SPECIALIZING SOCIAL NETWORKING SERVICES TO SUPPORT THE INDEPENDENCE OF ADOLESCENTS AND ADULTS WITH AUTISM

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Specializing Social Networking Services to Support the Independence of Adolescents and Adults with Autism

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To my beloved family,

from whom I have received endless support.

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SUMMARY

Many individuals with autism manifest problems in transitioning to adulthood due to social impairments, communication difficulties, and rigid behaviors. One of those challenges is developing a robust and sufficiently large network of people who can provide advice about a variety of everyday situations. In this dissertation, I investigate ways of supporting adolescents with high functioning autism in navigating their everyday life through specializing social networking services (SNSs).

As part of this work, I conducted a formative study to identify challenges and opportunities for the design of a specialized SNS to foster independence of individuals with autism. The study revealed three challenges: 1) it is difficult for individuals with autism to keep up with everyday tasks spontaneously; 2) pre-programmed interventions are not related to an individual's personal context; and 3) over-reliance creates a formidable burden for primary caregivers. To address some of these issues, I investigated how an existing SNS can support individuals with autism in navigating everyday situations. A four-week exploratory study with the SNS established communication circles of a young adult with autism, friends, family members and some extended members. I identified positive impacts of the focused communication circle on independence of individuals that facilitate asking questions and reaching out to online network members beyond a primary caregiver. I also discussed implications for enhancing features of existing SNSs to support the activity of information- or advice-seeking to cope with frustrations and challenges, which I refer to question-and-answer (Q&A) behavior.

Motivated by the formative studies, to characterize general Q&A behavior of individuals with autism, I investigated autism-specific online forum where a myriad of conversation threads has been generated. Drawing on a combination of quantitative and qualitative analysis, I estabilished a taxomony of questions asked by individuals with autism. I found the autism-specific online forum served Q&A platform where 66%

threads was initiated by questions. These questions addressed a variety of everyday social challenges ranging from tips to partake in a small talk at a hair salon to requests for financial planning advice. To enhance the Q&A experience, I proposed and evaluated a crowdsourcing approach for augmenting the kind of existing autism forums. The results revealed that crowd workers offered rapid, concise, and socially appropriate coping strategies without compromising emotional support.

Drawing on several formative studies and investigations, I synthesized design guidelines for *inquir.us*, a specialized social Q&A platform with features for scaffolding question creation and crowdsourcing answers. Through the initial exploratory study of inquir.us, I examined the Q&A behavior of individuals with autism on this platform and identified both opportunities and barriers to adoption for individuals with autism in the context of supporting transition skills for independence. I discuss lessons learned from the design exploration and provide implications for social computing systems research and design with and for the individuals with autism.

The contributions of this thesis are: (1) a rich description of challenges and opportunities related to attaining independent life using SNSs; (2) empirical studies of individuals with autism's online Q&A behavior; (3) design implications for designing a specialized SNS facilitating the Q&A interactions; and (3) the design and exploratory study of a social Q&A platform in the real world.

CHAPTER 1

INTRODUCTION

1.1   *Motivation*

The rise in the number of children diagnosed with autism began in the early 1990's, and children from that generation are beginning to transition from the protective school system to the much less protective adult world (NYTimes, 2010). For all young people, the key to a successful transition to adulthood is independence. However, attaining a satisfying independent life is a challenge, particularly for those with autism because of the qualitative characteristics of their social interaction and communication as well as their limited ability of self-determination. People living with autism[1] encounter a variety of difficult social situations throughout their daily lives. The unwritten rules of a complex social world create barriers for people with autism. Seeking clarification or advice about these social challenges is a key to navigating everyday life more effectively. Consequently, the assurance of a meaningful and independent life requires the continuing network of support from family, friends, and other caregivers. Such independence ranges from the ability to perform basic life skills to an ability to fully integrate into society by operating effectively in a variety of social situations. In this

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[1] From this point, I use the term autism to refer to high functioning autism conditions related to both a medical diagnosis on the autism spectrum, including Asperger's Syndrome, as well as the social definition used by those who identify with the autistic life experience. Though there is not a specific diagnostic definition for high functioning autism, or HFA, I use this term to represent individuals with autism who demonstrate the ability to communicate verbally.

dissertation, by "independence," I am referring to activities facilitated through the acquisition of such abilities as: 1) managing everyday situations by requesting help or advice; and 2) reaching out to a variety people beyond a primary caregiver to ask questions.

The field of assistive technology has made great advances in memory aids and instructional applications that increase independence of individuals affected by cognitive disabilities. For example, technologies assist profoundly disabled individuals by providing timely reminders of daily tasks and instructing them on the completion of tasks with multiple steps (Carmien & Fischer, 2008). Nevertheless, little research has been devoted to addressing the needs of socially-acquired information or advice tailored to the complex and subtle situations an adolescent or adult with autism will face. Such situations vary in terms of the immediacy of the need for an answer and the nature of a topic. How might technology support an individual's need for advice in diverse situations? I am interested in building technology that leverages social networks that support everyday life situations associated with the independence of adolescents and adults living on the autism spectrum.

The rise in social computing systems (e.g., social network sites, online communities) has spawned new opportunities to serve people with special needs. These systems can generate online social networks that supplement primary direct care providers, who are often overburdened. The systems also provide an opportunity for individuals to gain a wider perspective on topics of interest from people beyond they may know. I consider social networking services (SNSs) a subset of social computing systems to the extent that they particularly facilitate communication and collaboration across networks of online

contacts using a variety of different technical features[2] and social architectures[3] (D. M. Boyd & Ellison, 2007). Utilizing SNSs to support the independence of individuals with autism provides three opportunities. First, an SNS can leverage existing physical care networks composed of family and close friends by mediating online and offline communication among the network members. Second, the SNS creates a virtual space where users seek information or request help beyond the physical care network, such as crowd-sourced online volunteers. Harnessing this collective informal support online is an important value proposition for an SNS. Third, data produced through SNSs, particularly questions, reflect the most pressing issues for individuals with autism.

The existing SNSs originally designed for general use, however, the use poses challenges for individuals with autism, who struggle with understanding what and how to ask, how much to disclose, and whom to trust (Burke, Kraut, & Williams, 2010). Thus, the challenge is to identify meaningful features and architectures of SNSs that are specialized for individuals with autism and ways of supporting them in soliciting advice to cope with a variety of socially challenging situations. In my dissertation, I identify the underlying key components of a specialized SNS that is unique to support question and answer behavior of individuals with autism. I specifically investigate the combination of

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[2] Throughout this dissertation, I use *technical features* in this sense to include a wide variety of affordances of social networking services. The technical features include capabilities of creating social networks online, building sub-groups of the networks, and soliciting help or information from the group members, such as features presented as "lists" in Facebook or "circles" in Google+.

[3] I use the phrase *social architectures* to mean the structure of social networks in which various types of members (e.g., family, friends, online community members, and crowdsourced workers) interact or provide information based on the unique area of knowledge of members and their relationships with users.

SNS and crowdsourcing to ask questions in a structured manner and receive rapid and effective advice from networked members. My goal for this research is to provide design guidelines on ways to design social question-and-answer (Q&A) systems that are specialized to support individuals with autism in navigating everyday life independently and effectively.

1.2   Research Questions

The goals of this work are to better understand challenges and opportunities to support the individuals with autism in navigating everyday life and design special features of a variety of SNSs—from an existing social networking application to an online community and to a hybrid Q&A platform—that may be able to address some of the challenges faced by these individuals.

1. **RQ1: What are the design opportunities for supporting independence of individuals with autism?** RQ1-a: What are the current concerns and challenges for attaining independent life of those individuals?

2. **RQ2: How can an existing social networking service (SNS) assist individuals with autism in receiving advice to navigate everyday life?** RQ2-a: How does the use of a special feature of SNS, a focused communication circle, impact practices of question-and-answer (Q&A)?

3. **RQ3: What are the current Q&A practices and challenges for individuals with autism who seek advice from an autism-specific online forum**? RQ3-a: How can crowdsourcing address the challenges identified?

4. **RQ4: How should we design a social Q&A system specialized for supporting Q&A behavior of the individuals with autism?**

To answer **RQ1** and understand the meaning of independence for young adults with autism, I conducted literature review and formative studies. My goal was to identify challenges and opportunities for designing social networking services for the individuals with autism. In addressing **RQ2,** I investigated an existing social networking service as a Q&A tool to receive answers from online network members. In addressing **RQ3**, I studied the current question-and-answer behavior on a large autism-specific online forum and evaluated the effectiveness of crowdsourcing mechanism for generating rapid answers to the forum questions. In addressing **RQ4**, I designed *inquir.us* synthesizing design features from the previous studies. Using this system, I investigated the use of suggested features by small samples of students with autism.

1.3   Contributions

In this section, I summarize the contributions of this thesis. In addressing RQ1, I have contributed to the characterization of independence for the young adults with autism. Focusing on the people who are in the stage of transition to adulthood has allowed me to gain a richer understanding of the unique context. Through in-depth interviews and observations of 11 young adults with autism and their 13 caregivers, I provide an overall understanding of everyday challenges that impede successful independent life. Through interviews and observations of stakeholders, I identify opportunities for leveraging a strong-tie of local network members like family and friends to support the daily situations of individuals with autism. In addition, I provide empirically-driven design implications for a system that helps individuals practice life skills by facilitating quick responses from a network of caregivers.

In order to investigate RQ2, I describe an exploratory study to determine whether an existing SNS, *GroupMe*, enables an individual with autism to build a network and to initiate communication with members of that network. I focus on a specific feature of the

SNS, *circle* and report on how the use of this feature impacted three groups composed of an individual with autism and pre-determined circle members. I discuss implications for enhancing the circle feature in similar SNSs to support the activity of information- or advice-seeking to cope with challenges, which I refer to question-and-answer (Q&A) behavior.

My particular research focuses on enhancing the online social Q&A experience of individuals with autism. In addressing RQ3, I examine topics and types of questions posted to an autism-specific forum. I identify the issues that individuals with autism are really concerned about on a daily basis and how they address such concerns in the form of question-asking practice. I analyze 1,277 question threads in order to identify Q&A patterns of the autism forum users and to better understand the opportunities and limitations of the autism specific forum as a social Q&A system for individuals with autism. I suggest augmenting this forum with crowdsourcing and investigate whether crowd workers recruited through Amazon Mechanical Turk can offer answers to questions posted to the autism forum. I evaluate both forum answers and crowd answers with 6 adults with autism and 11 experts who work for individuals with autism using multiple metric of judging answer quality. The result of this research revealed the major distinctions between the forum answers and crowdsourced answers in terms of the speed, relative directness, conciseness, informational and emotional support, and perceived helpfulness provided. These distinctions lead to design guidelines for generating better questions and eliciting effective answers.

In order to investigate RQ4, I design and develop *inquir.us*, a social Q&A platform that scaffolds the creation of questions and includes crowd workers as supplemental responders to provide rapid, direct and informational support. I conduct an exploratory study intended to investigate key design features of the system for the students with autism. I discuss lessons learned from the design exploration and provide implications

for social computing systems research and design with and for the individuals with autism.

In this dissertation, I present three types of contributions—empirical finding, artifact, and methodology. Specifically, my research resulted in the following outputs:

1. A rich description of challenges and opportunities related to attaining independent life using SNSs. The formative interview studies provide deeper understanding of the problem space. The autism-specific online forum study highlights the topic of concerns and interests of individuals with autism and the type of support sought by these individuals.

2. Design considerations for augmenting and improving features of current SNSs mapped with limitations and opportunities identified by empirical evidence (e.g., design exercises, exploratory study with GroupMe and the autism forum, and crowdsourcing study)

3. The design and initial evaluation of a specialized social Q&A platform in the real world. Providing a better understanding of how we design such technologies to be used by individuals with autism.

1.4   Overview of Dissertation

This dissertation is divided into eight chapters.

In Chapter 2, I provide the theoretical underpinnings of my thesis research. I cover the theoretical background of adolescents and adults with autism and the transition support they need. I highlight the scope of the independence that can be supported by the use of technologies. I summarize several empirical investigations of the benefit of computer-mediated technology for these individuals. I also discuss the practice of question and answer mediated by SNSs as a potential approach for this thesis research.

In Chapter 3, I describe my formative research on understanding the current practices and challenges faced by adolescents and adults with autism and their caregivers. This chapter includes results from an empirical study of the autism domain and independence to generate technology design requirements.

In Chapter 4, I describe an empirical study examining how a special feature of an existing SNS, a focused communication circle, could help young adults with autism ask questions of extended online network members. I aim to identify the design considerations, challenges, and opportunities for improving that circle feature to support social Q&A behavior of individuals with autism.

In Chapter 5, I describe general social Q&A behavior in an autism-specific forum. I establish taxonomy of question based on the analysis of 1,277 Q&A threads and discuss a way to augmenting such forums with crowdsourcing.

In Chapter 6, I illustrate a crowdsourcing study aimed to generating answers beyond the autism-specific forum. I report on qualitative and quantitative findings based on the evaluation of the forum answers and the crowdsourced answers along with several answer quality metrics.

