

Pilot Test of the Maximizing Adolescent Post-Secondary Success (MAPSS) Intervention: Supporting Parents of Autistic Youth

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Importance: Parents play an essential role in the transition to adulthood for autistic youth, yet often feel they do not have adequate training and resources.

Objective: To evaluate data on the preliminary efficacy of and collect participant feedback about the Maximizing Adolescent Post-Secondary Success (MAPSS) intervention.

Design: Single-group, pretest–posttest pilot study.

Setting: Clinic.

Participants: Twenty-two families of autistic youth (ages 13–19 yr, 72.7% male).

Intervention: MAPSS is a group intervention for parent–youth dyads that is designed to guide parents in facilitating the development of independent skills for adulthood.

Outcomes and Measures: Measures included the Transition Preparation Activities Measure (T-PAM), Family Empowerment Scale (FES), 10-item Perceived Stress Scale (PSS–10), Adulthood Expectations Questionnaire (AEQ), Adaptive Behavior Assessment System–Third Edition (ABAS–3), and a study-specific participant feedback survey.

Results: Frequency of transition preparation activities (T-PAM) significantly increased from before to after the intervention, and although the frequency of preparation activities decreased by 1-mo follow-up, it remained significantly higher than at baseline. Parent self-efficacy (FES), parent expectations (AEQ), and parent sense of control over outcomes (AEQ) also significantly increased from preintervention to follow-up; however, parent coping (PSS–10) was unchanged. Youth self-care skills (ABAS–3) demonstrated improvements 6 mo after the completion of the intervention, although other areas of adaptive behavior did not significantly change. Feedback from parents suggested they had positive experiences and felt the intervention was beneficial.

Conclusions and Relevance: Our data suggest that the MAPSS intervention is an appropriate candidate for larger, controlled clinical trials.

What This Article Adds: With additional evidence, this intervention can offer guidelines for occupational therapists to work with autistic youth and their parents to prepare for adulthood.

For autistic¹ people, the transition to adulthood—set in motion by finishing high school—is often likened to falling off a cliff because of the drastic reduction in supports and services during this time (Levy & Perry, 2011). This transition can include entry into postsecondary education, employment, adult living situations, and adult social relationships. Studies on transition outcomes with autistic adults reveal a striking need to better support autistic adults as well as adolescents preparing for adulthood. A meta-analysis conducted by Steinhausen and colleagues (2016), which analyzed 12 unique samples of autistic adults (total $N = 828$), found that nearly half (48%) experienced what was

¹We use identity-first language (e.g., *autistic person*) in this article instead of person-first language (e.g., *person with autism*) to align with common preferences of autistic self-advocates.

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considered a poor overall outcome (i.e., requiring a high level of support, residential placement, or both), and 31% experienced a fair overall outcome (i.e., requiring support and supervision).

Interventions targeting life skills (i.e., basic and instrumental activities of daily living; [American Occupational Therapy Association, 2020](#)) for autistic youth are needed to support postsecondary success, especially in the areas of independent living and employment. One's skills in these areas can affect one's ability to live in the community without support and can have an impact on participation in other areas, such as social relationships and employment. Research has shown that autistic people who demonstrate more independent life skills (e.g., grooming and hygiene, household management, meal preparation) have a higher likelihood of sustaining paid employment ([Chan et al., 2018](#); [Taylor et al., 2015](#)).

Evidence also suggests that autistic youth with average or above-average intellectual abilities—who make up more than two-thirds (67%) of autistic people in the United States ([Maenner et al., 2020](#))—may be in particular need of evidence-based transition services, including those addressing life skills ([Taylor et al., 2015](#)). Indeed, one study suggested that autistic young adults with average to above-average intelligence scores were 3 times more likely to be disengaged from regular activities (e.g., unemployed, not attending school) compared with their autistic counterparts with intellectual disability (ID; [Taylor & Seltzer, 2011](#)). The authors of that study posited that their finding may be due to inadequacies in the transition and adult services systems for autistic youth without ID ([Taylor & Seltzer, 2011](#)).

Need for Parent-Based Intervention

Although interventions aimed at youth themselves are important, a growing body of evidence suggests the need for parent-focused interventions during the transition to adulthood. Parents of autistic youth must often make critical decisions about postsecondary activities (e.g., the types of supports their child needs, whether their child will seek higher education or employment opportunities) during or, ideally, before this transition period ([Lounds et al., 2007](#)). Parents of autistic youth also report considerable uncertainty when it comes to their child's future ([Kirby, Bagatell, & Baranek, 2020](#)), which can have the unintentional result of limiting opportunities for the child ([Cheak-Zamora et al., 2017](#)). Limited opportunities for decision making and skill development can restrict self-determination, which has been well established as a critical aspect of the transition to adulthood for youth with disabilities ([Paradiz et al., 2018](#)).

