



Published in final edited form as:

J Autism Dev Disord. 2023 August ; 53(8): 2933–2953. doi:10.1007/s10803-022-05598-9.

Appropriateness, Acceptability, and Feasibility of a Neurodiversity-Based Self-determination Program for Autistic Adults

T. A. Meridian McDonald¹, Salima Lalani¹, Ivy Chen^{1,2}, Claire M. Cotton¹, Lydia MacDonald¹, Lana J. Boursoulian¹, Jiahao Wang³, Beth A. Malow¹

¹Department of Neurology, Vanderbilt University Medical Center, 1161 21st Avenue South, A-0118 Medical Center North, Nashville, TN 37235, USA

²Present Address: Graduate Medical Sciences, Boston University School of Medicine, Boston, MA 02118, USA

³Faculty of Sciences, University of Sydney, Sydney, NSW 2218, Australia

Abstract

Published self-determination programs do not adequately address the needs of autistic adults. We designed a multi-component self-determination program, grounded in the neurodiversity paradigm, to help autistic adults achieve goals to improve their quality of life. The first phase involved 5 days of psychoeducation, practice, and social events; the second phase included 3 months of telecoaching; and the third phase included follow-up. Thirty-four university students coached 31 autistic adults on three evolving goals. On average, participants completed one goal per week. Most participants were satisfied with the program. We found that the program was appropriate, acceptable, and feasible. This program is a promising approach to helping autistic adults gain self-determination skills and improve their quality of life.

Keywords

Neurodiversity; Autism; Self-determination; Quality of life; Goals; Mindfulness

[✉]T. A. Meridian McDonald t.a.mcdonald@vumc.org.

Author Contributions BAM supervised the project. TAMM and BAM conceived the pilot program. TAMM developed the components for the program pilot and coach training; provided in-person and distance training for staff, coaches, and pilot participants; and oversaw preparation of the manuscript. IC assessed and troubleshooted parent-participant dynamics. SL conducted recruitment activities, prepared materials for the program, and assisted with organizing program events. TAMM provided psychological assessments, and BAM, LM, and LJB provided medical assessments. BAM, TAMM, IC, SL, and CMC were involved with all aspects of manuscript preparation.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10803-022-05598-9>.

Declarations

Conflict of interest The authors do not have any conflict of interest to disclose.

Ethical Approval This study was approved by the Social and Behavioral Sciences Institutional Review Board of Vanderbilt University (Approval Number: 170177).

Consent to Participate Informed consent was obtained from all participants in the study.

Introduction

Many autistic¹ adults without a co-occurring intellectual disability struggle with transitioning out of high school. After they leave a relatively enriched environment in high school, they face a *services cliff* (loss of services, programs, and other support) as they deal with the demands of adulthood, such as employment, education, living arrangements, and social relationships (Roux et al., 2015a, 2015b). Autistic adults continue to face these and other challenges (e.g., health, emotion regulation, transportation), which can negatively affect their quality of life (Roux et al., 2015a, 2015b). In fact, 25% of autistic adults are socially isolated, depend on their family (e.g., finances, housing, and transportation). Despite having similar expectations for transitioning into adult roles as their non-autistic peers (Anderson et al., 2016), autistic adults face difficulties transitioning fully to adult roles (e.g., employer, co-worker, romantic partner, and friendships after high school) (Roux et al., 2015a, 2015b). Services to support autistic adults are scarce and, with an increasing prevalence of autism (Maenner, 2021), more services are needed to support autistic adults as they transition to adulthood (Roux et al., 2015a, 2015b). Without these services, autistic adults experience high unemployment, increased risk of isolation, and low rates of independent living (Roux et al., 2015a, 2015b).

After high school, autistic adults may benefit from self-determination support. Self-determination is a person's ability to use their skills, knowledge, and beliefs to pursue goals and develop their autonomy, competence, and sense of relatedness to others (Deci & Ryan, 2000). Important components of self-determination in autists include being aware of their strengths and weaknesses, opportunities to make own choices, managing stress, advocacy, and developing a self-empowering identity. In high school, self-determination is associated with positive transition outcomes related to employment, socialization, advocacy, positive identity, and stress management (Kim, 2019). In autistic adults, individual differences in self-determination skills correlate with better outcomes. For example, autistic adults with greater awareness of their strengths and weaknesses had more positive interactions with employers and colleagues, showed higher confidence and self-acceptance, and garnered admiration from others (R. S. Smith & Sharp, 2013). Also, autistic adults with higher self-determination believe they need self-regulation strategies to handle social stress and environmental stressors (Kim, 2019; Müller et al., 2008). Further, autistic adults perceive that self-determination behaviors (e.g., being aware of their strengths and weaknesses, opportunities to make own choices, managing stress, advocacy, developing a self-empowering identity) positively affect quality of life and improve meaningfulness/well-being, experiences, and environments in vocational/employment and social/romantic contexts (Kim, 2019). These findings emphasize that autistic adults can learn and practice self-determination skills to improve their quality of life (Kim, 2019; Smith & Sharp, 2013).

Heterogeneity in Autism and Life Course Theory

Autists have highly heterogeneous strengths, needs, skills, capacity, and circumstances (McDonald, 2021; Roux et al., 2015a, 2015b; Späth & Jongsma, 2020). These factors

¹Most people with an autism diagnosis prefer identity first language, such as “autistic” or “autist” (Kenny et al., 2016).

include different social communication skills and focused, recurring, and/or self-stimulatory behaviors associated with autism (American Psychiatric Association, 2013). They also include co-occurring physical and psychological disabilities (Croen et al., 2015; Roux et al., 2015a, 2015b), personality (Rodgers et al., 2018), identity (McDonald, 2017, 2020), preferences, goals (Anderson et al., 2016; Späth & Jongasma, 2020), and expectations for the future (Anderson et al., 2016). For example, some adults may have good social networks but desire better employment outcomes, whereas others may have stable employment but struggle with making friends. The high heterogeneity of these factors creates challenges in developing one self-determination intervention that fits all autistic adults.

Multiple factors synergistically influence postsecondary outcomes and self-determination. According to life course theory, life-culminating social forces interact with individual characteristics to shape outcomes. These social forces consist of social circumstances, environmental conditions (e.g., normative expectations), and institutions that can shape developmental processes, which affect disabilities and outcomes (Hayward & Sheehan, 2016). For example, in the United States, violations of normative age-related expectations of adult social roles and behaviors (e.g., employment, independent living, social relationships) can be formally and informally sanctioned by the surrounding environment (Settersten, 2003). Evidence of such violations include the *housing and employment crises* in which most autistic adults continue to live in the family home (e.g., with parents) and/or face unemployment and underemployment, despite desiring to meet normative expectations of independent living and employment (IACC, NCI). Normative expectations can also impact the types of services, programs, and support available for autistic adults. For example, the surrounding society may prioritize the improvement of age-normative employment and education outcomes while stigmatizing and/or failing to support normative activities more typical of younger ages, such as in leisure, social, and other domains (Settersten, 2003). In this way, normative expectations can be simultaneously ableist and ageist as failure to meet normative age-related expectations can be formally and informally sanctioned within a person's surrounding environment (Davis, 2016; Settersten, 2003). For autistic adults, the multifactorial challenges to self-determination can result in social stigma and decreased quality of life, well-being, and autonomy (IACC, NCI). By addressing both the heterogeneous characteristics of autistic adults and the social, environmental, and institutional factors that influence those characteristics, autistic adults may develop self-determination skills that will improve their (self-determined) outcomes.

Self-determination Interventions for Autistic Adults

Few self-determination intervention programs have been developed specifically for autistic adults. Most programs for autists focus on attaining employment (Fullerton & Coyne, 1999; Nadig et al., 2018; Smith et al., 2019), which can improve autist's expectations of employment, attitudes related to self-determination, and decision-making abilities (Oswald et al., 2018). However, not all autistic adults struggle with attaining employment. Some struggle with postsecondary education, relationships, or independent living (Roux et al., 2015a, 2015b). Some may also need to develop foundational self-determination skills in non-vocational domains, such as recreation, which they can use for future vocational goals

as they develop skills and maturity (McGuire & McDonnell, 2008). This heterogeneity of needs calls for programs that address challenges beyond employment.

Many programs for autistic people situate the problem of self-determination as residing within autistic people (Williams, 2018). Correspondingly, many self-determination programs involve intensive *corrective* training on specific skills assumed to be universally lacking with this population and universally contributing to challenges with self-determination. For example, the Acquiring Career, Coping, Executive control, Social Skills (ACCESS) Program, shown to improve self-determination, requires participants to complete 90-min instructional sessions over 19 weeks (Oswald et al., 2018). This time-intensive instruction focuses on training in social skills, emotional coping skills, or other skill domains (Oswald et al., 2018). However, it is not clear that all autistic adults who experience challenges with self-determination need such intensive training in these skills.

Instead of assuming that the challenges of self-determination reside within autistic people, an alternate view posits that autistic people are situated in contexts that do not adequately support, and thus challenge, the development of their self-determination. According to this view, interventions that target autistic attributes (e.g., social and communication differences) for *correction* are ableist at best and, at worst, marginalize and disempower neurominorities (Späth & Jongsma, 2020; Williams, 2018). A better approach, then, may be to provide access to leadership skills training (e.g., self-advocacy, conflict resolution) along with other resources and skills to empower and support self-determination in autistic adults.

For children on the autism spectrum, parent involvement can help with skill building (Lang et al., 2010; Puleo & Kendall, 2011; Sofronoff, 2005) However, for autistic adults, program reliance on parents/supportive adults for participation in self-determination programs (for examples, see Nadig et al., 2018; Oswald et al., 2018; Smith et al., 2019) may undermine self-determination. Self-determination relies on intrinsic motivation that can be negatively affected by external expectations and/or consequences (rewards and punishments) (Bear et al., 2017). Thus, some parental behaviors (controlling, need thwarting) can undermine intrinsic motivation (Ryan & Deci, 2020; Schiffrin et al., 2019), interfere with goals and activities, and lower program acceptability (Smith et al., 2019). In fact, some autistic adults request that parents be excluded from intervention activities because they have a conflictual relationship (Nadig et al., 2018). Thus, autistic adults may need a self-determination program that lets them set and pursue goals across a range of life domains with minimal stakeholder involvement in the intervention. One domain-general intervention, Putting Feet on My Dreams, minimized parental involvement to blind the study for parent report of program outcomes (Fullerton & Coyne, 1999). After the program, 62% of participants showed improved goal-setting abilities and started more discussions about their goals at home. Also, 37% of students engaged in more self-directed actions toward goals.

