.79)
I/My adult with WS participated in this program with a good deal of enthusiasm.	4.61 (0.69)	4.54 (0.69)
The strategies used for addressing the topics of this program were effective.	4.57 (0.57)	4.61 (0.69)
I/My adult with WS learned new skills through participation in this program.	4.64 (0.62)	4.46 (0.69)
I/My adult with WS would be interested in participating in a program similar to this one in the future.	4.25 (1.10)	4.64 (0.73)
Overall, the program is beneficial for me/my adult with WS.	4.75 (0.52)	4.79 (0.42)
I would recommend this program to others with WS.	4.61 (0.63)	4.86 (0.45)
How comfortable did you feel supporting the adult with WS throughout the program? (n = 16)		3.56 (0.51)

assignments.” Many parents indicated that they would love for the participants to have a second follow-up class. Finally, some parents did indicate issues with technology and their participant being unable to practice social skills outside of the home or with less-familiar individuals due to the pandemic as small concerns.

Finally, 14 participants with WS participated in a focus group or interview, during which they discussed aspects of both feasibility and acceptability of the SSTP-WS. Regarding feasibility, participants overall felt the length of the program and each session were appropriate, and that the assignments were very easy to complete. No major issues or concerns were noted, but some recommendations were made regarding technology (e.g., have everyone mute

themselves unless called on to speak) to make the sessions run more smoothly. Regarding acceptability, participants overall indicated high acceptability of the program. They found the program very useful in increasing their social skills knowledge and confidence, felt as if they learned a lot about boundaries and different types of conversations, and enjoyed learning alongside their peers. Some individuals provided recommendations for specific content or topics, such as better ways to practice a skill in-session or better use of the homework.

Preliminary Efficacy

Intervention vs. Waitlist Control Group

Descriptive statistics for adults with WS and parents' scores on the social skills domain of the SSIS pre- and post-intervention for the intervention and waitlist control groups are presented in Table 4. Results for the repeated measures ANOVA model for parent scores revealed there was a significant interaction effect of time, $F(1, 20) = 16.42, p < .001$. Contrast statistics suggested a significant effect of change in time for the intervention group, $t(20) = -4.55, p < .001$, while the contrast statistic for the waitlist control group did not show a significant effect of change in time, $t(20) = 1.34, p = .197$. Conversely, there was no interaction effect of time for scores in social skills as rated by adults with WS.

Entire Sample Analyses

Descriptive statistics for adults with WS and parents' scores on the social skills domain of the SSIS pre- and post-intervention for the entire combined sample are presented in Table 5. After combining all parent data for pre-intervention and post-intervention, the effect of the intervention was found to be significant, $t(23) = -5.56, p < .001$. The Cohen's D for this effect was 1.134, indicating a large effect size (Cohen, 1988). Parents rated social skills to be significantly higher post-intervention. Participant with WS' ratings on the SSIS social skills domain, however, did not significantly change from pre- to post-intervention, $t(23) = -0.56,$

$p = .584$. Finally, a paired-samples t -test revealed significant improvements in scores on the social skills knowledge assessment from pre- to post-intervention, $t(23) = 02.66, p = .014$.

Discussion

The current study was conducted to evaluate the feasibility, acceptability, and preliminary efficacy of the SSTP-WS, a distance-delivered social skills training program designed to improve social functioning and outcomes for adults with WS. The intervention was considered both feasible and acceptable by participants with WS, their parents, and by the program facilitators. Parents of adults with WS reported improved social skills following participation in the SSTP-WS. Adults with WS also displayed improved social skills knowledge following participation in the SSTP-WS.