Evidence also suggests that in this population, parental thoughts and behaviors are predictive of young adult outcomes; specifically, parent expectations have been shown to mediate autistic youth's postsecondary outcomes ([Kirby, 2016](#)), and parent self-efficacy and expectations have been shown to predict parent choices about transition activities ([Holmes et al., 2018](#)). Empirically supported psychological theories of self-efficacy ([Bandura, 1977](#)) and expectations ([Eccles & Wigfield, 2002](#)) suggest that these constructs are modifiable and can result in altered behavior. Thus, interventions aimed at increasing parent self-efficacy and expectations for the future may help contribute to improved postsecondary outcomes for autistic people.

Development of the Maximizing Adolescent Post-Secondary Success Intervention

Given the critical need for improved postsecondary outcomes for autistic people, the unique needs of autistic youth anticipating receipt of a high school diploma, the importance of maximizing life skills for autistic youth, and the promise of parent-centered interventions, we developed a new intervention called *Maximizing Adolescent Post-Secondary Success* (MAPSS). Development of the MAPSS intervention was informed by our prior research, published empirical findings, and psychological theory. Our interdisciplinary team designed the intervention to support and empower parents to facilitate the development of adult life skills with their autistic adolescents, specifically for youth expecting a high school diploma. Before the current pilot study, we conducted a small feasibility study with four families ([Kirby et al., 2018](#)) and made adjustments to the program accordingly.

Study Purpose

In this article, we describe the pilot study we conducted to determine whether the MAPSS intervention has adequate potential for further, large-scale testing. We focused on the following three aims; our hypotheses were supported by the results of our feasibility study (Kirby et al., 2018).

- Aim 1 (primary): Determine whether parents report an increased frequency of transition preparation activities from before to after participation in the MAPSS program. We hypothesized that participant transition preparation scores would significantly increase between Time 1 (T1) and Time 2 (T2; pre- and postintervention) and would remain higher than at T1 1 mo after the intervention (Time 3 [T3]).
- Aim 2 (exploratory): Conduct a preliminary exploration of changes in measures of parent self-efficacy, coping, expectations, and sense of control over postsecondary youth outcomes from before to 1 mo after participation in the MAPSS intervention and in measures of youth adaptive behavior from before to 6 mo after participation in the MAPSS intervention (Time 4 [T4]). We hypothesized that parent self-efficacy, coping, expectations, and control scores would increase between T1 and T3 and that youth adaptive behavior scores would increase between T1 and T4.
- Aim 3: Examine parent satisfaction with the MAPSS intervention and parental perceptions of the program. We hypothesized that parents would report mean satisfaction scores of ≥ 3.5 on the 1–4 scale across items at T2. We also aimed to explore responses to open-ended questions to understand parent experiences in the program and receive suggestions for improvement.

Method

To pilot test the MAPSS intervention, we used a single-group, pretest–posttest design. We advertised through local organizations and recruited three successive groups of 5 to 8 families per group. All parent and adolescent participants provided informed consent or assent (if younger than age 18 yr) and received compensation for their participation in the study. All study procedures were approved by the University of Utah’s institutional review board.

Participants

We recruited parent participants who identified as a primary caregiver of an adolescent (ages 14–21 yr) with a diagnosis of autism, who was in high school, and who was anticipating receipt of a high school diploma.² Youth who had a diagnosis of co-occurring ID were not eligible to participate. The recruited sample included 22 families, with 6 autistic girls (27%) and 16 autistic boys (73%). One parent per adolescent was required to be the study participant, but a second parent or caregiver was eligible to join the sessions as well. Twenty-one of the parent participants were mothers (96%), but a total of 22 mothers and 7 fathers participated in MAPSS sessions. Parent participants ranged in age from 38 to 59 yr; see Table 1 for additional characteristics of the parent and youth participants. Many of the youth had co-occurring conditions per parent report, including anxiety ($n = 9$; 41%), attention deficit hyperactivity disorder ($n = 9$; 41%), and depression ($n = 3$; 14%).

Intervention

The MAPSS intervention was designed to be delivered in a group format. For 6 wk, one 90-min group session/wk was held for parents, and a concurrent session was run for the youth. The parent-focused portion of the MAPSS curriculum was designed to encourage parents to explore their own expectations and what they can do to support their child, as well as to expand their awareness of key topics, including youth self-determination, motivation, common challenges

²Inclusion criteria were expanded slightly in the final group to accommodate interested families and to allow us to gather information on the program’s utility for an expanded group. Three participants did not meet the initial criteria, including 1 parent of a 13-year-old, 1 parent of an 18-year-old who had just recently graduated from high school, and 1 parent of a youth who had recently switched from the diploma-seeking to the completion-certificate-seeking track.

