



Autism Speaks Canada Family Services Community Grant 2020 Project Update

Agency Name: York ASD Partnership

Project Name and Description: *Transitioning Together*

Transitioning Together is a multi-family group psychoeducation program developed at the University of Wisconsin for families of transitional age youth with autism spectrum disorder (ASD). *Transitioning Together* aims to (1) provide education and support to parents, (2) foster social interaction and learning for adolescents, and (3) emphasize positivity and problem solving. The program is designed for families of youth across the full spectrum of autism but the training focuses primarily on how to work with families of adolescents with ASD transitioning to adulthood without a co-occurring intellectual disability.

The goal of this project was to train local facilitators from several York ASD Partnership agencies in the delivery of *Transitioning Together* (an evidence based, recognized program), adapt the curriculum to meet local needs and resources and to deliver the program to interested transitional age youth and families in York Region. This was the first time this program would be delivered in Canada. Additionally, research into the programs' efficacy was conducted by a team from the department of Disability Studies at Brock University.

Family Feedback

These are some of the comments made by parents/caregivers after their participation in *Transitioning Together*.

"This was an amazing program for my child. I got a lot out of it, but my child got even more..."

"I gained new insight. It provided some good resources. It was great to have a regular peer time for my son."^[1]_[SEP]

"It has given us more confidence that we are able to find the resources that our child needs. This will have a positive effect on the whole family."

"It's given us a lot of food for thought: lot of things that I need to start looking into to help advocate for my son's needs."

"We can start to talk about the future with more concrete information."

"[*Transitioning Together*] gave us new avenues to explore, and it was nice to see my child engaged in something new. I wish there were groups like this that were ongoing. Again, thank you!"

"Excellent program and highly recommend it..."

"It was a great group of facilitators and fellow families. I really enjoyed the sessions."

"It gave a solid reassurance that we're doing the right things for our son."

"I am glad that I participated. I received some very good info."

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Project Final Report

The York ASD Partnership (YASDP) is a voluntary collaboration of publically-funded organizations that are the foundation of York Region's service system for children, youth and adults. The YASDP has achieved a high level of collaboration having worked together for over 10 years. There continues to be a strong commitment by the YASDP to cross-sectoral training opportunities that strengthen the collaborative capacity of the system of support and enhance service provision to youth and young adults with ASD who are transitioning from the children's service sector to the adult service sector.

Project Implementation

Autism Speaks Canada Recognition

All training and promotional materials used by the University of Wisconsin and by the YASDP agencies throughout the program contain the Autism Speaks Canada logo. As well, each training session began with verbal acknowledgement of Autism Speaks Canada as the funding source for this opportunity. The YASDP website recently went live and includes acknowledgement of this Family Services Grant from Autism Speaks Canada. www.yorkasdpartnership.org
This report will be posted on the website after it is presented to the full YASDP in January 2022.

“Train the Trainer”

In the spring of 2020, YASDP contracted with Dr. Leann Smith Dewalt and her associate, Kate Szidon, from the Waisman Center, University of Wisconsin to provide the two-day training program for YASDP agency teams to learn how to implement the research-based *Transitioning Together*. This is a program for youth with autism spectrum disorder (ASD) and their families. Due to the restrictions imposed by the Covid-19 pandemic, it was agreed that both the training and the follow-up coaching would be provided virtually. As well, group sessions for families and youth would also be delivered virtually.

Also in the spring of 2020, all the participating YASDP agencies identified the staff who would be facilitating the *Transitioning Together* program. These staff provided an outline of their educational background, knowledge and skills to assist the trainers from University of Wisconsin in customizing the training sessions.

Training was provided in the fall of 2021 over four half-day sessions to 20 staff from five (5) Partnership agencies. These agencies were Kerry’s Place Autism Services, Community Living York South, York Support Services Network, MacKenzie Health Centre for Behavioural Health Sciences and Catulpa Community Support Services. In addition, a research assistant from Brock University and a representative of the YASDP attended the training. After completion of the training, Catulpa Community Services withdrew from the research component of the project. Two follow-up coaching sessions were delivered to facilitators by the team from University of Wisconsin on March 1, 2021 and May 4, 2021.