Due to the limitations of published self-determination programs for autistic adults, we believe that this population may benefit from a program that is flexible, honors neurodiversity, emphasizes pursuing goals, limits parent involvement, includes peer-coaching, and exposes participants to a range of leadership skill-building curriculum. To address this need, we created a multi-component self-determination program that supports

goal-attainment skills in autistic adults. This pilot program incorporated the life course theory model (Fig. 1) and neurodiversity paradigm in its framework. We then assessed the acceptability, appropriateness, and feasibility of the program for young autistic adults in the United States.

Methods

Development of a Multi-component Self-determination Program

The dynamic model of life course theory describes how variation in past experiences combine with individual and environmental factors to affect a person's wants and needs (Elder et al., 2003). To address this heterogeneity, our program included components that address and support self-determination, such as goal attainment, emotional regulation, self-advocacy, problem-solving, and other factors (Table 1). This approach helps participants increase their self-determination skills and abilities (e.g., decision-making, problem-solving, resilience) while maintaining a relationship between their current self-determination wants and needs and their personal characteristics and environmental factors (Wehmeyer et al., 2017). In multiple stages of the program, we also incorporated the neurodiversity paradigm by incorporating autistic people at every stage of the research (e.g., design, implementation, co-teaching, data analysis) (Botha, 2021; Gillespie-Lynch et al., 2017).

Self-determination Learning Model of Instruction

One approach to helping autistic adults with self-determination is the Self-Determined Learning Model of Instruction (SDLMI). This model was originally designed to address academic goal attainment by helping participants self-identify goals, goal steps, and potential barriers, and assisting with problem-solving (Lee et al., 2015). SDLMI improves academic and transition skills and outcomes (Lee et al., 2015). We believe the steps of SDLMI are flexible enough to be applied to goals across many life domains. As participants pursue goals, they experience opportunities to develop self-determination skills, including self-regulation, self-monitoring, and self-evaluation.

Complementary Skills for Self-determination

Successful self-determination relies on a wide range of skills, such as conflict resolution, stress and emotion regulation, self-advocacy and disclosure, and other empowering skills (e.g., community engagement and transportation use) (Anctil et al., 2008; Nonnemacher & Bambara, 2011; Roth et al., 2019; Sprague & Hayes, 2000). Because autistic adults may face challenges with communication and social interaction in the context of pursuing self-determined goals, they may benefit from training and practice in skills with explicit goals and steps for these types of social interactions. Self-advocacy, a critical self-determination skill for people with disabilities (Test et al., 2005), involves identifying needs, knowledge of rights, and communication skills. It also involves self-leadership to address needs, such as asking for help or advocating for change (Wehmeyer et al., 2017). Self-advocacy can also require disclosure, which can take many forms ranging from revealing a diagnosis to describing a specific need or symptom (Scorgie & Scorgie, 2017). This disclosure can be met with resistance or have adverse consequences. For example, the Healthcare Toolkit for Autistic Adults and Primary Care Providers, created by the Academic-Autistic

Spectrum Partnership in Research and Education (Nicolaidis et al., 2016), identifies several reasons for disclosing the diagnosis of autism, such as increasing understanding, improving communication, and obtaining accommodations. However, the toolkit also identifies several potential consequences, including creating misunderstanding, experiencing discrimination, and feeling concerned about confidentiality.

To mitigate some of these challenges, conflict-resolution skills can be coupled with self-advocacy and self-determination skills to increase success with problem-solving. Conflict-resolution skills facilitate the peaceful resolution of disagreement or perceived conflicts of interests (Mayer, 2012). Conflict-resolution skills are explicit and flexible leadership skills that can help autistic adults negotiate perceived conflicts of interest relating to their wants and needs, navigate disclosure, and repair misunderstandings arising from differences in expectations of social behavior.

The process of setting and pursuing goals is often not straightforward. The process can be frustrating and complicated, requiring autistic adults to have emotion and stress regulation skills to ensure their success (Roth et al., 2019). Thus, an intervention that improves self-regulation, such as mindfulness therapies, can help autistic adults stay motivated and engage in self-advocacy and conflict management. Because autistic adults are highly heterogeneous, some mindfulness therapy approaches, such as mindfulness based stress reduction (MSBR), may be more appropriate for this population. Such approaches impose a lower cognitive and emotional load while individuals develop awareness of environmental elements without feeling judgment (Sizoo & Kuiper, 2017).

Autistic adults in self-determination programs can also benefit from coaching support from peers. Most research on peer-mediated interventions for autists occurs in children and adolescents (Carter et al., 2017; Chan et al., 2009); however, some of these models also occur in adult academic settings (e.g., college) (Rando et al., 2016; Viesel et al., 2020). Some of these peer-coaching models address specific goals, such as increasing school performance, developing social skills, or enhancing social interactions (Bene et al., 2014; Watkins et al., 2015; Wong et al., 2015). Other programs have more general goals with expected outcomes (Cornett & Knight, 2009). Despite their differences, peer-coaching models can be tailored to meet the unique needs, goals, skills, and barriers of each autistic adult.

We created a self-determination program that comprised three phases: an immersion phase, coaching phase, and follow-up phase. During the 5-day immersion phase, participants learned important skills to support goal attainment, and they identified and developed their initial goals. This multi-component psychoeducation included guidance on nutrition, exercise, self-advocacy (disclosure and conflict resolution), MSBR, community engagement, and transportation use. During the 3-month coaching phase, participants met with peer coaches to discuss progress on their goals and identify next steps. The follow-up phase involved social events for all participants. During each phase, we collected data to understand the acceptability, appropriateness, and feasibility of our multi-component self-determination program.

Participants

Participants were between 18 and 34 years old (young adults as defined by the US Census Vespa, 2017); had either graduated from high school, or equivalent, or exited from high school; had a clinical or educational diagnosis of autism; and had a verbal, standardized intelligence quotient ≥ 70 . This intelligence quotient allowed us to create groups with similar communication skills, as groups with diverse skill levels or needs can pose challenges (e.g., group cohesion) among groups (Jacobs et al., 2018). Participants were excluded if they had any untreated sleep, medical, or psychiatric condition(s), as assessed during screening. Participants with a diagnosis of autism who had not received the Autism Diagnostic Observation Schedule-2 (ADOS-2; Lord et al., 2000) and/or an IQ assessment within the past 5 years underwent an ADOS-2 and the Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler and Zhou, 2011). Table 2 displays relevant participant characteristics.

To recruit participants, we distributed flyers through electronic recruitment databases and regional providers for the autistic community around a mid-size city in the Southeast region of the United States. We also searched electronic databases from other health care and intervention studies to recruit participants interested in participating in research studies. Participants were offered up to \$150 to complete the study. Participants were placed in groups of no more than 12 participants. The ideal group size can range from three to 15 members depending on the purpose of the group and the characteristics of group members (Jacobs et al., 2018).

Recruited participants completed a demographics survey in Research Electronic Data Capture (REDCap), a secure, HIPAA-compliant web application for building and managing online surveys and databases (Harris et al., 2009). The demographics survey asked if they were employed or in a postsecondary education or training program. Participants who did not fit these criteria were categorized as not in employment, education, or training. All other participants were labeled as in employment, education, and/or training.

Screening

During the first screening visit, participants signed informed consent forms that detailed the intervention components and assessments. Then, their sleep history was documented, and they were screened for undiagnosed sleep, medical, and psychiatric disorders through a 30-min interview with a licensed medical professional. If the participant had conditions that would hinder their participation, their enrollment was postponed until their conditions were medically addressed.

During the second screening visit, participants who could not submit their recent ADOS-2 or WASI-II results underwent psychological testing. Participants also learned how to use the actigraphy watch, sleep diary, and food diary; they also learned how to use REDCap to complete surveys. Participants were asked to complete pre-intervention demographics surveys during the visit or within 1 week after their consent, and again 1 week before the intervention.

Coach Recruitment and Training

We recruited 34 university students to volunteer as coaches, most of whom coached multiple cohorts. Students were recruited via email advertising to the student body or visiting classes in the medical and social sciences. All coaches consented to background checks performed through the institution and completed online research ethics training for social and behavioral sciences with the Collaborative Institutional Training Initiative. Coaches also attended training on the intervention approaches and practices related to autism characteristics, neurodiversity, SDLMI, coaching skills, and Goal Attainment Scaling (GAS). They also learned skills in active listening and coaching using the Socratic Method. This method is a cornerstone of coaching and cognitive behavioral therapy. It uses context-dependent questions that help recipients reflect, reach conclusions, and solve problems independent of a coach or therapist (Neenan, 2009). The Socratic Method is ideally suited to help autistic adults identify and set goals, and to problem-solve obstacles that arise while attaining goals. Table 3 describes the training components in greater detail.

Psychoeducation Components of the Immersion Phase

During the first week of the intervention, participants attended five intensive psychoeducational sessions at different locations in the community. Community locations varied across cohorts due to availability, but they generally included locations such as the local zoo, art museum, theater, university, and science center. Most of the community locations provided a room/space where we could carry out instructional components of the intervention. Coaches were not required to attend these sessions; however, two to eight coaches were available at any one time during the sessions.

Each day of the program was divided into two parts. During the first half of each day, we covered the psychoeducational components. Participants worked independently and with circulating coaches as needed to create three goals and discuss their corresponding levels of attainment. During the second half of each day, participants engaged in activities that provided concrete examples of how to connect goals (e.g., employment, education, relationships, health and well-being) to community engagement. The activities also supported group interaction and bonding. A sample schedule is shown in Fig. 2.

Peer-Coaching Phase

During the coaching phase, participants began pursuing the three goals they developed during the immersion week. For the next 12 weeks, participants met weekly, one-on-one, with a coach for virtual (teleconference or phone) coaching sessions. Each week, participants met with a different coach to reduce the risk of coach dependence. Before or during each coaching session, participants shared their goal-attainment progress in a REDCap survey containing a GAS template. During the coaching session, coaches asked participants about their experiences over the past week as they pursued their goals. Coaches also provided positive reinforcement (praise and encouragement) for goal progress and helped participants problem-solve setbacks, barriers, and other challenges. Coaches also recorded the participant's progress using the GAS template. Finally, coaches and participants identified specific actions steps and assigned them to the GAS form for the upcoming week.