Acceptability and Feasibility

Given that few interventions have been designed to address social skills deficits for adults with WS and that the intervention required delivery via telehealth, a primary aim of the current study was to assess the feasibility and acceptability of the SSTP-WS, as perceived by multiple stakeholders. The facilitators of the SSTP-WS evaluated the program positively, stating that the curriculum was easy to follow, the program offered participants opportunities to practice skills, and they observed that the participants were highly engaged in group activities and discussions. Although facilitators found the program delivery to be feasible, they did recommend more time for group discussion and they indicated that preparation for delivering the SSTP-WS was time intensive. Adults with WS and their parents both reported satisfaction with the SSTP-WS. Although there were some technological difficulties, all participants were able to overcome these barriers and participate in the biweekly sessions. Further evidence of feasibility of the SSTP-WS was demonstrated

Table 4 Adult with WS and Parent Mean (Standard Deviation) Total Social Skills Domain Scores of the Social Skills Improvement System for Intervention and Waitlist Control Groups

Variable	Intervention (n = 12)		Waitlist Control (n = 10)	
	Pre	Post	Pre	Post
Adult with WS	117.25 (19.84)	118.17 (16.00)	92.67 (25.85)	94.42 (27.71)
Parent	84.08 (15.17)	100.25 (14.11)	81.50 (21.01)	76.17 (22.68)

Note. WS = Williams Syndrome

Table 5 Adult with WS and Parent Mean (Standard Deviation) Total Social Skills Domain Scores of the Social Skills Improvement System and Mean Social Skills Knowledge Scores Pre-Intervention and Post-Intervention for the Total Sample

Variable	Pre-Intervention	Post-Intervention
Adults with WS		
SSIS Social Skills	108.00 (24.43)	109.79 (21.54)
Social Skills Knowledge	18.79 (4.64)	21.08 (3.32)
Parent		
SSIS Social Skills	81.21 (17.97)	97.04 (16.96)

Note. WS = Williams Syndrome; SSIS = Social Skills Improvement System

through the high attendance and homework completion rates, and low attrition, as no participants dropped out of the intervention. Several participants also expressed a motivation to participate in similar future programs. The feedback from all stakeholders will help to refine the curriculum for future participants.

Preliminary Efficacy

A secondary aim of the current study was to use a waitlist control design to examine whether the SSTP-WS (intervention group) led to improvements in social skills over and above changes in social skills that might occur naturally over time (waitlist control group), as assessed by the social skills domain of the SSIS. The SSTP-WS intervention group, compared to the waitlist control group, made significant improvements in social skills following participation in the SSTP-WS. These findings were then replicated after combining the intervention and waitlist control group participants to explore effects of the SSTP-WS intervention in a larger sample. Significant gains were found from pre-intervention to post-intervention on the social skills domain of the SSIS, as rated by parents. Further, participants with WS displayed significant gains in social skills knowledge from pre-intervention to post-intervention.

Although these preliminary findings of efficacy are encouraging, there were differences between parent and self-reported social skills. The discrepancies in parent versus self-report are not surprising or uncommon for adults with WS. Indeed, previous research has highlighted the difficulties that adults with WS experience when rating their own behavior and has found that adults with WS are in fact unreliable reporters of their own social behaviors (Fisher et al., 2014; Järvinen-Pasley et al., 2010; Lough & Fisher, 2016). Given that the adults with WS in the current study rated their pre-intervention social skills nearly 20 points higher than their parents, it is not surprising that adults with WS did not improve in their self-reported social skills ratings, as they already perceived themselves to have strong social skills. These findings point to the need to incorporate lessons in the SSTP-WS on how to reflect on and recognize their own social skills strengths and deficits.

Limitations

Although our preliminary data suggest that the SSTP-WS is feasible, acceptable, and effective, our results must be interpreted with the following limitations in mind. First, our sample may not be representative of all individuals with WS. All participants were connected in some way with the

WSA, an organization for families of individuals with WS that provides resources and referrals, as well as a supportive community. Given these connections, it is possible that participants in the current study had more social support, community engagement, and parental involvement than other individuals with WS. Second, because of the nature of the distance delivered intervention, our sample excluded people without internet access or a computer/tablet. Those adults with WS who are not connected to the WSA and are not using internet-based technology may have different characteristics than the adults in our groups.