In Chapter 7, I illustrate the key design features of a social Q&A system specialized for addressing everyday challenges that individuals with autism often face. I present limitations and potential areas to improve the system reflecting upon the study results.

In Chapter 8, I summarized the contributions and limitations of my thesis and opportunities for future work.

CHAPTER 2

RELATED WORK

In this chapter, I discuss background and related work that informs the creation of a specialized social Q&A system that enables users to receive feedback from online social networks. Of particular interest here is the support the system can provide for a particular type of users: adolescents and adults on the high-functioning end of the autism spectrum who seek information, advice and support on a variety of topics. I first describe related work drawing from autism studies and psychology to characterize what independence means to the autism community and what independence challenges are remaining. Second, I describe how support for autism fits into the areas of computer-mediated communication and social Q&A.

2.1 Characterizing Independence of Adolescents with Autism

2.1.1 Backgrounds: What does independence mean for autism

Despite their intellectual strengths, adolescents and adults on the high-functioning end of the spectrum report difficulties in obtaining and sustaining employment; living independently; developing friendships and long-term relationships (Howlin, Goode, Hutton, & Rutter, 2004). In their everyday lives, individuals with autism face challenges with organization, initiation, and generalization skills (Carnahan, Hume, Clarke, & Borders, 2009). These challenges impact their communication and social skills (Muller, Schuler, & Yates, 2008). Reduced social effectiveness is a core characteristic of autism that results in significant difficulties in transitioning to adolescence and adulthood, when successful social relationships are the key to almost every achievement (Hume,

Loftin, & Lantz, 2009). Even individuals who successfully transition to independent living still report that they often struggle with managing everyday tasks like cooking, taking medications, personal hygiene and other tasks (Carnahan et al., 2009).

Lack of transitioning to independent living affects both individuals and their families. The constant support that these individuals require takes a toll on the relationship with their primary caregivers (Krauss, Seltzer, & Jacobson, 2005). 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 (Taylor & Seltzer, 2010). In addition, over-reliance on a primary caregiver also leads to problems such as difficulty broadening one's social network, reaching out to appropriate people to get advice about a wider perspective on topics of interest, and tapping into other available resources (Krauss et al., 2005).

Over the past decade, several autism associations have developed transition guidelines (Southwest Autism Research and Resource Center, 2000; Virginia Department of Education, 2010). Researchers have suggested that assisting young adults in building everyday life skills is the first step toward ensuring a smooth transition to independent living. The areas of skills include: maintaining good hygiene; staying on schedule; good health habits; work and professional life; financial management; leisure and social activity; and managing household chores.

My research identifies and eventually provides potential supports in the areas of independent living which include: 1) improved social relationships; 2) decrease in over-reliance on primary caregivers; and 3) acquisition of information or advice about everyday situations. I explore how technology supports the aspects of independent living by mediating communication between an individual with autism and his/her

caregivers in flexible ways. In Chapter 3, I present my formative work that investigates independence challenges and design opportunities.

2.1.2 Understanding abilities to achieve independent living

Researchers have identified a number of features comprising the essence of independence of individuals with autism and psychological and social factors associated with it (Carnahan et al., 2009; King, Baldwin, Currie, & Evans, 2005). Independence can be achieved to the degree that individuals are engaged in or able to develop desired abilities. Short-term outcomes that can be precursors to successful engagement in those abilities have been identified: (King et al., 2005)

- **Enhanced knowledge of self** is based on awareness of personal strengths and weaknesses, needs, and goals. It includes knowledge of disability and associated accommodations. Being aware of the need to initiate or request help is critical.

- **Enhanced skills** include self-determination skills such as communication-initiating, decision-making, and problem-solving. Learning vocational skills, social and interpersonal skills, employment and work skills, and skills in the use of leisure time are also essential to independence.

- **Enhanced perception of support** results from friendships, mentorships, and the availability of assistance in accessing mandated services and supports beyond a small set of closed network of caregivers.

- **Supportive environments** refer to systems, settings, and people that provide informational and emotional support.

Researchers have suggested that the availability of a supportive social network (family, employment, social services) may affect the quality of life in individuals with autism (Howlin, 2002). Using self-report measures from 58 high-functioning adults with

autism, Renty and Roeyers found no significant association between quality of life measures (e.g., satisfaction, competency, independence, social belonging) and autistic traits (Renty & Roeyers, 2006). However, quality of life was associated with the level of perceived informal support in the areas of accommodation, activities, autism-specific information, and social relationships.

Indeed, independence can be facilitated through acquisition of such abilities: 1) getting motivated to initiate and request help in a variety of situations with the minimal aid of a primary caregiver; and 2) reaching out to a supportive social network to fully integrate into society by operating effectively.

2.1.3   Technology for increasing independence

The use of technology to support independence of individuals affected by cognitive disabilities has been the focus of considerable research within the HCI research community. Prompting systems have been used to assist individuals with cognitive disabilities by providing timely reminders of upcoming day-to-day tasks and completion of multiple-step tasks (Wu, Birnholtz, Richards, Baecker, & Massimi, 2008). 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 (Carmien et al., 2005). Similarly, self-operated prompting systems have also been used for individuals with autism to help them stay focused on specific tasks (Mechling & Savidge, 2011). 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.

A growing number of existing systems offer computational support for individuals with special needs, augmented by interactive technologies. For instance, an interactive

story-telling instructional module has been suggested to enable adolescents with high functioning autism to independently practice social problem solving skills (F.A. Boujarwah, Hong, Arriaga, Abowd, & Isbell, 2010). Researchers leverage crowdsourcing to help caregivers produce a variety of social problem solving skill modules (F. A. Boujarwah, Abowd, & Arriaga, 2012). However, much of the previous research in this area has focused on the technology design itself rather than any potential interventions or ecological approaches that benefit both the individual with autism and the community of people who are involved in the care of individuals with autism. In the next section, I explore how computer-mediated communication technology can be used to address the needs of individuals with autism and in what ways technology can empower the supportive social networks.

2.2 Computer-Mediated Communication Technology for Autism Support

In computer-medicated communication (CMC) technologies, including social networking sites and online communities, users can disclose the challenges they face, broadcast requests for information or advice, and share personal experiences. One study of the use of Facebook among neurotypical college students found that they were better able to cope with personal problems when they received online suggestions from a community of people (N. B. Ellison, Steinfield, & Lampe, 2007). In fact, many adults already use CMC to present themselves online. A recent study of blogs by users with autism revealed a significant difference in language styles that served as an indicator of mental status of autism community members and of topics that they are most concerned about (Biyani & Caragea, 2012). Thus, CMC technology can create a venue in which users address their needs. Furthermore, communication data produced through CMC

technology can be a reflection of the current issues most pressing for the individuals with autism.

The nature of the Internet—interacting one-to-one or one-to-many with visual anonymity and time flexibility—offers opportunities for individuals with autism who feel pressured by interpersonal communication (Benford, 2008). A study of people with low self-esteem found that they prefer to communicate via email when there was a greater chance of rejection (Joinson, 2004). In addition, shy individuals, who have low confidence in social communication, reported that they could communicate easier online due to various reasons: not seeing the communication partner(s); not being seen themselves; being anonymous; and reduced fear of rejection or negative feedback (Roberts, Smith, & Pollock, 2000). Recent studies of social network sites and online communities conclude that they can provide those who have low self-esteem and limited social networks with informational and emotional support and social companionship (Burke, Kraut, & Marlow, 2011). Individuals with low social skills or on the autism spectrum often learn various styles of interaction that were often opaque to them through the silent observation and the passive consumption of communication (Burke et al., 2011, 2010; Hong, Yarosh, Kim, Abowd, & Arriaga, 2013). Thus, for socially anxious people, CMC provides a motivation to communicate while avoiding feared aspects of face-to-face communication. This dissertation research investigates what features of CMC technology can facilitate the process of information seeking or requests for help and how these features elicit high quality answers for the requests.

CMC technologies also afford a novel form of social support for individuals who need special assistance, complementing that is available from personal networks or local resources offline. Social support may be obtained from a variety of sources including, friends, family, co-workers, and even strangers. An online forum is a notable example of a venue in which features of CMC technology facilitates the formation of social support

groups for people with disabilities who have difficulty in accessing face-to-face support groups. They bring opportunities for the exchange of information, ideas, discussion, advice and emotional support from first-hand experience and expertise. The benefit of seeking support from online forums is the interaction with people who offer a perspective that differs from that of family and physical social contacts. There is the opportunity to access a wider range of views, based on personal experience and knowledge of the domain, with perhaps more time than would be available from a professional, friend or family member (Benford, 2008). Researchers have suggested that such weak-ties (Granovetter, 1973)—people whose relationships to an individual are separate to the pressure and dynamics of close family and friendships—may be more supportive due to their objectivity as well as diversity. Seeking information or requesting help from weak-ties, in conditions of perceived anonymity and privacy, might serve to ease the disclosure of stigmatizing or embarrassing information, and eliminate or lessen some perceived burden on close relationships.

In sum, CMC technologies are deeply wired into some users' everyday lives, and facilitate soliciting information from one's social connections, or from particular online communities leveraging weak-ties. Despite the social benefits of CMC technologies, users with autism experience specific barriers to adopting them due to their difficulties in understanding social norms and managing trusted and healthy online interpersonal relationships (Burke et al., 2010). Thus, this dissertation research explores how best to support individuals with high functioning autism as they seek information and advice about concerns in a secure manner.

2.3   *Social Question and Answer (Q&A) Service and Research*

This dissertation research explores social question-and-answer as a key feature of a specialized social networking service that allows users with autism to solicit information

and provide support. Increasingly more attention, both in academia and in practice, has been given to collaborative information seeking (M. R. Morris, 2013), with emphasis on questioning and answering behavior in online social media. In 2013, CSCW and social computing researchers organized a workshop dedicated to exploring the use of social media for question asking (SMQA) (Ackerman et al., 2013). These researchers provided the following definition of social media question asking:

> Social interactions mediated by information and communication technologies often play a role in information seeking. One common form that such interactions can take is social media question asking, in which a user appropriates Internet technologies to ask a question in natural language to either their own social circle, strangers, or topical experts.

The workshop participants reviewed the current state of research in SMQA including tools or venues in which the phenomenon of social question and answer behavior occur. These tools include personal social network sites (e.g., Facebook, Google+), social Q&A sites and systems (e.g., Quora, Yahoo! Answers, Microsoft Live QnA), and human computation or crowdsourcing like Amazon Mechanical Turk. The use of these SMQA tools for various communities such as blind users, teens, citizens in developing countries, online content creators, and mobile users has been discussed. Of particular interest here are: 1) the extent to which features and structures of the existing SMQA tools can engage users in collaborative information seeking; and 2) the technical and social challenges of the existing SMQA tools for individuals with autism.

2.3.1 Tools for social Q&A

Previous research has largely focused on how people fulfill their information needs using various social media as a Q&A tool by 1) making requests of their personal network via social network sites or targeted audiences online; 2) posting questions to a

social Q&A site (e.g., Yahoo! Answers, Quora) where people not known personally, or strangers can offer answers; or 3) broadcasting requests for information or support to an online forum targeted at a particular community.

2.3.1.1. Friendsourcing via Social Media

The appropriation of personal social network sites, like Facebook or Twitter, in which a user poses questions to friends or contacts, is a common way to express information needs (N. B. Ellison et al., 2007; Lampe, Vitak, Gray, & Ellison, 2012; M. Morris, Teevan, & Panovich, 2010). A key benefit of soliciting help or information through social networks is that they provide an individual with access to direct communication to the right set of people. Morris et al. (M. Morris et al., 2010) conducted a survey that examined the use of personal connections within Facebook for asking questions. They found that more than half of participants reported that they posted questions to Facebook statuses on various topics such as technology, leisure and social activities, and philosophical inquires. The study also revealed that many questions were likely to be answered by close friends. However, asking overly personal inquiries about topics such as health, dating, religion, and finance, seems to be inappropriate within the site or at least through the mechanisms revealed in this study.

The disclosure of highly personal information is sometimes necessary when seeking help or advice, but it inevitably raises tensions around one's privacy and social identity. To tackle this social dilemma, Newman et al. (Newman, Lauterbach, Munson, Resnick, & Morris, 2011) proposed a mechanism that builds customized support groups for focused communication, for example, groups consisting of individuals that a user selects for the health-related goal. This approach is echoed by recent work investigating selective and targeted sharing practices in Google+ (Kairam, Brzozowski, Huffaker, & Chi, 2012). In that study, participants generated custom circles across life facets (professional life), tie strength, and topical interest. More importantly, the result showed

these groups are utilized for specific purposes (e.g., selectively sharing health and nutrition content with those who might be interested.) Accordingly, tailoring the way of broadcasting questions based on types of questions and types of audiences over social network sites is an important design consideration in the area of social media question asking.