For goal setting, we chose three goals to avoid over-whelming participants and help ensure they could make progress if they faced barriers. We allowed overarching goals to be lofty, or potentially unattainable. However, we asked that action steps toward the overarching goals be guided by “SMART” (specific, measurable, attainable, relevant, and time-bound) principles (Bovend’Eerd et al., 2009) aimed to help participants achieve larger goals over time or adapt to challenges they experience while attaining their goals. We then combined SMART goals with a modified GAS procedure in which participants rated their progress toward their goals as (0) no progress/change; (1) some progress/change, but not enough to consider the SMART goal as *attained*; (2) sufficient progress/change for attainment; (3) greater than expected attainment; or (4) much greater than expected attainment. SMART goals align with a wide number of goal-setting theories, including GAS and the SDLMI (Swann et al., 2020). Although SMART goals are effective for motivating people to attain goals, they can create greater pressure and lower perception of goal attainment progress than open goals (Swann et al., 2020). We addressed this issue by combining SMART goals with GAS (to allow for flexible levels of attainment) and SDLMI (to allow for lofty or vague overarching goals). If participants finished a goal during any week of the coaching phase, they were encouraged to add a new goal so that they were always working toward three goals. Participants could also choose to change or abandon an overarching goal or action step and replace it based on their experiences and preferences.

Post-Program Social Gatherings

After each cohort completed the program, participants attended an optional social gathering (e.g., dinners, recreation center, theatre) to discuss their experiences and progress in the program, create a sense of closure, and develop ongoing connections. Participants who previously completed the program were also invited to attend each gathering.

Study Measures

For a successful self-determination program focused on the neurodiversity paradigm, autistic adults must feel a strong social validity about the program. Social validity refers to the social importance, appropriateness, and acceptability that a participant believes about the goals and procedures of a program, intervention, or treatment (Carter & Wheeler, 2019). To assess the social validity of our pilot program, we measured the appropriateness, acceptability, and feasibility of our multi-component self-determination program during the immersion and coaching phases, at the end of the intervention, and at follow-up. The sections below describe the specific measurements and data analysis (descriptive statistics) for each of these aspects.

Appropriateness

For this study, we defined appropriateness as the “perceived fit of the innovation to address a particular issue or problem” (Proctor et al., 2011, p. 70). We assessed whether participants set and attained goals. We also tracked the topics of participant goals to determine whether they were heterogeneous and whether the program was flexible enough to support a wide range of goals. During the exit interview, we measured appropriateness of program duration by asking participants specific questions about the length of the program. Five months

after they completed the program, we asked participants questions about how the program affected their lives. See Table 4 for questions used to assess appropriateness.

To track goals, participants completed GAS forms related to their weekly progress in goal attainment. They also completed forms outlining the following week's goal-attainment plan. Participants uploaded these forms to REDCap before their next coaching session. Coaches completed an identical form during the coaching sessions. The total number of goals recorded as completed was tallied for each participant and averaged across coaching sessions. We determined the percent agreement between the participants and coaches record of goal attainment.

To examine the heterogeneity of participant goals, we organized a sample of the participants goals into categories based on major life domains. Goals were categorized as “heterogeneous” if they centered on topics beyond employment, independent living, and financial outcomes (common outcomes of self-determination studies and interventions; Cheak-Zamora et al., 2020) to include health, well-being, leisure, hobbies, and other goal pursuits set by the participants.

For the data analysis, percentages were calculated for the dichotomous and categorical questions. The Likert scale questions were quantitatively analyzed [mean (M) and standard deviation (SD)]. The comments from the 5-month follow-up were initially coded (“not improved/neutral” and “improved”) by two program-naïve, independent raters to ensure that interpretations of perceived improvements were robust, objective, and consistent (O'Connor & Joffe, 2020). Krippendorff's alpha was used to estimate the reliability between the two raters. Krippendorff's alpha is an inferential point estimate and confidence interval that is considered superior to calculating the non-inferential basic percentage agreement (O'Connor & Joffe, 2020). Krippendorff's alpha was analyzed using the `kripp.alpha` function of the `irr` package (version 0.84.1; Gamer & Lemon, 2012) within the statistical software program R (version 3.6.2). Then, the first, second, and fourth authors collaboratively interpreted and summarized the content of the analyzed comments. This collaborative analysis allows diverse perspectives to inform interpretation and is appropriate when data are transparent (Cornish et al., 2014).

Acceptability

We defined acceptability as the satisfaction and “palatability” of the program as perceived by the participants (Proctor et al., 2011, p 67). To assess whether participants were satisfied with working in the program, we collected their feedback at several phases of the program. During each day of the immersion week, we asked participants to complete anonymous surveys. Participants could choose if they wanted to complete the surveys and if they wanted to return their surveys to program staff. Returned surveys were analyzed by averaging the ratings, assessing which activities were liked, and categorizing the comments into specific groups. During the follow-up phase (5 months after the intervention), we collected feedback on the acceptability of the coaching phase by asking participants about their level of satisfaction with the coaching sessions. Our measures of acceptability are shown on Table 4. For the data analysis, Likert scale questions were quantitatively analyzed (M and SD). We

examined the circled items on the anonymous survey to determine if any item was circled by none or, conversely, all of the participants.

We combined the comments on the anonymous survey because separating them did not provide meaningful results (e.g., program compliments in the suggestions section). We analyzed the combined comments using directed content analysis. Such analysis describes phenomena (Elo & Kyngäs, 2008) using predetermined codes and allows additional codes to be generated during the coding process (Hsieh & Shannon, 2005). We used the program components (e.g., goal planning, mindfulness, activities) to guide our analysis of the anonymous survey. We calculated the percentage of provided comments for the “liked” and “disliked” aspects of the coaching sessions. The first, second, and fourth authors collaboratively interpreted (until consensus was attained) and summarized the content of the comments on the anonymous survey and the open-ended questions from the exit interview.

Feasibility

We defined feasibility as whether the program, and its combined components, can be implemented with these populations (autistic adults and volunteer peer coaches) (Proctor et al., 2011). We evaluated feasibility to capitalize on lessons learned while refining the program. For each cohort, we recorded any factors that hindered the feasibility (e.g., parent over-involvement, communication challenges, obstacles with goal setting and attainment) of our study, and we adapted our protocols for subsequent cohorts. We also recorded rates and reasons for attrition. Our assessment centered on the following questions: (1) is this type of program possible? (2) what are some challenges that threaten the feasibility of this program? and (3) what aspects are critical to ensure feasibility?

After each coaching session, coaches could complete an optional form to share their concerns about interacting with the participants, what went well or poorly during the session, and what advice they had for future coaches. Coaches could also alert program staff about any concerns they had about the coaching session. We coded, organized, and summarized these comments with content analysis.

Results

We enrolled 46 autistic adults. Of these, three did not meet screening criteria, and five experienced conflicts with their work or school schedules and did not attend/complete the immersion week or coaching sessions. Two participants withdrew, one due to family illness and one due to social anxiety. Five participants were withdrawn, one when a parent persisted in setting the participant’s goals and four for not completing any study procedures. The remaining 31 participants were divided into four cohorts of approximately eight participants each.

Appropriateness

Most participants (81%) indicated that 3 months of coaching was the right amount of time, and the remaining (19%) wanted more time. None of the participants wanted less time. These results suggest that most participants believed they made self-satisfactory progress without developing program dependence.

Participants accomplished an average of one goal per week ($M = 0.96$, $SD = 0.77$, Range = 0–31). The average weekly goal attainment varied between cohorts: 0.4 (cohort 1), 0.89 (cohort 2), 1.27 (cohort 3), and 0.78 (cohort 4).

The number of coaching sessions attended explained 36% of the variation in the reported goals attained [$R^2 = .36$, $F(1, 36) = 20.17$; $p < .01$]. Participants set goals across a variety of domains, such as recreation/leisure, employment/vocation, social skills/emotion regulation, relationships, health and well-being, daily skills/self-care, finances, and transportation. See Table 5 for examples of goals set in these domains during the intervention.

Thirteen participants provided comments regarding their perceived improvement across the five domains. Table 6 shows the observed agreement as well as Krippendorff's point estimate and confidence interval for each of the domains. Most participants (85%) perceived improved social factors, such as increased confidence and self-advocacy, as well as trying new things. More than half of participants described improvements in managing stress (62%) and conflicts (54%), and most (80%) described improvements related to goals. Participants often described specific improvements in their ability to set goals and goals steps (e.g., "the...program has taught me to set goals and determine what steps I need to take in order to achieve those goals"). One person shared that the program increased their ability to acknowledge accomplishing smaller steps toward a larger goal: "... [the program] does help provide a different perspective when it comes to how the goal is accomplished and how much of it is accomplished. It allows a person to feel successful regardless of the degree of accomplishment". Some participants (23%) mentioned how coaching improved their goal attainment, (e.g., "the coaching sessions helped in setting and reaching goals for myself"). A little more than half of participants (54%) indicated improvements in other aspects of their lives, such as disclosing details, enhancing relationships, feeling less alone, and gaining employment.

Acceptability

Participants rated the immersion week as highly acceptable ($M = 4.58$, $SD = 0.63$). Participants preferred a variety of components, and every component was preferred by at least one participant. As shown in Table 7, participants enjoyed specific locations and activities, including the zoo, health center, theater, art museums, and science centers. For example, one person stated that "[e]xploring the zoo is always fun. The tour and encounters made me want to volunteer to form close relationships with the animals and people." Participants also often appreciated psychoeducation topics focused on mindfulness, conflict resolution, disclosure, self-advocacy, and self-determination. For example, one participant stated, "I learned a lot and applied some of the information I learned about automatic thoughts, goal planning and disclosure. Really looked forward to those." Another participant stated, "[t]he resolving personal conflicts presentation gave me new insights into myself."

Among 31 participants, 26 completed post-intervention surveys on acceptability of the coaching sessions. Most participants (65%) were very satisfied with the coaching sessions ($M = 4.42$, $SD = 0.99$), and only 4% were dissatisfied. More than 80% of participants would recommend the program, and 19% might recommend the program. No participants stated that they would not recommend the program. Reasons for recommending the program

included the program's impact on goal setting and problem-solving, appropriateness for the autistic community or identity, improvements in life outlook, and an opportunity to engage in social activities with others. Only one participant shared a negative comment about the program, stating that the program was time-consuming. This participant also indicated that they would not have participated in the program if they understood the study procedures. Most participants stated that they would like (46%) or might like (50%) to receive this type of coaching in the future. Only one participant (4%) stated they would not like to receive this type of coaching in the future.