Table 1. Characteristics of Parent and Youth Participants (N = 22)

Characteristic	M (SD), Range, or n (%)
Youth Participants	
Age, yr	15.73 (1.52), 14–19
Gender	
Male	16 (72.7)
Female	6 (27.3)
Autism severity	
Mild	4 (18.2)
Moderate	2 (9.1)
Severe	16 (72.7)
IQ	101.91 (12.63), 81–129
Race or ethnicity	
White or Caucasian, non-Hispanic, non-Latino	16 (72.7)
Asian	0 (0)
Black or African-American	1 (4.5)
Hispanic or Latino	2 (9.1)
Mixed	3 (13.6)
Parent or Caregiver Participants	
Age, yr	44.73 (6.32), 38–59
Gender	
Male	1 (4.5)
Female	21 (95.5)
Race or ethnicity	
White or Caucasian, non-Hispanic, non-Latino	18 (81.8)
Asian	1 (4.5)
Black or African-American	0 (0)
Hispanic or Latino	2 (9.1)
Mixed	1 (4.5)
Annual household income, \$	
<30,000	2 (9.1)
30,000–79,999	9 (40.9)
80,000–149,999	8 (36.4)
≥150,000	3 (13.6)

Note. Percentages may not total 100 because of rounding.

each group, and they allowed for slight adjustments that could improve the program (Arain et al., 2010). One notable change was made during the pilot study. For the first two groups, 1 week (Week 4) was dedicated to parent stress and self-care. On the basis of participant feedback (described in the “Results” section) and group leaders’ assessments of this session (i.e., that discussing their stress in a group context was not productive), we decided to remove this as a MAPSS session topic but continue to offer take-home resources and ideas for families on it. Moreover, we felt that the absence of formal conversation about youth autistic identity and neurodiversity in the first two groups was a limitation.

Although it had emerged naturally in the first two groups, we determined that focused content would improve the program, and we therefore replaced the prior content for Week 4. Before implementing this new topic, we invited participants from the first two groups to return and participate in a trial run of it. We conducted a 90-min pilot session with 4 prior participants and then held a 30-min feedback session afterward. The parents provided positive feedback about this new topic, and all were highly supportive of its substitution for the parent stress and self-care topic.

(e.g., executive functioning, sensory processing), and identity (e.g., supporting autistic identity and neurodiversity). The MAPSS intervention follows a semi-structured curriculum, guided by facilitators with expertise in working with autistic youth (the outline of MAPSS weekly topics is presented in Table 2). The facilitators provided concise, evidence-based information supported by visual and text material in the workbooks; guided the discussion; and encouraged parents to relate the topics back to their personal experiences and record reflections and ideas for implementation in the workbook.

The youth group was run by a licensed occupational therapist and was flexible in design to allow a focus on the life skill areas of interest to the youths and to adapt to their needs. At the first session, the occupational therapist solicited ideas for skills the youths wanted to learn. The overarching goals of the group were to encourage the youths to think about their adult futures and begin practicing adult life skills (rather than to gain any specific, predetermined skills).

At each session, parent–youth dyads together set individual goals for the coming week, with support from project staff. Goals varied widely, depending on individual needs. Examples of goals included learning to do laundry, practicing driving, answering the phone, inquiring about job applications at a local business, meal planning and cooking, emailing service providers, and using credit cards in stores and online.

Because this was a pilot study, the group leaders evaluated the program each week and at the completion of

Table 2. Summary of Participant Feedback About the MAPSS Intervention

Item	M (SD)
Rate your satisfaction with the following ^a	
Length of MAPSS sessions (90 min)	3.76 (0.44)
Length of MAPSS program (6 wk)	3.43 (0.81)
Timing (weekday evening: 6:00 p.m.–7:30 p.m.)	3.45 (0.61)
Group leaders	3.90 (0.30)
Parent group discussions and activities	3.48 (0.75)
Teen group activities	3.65 (0.59)
Overall, how satisfied are you with the MAPSS program?	3.76 (0.54)
Rate how valuable you found the following ^b	
Meeting and talking with other parents who have similar experiences	3.90 (0.30)
Reminders and motivation to work on skills for adulthood	3.86 (0.36)
Setting goals with your teen each week	3.81 (0.51)
Your teen's participation in the life skills group	3.60 (0.60)
The MAPSS workbook	3.62 (0.59)
Take-home information	3.62 (0.59)
Week 1: Parents' role in transition	3.80 (0.52)
Week 2: Motivating teens	3.81 (0.51)
Week 3: Determining what your teen needs	3.86 (0.48)
Week 4: Stress and transition: Caring for yourself (Groups 1 and 2) ^c	3.62 (0.63)
Week 4: Understanding your teen (Group 3) ^c	4.00 (0.00)
Week 5: Facilitating self-determination and independence	3.85 (0.49)
Week 6: Expectations for the future	3.75 (0.55)

Note. MAPSS = Maximizing Post-Secondary Success.
^aRange = 1 (*not satisfied*) to 4 (*very satisfied*). ^bRange = 1 (*not valuable*) to 4 (*very valuable*). ^cWeek 4 content differed for Groups 1 and 2 and Group 3.

