

**Study Protocol For**  
**R34MH111489 - Engaging Siblings of Adults with Autism in Future Planning**  
**Version Date: February 1, 2016**

## **SIGNIFICANCE**

### **The Existing Service Delivery System is Inadequate to Meet the Needs of Adults with Autism**

The current service delivery system is not adequately poised to meet the needs of the aging population of adults with autism spectrum disorder (ASD). We are in the wake of an emerging and pressing public health crisis, with current prevalence estimates of 1 in 68 children with an ASD.<sup>1</sup> In the next decade, over one half million youths with ASD will enter adulthood.<sup>2</sup> Few empirically-based, high-quality services are accessible to adults with ASD, despite their ongoing need for such services across multiple sectors. ASD symptoms are persistent and pervasive across the life course and include behavioral challenges, comorbid medical and psychiatric conditions, and marked difficulty in adapting to changing circumstances.<sup>3-6</sup> These ASD-related characteristics have documented impacts on appropriate service receipt and on the family.

### **Future Planning is Necessary to Ensure Adequate Service Participation among Adults with ASD**

Due to an unavailable, inaccessible, and uncoordinated service system, families play a large role in service coordination for adults with ASD.<sup>7,8</sup> Responsibilities associated with navigating complex systems of care, coordinating care across systems, and advocating for services frequently falls on family members (mostly parents).<sup>9</sup> Yet, families often express insufficient knowledge of available services and lack of clarity on the process for engaging with these services, which impedes taking action on future planning. Future planning can also be delayed for emotional reasons (e.g., facing the possibility of relying on outside supports as the family ages). Poorly-coordinated services are associated with poorer functional outcomes across domains of functioning for the adult with ASD.<sup>4</sup> Thus, lifespan approaches to service planning require attention to both short- and long-term goals, and barriers to carrying out these goals must be proactively addressed. Families would benefit from programs to help them identify and address practical and emotional barriers to future planning. Yet, few interventions are available to support families in this process.<sup>10</sup>

### **Siblings are Well Positioned to Assume a Central Role in Future Planning**

Siblings are the future generation of caregivers and often become the guardians for their brother/sister with ASD when parents are no longer able to provide care due to illness or death.<sup>11</sup> Yet, siblings are absent from the empirical literature focused on adult services in ASD. Siblings are a logical choice for providing lifelong support for their brothers/sisters with ASD. Sibling relationships typically last the longest of all human relationships,<sup>12</sup> and adult siblings often possess unique and important information about their brother/sister with disability.<sup>13</sup> Despite the behavioral, social, and communication difficulties of ASD that can disrupt sibling intimacy,<sup>14</sup> siblings are socializing agents who provide social support to their brother/sister with disability.<sup>15,16</sup> Siblings are often less protective than parents<sup>17</sup> and therefore better able to promote independence in the adult with ASD.<sup>16</sup> Most adult siblings of individuals with disability anticipate that they will provide more support in the future.<sup>18</sup> Many want to be involved in future planning but report that they are often not included.<sup>11,19</sup> Indeed, adults who have a brother/sister with disability expressed that they wanted: (1) to be included in future planning; (2) information and support on future planning, including financial and legal planning, guardianship transitions, estate planning, and help with system navigation; and (3) strategies for approaching parents to begin the dialogue about contributing to future planning.<sup>19</sup> These findings are consistent with our preliminary work (see below) and led to the proposed project.

### **Systematic Barriers Limiting Sibling Involvement in Future Planning can be Addressed**

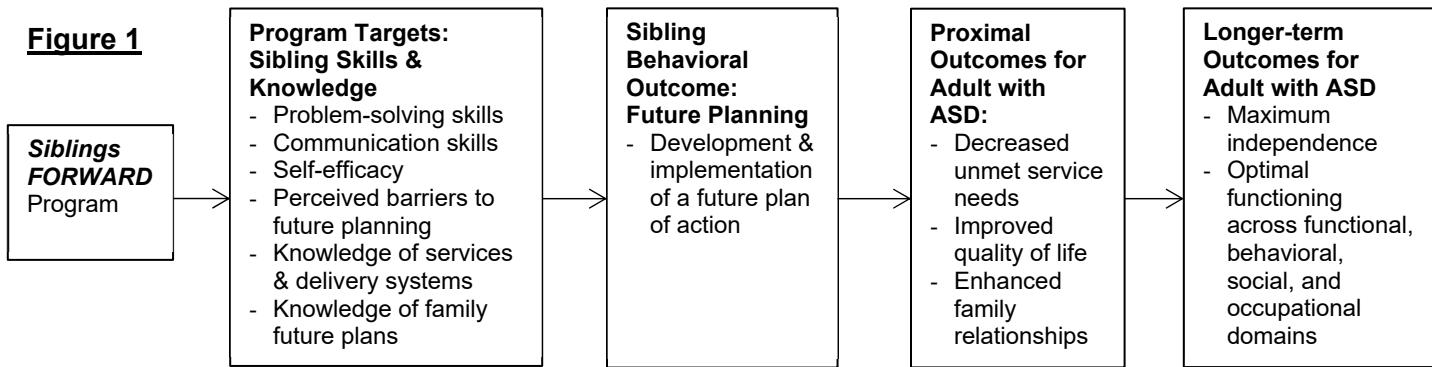
The longevity of sibling relationships and siblings' desire for more meaningful involvement in planning suggest that siblings are an untapped resource with the potential to provide consistent support over the life course for adults with ASD. A scoping review of caregiver support programs identified 14 governmental (e.g., care coordination and home/financial supports) or psychosocial programs.<sup>10</sup> Three of the four psychosocial programs focused on serving aging parents,<sup>20-22</sup> and only one ("Future is Now") included adult siblings in future planning.<sup>23</sup> Family members who participated in "Future is Now" completed a letter of intent (non-legal document that includes family information and future preferences), were more likely to initiate residential planning and developing a special needs trust, and reported decreased caregiving burden. Although the program was inclusive of siblings, only 1 of the 28 family caregivers in the intervention group was a sibling.<sup>23</sup>

The low rate of sibling involvement in "Future is Now" contrasts research documenting siblings' desire to be involved in future planning<sup>11,18,19,24</sup> and guided our preliminary research to better understand the reasons underlying siblings' limited participation in future planning. Our findings were consistent with previous work showing that (1) parents may not want to "burden" other children in the family and would prefer to let them live their lives (2) adult siblings may not live in close proximity to parents and/or their brother/sister with disability, (3) services described as "family-centered" often only include parents, and professionals are encouraged to collaborate with parents, not siblings and (4) siblings report limited knowledge and fear of complex service systems.<sup>25-28</sup> In response, we have begun to develop a program that specifically addresses these barriers to sibling participation in future planning.