Supplementary Table 1 shows participant comments about favored and disfavored aspects of the coaching sessions. Approximately 80% of participants liked the coaching sessions. Their reasons for liking the coaching sessions included having a weekly social opportunity to talk to someone about their goals, receiving encouragement and empathetic interactions, being held accountable, receiving support for problem-solving, and having an opportunity for personal growth. For example, one participant described the coaching sessions as “[h]olding me accountable regarding the accomplishment of my goals. I also liked the coaches themselves.” Another stated that the “[m]ajority of my coaches didn't ‘stick to a script’ or ‘go through the motions.’ Most seemed to have a genuine interest in my passions and goals.” Approximately 27% of participants shared what they would have preferred about the coaching sessions, including wanting a consistent coach, more specific advice, and more flexibility in scheduling coaching sessions. For example, one participant didn't like “having a different coach each time because I then had to start over with explaining my goals to each person. Also, I would've preferred just one coach so that I could inform them of my progress every so often.” Others expressed disliking when coaching sessions were canceled or missed. Finally, one participant indicated mixed feelings of effort and benefit: “the weekly calls were rather annoying, but it was all worth it.”

Feasibility

Overall, the immersion program and coaching sessions were both feasible and useful. However, the feasibility of supporting self-determination was impacted by parent involvement, communication challenges, and obstacles with goal setting and attainment. Some parents insisted on being involved with goal setting and telecoaching. Some coaches shared concerns with staff about whether communicating with parents during telecoaching sessions was appropriate, particularly when parents controlled the goal domains, topics, and actions for attainment. One coach reported that parents who interjected and answered questions for the participant was “potentially blocking rather than facilitating self-determination.” As expected, coaches experienced challenges with participant communication styles and goal-setting/attainment skills. These coaches gave feedback to other coaches that highlighted the participant-specific challenges, echoed the training advice, or provided helpful suggestions for addressing challenges. These communication hand-offs supported continuity tailored to the needs of each participant. Supplementary Table 2 highlights some challenges of the coaching sessions and the coaches suggestions to address those challenges.

Other Lessons Learned

Recruiting participants took about 6 months for each cohort. Although we recruited by posting flyers in the community and via referrals from other research teams and listservs, we struggled to reach communities of autistic adults. Our method to recruit student coaches improved across the cohorts. Initially, we posted flyers on bulletin boards within relevant university academic departments (e.g., psychology; medicine, health, and society). Later, we visited classrooms and advertised through listservs for university departments and student organizations/clubs.

Participant group size and cohesion were important. During the immersion week, the ideal group size was five to 12 participants. When fewer than five participants were in a group, participants received too much attention, creating social discomfort. As the number of participants increased, the group became less manageable. Creating groups of individuals with similar communication skills was also important for group cohesion. Groups with similar communication skills seemed to decrease stigma and optimize environments for practice during dyad activities.

Participants desired free time for in-group social interactions and for working together in practice groups. However, some participants wanted to skip the social activity, or they seemed to need more time to warm up to social interactions. These individuals often preferred interacting with study staff or coaches over other participants.

We found that having student coaches available during the immersion week was valuable. These coaches could move around the room to assist participants one-on-one or facilitate paired activities, and they could help instructors model specific psychoeducational skills. During the coaching phase, coaches were essential for recording participant goals, as many participants did not reliably complete GAS forms either before or during the sessions.

Discussion

This pilot study sought to address the high heterogeneity of strengths, needs, skillsets, and life-course circumstances of autistic adults through a domain-general, multicomponent self-determination program. This study combined several evidence-based interventions (e.g., SDLMI, GAS, MBSR, peer-coaching) with additional components (e.g., strategies for disclosure, self-advocacy training, conflict management) to help autistic adults set and attain self-determined goals. Overall, we found that our program was appropriate, acceptable, and feasible.

Appropriateness

Our program focused on helping autistic adults set and attain goals. On average, participants accomplished nearly one goal per week. However, goal attainment varied across participants. For example, some participants attained at least 30 goals across the coaching phase, whereas one participant made some progress, but never indicated making enough progress to meet the description of “attained a goal.” This participant completed the program in the first cohort, when coaches may have been less skilled with helping participants identify attainable steps and/or progress. Indeed, the average goal attainment for cohort 1 was 0.4

goals per week, whereas the average goal attainment for cohorts 2 through 4 ranged between 0.8 and 1.3 per week. For cohorts 2 through 4, we placed greater emphasis on identifying steps that were more attainable for the lowest attainment level of the GAS.

When participants achieved concrete action on self-determined goals, they felt empowered and motivated. Such empowerment is tightly coupled with the ability to make and pursue self-determined, self-regulated goals (Wehmeyer, 2004). As expected, we found that goal attainment correlated with the number of coaching sessions attended, suggesting that coaching sessions may have increased participant accountability and motivation. Interestingly, some participants occasionally uploaded a new GAS even when they did not attend a coaching session. These participants may have used the uploading process as a form of accountability.

Based on life course theory and the neurodiversity paradigm, we hypothesized that participants would prioritize a wide range of goals and have variable preferences and skills. Given the postsecondary challenges that autistic adults experience in employment, education, and relationships (Roux et al., 2015), we expected that many participants would identify goals in these domains. Although many of our participants set goals in these three domains, they also set goals in other domains, such as health and well-being, daily skills/self-care, finances, recreation, and transportation. This variety of goals suggests that self-determination programs need to address goals beyond employment and education, and give more attention to other important aspects of a self-determined life, such as leisure-related goals (Angell et al., 2019), that support well-being and overall quality of life. Future work may examine the relationship between all these domains and other factors in this population.

Some participants were interested in habits to improve health, productivity, or daily living. Such habits can help them make good choices for a wide range of life domains (Gardner et al., 2020). For example, poor personal hygiene is a risk factor for preventable health conditions and social rejection (Ramos-Morcillo et al., 2019). By developing healthy habits for personal hygiene, autists may increase confidence and acceptability in social contexts, such as making friends or finding roommates. Some participants also identified goals related to leisure, social interactions, or meaningfulness. Leisure activities can restore mental, emotional, and physical health; and they can help people prevent, cope, and transcend negative life events (Caldwell, 2005; Mannell, 2007). Similarly, a person feeling that they have a meaningful life can lead to better outcomes in physical and mental health (Steptoe & Fancourt, 2019). Also, goals in these domains are intrinsically motivating and can help participants practice self-determination skills that can be applied to other types of goals. They can also give participants a sense of accomplishment or belonging and help build relationships. All these factors can improve well-being.

Acceptability

Self-determination relies on intrinsic motivation (Ryan & Deci, 2020), which is fueled by acceptability. For a self-determination program to be successful, participants must believe that the program is an acceptable fit for their goals. With this belief, participants are more likely to have favorable adherence and clinical/program outcomes, as well as a lower attrition rate (Sekhon et al., 2017). Yet, many interventions for autistic adults do not measure

acceptability (McDonald & Machalicek, 2013). One group measured acceptability with benchmarks of 60% completion of study procedures for their self-determination program. Unfortunately, their program did not meet these benchmarks (Smith et al., 2019).

We measured acceptability through ratings and qualitative comments about program components, such as the locations, events, psychoeducation, and coaching sessions. Because autistic adults have highly heterogeneous characteristics, skills, and circumstances (Hull, 2014), we expected that participants would have different preferences across program components. Although participants valued different components, they believed all intervention components were highly acceptable. Most participants enjoyed the coaching sessions, and up-to-half were interested in future sessions. These participants may perceive value in having coaching support for future self-determination needs. Participants who did not want this type of coaching in the future may have thought the program addressed their needs (through the acquisition of knowledge and practice) and that they would not require additional coaching in the future. Many participants also enjoyed the social events with other autistic adults. Overall, most participants would recommend the program to others.

One participant indicated that they would not have started the study if they had fully understood the study procedures in advance. Based on multiple sources of data from this participant (e.g., GAS forms, survey responses), this participant seemed to believe that they already had much of the knowledge and skills that the program offered. This belief may be due to their personal drive to acquire this information on their own before enrolling in the program. Their personal drive also fueled their main goal of applying and attending graduate school in a psychology/counseling field. The participant, however, remained in the program and stated that the program was informative for their future career goals. The participant's advanced skills and knowledge were also noted by program staff.

Autistic adults deal with many demands of adulthood, such as employment and education (Hull, 2014). Thus, self-determination programs need to consider the time that autistic adults will need to commit to the program. Only one participant indicated that the program was too time-consuming, echoing concerns from people who did not enroll due to schedule conflicts or other time constraints. Most participants lost to attrition had conflicts with work or school schedules, and some did not complete study requirements, such as attending the immersion week or coaching sessions. Such participants may benefit from a scaled down version of the program, such as weekend workshops. In future work, researchers might examine motivational or logistical issues that can affect acceptability or the ability to participate.

Most autistic people (at least 95%) have one or more co-occurring physical or mental health conditions (Levy et al., 2010; Soke et al., 2018). These co-occurring conditions may limit their ability to participate in self-determination programs. For example, in our program, one participant could not participate because of their social anxiety. Thus, some participants may need additional support or therapy to address co-occurring conditions, such as anxiety or depression, before they are ready for a self-determination program.

Although parents often have their adult children's best interests at heart, one threat to program acceptability is parental involvement. In previous studies, autistic adults believed

that parent involvement was unacceptable and undermined their motivation and ability to practice self-determination (T. J. Smith et al., 2019). Also, Parents who are overinvolved with their adult children with developmental disabilities have strained relationships with their children such as making decisions for their children based on the parents personal needs, being demanding and rarely satisfied, and distrusting providers (van Ingen et al., 2008). As a result, we followed an approach similar to Fullerton and Coyne (1999) by deliberately excluding parents from our program. However, some parents joined the telecoaching sessions, where they would answer for participants or even set goals for them. Consequently, coaches repeatedly redirected questions back to participants. And when coaches asked participants how they felt about their parents' thoughts, participants would sometimes give agreeable answers, such as "Yeah, I think that's fine." This type of parent intrusion caused one participant to withdraw from the study. Thus, a successful self-determination program will need to manage parental involvement.

To mitigate some of the challenges with parent over-involvement, we developed a self-determination toolkit for parents and caretakers to guide them on how to support their young adults. This toolkit is freely available to the public (McDonald et al., 2020). Similar programs could consider adding a parent component and/or providing parents with a self-determination toolkit to teach them the importance of self-determination and ways to encourage and support its development.

Feasibility

Our self-determination program was feasible for participants and coaches. To support the feasibility of our program, we enlisted university students to volunteer as peer coaches. This approach minimized costs and maximized flexibility in scheduling telecoaching without barriers associated with in-person sessions, such as transportation or work/life demands. Both participants and coaches valued this flexibility. Only a few participants described scheduling issues with coaches, and many coaches volunteered for multiple semesters. We also involved coaches in program development by establishing internal processes to support communication between coaches and staff. We also garnered advice and feedback from coaches to help each other and improve the program.

