

# Designing a Social Network to Support the Independence of Young Adults with Autism

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## ABSTRACT

Independence is key to a successful transition to adulthood for individuals with autism. Social support is a crucial factor for achieving adaptive self-help life skills. In this paper we describe the results of a formative design exercise with young adults with autism and their caregivers to uncover opportunities for social networks to promote independence and facilitate coordination. We propose the concept of *SocialMirror*, a device connected to an online social network that allows the young adult to seek advice from a trusted and responsive network of family, friends and professionals. Focus group discussions reveal the potential for *SocialMirror* to increase motivation to learn everyday life skills among young adults with autism and to foster collaboration among a distributed care network. We present design considerations to leverage a small trusted network that balances quick response with safeguards for privacy and security of young adults with autism.

## Author Keywords

Autism, independence, social network, collaborative care

## ACM Classification Keywords

H.5.3 Group and Organization Interfaces: Collaborative computing, Computer-supported cooperative work

## General Terms

Design, Human Factors

## INTRODUCTION

The rise in the number of children diagnosed with autism began in the early 1990s. Since then, these individuals have transitioned from a protective school system to a much less protective adult world. [17]. Challenges in self-care, everyday life chores, and social communication adversely impact the attainment of independent functioning in adulthood. Several studies reveal that adults with autism, even those with higher intellectual abilities, rely heavily on their families' support in employment, living, and

relationships [9,23]. The challenges of day-to-day functioning lead to higher dependency and create a formidable burden for caregivers [13]. We contend that appropriate social support is critical for independence of adults with autism [16] and decreasing the burden currently shouldered by primary caregivers [13].

Our research goal is to design a system to promote independence and facilitate collaboration around caregiving activities for adolescents and adults with autism. To this end, we created a concept called *SocialMirror*, a specialized online social network embedded into everyday life to support young adults with autism. In this paper, we describe the results of design exercises conducted with 12 young adults with autism and 16 caregivers actively involved in planning and supporting the transition to adulthood.

We propose two major CSCW contributions. First, we introduce a novel social networking concept for individuals with autism and their caregivers. Second, we provide empirically driven design implications for a system that helps individuals practice life skills in a social context by facilitating quick responses from a network of caregivers.

We begin by reviewing related work and discussing social and technological support for independent living. Next, we explain our overall design process, and present the design of *SocialMirror* along with usage scenarios. We describe the result of focus groups and highlight potential impacts and barriers to utilization of this social network by young adults with autism as well their caregivers. Finally, we conclude with considerations for leveraging a trusted network for balancing quick response while safeguarding the privacy and security of young adults with autism.

## RELATED WORK

### Autism and Independence Challenges

Young adults with autism face challenges in the area of organization, initiation, and generalization skills [3]. These challenges impact their communication, and social skills [16]. They also impede development of successful independent skills [10], increasing the need for adult prompting and continuous support [13]. For this reason few adults with autism live outside of their parent's home or are employed [9]. Even individuals who successfully transition to independent living still report that they often struggle

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with domestic tasks like cooking, taking medications, personal hygiene and other tasks [3,13].

The constant support that these individuals require also takes a toll on the relationship with their primary caregivers. Compared to parents whose child with autism lives away from home, parents who still have their child in the home report that the need to help with daily schedule management, child security, and constant prompts to perform everyday tasks contributes to their heightened stress level and negatively affects the quality of the relationship with their child [13, 23].

#### **Prompting System for Independent Daily Tasks**

Prompting systems have been used to assist individuals with cognitive disabilities in providing timely reminders of upcoming day-to-day tasks and completion of multiple step tasks [24]. For instance, a mobile prompting platform, MAPS (Memory Aiding Prompting System), provides directions from one location in a building to another and instructs individuals to attend to tasks on a minute-by-minute basis [2]. Similarly, self-operated prompting systems have also been used for individuals with autism to help them stay focused on specific tasks [15]. However, such technological interventions are still limited to giving individuals pre-programmed instructions. The real challenge is to provide personalized information tailored to the current situation the individual is facing.

#### **Social Software for Supportive Activities**

A growing number of studies highlight social software that supports a variety of community relationships in health [21] and wellness [6]. One study found that people were better able to cope with personal problems when they received online suggestions from a community of people [4]. Researchers have investigated the presence of supportive relationships online [20]. For example, websites, such as PatientsLikeMe [19], provide a social space for patients to update and share their status and ask for help. However, there are issues regarding a patients' uncertainty about what to post, and the workload in keeping their status updated [20]. To ease the workload of this type of support, software has been developed that allows the individual and his or her social network to share their calendars [5] and wellness information [6]. Collectively, such social software facilitates on-demand support for the individual by harnessing the collective intelligence.