Curriculum Adaptations

Resource materials and a curriculum outline were provided by the University of Wisconsin as part of the training program. However, substantial adaptations and additions were needed to ensure the curriculum was appropriate for York Region and accurately reflected the services provided and addressed the specific needs of local youth and families. This review occurred throughout the fall of 2020 and the early winter of 2021. During program delivery facilitators also identified challenges related to virtual delivery and continually made modifications to the content to better meet the needs of the participant families.

Program Delivery - Intake

The research team at Brock University (Dr. Priscilla Burnham Riosa and Shona Mills) completed intake for participating families. This included initial contact and a subsequent in-depth interview to determine eligibility and group composition. Fifty-one (51) families applied to the program. Thirty-eight (38) of these were

screened. Eleven (11) families did not meet criteria due to age and two (2) families did not complete the screening survey. Of these, twenty-nine (29) families were determined to be eligible for the project. Eight (8) families were deemed ineligible due to the communication challenges of the youth with ASD. There were twenty-nine (29) families who were eligible, of these, five (5) were no longer interested and one (1) withdrew. Fifteen (15) families participated in the first delivery sessions. The remaining families participated in the second delivery session. Additional families/individuals completed intake for the second session.

It should be noted that the number of participants scheduled for both delivery sessions was lower than proposed or expected. It is believed that this was primarily due to the impact of the Covid-19 pandemic. Families and youth had been spending a significant number of hours each day engaged in virtual work or education so the prospect of additional virtual training had less appeal than anticipated. Several participants commented on the challenges of “Zoom fatigue”. As well, recruitment of families through individual service providers and school personnel was limited by Covid-19 protocols.

Program Delivery: Phase 1

Three sessions were delivered to youth and their families in phase one of program delivery. Two groups were facilitated by Kerry’s Place Autism Services. These groups ran from March 23, 2021 to May 11, 2021 for a total of nine (9) participant families. The third group was co-facilitated by York Support Services Network and Community Living York South. This group began March 4, 2021, and ended April 22, 2021 for seven (7) participant families.

Program Delivery: Phase 2

Three sessions were delivered in phase 2 in the spring of 2021. Session one ran from May 6, 2021 to June 24, 2021 facilitated by MacKenzie Health Centre for Behavioural Health Sciences. Session two ran from May 6, 2021 to June 24, 2021 co-facilitated by York Support Services Network and Community Living York South. The third session ran from May 18, 2021 to July 6, 2021 facilitated by Kerry’s Place Autism Services. Thirteen (13) families started these groups and ten (10) completed the program.

Research

Research into the efficacy of the *Transitioning Together* project was conducted by Dr. Priscillia Burnham Riosa and Shona Mills from Brock University. The research addressed two components of the project: the impact of the training on the facilitators and the impact of the program on youth with ASD and their families/caregivers.

In terms of the facilitators, twenty-three facilitators completed the training. Prior to completing the training they each rated their knowledge of ASD and provided information about their education, certifications and their work experience including experience with group facilitation. They also completed a survey both pre and post training where they evaluated their changes in knowledge and confidence. Results indicated a positive change in knowledge in a variety of categories including assisting youth in setting goals, autism, impact of ASD, community supports, transition planning, coping strategies, adults with ASD, well-being of parents, employment services, post-secondary services and legal issues. They also indicated a positive change in confidence in various categories including support to families, parent's problem solving, education to families, youth setting goals, youth social interaction, youth problem solving, using timelines and using eco-maps.

Facilitators also gave feedback on the *Transitioning Together* training and the majority indicated they felt that the content, timing, length of training, training methods was extremely or somewhat appropriate, the materials were extremely or very useful, the online delivery and trainers was effective and training was relevant. A significant number of facilitators (79%) reported technical issues that negatively impacted the training experience. However, the majority still reported the training was extremely or very valuable to future work, that they were extremely or somewhat likely to apply what they learned and more than half indicated that they learned something new. The majority (70%) indicated that it would change future practice and they would use the *Transitioning Together* information, strategies or activities with families or youth with ASD

Overall, trainees reported positive changes in their reported knowledge related to ASD and the transition to adulthood and their confidence in supporting transition aged youth on the spectrum and their families following the training. These findings are noteworthy given the unexpected pivot to online delivery of this training program because of the global pandemic

Program Evaluation

A total of twenty-nine (29) families enrolled in *Transitioning Together* and twenty-six (26) completed the research study.