Third, there were missing time 1 surveys from two parents and three adults with WS in the waitlist control group; with a small number of participants this could impact preliminary results. Fourth, knowledge gain and skill acquisition are different (e.g., see Fisher et al., 2014). Because of the limited availability of trusted companions and social restrictions caused by the COVID-19 pandemic, we were not able to not assess how skills were used in naturalistic settings, nor were we able to employ direct observation, which is considered a primary or first-line choice in assessing social behaviors (Merrell, 2001). Further, COVID-19 restrictions prevented many of the participants from practicing their skills in community settings, potentially limiting skill acquisition and demonstration. Rather, parents reported that participants were able to practice with caregivers at home and with others over the phone. Thus, parental assessments of social skills improvement may have been based on interactions with a very small group of people well-known to the participants. Given the parent- and self-report nature of these assessments, responses may also have been biased. Fifth, the current study did not include long-term follow-up assessments to determine if improved social skills maintained over time or to assess skill generalization once COVID-19 physical distancing restrictions were relaxed.

Finally, the SSIS is not commonly used with adults, as it was developed and validated for individuals under the age of 18. Given its sensitivity to changes in social skills over time and as a result of interventions (Gresham & Elliot, 2008), however, we chose to use the total raw scores for the social skills domain for the current study. Cronbach's alphas for both adults with WS and their parents were strong, reducing concerns about measurement validity.

Implications for Practice

For individuals with a low-incidence disability such as WS, it is difficult to have regular face-to-face meetings, training sessions, or support groups with others who share their disability characteristics. Providing opportunities to connect virtually can address this issue. The current study provides

preliminary evidence that individuals with WS can learn social skills through a distance-delivered SSTP. Participants joined the program from 16 different states across 4 different time zones, providing the participants an opportunity to broaden their social connections by getting to know others who lived in various parts of the United States. It also provided them access to professionals with knowledge of WS and to a program designed to meet the specific needs of the WS behavioral phenotype. Given the positive effects, service providers (e.g., behavioral therapists and counselors) should consider telehealth as a feasible alternative to working with and supporting groups of individuals with WS and other rare disabilities.

The SSTP-WS also provided opportunities for the participants with WS to practice social skills in a supported environment. This is important as individuals need opportunities for success and for making mistakes with support and constructive feedback. Gresham et al., (2001) discussed three types of social skills deficits: acquisition, performance, and fluency. The SSTP-WS can address all three types. To address acquisition deficits, participants learned about which social behaviors are appropriate with specific people and in what settings. To address performance deficits, the SSTP-WS provided opportunities for practicing the social skills both inside and outside of the instructional setting. For fluency deficits, participants had the opportunity to see skilled models of social behavior and receive reinforcement for their own skilled performances.

Future Directions

Future research should involve replication of the lessons with more groups of individuals with WS and should evaluate different characteristics of individuals with WS that might be related to greater or less success with the program. For example, future research could investigate matching content lessons to the abilities of the group. Some lessons may need to be enhanced for those with more knowledge and experience; other lessons may need to be adapted to be made more accessible for some adults with WS. Future research should also include further examination of the use of a trusted companion within the group format to aide in social skills development outside of attending the group.

Finally, future research needs to grapple with an issue common to all social skills training programs: the need for better measurement to evaluate change in behavior and social outcomes. Gresham et al., (2001) stated that socially valid measures such as teacher or parent judgments “are not particularly sensitive in detecting short-term treatment effects” (p. 339). The question becomes, how much of a difference is required for it to be noticed by significant others

in the individual’s life? Therefore, future research should investigate more direct measures of social behavior and longer-term effects of SSTPs. Future research may consider moving beyond measuring knowledge of appropriate social skills to *in situ* behavioral assessment through direct observation. For the SSTP-WS and other distance-delivered interventions, this could include engaging the trusted companion in data collection. Future research may also consider a longer-term intervention perhaps in the format of a social support group. Research could then effectively address: (a) do individuals participating in such social skills training programs have more and higher quality social interactions? And (b) do they have more satisfying friendships?

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Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the University Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent: The current study was approved by the University Institutional Review Board. Informed consent was obtained from all individual participants included in the study prior to completing the first set of questionnaires.

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