We propose that a similar opportunity exists to empower the autism community through social support. Individuals with autism have close-knit trusted networks that may include parents, siblings, relatives, friends on the autism spectrum, volunteers, residential staff, teachers, therapists, and other professionals. These care networks can play a key role in personal growth, acquisition of new skills, expanded social benefits, and access to community resources [13]. The Internet can be especially important for adults with autism with few formal supports, as online communities allow them to establish a collective informal support network. This may include both practical supports, such as

job interview skills and emotional support, such as sharing of experiences and feelings [14]. Although this research acknowledges the benefits of both offline and online networks to support an individual, many concerns remain about building trusted relationships with anonymous groups for individuals on the spectrum [1].

#### **RESEARCH CONTEXT AND METHODS**

Our research employed a three-phase design process, summarized in Table 1. Our goal was to generate concrete design ideas for how technology would support the independence of individuals with autism from adolescence into adulthood.

The first phase involved three months of informal participant observation to better understand the needs of young adults with respect to performing everyday life skills in a social world [11]. Through a special invitation from a local autism center, three of the co-authors attended weekly social group meetings for adults (all over 25 years old) with high functioning forms of autism, or HFA, such as Asperger's Syndrome.<sup>1</sup> The purpose of this weekly social group was to allow individuals with autism and neurotypical volunteers to engage in fun social activities like bowling and trivia. This event not only enabled the individual with autism to socialize in a real but low stress environment, but also afforded us the opportunity to establish a rapport with the primary stakeholders of our design exercise. We gained valuable insights into a variety of everyday challenges that impede successful independent life.

Soon after meeting the adults, we began to imagine possible designs to mediate the challenges we observed. Initial ideas included building a mobile system that prompts pre-programmed instructions on how the individual should behave appropriately in response to a certain context such as time and location. We imagined such a system might be beneficial to the individuals, but remained uncertain about how the caregivers would react.

We conducted semi-structured interviews (Phase 2) with 13 caregivers to help us understand their concerns about the transition to adulthood and to discuss whether an imagined system could support their current practices and alleviate their concerns. The participants, recruited from the local autism research community, included high school teachers (n=8), a parent (n=1), a counselor (n=1), adult program coordinators (n=2), and a transition specialist (n=1). The preliminary results derived from these interviews motivated three design guidelines: (1) *motivate engagement in self-care activities*, (2) *embed advice in the context of the day's events*, and (3) *leverage a natural network of individuals and caregivers*.

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<sup>1</sup> Though there is not a specific diagnostic definition for high functioning autism, or HFA, we use this label in this paper to represent individuals with autism who demonstrate the ability to communicate verbally.

A conceptual breakthrough came during the process of developing the guidelines. We realized that harnessing human intelligence to address the challenges faced by an individual would have a greater impact than relying on a single technology. This insight led us to speculate about the power of social networking, which could provide in-situ feedback to the individual by connecting him or her with a distributed network of qualified and available advisers.

We proposed a full-length mirror display as an initial embodiment of a social networking tool embedded in the natural environment. Dubbed the SocialMirror, this initial idea was intended to demonstrate the need to connect to advice on personal appearance and hygiene from within the home. We felt it is important to make this initial idea very concrete in order to further elicit reactions from potential stakeholders. We produced paper mockups, including screenshots of a social networking website and application, a simple prototype implemented with the Facebook API, and a concept video that presented various usage scenarios. We used these design mockups and the concept video in Phase 3 as the basis for a series of focus group studies with students, adults and caregivers.

Prior to the focus groups, we wanted to investigate whether our research procedures and questions were suitable for the participants. We conducted a pilot interview with a 26-year-old adult with HFA who moved away from home to go to college. Throughout the pilot study, we acknowledged structured interviews alone are not suitable for individuals with cognitive difficulties because they struggle with recalling and describing their experiences [24]. The modified procedure included introducing a set of pictures (Figure 1) that contained examples about real life problems to help the participants elaborate their own problems. We then showed the video mockup [8], to enable a discussion about how the participants would use such a system and in what contexts it would be useful.

After the pilot interview, we conducted focus group sessions with four groups of participants: The first group included three teachers and three students with HFA (mean age = 23) from a community school. The students currently lived with their guardians, but planned to live alone in the future. The second group was a mother and her son (age 27) with HFA who had successfully lived alone for two years, but recently returned to the family due to financial issues. The third group also was a mother and her son (age 35) with HFA who is living with a roommate on the autism spectrum. The fourth group involved a social skills coach and 6 young adults (mean age = 21.7) with HFA who meet regularly for a social evening out.

At the beginning of the session, individuals with autism and their caregivers were interviewed separately to minimize any potential influence of caregivers on the individuals with autism. We asked individuals what concerns they have for daily life, how they seek out a person to help them, and whom they would be most comfortable to ask.