This research evaluated the effects of *Transitioning Together* on various parent, child and parent-child outcomes before, after and 1 month following the program. The study measured parent well-being, general life stress, parental problem solving and caregiver resilience and measured youth well-being, parent-reported autistic symptoms and youth-reported empowerment. The research also assessed parent-child relationships.

The research sample included parents with youth who had varying degrees of social communications and cognitive abilities. Results indicated no significant

outcome changes on any of the parent or youth measures. However, a sub-analysis of outcomes that excluded families with youth with cognitive challenges found changes in all measures. Therefore, it is possible that this was a result of the varying cognitive levels of the youth attending since program was designed for those with average or above average cognitive abilities.

Responses to open-ended questions from parents were quite positive and some commented on the positive impact on their child and on the opportunity to engage in discussions about transitions with other parents.

The closed ended questions elicited a range of responses. However, the overall satisfaction rating of *Transitioning Together* yielded a score 3.9 out of 5 from parents and 3.6 out of 5 from youth.

The complete research report is attached to this report as Addendum A.

Project Challenges – Impact of Covid-19

1. *Transitioning Together* Facilitator Training:

Face to face training was not possible due to the closure of the US/Canada border to non-essential travel. As a result, the training was delivered virtually over 4 half-day sessions instead of 2 full day in person sessions which impacted the continuity of the training. Some participants experienced technical difficulties.

2. *Transitioning Together* Program Delivery:

Pandemic restrictions meant that face to face sessions were not possible and the program was delivered virtually to both parent/caregiver and youth groups. As mentioned earlier, “zoom fatigue” was evident for both parents/caregivers and youth. Facilitators also indicated that virtual delivery makes it more difficult to engage the reluctant or shy participant. The ability to turn off cameras made it easier for the reluctant or shy participant to stay in the background.

3. *Transitioning Together* Curriculum Adaptation:

Many curriculum adaptations were required in order to deliver the material effectively in a virtual format. The adaptations occurred throughout delivery of both phases of the project.

4. *Transitioning Together* Virtual Format:

The trainers from the University of Wisconsin and the facilitators in York Region have had limited experience in delivering programs in a completely virtual format which required ongoing adaptation and flexibility.

5. *Transitioning Together*: Participant Family Recruitment:

As noted previously, the number of participant families was lower than expected. Recruitment efforts were made many times in multiple formats. It is the belief of the project team that this is a result of delivering the program virtually. Families and youth have been spending a significant number of hours each day engaged in virtual work or education so the prospect of additional virtual training had less appeal than anticipated. Several participants commented on the challenges of “Zoom fatigue”.

Learnings and Unexpected Outcomes of the *Transitioning Together* Project

1. Application to present the *Transitioning Together* project research outcomes at INSAR in 2022 with YASDP listed as co-author.
2. Presentation of the *Transitioning Together* project research outcomes at the Health and Wellbeing in Developmental Disabilities conference in February, 2022 with YASDP listed as co-author.
3. Adapted *Transitioning Together* - Several families who applied for the *Transitioning Together* project were determined to be not eligible due to the significant cognitive and social communication challenges experienced by the individual with ASD. These challenges would have presented barriers in an on-line delivery format and negatively impacted the other participants. As a result, Dr. Burnham Riosa proposed creating an adapted curriculum that would meet the needs of these individuals. This proposal was given the full support of the York ASD Partnership and Dr Leann Smith Dewalt at the University of Wisconsin. Dr. Burnham Riosa then submitted a proposal for funding for this project to the Brock University research department.