Limitations

Our pilot program has several factors that limit its generalizability. First, as shown in Table 2, our cohort comprised predominately male, White, non-Hispanic autists. Future research should examine the acceptability of the program by other populations. Although our population was predominantly male, we had a greater proportion of females than the 4:1 or 3:1 male:female ratio often found in prevalence studies (Loomes et al., 2017). Because women are underrepresented in autism studies, their greater representation in our cohort is also a strength of our study (Lai et al., 2015). As is common in some pilot studies, our study did not include a control group (Leon et al., 2011), so we cannot decipher whether goal attainment was due to the program. In future programs, researchers should randomize participants to a program or standard treatment group before assessing outcomes. Also, small sample sizes in pilot studies are often determined by the pragmatics of recruitment (Leon et al., 2011). In our program, participants may have had more self-determination

and motivation than autistic adults who chose not to participate. Further, we do not know whether participants applied the psychoeducation and skills practiced during immersion week to advance their goal attainment. Finally, we modified our pilot program over four cohorts/iterations. Based on lessons learned across iterations, future programs could establish a final protocol for conducting the program.

Conclusions

In this study, we introduce a multi-component self-determination program based on life course theory and the neurodiversity paradigm. We designed this self-determination program to flexibly address the high heterogeneity among autistic adults without a co-occurring intellectual disability. By participating in this program, autistic adults learned skills on goal setting and attainment, emotion regulation and stress management, self-advocacy and disclosure, and conflict resolution. Our program was appropriate because participants successfully attained their goals and attributed their improvements in other life domains to the skills and experiences they gained in the program. Also, our program was acceptable based on participants' approval of the program and willingness to recommend the program to others. Finally, our program was feasible because we enlisted volunteer students to serve as peer coaches, creating a cost-effective and flexible method to support the self-determination needs of autistic adults. The success of our self-determination program supports that programs and services based on the neurodiversity paradigm may empower autistic and other neurodivergent populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

We thank Andrea Arguello, Megan Harden, and Megan Alder for their contributions to the operational success of the pilot program during immersion week and management of the coaching sessions. We also thank Julie Lounds Taylor, Erik Carter, Blythe Corbett, Katherine Gotham, Vanessa Beasley, David Griffin, and Zachary J. Williams for their advisory roles. We thank our community sites for the immersion week, including the Nashville Zoo, Adventure Science Center, Frist Art Museum, Vanderbilt Recreation and Wellness Center, Nashville Children's Theatre, Cheekwood Estate and Gardens, and Tennessee Performing Arts Center. We also thank Crystal R. Herron for editorial support.

Funding

This work was supported by a Vanderbilt University Trans-Institutional Program Grant, and National Heart, Lung, and Blood Institute of the National Institutes of Health under Award Number K12HL137943, USA.

References

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders. American Psychiatric Association. 10.1176/appi.books.9780890425596
- Anctil TM, Ishikawa ME, & Tao Scott A (2008). Academic identity development through self-determination: Successful college students with learning disabilities. *Career Development for Exceptional Individuals*, 31(3), 164–174. 10.1177/0885728808315331
- Anderson KA, McDonald TA, Edsall D, Smith LE, & Taylor JL (2016). Postsecondary expectations of high-school students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 31(1), 16–26. 10.1177/1088357615610107 [PubMed: 29151780]

- Angell AM, Carroll TC, Bagatell N, Chen C, Kramer JM, Schwartz A, Tallon MB, & Hammel J (2019). Understanding self-determination as a crucial component in promoting the distinct value of occupational therapy in post-secondary transition planning. *Journal of Occupational Therapy, Schools, & Early Intervention*, 12(1), 129–143. 10.1080/19411243.2018.1496870
- Bear GG, Slaughter JC, Mantz LS, & Farley-Ripple E (2017). Rewards, praise, and punitive consequences: Relations with intrinsic and extrinsic motivation. *Teaching and Teacher Education*, 65, 10–20. 10.1016/j.tate.2017.03.001
- Bene K, Banda DR, & Brown D (2014). A meta-analysis of peer-mediated instructional arrangements and autism. *Review Journal of Autism and Developmental Disorders*, 1(2), 135–142. 10.1007/s40489-014-0014-9
- Botha M (2021). Academic, activist, or advocate? Angry, entangled, and emerging: A critical reflection on autism knowledge production. *Frontiers in Psychology*. 10.3389/fpsyg.2021.727542
- Bovend'Eerdt TJ, Botell RE, & Wade DT (2009). Writing SMART rehabilitation goals and achieving goal attainment scaling: A practical guide. *Clinical Rehabilitation*, 23(4), 352–361. 10.1177/0269215508101741 [PubMed: 19237435]
- Caldwell LL (2005). Leisure and health: Why is leisure therapeutic? *British Journal of Guidance & Counselling*, 33(1), 7–26. 10.1080/03069880412331335939
- Carter EW, Gustafson JR, Sreckovic MA, Dykstra Steinbrenner JR, Pierce NP, Bord A, Stabel A, Rogers S, Czerw A, & Mullins T (2017). Efficacy of peer support interventions in general education classrooms for high school students with autism spectrum disorder. *Remedial and Special Education*, 38(4), 207–221. 10.1177/0741932516672067
- Carter SL, & Wheeler JJ (2019). *The social validity manual: Subjective evaluation of interventions*. Academic Press.
- Chan JM, Lang R, Rispoli M, O'Reilly M, Sigafoos J, & Cole H (2009). Use of peer-mediated interventions in the treatment of autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 3(4), 876–889. 10.1016/j.rasd.2009.04.003
- Cheak-Zamora NC, Maurer-Batjer A, Malow BA, & Coleman A (2020). Self-determination in young adults with autism spectrum disorder. *Autism: the International Journal of Research and Practice*, 24(3), 605–616. 10.1177/1362361319877329 [PubMed: 31561711]
- Cornett J, & Knight J (2009). Research on coaching. *Coaching: Approaches & perspectives* (pp. 192–216). Corwin Press.
- Cornish F, Gillespie A, & Zittoun T (2014). Collaborative analysis of qualitative data. In Flick U (Ed.), *The SAGE handbook of qualitative data analysis* (pp. 9–93). SAGE Publications Ltd. 10.4135/9781446282243.n6
- Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, & Kripke C (2015). The health status of adults on the autism spectrum. *Autism: the International Journal of Research and Practice*, 19(7), 814–823. 10.1177/1362361315577517 [PubMed: 25911091]
- Davis LJ (Ed.). (2016). *The disability studies reader* (5th ed.). Routledge. 10.4324/9781315680668
- Deci EL, & Ryan RM (2000). The “what” and “why” of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry*, 11(4), 227–268. 10.1207/S15327965PLI1104_01
- Elder GH, Johnson MK, & Crosnoe R (2003). The emergence and development of life course theory. In Mortimer JT & Shanahan MJ (Eds.), *Handbook of the life course* (pp. 3–19). Springer. 10.1007/978-0-306-48247-2_1
- Elo S, & Kyngäs H (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115. 10.1111/j.1365-2648.2007.04569.x [PubMed: 18352969]
- Foden T, & Anderson C (2011). Adults with ASD: deciding when to disclose | Interactive Autism Network [Organization]. Interactive Autism Network: Linking the Autism Community and Researchers. Retrieved March 6, 2022, from https://iancommunity.org/cs/adults/deciding_when_to_disclose
- Fullerton A, & Coyne P (1999). Developing skills and concepts for self-determination in young adults with autism. *Focus on Autism and Other Developmental Disabilities*. 14(1), 42–52. 10.1177/108835769901400106

- Gamer M, & Lemon J (2012). Various coefficients of interrater reliability and agreement. R package version 0.84.1
- Gardner B, Lally P, & Rebar AL (2020). Does habit weaken the relationship between intention and behaviour? Revisiting the habit-intention interaction hypothesis. *Social and Personality Psychology Compass*. 10.1111/spc3.12553
- Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, & Schwartzman B (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*. 10.3389/fpsyg.2017.00438
- Hallgren KA (2012). Computing inter-rater reliability for observational data: An overview and tutorial. *Tutorials in Quantitative Methods for Psychology*, 8(1), 23–34. 10.20982/tqmp.08.1.p023 [PubMed: 22833776]
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, & Conde JG (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Bio-medical Informatics*, 42(2), 377–381. 10.1016/j.jbi.2008.08.010
- Hayward MD, & Sheehan CM (2016). Does the body forget? Adult health, life course dynamics, and social change. *Handbook of the life course* (Vol. II, pp. 355–368). Springer International Publishing.
- Hsieh H-F, & Shannon SE (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. 10.1177/1049732305276687 [PubMed: 16204405]
- Hull KB (2014). Group therapy techniques with children, adolescents, and adults on the autism spectrum: Growth and connection for all ages. In *Group therapy techniques with children, adolescents, and adults on the autism spectrum: Growth and connection for all ages* (p. Chapter ix, 153 Pages). Jason Aronson (Lanham, MD, US). Retrieved March 2, 2022, from <https://www.proquest.com/psycinfo/docview/1518034646/18B6746817384D41PQ/23>
- Jacobs EE, Schimmel CJ, Masson RL, & Harvill RL (2018). *Group counseling: Strategies and skills* (Eighth). Cengage Learning.
- Katz V, & Moose CA (1999). Safety zone cops talk. Portland Police Bureau.
- Kenny L, Hattersley C, Molins B, Buckley C, Povey C, & Pellicano E (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. 10.1177/1362361315588200 [PubMed: 26134030]
- Kim SY (2019). The experiences of adults with autism spectrum disorder: Self-determination and quality of life. *Research in autism spectrum disorders* (Vol. 60, pp. 1–15). Elsevier Ltd.
- Lai M-C, Baron-Cohen S, & Buxbaum JD (2015). Understanding autism in the light of sex/gender. *Molecular Autism*, 6(1), 24. 10.1186/s13229-015-0021-4 [PubMed: 25973161]
- Lang R, Koegel LK, Ashbaugh K, Regester A, Ence W, & Smith W (2010). Physical exercise and individuals with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, 4(4), 565–576. 10.1016/j.rasd.2010.01.006
- Lee S-H, Wehmeyer ML, & Shogren KA (2015). Effect of instruction with the self-determined learning model of instruction on students with disabilities: A meta-analysis. *Education and Training in Autism and Developmental Disabilities*, 50(2), 237–247.
- Leon AC, Davis LL, & Kraemer HC (2011). The role and interpretation of pilot studies in clinical research. *Journal of Psychiatric Research*, 45(5), 626–629. 10.1016/j.jpsychires.2010.10.008 [PubMed: 21035130]
- Levy SE, Giarelli E, Lee L-C, Schieve LA, Kirby RS, Cunniff C, Nicholas J, Reaven J, & Rice CE (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 31(4), 267–275. 10.1097/DBP.0b013e3181d5d03b [PubMed: 20431403]
- Loomes R, Hull L, & Mandy WPL (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry*, 56(6), 466–474. 10.1016/j.jaac.2017.03.013 [PubMed: 28545751]
- Lord C, Risi S, Lambrecht L, Cook EH Jr., Leventhal BL, DiLavore PC, Pickles A, & Rutter M (2000). The autism diagnostic observation schedule—generic: A standard measure of social