2.3.1.2. Social Q&A sites and systems

Social Q&A sites are web-based systems that provide capabilities to ask questions in natural language to a larger number of people that are not known personally. The sites are designed specially for Q&A purposes (e.g., Quora, Yahoo! Answers, Naver Knolwedge iN). The questions and answers come from complete strangers or near strangers as opposed to friends or followers in a personal social network. The audiences of potential answerers are much larger on a social Q&A site than a personal social network site. Researchers have identified two categories of questions posted to social Q&A sites: informational questions which solicit specific facts (e.g., What's the difference between Burma and Myanmar?) and conversational questions which are intended to promote discussion (e.g., Do you drink Coke or Pepsi?) (Harper, Moy, & Konstan, 2009). They found that the conversational questions have much lower potential archival value than informational questions. However, conversational questions include interesting aspects that could motivate individuals with autism to communicate. In addition, discussion around the conversational questions can make social and cultural norms visible. Thus, conversational questions may have higher archival value for those with autism who struggle with understanding complex social activities.

Social Q&A systems include the augmentation of general applications such as Short Message Service (SMS) or Instant Messaging (IM) for Q&A purposes. A notable example is ReachOut, a chat-based IM application that facilitates peer support via the Q&A process in an organization (Ribak, Jacovi, & Soroka, 2002). Despite the capability of these

applications that assist people in getting quick answers, most of the responses were provided by only a small circle of the very active users (Ribak et al., 2002). To determine the effective social structure that leads to quality answers, researchers examine the latency, usefulness and quality of answers by differentiating the size of community size and the diversity of contacts in IM-based Q&A systems (White, Richardson, & Liu, 2011). While the larger community size leads to the increase in the fast and useful responses, the increased heterogeneity (higher contact rate) sacrifices the quality of answer (White et al., 2011).

2.3.1.3. Online forums or communities as Q&A system

Online forums or communities have a vast numbers of domain- or community-specific discussion posts generated by member interactions that tend to be very topic-oriented. Information-seeking and help-requesting in a form of question-asking are prevalent activities in online forums. Huh et al. (2012) examine online communities in which "collaborative help" is provided to benefit end-user technical support or personal health problems. In the study of an online community for diabetes, collaborative help—sharing help among peer patients—is identified as an operationalization strategy that makes patients' everyday experience in managing diabetes into generalizable forms that others can appropriate (Huh & Ackerman, 2012).

Online Q&A forums provide a venue to explore substantial research questions about outcome measures such as responsiveness and answer quality. Compared to an average two-hour response time on a social Q&A site (Microsoft's Live QnA) (Hsieh & Counts, 2009), response times on online forums tend to be longer. For instance, nine hours was the expected time to receive a response about questions on a Java developer forum (Zhang & Ackerman, 2007).

Online Q&A forums have integrated many compelling features to increase responsiveness and answer quality. Locating an appropriate "expert" by navigating question categories may be one way to improve the effectiveness. Civan et al. suggested technical features of an online community that facilitate cancer patients' expertise sharing, namely the expertise locator (Civan-Hartzler et al., 2010). It enables identifying potential expertise based on certain selection criteria: type and level of knowledge of disease, trustworthiness and clarity of profile, connection to cancer, availability, strength of relationship with the information seeker, and lifestyle and personal interest. The profile feature in the system could mediate question asking, search results filtering, and responder recommendations. Research exploring the impact of these features on the quality of Q&A would help designers better understand when and where to deploy such features in their own online communities.

2.3.2   Soliciting information from In-Group communities

Individuals with autism are known to have cognitive and social skills deficits that lead them to require support to cope with challenges in navigating daily life (Virginia Department of Education, 2010). Many users with autism go to autism-specific communities to gather advice and foster self-advocacy from others with similar concerns and difficulties. I characterize the autism-specific online community, as an example of an *in-group* as defined by Tajfel (Tajfel, 1982). In-group is a social group to which an individual psychologically identifies as being a member based on the following one's cognition and value: 1) a sense of awareness to similarities and differences; 2) a perceived value connotations as being a member; and 3) a willingness to provide emotional comfort and support to its members. The conceptual in-group membership has been instantiated by computer-mediated communication (CMC) technologies, such as online communities dedicated to a particular group concerned with a range of issues,

for example breast cancer (Wang, Kraut, & Levine, 2012), motherhood (Schoenebeck, 2013), and chronic disease (Huh & Ackerman, 2012).

Previous research has largely focused on how people fulfill their various social support needs by disclosing personal experiences to people with similar conditions in these specialized online communities. According to a breast cancer community study, both informational and emotional forms of support are critical to a support-seeker's satisfaction (Vlahovic, Wang, Kraut, & Levine, 2014). A study of CMC technology used by adults with autism revealed that these in-group online communities offer greater emotional support through the sharing of feelings which lead to a perceived increase in quality of life (Burke et al., 2010). Thus, an online autism community is a place where a myriad of conversations have been generated to meet emotional and socialization needs for increasing self-esteem and self-confidence of the users.

Indeed, not only do users of in-group communities seek emotional support from its members, but they also request information or advice in the form of an explicit question (Vlahovic et al., 2014). Requests or questions posted to an in-group community, in turn, can provide a lens for analyzing various types of social support sought by members of the special group. In Chapter 5, I focus on support-seeking threads in an online autism community to identify current needs and concerns of the members. I also investigate how their requests are addressed by the responses of others. While a large body of research has explored the emotional impact of responses provided to a requester, less is known about the practical value of responses from the in-group who are likely struggling with similar concerns. Thus, I investigate the characteristics of autism community responses as well as the responses from outside of the community.

2.3.3 Crowdsourcing advice from Out-Group individuals

A human computation approach, namely crowdsourcing in which anonymous, paid workers such as those on Amazon's Mechanical Turk Service provide information or advice for a special population is an area of increasing interest. For example, online crowd-workers generated empathetic and encouraging responses to help depressed users cope with stressful situations (R. Morris & Picard, 2012). The VizWiz application is a notable example of how crowdsourcing can be employed as an assistive tool for the visually impaired community (Bigham, Jayant, Ji, & Little, 2010). The application allows blind users to receive crowdsourced answers to their question in almost real-time. Burton et al. (Burton, Brady, Brewer, & Neylan, 2012) tested the feasibility of VizWiz for the specific situation of providing fashion-related advice. They found volunteer responders vetted by researchers offered not only visual support (e.g., what color is this shirt?) but also subjective advice such as matching or appropriateness for certain occasions. This finding indicates that general non-expert volunteers can be targeted to answer such questions eliciting subjective opinion.

Soliciting online advice on daily living from both strong-ties as well as weak-ties is called friendsourcing and is a common information-seeking behavior (M. Morris et al., 2010). In Chapter 3, I explored a social media-based remote assistance for adolescents with autism (Hong et al., 2013). This study revealed that obtaining ideas and perspectives from one's weak-ties beyond an immediate caregiver could improve their independence. Building upon the prior work, I seek to determine whether people outside of an in-group autism community could be leveraged to provide a wider perspective of everyday life.

Researchers are increasingly beginning to consider crowdsourcing approaches to exploiting non-ties, the crowd workers, to support information seeking in one's everyday life (Jeong, Morris, Teevan, & Liebling, n.d.; M. Morris, Inkpen, & Venolia,

2014). Crowd workers—belonging to what Tajfel calls an *out-group* when compared to a specific online community made up of self-selected members (Tajfel, 1982)—individually come and go, but the pool of workers is available to perform tasks at any moment. Jeong et al. studied whether crowd workers could provide answers to everyday questions on Twitter, such as "about to get my nails done. What colour shall I get?" (Jeong et al., 2013). They found that the overall quality of crowdsourced answers was similar to the quality of friendsourced answers. Receiving answers from strangers can be a positive experience for some, as strangers could be more honest and provide a wider variety of responses, though challenges associated with too many differing opinions and a decoupling from important context remain (M. Morris et al., 2014).

Not only does crowdsourcing provide useful information to the general population, but it also supports specialized communities. Crowd workers on Amazon Mechanical Turk (MTurk) have been used to provide helpful information to caregivers of individuals with autism (F. A. Boujarwah et al., 2012). However, it has not been investigated whether the crowd workers can directly benefit individuals with autism. I, therefore, hope to further clarify those benefits and identify an opportunity to improve upon the in-group discussion through the introduction of out-group answers.

In conclusion, crowdsourcing Q&A applications that take advantage of anonymous workers online can be especially effective to gain a wide perspective of advice about everyday situations in nearly-real-time. My dissertation research investigates a way of generating effective answers via crowdsourcing techniques.

2.4   Conclusion

In this chapter, I discussed a number of topics related to my work. This chapter includes a discussion of challenges adolescents and adults on the high-functioning end of the autism spectrum face and how these challenges impact independent living. I then have

given a brief overview of related social computing systems that facilitate communication and collaboration to support the important aspects of independent living. I conclude with the purpose of using a social Q&A system to understand the effect of social networking service as a means for increasing independence of individuals with autism. While "independence" is a broad concept, I operationalize it through meaningful activities that contribute to: 1) building, maintaining and broadening social connections, 2) decreasing over-reliance on primary caregivers; and 3) gaining quality information and advice about life and social skills.

CHAPTER 3

OPPORTUNITIES FOR TECHNOLOGIES TO SUPPORT INDIVIDUALS WITH AUTISM

3.1   Overview

I began my exploration of opportunities of building a technology to support the independence of individuals with autism by conducting a two-phase formative study with 12 adolescents with autism and 16 caregivers actively involved in planning and supporting the transition to adulthood. In order to better understand how assistance with transition works, what difficulties are inherent in current practices, and how the situation could be improved, I conducted interviews with local autism community members and developed design guidelines driven by findings from the interviews.

Informed by these design guidelines, I proposed the concept of SocialMirror, an artifact connected to an online social networking service that allows the young adult to seek advice from a trusted and responsive network of family, friends and professionals. I conducted four focus group interviews with groups of individuals with autism and their caregivers to provoke discussions about how SocialMirror might fit within or complicate their practices. This chapter concludes with a discussion of design considerations aimed at specializing social networking services toward better supporting the work of building a trusted network that provides quick and trusted advice on everyday situations young adults with autism are facing.

3.2   Study Procedure and Methods

I employed a two-phase study process, summarized in Table 3.1. The goal was to generate concrete design ideas for how technology would support the independence of individuals with autism from adolescence into adulthood.

Table 3.1: Methods and activities for each design phase

Research Phase	Methods	Participants & Activities
Phase 1	Semi-structured Interview	• Participants: 13 caregivers • Discussed topic of barriers to independent life • Identified everyday challenges and strategies to cope with • Goal: Design refinement and documentation
Phase 2	Homogenous Focus Group Interview	• Participants: A pilot participant (A man with HFA) • Group #1: 3 men (mean age=23) with autism and 3 teachers • Group #2: A man (age 27) with HFA and his mother • Group #3: A man (age 35) with HFA and his mother • Group #4: 5 men and 1women (mean age=21.7) with HFA and a coach
	Heterogeneous Focus Group Interview	• Review and critique the technology (SocialMirror) • Discuss topic of concerns using social networking service • Goal: Design requirements and considerations

3.2.1   Semi-structured interview

I conducted semi-structured interviews with 13 caregivers to understand their concerns about the transition to adulthood. 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.

3.2.2   Initial prototype design

A conceptual breakthrough came during the process of developing the guidelines. I recognized 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 me to speculate about the power of social networking tools, which could provide in situ feedback to the individual by connecting him or her with a distributed network of available individuals. Thus, I proposed a full-length mirror display as an initial embodiment of a social networking service embedded in the natural environment. I produced paper mockups, including screenshots of a social network site, a simple prototype implemented with the Facebook API, and a video that presented various usage scenarios. I used these design mockups and the concept video in Phase 2 as the basis for a series of focus group studies with students, adults and caregivers.

3.2.3   Focus group interview

I conducted focus group sessions with four groups of participants. Table 2 describes the demographic information of participants. 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. I 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. Conversely, I 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 may or may not address their needs and concerns.

All interviews were recorded and transcribed. Three researchers coded the data and the quotes presented in this chapter are representative of broad themes of agreement grounded in our data (Corbin & Strauss, 2008). The researchers then iteratively clustered

these codes into higher-level category groupings until we arrived at the themes that I will describe in the design guidelines and focus group results sections.

3.3   Results

Through the formative interviews, I gained a better understanding of how assistance with transition works, what difficulties are inherent in current practices, and how the situation could be improved. Individuals with autism demand and desire independence, yet specific problems impede their ability to perform everyday tasks successfully. Few interventions support the 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 of a primary caregiver to complete daily tasks. The design guidelines developed from the analysis led me to develop a system that supports individuals with autism in learning adaptive self-care skills through collaborative advice provided by a social networking service to lessen over-reliance on a primary caregiver.

3.3.1   Initial design guidelines

In this section, I discuss the three design guidelines to overcome identified everyday challenges. Guidelines include: (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.

3.3.1.1.   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, getting dressed up) or household chores. One participant 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 the level of dirtiness or disorganization that you and I might see. It then ends up getting anxious and frustrated."*

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. 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.

3.3.1.2. 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: *"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."*

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 nearly real-time 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.

3.3.1.3. Leverage a natural network of caregivers

Individuals with autism have a strong-tie network composed of primary (typically parents) and secondary (relatives, friends) caregivers, as well as a weak-tie network, such as neurotypical volunteers. Not surprisingly, findings of this study confirm that primary caregivers 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"*

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 potential caregivers (e.g., residential staff, peer group coordinator).