The proposal included focus groups with families with a youth with cognitive and social communication challenges to gather information on the needs of these youth and determine the best methods of engaging them in group activities. The researcher would then adapt the program curriculum and subsequently deliver and evaluate the adapted program. This project has received approval from Brock University and will be conducted throughout 2022.

Ongoing Transitioning Together Delivery

York Support Services Network (YSSN) offered an additional group in the fall of 2021 serving ten (10) families and plan to offer another group in the spring of 2022. Community Living York South (CLYS) offered staff support for the YSSN sessions and plan to partner with other agencies as needed. Kerry's Place Autism Service is planning to offer an additional group in the spring of 2022.

Autism Speaks Family Services Community Grant 2020 Budget as of December 31, 2021

	Budget \$35,000	Expenses
Autism Speaks Grant Budget Total		
<i>Autism Speaks Budget: Direct Personnel</i>	20,924	21,559.83
<i>Autism Speaks Budget: Purchased Svs Training</i>	2,776	2,776.00
<i>Autism Speaks Budget: Purchased Svs Research & Eval</i>	10,000	10,000.00
<i>Autism Speaks Budget: Supplies & Material</i>	1,300	664.17
		35,000
Balance		

Addendum A

York ASD Partnership 2020/2021: A Brief Report on the Transitioning Together Virtual Training and Program Evaluation

This project was supported by an Autism Speaks Canada Family Services Community Grant awarded to the York ASD Partnership (FSCG-2019-10)



Transitioning Together Synchronous Online Training Evaluation

Overview of Trainees Who Participated in the Virtual Training

Twenty-three program facilitators (“trainees”) participated in a 4-session synchronous virtual *Transitioning Together* facilitator training program. Most program facilitator trainees ($n = 21$) rated having “extensive” or “some” knowledge of ASD. When asked to list their relevant qualifications related to working with people on the spectrum and their families, 19 trainees reported having formal education (e.g., master's degree, undergraduate degree, diploma, or certificate), 7 trainees reported non-formal education (e.g., community workshops or modules), 5 trainees reported having a specific certification (e.g., Board Certified Behavior Analyst, Nonviolent Crisis Intervention instructor/certificate, first aid/CPR, and Crisis Prevention Institute certification), and 5 trainees reported general work or personal experience.

When the trainees were asked about their professional experience working with families with a member with ASD, they described working with various age groups (e.g., children, youth and adults with ASD or other developmental disabilities) across a variety of settings (e.g., group homes, schools, home (respite care), centers, and agencies providing behavioural services), through their past and current roles (e.g., coordinators, interventionists, mentors, educators, facilitators, support personnel, resource workers, therapists, and consultants). Additional trainee characteristics are reported in Table 1.

Table 1
Characteristics of Program Facilitator Trainees

Characteristics	<i>n</i>	<i>%</i>
Years of work experience		
0 to < 1 year	1	4
1 year to < 2 years	1	4
2 years to < 3 years	3	13
3 years < 4 years	4	4
4 years to < 5 years	2	9
5 + years	15	65
Facilitating/co-facilitating group experience		
Yes	18	78
No	5	22
With individuals with ASD or their families		
Yes	12	67 ^a
With a focus on the transition to adulthood		
Yes	6	50 ^b