Instrumentation

We collected measures at baseline, immediately post-intervention, 1 mo postintervention, and 6 mo postintervention using REDCap software (<https://www.project-redcap.org/>). At baseline, we collected demographic data from parents. We also administered the Wechsler Abbreviated Scale of Intelligence, Second Edition (Wechsler, 2011), to the youth participants to provide an estimation of cognitive level; parents completed the Social Responsiveness Scale, Second Edition (Constantino & Gruber, 2012), so we could get an estimate of youth autism severity.

Pre-Post Measures

The pre-post measures we used demonstrated acceptable internal consistency with a national sample of 269 parents of autistic youth without ID in prior work (Kirby, Feldman, et al., 2020); α coefficients from that study are reported in the following paragraphs. Before T1, a nonrandom subsample of 10 parent participants (i.e., those who signed up early enough and were willing) completed study measures over a 6-wk nonintervention period, demonstrating no significant changes ($p \geq .10$) on any of the measures.

Transition Preparation Activities. Our primary outcome measure was the frequency of parent and youth transition preparation activities ($\alpha = .79$) on the Transition Preparation Activities Measure (T-PAM; Kirby, n.d.-b). The T-PAM in-

cludes 14 questions, measured on a 5-point Likert-type scale that ranges from 1 (*very rarely or never*) to 5 (*very often*), about the frequency of various activities in which the parent respondent, the youth, or both had engaged over the past month. Nine youth activities are presented in the T-PAM, including completing chores, receiving transition-related school services, receiving transition-related services outside of school, engaging in volunteer work or paid work, and working toward goals related to the future, as well as four parent/family activities, including receiving transition-related information and having discussions about the future.

Secondary Parent Outcomes. The four secondary parent outcomes of interest included (1) parent self-efficacy as measured by the Competency factor ($\alpha = .82$) of the Family Empowerment Scale (FES; Koren et al., 1992; Singh et al., 1995), (2) parent coping as measured by the Ability to Cope factor ($\alpha = .78$) of the 10-item Perceived Stress Scale (PSS-10; Cohen, 1994), (3) parent postsecondary expectations as measured by the Likelihood scale ($\alpha = .88$) of the Adulthood Expectations Questionnaire (AEQ; Kirby, n.d.-a), and (4) parent sense of control over youth outcomes as measured by the Control scale ($\alpha = .82$) of the AEQ. The AEQ is a 12-item measure that includes items based on questions from the National Longitudinal Transition Study-2 (NLTS2; see <https://www.nlts2.org>). Likelihood questions on the AEQ inquire about parents' perspectives of the likelihood that their child will achieve various adult outcomes and are closely based on the parental expectation questions from the NLTS2; however, the scale was altered to fit a 5-point Likert-type format (1 = *very unlikely* to 5 = *very likely*). The Control scale includes questions that assess parents' perception of their own control over outcomes, measured on a 4-point scale (1 = *no control* to 4 = *a great deal of*

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control). The outcomes presented within each domain of the AEQ include attending college or pursuing higher education, living away from home without supervision, getting a paid job, and financial independence.

Adaptive Behavior. At both T1 and 6 mo postintervention (T4), parents completed selected parts of the Adaptive Behavior Assessment System—Third Edition (ABAS-3; Harrison & Oakland, 2015) to explore long-term changes in youth adaptive behavior skills. We chose specific adaptive skill areas of the ABAS-3 most closely related to the content of the MAPSS program: Community Use ($\alpha = .89-.96$), Functional Academics ($\alpha = .92-.95$), Home Living ($\alpha = .95-.96$), Self-Care ($\alpha = .91-.97$), and Self-Direction ($\alpha = .96-.97$; Harrison & Oakland, 2015).

Participant Feedback

Upon program completion (at T2), we collected feedback from the parents through a survey that included scale items and open-ended questions. Quantitative feedback (19 items) was rated on satisfaction (7 items on a scale that ranged from 1 [*not satisfied*] to 4 [*very satisfied*]) and value (12 items on a scale that ranged from 1 [*not valuable*] to 4 [*very valuable*]), including questions related to both the form and content of the MAPSS intervention. Open-ended questions asked about what participants felt were the least important and most important aspects of the program as well as whether and how the program had changed their thinking or behavior. A final open-ended question provided an opportunity for parents to provide any additional feedback.