Research Phase	Methods	Participants & Activities
Phase1	Participant Observation	<ul style="list-style-type: none"> <li>Participants: 11 adults with autism</li> <li>Attended in social activities for adults with autism</li> <li>Goal: Design inspiration</li> </ul>
Phase2	Semi-structured Interview	<ul style="list-style-type: none"> <li>Participants: 13 caregivers</li> <li>Discussed topic of barriers to independent life</li> <li>Identified everyday challenges and strategies to cope with</li> <li>Goal: Design refinement and documentation</li> </ul>
Phase3	Homogenous Focus Group Interview	<ul style="list-style-type: none"> <li>Participants: A pilot participant (A man with HFA)</li> <li>Group #1 (3 men with autism and 3 teachers)</li> <li>Group #2 (A man with HFA and his mother)</li> <li>Group #3 (A man with HFA and his mother)</li> <li>Group #4 (5 men and 1 women with HFA and a coach)</li> <li>Review and critique the SocialMirror concept</li> <li>Discuss topic of concerns using social network</li> <li>Goal: Design requirements and considerations</li> </ul>
	Heterogeneous Focus Group Interview	

**Table 1. Methods and Activities for each design phase.**

Conversely, we asked caregivers about challenges to understanding the needs of individuals, ways to provide help, and potential people they would allow answering questions from the individuals with autism. Once this session was completed, the two groups of participants were brought together and shown an initial prototype and video of SocialMirror to elicit comments on how this specialized social networking service concept may or may not address their needs and concerns.



**Figure 1. Life skills cards used in the focus group interviews before the introduction of SocialMirror.**

All interviews were recorded and transcribed. Three researchers coded the data and the quotes presented in this paper are representative of broad themes of agreement grounded in our data [22]. We then iteratively clustered these codes into higher-level category groupings until we arrived at the themes that we will describe in the design guidelines and focus group results sections.

## DESIGN GUIDELINES

The formative interviews with caregivers (Phase 2) yielded two results. First, we gained a better understanding of how assistance with transition works, what difficulties are inherent in current practices, and how the situation could be improved. Second, we identified guidelines to direct the design of technology for individuals and their caregivers seeking to help support independence in everyday living.

### Motivate Engagement in Self-help Activities

Many caregivers reported challenges for individuals with autism in the initiation and motivation for performing everyday life skills, such as self-help activities (e.g., shaving, dressing, managing personal hygiene) or household chores. One participant (P1) is a father of a 23-year-old son with autism. He indicated that it is difficult for his son to notice and attend to the relevant aspects of himself and his environment: "... He struggles with cleaning, and he's really not good at self-monitoring. He doesn't see a room and the level of dirtiness or disorganization that you and I might see. As a result, he ends up getting anxious and frustrated." (P1)

Without external motivation, individuals with autism may not initiate self-care activities. Because the individuals with autism rarely know *whether* they have a problem with this area, direct prompting has been a dominant way to trigger self-help activities. One teacher explains: "*We have discussions about dirty and greasy hair... we go to the bathroom to see the mirror and I'd say this is not fine. Here, my hair is clean because I washed it this morning. Now, let's look at yours. See how it separates?*" (P4) However, caregivers pointed out this prompting at every single step would not be the ultimate solution because it may cause overreliance. Therefore, any support must help the individual identify what help he needs and initiate communication to seek help spontaneously.

### Embed Advice in the Context of the Day's Events

Individuals with autism often have prepared scripts, or protocols, describing details of how to carry out an activity, but they often have difficulty understanding when to use that script. For example, caregivers stated that knowing *when* to do laundry is as important as knowing *how* to do laundry. For this reason, existing interventions that provide pre-made protocols, such as scripted to-do lists or visual cues for how to complete the activity, are not enough. Three teachers noted that individuals with autism have difficulty associating the protocol or visual cue with their ongoing activities.

Teachers and parents strive a great deal to integrate the protocols into the individual's daily routine so that the individual applies them to actual activities rather than

simply having the directions available. "*Sitting in a computer terminal in isolation going through life and social skill programs, in my experience, does not give good results [...] skill training has to be a portion of the day.*" (P3)

A notable example of the importance of the contextualization of skill training was shared calendar management. One of the high school teachers stated that each student in her school is required to have an electronic calendar that is shared with the teachers. The day's events appear on the calendar, allowing teachers to remind their students what they learned in school and to deliver adaptive advice when needed. Such schedule sharing can have a great impact on facilitating skill training by providing in-situ advice about what, when, and where the skill will be performed. For individuals with autism who may be resistant or unable to ask for help, a shared schedule provides a simple mechanism to facilitate intervention.

### Leverage a Natural Network of Caregivers

Not surprisingly, our findings confirm that primary caregivers, usually parents, play a major role in orchestrating the transition from the family home to independent living. This centralized role raised concerns about overreliance or dependence on one-to-one support. A father described his son as inclined to rely on him too much, and to get extremely anxious if he was unavailable to answer questions over the phone: "*He has a tendency to call me too much to ask me for help coping with his problems*" (P1) For this father and other participants, being able to anticipate possible scenarios with other caregivers in advance of important events (e.g., job interviews) would be a good strategy to alleviate the anxiety felt when parents are unable to help immediately.

The natural formation of a supportive network benefits not only individuals with autism, by enabling on-demand support, but also benefits their caregivers by distributing caretaking responsibilities. Leveraging the existing network that provides support to the individual with autism, along with building up a wider trusted network, should be a primary consideration in developing a system to support transition to independence. A system that leverages the individual's social network provides caregivers with continued contact with the individual, but also a sustained communication channel with the other caregivers (e.g., residential staff).