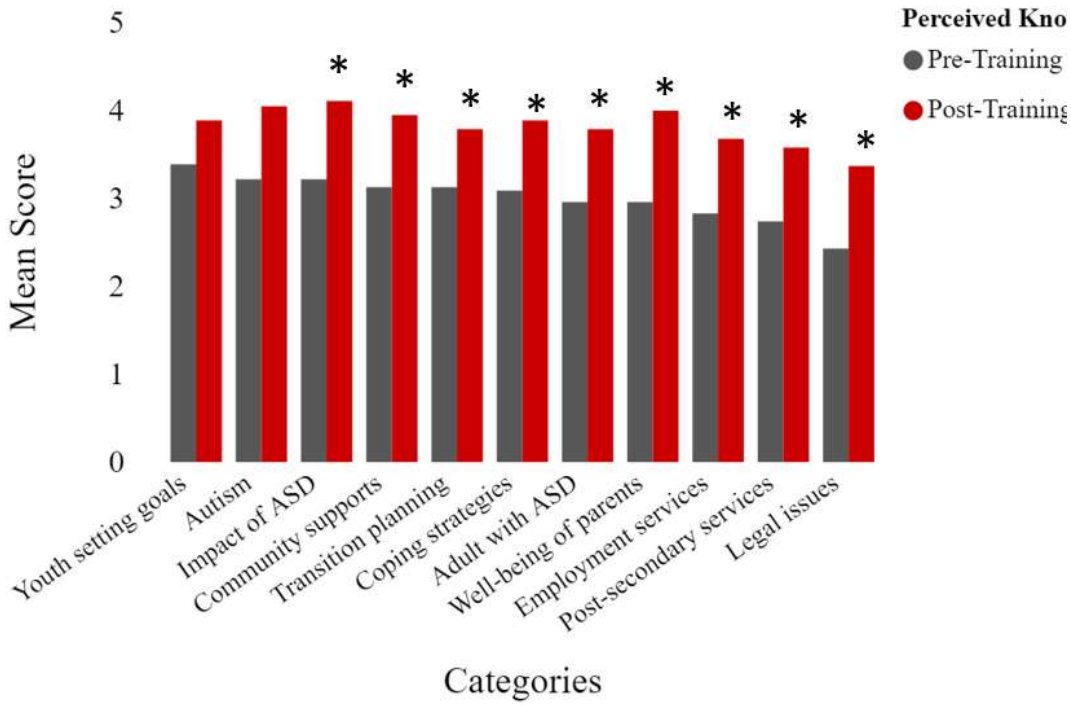
Note. ^aPercent calculation is based on a denominator of 18; ^bPercent calculation is based on a denominator of 12 (i.e., number of participants who (co-)facilitated a group for individuals with ASD or their families previously).

Program Facilitator Pre- and Post-Training Survey Results

Following the training program, participants reported a positive change in their **knowledge** and **confidence** in areas related to delivering *Transitioning Together*. See Figures 1 and 2 below for self-reported trainee perceived changes in knowledge and confidence, respectively.

Figure 1

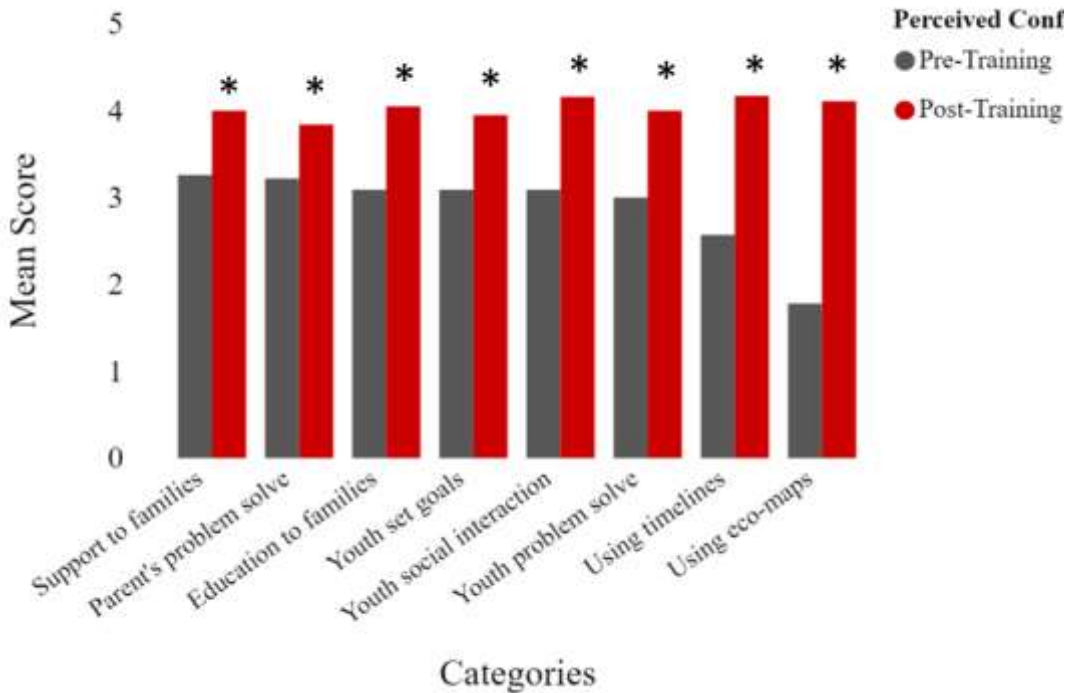
Changes in Program Facilitator Perceived Knowledge