- and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30(3), 205–223. 10.1023/A:1005592401947 [PubMed: 11055457]
- Maenner MJ (2021). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2018. *MMWR Surveillance Summaries*. 10.15585/mmwr.ss7011a1
- Mannell RC (2007). Leisure, health and well-being. *World Leisure Journal*, 49(3), 114–128. 10.1080/04419057.2007.9674499
- Mayer BS (2012). *The dynamics of conflict: A guide to engagement and intervention*. Jossey-Bass. <http://www.books24x7.com/marc.asp?bookid=46251>
- McDonald TAM (2017). Discriminative and criterion validity of the autism spectrum identity scale (ASIS). *Journal of Autism and Developmental Disorders*, 47(10), 3018–3028. 10.1007/s10803-017-3221-2 [PubMed: 28685412]
- McDonald TAM (2020). Autism identity and the “Lost Generation”: Structural validation of the autism spectrum identity scale and comparison of diagnosed and self-diagnosed adults on the autism spectrum. *Autism in Adulthood*, 2(1), 13–23. 10.1089/aut.2019.0069 [PubMed: 34485832]
- McDonald TAM (2021). The broader autism phenotype constellations–disability matrix paradigm: Theoretical model for autism and the broader autism phenotype. *Medical Hypotheses*, 146, 110456. 10.1016/j.mehy.2020.110456 [PubMed: 33412500]
- McDonald TAM, & Machalicek W (2013). Systematic review of intervention research with adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 7(11), 1439–1460. 10.1016/j.rasd.2013.07.015
- McDonald TM, Taylor JL, Loring WA, Chen I, & Malow BA (2020). Setting and pursuing self-determined Goals [Toolkit]. Vanderbilt Kennedy Center. 1–24. <https://vkc.vumc.org/assets/files/resources/selfdetermination-toolkit.pdf>
- McGuire J, & McDonnell J (2008). Relationships between recreation and levels of self-determination for adolescents and young adults with disabilities. *Career Development for Exceptional Individuals*, 31(3), 154–163. 10.1177/0885728808315333
- Müller E, Schuler A, & Yates GB (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism: the International Journal of Research and Practice*, 12(2), 173–190. [PubMed: 18308766]
- Nadig A, Flanagan T, White K, & Bhatnagar S (2018). Results of a RCT on a transition support program for adults with ASD: Effects on self-determination and quality of life. *Autism Research*, 11(12), 1712–1728. 10.1002/aur.2027 [PubMed: 30451392]
- Neenan M (2009). Using socratic questioning in coaching. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*, 27(4), 249–264. 10.1007/s10942-007-0076-z
- Nicolaidis C, Raymaker D, McDonald K, Kapp S, Weiner M, Ashkenazy E, Gerrity M, Kripke C, Platt L, & Baggs A (2016). The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. *Journal of General Internal Medicine*, 31(10), 1180–1189. 10.1007/s11606-016-3763-6 [PubMed: 27271730]
- Nonnemacher SL, & Bambara LM (2011). “I’m supposed to be in charge”: Self-advocates’ perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49(5), 327–340. 10.1352/1934-9556-49.5.327 [PubMed: 21905826]
- O’Connor C, & Joffe H (2020). Intercoder reliability in qualitative research: Debates and practical guidelines. *International Journal of Qualitative Methods*, 19, 1609406919899220. 10.1177/1609406919899220
- Oswald TM, Winder-Patel B, Ruder S, Xing G, Stahmer A, & Solomon M (2018). A pilot randomized controlled trial of the ACCESS program: A group intervention to improve social, adaptive functioning, stress coping, and self-determination outcomes in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(5), 1742–1760. 10.1007/s10803-017-3421-9 [PubMed: 29234931]
- Price R, Marsh AJ, & Fisher MH (2018). Teaching young adults with intellectual and developmental disabilities community-based navigation skills to take public transportation. *Behavior Analysis in Practice*, 11(1), 46–50. 10.1007/s40617-017-0202-z [PubMed: 29556448]

- Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, & Hensley M (2011). Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(2), 65–76. 10.1007/s10488-010-0319-7 [PubMed: 20957426]
- Puleo CM, & Kendall PC (2011). Anxiety disorders in typically developing youth: Autism spectrum symptoms as a predictor of cognitive-behavioral treatment. *Journal of Autism and Developmental Disorders*, 41(3), 275–286. 10.1007/s10803-010-1047-2 [PubMed: 20694508]
- Ramos-Morcillo AJ, Moreno-Martínez FJ, Hernández Susarte AM, Hueso-Montoro C, & Ruzafa-Martínez M (2019). Social determinants of health, the family, and children's personal hygiene: A comparative study. *International Journal of Environmental Research and Public Health*, 16(23), 4713. 10.3390/ijerph16234713 [PubMed: 31779283]
- Rando H, Huber M, & Oswald G (2016). An academic coaching model intervention for college students on the autism spectrum. *Journal of Postsecondary Education & Disability*, 29(3), 257–262.
- Rodgers JD, Lodi-Smith J, Hill PL, Spain SM, Lopata C, & Thomeer ML (2018). Brief report: Personality mediates the relationship between autism quotient and well-being: A conceptual replication using self-report. *Journal of Autism and Developmental Disorders*, 48(1), 307–315. 10.1007/s10803-017-3290-2 [PubMed: 28918443]
- Roth G, Vansteenkiste M, & Ryan RM (2019). Integrative emotion regulation: Process and development from a self-determination theory perspective. *Development and Psychopathology*, 31(3), 945–956. 10.1017/S0954579419000403 [PubMed: 31113502]
- Roux AM, Shattuck PT, Rast JE, Rava JA, & Anderson KA (2015a). National Autism Indicators report: Transition into young adulthood (National Autism Indicators Report, p. 68). Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University. Retrieved May 11, 2018, from <http://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Transition-to-Adulthood/>
- Roux AM, Shattuck PT, Rava JE, Julianna A, & Kristy A (2015b). PA: Life course outcomes research program. In National Autism Indicators Report: Transition into Young Adulthood. Philadelphia
- Ryan RM, & Deci EL (2020). Intrinsic and extrinsic motivation from a self-determination theory perspective: Definitions, theory, practices, and future directions. *Contemporary Educational Psychology*, 61, 101860. 10.1016/j.cedpsych.2020.101860
- Schiffirin HH, Erchull MJ, Sendrick E, Yost JC, Power V, & Saldanha ER (2019). The effects of maternal and paternal helicopter parenting on the self-determination and well-being of emerging adults. *Journal of Child and Family Studies*, 28(12), 3346–3359. 10.1007/s10826-019-01513-6
- Scorgie K, & Scorgie S (2017). The disclosure dilemma: Disability, identity and self-determination. *Counseling and coaching in times of crisis and transition*. Routledge.
- Sekhon M, Cartwright M, & Francis JJ (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC Health Services Research*, 17(1), 88. 10.1186/s12913-017-2031-8 [PubMed: 28126032]
- Settersten RA (2003). Age structuring and the rhythm of the life course. In Mortimer JT & Shanahan MJ (Eds.), *Handbook of the life course* (pp. 81–98). Springer US. 10.1007/978-0-306-48247-2_4
- Shogren KA, Raley SK, Burke KM, & Wehmeyer ML (2019). The Self-Determined Learning Model of Instruction (SDLMI) Teacher's Guide. Kansas University Center on Developmental Disabilities.
- Sizoo BB, & Kuiper E (2017). Cognitive behavioural therapy and mindfulness based stress reduction may be equally effective in reducing anxiety and depression in adults with autism spectrum disorders. *Research in Developmental Disabilities*, 64, 47–55. 10.1016/j.ridd.2017.03.004 [PubMed: 28342404]
- Smith RS, & Sharp J (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with Asperger syndrome. *Journal of Autism and Developmental Disorders*, 43(4), 891–910. 10.1007/s10803-012-1633-6 [PubMed: 22923038]
- Smith TJ, Ching D, Weston A, & Dillahunt-Aspillaga CJ (2019). Achieving competitive, customized employment through specialized services (ACCESS). *Journal of Vocational Rehabilitation*, 50(3), 249–258. 10.3233/JVR-191004