3.3.2 SocialMirror design and implementation[4]

Inspired by these three design guidelines, I developed a prototype, SocialMirror. Figure 3.1 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 a social networking service that sends questions to a trusted set of family, friends and professionals. For example, an individual 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.

| SocialMirror in the home for individuals with | Social network system for caregivers to deliver real-time feedback to the SocialMirror |
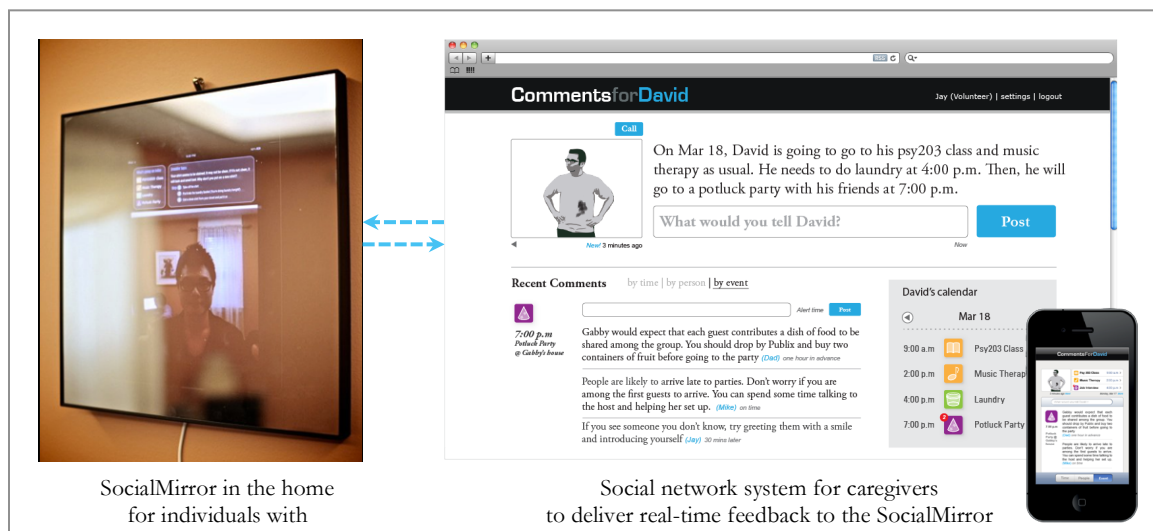
Figure 3.1: SocialMirror deployed in home (left) and social networking service as seen by a caregiver (right)

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[4] Detailed SocialMirror design features can be found in (Hong et al., 2012b) A video prototype of SocialMirror (Hong et al., 2012a) depicts three usage scenarios for a fictitious 22-year old individual with autism: https://www.youtube.com/watch?v=nGs1464Epwg

3.3.3 Focus group results

Focus group interviews centered around SocialMirror revealed a range of insights on potential benefits and barriers to the adoption of such a specialized social networking service in young adults' lives. Benefits include: (1) encouraging individuals to ask questions; (2) distributing caregiving responsibilities over the network members; and (3) increasing connectivity and reciprocity that may help them overcome social isolation. Potential challenges include: (1) safety and privacy; (2) conflicting advice across multiple caregivers; and (3) intensified tension between an individual and his/her parents.

3.3.3.1. Encouraging individuals to ask questions

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 findings suggest that SocialMirror, through simple connection to networks of information agents, 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.'"*

While most participants reacted favorably to the idea of a mirror as a simple querying channel, the 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."*

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 topic of individual's interests, strength and weakness) may be required.

3.3.3.2. Distributing caregiving responsibilities across network members

Parents and caregivers agreed on the value of a social networking service that distributes 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, "trusted 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."*

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."*

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 classmates, queries about attire go to siblings or cousins).

3.3.3.3. Increasing connectivity and reciprocity

The concept of SocialMirror 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). 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 in the focus group sessions stated that they understood the value of communicating about life skills via an online community and demonstrated their willingness 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). Many young adults in this study anticipated the social reciprocity and emotional support they would attain through Social Mirror. 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…'look what I got on my haircut!'…or I would share random ideas. It would be more for fun."*

I 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]."*

3.3.3.4. Open challenge 1: Safety and privacy

Our participants engaged with the concept and quickly came up with situations where they could use the technology. However, 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 (Burke et al., 2010). 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)

3.3.3.5. Open challenge 2: 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.

3.3.3.6. Open challenge 3: 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 this 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.

3.4 Discussion

Based on the concerns identified as privacy and security, conflict of ideas, and intensified tensions, I present the design opportunities for leveraging a trusted network that balances quick response with safeguards to ensure the privacy and security of the young adults.

3.4.1 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 (Skeels, Unruh, Powell, & Pratt, 2010). 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 (Burke et al., 2010). 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. I address this dilemma by introducing a scaffolded network building model, which is initiated by a group of people living or interacting with adults with autism on a regular basis (e.g., family members, school counselors). I propose that these network members can then invite other trusted individuals, such as extended family members or teachers who work in other schools. The network-building mechanism allows the individual to choose from whom to receive advice. 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.

3.4.2 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. 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 intimate 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 topics of queries (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 interaction history between the individual and the member.

3.4.3 Support internal negotiation

This 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 (Ostrom, 1990). Kollok suggested the use of an internal negotiation system, which is a low-cost conflict resolution mechanism implemented by members of a community (Kollock, 1997). 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 question 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 question topic could have the authority to resolve conflicts before the advice are delivered to the individual.

In sum, a scaffolded member recruitment mechanism, layered distribution of queries, and an internal negotiation system could be used in a social networking service for the individuals with autism. 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.

3.5   Conclusion

To expand our knowledge of needs and concerns about independence, I conducted interviews focusing on the challenges they face. The findings from the formative interviews address concerns and needs associated with the independence:

- Many individuals with autism are socially isolated. These individuals are likely to be less motivated to build social connections and initiate communication to ask for help or advice.

- Although they have a potential support network comprised of primary, secondary caregivers and volunteers, they overly rely on a small set of people, typically a primary caregiver. They do not have a robust and sufficiently large network of people who can provide advice about various situations.

- No existing intervention or technology satisfies ongoing information needs. Receiving adaptive advice on varied situations they are facing is critical to developing life and social skills that can help them increase their independence.

Thus, I operationalize 'independence' as meaningful activities that contribute to development of on- and off-line social connections, decrease in over-reliance on primary caregivers, and acquisition of information or advice about everyday situations.

This preliminary study reveals an ideal match between the independence challenges that individuals with autism are facing and the opportunities that SNSs can provide: assisting them in managing everyday situations by requesting help or advice; and reaching out to appropriate people beyond a primary caregiver to request help. A specialized SNS provided to the individuals with autism could encourage them to ask for help, distribute caregiving responsibilities across network members, and increase the connectedness and reciprocity. However, the concerns associated with the adoption of

SNSs have been identified as safety and privacy, conflict of ideas between caregivers, and tension between the young adults and their parents. I suggest features or mechanisms of SNSs to mitigate these concerns.

The proposed features for designing such a specialized SNS, including a scaffolded network-building mechanism, a network layered by the degree of query sensitivity, and an internal negotiation system, are a rich space for further investigation. In fact, such features have been implemented as sub-grouping mechanisms in existing SNSs (e.g., list in Facebook and circle in Google+). However, the identified design opportunities heavily rely on interview data that speculate about the potential impact of SocialMirror. There is no way to know a priori if these features will actually be beneficial. I will describe an empirical study to determine whether an existing SNS that has similar features I proposed can support individuals with autism.

The contributions of this chapter are as follows:

- I identify concerns and needs associated with independence of young adults with autism. The term of 'independence' has been operationalized to determine the impact of SNS for the following study presented in Chapter 4.

- I introduce a novel social networking concept for individuals with autism and their caregivers.

- I provide empirically driven design implications for a SNS that helps individuals learn life skills by facilitating quick responses from a network of caregivers.

CHAPTER 4

INVESTIGATING THE USE OF A CIRCLE FEATURE IN A SNS FOR Q&A

4.1 Overview

The study described in suggests that building social support networks is crucial both for less-independent individuals with autism and for their caregivers. The capabilities of a SNS might help young adults with autism garner support from the networks of family and friends. However, there is no empirical evidence if SNS features like pre-determined network building and topical-based grouping are actually beneficial in a real world setting.

Over the past years, interesting new features to SNS have been introduced to encourage and support different communicative patterns. One of those specialized features, the focused communication circle, is of particular interest to the work presented this chapter. In 2010, "circle", a unique feature of grouping and directing mechanism of a social networking service (Google+) was released. Facebook and other social networking services also have provided similar opportunities. The ability to direct conversations either to a set of people with a common social connection (e.g., family, friends, co-workers) or to those interested in a particular topic (e.g., health, job coaching) may be a promising way to break the trend of over-reliance on the primary caregivers for individuals with autism.

I speculated that the circle mechanism might address everyday life situations of individuals with autism and help them receive help or advice from their physical social connections. Thus, I wanted to understand how users create their social networks using the circle mechanism and how this feature affects their relationships and caregiving practices in the real world setting. To do this, I conducted an exploratory study with an existing SNS, GroupMe, which I considered as a scaled-down model of SocialMirror. I asked three young adults with autism to use GroupMe which allowed them to create various communication circles, include existing social contacts in the circle, and direct questions to each circle depending on the topic of questions. I used a mixed-method evaluation, combining objective measures of system use— specifically, the activity of communication and the formation of networks from the server logs—with self-report surveys to accurately measure the subjective matters about the strength of their interpersonal relationships and the perceived benefits from the relationship. This chapter concludes with a discussion of technical and social challenges that could be translated into what is missing in these types of existing SNSs that compels special capabilities of a SNS for the individuals with autism.

4.2 Methods

I hypothesized the SNS's communication circle would impact: 1) the patterns of support; and 2) the relationship between an individual with autism and his or her caregivers. To examine this idea, I enrolled three groups that were comprised of an individual with autism, their primary caregiver, and a flexible number of extended network members.

4.2.1 Technology probes with an existing SNS

Technology probes (Hutchinson et al., 2003) was adopted as a methodology to capture the daily activities of this study participants. Instead of seeding "new" technology in the existing context, I explored the repurposing of a general SNS for a specific situation, the

day-to-day support of individuals with autism. I expected the participants to provide feedback on how the use of the SNS may or may not have addressed their needs and concerns and to critique the technology by describing their experiences with it.

The cross-platform SNS, *GroupMe* (See Figure 4.1), was used for three reasons. First, it facilitates the network creation process. Users can smoothly transfer existing connections offline to GroupMe members using contact information (e.g., phone number, email address) stored in their communication devices. It allowed me to track those who were already involved in offline support and how they moved to online support. Another reason for choosing GroupMe was that it facilitates user-generated groupings of contacts which I refer to as a "focused communication circle." It enables users to sort their contacts so that they can selectively communicate with circle members and broadcast messages to circles they wish to communicate with. Lastly, GroupMe has a unique communication mode. Users can access GroupMe not only through a web interface but also on mobile phones. Even if users do not have a smartphone, they can still broadcast messages through text via a regular cellphone. The use of various communication modes allowed me to determine effective ways of asking and providing support.
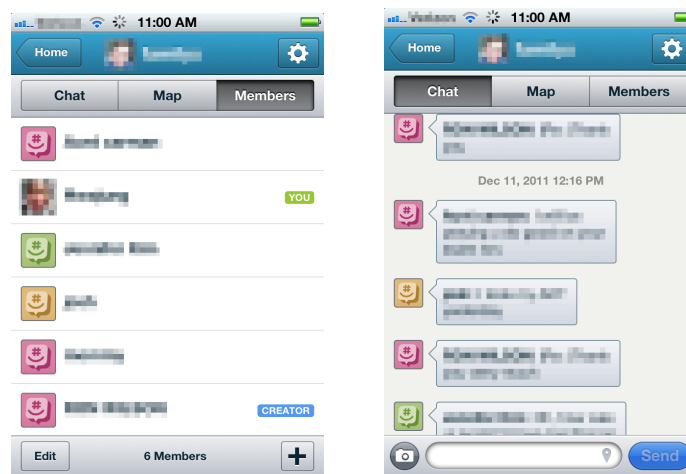
Figure 4.1: Two screen shots from GroupMe mobile app:
Members view of G1's circle (left); chat view of G1's circle (right)

4.2.2 Participants

I recruited three young adults (Andrew, Sarah, and Paul)[5] who self-identified as having Asperger's Syndrome (AS) and whose primary caregivers were their mothers. The demographic information is summarized in Table 4.1. All three pairs invited their existing networks such as other family members, relatives, and friends (Total: 20) to join the GroupMe study. Two researchers joined as members of GroupMe for all three groups because I was interested in how young adults react to the inclusion of someone that they do not know well in their existing network. To authenticate the researchers' presence in the group, I asked the participants to consider us as proxies for community volunteers like church youth group members who could be invited to participate in the future study.