Note. $N = 23$. All red bars for perceived knowledge with a * denote a statistically significant change.

Figure 2

Changes in Program Facilitator Perceived Confidence



Note. $N = 23$. All red bars for perceived confidence with a * denote a statistically significant change.

Program Facilitator Virtual *Transitioning Together* Training Feedback

Nineteen trainees completed the virtual *Transitioning Together* feedback survey. The majority ($n = 17$) of trainees attended all four training sessions. The majority of trainees reported the content, timing (e.g., Tuesday mornings), length of the training (4 weekly sessions), training methods (lecture, discussion, role play, demonstration of sessions, etc.) were either “extremely” or “somewhat appropriate”, and the materials provided to deliver *Transitioning Together* were either “extremely” or “very useful”. Most trainees also indicated the online delivery and trainers were effective, and that the training was relevant to their professional development. Most trainees were highly motivated to learn the training content and reported that they understood the training content. However, when asked if the trainees experienced any technical issues, 79% indicated that this was the case. When asked to describe the technology issues and how they affected the training experience, trainees indicated WebEx, sound, internet connection, and broken links were the technology issues that negatively affected their training experience. Despite the technical issues, most of the trainees stated that the training was “extremely” or “very valuable” to their future professional work and that they were either “extremely” or “somewhat likely” to apply what they learned during the training in their future professional work. Overall, most trainees were satisfied with the *Transitioning Together* training, and would likely recommend the training to their colleagues.

More than half of the trainees learned something new from the training. When asked to describe the new information the trainees learned, they indicated they learned how to run the group sessions, use problem-solving, help youth set goals, and use an eco-map and timeline. Over 70% of the trainees stated they would do something different in their professional practice after taking the *Transitioning Together* training. When asked to describe what the trainees would do differently in their professional practice, they indicated they would use the *Transitioning Together* information, strategies, or activities with families or youth with ASD. Six of the 23 (26%) trainees reported additional comments or concerns. Overall, this feedback was positive and included suggestions to improve the training experience. One participant commented as follows: “I found this to be a helpful training, this was my first virtual training, and I was pleasantly surprised how well it went for me. Thank you for the opportunity.” Another participant stated, “more activities for hands on learning should be implemented for live streaming” and suggest pre-recorded “teaching elements” and providing “PowerPoints a head of time, [so] the live streaming can be more adapted to each participant’s level of knowledge with activities and conversation of how to implement the program.” Similarly, another participant described the benefits of watching group sessions: “...seeing some group sessions of the program would have been helpful”.

Online Training Summary

Overall, trainees reported positive changes in their reported knowledge related to ASD and the transition to adulthood and their confidence in supporting transition aged youth on the spectrum and their families following training. These findings are noteworthy given the unexpected pivot to online delivery of this training program because of the global pandemic. This evaluation had two major limitations that are worth mentioning. First, we conducted a pre-post evaluation, which limits how confident we can be that only the training impacted the reported changes in trainee perceptions. Second, we measured trainees’ perceived knowledge and confidence, which may not translate to actual performance skills when delivering the program. Future work should continue to evaluate the *Transitioning Together* training program and assess each trainee’s ability to perform the skills required to deliver the program with fidelity.

2. Transitioning Together Program Evaluation

The purpose of this study was to examine the effectiveness of *Transitioning Together* at improving the parent, youth, and parent-child relational outcomes among families in Ontario. Twenty-nine eligible families (parent-youth dyads) were enrolled in *Transitioning Together* and 26 families completed the study. Across five York ASD Partnership-affiliated treatment organizations, *Transitioning Together* was delivered by 17 practitioners virtually to families in one of six winter/spring 2021 or spring/summer 2021 offerings.