- Sofronoff K (2005). Counseling adolescents. In Baker LJ & Welkowitz LA (Eds.), *Asperger's syndrome: Intervening in schools, clinics, and communities* (pp. 135–153). Lawrence Erlbaum Associates Publishers.
- Soke GN, Maenner MJ, Christensen D, Kurzius-Spencer M, & Schieve LA (2018). Prevalence of co-occurring medical and behavioral conditions/symptoms among 4 and 8-year-old children with autism spectrum disorder in selected areas of the United States in 2010. *Journal of Autism and Developmental Disorders*, 48(8), 2663–2676. 10.1007/s10803-018-3521-1 [PubMed: 29524016]
- Späth EMA, & Jongasma KR (2020). Autism, autonomy, and authenticity. *Medicine, Health Care and Philosophy*, 23(1), 73–80. 10.1007/s11019-019-09909-3 [PubMed: 31165390]
- Sprague J, & Hayes J (2000). Self-determination and empowerment: A feminist standpoint analysis of talk about disability. *American Journal of Community Psychology*, 28(5), 671–695. 10.1023/A:1005197704441 [PubMed: 11043110]
- Stahl B, & Goldstein E (2010). *A mindfulness-based stress reduction workbook*. New Harbinger Publications.
- Steptoe A, & Fancourt D (2019). Leading a meaningful life at older ages and its relationship with social engagement, prosperity, health, biology, and time use. *Proceedings of the National Academy of Sciences*, 116(4), 1207–1212. 10.1073/pnas.1814723116
- Swann C, Hooper A, Schweickel MJ, Peoples G, Mullan J, Hutto D, Allen MS, & Vella SA (2020). Comparing the effects of goal types in a walking session with healthy adults: Preliminary evidence for open goals in physical activity. *Psychology of Sport and Exercise*, 47, 101475. 10.1016/j.psychsport.2019.01.003
- Test DW, Fowler CH, Wood WM, Brewer DM, & Eddy S (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education*, 26(1), 43–54. 10.1177/07419325050260010601
- van Ingen DJ, Moore LL, & Fuemmeler JA (2008). Parental overinvolvement: A Qualitative Study. *Journal of Developmental and Physical Disabilities*, 20(5), 449–465. 10.1007/s10882-008-9113-9
- Vespa J (2017). *The Changing Economics and Demographics of Young Adulthood: 1975–2016* (Government No. P20–579; Current Population Reports, pp. 1–23). United States Census Bureau. Retrieved December 7, 2021, from <https://www.census.gov/library/publications/2017/demo/p20-579.html>
- Viezel KD, Williams E, & Dotson WH (2020). College-based support programs for students with autism. *Focus on Autism and Other Developmental Disabilities*, 35(4), 234–245. 10.1177/1088357620954369
- Watkins L, O'Reilly M, Kuhn M, Gevarter C, Lancioni GE, Sigafoos J, & Lang R (2015). A review of peer-mediated social interaction interventions for students with autism in inclusive settings. *Journal of Autism and Developmental Disorders*, 45(4), 1070–1083. 10.1007/s10803-014-2264-x [PubMed: 25272953]
- Webne-Behrman H (2009). *8 Steps for conflict resolution*. University of Wisconsin-Madison.
- Wechsler D, Zhou X, Psychological Corporation, & Assessment Library Materials (University of Lethbridge. Faculty of Education. Curriculum Laboratory). (2011). *WASI-II Wechsler abbreviated scale of intelligence*
- Wehmeyer ML (2004). Self-determination and the empowerment of people with disabilities. Retrieved March 2, 2022, from <https://kuscholarworks.ku.edu/handle/1808/10942>
- Wehmeyer ML, Shogren KA, Little TD, & Lopez SJ (2017). *Development of self-determination through the life-course*. Springer Netherlands. Retrieved March 6, 2022, from <http://ebookcentral.proquest.com/lib/vand/detail.action?docID=4810068>
- Williams A (2018). Autonomously autistic: Exposing the locus of autistic pathology. *Canadian Journal of Disability Studies*, 7(2), 60–82. 10.15353/cjds.v7i2.423
- Wong C, Odom SL, Hume KA, Cox AW, Fettig A, Kucharczyk S, Brock ME, Plavnick JB, Fleury VP, & Schultz TR (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, 45(7), 1951–1966. 10.1007/s10803-014-2351-z [PubMed: 25578338]

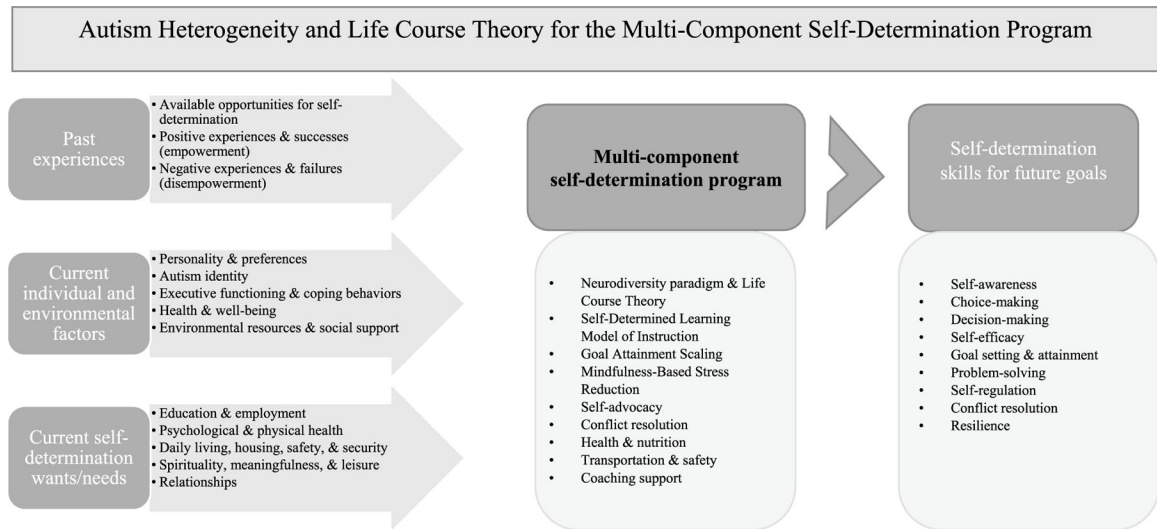


Fig. 1. Life course theory and heterogeneity for the autism spectrum and self-determination. Autistic adults have high heterogeneity in their experiences, characteristics, wants, and needs. This heterogeneity requires a flexible, multi-component program that provides a range of support for self-determination. Engaging in intrinsically motivated self-determination processes further develops self-determination skills for future goals

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Sample Immersion Week Activity Schedule

	9:00 a.m.-Noon	Noon-1:00 p.m.	1:00 p.m.-4:00 p.m.
Monday Location: Zoo	Overview of Programming Meditation, goal planning, cognition and self-regulation, transportation	Lunch Practice meditation	Activities Zoo tour, animal encounter with zoo representatives, zoo representatives discuss employment paths
Tuesday Location: Health & wellness center	Nutrition Good health for goals, nutrition needs, meal preparation, goal planning	Lunch Practice meditation	Activities Tour of gym equipment, yoga activity, at- home exercise instruction, chair massages
Wednesday Location: Art museum	Self-Advocacy Self-determination, self- advocacy, disclosure, goal planning	Lunch Practice meditation	Activities Museum tour, art activity, representatives discuss employment paths
Thursday Location: Music hall	Conflict Resolution Mindfulness, stress and emotion regulation, conflict resolution, finalize goals, field trip	Lunch Practice meditation	Activities Leisure and/or social activities, board games, music, arts & crafts, dance, theatre improvisation
Friday Location: University	Resilience Mindfulness, self-compassion, loving kindness, community safety, review field-trip plan	Lunch (Individualized)	Activities Individualized field trips based on goals, social interests, transportation, health employment/volunteering

Fig. 2. Sample schedule for the 5-day immersion week. Participants met at different community locations during the week. Most days consisted of psychoeducation content in the morning, followed by lunch, and then finishing with activities related to the location

Table 1

Description of program components

Component	Description
Goal development	Instruction on how to create goals, break them down into practical steps, and assess goal progress on a weekly basis. These skills are further applied during the coaching phase. For a more complete description, see Table 3
Self-determined learning model of instruction (Shogren et al., 2019)	Three-phase model (i.e., set a goal, take action, and adjust goal or plan) to set and pursue goals. Each phase contains guidelines and processes
Goal attainment scaling (Bovend'Eerd et al., 2009)	The Goal Attainment Scaling identifies five levels of goal attainment (0–4) ranging from no progress to progress that was much greater than anticipated. Each goal must be relevant, understandable, measurable, behavioral, attainable, and timebound
Self-advocacy	Learning “high-level leadership skills” for negotiating with others to accomplish goals
Self-advocacy (Test et al., 2005)	Participants were shown how self-advocacy is a leadership skill essential for self-determination. They also learned steps to self-advocacy: identifying needs/ strengths/preferences, understanding the situation/environment/resources/rights, communication (e.g., listening, negotiation, compromise), and leadership (e.g., identifying allies, working with others).
Disclosure (Foden & Anderson, 2011)	Participants were shown the positive and negative consequences of disclosure to understand the proper time and methods to disclose their autism identity and/or specific needs with others
Active listening (Stahl & Goldstein, 2010)	Participants learned the importance and skills required to engage in active listening for self-advocacy
Conflict resolution (Webne-Behrman, 2009)	The eight steps of conflict resolution include: assess current state of mind, clarify personal needs, find a safe place to negotiate, adopt a listening stance, assert needs, maintain flexible problem-solving, manage impasses, and find compromise. Participants were then asked to think about a conflict they experienced and describe how they would handle that conflict differently with the skills they learned
Mindfulness (Stahl & Goldstein, 2010)	Activities to enhance emotion regulation and resilience for problem-solving and conflict management
Yoga	30-min yoga session for beginners targeted body awareness to improve health and emotion regulation
Raisin exercise	Participants investigated one part of their lunch using their senses. Then they described their thoughts and sensations to help develop awareness of their environment, actions, and physical and mental responses
Identifying emotion words	Participants were asked to describe their thoughts and feelings associated with emotions selected from a list. The goal was to understand unique emotion profiles for each participant
Feeling emotions in the body	After selecting and describing their different emotions, participants were asked to show where in their body they express each emotion to understand where emotions are expressed
Automatic negative thoughts	Participants learned how to identify automatic thoughts and replace them with more appropriate and productive alternatives
Self-compassion	Participants learned that self-criticism is a normal part of goal attainment, especially when expectations are not being met. In tough situations, they needed to acknowledge their weaknesses and strengths and move toward self-compassion
Loving kindness	Participants learned how they should see others as people with variable strengths and weaknesses. Building on self-compassion, they learned how to extend this kindness to others
Community living	Importance of transportation and maintaining community safety related to a range of goals
Transportation (Price et al., 2018)	Participants learned how to use Google maps, rideshares, public transportation, and biking routes. They also learned about options for driving school and occupational therapy for driving
Safety (Katz & Moose, 1999)	Participants were shown how to protect themselves and their belongings in public. They learned how to interact with police officers and disclose their autism identity when needed

Table 2

Participant demographics

Characteristic	Male (n = 20) N (%)	Female (n = 11) N (%)
Race		
Black/African American	2 (10)	1 (9)
Caucasian	17 (85)	9 (82)
Multiracial	1 (5)	1 (9)
Ethnicity		
Hispanic or Latino	2 (10)	0 (0)
Not Hispanic or Latino	17 (85)	10 (91)
Prefer not to disclose	1 (5)	1 (9)
Highest education attainment		
Less than high school ^a	1 (0)	0 (0)
High school	3 (15)	8 (73)
Some college	3 (15)	0 (0)
Currently in college	6 (30)	1 (9)
College graduate	7 (35)	2 (18)
NEET status ^b	6 (30)	9 (82)
	Mean (SD)	Mean (SD)
Age, years	23.85 (3.80)	24.55 (5.72)
Age at diagnosis, years	11.25 (8.65)	15.73 (7.76)
IQ	104.75 (14.97)	95.64 (16.83)

^aParticipants could exit the education system without a high school diploma

^bNEET: not in education, employment, or training

Table 3

Description of coach training components

Component	Purpose
Autism characteristics	Overview of autism characteristics from the DSM-5; reframing autistic characteristics from a neutral perspective
Neurodiversity	Description of neurodiversity, the neurodiversity paradigm and autism, and the neurodiversity movement
Self-Determination Model of Instruction	Description and practice with the model ^a
Active listening and coaching	Trainees practice active listening ^a and coaching using the Socratic Method
Goal Attainment Scaling	Trainees practice creating scaled goals ^a
Crisis management	Trainees learn local, state, and federal definitions and responsibilities for identifying and reporting abuse; process steps for identifying and managing crisis (potential harm to self or others); internal and external processes and resources