In summary, we note that individuals with autism demand and desire independence, yet specific problems (e.g., little motivation for self-care) impede their ability to perform everyday life tasks successfully. Few interventions support individuals' ongoing activities. Even in cases where adults with autism manage to live in a semi-independent living facility, they often rely on repeated promptings and direct supervision to complete day-to-day activities. The design guidelines developed from our analysis led us to develop a system that supports individuals with autism in learning adaptive self-care skills through collaborative advice from a social network.

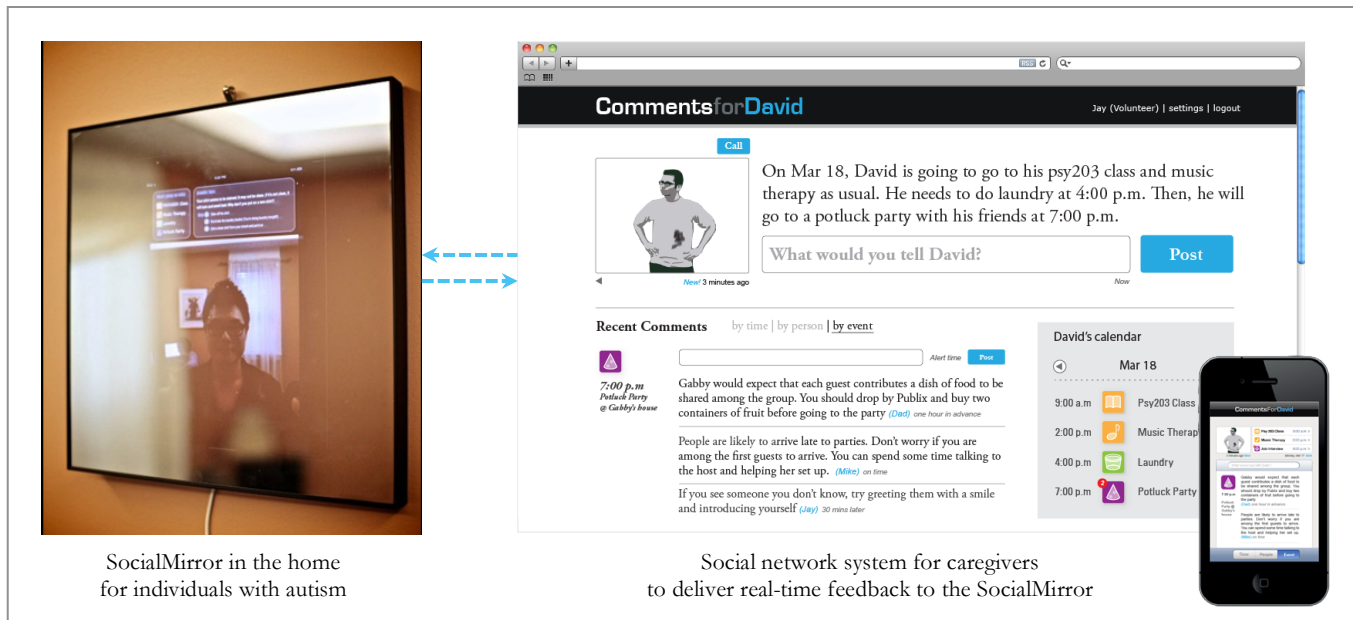


Figure 2. SocialMirror deployed in home (left) and social network service as seen by a caregiver (right).

### SOCIALMIRROR: SYSTEM DESIGN

Inspired by these three design guidelines, we developed a prototype, *SocialMirror*. Figure 2 provides an example of how we might embed a life skills support mechanism into everyday objects in the home. SocialMirror consists of two parts. First, an interactive display integrated into a mirror provides the opportunity to ask and receive advice with an attached day's calendar. Second, the system is connected to an online social network that sends questions to a trusted set of family, friends and professionals. At the beginning of each day or the night before, an individual with autism can see his calendar that indicates his day's events. He can take a picture of himself and send a question to his social network if he feels the need to ask for advice. For example, he might want to know if he is dressed appropriately for an upcoming event on his calendar. SocialMirror helps to contextualize the request to the rest of the network by attaching the picture, the question, and the day's calendar of events for all in the trusted network to see. When answers arrive from the support network, they are immediately reflected back to the individual. SocialMirror is also available as a webpage or a smartphone application, facilitating access to the support network at any time and from anywhere.

#### Mirror: A Natural Object for Asking and Getting Advice

The creation of a natural communication medium via an interactive display embedded in mirror provides a foundation for unobtrusive connection between young adults and their social network. The mirror is a display, and in fact its natural affordance could be made to sense when the individuals is in front of it and prompt them to seek advice on appearance or the day's activities. The networked SocialMirror allows them to be aware of their current status and helps them get feedback about their status from

multiple caregivers. The feedback is also automatically replicated on the individual's 'portable mirror' (e.g., cell phone), in order to allow him or her to carry it around on-the-go (e.g., kitchen, school, or grocery store) and refer to it throughout the day.