## Brother/Sister FORWARD is Expected to Engage Siblings and Improve Long-Term Outcomes of Adults with ASD

The goal of the proposed research is to engage adult siblings in the process of person-centered future planning for their brother/sister with ASD. **Brother/Sister FORWARD (Focusing on Relationships, Well-being, and Responsibility aheadD)** targets common barriers to sibling involvement in family future planning, including improving family communication around difficult topics, increasing siblings' knowledge of and confidence in accessing ASD service systems, and anticipating and proactively problem-solving barriers to future planning. We are developing this program in close collaboration with family support personnel who work in local Arc chapters – the typical service settings for families – to increase the program's usefulness and acceptability among providers who would implement the program on a larger scale in the future. Siblings will participate in individual, personalized telehealth modules to address barriers related to geographical separation. Adults with ASD will collaborate to the extent possible to ensure a person-centered approach. The program is flexible in order to account for marked heterogeneity across severity ASD of symptoms, patterns of strengths and limitations, developmental trajectory, and functional status.<sup>29</sup> Participating siblings will create a plan of action that will be highly individualized and informed by the characteristics and service needs of the adult with ASD, his/her current degree of involvement in ASD services, and family context and values.

**Figure 1** illustrates the conceptual model and anticipated outcomes of the Siblings FORWARD program. In this formative stage of research, we will focus on engaging the program targets that are hypothesized to mediate longer-term program benefits. These targets include siblings' skills, knowledge, self-efficacy, and behaviors (creating and implementing a plan of action). Ultimately, greater sibling involvement in family future planning will result in optimal independence and functioning in adults with ASD, through more seamless continuity of care across the life course of the adult with ASD.



## The Proposed Program is Closely Aligned with Research Priorities for Services for Adults with ASD

The proposed research will develop and test a program to improve future planning for adults with ASD as parents age and adult siblings assume greater caregiving roles, in close collaboration with the Arc at the national, state, and local levels. This application focuses on several research objectives outlined in RFA-MH-17-205 (ServASD II: Pilot Studies of Service Strategies for Adults with ASD), and accordingly addresses key research objectives of the 2013 Interagency Autism Coordinating Committee's (IACC) Strategic Plan for ASD Research.<sup>30</sup> This proposal responds to the RFA's objectives to test the effectiveness of (1) "strategies to support families in accessing and navigating complex multi-sector systems of care, including increasing capacity to find or effectively advocate for services and to create informal supports and services for adults with ASD" and (2) "provider- and systems-level strategies in facilitating receipt of services and coordination and continuity of care for adults with ASD." The proposed work is further aligned with the IACC's aspirational goals of developing high-quality, evidence-based community services and supports across the lifespan of individuals with ASD and maximizing their potential to live self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports. In this regard, siblings' continued presence across the lifespan, provision of social support, and tendency to promote independence in the adult with ASD makes them a strong choice for future planning. The program is person-centered and flexible to accommodate heterogeneity in ASD presentation.

## INNOVATION

- **Siblings:** To our knowledge, this is the first program that specifically targets adult siblings in future planning. Siblings' enduring presence in the life of the adult with ASD and their documented interest in assuming a central role in future planning make them a logical choice for family engagement efforts, including envisioning and coordinating services across multiple systems.

- **Telehealth:** Telehealth approaches have been occasionally used in small studies of parents of young children with ASD,<sup>31-36</sup> CBT intervention for adolescents with ASD;<sup>37</sup> or ASD diagnosis in children<sup>38</sup> or adults.<sup>39</sup> Yet, telehealth approaches remain rare in ASD research and have not been examined in the context of adult ASD services. Telehealth addresses the geographical and practical considerations of a sibling-focused program, which is expected to lead to increased accessibility, acceptability, and participation. The low cost, clinical utility, and potential for widespread adoption is perceived as valuable to our community partners (see Support Letters).
- **Community-Based Design:** Community partners have already contributed to the design and aims of the proposed work and will continue to take a central role across all stages of the research design, implementation, dissemination, and future directions. Community input has been gleaned from professionals representing the Arc at the local, state, and national levels; an adult with ASD; young- and middle-adult siblings of individuals with ASD; parents of adults with ASD; and community organizations representing adults with ASD (e.g., AANE) and siblings (Sibling Leadership Network). This intensive community involvement is expected to considerably increase the degree to which our program targets relevant topics/skills in an acceptable format that has the potential for widespread uptake among providers who serve a heterogeneous group of families with ASD and similar disorders.
- **Individualized Approach.** We have designed a person-centered program that incorporates the adult with ASD and allows for a flexible approach informed by aspects of the ASD presentation, individual service needs, values, and family considerations. This individualized approach is expected to increase the utility of the intervention for all families served within community settings, regardless of their specific needs.

## PRELIMINARY STUDIES

The research team has complementary expertise (Table 1). The proposed project is informed by the PIs' past research on siblings and by recent investigation into the barriers to future planning experienced by adult siblings. Dr. Long's work with 8- to 17-year-old siblings of children with ASD showed that siblings as young as age 8 are already planning for their future caretaking roles, particularly in Latino families.<sup>40</sup> Similar findings have been found in Dr. Orsmond's work showing that 60% of adult siblings expected to assume primary caregiving responsibility for their brother/sister with disability in the future.<sup>41</sup> Higher sibling involvement was found among sisters,<sup>41</sup> in families with greater closeness,<sup>41</sup> and when the mother had declining health.<sup>42</sup> Competing family responsibilities (e.g., young children at home) limited siblings' involvement,<sup>41</sup> suggesting the need for a flexible approach (e.g., telehealth).

Some siblings of individuals with ASD may need more personalized support to be effectively involved in future planning. Dr. Orsmond's research highlights the unique needs and risk factors of adolescent and adult siblings who have a brother/sister with ASD, including siblings' higher rates of distress, particularly when siblings exhibit features of the broader autism phenotype (BAP), experienced family stress, and when the brother/sister with ASD had more severe behavior problems.<sup>43,44</sup>

In preparation for the proposed research, we conducted focus groups, interviewed service providers, and engaged a sibling in future planning as a case study. In focus groups of parents of transition age youth with cognitive, emotional, or social challenges, mothers discussed sibling involvement in the future. They articulated anxiety about the future of their son/daughter with disability but expected that siblings would assume caregiving responsibility. One mother expressed a commonly shared sentiment: "We never would put it on her. It's not her responsibility. But I know she will be there for her."

Interviews with service providers highlighted the challenges of involving adult siblings in future planning. Consistently, family support personnel at local Arc chapters reported that they worked with siblings at the time of parental illness/death or afterwards but emphasized the need to engage siblings proactively. There was overwhelming enthusiasm for creating Siblings FORWARD and offers to assist. Interviews highlighted: (1) the timeliness due to increases in services needed to support adults with ASD; (2) the need to connect with siblings before family crisis; and (3) that the proposed program fit within the scope of services provided by family support personnel at the Arc. In addition to national trends, recent legislation in MA has greatly increased the number of adults with ASD who are eligible to receive services from the Department of Developmental Services; thus, providers expect a phenomenal increase in demand for adult ASD services.