Table 4.1: Summary of participants' profile, questionnaire result, and usage logs

Network	Individuals with Asperger's	GroupMe Members
G1	**Andrew** (age: 19 | College student | AS) - Moderately independent - Less confident (2 out of 5) about staying on schedule - Feature cellphone user - Recently joined Facebook (FB), access weekly - Created 69 out of 147 messages (50%) - Initiated 11 out of 18 threads (61%)	Mother Brother Aunt Researcher 1 Researcher 2
G2	**Sarah** (age: 16 | Middle school student | AS) - Less independent - Not confident (1 out of 5) about managing good hygiene and leisure and social activities - Feature cellphone user - Access Facebook daily, produce a number of videos on her YouTube channel - Created 81 out of 186 messages (43%) - Initiated 7 out of 23 threads (30%)	Mother Father Mother's friend1 Mother's friend2 Family friend Friend* Friend's mother*
G3	**Paul** (age: 28 | Technical assistant | AS) - Moderately independent - Less confident (2 out of 5) about social activities - Smartphone user - Access FB daily, but do not write on the wall - Created 69 out of 250 messages (28%) - Initiated 8 out of 32 thread (25%)	Mother Father Aunt Cousin Family friend*

*: Members who invited after pre-study phase

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[5] Names are pseudonyms.

4.2.3 Study procedure

The study consisted of three phases: the pre-study, the field study, and the post-study.

Pre-Study. Individual with autism and their primary caregiver took part in an opening interview, a questionnaire, and a tutorial. The materials used are included in Appendix A. The questionnaire included the following:

1. Information about current needs and concerns associated with independence with perceived levels of importance and competency independent living skills in seven areas defined by the Virginia Department of Education (VDE) transition guidebook (Virginia Department of Education, 2010): maintaining good hygiene, staying on schedule, good health habits, work and professional life, financial management, leisure and social activity, and managing household chores.

2. A form on which both listed known relatives and friends who had helped or who would be able to help the individual acquire these living skills.

3. Information about the relationship with each person on the list and the individual's perceived strength of the relationship in terms of closeness (Likert scale 1-5) and intensity (i.e., the frequency of contact).

Participants were asked to create groups on GroupMe using the list they had developed (see #2 above), and invite me as an observer of the conversations. This approach allowed us to capture data and the context in which the participants sent messages and any changes that they made to group memberships.

Field Study. Over the course of 4 weeks, each participant interacted with invited members through GroupMe. Log data from the GroupMe system was collected during this period.

Post Study. After the fourth week, each participant and his/her primary caregiver took part in debriefing interviews and filled out post-study questionnaires, which included the same form (see #3 above). I then conducted semi-structured interviews with each group, asking them about their overall experience interacting on GroupMe, the benefits of using GroupMe, its technical and social barriers, and the effects of the application on their support activities and interpersonal relationships. The materials used during the debriefing included lists of the group members that they had invited and the messages they generated. The purpose of the debriefing was to encourage the participants to reflect on the use of GroupMe, to explore the rationale for their interaction with the system, and to expand on the context of message threads pulled from the log.

4.2.4 Data Analysis

The study produced a rich dataset. Messages produced by participants were stored on our server. I refer to this data as the **usage logs**. I conducted two phases of analysis of the usage logs and questionnaire responses. First, a descriptive analysis was conducted to examine the relationship between questionnaire responses and the overall communication patterns generated from the usage logs. I also collected fine-granularity scale conversational data such as messages exchanged on GroupMe. I then grouped the messages by VDE skill topics area, and defined the group of messages as a conversation thread. I examined the relationship between the conversation threads and the concerns around independence which participants reported.

Concurrently, I and another researcher conducted in-depth qualitative analysis of transcribed interview data and logged messages. Two researchers conducted an initial round of open coding and memoing to create thematic connections using a data-driven approach (Seidman, 2006). By applying a triangulation of descriptive quantitative analysis of the system logs and questionnaires and the interviews, I was able not only to

assess the functional value of the technology but also to understand the social value from the perspective of daily interaction.

4.3 Results

4.3.1 Overall usage

I begin by describing the general patterns of communication extracted from the GroupMe usage logs. I recorded a total of 73 threads (583 messages) from our three participants' groups.

4.3.1.1. Membership

All three groups communicated within a single focused communication circle of GroupMe that consisted of five to seven members. In the pre-study, I worked with participants to create their first social support circle in GroupMe; I also encouraged them to add new members and create additional circles as the study progressed. However, I observed only a few instances in which new people were added to existing groups (two new members to G1 and one new member to G3), and none of the participants created new circles during the study. Pre and post assessments of the closeness showed that all three participants had an increased perception of closeness to the extended network members (61%, 8 out of 13 relationships). Two of the three participants showed no change in the closeness to their primary caregivers and one showed a decrease in closeness.

4.3.1.2. Communication patterns

The three groups showed both common and distinct patterns of communication. All three individuals with autism were the most active communication participants in their groups (Andrew: 50%, 69 out of 147 messages, Sarah: 43%, 81 out of 186 messages, Paul: 28%, 69 out of 250 messages). Of the three young adults, Andrew was the most active

communication initiator (61%, 11 out of 18 threads) followed by Paul (30%, 7 out of 23) and Sarah (25%, 8 out of 32). The initiation in both Sarah's and Paul's groups were more evenly distributed among the members of their groups. I found that the mothers, who were providing prompts both online and offline in all of the groups, were more engaged during the first week, but they reduced their engagement in the remaining weeks when invited group members increased their activity. For instance, Andrew's mother participated in 75% threads at the first week, but 2% of threads the remaining weeks (Sarah's mother: 43% to 36%, Paul's mother: 88% to 64%).

4.3.1.3. Communication topics

Overall, the system addressed an ongoing issue that all of the participants with autism faced—that of socializing (see Figure 4.2). Social and leisure activity was the dominant theme. The second most frequently discussed topic was schedule management. Participants also generated phatic communication, or greetings, almost every day and it often emerged as other topics such as social activity planning. Two participants discussed health-related concerns such as physical discomfort and sickness.
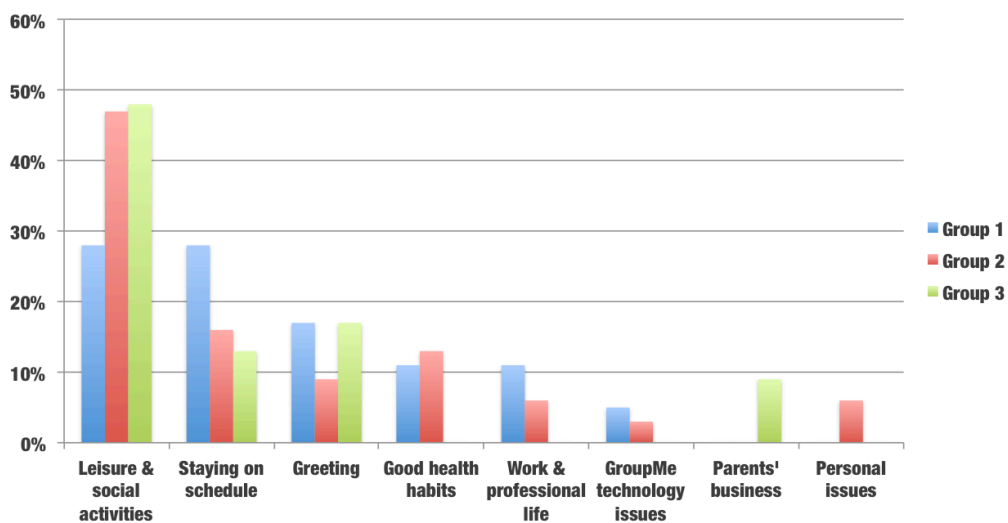
Figure 4.2: Communication topics discussed on GroupMe

Those two participants had conversations related to job and professional life, such as an upcoming job interview. However, none of the participants discussed house chores and attire- or hygiene-related issues through GroupMe. I also looked at the association between the skill importance and competency questionnaire response and the topics of communication participants generated. Sara and Paul reported that they had least confidence in social and leisure activities among the seven skills area. I found that almost half of Sarah's (47%) and Paul's (48%) threads were related to social activities (e.g., offering a movie night, buying a gift for a friend, planning a potluck party). Andrew ranked schedule management as the skill that he was least confident in and it was one of the most frequently discussed topics (28%) in his group threads.

4.3.1.4. Summary of overall usage patterns

I made the following four observations about the characteristics and the impact of the communication circle.

- First, participants made limited changes to the membership in the circles following the initial deployment and they did not add any new circles. The members were, however, actively engaged in communicating within a single circle. The circle was based on their social connections rather than on a particular topic.

- Next, GroupMe motivated participants to initiate communication and the responsibility for responding was shared among the members.

- Thirdly, the application was utilized to address some of the participants' ongoing needs, but some sensitive topics were not broached on the system.

- Lastly, the participants perceived that their engagement with the various members of their extended network, but not their primary caregiver, was improved between pre- and post-study.

4.3.2 Qualitative findings

Building upon the results from the survey and log data, I was interested in whether the use of GroupMe impacted existing support practices and therefore mitigated the over-reliance on the primary caregiver. The findings indicated that participants were highly motivated to engage in GroupMe; they perceived that the application was beneficial for both improving the care network and extending social relationships.

4.3.2.1. The comfort of a small circle

GroupMe was perceived as a comfort zone in which the individuals could extend conversations to a controlled set of individuals. Though some participants also had access to other social media, the prescribed nature of GroupMe appears to have ameliorated some of the social anxiety related to communicating with a large group. Sarah complained: *"I have too many people on Facebook, but I'm not actually comfortable talking with them."* She reported feeling more comfortable sharing on GroupMe: *"I'm still at the point where I'm afraid to walk up to somebody, get their attention, and say this is what I need. I'm learning that it's easier when I know the people are there for me."*

Our participants, both individuals with autism and their caregivers, reported that they were satisfied communicating with those in the circle they first created, so they did not want to create more circles. In the study, I saw situations that might explain why no more circles were created. While family members understood the purpose of using GroupMe and knew how to use it in advance, friends could not acquire information about how to participate. In addition, participants had difficulty inviting others to GroupMe because of strict social norms that managed certain relationships (e.g., the teacher-student relationship). For example, Andrew asked his teacher to join GroupMe, but teachers were not allowed to contact students through personal social media.

4.3.2.2. Immediacy of response

An individual and his primary caregiver valued the focused communication circle because of the immediacy of the response. Participants noted positive feelings about GroupMe as a personalized Q&A system. For example, Andrew had a job interview and asked a question: `[Message] I have an interview tonight and I need to know some questions to ask what should I ask.`

Shortly thereafter, his aunt responded: `[Message] Ask for details regarding their training for new employees. […] They might ask u for 2 or 3 of your best and worst qualities and why, so be prepared to tell them what they are. I would say one is that you are creative […] and another is trusting of people. That one can be a positive and a negative.`

Andrew emphasized that the immediacy of GroupMe was his favorite feature: *"It makes everything a lot quicker […] I don't have to keep going to my contacts to find someone. I just got an answer to what I needed. Quicker!"*

Andrew's mother added: *"He liked the dialog in GroupMe because it is faster and convenient and because I'm very long [winded]. When I teach, I will go from the very beginning to the end, like a half hour answer, like 'Andrew, you are going for an interview. Make sure that you have eye contact, be sure to shake hands, be sure that you say thank you.' […] GroupMe response, when he asked, was very simple and concise."*

Although I was concerned that members might be less inclined to respond to posts and instead rely upon others to take responsibility, I observed no such reluctance during the study period. All queries were answered by at least one group member within an hour. The average response time was 10.3 minutes. Members with existing relationships tended to make the networks more responsive and supportive. Further, participation in the same circle allowed members to expedite action on an individual's request because

they could determine immediately whether the request had been handled by others or whether the poster was still awaiting a response.

4.3.2.3. Instrumental and informational support

Individuals and their primary caregivers adopted GroupMe for providing and receiving practical and informational support. Through the instrumental support seeking process, individuals could harness various ideas and perspectives. Sarah's mother commented: *"I liked GroupMe because when she [Sarah] posted something I didn't feel that I had an answer, but the other people that I trusted were able to answer."*

Andrew's mother noted advice from members helped Andrew prepare for various scenarios he and the mother never expected: *"The best thing was when he was going for the interview, he got replies from everyone and they were all different."*

On another day Andrew asked a question: `[Message] I am at a grocery store and what should I get my friend who is in the hospital`. Everyone told him different gift ideas. For example, his mother suggested: `[Message] Chocolates, flowers, cards`. A researcher in his group asked a question to understand details: `[Message] How sick was your friend? If it's severe, snacks might not be a good idea`. Andrew chose to wait awhile in order to collect ideas and then decided to buy a card. His mother valued GroupMe because he no longer was dependent solely on her opinion. More importantly, Andrew and his mother appreciated that the opportunity to weigh a variety of ideas could lead to more flexible decision-making, an important step toward independence.