#### Controlled Access: Safe and Trusted Network

While existing social technology often serves to form and maintain weak ties, the goal of our system is to extend pre-existing strong ties with intimate acquaintances, people whom the individual is able to trust such as family members, friends, and other professionals (e.g., teachers, counselors, job coaches, and transition specialists). This trusted network can also be expanded to include 'trusted strangers,' people who are willing to commit their time to help the individual in order to successfully distribute a main caregiver's workload and give the individual trustworthy feedback. One can imagine a trusted stranger as a close associate of one of the main caregivers (e.g. the mother's friend), or a trained professional or volunteer that is contracted for service by the individual or family.

We envision that primary caregivers will act as gatekeepers to ensure a safe environment for their children. Members of the extended social network are initially vetted by the caregivers. This process results in a reliable trusted network and ensures that the individual is aware of who the extended caregivers are in his or her social network.

#### Picture: Spontaneous Communication Medium

We use a picture taken by the individual as a communication medium between an individual and the trusted network. The picture is intended to let the individual easily initiate contact with their trusted network and explain the need for advice. Since individuals with autism often have difficulties initiating conversations [1], the simple

picture-mediated interaction may allow them to initiate communication more easily without the need for a detailed verbal explanation.

### Calendar: Day's Events with Visual Support

While existing calendars only show the time and the day's events in textual form, our calendar additionally includes representative imagery to illustrate the activity. Visual support is particularly beneficial to individuals with autism because it helps make abstract concepts concrete and capitalizes on their inherent visual learning strengths [7]. The representative images of each activity are classified into three categories: daily chores, official appointments, and social events. We differentiate these three event categories using different colors: green, yellow, and purple.

### Contextualized comments on picture and calendar

To help the trusted network provide appropriate and contextualized instructions, the system allows members of the network to view upcoming events in the individual's calendar and the shared pictures that show his or her current status. By allowing multiple caregivers to provide comments on the shared schedule and picture, the system can facilitate communications among caregivers. The trusted network can give the following three types of comments.

*On-demand Commenting:* The trusted network gives feedback on the individual's queries or shared picture. This request implies that the individual requires feedback on his or her current situation as soon as possible, so a prompt reply is essential. When members of the trusted network get a notification that the individual has posted a request, they can add comments on the post. These comments are displayed right below the picture, so the individual can see the comments along with the related picture.

*Allocated Commenting:* Members of the trusted network can also assign relevant comments to a specific event on the calendar before the event takes place, and additionally specify the time when their comments are to be delivered to the individual (e.g., 10 minutes before the event). The individual is able to see the comments either by accessing the calendar or through the alert that is sent at the designated time.

*Sub-Commenting:* Even with a small number of people in the trusted network, the amount of comments provided may be overwhelming to the individual. Thus, the system contains a sub-commenting feature that aggregates multiple comments under a same topic. Under an original comment, multiple people in the network can provide more sophisticated advice. The main goal of this feature is to reduce the number of comments that the individual sees at any one time, and to allow the network to come to a consensus before a piece of advice is presented to the individual.

### USAGE SCENARIOS

A video prototype of SocialMirror depicts three usage scenarios for David, a fictitious 22-year old with HFA [8].

Table 2 summarizes those scenarios. We implemented an initial prototype of SocialMirror that includes the hardware, a 7" tablet combined with a reflective panel (See Figure 2), and two essential social networking capabilities using the Facebook API, sending a picture to a group of registered people and receiving their comments.

<b>Scenario1</b>	Supporting self-care to stay neat and tidy.
<b>Scenario2</b>	Advice for acquiring better professional etiquette.
<b>Scenario3</b>	Learning subtle social rules in the moment.

**Table 2. Usage scenarios in the video prototype.**

### FOCUS GROUP RESULTS

In summarizing the results of the focus groups, we describe reactions to the form factor of SocialMirror, how its blending of functional and social capabilities were received, and its potential for empowering a community of caregivers. We also sought to understand potential barriers to adoptions.

### Form Factor Influence

SocialMirror is designed to stimulate spontaneous advice seeking by the individual with autism. It is meant to engage him or her in learning life skills and social norms suggested by others. The overall physical elements, such as the size of the display, the location of the mirror, and the interface itself, can all influence the willingness of the individual to initiate communication through the system. The form factor we suggested was a large mirror (head to waist) located in bedroom. An individual with HFA commented that SocialMirror might encourage spontaneous communication because it would be seen when they are most likely to require help: *"It would be nice to know whether I look fine. If not, what should I improve, like how can I look better, more appealing?"* (I1)