Finally, a case study examined the experience of a 24-year-old sister who used a new online tool (Build your Plan™) available through the Arc's Center for Future Planning™. This sibling is motivated to become more involved in family future planning for her older sister who is non-verbal, uses a wheelchair, and lives in

Table 1: Expertise Matrix	
<b>Content</b>	
Adults with Autism	Orsmond
Siblings	Orsmond, Long
Autism Service Delivery	Community Adv. Board
<b>Methods</b>	
Community Partnerships	Long
Qualitative Methods	Long
Intervention Development	Orsmond, Long, Comer
Telehealth	Comer

the family home. She is concerned about the lack of long-term residential plans. Although it is advertised as involving siblings, the Build your Plan tool was perceived to be exclusively designed for parents (e.g., all questions referred to “your son or daughter”). She reported that the tool prompted her to think about some new issues (e.g., guardianship, financial planning), but that the resources suggested were not specific enough to be helpful. She expressed anxiety when the website led her to local resources that were non-existent. The tool did facilitate engagement in future planning with her mother; she had to ask her mother for information, and the two of them learned new financial planning information when exploring the tool together. But, she did not approach her father about future planning because she said he “tended to get emotional when discussing the topic.” She stated she would like strategies for how to approach him. After 6 weeks of individual planning, she identified two positive outcomes: (1) her parents made an appointment with a special needs lawyer and (2) she planned to contact and visit one residential option. In sum, possible gains of engaging with the planning tool were offset by increased anxiety, perceptions of limited helpfulness, and remaining needs in terms of skills for communicating with parents and problem-solving barriers to identifying and obtaining necessary services.

## **APPROACH**

### **Overview**

The goal of the proposed research is to develop and evaluate the Siblings FORWARD program using behavioral telehealth technology. First, we aim to develop the 6-session Siblings FORWARD program in collaboration with community organizations. Siblings, adults with ASD, and community providers will give feedback on the proposed program through focus groups and/or individual interviews. Second, feasibility of the Siblings FORWARD program will be evaluated through an open trial (N=5 families). We will assess recruitment capability, appropriateness of outcome measures, program acceptability, and viability of the procedures. Finally, we will conduct a pilot randomized controlled trial (RCT) (N=36 families) to examine effects on the proposed targets and whether sibling involvement led to the creation of a plan of action for future planning.

### **Sample & Recruitment**

Community Advisory Board. Future planning for adults with ASD is complex due to the multiple systems of care, frequent perceptions of unmet needs, legal and ethical considerations, and emotional aspects. This complexity increases the challenges of creating a program such as Siblings FORWARD and will require early and frequent involvement of stakeholders with experiences relevant to adults with ASD. Thus, the first step of the proposed research will be to engage members of the community advisory board (CAB). We have assembled a team with personal and/or professional expertise related to adult ASD (Table 2). These individuals have already agreed to serve on the CAB (see Support Letters); therefore, meetings will commence immediately if the project is funded. The CAB will meet quarterly during the project in order to (1) provide feedback on initial drafts of the program content and implementation plan, including identifying unanticipated barriers, (2) strengthen our ties with the community in which the intervention will be implemented currently and in the future, and (3) ensure community acceptability to support future implementation and dissemination. To ensure the quality of feedback and strength of relationships, CAB meetings will be held in-person at a convenient time and location.

Service Providers. Five focus groups will be conducted (N=6-8 members in each group) to obtain feedback on the content and format of the program, including three focus groups with adult siblings and two with providers experienced in serving adults with ASD and their families. Service providers will be recruited primarily through local Arc organizations (e.g., family support staff). There are 10 Arc chapters located within a 30-mile radius of Boston; we will also conduct service provider focus groups at the Arc’s national convention. This is adequate to ensure a sample size of 12-16 providers for focus groups.

Siblings and Adults with ASD. *Siblings* will be enrolled in three focus groups (N=18-24), the open trial (N=5), and the RCT (N=36). For focus groups, siblings who live in the greater Boston area will be enrolled. For the open trial and RCT, siblings will be enrolled regardless of their geographic location; this is possible due to the telehealth delivery format. Sibling inclusion criteria include (1) one or more adult brother(s) or sister(s) with ASD who are either biologically related and/or were raised in the same family of origin (e.g., adopted, step, or foster siblings), (2) age 18+, and (3) English fluency. Siblings will be excluded if they have a disability that would interfere with their ability to engage meaningfully in future planning for the adult with ASD. *Adults with ASD* (N=8-10) will participate in individual interviews during the first stage of the project and will complete self-report measures during the open trial and RCT if capable (with support if needed). Inclusion criteria for the adults with ASD include (1) an ASD diagnosis, (2) an adult brother/sister (i.e., a sibling), (3) age 21+, and (4)

<b>Table 2: Community Advisory Board</b>	
<b>Name</b>	<b>Expertise / Role</b>
Stephen Shore	Adult with ASD
John Kramer	Adult sibling; Co-founder of Sibling Leadership Network
Daniela Caruso	Parent of youth with ASD & lawyer
Kerry Mahoney	Arc of Massachusetts
Michelle Alkon	Director of Adult Services, AANE, & parent of youth with ASD

English fluency if verbal. For the focus groups, adults with ASD will be excluded if their abilities would preclude participation in an interview about future planning (e.g., due to significant cognitive or language challenges).

Across the three phases of the proposed research, 59-65 families will be enrolled. A sample size range allows for flexibility with regard to saturation of qualitative data. For the focus groups, siblings will be recruited through local Arc chapters, the Massachusetts Sibling Support Network (MSSN), Asperger/Autism Network (AANE), and at the National Arc convention (see Support Letters). For the open trial and RCT, siblings will be recruited via local Arc chapters and the MSSN. We will primarily partner with the Northeast Arc (Danvers, MA) and the Brockton Area Arc (Brockton, MA) for recruitment for the open trial and RCT. These two chapters were chosen due to the presence of family support programs, outreach to siblings, and higher racial, ethnic, and economic diversity in their families served. If needed, we will recruit outside of the service system (e.g., through local media, universities, and listservs).

## Procedures

Focus Groups and Individual Interviews. The first phase of data collection involves focus groups with siblings, separate focus groups with service providers, and individual interviews with adults with ASD. Focus groups will be held at local Arc locations to maximize convenience for participants. The focus groups will aim to understand current planning, including: (1) siblings' knowledge of their families' current approach for future planning and the presence of services to support them through this process, (2) domains which should be included in future planning (e.g., medical, mental health, guardianship, living situation, vocational/volunteer involvement, financial planning, etc.), (3) barriers to sibling involvement in family future planning; (4) changing needs of the adult with ASD as he/she and parents age, (5) families' approaches to communicating about the future, and (6) nature of siblings' current involvement. Focus groups also will probe siblings' and providers' perceptions of Siblings FORWARD, including: (1) their enthusiasm for a program to engage siblings in future planning, (2) preferences for program components, format, and timing, (3) ideas on how to maximize flexibility so that the program has the broadest possible reach and benefit, and (4) ideas on how to incorporate the preferences of the adult with ASD (Appendix 1). Participants will be presented with an overview of the program and asked to provide feedback on the content, format, and materials.