Data Analyses

We used IBM SPSS Statistics (Version 26; IBM Corp., Armonk, NY) for data analysis, beginning with the calculation of descriptive statistics on demographic questions and all study measures. We also compiled summary information about participant retention. To address Aims 1 and 2, we ran paired-samples *t* tests. For Aim 1, we used *t* tests to compare T1 and T2 T-PAM transition preparation activity frequency scores, as well as those between T1 and T3. For Aim 2, we used a series of *t* tests to compare T1 and T3 parent self-efficacy (FES), coping (PSS-10), expectations (AEQ), and control (AEQ) scores. Finally, also for Aim 2, we used *t* tests to compare T1 and T4 scores on the five selected adaptive skill areas of the ABAS-3.

To address the first part of Aim 3, regarding participant satisfaction, we examined means and standard deviations on satisfaction rating scores and compared them with our hypothesis. To address the second part of Aim 3, regarding parental perceptions, we reviewed open-ended responses using a descriptive qualitative approach (Sandelowski, 1996). We reviewed all open-ended responses and grouped similar responses to summarize recommendations and overall impressions of participants.

Results

All 22 families who consented to participate remained in the program and completed postintervention measures for at least one time point (100% retention rate). Table 3 contains descriptive statistics summarizing participant responses on the outcome measures at each relevant time point, as well as *t* test results for Aims 1 and 2.

Aim 1: Transition Preparation Activities

Pre- and poststudy T-PAM results supported the primary hypothesis that transition preparation activities would increase from before to after the intervention (T1 to T2, $p = .000$), and although frequency scores decreased between T2 and T3, they remained significantly higher than at T1 ($p = .033$).

Aim 2: Secondary Parent Outcomes and Youth Adaptive Behavior

As hypothesized, we identified increases between T1 and T3 for expectation likelihood scores ($p = .007$) and parent sense of control over outcomes ($p = .002$); however, counter to our original hypothesis, coping scores did not increase

Table 3. Means, Standard Deviations, and Cross-Time Point Comparisons of Key Study Measures

Measure	<i>M (SD)</i>				<i>t^a</i>		
	T1 (<i>n</i> = 22)	T2 (<i>n</i> = 21)	T3 (<i>n</i> = 22)	T4 (<i>n</i> = 20)	T1-T2	T1-T3	T1-T4
Transition preparation activities	38.55 (8.12)	49.91 (9.29)	42.60 (9.06)		-5.43***	-2.28*	
Parent self-efficacy	30.68 (4.96)		31.77 (5.27)			-1.90	
Parent coping	10.45 (3.47)		10.41 (2.92)			0.086	
Parent expectations (likelihood)	20.14 (5.38)		21.97 (4.49)			-2.99**	
Parent sense of control	15.23 (3.62)		16.68 (3.32)			-3.55**	
Adaptive behavior							
Community Use	36.24 (14.93)			38.25 (11.13)			-1.452
Functional Academics	47.05 (11.77)			48.63 (10.81)			-1.536
Home Living	46.50 (13.46)			49.09 (12.79)			-1.761
Self-Care	60.02 (11.64)			62.22 (11.42)			-4.008**
Self-Direction	41.82 (12.71)			43.52 (12.84)			-1.451

Note. T1 = Time 1 (preintervention); T2 = Time 2 (postintervention); T3 = Time 3 (1 mo after intervention); T4 = Time 4 (6 mo after intervention).
^aFor T1-T2, *df* = 20; for T1-T3, *df* = 21; for T1-T4, *df* = 19.
 p* < .05. *p* < .01. ****p* < .001.

(*p* = .932). Youth life skills increased slightly within each adaptive behavior skill area between T1 and T4; differences did not reach significance for Community Use (*p* = .164), Functional Academics (*p* = .142), Home Living (*p* = .095), or Self-Direction (*p* = .164), but were significant for Self-Care (*p* = .001).

Aim 3: Parent Satisfaction and Perception of Program

Table 2 contains summary participant feedback about the program; the aggregate average of participant ratings, rated 1 through 4, was 3.81. Three items fell slightly below the hypothesized threshold of 3.5: “Length of MAPSS program (6 weeks)” (*M* = 3.43), “Timing of MAPSS program (weekday evenings 6:00 p.m.–7:30 p.m.)” (*M* = 3.45), and “Parent group discussions and activities” (*M* = 3.48). We used the open-ended responses to seek additional clarity about why those items were rated lower than the others. Regarding the length, some participants indicated in open-ended responses that they felt the program should be longer. The following quotes from three different parents illustrate this: “I feel it would be so beneficial for parents and the children to have the support of a program like this long term. Not just 6 weeks”; “Make it 8 weeks”; and “Make it longer.” Regarding timing, 1 participant wrote that their spouse had to rush from work to attend and would have liked the sessions to be held slightly later. Regarding the parent group, some participants expressed specific dislike of one session (for the first and second groups) that covered parent stress (“The section on taking care of self was the least valuable to me” and “The caring-for-yourself part”). As noted previously, on the basis of parent feedback and the assessment of the group facilitators and researchers, we changed the topic of this session before the third group to instead cover identity and neurodiversity. This change was extremely well received, as demonstrated by the 4.0 rating by all parents in that group.