Beyond the physical form factor, the mirror is also a conceptual metaphor that affects the perceived usage. Our findings suggest that SocialMirror, through simple connection to a social network of advisers, serves as a tool to 'reflect' on the social norms and conventions that might seem opaque to many individuals with autism. A student with HFA said: *"For the longest time I wore socks with sandals, and I still have no problem doing it. But, if I have the mirror, I will stop doing it because people will start saying over the mirror, 'Hey, it's not okay, you have to stop.'"* (I5) We noticed that SocialMirror could be used to confirm the fact that a suggestion from a caregiver is supported by general social norms. A counselor noted: *"Now I can simply tell the student if you don't believe me go ask the mirror."* (C3)

Participants addressed the necessity of a portable version of SocialMirror, since opportunities to learn life skills arise in places beyond the bedroom where the mirror would be located. For instance, if an individual needed guidance with a recipe while preparing a meal, he or she could easily bring a portable version into the kitchen to interact with others while cooking. Participants also expressed a desire to use SocialMirror outside the home. A student said: *"I would use*

*this in school or church to get social etiquette like what I should be saying to people.” (I2)*

While most participants reacted favorably to the idea of a mirror as a simple querying channel, our results also indicate challenges for SocialMirror. For some passive students, the form factor would not in and of itself promote the desire to ask for help. Furthermore, just because the individual receives prompts or advice does not mean he will follow them. A man with HFA told us that: *“I don’t like being forced to feel or to do something. I like to be relaxed and comfortable, and not being reminded constantly of all the million things I have to do is nice.” (I1)* To encourage the individual to seek advice, encouragement both from the system itself (e.g., personalized help reminder) and from the social network (e.g., rewarding, offering help based on the individual’s interests) may be required.

### **Blended Functional and Social Capabilities**

Our participants resonated strongly with the concept of integrating pictures and calendars to give context to the feedback they receive. The focus group interviews revealed an interesting blend between the functionality of a calendar and the social aspect of a picture. This blending suggested two potential targets for increasing independence, elaborating problems and schedule structuring.

#### *Supporting Elaboration of Problems*

In our attempts to design a simple way to ask for help, we focused on the particular difficulty individuals with autism experience in dealing with new situations and verbalizing when they need help. One study participant noted that the ability to share a picture would enable him to explain the context of his problem without the complex information processing required when writing out a full explanation.

Caregivers also reported that the ability to ‘see’ the problem the individual is encountering by means of a picture would facilitate communication, allowing them to provide better support. One of the teacher in the first focus noted: *“I would feel better if I had a kid calling me because they don’t know how to handle the situation, and if I can see the situation I am going to feel more useful to this kid. I also can make them take a picture to help me to understand the situation. It will help the individual to explain their current situation in detail.” (C2)*

However, the picture-mediated inquiry may not be appropriate to an emergency situation due to the delay in communication. A feature that allows for synchronous communication was suggested: *“If there is a situation that they didn’t know they have an exam at school, but unexpectedly after they get into the class room they realize that they have the exam. You may include the button like instant message or call for unexpected situations when they need immediate help.” (I5)*

#### *Structuring the Schedule*

Participants were very excited to see a day calendar on the mirror since they already employ a calendar to help them stay on schedule. One individual always carried a small notebook to keep up with schedule updates. Also, teachers noted that their students were asked to set up an electronic calendar (e.g., Google calendar) that sends alerts to their

mobile phone. A common problem that our participants stated was that it was difficult to deal with sudden changes to their daily plans. They expressed that being able to see the events for the day on SocialMirror would help them anticipate what would be going on for that day: *“I sometimes don’t know about schedule details like few days or last minutes, so that would be very helpful for me to know what I expect in a [given] day.” (I2)*

Another commonly cited challenge and opportunity for SocialMirror is time estimation: *“I guess another challenge of mine would be accurately estimating time for each event.” (I5)* Participants often found comfort in strict plans in detail including start, end and transition time. They recommended integrating an estimated “time per event” into SocialMirror’s calendar. Beyond the day’s scheduling, participants expressed that SocialMirror had the potential to alert them to anticipated challenges and skills to cope with the challenges for events in the future. Sharing the individual’s calendar in advance would enable multiple members to think about issues that might arise in advance and provide adaptive prompts before the event starts.

### **Community Empowerment**

#### *Distribution of Labor*

Parents and caregivers agreed on the value of a social network to distribute the labor associated with providing support to an individual. A counselor noted that an extended trusted network was desirable because an individual’s needs become more complex as he or she assumes independence. She defined a term, “trust committee,” as a collective stable group of supportive people who can provide advice. She also envisioned that the social networking system could allow the trust committee to have access to the individual who needs help at anytime and anywhere: *“If you can harness all the people that care about that individual, that seems to me really powerful. Everybody is tuned in at a given time.” (C3)* She noted that a main primary caregiver does not need to be always available, but can still play a central role in monitoring the network and having the final say on any influential decision.

However, distribution of labor across multiple caregivers may result in blurring the obligation to respond: *“Sending [a query] to everyone at once can be tricky because people would be like, “Well, I would respond, but I’m busy. I bet one of his other friends will respond.” And if they all say that, then no one ends up responding. It’s the diffusion of responsibility.” (I1)* Participants recognized such challenges for SocialMirror and converted them into potential new features, such as one where the queries can be targeted ahead of time (e.g., financial queries go to parents, homework queries go to teachers, queries about attire go to siblings or cousins).