Adults with ASD will complete qualitative interviews at a setting of their choice (e.g., home, agency, study office). We will continue to enroll siblings, adults with ASD, and/or service providers until saturation is reached in the primary research questions (i.e., when more interviews do not generate additional information).<sup>45</sup> The goal of the individual interviews will be to probe participants' experiences with planning, preferences for sibling involvement in future planning, reactions to the program being developed, and ideas for how to best capture the input of adults with ASD when developing future plans.

Focus groups and interviews will be recorded, transcribed verbatim, and checked for accuracy. Transcripts will be entered into a qualitative software program, NVivo11,<sup>46</sup> to facilitate coding and analysis.

Open Trial. Once the program is finalized, an open trial of 5 siblings will be conducted to identify and trouble-shoot barriers to implementation. This step is crucial due to the plan to utilize community providers to deliver the program in a telehealth format (see below). Each service provider will receive in-depth training on the principles and components of the program prior to implementation and will participate in weekly meetings to monitor progress, troubleshoot concerns, and receive intensive consultation on the program. Siblings will participate in the six-session program and will complete a battery of questionnaires pre- and post-participation and 3 months later (see Measures below). Siblings and service providers will participate in exit interviews to collect overall perceptions of the program, assess program satisfaction, and identify areas for improvement. Service provider fidelity to the program core components will be monitored and evaluated.

RCT. The final phase of the proposed project will implement an RCT to examine whether the program is feasible and associated with improvements in the treatment targets (see Measures and Figure 1). Thirty-six siblings will be recruited and randomly assigned to participate in Siblings FORWARD (N=18) or receive written materials about future planning (N=18). Siblings assigned to Siblings FORWARD will complete Time 1 (pre-program) measures, participate in the 6-session intervention over 4 months, complete Time 2 measures immediately after program completion, and complete Time 3 measures 3 months later. Those assigned to the control condition will complete Time 1 measures at the time of enrollment, Time 2 measures 4 months after enrollment, and Time 3 measures 7 months after enrollment. With the exception of the clinician rating of the sibling's ASD symptoms (see Measures), all data will be collected by the Boston University study team via home visits in order to separate data collection from the Arc providers. Adults with ADS and their families will determine whether the adult with ASD can complete the questionnaires (see Methods). When possible, the adult with ASD will complete the measures independently in the presence of a Boston University research team member. These measures can also be completed with the support of a research team member, sibling, parent, or service provider. Given possible geographic separation, sibling data will be collected via mailed questionnaire packets. We will track this data collection method to inform future data collection logistics.

## Siblings FORWARD Program Description

The goal of the Siblings FORWARD program is to increase siblings' skills, knowledge, and self-efficacy to enable them to assume a greater role in future planning for their brother/sister with ASD. Program completion is expected to be associated with a higher likelihood of developing and implementing a future plan of action that includes short- and long-term planning goals. In turn, improved future planning is expected to be associated with longer-term improvements in unmet needs, quality of life, and family relationships for the adult with ASD (Figure 1). The Siblings FORWARD program will be delivered in six sessions over a 4-month period. Siblings will participate in all interactive online sessions guided by an Arc family support staff member; the adult with ASD will participate in one session, when possible. To increase future uptake and scalability, the program will be delivered by community providers with expertise in serving adults with ASD and their families. Sessions will equip sibling participants with concrete skills necessary to actively engage in future planning. Sessions follow a deliberate sequence starting with assessment of siblings' current involvement and skills and motivational interviewing techniques<sup>47</sup> to bolster siblings' motivation for future planning; followed by instruction on skills related to communication<sup>48</sup> and problem-solving,<sup>49</sup> education about existing services and systems; application of problem-solving and communication skills to their plan of action; incorporation of the adult with ASD into the planning process; and final application of skills to the creation of a document outlining concrete next steps for the sibling's involvement in future planning. Content is outlined in Table 3 and Appendix 2.

**Table 3: Program Description**

<b>Target</b>	<b>Description</b>
Session 1: Assessment & Motivation (Sibling) – 75 minutes	The initial session will assess the extent to which future plans are in place, the extent to which the sibling is informed about future plans, siblings' perceptions of their own and their families' motivation and readiness to engage in the process, family values regarding family roles and care preferences, and initial goals for sibling involvement in family future planning for the adult with ASD. This session will include a motivational interviewing component to increase siblings' engagement with future planning. Finally, the sibling will draft a first version of their plan of action, including high-level goals. <u>Between-session tasks:</u> (1) learn about the family's existing future plans (if any) and (2) refine their goals for program participation and role in the life of their brother/sister with ASD.
Session 2: Family Communication (Sibling) – 60 minutes	Siblings will be taught to use effective communication skills with their family members (e.g., parents and the individual with ASD). The sibling will be given instruction in basic communication skills (e.g., using "I" statements, reading others' body language, maintaining a collaborative tone, etc). Then, he/she will practice these skills in session by role-playing how they might talk to family members about their initial plan of action that was outlined in Session 1. The sibling will set specific goals regarding communicating with family members (parents, brother/sister with ASD, other siblings, etc.) about specific topics identified in session (e.g., financial planning). <u>Between-session assignment:</u> work toward meeting the family communication goals outlined in session.
Session 3: Systems Navigation & Participation (Sibling) – 60 minutes	Siblings will be provided with psychoeducation about the continuum of care across community, residential, medical, mental health, and occupational/educational settings. Then, they will be taught strategies for effectively navigating and interfacing with these systems in order to support the individual with ASD, including prioritizing which service needs should be addressed initially and role-playing conversations with community organizations. Siblings will be provided with a packet of information regarding services for adults with ASD and a tip sheet developed specifically for siblings who engage in future planning. <u>Between-session assignments:</u> Review the informational packet and identify resources or domains that are most relevant.
Session 4: Anticipating & Problem-Solving Barriers (Sibling) – 60 minutes	Siblings will be taught skills for problem-solving, including narrowly defining a problem, identifying options, evaluating the likely outcome of each option, and selecting the most promising option. Problem-solving will be taught as an iterative process in which each attempt at solving the problem is evaluated to inform next steps. After learning the basic skill, siblings will be asked to identify potential barriers (practical or emotional) to implementing their plan of action and to problem-solve strategies to address the barriers. Finally, the sibling will be urged to set expectations and goals in preparation for the joint session involving their brother/sister with ASD (Session 5). <u>Between-session assignment:</u> (1) practice the problem-solving skill with additional barriers identified in session, (2) carry out one of the options selected during the problem-solving exercise (e.g., "ask Mom to sign a release of information form so that I can talk directly to Mario's doctor"), and (3) invite family member with ASD to participate in Session 5, if appropriate.
Session 5: Integrating the Family Member with ASD (Sibling & Adult with ASD) – 60 minutes	This session will involve the sibling and the adult with ASD to ensure that his/her preferences and values are a central consideration in the process of future planning. It is expected that siblings will utilize previously-learned communication and problem-solving skills, as well as knowledge of the systems of care relevant for adults with ASD. This session will be highly individualized, but the provider will play an active role in structuring the session and ensuring that the focus remains on future planning. Every effort will be made to incorporate the adult with ASD into this session. When the adult with ASD is truly not able to participate productively, the sibling will be asked to reflect on their perceptions of their brother's/sister's preferences (e.g., based on their responses to previous services or experiences). <u>Between-session assignment:</u> Revise their future goals and next steps to incorporate their brother's/sister's input, including identifying and problem-solving additional barriers.