Qualitative Responses

Our first open-ended question inquired about aspects of the program that parents deemed least important or helpful. In response, most participants indicated that they did not know or explicitly wrote that nothing was not helpful (e.g., “I really cannot think of anything,” “It was all helpful,” “I thought all the information was thought provoking and useful”). A few did identify concerns, some of which were outlined in the previous section (i.e., program was too short, did not like the parent stress content, bothered by other parents’ behavior, and lessons were too simple).

Our second open-ended question inquired about aspects of the program that were most important or helpful, in response to which participants indicated aspects such as “goal setting,” “sharing with others,” “new strategies,” “raising

expectations,” and “class for our children” (referring to the life skills group for the youths). Some parents provided further detail outlining what they learned in the program:

It really opened my eyes to the following: first, that I need to stop “rescuing” my son and instead give him more control and experience some failures, second, that my goals with my son have been way too broad in the past and thus doomed to failure, and the last thing I realized is that sometimes my expectations for my son are not grand enough, so we are going to raise the bar a bit.

and

Lots of things! Learning to break down behaviors into steps, accept partial success, start with goals that my child WILL do (then build on that), recognize what skills my child does have already, accept that my child will take longer than normal to attain most goals (so not to give up!).

Our third open-ended question inquired about changes in how parents thought about preparing for the future or in what they work on at home with their adolescent. Parents indicated changes in their thinking, such as “Child is more capable,” “I need to provide more opportunities for autonomy,” “The importance of goal setting,” and “Focus on what child wants and involve them more.” One parent also wrote, “I was really surprised how simply setting and working on goals with my son was so empowering. It helped me realize that I set goals and find resources and opportunities for him frequently and how to include him more.”

Discussion

The results of this pilot test of the MAPSS intervention suggest that it was well received by participants and was associated with modest increases in key parent factors, including self-efficacy, expectations, and a sense of control over outcomes. Because of the single-group design we cannot necessarily attribute observed changes to the intervention; however, coupled with the parents’ qualitative descriptions, this study provides preliminary evidence suggesting further testing of the MAPSS intervention is warranted.

The observed increases in transition preparation activities suggest that MAPSS activities may provide useful support to promote the implementation of transition preparation activities in the everyday lives of autistic youth and their families. Activities included in MAPSS, such as goal setting, are widely considered to be critical aspects of the transition process (Hendricks & Wehman, 2009). We observed that frequency of transition preparation activities remained considerably higher 1 mo after the intervention than at baseline; however, we did observe a decline from immediately after the intervention, suggesting that families would benefit from some kind of continued support to help them maintain the progress they gained during the program. Health behavior change research suggests that maintenance can be supported by personal factors, such as self-efficacy and outcome expectations (Murray et al., 2018), both of which increased from pre- to postintervention in this study. Future work should consider additional strategies for maintenance, such as text message or email reminders (Muench & Baumel, 2017).

As we hypothesized, increases in parent self-efficacy and expectations accompanied increases in transition preparation activities. This provides further evidence to support the notion articulated in previous literature that parents who have higher self-efficacy and higher expectations are more likely to engage with their youth in transition preparation activities (Holmes et al., 2018). The lack of observed changes in parent coping skills after participating in the study is not surprising given the feedback we received about the parent stress content and our subsequent removal of that content for the third group. Future research is needed to identify acceptable and effective interventions for parent stress during the transition to adulthood. Alternative approaches, such as individual or family therapy tailored to the needs of parents of autistic youth (Helps, 2016), may be more appropriate to address parent stress and increase parent coping.

After 6 mo, we observed very slight increases in adaptive behavior, with self-care skills increasing significantly. In the program, we purposefully did not dictate what goals families should be working toward to ensure the goals had individual and family meaning and matched their current needs. Therefore, it may be that self-care skills were the most important

need for youth. We hope that other adaptive behavior skills would demonstrate improvement over a longer period if families were continuing to engage in transition preparation activities and setting other goals. Research on autistic youth with co-occurring ID suggests that those with more independent daily living skills have a greater odds of being employed (Chan et al., 2018). Among autistic youth with average or above-average cognition, such as those included in this MAPSS pilot study, some daily living skills (e.g., meal preparation) have been shown to be associated with greater consistency of engagement in employment or postsecondary education (Taylor et al., 2015). Thus, increases in adaptive behavior are believed to be positive and may support greater postsecondary goal achievement.