#### *Catalyzing Collaborative Helping Activities*

The most commonly expressed benefit of distributed caregiving to the individuals themselves was that they could learn new skills and acquire new capabilities as a result of getting advice from multiple sources. A student noted that SocialMirror would help him be more flexible in dealing

with a new unexpected situation: *"If there are multiple suggestions, I would go for a backup and see what the next best one was to deal with [a situation]."* (I2) Caregivers also saw that an additional benefit of SocialMirror is that their children would not be confined to receiving advice solely from them. A mother of a man with HFA (I5) pointed out, *"I think also it's better if he goes outside the parental network because – there are so many little things I saw that we do already. Now, if it came from somebody else, it might be so much better. So, this would be kind of different I'm thinking."* (C4)

Participants also noted that SocialMirror would become a powerful tool to connect the caregivers and facilitate communication between the various care domains (e.g., home, school, job). Typically, once a student learns a particular activity at school, a protocol describing the procedure is sent to the parents so that it can be practiced at home as well. This reporting procedure between caregivers could be easily transmitted through the social network.

#### **Connectedness and Reciprocity**

Our concept emphasizes features inherent in social networking — bridging, bonding, and maintaining relationships between an individual and strong ties (e.g., parents, siblings, or close friends) or weak ties (e.g., residential coordinators, counselors, neurotypical volunteers) [4]. However, at the outset it was not clear if the benefit of such social properties would hold for individuals with autism, who often lack the motivation to engage in social interaction. In contrast, all young adults that participated in the design exercise stated that they understood the value of communicating about life skills via an online community and were eager to get involved in a long-term study. This may have been related to their age and previous experiences with various social networking services (e.g. Twitter, Facebook, MySpace, SecondLife). Several participants stated they wanted to keep connected with their peers not just for feedback, but also for fun: *"Let's say if I got a haircut, I would share my haircut, 'look what I got on my haircut'... or I would share random ideas. It would be more for fun."* (I6)

During the demonstration session, one participant suddenly took a picture with a hilarious facial expression. Teachers and students in the focus group session were laughing and talking about what he did. In this example, we found a side activity that we did not anticipate; that is, sharing an interesting moment and jokes could augment the main activity of 'asking for help,' making it a more casual and fun experience.

We also noticed that the participants themselves acknowledged the benefit of bridging weak ties with physical distances. A mother stated she would want to invite relatives who live in another state to join her son's SocialMirror network: *"It would be good way for him to stay in contact with his cousins and other family members, a couple of different folks that are not at home, or not where he's living [out of state]."* (C4)

The individuals with autism in our study anticipated the social reciprocity and emotional support they would attain through Social Mirror. One individual noted: *"I'll ask a friend like 'Hey, I'll do dinner today, you cook dinner tomorrow.' That's the social thing. Well, I guess I've asked for help communicating with others."* (I1) Many young adults in our study reported they would feel more attached to their peers and get more engaged in what peers suggested through such reciprocal activities.

#### **Barriers to Utilizing Social Network**

The participants engaged with the concept and quickly came up with situations where they could use the technology. However, we also identified concerns associated with using a social network. The potential challenges include safety and privacy, conflicting advice from multiple caregivers, and intensified tension between an individual and his or her parents.

#### **Safety and Privacy**

Participants expressed concern about being involved in bad incidents such as bullying and being taken advantage of in cyberspace: *"I think the area that would be of concern that I would have is the young adults, because they are very trusting. So the importance of who he entrusts that social network to and he could have a bad choice there."* (C4) This echoes other findings related to safety and privacy issues in computer-mediated communication for adults on the autism spectrum [1]. Although SocialMirror affords primary caregivers the gatekeeping authority to confirm network membership, participants still voiced their concerns. A teacher commented that SocialMirror could mislead the individuals with autism because they are very rule-driven and likely to interpret each comment too literally.

The individuals themselves also raised the issue of personal information disclosure. They noted that in asking advice from trusted friends, they might share details that reveal their personal information and lifestyles. Consequently, they were concerned that SocialMirror might become a surveillance camera that monitored their everyday activities: *"What if someone comes in and they can turn on your mirror or webpage and read all the messages, all the concerns you've had. That would be uncomfortable."* (I1) To address the privacy concern, this participant came up with the idea of controlling visibility based on the relationship: *"I will keep that [information] limited to my intimate family members, or my friends. I don't want everybody to know about my issues."* (I1)

#### **Conflict of Ideas**

As participants stated, the dynamics of members in the social network can broaden opportunities to get feedback from differing perspectives. However, it increases the potential for confusion if two or more pieces of advice are in conflict. One participant clearly suggested a way to reconcile such conflicts: *"Would it make sense to have certain people in certain categories for certain things?"* (C1) It is clear that management of conflicting advice needs serious consideration in a deployed system.