<u>Session 6:</u> Development of a Sibling Plan of Action (Sibling) – 60 minutes	<p>The program will culminate with the creation of a sibling plan of action outlining their involvement in family future planning. This plan will include long-term goals, proximal goals, and concrete next steps. Siblings will be asked to identify goals and next steps across multiple domains, including occupational/educational placement, residential placement, guardianship and legal issues, mental health, medical treatment, and financial planning. The siblings' plan of action will be highly individualized and informed by their brother's/sister's specific ASD symptoms, developmental level, current involvement in ASD support services, and family context and values. <u>Follow-up assignment:</u> Carry out next steps on plan of action.</p>
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**Flexible Implementation.** The program is designed to offer maximum flexibility with regard to family values and preferences for services, ASD severity and associated treatment needs, and geographic distribution of families. As such, the program will correspond to the unique needs and preferences of each participating sibling and his or her family. For example, siblings from families with strong cultural values emphasizing home-based care may focus on exploring options for home-based support and problem-solving barriers to being the primary caretaker (e.g., the sibling's own employment or family needs). For siblings from families that have already begun the process of future planning, siblings will focus on identifying next steps for the family future plan and problem-solving barriers that may interfere with moving the plan forward. In contrast, siblings from families who are reluctant to engage in future planning may focus on increasing motivation and processing emotional aspects of future planning. With regard to ASD presentation, we expect the adults with ASD to present with a wide range of functionality that will influence the nature of their service needs and their degree of involvement in Siblings FORWARD. In all cases, we will attempt to elicit their input. Adults with ASD who are able to participate will be asked to engage in collaborative planning with the sibling. For those who may not be able to do so, we will help the sibling explore other ways to take their brother's/sister's wishes into account, such as reflecting on their response to previous interventions or living arrangements. In families with multiple siblings, we will ask the family to identify one sibling to be the primary participant in Siblings FORWARD; however, other siblings will provide input via between-session conversations with the participating sibling.

**Focus Group and Open Trial Feedback: Examples of Protocol Modifications.** The RCT will be informed by data collected during the earlier phases of the project. For example, if qualitative data reveals that the adult with ASD should have a more active role, we can incorporate him/her into more sessions earlier in the program. If the process of transferring knowledge from parents to siblings presents practical or interpersonal challenges, we may incorporate a joint parent-sibling session to address the emotional and practical aspects of caregiver role transitions. If the community providers are uncomfortable incorporating the telehealth technology, we may add more training sessions or provide additional technical support. If siblings and/or community providers do not have time to engage in the entire intervention, we may try to isolate the most important components and prioritize delivery of these components. We fully anticipate to encounter barriers and are prepared to update the program content, format, or delivery based on this feedback.

**Training & Fidelity.** Fidelity to the program will be ensured in several ways: (1) the content and structure of the sessions will be standardized in a manual; (2) service providers will participate in intensive training for the Siblings FORWARD program covering conceptual foundations of the program, the experiences of adult siblings of adults with ASD, the current services available to this population, and tenets of culturally-sensitive care. Training will be provided for each session, with role plays to ensure standard delivery; (3) after training, all providers will participate in weekly consultation sessions with the PIs; (4) all sessions will be video recorded and used for consultation and to ensure that protocols are being implemented as intended; (5) all service providers will complete session content checklists following each session; and (6) 20% of session video recordings will be independently rated for adherence to the treatment manuals. We anticipate some provider attrition over the course of study implementation; intensive trainings will be held as needed with new providers.

**Control Condition.** Currently, the standard of care is minimal sibling involvement in future planning or therapeutic activities for their brother/sister with ASD. Some organizations have created resources targeted toward parents (e.g., the Arc's Build Your Plan™ tool), but our preliminary data show that these resources are often perceived by siblings to be minimally helpful and/or overwhelming, which serves to increase their anxiety and decrease the likelihood that they will take action. Several organizations have recently published "tip sheets" for siblings who wish to have a larger role in future planning. The extent to which these tip sheets are accessed by siblings or helpful as standalone resources is unknown, but they are frequently the only resource available to siblings. Given that tip sheets are inexpensive and easy to create and disseminate, it will be important for the proposed project to demonstrate that the outcomes of the Siblings FORWARD program warrant the extra time and resources. Therefore, the control condition will involve providing the same tip sheets and packet of information about resources for adults with ASD as those distributed in Session 3 of the Siblings FORWARD program. After all outcome data are collected from the program and control groups, siblings in the control condition will be offered the opportunity to participate in the Siblings FORWARD program.

**Telehealth Technology. Rationale:** The Siblings FORWARD program will be delivered via synchronous videoteleconferencing (VTC) technology. VTC technology enables the secure delivery of interactive meetings that incorporate audio and video streams of data across multiple sites.<sup>50</sup> The considerable growth of VTC interventions over the last few years has been bolstered by technological advances in VTC, portability of the technology, decreased costs, and increased internet access and technological literacy of the general population.<sup>51</sup> This approach has been employed to overcome geographical barriers to care, which has led to increased availability, accessibility, and acceptability of mental health care delivered remotely.<sup>52</sup> Although most telehealth research focuses on individuals, recent work supports the feasibility of family-based telehealth.<sup>52</sup>

***Application to Current Proposal:*** Common barriers to sibling involvement in future planning include geographical separation from the individual with ASD and/or parents and the sibling's concurrent midlife demands (e.g., responsibilities to children, spouse, aging parents, or employer). The application of VTC technology will directly address these barriers and increase accessibility and program engagement. Most sessions will be delivered in a one-on-one format between the provider (in his/her office) and sibling participant (at home). In addition to audio and video streams, the VTC platform offers a shared desktop function in which both the provider and the sibling can view and edit documents in real time and access the documents between sessions to reinforce skills. This shared desktop function will be used to create program documents (e.g., the sibling plan of action). When the adult with ASD participates in session, families will have the choice of having the sibling and adult in the same room or setting up a 3-way VTC session. Finally, the ease of video recording will facilitate close consultation between the PIs and the service providers delivering the program.