On the feedback survey, parents reported high satisfaction with the program. Qualitative quotes from parents illustrated how their thought processes and behaviors were influenced by the intervention. Open-ended responses from parents also provided specific guidance for areas of improvement, many of which were implemented before we conducted the final group of this pilot study. One request that we did not implement was related to some parents' comments that they would have liked the program to be longer. This could be attempted in future studies, but it should be carefully considered because of several factors: Only a minority of parents indicated a request for it to be longer, this would increase the financial costs of the program, and this would increase the time burden on families. Given that we had 100% retention and results that demonstrated promise with the 6-wk program, alterations to length should be cautiously implemented.

In our third group, we replaced content on parent stress with new content about neurodiversity and identity for autistic youth. During this session we introduced the concepts of neurodiversity, identity-first language, and ways that parents can support their autistic youth to accomplish their goals while being supportive of autistic ways of being and fostering a positive view of autism identity in their family (Kapp et al., 2013). We contrasted this with traditional professional and research foci of trying to suppress autistic traits and "normalize" autistic youth (Robertson, 2010). This content seems to be a critical component of parent education for autistic youth, especially given emerging research that suppression of autistic traits may be associated with burnout and mental health struggles (Cage & Troxell-Whitman, 2019; Cassidy et al., 2020). In our study, this content was very well received by parent participants.

Limitations and Future Directions

The findings from this pilot study are limited by the small sample size; demographic homogeneity; and the single-group, nonrandomized design. Future studies using the MAPSS intervention must include control groups, ideally with an active control condition (e.g., a parent support group), to confirm that changes observed in this pilot study were not due to natural changes over time or nonspecific aspects of the intervention. Future studies should also work to recruit more diverse samples. A notable challenge to this line of research is that the ultimate intention is to make long-term changes in youth outcomes, so studies with long-term follow-up are necessary to examine the extent to which the MAPSS intervention results in meaningful long-term change. Future studies would also benefit from inclusion of additional shorter term youth outcomes, such as self-determination, as well as feedback from the autistic youth.

Implications for Occupational Therapy Practice

Although more research on the MAPSS intervention is still needed, the findings of this study suggest that occupational therapy practitioners can do the following:

- Provide strategies and tools to support autistic youth to prepare for adult life,
- Engage with parents of autistic youth to help them prepare for the transition to adulthood and to promote parental self-efficacy,
- Support families of autistic youth and the youth themselves to increase expectations of what is possible in adulthood and to engage in shared short- and long-term goal setting, and

- Express support for autistic identity and neurodiversity and work to help youth (and parents) to explore ways to accomplish their goals and successfully participate in meaningful occupations of adulthood within a neurodiversity framework.

Conclusions

The MAPSS intervention is a novel program aimed at supporting parents of autistic youth to promote the development of life skills for increased independence and goal achievement in adulthood. The results support the appropriateness of continued development and testing of the MAPSS intervention to support parents of autistic adolescents and the adolescents themselves to prepare for adult life. ■

References

- American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, 74(Suppl. 2), 7412410010. <https://doi.org/10.5014/ajot.2020.74S2001>
- Arain, M., Campbell, M. J., Cooper, C. L., & Lancaster, G. A. (2010). What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC Medical Research Methodology*, 10, 67. <https://doi.org/10.1186/1471-2288-10-67>
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84, 191–215. <https://doi.org/10.1037/0033-295X.84.2.191>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 49, 1899–1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders*, 50, 3638–3648. <https://doi.org/10.1007/s10803-019-04323-3>
- Chan, W., Smith, L. E., Hong, J., Greenberg, J. S., Lounds Taylor, J., & Mailick, M. R. (2018). Factors associated with sustained community employment among adults with autism and co-occurring intellectual disability. *Autism*, 22, 794–803. <https://doi.org/10.1177/1362361317703760>
- Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., & Koegler, E. (2017). Exploration and comparison of adolescents with autism spectrum disorder and their caregiver's perspectives on transitioning to adult health care and adulthood. *Journal of Pediatric Psychology*, 42, 1028–1039. <https://doi.org/10.1093/jpepsy/jsx075>
- Cohen, S. (1994). *Perceived Stress Scale*. Mind Garden. <http://www.mindgarden.com/documents/PerceivedStressScale.pdf>
- Constantino, J. N., & Gruber, C. P. (2012). *Social Responsiveness Scale* (2nd ed.). Western Psychological Services.
- Eccles, J. S., & Wigfield, A. (2002). Motivational beliefs, values, and goals. *Annual Review of Psychology*, 53, 109–132. <https://doi.org/10.1146/annurev.psych.53.100901.135153>
- Harrison, P. L., & Oakland, T. (2015). *Adaptive Behavior Assessment System* (3rd ed.). Western Psychological Services.
- Helps, S. (2016). Systemic psychotherapy with families where someone has an autism spectrum condition. *NeuroRehabilitation*, 38, 223–230. <https://doi.org/10.3233/NRE-161314>
- Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24, 77–88. <https://doi.org/10.1177/1088357608329827>
- Holmes, L. G., Kirby, A. V., Strassberg, D. S., & Himle, M. B. (2018). Parent expectations and preparatory activities as adolescents with ASD transition to adulthood. *Journal of Autism and Developmental Disorders*, 48, 2925–2937. <https://doi.org/10.1007/s10803-018-3545-6>
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49, 59–71. <https://doi.org/10.1037/a0028353>
- Kirby, A. V. (n.d.-a). *Adulthood Expectations Questionnaire (AEQ)* [Unpublished manuscript]. Department of Occupational and Recreational Therapies, University of Utah.
- Kirby, A. V. (n.d.-b). *Transition Preparation Activities Measure (T-PAM)* [Unpublished manuscript]. Department of Occupational and Recreational Therapies, University of Utah.
- Kirby, A. V. (2016). Parent expectations mediate outcomes for young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 1643–1655. <https://doi.org/10.1007/s10803-015-2691-3>
- Kirby, A. V., Bagatell, N., & Baranek, G. T. (2020). The formation of postsecondary expectations among parents of youth with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, 35, 118–128. <https://doi.org/10.1177/1088357619881221>
- Kirby, A. V., Cottle, K. J., Himle, M. B., Diener, M., Wright, C., & Hoffman, J. (2018, May 9–12). *Maximizing adolescent post-secondary success: Development and refinement of a novel intervention for parents of youth with ASD* [Poster]. Annual meeting of the International Society for Autism Research, Rotterdam, the Netherlands. <https://insar.confex.com/insar/2018/webprogram/Paper26675.html>