4.3.2.4. Legitimate peripheral participation

GroupMe members can choose not to respond to conversation threads. I found that in these situation individuals with autism were able to observe how dialog evolved among the different members. The passive engagement allowed participants to learn

communication norms that were often opaque to them. Such silent observation also gave them access to various styles of interaction that they could later mimic. On an occasion Paul simply posed a question about a boxing match: `[Message] Question: Mayweather or Cotto?` The thread evolved and ultimately Paul's family and friends gathered to watch the fight. Paul remained quiet while others exchanged messages to coordinate a potluck. At that point, he joined the conversation: `[Message] I will handle dessert`. He commented later that this dialog was the highlight of his GroupMe trial. By providing the opportunity for such silent participation, GroupMe could help individuals learn communication skills that may enrich their future interactions.

4.3.2.5. Opening up richer social interaction both online and offline

All individuals lived in their parents' homes. One of the concerns often reported was that the individual's social interaction was very dependent on their primary caregivers. Thus, mothers expressed concerns that their children might be socially isolated if they moved away from home. In the pre-interview, Paul's mother was worried that: *"He tends to isolate in his room, listening to music… Having access to people, knowing how to go and find activity is crucial."*

As conversations grew and expanded, opportunities arose for enriched social relations. For example, Paul's mother appreciated the fact that GroupMe increased interaction between Paul and his aunt: *"They're close in age. She lives on the south side of the town. Paul and [his aunt] didn't even talk that often. But, I think he would see her at Thanksgiving or Christmas. I feel there's more interaction. So, I think that's the best part of it."*

Consequently, these GroupMe conversations led Paul and his aunt to attend a concert together. Paul confirmed the use of GroupMe made the social event happen: *"We never did it before. It was the first time that I invited her to go to a concert."* Paul's mother

reported that GroupMe fostered improved interaction between her son and other members and, in turn, helped Paul interact with others more spontaneously than before.

The conversations on GroupMe also helped to identify and meet individual needs even primary caregivers had overlooked. For instance, a friend of Sarah's mother treated her to an age appropriate treat: `[Message] Hey Sarah, you know I'm a nail tech so I'd love for you to come get your nails done and get to know you:-) let's plan something!` Sarah's reaction was one of delight: *"[When I got this message] I felt 'Oh, I want to do that.' Honestly, I never really had friends ask me if I can go with them for the nail stuffs. So, I felt like 'WOW'. I never thought of that. So, it was surprising to me."*

Sarah's mother found that GroupMe also provided members with a different view of her daughter: *"I think [GroupMe] gives [other members] a little more insight into her, like how she thinks. I think this is a good way for them to see her as more a person coming into the adulthood and to see that she's just not a kid playing. I think it helped them to see her as more mature and older."* This positive experience increased Sarah's sense of closeness to the mother's friend. In fact, Sarah rated her closeness with the mother's friend as 2 ("I barely know this person") in the pre-questionnaire, but listed a 5 ("we're very close") after the study.

4.3.2.6. Open challenge 1: Managing circle memberships

The use of GroupMe increased the chance to communicate with extended network members and therefore strengthened the relationships between an individual and the network members. However, individuals and primary caregivers did not always assign the same significance to relationships or value the same method of maintaining contact with others. Questions exist, therefore, about who should control the social network, the individual or the primary caregiver, or both. Because the goal is to support an individual's transition to independence and adulthood, conflicts between the individual and the caregiver will inevitably emerge. Disagreements could arise in situations where

the caregiver may invite a person with whom the individual is not comfortable or, alternatively, where an individual may seek to include a person whom the parent does not see as being *"on the same page [with] our beliefs."* In fact, the mothers did not think they needed to have complete authority of managing membership. Rather, they anticipated that their children could develop an ability to create a social network on their own through GroupMe: *"I want him to be outside of family and friends … I want him to be able to develop his own network of friends." (Paul's mom)*

Another issue to consider is an inevitable tension between creating a circle of known and trusted participants versus extending participation to others less well know in order to increase social opportunities, such as the diversity of relationships and ideas. Sarah's mother noted that open participation in the network might lead her to worry about the quality of the provided responses: *"When she posts something on Facebook, she could get a ton of friends she does not know well. So the younger kids may not have quite thought out their answers."* She noted that members of the network needed to be vetted on a number of characteristics including: *"[their ability to] understand her strength and her weaknesses with Asperger's […] They need to understand what our religious beliefs are so that they don't suggest for her to do things that we wouldn't allow…"*

4.3.2.7. Open challenge 2: Managing and distributing communication in a circle

GroupMe is basically a group broadcasting system. Participants used the technology appropriately to address the whole group (e.g., `[Paul's Message] what are all your plans for this weekend?`). However, group broadcasts and the resulting responses created significant message volume, which proved problematic for some members. Participant mentioned that participation became over-burdened when receiving too many messages, particularly for a topic they did not want to contribute to. This led one member to drop out on the first day. During the post interview, Sarah's mother noted: *"I had one person at the first day who said that 'take me off.' […] When you're*

getting responses from everybody, that can get to be way too much." She tried to ameliorate the traffic flow: "There was a couple of times that I was supposed to respond to say something, but I didn't because I thought, 'well, I don't want to bother everyone with this.'" To cope with the group format, if a conversation between others became irrelevant or uninteresting, participants often stopped conversation on GroupMe and switched to other channels (e.g., phone call) to directly communicate with a selected person. Participants had to negotiate when they needed to sign off GroupMe and to determine to whom to direct their message, but it was not easy to determine whether a member was available for such communication.

4.4 Discussion

GroupMe helped our participants establish a communication circle with a pre-defined set of people to broadcast requests for help. Our results also suggest that GroupMe could be used as a special question-and-answer tool to receive feedback beyond primary caregivers who were often overburdened. In the following, I discuss lessons learned from this study and provide a set of design alternatives to augment existing SNSs to better serve individuals with autism.

4.4.1 Impacts on the initiation of communication

General SNS users create diverse circles by reflecting their facets of life, tie-strength, and topical interests (Kairam et al., 2012). I expected to observe the similar behavior from our participants, but found that instead they created a unified circle and posted a variety of queries and comments to the circle. In the first few days or week, the individuals relied on their mothers' prompts to initiate conversations or to request help, but the participation of the primary caregivers dwindled as that of others increased. This demonstrates a distribution of responsibility for answering requests of help among

members. Thus, it is seen that SNS may indeed lessen the over-reliance on primary caregivers.

Because social isolation impacts the independence of young adults with disabilities and since SNS is inherently social and informal, it is therefore an appropriate outlet for discourse on social and leisure topics. However, request for help on other areas requiring more instrumental assistance, such as hygiene or attire management, did not occur. One explanation is that such questions may have been too sensitive to share in a SNS setting, or the individuals may not have known how to articulate the problem (e.g., a question about a romantic relationship that the individual does not want to ask parents, or a number of questions about cosmetics that a woman would only want to ask a female). The unified circle may not always be suitable for discussing those unique questions. Some questions or requests would be applicable to only a few members in the circle. I later consider a design opportunity that could address this challenge by proposing an alternative way to create circles in the existing system.

4.4.2 Impacts on the collaboration patterns

The findings support the notion that the key feature of circles mediates participants' communicative expression in two ways—passive engagement and active involvement. First, the findings resonate with the conclusion arising from past research that found SNS affords opportunities for passive engagement that confers informational and social benefits to those with low self-esteem (Burke et al., 2011). The three young adults in our study reported that they sometimes neither initiate the group conversation nor participate in it extensively, but they actually read the stream and sought to understand the intentions of the other members as they communicated. A shared discussion thread itself may serve as a tool for individuals with autism to learn social skills by allowing them to passively observe how people initiate a discussion topic and respond to others. Conversely, observing threads helped members understand some facts about the

individual with autism. Thus, the discussion thread also could be a tool for critical reflection of an individual's emerging needs and concerns.

Next, active involvement allowed participants to get both immediate responses, and over time, multiple responses to a request. While I speculated the possible risk of conflicting advice among SNS members holding different perspectives in Chapter 3, I saw no evidence of this potential conflict in practice. However, caregivers still raised concerns about including members that do not share the caregivers' values. They wanted others to understand the specific context of their children such as the children's strengths and weaknesses related to Asperger's. I consider a design opportunity that could improve value transparency and accountability.

4.4.3   Impacts on the strength of the relationship

GroupMe facilitated various communication practices that led to an increased sense of closeness to the members whom they did not know well before the study. The four-week field study also revealed offline socialization that was spurred by online interaction, resulting in positive experiences both for the young adults and for their caregivers who want their children to seek social opportunities. However, the use of circle feature might have an unexpected impact on the off-line network relationships in a long-term deployment. One can imagine that being in a circle centered around supporting the needs of one individual including all of the other members' messages directed to the individual, can become quite annoying to an uninterested group member. I consider this challenge as a design opportunity for fine-grained circle and effective message delivery mechanism.

4.5   *Design Opportunities*

GroupMe was an appealing tool to use in this investigation because it was freely available and offered cross-platform support for desktop, smartphone and feature phone

users. Having conducted this exploratory study, I see several opportunities to build specific features on top of a circle service like GroupMe.

4.5.1 Prompting temporal and contextual circle formation

Current approaches to creating circles focus on setting up groups for the purpose of controlling who receives particular messages. At the outset of our study, it was not clear to our participants whether and to what extent they should assign their family and friends to different circles. Furthermore, inexperienced individuals may not know what types of questions their social network members would be willing to answer. Therefore, one design recommendation is to have the system suggest both the theme for various circles and ideal members for focused communication within each circle.

Future systems could, at any time, explicitly aid in circle creation by suggesting topics and proactively help in inviting people that one might find beneficial for discussing the topic. Initially, a basic set of topics for circles could come from the seven independence skill areas, and group members could be invited to join any of the circles they wished. Additional circle topics may also evolve automatically in the context of ongoing conversations within the system. Therefore, a circle may not be a permanent entity; rather, it would be more contextual or perhaps ephemeral as an individual's concerns or interests change. One direction for future work, then, will be to determine the factors and mechanisms that will produce valuable suggestions for circle formation and membership.

4.5.2 Requesting and offering help via profile articulation

Knowledge about the individual's personality, personal and professional goals, and interests may help group members provide more effective support. To that end, a system could prompt and help young adults with autism to openly advertise their limitations so that group members can proactively provide advice or suggestions on

those topics. This mechanism can be embedded in SNS profile management since a profile does not just depict one's identity, but mediates communication (D. Boyd & Heer, 2006). A young adult could thus identify skill areas that they want to improve. Conversely, the system may allow members to browse the needs articulated by the individual and choose which topics they would like to support. Other relevant system features could include prompts to group members regarding the areas that the individual identified as ones in which he or she has limited capabilities. These reminders could lead the members to reach out to the individual with specific information or suggestions.

Another profile idea is that expressed by primary caregivers who want to ensure that member's giving advice share the values and priorities as the primary caregiver's family. The primary caregiver may know this for individuals they already knew outside of the SNS, but for other unknown individuals, some form of profile information may make transparent a value mismatch.

4.5.3   Supporting fine-grained communication control

As I discussed above, the downside of GroupMe included a high volume of messages. Since individuals had no way of knowing whether members were available to communicate, they tended to broadcast a message to the entire group first, and only directed subsequent messages to a particular individual once someone responded to the initial broadcasted message. Thus, tensions arose as the individual generated significant message volumes at times when members were not available to provide support. The current all-or-nothing mechanism for participation in the discussions within a circle is inadequate. I see the need for more fine-grained controls on discussion threads that enable a circle participant to opt in and out of various discussion threads, or allow active participants in a thread discussion to limit those who can see further messages.

Another solution would be scheduling times available to participate in circle in advance. The ability for group members to signal their availability to real-time support might help to ensure that a request for help is targeted at the right people at the right time. For example, a simple feature that turned off the circle participation temporarily could serve both to signal to the individual that a particular circle member is not available, as well as simultaneously encouraging other members to make themselves available to cover for the diminished circle size. Intelligence embedded in the system could also play a role; for example, recurring "unavailability" could be predicted based on the members' past behavior within the circle. A new design could attempt to handle the situation when too few members are available to participate. One possibility I have explored is the creation of a service of a "trusted stranger," volunteers willing to provide input but who remain anonymous to members of a circle. I will return to this notion of the trusted stranger in Chapter 7.

4.6   Conclusion

I investigated the opportunities and challenges of using an existing SNS, GroupMe, to increase the independence of young adults with autism. I examined a specific feature, the focused communication circle that enables broadcast communication to a pre-defined set of people, particularly in the context of requesting help or advice. The findings indicated that communication mediated by the focused communication circle impacted the on- and off-line relationship between the individual and online network members while mitigating concerns about over-reliance on primary caregivers.

GroupMe allows users to ask questions to fairly small and trusted members, receive immediate responses, and learn communication skills by observing others' responses. This leads to richer on- and off-line social interaction. On the other hand, the exploration of GroupMe identified technical and social dilemmas; a unified circle that involves all

online network members in every communication loop might not always be suitable for discussing some questions. The partial coverage of question areas and the reliance on the pre-defined small network might hinder receiving a wide perspective of answers. These challenges therefore allow me to understand what is missing in these types of SNSs, motivating the development of richer functionality. The identified new design features, including contextual circle formation, profile articulation, and fine-grained communication control mechanism, provide promising directions for future work.