***Equipment:*** Providers and sibling participants will each require hardware (computer or tablet with webcam and microphone), WebEx software, and a network connection. **Hardware:** Standard consumer desktop, laptop, or tablet systems are sufficient to implement the VTC software and have adequate visual display. The built-in webcams and unidimensional, dynamic-transducer microphones typical of most consumer computers are sufficient to implement VTC technology. Therefore, we expect that participants' own computers/tablets will be sufficient to operate the VTC technology, but this will be measured as a feasibility outcome. If a participant's setup does not meet these minimum specifications (outlined in Appendix 3), the study team will loan a tablet and 4 months of high speed internet access (see below) to the participant. **Software:** In line with recommendations to ensure utmost confidentiality, we will implement a standards-based (vs. consumer-based) application that incorporates firewalls, encrypts communications, and meets HIPAA regulations.<sup>50,53</sup> Standards-based systems adhere to publically-available standards set forth by the regulating bodies (e.g., the International Telecommunications Union standardization sector). A software-based codec (which encodes and decodes audiovisual data sent between devices) will be used to eliminate the need for additional equipment in the siblings' homes; software-based codecs are associated with some AV quality loss but greater flexibility in use.<sup>50</sup> Based on a review of existing VTC providers and the requirements of the proposed research, we plan to use WebEx software. More information about WebEx and associated security features is provided in Appendix 3. **Connectivity:** Since VTC requires real-time exchange of AV information, the minimum bandwidth (i.e., the rate at which information is transmitted over an online connection) recommended for VTC is 384 kb per second.<sup>54</sup> This minimum bandwidth is met with the basic plans offered by most internet providers.

***Implementation:*** The research team will ensure that providers' and siblings' computer set-ups are sufficient for the VTC technology (e.g., adequate display resolution, sufficient bandwidth, sufficient RAM to run the WebEx software, etc.; see Appendix 3). We have budgeted for 5 tablets that meet our minimum specifications and will loan these tablets to sibling participants, if necessary. Service providers will be given intensive, hands-on training on how to implement the technology (see Appendix 3 for licensure considerations). Prior to the first program session, each sibling will participate in a brief session focused on the practical aspects of gaining familiarity with the WebEx technology. This introductory session is expected to minimize disruptions and increase engagement in subsequent, substantive sessions.<sup>52-54</sup>

***Expertise:*** Dr. Comer (consultant) is an internationally recognized expert on VTC technology in behavioral telehealth. He has authored 7 articles and obtained 4 grants focused on this methodology. He has used VTC technology in multiple research projects, including several collaborations with the PIs' home institution, Boston University. He will oversee purchasing and implementing hardware and software, ensuring security, maximizing VTC functionality, and ensuring continued engagement and alliance with participants using this novel delivery approach. The Project Manager will work closely with Dr. Comer and will assume primary responsibility for ongoing maintenance of the equipment and incorporating updates to software and/or regulatory policies to ensure that the technology implementation remains current and maximally functional.

## **Measures**

Siblings will complete all written measures unless indicated otherwise. Measures are organized according to baseline characteristics, treatment targets, and proximal outcomes expected to change as a function of program participation. Baseline characteristics related to the functioning of the adult with ASD (i.e., all except

demographics) are also considered longer-term outcomes that are expected to improve over time but which are not expected to change within the time frame of the proposed data collection. In the current work, baseline characteristics will be used to characterize the sample. In future, larger-scale work, these variables will be examined as possible moderators of treatment effectiveness.

#### Baseline Characteristics (Measured at Time 1)

1. Demographics. Family demographic questions include race/ethnicity, gender, family membership (age and gender of siblings), family income, native language, education and employment, and type and size of community. This information will be collected for the adult with ASD, sibling, and parent (when known).
2. Adult with ASD: Autism Symptom Severity. Siblings will rate their brother/sister's ASD symptoms using the Current form of the Social Communication Questionnaire (SCQ).<sup>55</sup> The SCQ is a 40-item proxy-report measure used to assess the presence of specific autistic behaviors. The items represent three areas of functioning: reciprocal social interaction, language and communication, and repetitive and stereotypical behaviors, where higher scores indicate more severe behaviors. The SCQ has established psychometric properties in children and adults and has good reliability and convergent validity.<sup>56,57</sup> The SCQ manual provides additional information on factor analyses, item validity, and ROC analyses that support its validity. Psychometric properties are good, with alpha reliabilities ranging from .84 to .93 in older age groups.<sup>55</sup>
3. Adult with ASD: Maladaptive Behaviors. Siblings will rate the severity of maladaptive behaviors exhibited by their brother/sister with ASD using the Scales of Independent Behavior-Revised (SIB-R).<sup>58</sup> The SIB-R Maladaptive Behaviors scale consists of 8 categories of behavior problems divided into 3 domains: internalizing, externalizing, and asocial behavior. Standard algorithms translate the frequency and severity ratings into a general summary score. Reliability and validity have been established.<sup>58</sup> We have used this measure in prior research with adult siblings of individuals with ASD.<sup>43</sup>
4. Adult with ASD: Functional Independence. Siblings will rate their brother/sister's functional independence using the Waisman Activities of Daily Living Scale (W-ADL).<sup>59</sup> The 17 items cover the domains of personal care, housekeeping, and mealtime activities. Each item is rated on a 3-point scale (0=does not perform the task at all; 1=performs the task with help; 2=performs the task independently). Items will be summed for a total score. Good reliability (alpha > .90) has been reported.<sup>59</sup>
5. Broader Autism Phenotype (BAP) Characteristics in the Sibling. Sibling FORWARD program facilitators will rate each sibling's social pragmatic communication skills using the Adult Pragmatic Rating Scale<sup>60</sup> after Session 1. This measure has been used to evaluate the communication of parents of individuals with ASD and is conceptualized as a marker of the BAP. Eighteen behaviors are rated on a 3-point scale with specific descriptors. Items query grammatical errors and speech complexity, verbal intonation, verbal behavior about own emotional state, organization and clarity of verbal communication, descriptive and emotional gestures, appropriateness of detail and references in communication, candidness of communication, mispronunciation and articulation, eye contact, range of facial expression, expressed empathy, and habitual laughter. This information will not be collected from control siblings.

#### Program Targets: Sibling Future Planning Knowledge & Skills (Measured at Time 1, Time 2, & Time 3)

1. Problem Solving Skills. Siblings will complete the Social Problem-Solving Skills Inventory-Revised (SPSI-R).<sup>61</sup> This 52-item self-report measure was used in a problem-solving intervention with mothers of children with ASD.<sup>62</sup> Five dimensions assess how the individual strategically approaches a situation (positive problem orientation, negative problem orientation, rational problem solving, impulsivity carelessness style, and avoidance style). Siblings will rate the extent to which each item is 1 (not at all true) to 5 (extremely true) of them. Higher scores indicate better problem-solving skills. Good reliability is reported.<sup>63</sup>
2. Family Communication about Future Planning. Siblings will rate the frequency with which they have had family discussions about planning for the future of their brother/sister with ASD. Siblings will respond to a 1-item measure previously used in a study evaluating a peer-support program for aging caregivers of adults with intellectual and developmental disabilities.<sup>23</sup> The item is scored on a 3-point scale (not discussed at all, discussed somewhat, discussed a great deal).
3. Future Planning Self-Efficacy. We will adapt the Caregiving Self-Efficacy Scale<sup>64</sup> that has been used by with parents and adult siblings to evaluate participation in a peer-support intervention for aging caregivers.<sup>23</sup> The scale consists of 6 items rated on a 4-point scale (strongly disagree to strong agree). Sample items include: I honestly believe I can be a good caregiver to my relative; If anyone can find the answer to what is troubling my relative, I can. The scale has good reported reliability (alphas .73-.82).<sup>23</sup>
4. Sibling Barriers to Future Planning. Siblings will complete a list of barriers to future planning adapted from a measure used by Heller and Caldwell.<sup>23</sup> The original list included 12 barriers such as: difficulty finding helpful contact persons within the service system, emotional barriers involved with thinking their parents' mortality, or disagreement with a relative with a disability about the future.
5. Knowledge of adult services and delivery systems. Siblings will rate their knowledge of the services received or needed by their brother/sister with ASD.<sup>65</sup> We will use a list of 12 adult services: physical