- Kirby, A. V., Feldman, K. J. C., Hoffman, J. M., Diener, M. L., & Himle, M. B. (2020). Transition preparation activities and expectations for the transition to adulthood among parents of autistic youth. *Research in Autism Spectrum Disorders*, 78, 101640. <https://doi.org/10.1016/j.rasd.2020.101640>
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37, 305–321. <https://doi.org/10.1037/h0079106>
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*, 5, 1271–1282. <https://doi.org/10.1016/j.rasd.2011.01.023>
- Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. T. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal of Mental Retardation*, 112, 401–417. [https://doi.org/10.1352/0895-8017\(2007\)112\[401:TACIAA\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2007)112[401:TACIAA]2.0.CO;2)
- Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., . . . Dietz, P. M. (2020). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 69(4), 1–12. <https://doi.org/10.15585/mmwr.ss6904a1>
- Muench, F., & Baumel, A. (2017). More than a text message: Dismantling digital triggers to curate behavior change in patient-centered health interventions. *Journal of Medical Internet Research*, 19, e147. <https://doi.org/10.2196/jmir.7463>
- Murray, J. M., Brennan, S. F., French, D. P., Patterson, C. C., Kee, F., & Hunter, R. F. (2018). Mediators of behavior change maintenance in physical activity interventions for young and middle-aged adults: A systematic review. *Annals of Behavioral Medicine*, 52, 513–529. <https://doi.org/10.1093/abm/kay012>
- Paradiz, V., Kelso, S., Nelson, A., & Earl, A. (2018). Essential self-advocacy and transition. *Pediatrics*, 141(Suppl. 4), S373–S377. <https://doi.org/10.1542/peds.2016-4300P>
- Robertson, S. M. (2010). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, 30. <https://doi.org/10.18061/dsq.v30i1.1069>
- Sandelowski, M. (1996). Using qualitative methods in intervention studies. *Research in Nursing and Health*, 19, 359–364. [https://doi.org/10.1002/\(SICI\)1098-240X\(199608\)19:4<359::AID-NUR9>3.0.CO;2-H](https://doi.org/10.1002/(SICI)1098-240X(199608)19:4<359::AID-NUR9>3.0.CO;2-H)
- Singh, N. N., Curtis, J. W., Ellis, C. R., Nicholson, M. W., Villani, T. M., & Wechsler, H. A. (1995). Psychometric analysis of the Family Empowerment Scale. *Journal of Emotional and Behavioral Disorders*, 3, 85–91. <https://doi.org/10.1177/106342669500300203>
- Steinhausen, H. C., Mohr Jensen, C., & Lauritsen, M. B. (2016). A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica*, 133, 445–452. <https://doi.org/10.1111/acps.12559>
- Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, 19, 785–793. <https://doi.org/10.1177/1362361315585643>
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41, 566–574. <https://doi.org/10.1007/s10803-010-1070-3>
- Wechsler, D. (2011). *Wechsler Abbreviated Scale of Intelligence, Second Edition*. NCS Pearson.

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