The contributions of this chapter are as follows:

- In a four-week deployment study with three individuals and their own small online support network, I demonstrated the effectiveness and the shortcomings of a focused communication circle feature for supporting everyday situations of individuals with autism through a deployment of an existing SNS, GroupMe.

- I used a mixed-methods approach to analyze the impact of GroupMe and its implementations of the focused communication circle on a variety of independence dimensions: initiation of questions or requests for help, topics of questions, and strength of relationships with network members.

- I developed modified features for the focused communication circle—contextual circle formation, profile articulation, and fine-grained communication control mechanism—which can be translated into the direction of future design of a special social networking service for the individuals with autism.

CHAPTER 5

QUESTION AND ANSWER BEHAVIOR IN AN AUTISM FORUM

In Chapter 4, I described how an existing SNS could help young adults with autism ask questions of extended online network members. I further discussed implications for enhancing the focused communication circle features to better support question-and-answer (Q&A) behavior. In this research context, Q&A behavior refers to the activities of information- or advice-seeking to cope with everyday frustrations and challenges. However, this study represented the Q&A behavior of only three individuals.

In this chapter, I specifically focus on characterizing general Q&A behavior occurred in a naturally emerged setting such as an autism online forum. A large set of Q&A data generated by individuals with autism can shed light on topics of primary interests, needs, and concerns. Drawing on a combination of quantitative and qualitative analysis of a dataset of Q&A on an online autism forum, I characterize the topic and type of questions in an attempt to determine the kinds of support is sought by individuals. Using the forum as a motivating example, I discuss design opportunities for improving the practice of Q&A that supports the unique needs and experiences of individuals with autism.

5.1   Introduction and Motivation

In Chapter 4, I suggested existing SNS could be used as a Q&A platform where individuals with autism seek rapid and diverse feedback to cope with a variety of daily

challenges. The results also illuminated what some young adults and adults with autism are concerned with on a daily basis and how they have addressed such concerns in a form of question-asking. However, questions asked by three individuals might not be representative of individuals with autism at large. It motivated me to find other data sources that provide a large sample of questions produced in a naturalistic setting, such as online forums with many participants and a large number of discussion threads covering a variety of topics.

Increasingly, individuals with autism turn to existing social media platforms, such as online forums, to share personal experiences about living with autism (Burke et al., 2010). The affordance of online forums can help them seek support by broadcasting questions to a virtually-connected network and obtaining answers from members of the network (i.e., online buddies) (M. R. Morris, 2013). Requests or questions posted to the forums, in turn, can provide a lens for analyzing various types of social support sought by members of the special group. I focus on analyzing support-seeking threads in an online autism forum to identify current needs and concerns of the members. I also investigate how their requests are addressed by the responses of others.

In what follows, I present a study of an online forum for adults that self-identify as being on the autism spectrum. Using a dataset of 28,960 posts organized into 1,945 threads, I explore in depth question-asking behaviors of individual users. I report on the taxonomy of question topics and types. The topics of questions asked in a forum highlights current needs and concerns of the members of the forum. The types of questions present the forms of support the members sought. I also chracterize questions that go answered and unanswered to identify drawbacks of the current autism forum in supporting everyday help and information seeking. By considering what questions they ask, and how those questions are asked and answered, I provide design insights to improve their online advice-seeking experience.

5.2 Methods

I first describe the online autism forum that was a source of our data. Then, I describe the data collection process. Finally, I outline the analysis process.

5.2.1 Research site

This study investigated threads from the public discussion boards of a large online autism community[6] with more than 6,000 registered members and 19 discussion boards organized by such criteria as users (e.g., family and friends), topics of concern (e.g., love, relationship and dating), and interests (e.g., technology). In these boards, individuals that self-identify as being on the autism spectrum post questions, self-disclose personal stories, and impart health-related information (e.g., diagnosis, treatment). Thus, this discussion board platform is a rich environment for studying what kinds of support individuals with autism seek. As of January 2015, the forum contained 9,507 threads and 180,259 individual posts.

The forum's title suggests that members might have Asperger's syndrome, but members of the site do not necessarily have an official diagnosis of autism. Neurotypical individuals (people who are not on the autism spectrum) are also allowed to participate in the community. Upon registering, the user is asked to generate a profile with a pseudonym and indicate his or her diagnostic status. Because of the level of privacy safeguards, it is virtually impossible to confirm the demographics of individual members. My observations on the site suggest that its user base appears to consist largely of individuals with autism, but some are also family members, friends, or spouses of individuals with autism.

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[6] I do not reveal the name of the site for the data privacy.

5.2.2 Data collection

Among the discussion boards presented in Table 5.1, I excluded discussion boards that were website-specific (1, 2), those mainly used by family and friends of individuals on the spectrum (5) or researchers (6), and one for amusement (15). Thus, I focused on ten discussion boards (3, 4, 7, 8, 9, 10, 11, 12, 13, 14) in which the forum users discuss their everyday experiences, concerns, and challenges. Using the python library Beatifulsoup4 (BeautifulSoup4), I collected 1,945 threads (28,960 individual posts) from the discussion board archives over a time period from June 1, 2010 to July 27, 2013. For a given post, I extracted associated metadata such as the author identifier and posting timestamps.

Table 5.1: A list of Discussion Boards on the autism forum

Public forums	Discussion boards	Threads (Posts)
The website specific	1) Announcement	34 (214)
	2) Introduce yourself	906 (5,336)
Autism spectrum	3) Asperger's syndrome, Autism and HFA	742 (10,232)
	4) PDD-NOS, Social Anxiety and Others	69 (1,337)
	5) Friends and Family	128 (1,198)
	6) Autism News, Events and Research	206 (746)
Specific discussion	7) Obsessions and Interests	241 (4,001)
	8) Friendships and Social Skills	193 (2,518)
	9) Education and Employment	119 (1,583)
	10) Love, Relationships and Dating	142 (2,091)
	11) Autism Spectrum Help and Support	139 (1,283)
Topic-based discussion	12) Off-topic discussion	396 (5,116)
	13) Entertainment discussion	166 (5,264)
	14) Computers/technology discussion	106 (1,112)
	15) Forum Games	57 (2,694)

To build our Q&A dataset, I considered the initial post to be the (potential) question and the subsequent posts to be the replies. I wanted to analyze threads (initial post plus reply posts) that began with a question from an individual with autism, so I had to

determine manually whether the author of an initial post had autism and whether the post was a question.

Does the author have autism? Obtaining the profile of the author of a post ("poster") in the public access mode is not possible, so I was careful when screening each post for "signals" that the poster was on the spectrum. This process was facilitated by a writing convention when inquiring about autism-specific issues. Posters would often disclose their status in the question ("I was diagnosed with Aspergers when I was 14, and I am now 23."). Posts by members that were self-described as "not on the spectrum, or neurotypical (NT)," were discarded. I also retained posts that had no clear indication one way or another.

Is the initial post a question? I wanted to analyze threads that only begin with a question and exclude others from our subsequent analysis. For example, I excluded threads containing a initial post that is best described as general discussion points, information being provided, or simple notes about users' thoughts. I applied a manual filtering process to detect a question post using the following heuristics: (1) ending with a quesiton mark; (2) starting with one of five wh question words; (3) having explicit or implicit indicators for soliciting answers, such as want, wonder, need, advice, help, suggestion, tip, opinion, response, feedback, support, please, problem, issue, trouble, any, anyone, or someone.

The filtering process done by myself as a single coder resulted in a dataset of 1,277 question posts and 20,472 reply posts that were identified as question threads that were likely to be created by individuals with autism. This data was the basis for the analysis.

5.2.3 Analysis

To better understand the nature of questions posted by individuals with autism, I analyzed the dataset along with another coder. Each question post was categozied along two dimensions: question topic and question type.

Question topic pertained to the content of the question and captured the area of concern for the poster. Topics were initially classified by seven areas of living skills presented in Chapter 4 (Virginia Department of Education, 2010).

Question type pertained to characterizing the type of support or the expected form of the response sought by the poster. The question posts were coded into one of several types adapted from the taxonomy in Morris et al's work on types of Q&A in social media (M. Morris et al., 2010) and Ellison et al's work on types of requests for help on Facebook (N. Ellison et al., 2013).

Two coders used the initial coding scheme to categorize a random subset (n=100) of the entire set of question posts (N=1,277), and discussed disagreements until we reached consensus. The coding scheme was revised to accommodate new topics and types that emerged from this process presented in Table 5.3 and Table 5.4. I then manually categorized the remaining questions (n=1,177) using the agreed-upon coding scheme. As a further check on the coding, a second rater redundantly rated 80 questions randomly sampled from the 1,177 question posts. Cohen's Kappa (κ) revealed moderate agreement for the question topic (κ=.61) and substantial agreement for the question type (κ=.78).

5.3   Results

Table 5.2 provides descriptive statistics for our Q&A dataset of the forum. 92% (n=1,179) of the question posts received feedback from at least one of the overall 967 respondents. 8% (n=98) of question posts received no responses. 10% of the questions that were

answered (n=133) received the first response after a long delay (one month or more) by only a few respondents. When these responses are included, the average response time was 115.9 hours, or 4.8 days (*M*=2.5, *SD*=738.6). When the 10% delayed responses are excluded, the average latency for questions answered was 21.6 hours (*M*=2.1, *SD*=72.4), and over 50% of questions were answered by at least one person within a day.

Table 5.2: Basic Descriptive Statistics of the Q&A Dataset

Total number of question posts	1,277
Total number of replies to question posts	20,472
Total number of question poster	387
Average replies per question post	17
Mean length of question post (words)	158
Mean length of replies (words)	90
Average response time (hours)	115.9

5.3.1   Question topics: Everyday concerns

Table 5.3 shows the seven topics and subtopics within each category. One might assume that autism-specific topics would dominate the questions because the most active forum was *AS, Autism and HFA*. However, the topic analysis revealed that, across the discussion boards, the most frequently asked questions related to *social skills*. Questions ranged from asking for communication strategies (e.g., a way to ease the stress of making eye contact) to suggestions for managing interpersonal relationships. Questions in this category sought common social and cultural norms (e.g., "What should I do for my sister's baby shower?") and subjective opinions about overcoming difficulties in initiating or maintaining relationships (e.g., "How do I get over my recent breakup?").

Table 5.3: Question Topic Categories from the 1,277 questions

Category	Subcategories	Percent
Social skills 26.5%	Communication skills 4.9%	"When I'm with friends and try to talk, It's just a mumble. Does anyone else have problems with their speech or their voice?"
	Managing Social relationships with family, friends, romantic, professional 14.4%	"I was wondering if there were people out there who could post about long-term relationships they have had and if they have been successful."
	Norms and culture 5.2%	"I have been invited to participate in my sister's baby shower this coming Saturday. I don't know what I am going to do with so many people around. Any suggestions?"
	Online 2.0%	"After losing my two closest friends, I decided to take refuge in other pastimes. I am looking for places to re-build my life online."
Leisure and entertainment 23.3%	Hobby / interests 5.6%	"How many of you watched the Wimbledon tennis final?"
	Events 2.4%	"Do any of you have Christmas plans?"
	Technology and media 11.3%	"I used to make a lot of YouTube videos and it could possibly be my future goal. Who here is into filmmaking and animation?"
	Other 4.0%	"Which sides are the most of us on, conservative or liberal, or in between?"
Autism or AS specific inquiries 19.8%	Diagnosis 6.3%	"Any recommendations for an online AS test that is considered the best for adults?"
	Behaviors and symptoms 9.9%	"Does anyone else get a little annoyed by loud noises?"
	Resources 3.7%	"Having no connections is making this difficult. Does anyone know A university's center that assists people on the spectrum?"
Mental health 9.2%	Anger / anxiety / depression 5.8%	"What helps you get through the hard days? (I'm thinking other than meds or therapy)"
	Isolation 2.0%	"Over the last few years, I've become more socially isolated and I literally have no social life. Has anyone else been through severe isolation and depression like this?

	Obsession 1.5%	"I was just wondering if anyone had any ideas on how to break that circling you do in your mind where you think of past times you didn't get things right."
Work and education **8.5%**	Academic skills 3.6%	"I didn't do quite well with maths. I've tried revising but it seems so difficult. How can I improve my grades?"
	Workplaces 4.9%	"How do I know if I got the Job after an Interview?
Everyday skills **7.2%**	Health habits 2.6%	"I went two full days with no food, just ice water. It feels good to eat much less and I am not overweight. Have others done this?"
	Hygiene 0.8%	"What do you use when you're taking a bath or shower? Soap or shower gel?
	Home 0.8%	"Have you shared a house or apartment with other people? Could you cope with it?"
	Money / finance 08%	"Have you ever earned money online? Which money-making sites have you had luck with?"
	Transportation 0.5%	"I got myself into a very dangerous situation without realizing it. I'm worried that every time I get into my car, I could get into serious trouble. What should I do?"
	Other 0.5%	"Are there any strategies that you use to manage schedules or complete tasks on time?"