therapy, occupational therapy, speech and language therapy, psychological or psychiatric services, crisis/intervention services, personal care assistance, agency sponsored recreational or social activities, transportation services, income support, vocational services, respite services, and Medicaid. Siblings will rate whether or not their brother/sister currently receives the services, or if they do not know. If they know that their brother/sister is not receiving a service, they will indicate whether or not that service is needed. If they know that their brother/sister is receiving the service, siblings will respond to more detailed follow-up questions about the services received.

6. **Sibling's Knowledge of Family Future Plan**. Siblings will complete a checklist of their knowledge (yes/no/ don't know) of whether their family has established: (1) a will, (2) a special needs trust, (3), a financial plan; (4) a letter of intent; (5) a long-term residential plan; or (6) determination of future guardianship. These questions will be adapted from items used in Dr. Orsmond's collaborative study with Dr. Seltzer (R01 AG08768, Seltzer, PI). For the proposed work, this measure has been adapted to include follow-up interview questions to assess siblings' degree of knowledge about the information outlined in these documents or their parents' decisions/plans.

#### Proximal Outcomes: Sibling Behavior & Adults with ASD (Timing indicated below)

1. **Sibling Plan of Action (T2)**. Siblings will submit a written plan of action at the final session; control participants will complete this plan at Time 2. We will use a template on which siblings will detail their short- and long-term goals with respect to family future planning and concrete next steps. Researchers will rate each plan according to the following criteria: (1) inclusion of short- and long-term goals and next steps, (2) appropriate scope of next steps, (3) alignment with the needs and/or preferences of the adult with ASD, (4) accuracy (e.g., are they identifying the right resources to meet the identified goal?), and (5) sufficient detail (e.g., including the names and phone numbers of actual resources vs. making vague plans). At the 3-month follow up time point, we will assess whether or not the sibling attempted or achieved their primary short-term goal, the steps they took to achieve their goal, and concrete outcomes of the sibling's engagement in family future planning (e.g., family made an appointment with a special needs lawyer).
2. **Adult with ASD: Quality of Life (T1 & T3). Proxy report**: Siblings will rate their brother/sister's quality of life using the Life Experiences Checklist.<sup>66</sup> This has been used as a proxy-report measure by family members and support staff to rate the QOL of adult with ASD.<sup>67,68</sup> Five sections cover the individual's home environment, leisure activities, relationships, freedom, and opportunities. **Self-report**: Adults with ASD will complete the WHOQOL-BREF, a shorter version of World Health Organization Quality of Life assessment, the WHOQOL-100,<sup>69</sup> which includes 26 items rated on a 5-point scale addressing physical and psychological health, social relationships, and environment. This measure has been used with adults with ASD,<sup>68</sup> including Dr. Orsmond's collaborative study with Dr. Seltzer. We will modify administration as described by Hong and colleagues<sup>70</sup> to ensure greater accessibility across the autism spectrum.
3. **Adult with ASD: Unmet Needs**. Adults with ASD will report on their perceptions of unmet needs using items that Nicolaidis and colleagues<sup>71</sup> adapted for adults with ASD using items from the 2002/ 2003 Joint US Canada Survey<sup>72</sup> and 2007 National Health Interview Survey Questionnaire—Adult Access to Health Care and Utilization.<sup>73</sup> They will report on unmet needs in medical care, mental healthcare or counseling, preventive services, emergency department visits, outpatient visits, and hospitalizations. In collaboration with the CAB, we will add items probing unmet needs in residential and occupational domains.
4. **Adult with ASD: Perceptions of Family Relationships**: Adults with ASD will complete the 11-item Family subscale of the Social and Emotional Loneliness Scale for Adults<sup>74</sup> (e.g., "No one in my family cares about me," "I wish my family were more concerned about my welfare"). This scale has adequate reliability and validity<sup>74</sup> and has been used in adults with ASD.<sup>75</sup>

#### **Data Analysis**

*Aim 1: To develop the Siblings FORWARD program.* Directive content analysis will be used to interpret the data and transcripts from the focus groups and individual interviews.<sup>76</sup> Directive content analysis will result in refined objectives, content, and format of the Siblings FORWARD program that will be implemented and assessed in the subsequent open trial and RCT. In a series of recursive analyses, the first level of analysis will involve open coding, a strategy which involves investigators identifying all responses to focus group questions. To ensure reliability of interpretations, analyses of transcripts require multiple readings and coding by multiple investigators. The analytic team (Drs. Orsmond and Long) will each independently openly code one focus group transcript. We will then jointly compare and contrast the individual coding to identify recurring patterns in the responses to each question to develop initial operational definitions that describe the conceptual categories for each question. Specifically, we will identify conceptual categories related to family/sibling involvement in future planning, unmet needs of adults with ASD, and perceptions of the Siblings FORWARD program being developed. Coding will be done in NVivo<sup>46</sup> to facilitate sorting and comparison of the data.

The second level of analysis, axial coding, will focus on sorting and classifying the constructs to explicate the perspectives of the siblings, service providers, and adults with ASD. Using the agreed upon coding definitions, each investigator will independently code the remaining transcripts from the focus groups and interviews. The team will discuss relevant codes and establish axial coding categories in which subcategories from the open coding are then regrouped into more conceptual categories that refer to types of existing and future supports and services and barriers to implementation to promote increased sibling engagement and positive outcomes for the adult with ASD. Once a new set of subcategories has been identified, the research team will independently examine all transcripts to further develop the objectives, content, and format of the Siblings FORWARD program. We will conduct ongoing validity checks regarding analytic categories, revising the coding scheme as needed. NVivo will be used to organize the data according to the axial coding scheme. We will compare and contrast the data across all focus groups and in-depth interviews.

We will ensure that our analyses are credible using several procedures. For both open and axial coding, each coder will compare their findings to assess coder interpretations. Through discussion and comparison of the coder's reasoning, coder discrepancies will be resolved and coding definitions and constructs will be modified. To address the theoretical validity of our interpretations, we will discuss initial open codes and survey questions with the CAB.

*Aim 2: To assess feasibility and acceptability of the Siblings FORWARD program.* Qualitative feasibility and acceptability data will be collected during the open trial and RCT portions of the proposed project.