DSM-5, Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

^aSee Table 1 for description

Table 4
 Measures of appropriateness, acceptability, and feasibility of the self-determination program

Outcome	Measures	Measure type	Source	
Appropriateness	Number of goals attained	Dichotomous (“goal attained,” “goal not attained”)	Self-report on weekly GAS forms	
	Topics of goals set	Open-ended	Self-report on weekly GAS forms	
	Was 3 months enough time for the coaching sessions?	Survey question Dichotomous (“yes,” “no”)	Self-report at exit interview	
Acceptability	Would you have preferred more or fewer weeks of coaching?	Survey question Categorical (“more,” “fewer,” “3 months was the right amount”)	Self-report at exit interview	
	How has the program impacted your life in the following ways?	Survey question Open-ended	Self-report at 3-month follow-up	
	a. Interaction with others or other aspects of your social life			
	b. Ability to manage stress			
	c. Ability to manage conflicts			
d. Feeling like you can accomplish future goals				
e. Other aspects of your life				
Satisfaction with immersion week questions:	Satisfaction with immersion week questions:		Self-report at the end of each immersion day	
	a. Please rate your overall satisfaction with today’s program	a. 5-point Likert scale (very dissatisfied to very satisfied)		
	b. Please circle which things you liked about today’s program	b. List of the day’s program components		
	c. Please provide comments on one or two items that you particularly liked	c. Open-ended		
	d. Feel free to include any additional comments or suggestions you might have about today’s program	d. Open-ended		
	Satisfaction with coaching sessions	Satisfaction with coaching sessions		Self-report at exit interview
		a. How satisfied were you with the coaching sessions?	a. 5-point Likert scale (very dissatisfied to very satisfied)	
		b. What did you like about the coaching sessions?	b. Open-ended	
		c. What did you dislike about the coaching sessions?	c. Open-ended	
		d. What should be added or changed about the coaching session or program as a whole?	d. Open-ended	
		e. Would you recommend this program to other people?	e. Categorical (“yes,” “no,” “maybe”)	
	f. Why or why not [recommend this program to other people]?	f. Open-ended		

Outcome	Measures	Would you be interested in receiving this type of coaching in the future?	Measure type	Source
Feasibility	g.	Would you be interested in receiving this type of coaching in the future?	g.	Categorical (“yes,” “no,” “maybe”)
	a.	Coaching session challenges and suggestions	a.	Open-ended
	b.	Program notes regarding feasibility	b.	Open-ended
	a.			Weekly coach feedback forms
	b.			Notes maintained by program coordinator

Table 5

it's goals organized by common life domains

Employment/education	Social skills/emotional regulation	Relationships	Health and well-being	Daily skills/Self-care	Finances	Transportation	Other
Restart Youtube channel for singing career	Cope better with stress	Spend time with my siblings and family-go see a movie with them-take a hike with them around the neighborhood	Enroll with a weight management doctor and try to figure out what is hindering [the participant] me form [sic] losing weight [sic]-to lose more weight on the 12-week weight control program	To learn a new life skill	Start saving money	I want to drive with my parents to [place] for [an event] and drive further distances-I will drive 5-7 days each week to get myself out of the house	Find other resources for support for after [the self-determination program] is over
Get better at using art software-create three design pieces in illustrator a week	Work on not losing temper when plans don't work out	Keep in touch/maintain relationship with friends	Get in habit of going to the to-do list	To have fun in personal time outside of work	Follow up on financial aid and make sure everything is taken care of-pursue student loans	Get driver's license	Taking steps to cut down on obligations, which include working at target, playing piano for church, piano tunings, and volunteering to teach piano lessons
Get Masters Degree	Not worrying about the future	Meet more people and tell them about myself-make new friends-be able to go to more social events and hang out with friends more	Sustain a paleo diet-go grocery shopping and order meal delivery service	Get a hair cut		Visit grandparents in Oregon	Adopt a new pet
To get an HR [human resources] job in the school	Keeping my mind off things that could bring me down (missing friends, death of grandmother)	Get a girlfriend	To exercise regularly	Get in habit of going to the to-do list			
To get through interviews and get a job-	Increase self-advocacy	Maintain social life while doing homework	Adopt a healthy diet	Continue to cook independently twice a week			
Get life guard [sic]-certificiate-work on breath stroke, freestyle, back boarding	Increase communication skills	Set up things for fun weekend with friends while parents are gone	Eat less fried foods and one new fruit-eat more vegetables-drink more water (multiple weeks-create habit	Clean and organize room			
Apply for three full time positions			Work out	Doing chores around the house (ex. laundry, dishes, clean room, help cook)			
Go through 90				Live independently			

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

employment/education	Social skills/emotional regulation	Relationships	Health and well-being	Daily skills/Self-care	Finances	Transportation	Other
<ul style="list-style-type: none"> day period with good feedback from employers and keep job Look for a college or university with a good computer science program-organize research articles and notes from college Take steps to get an internship for next summer-apply to at least 10 internships Routinely organize course work and study schedule Make progress on first app...fix major stuck error and continue new questline-learn more about the app making program I'm using 			<ul style="list-style-type: none"> • Take mineral pill everyday 				

J Autism Dev Disord. Author manuscript; available in PMC 2024 August 01.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

employment/education	Social skills/emotional regulation	Relationships	Health and well-being	Daily skills/Self-care	Finances	Transportation	Other
----------------------	------------------------------------	---------------	-----------------------	------------------------	----------	----------------	-------

to make
more
complex
apps

Table 6

Interrater reliability (observed agreement and Krippendorff's alpha of the two project-naïve raters for each of the domains)

Domain	Observed agreement (%)	Kripp. α point estimate^a (%)	Confidence interval
Conflict	92.3	85.2	.51–1.00
Social	84.6	67.9	–.04–1.00
Stress	92.3	84.9	.44–1.00
Goal	92.3	81.2	.38–1.00
Other	100.0	100.0	1.00–1.00

^aKrippendorff's alpha point estimate values > .80 indicate near perfect reliability (Hallgren, 2012)

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 7

Participant feedback regarding preferred self-determination psychoeducation, settings, and activities

Self-determination psychoeducation	
Goal planning	<ul style="list-style-type: none"> • “Having a person talk with me one on one about the goals was very helpful” • “Goal planning was very interesting and creative” • “Goal planning. The lady sitting besides me were the Presenter and instructor.” • “The goal planning was very useful for me” • “Goal planning” • “Self Determination. I liked how the presenter and the helper helped me” • “The goal planning helped me create an outline of what I want and need to do and helped me organize my thoughts” • “Goals”
Psychoeducation	
Self-advocacy	<ul style="list-style-type: none"> • “Disclosure” • “Disclosure, Self advocacy” • “Disclosure is always hard for me. I always worry about people’s reaction to my Asperger’s. Too much intensity, stop singling me out, felt almost ‘fear based’” • “I learned a lot and applied some of the information I learned about automatic thoughts, goal planning, and disclosure. Really looked forward to those” • “The part about disclosure was important as it dealt with a significant aspect of life for those on the spectrum” • “Resolving conflicts was particularly helpful” • “The resolving personal conflicts presentation gave me new insights into myself”
Mindfulness	<ul style="list-style-type: none"> • “The two wolves story is one that is very touching” • “The thought and self section was nice because you could learn about the others and help yourself” • “I learned a lot and applied some of the information I learned about automatic thoughts, goal planning, and disclosure. Really looked forward to those” • “The mindfulness video was a good reminder on staying aware of one’s emotions and how they affect one’s thoughts and actions” • “I liked the mindfulness videos” • “I really enjoyed the mindfulness discussion” • “The mindful emotions was fun”
Settings and activities	
Zoo	<ul style="list-style-type: none"> • “Exploring the zoo is always fun. The tour and encounters made me want to volunteer to form close relationships with the animals and people” • “More animal encounters” • “The animals and the general atmosphere were great, and the morning was productive”

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

- "I loved the chinchilla and kangaroos"
- "On Zoo visit day; animal encounter, seeing giraffes, meerkats, many species of lorikeets, and 1 or 2 other species of birds"
- "The tour of the zoo was informative, and it was nice to learn about volunteer work"
- "Friendly Doreates? Snake!"
- "Zipline"
- "Ask for mosquito repellent when at the zoo"
- "Had a great time at the zoo"
- "Exploring the Nashville Zoo was an absolute joy!"
- "Exploring the zoo was really fun"
- Whenever I'm down or upset yoga and meditation always help me relax. Fitness buff"
- "Billiards Are fun with friends"
- "Already knew about food groups and exercise routine"
- "Yoga was awesome"
- "Almost everything was good, especially the nutrition"
- "I wasn't real big on the meditation"
- "Eat well. Food group"
- "Serving sizes was appropriate. Free time was enjoyable"
- "The tour around the rec center and the free time to play billiards"
- "Creating a healthy lunch was great because it was very creative and tasty"
- "I would like display games. I would like to do telecommunicative games"
- "I like the lunch and snack. I loved playing pool"
- "The chair massages were really relaxing. So was the yoga"
- "I felt like I knew a lot of this material before. For those who needed or wanted this training, I think it was very beneficial"
- "I liked the free time and the yoga. I will exercise more"
- "I really enjoyed the healthy snacks. I will choose healthy snacks going forward"
- "The advice and information on food and diet may seem basic but it was very helpful as it provided good reminders on the necessity of a well-balanced diet. I enjoyed the recreational free time"
- "I loved the chair massages and the yoga. They were the best parts of my day"
- "I liked the theatre improv activity because it was fun and helped us to get to know people"
- "I enjoyed the whole experience"
- "The day program: theatre/improv activity (freeze and describe). Determining my closest fit in a certain topic based on my positioning"
- "I thought the music study was interesting even though slightly awkward"

Recreation
Center-yoga,
billiards,
nutrition

Theater/Improv/
Music

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

- "I liked the activity with music"
- "I really enjoyed the activity with music and going over our goals"
- "The theater part was awesome"
- "I enjoyed the theatre and the free time"
- "I liked laughing and making other people laugh during the awkward, yet silly theatre games"
- "The [museum] is one of my favorite places to go if I feel artistic. My mom worked there for years at the resource center Buddha Art. Always interests me greatly"
- "The tour should have the choice to join or wander"
- "would like to tour the place independently, not in group"
- "The science [museum] was fun and the exhibits were interesting"

Art museums