### ***Tension between Young Adults and Parents***

In the SocialMirror system, parents are expected to safeguard the social network by acting as the gatekeeper for membership in the network. However this role may intensify the tension between the parent and the child. An adult expressed a strong objection to having parents act as moderators: *"I'm completely opposed to giving someone else control in my social life."* (I1) The individual noted that simply offering help doesn't mean that the individual will accept it: *"I haven't been as receptive to help, because my parents will a lot of times offer to help, but I just don't want their help."* (I1) Furthermore, the participant noted that parental involvement in his social network would not produce independence. A teacher emphasized the importance of respecting the individuals' free will: *"You don't want to force or control people. You're supposed to educate and encourage."* (C2)

This reinforces the idea that creating the network must be the role of the individual and the primary caregiver's role is to support him in his decisions. In fact, parents in our study did not think they needed to have complete authority. Rather, they expressed that they would want to create the network together with their son or daughter to encourage them to think about strategies to deal with potential risks.

### **DISCUSSION**

In summary, SocialMirror has a potential to both promote the independence of individuals with autism and to facilitate collaboration among their caregivers. The central features of the SocialMirror system include a natural form factor, blended functionality and sociability, and community empowerment leveraged by the distribution of labor associated with supporting an individual with autism. The concerns associated with a social network have been identified as safety and privacy, conflict of ideas between caregivers, and tension between the young adults and their parents. In this section, we present the design consideration for leveraging a trusted network that balances quick response with safeguards to ensure the privacy and security of the young adults with autism.

#### **Scaffolded Network Building**

Building a social network for young adults with autism and caregivers is not as straightforward as building a social support network for group coordination for the general public [20]. Previous research indicates that a deficit in understanding social rules leads to difficulty for individuals with autism in deciding whom to trust and how much personal detail to disclose in an online community [1]. A network vetted by a primary caregiver can ensure the safety of the individual, but such limiting of the network may decrease the possibility of getting quick responses. We address this dilemma by introducing a scaffolded network building model, which is initiated by a group of people living or working with adults with autism on a regular basis (e.g., family members, school counselors). We propose that these network members can then invite other trusted individuals, such as extended family members or teachers

who work in other schools. With respect to individuals' autonomy and free will, the network-building mechanism allows the individual to choose whom to get advice from. To protect the individual from choosing potentially deviant people who request membership, a newly added member should be under review until a trusted member approves them.

#### **Layering a Network by Classes of Queries**

SocialMirror allows individuals to ask a community of family and friends for advice, instead of a single person who may feel obligated to help. However, there is a risk that the picture- and the calendar-sharing feature may encroach on the individual's privacy. Many participants reported concerns with disclosing too many personal details, and felt uncomfortable with everyone knowing the details of their struggles. However, they did express great interest in sharing sensitive queries with those they are close to. This suggests that there should be classes of queries and layers within the network, such that close advisors respond to intimate questions, while peers advise on less important issues. Applying a degree of sensitivity to the queries and assigning them to a member with the appropriate level of closeness would enable the use of a larger network without sacrificing privacy. Fine- or coarse-grained access could also be provided for network layering. Fine-grained access would allow a particular group to see all types of queries (e.g., all pictures and events) while preventing others from seeing certain pictures or events on the calendar (e.g., financial tasks could only be seen by people authorized to access the individual's checking account). Another approach is a layering mechanism in which closeness is based on the relationship and communication history between the individual and the member.

#### **Internal Negotiation System**

Our study has highlighted how the use of SocialMirror with a range of different stakeholders involved in the transitioning of adults with autism could generate social tensions. For instance, multiple caregivers could provide different or even conflicting solutions that may be confusing to the individual with autism. In general, a successful online community requires a system that reconciles the conflicts [18]. Kollok suggested the use of an internal negotiation system, which is a low-cost conflict resolution mechanism implemented by members of a community [12]. One possible way to facilitate the internal negotiation could be resource distribution and allocation. For instance, one or more members could assign themselves to a certain support category (e.g., cooking, cleaning, dressing up, or socializing). This would decrease the chances of getting overlapping or conflicting responses, while increasing the opportunity to get a response because of increased commitment, but lighter workload. Additionally, a 'committee' for each query area could have the authority to resolve conflicts before the comments are delivered to the individual.

In short, a scaffolded member recruitment mechanism, layered distribution of queries, and an internal negotiation system could be used in a supportive trusted social network. Such considerations are invaluable in mitigating the risks associated with safety and trust, conflicts in suggestions, and tension between the adults with autism and their caregivers. These strategies will ensure potential impact on long-term independence.

## CONCLUSION

Our research was aimed at providing young adults with autism who are in transition to adulthood with a safe and responsive social network that allows them to get information and advice about their everyday life. Our study investigated the potential for the proposed SocialMirror system that promotes independence and facilitates collaboration among the social network. The identified implications for designing such a supportive network, including a scaffolded network-building mechanism, a network layered by the degree of query sensitivity, and an internal negotiation system, promise to generalize to other groups beyond individuals with autism. In so doing, independent living can become a reality for other segments of the population who require extended support.

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