Acceptability (open trial and RCT): Qualitative data about perceptions of program usefulness and value collected during exit interviews with providers and participants will be evaluated using the qualitative methods outlined for Aim 1. Participant understanding of measures and procedures (open trial): Missing data and inconsistent response patterns on measures completed by siblings will be recorded. Data collection time will be calculated descriptively (mean, standard deviation, and range); participant burden associated with completing study measures will be captured qualitatively and summarized using content analysis. Enrollment and retention (RCT): Enrollment will be evaluated by calculating the number of eligible participants who chose to enroll in the trial. Descriptive statistics show the average number of sessions completed by participants and retention and follow-up rates. To assess selective attrition, we will evaluate the demographic and clinical characteristics of participants who completed the program versus those who did not using t-tests and chi squares. Adherence (RCT): Providers' fidelity to the manual will be assessed by evaluating video recordings of sessions against checklists of required components and calculating the percentage of required components that were present in each session; 20% of sessions will be coded for fidelity. Appropriateness of outcome measures (RCT): Psychometric properties of measures (alpha coefficients, means, SDs) and descriptive statistics of change scores from pre- to post-program time points (including confidence intervals) will be calculated.

*Aim 3: To assess the outcomes of participation in the Siblings FORWARD program.* We will examine whether the program shows promise of being successful with the intended population by conducting two-way repeated measures ANOVAs examining main effects of intervention condition (Siblings FORWARD vs. control) and repeated for assessment (pre- post- and 3-month follow up) on measures for program targets (sibling problem solving skills, family communication, future planning self-efficacy, barriers to future planning, and knowledge of services and family future plans) and proximal outcomes (sibling plan of action and adult with ASD quality of life, perceptions of unmet needs, and family relationships). Post-hoc tests will be used in multiple comparisons between groups and within each group. Effect sizes (Cohen's d) will be calculated using the mean difference of the changes recorded from pre- to post-program. We will also analyze percent change and reliable change.<sup>77</sup> If data are missing, analyses will be performed using the 'last observation carried forward' method for intention-to-treat analysis. We will examine descriptive statistics (mean, SD, confidence intervals) at the participant level for patterns and direction of change on outcome measures. We will conduct intent-to-treat analyses if there is program attrition. Finally, we will examine benefit of the program to control participants who elect to participate in the Siblings FORWARD program using one-way ANOVAs (pre to post-program) on treatment targets and proximal outcomes.

We will conduct a preliminary investigation of potential moderators of program effectiveness, including characteristics of the sibling (BAP), family (income, race/ethnicity, English as the primary language, number of family members with ASD), and adult with ASD (severity of ASD symptoms, problem behaviors, functional independence). We will calculate correlations between these variables and change scores in primary outcome variables, and independent samples t-tests between these variables and program completion status.

## Design Considerations & Future Directions

Our decision to focus on siblings (and exclude families without siblings) responds to the literature identifying siblings' preference to assume a greater role in their brother's/sister's planning and indicating that "family-centered" programs are perceived as focusing exclusively on parents.<sup>26,27</sup> This allows us to tailor the program to siblings' unique role and ascertain program feasibility within this specific population. In the future,

we may expand the program to include families without eligible siblings; these families may enroll cousins, nieces/ nephews, close friends, etc. Our decision to enroll a heterogeneous sample across ASD severity, age, service needs, and extent of existing family planning follows from our strong desire to design a program that can be incorporated into community settings (which serve heterogeneous populations) in the future. We have attempted to make the materials and session goals flexible enough to be applied across varying ASD presentations and family situations. If successful, we expect that this model can be applied to other disability populations in addition to ASD. Similarly, our decision for community providers to deliver the program corresponds to our goal of incorporating community input from the outset and designing a program that can be feasibly implemented on a larger scale. We expect some provider turnover and are prepared to provide in-depth training to subsequent staff and to guide participants through therapeutic aspects of staff transition.

Based on conversations with state- and national-level Arc executives (see Support Letters), we plan to roll out

future iterations of the program on a much larger scale. The decision to exclusively utilize telehealth technology is due to the small nature of the study and our desire to make this novel delivery method universally applied. In future iterations of the program, we will likely give siblings the option of participating in person. Similarly, the focus on English-speaking families is also due to the small scope of the proposed project and limited resources. We plan to develop program materials in Spanish as a proximal follow-up to this proposed work, and we will incorporate Spanish language providers and/or interpreters into future trials. We have attempted to reduce disparities by taking a community-based approach and selecting Arc chapters with high diversity in terms of race, ethnicity, and income. The inclusion of the adult with ASD corresponds to attempts to develop truly person-centered future plans. We expect that the degree and nature of involvement of the adult with ASD will vary widely, and we will collect detailed feedback about how to increase their involvement as much as possible. Finally, the utilization of an information-only control condition corresponds to the current standard of care in which siblings are seldom involved in future planning at all. Additional future directions in subsequent, larger-scale trials include longer-term follow-up of participants to assess program efficacy and increased examination of mediators and moderators.

**Table 4: Timeline & Milestones**

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Y1	Jan-Mar	<ul style="list-style-type: none"> <li>- Convene CAB to review qualitative goals</li> <li>- Hire &amp; train staff</li> <li>- Finalize recruitment procedures</li> </ul>
	Apr-June	<ul style="list-style-type: none"> <li>- Recruit &amp; conduct focus groups/interviews with service providers (N=12-16), siblings (N=18-24), &amp; adults with ASD (N=8)</li> <li>- Analyze qualitative findings</li> <li>- Finalize program manual by incorporating qualitative findings &amp; CAB input</li> <li>- Set up WebEx technology</li> </ul>
	July-Dec	<ul style="list-style-type: none"> <li>- Provide in-depth training on program delivery to providers</li> <li>- Conduct open trial (N=5)</li> <li>- Provide ongoing, intensive consultation to community providers</li> <li>- Collect, analyze, &amp; iteratively implement feasibility &amp; acceptability data from open trial participants &amp; providers</li> </ul>
Y2	Jan-Dec	<ul style="list-style-type: none"> <li>- Implement the RCT by enrolling ~2 families per month (24 siblings)</li> <li>- Prepare conference papers &amp; manuscripts from qualitative data</li> </ul>
Y3	Jan-June	<ul style="list-style-type: none"> <li>- Continue RCT by enrolling ~2 families per month (12 additional siblings)</li> </ul>
	July-Sept	<ul style="list-style-type: none"> <li>- Finish collecting 3-month follow-up data</li> <li>- Offer Siblings FORWARD program to control siblings</li> </ul>
	Oct-Dec	<ul style="list-style-type: none"> <li>- Collect post-program data for control sibs who later enrolled in Siblings FORWARD</li> <li>- Conduct quantitative &amp; qualitative analyses from RCT</li> <li>- Revise and finalize program manual</li> <li>- Prepare conference papers &amp; manuscripts</li> <li>- Prepare grant application for a larger-scale trial of the program</li> </ul>