In this study, we evaluated the effects of *Transitioning Together* on various parent, child, and parent-child outcomes before, after, and 1-month following the program. Parent well-being was measured by administering parent-reported questions to

assess parental depressive symptoms (*Center for Epidemiological Studies Depression Scale*; Radloff, 1977), general life stress (*Perceived Stress Scale*; Cohen & Williamson, 1988), parental problem solving (item from the *Family Empowerment Scale*; Koren et al., 1992), and caregiver resilience (*Brief Resilience Coping Scale*; Sinclair & Wallston, 2004). Youth well-being was measured through parent- and youth-reported youth social interactions, parent-reported autistic symptoms (*Social Responsiveness Scale, Second Edition*; Constantino, 2012), and youth-reported empowerment related to managing their mental health, related services and supports, and to positively affect related service systems (*Youth Empowerment Scale*, Walker & Powers, 2007). We also assessed the parent-child relationship by asking caregivers to speak about their child for 5 minutes. These brief interviews were recorded, transcribed, and are being coded for words and statements that reflect expressed emotion (e.g., warmth, criticism, positive and negative emotion words).

In general, our community sample of family participants included parents with youth who had varying degrees of social communication and cognitive abilities. While we attempted to include families with a youth who had at least average intellectual functioning using our screening question (“Can your child speak in complex sentences?”), our subsequent intellectual functioning tests following study enrollment indicated that our sample included participants with lower-than-expected IQs. For the overall sample of 26 parent-youth dyads, youth had an average IQ score of 92 ($SD = 21.0$; range = 44-121). When examining the parent and child outcomes across the entire sample, there were no significant outcome changes on any of the parent or youth measures. It is important to underscore that the original *Transitioning Together* program was designed for families with youth with average intellectual functioning and hence it is possible that these findings were related to the nature of the content and its intended audience (e.g., presentation of information, specific resources recommended throughout the sessions). However, when examining a subset of the sample (i.e., only looking at the results of youth with at least average IQs of 85+), some notable changes in outcome measures were identified. For example, significant positive changes in parent-reported depressive symptoms ($p = 0.045$), parent-reported youth social activities ($p = 0.040$), parent-reports of being happy about or proud of their child ($p = 0.02$). No youth-reported changes were observed in this subsample.

We also collected open- and closed-ended responses from parents following the program. Regarding the open-ended responses, many parents’ experiences were positive. For example, some parents reported that it gave them more confidence to find resources for their children and the information throughout the weekly sessions was very useful and parents reported that they would use this information as references in the future. Some parents commented on the positive impact that the program had on their children. Parents also reported that the program provided a gateway to discussing the transition to adulthood with other caregivers and their children with concrete information as a basis. Several parents enjoyed the program (“excellent program”, “exceptional”, “learned a lot”, “extremely rewarding”) and

were happy that they participated. Some of the challenges that parents had was around the timing of the program (e.g., too late, sessions too short) and difficulties with synchronous virtual platforms (e.g., difficult to share online and make connections with other parents compared to in person).

Many parents' and youths' closed-ended responses were similarly positive. Parents and youth provided their quantitative feedback on their acceptability of the program overall. Parent-reported questions included statements such as "How valuable was the information presented to you during the program?", "How valuable was it to interact and learn from other families?", and "Since completing the program, how likely are you to take specific actions to advocate for your son or daughter?". Responses to items on this measure ranged from 1 ("Not satisfied") to 5 ("Extremely satisfied"). Youth reported relatively neutral ratings to questions about their experiences with the program. For example, when asked about how satisfied they were with their contributions to the group sessions, the average rating was 3.4 out of 5. Similarly, when asked how connected they felt to other members of the youth group, they reported an average rating of 3.1 out of 5. On an overall satisfaction rating of *Transitioning Together*, parents rated it with an average score of 3.9 out of 5 points. Similarly, youth reported an average score of 3.6 out of 5 points, suggesting that in general, parents and youth were satisfied with the program.