Among the various types of social relationships, romantic or love relationship questions were posted most frequently. Not only did users ask questions about real-life relationships, but also 2% (n=24) concerned how to maintain healthy "online" relationships. The next most popular topic discussed in the autism forum was *Leisure and entertainment*, including questions about hobbies, interests, events (e.g., holidays), technology and media (e.g., TV shows), and philosophical subjects (e.g., religion). Among these subcategories, the dominant subject was technology and media. Questions ranged from soliciting information on learning C# (a programming language) to finding people interested in a specific role-playing game for further in-depth discussion. *Autism-or AS-specific inquiries* were related to receiving diagnoses, understanding behaviors and

symptoms affected by autism, or soliciting information or support targeting those on the autism spectrum. *Mental health* questions dealt with concerns about isolation, anxiety, depression, obsession, and anger management (e.g., how to cope with a "meltdown" in an unexpected situation). *Work and education* questions addressed transition to adulthood, including entering college or starting a new job. Work-related questions related to job searches, professional matters, work ethics, and career development. Education questions ranged from seeking educational resources to improving academic skills and adjusting to college life. The *Everyday skills* category included questions about, or requests for help in, performing day-to-day activities related to home, hygiene, health habits (e.g., food, sleep), financial management, transportation, schedules, or a combination of these areas (e.g., *"I'm sharing an apartment with a roommate. How should we divide house chores and the budget for living expenses?"*).

5.3.2 Question types: Expected type of support

The types of questions were associated with specific linguistic styles and forms of responses and support an asker expected. Table 5.4 lists the definitions and the prevalence of the different question types.

The most popular question type, *recommendation or suggestion*, seeks subjective and open-ended responses. The second most popular types, *opinion/poll* and *rhetorical* questions, also requested subjective opinions or thoughts. *Opinion/poll* questions solicited feedback or assessment in response to the asker's choices or a vote for a decision. *Rhetorical* questions asked for subjective opinions or personal experience that may convey emotional value, but they did not necessarily convey informational value. The online autism communities like the forum I studied are a primary venue where users are engaged in interaction with others on the autism spectrum to meet emotional and socialization needs. Users often address these needs by asking rhetorical questions.

Table 5.4: Question Type Categories, Definitions, and Examples from the 1,277 questions

Type	Definitions
	Examples
Recommendation or suggestion* **34**%	A subjective and open-ended request for suggestions
	"I get jealous when my best friend hangs out with other people. What should I do to maintain healthier friendships?"
Opinion or poll* **22**%	A question that requests a subjective opinion or assessment in response to the asker's choices; or a request a selection of a specific item among several alternatives; or a solicitation of preferences
	" 'If you're outfit consists of a hat, t-shirt, long baggy shorts or jeans and tennis shoes, you will be turned away.' I saw this on a restaurant's website. This is my usual outfit when I'm not at work. So, should I change my clothes or I eat elsewhere?"
Rhetorical* **22**%	A conversational question that is intended to prompt discussion or that does not necessarily expect practical information or help
	"What did everyone do over the long weekend?"
Affirmation or validation **14**%	A request for affirmation or validation of thoughts, beliefs, or doubts the asker has; or a question to just find someone who is "on the same page" or share a similar characteristic
	"How do you feel when you are late? Is it common among those with Aspergers/Autism to hate being late and get anxious?"
Factual knowledge* **4**%	A question for soliciting objective answers or information
	"I am wondering whether ADD / ADHD should be part of the Autism Spectrum Disorder spectrum."
Favors* **2**%	A call for action, help, service, items, physical assistance, or consultation
	"I understand written English, but not spoken English. I want to know what this song (YouTube link) says. Can I ask you to write the English portions?"

* Question types pre-defined by (M. Morris et al., 2010) and (N. Ellison et al., 2013)

Affirmation was a distinctive category, which has not been reported in previous work on general Q&A behavior. Affirmation questions generally were aimed at validating thoughts, beliefs, misconceptions, or doubts. For instance, common questions included,

"Am I weird?", "Is it just me?", and *"Similar problems, anyone?"* In addition, these questions often revealed specific details about the personal problems in an effort to solicit coping strategies from others with similar experiences. In this way, the forum members sought to understand themselves and to determine if their concerns or opinions can be traced to their autism or if they are experienced by everyone. One distinctive linguistic pattern observed was that a number (53%) of affirmation questions included the phrases, "is it just me" or "anyone else." The users appeared to ask such *affirmation* questions either to request opinions or to gain empathy.

Factual knowledge questions included the solicitation of objective answers or information. The least-asked question types were *Favor* questions, which included requests for action (e.g., leaving a support message for a donation event or organizing a local socialization group), service (e.g., editing a presentation script), and consultation (e.g., one-to-one mentorship service).

Except for factual knowledge questions (4%) and requests for favors (2%), the majority of questions (94%) sought subjective answers. The original taxonomy emerged from analyzing Q&A behavior on social networking sites. Some special types of questions in the original taxonomy (e.g., "invitation", "offer", and "social connection") that require strong pre-existing social connections were rarely identified in the public boards.

5.3.3   Topics and types of unanswered questions

I also examined how the topic and type related to whether or not the question received a response. As I noted, 8% (n=102) of the 1,277 posts received no response and 10% posts (n=129) received long-delayed responses. Table 5.5 shows the distribution of the unanswered and delayed questions by topic and type. Our results indicate that questions that are likely to go unanswered require specific information. For example,

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entertainment and *work and education* and *factual information* questions require interest in the topic or knowledge about the specific area described in the question. Questions also less likely to receive a response include *favor* questions which request special action by the respondent and sometimes require offline physical assistance.

Table 5.5: Distribution of Question Topics and Expected Answer Types For 231 Unanswered or Long-delayed questions

Topics	No response	Types	No response
Social skills	3.8% out of 338	Recommendation	14.0% out of 434
Leisure and entertainment	12.0% out of 297	Opinion and poll	9.6% out of 281
Autism-specific	8.2% out of 252	Rhetorical	8.2% out of 281
Mental health	3.4% out of 117	Affirmation	5.3% out of 178
Work and education	10.3% out of 108	Factual knowledge	14.5% out of 51
Everyday skills	3.5% out of 92	Favor	31.5% of 26

5.4   Discussion

5.4.1   Soliciting subjective advice on a variety of life situations

The majority of posts (66%, n=1,277) over the 1,945 threads collected for this study were initiated by questions or requests for information related to the users' everyday situations. The results suggested the autism forum might serve as a question-and-answer tool that addresses some demands or challenges of individuals with autism.

The most popular topic, *social skills,* is related to inherent difficulties with communication and social interaction skills of individuals with autism. It could be one explanation for why questions regarding *social skills* accounted for about 30% of questions asked on the forum.

However, questions asked by the forum users were not confined to autism-specific topics. I found that question topics discussed on the forum, such as entertainment,

technology, home and family and professional, greatly overlapped with the popular topics queried by Americans in 2004 (Beitzel, Jensen, Chowdhury, Grossman, & Frieder, 2004), as well as the topics of questions requested by 249 participants of a survey presented in the Morris et al.'s work (M. Morris et al., 2010). Researchers revealed such specific topical interests facilitate social skills training sessions for adolescents with autism (Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007). The autism forum may provide users with opportunities for finding topics that may be of mutual interests and seeking a potential audience or cohorts capable of enthusiasm for unique interests.

The autism forum contains a significant number of questions widely considered as personal, such as dating, health, and financial issues. One explanation is that the nature of the community could motivate users to seek advice about the personal matters from people beyond they may know. The personal and sensitive topics may be embarrassing to ask of a pre-existing social network (M. Morris et al., 2010), such as immediate family or friends, but seem appropriate to ask others who do not know the asker.

5.4.2   Seeking a special type of emotional support: Affirmation

Regarding the types of responses expected, our findings revealed that the online autism forum users primarily seek subjectively-oriented suggestions and opinions. More importantly, "affirmation" is identified as a new type of online questions that emerged through our observation. This type of question demonstrates the unique question-asking patterns of these individuals and provides insight into the form of response that they consider most beneficial. The purpose of asking affirmation questions is to confirm that others are on the same page or that they understand or empathize with the issue raised. Affirmation questions sometimes request the sharing of one's experience at a fine-grained level of detail to provide an exemplar of behavior. Thus, asking or answering such questions has a greater risk of revealing too many personal details and others' information (e.g., the name of friend who purposely ignores and avoids me, company

information where I was laid off for downsizing). As Burke et al. noted (Burke et al., 2010), determining whether the individual's behavior conforms to the norm is difficult. Thus, a deliberate mechanism is needed to help individuals with autism frame a question appropriately based on the purpose of the question and the expected response form.

5.4.3   Challenge 1: Addressing the intent and the urgency of questions

The forum users encountered several challenges. First, the empirical question-response latency of the forum shows that it is not suitable for an immediate response. While the response rate is relatively high, the average time to receive a response (21.4 hours) from the autism forum members is disappointing compared to response time in other forums, such as Java developer forum (9 hours) (Zhang & Ackerman, 2007) or MS Live QnA site (almost 3 hours) (Hsieh & Counts, 2009). The response rate and time could be influenced by topics that require personal interest or specific knowledge. For example, questions related to entertainment, the topic containing the most unanswered questions, specify audiences who might be interested and knowledgeable in a certain topic. I suspect that questions are not answered because there might be insufficient responders who are knowledgeable about the topic. Another possible explanation is the conversational nature of the forum. The autism forum allows free-form discussion. Asking a question or requesting advice is a subset of activities in the forum. Studies of social network information seeking (Burke, Joyce, Kim, Anand, & Kraut, 2007; Teevan, Morris, & Panovich, 2011) show that the way a question is phrased affects the response speed, rate and quality in an online discussion. Thus, a design opportunity exists for guiding individuals with autism to create questions if necessary to increase the likelihood of receiving rapid and effective response. I will revisit this idea as one of design goal discussed in Chapter 7.

5.4.4   Challenge 2: Limited perspectives

A majority of the questions on the forum were related to social skills, yet members asked others with the same core deficit to receive the answers. Not only did the forum users request feedback about difficulties in initiating and maintaining interpersonal relationships by disclosing very personal stories, they also wanted to verify widely adopted norms and etiquettes that could be considered "socially" objective information. However, asking social skills questions of the forum raises challenges when a forum only has similar personal characteristic deficits. Thus, the population bias on the forum sometimes "may" lead to a limited perspective on problem-solving. I showed in chapter 4 that participants of the GroupMe study valued the diversity of answers provided by online network members came from a broad range of backgrounds. Furthermore, the perspectives offered by a variety of individuals is an important resource for dealing with complex social situations (Ochs & Kremer-Sadlik, 2004). I will discuss the way of obtaining answers from people beyond autism peers in the next section.

5.5   Design Considerations

Having conducted the analysis of the online forum, I identified several design opportunities for improving social Q&A interactions for the individuals with autism: (1) scaffolding question creation; and (2) crowdsourcing responses beyond the autism community.

5.5.1   Scaffold the creation of better questions

Clarifying what a question asker wants to obtain may elicit a better answer. Thus, I can build upon analysis of online rhetorical patterns that elicit the most informative responses (Burke et al., 2007). An analysis of distinctive communication patterns could identify the purpose of the question, which could be used to guide people towards meeting the expected topic of support they need. As I noted in Section 5.4.1, some of

frequently discussed topics (e.g., entertainment) are pre-defined by the forum and this might help a user initiate a question within a focused area. In Chapter 7, I will present the idea of providing pre-defined question topics to scaffold the question creation process.

Regarding the expected type of support, I identified a recurring rhetorical strategy for certain types of questions (e.g., "is it just me?" and "Is it appropriate behavior?" found in affirmation questions). By detecting such linguistic patterns, a system could provide a standard form to solicit the user's requirements for their question (e.g., an expected answers type: poll or plain question; a topical label; target audiences). Also, such affirmation questions request aggregate feedback from a number of people to gain socially approved or verified knowledge. In that sense, they are a special kind of opinion/poll question type provided to a large number of potential responders. Providing responders with a poll so that the responses could be aggregated may help individuals with autism understand social conventions generally adopted by society.

5.5.2   Reaching out to responders outside the autism community

This study shows that individuals with autism have many of the same questions and concerns in their everyday lives as everyone else. They not only want to know autism-specific issues like diagnosis, medication, or intervention, but also want to understand general social norms and skills that may help them more smoothly acculturate to the community in which they live. Thus, obtaining responses beyond the autism community may gain a wide perspective on socially appropriate behavior.

Slow or no response might be caused by the lack of diversity or expertise in this community and could also be addressed by identifying respondents with a more diverse background. One idea proposed is to leverage qualified crowd workers to increase the likelihood of diverse, relevant, and quick responses. Relying on crowd workers to provide real-time advice on everyday life challenges has already been explored for blind

users (Bigham et al., 2010). However, in contrast to the questions posed by blind users, which largely seek objective information (e.g., reading a label on the bottle), our study reveals that the majority of questions asked by individuals with autism request subjective opinions or suggestions. In Chapter 6 and Chapter 7, I investigated how a crowdsourcing mechanism can be integrated into the existing forum structure and how this feature can support the Q&A practice of the individuals with autism.

5.6   Conclusion

The study of an autism forum's 1,277 question threads posted over a three-year period combined with qualitative and quantitative analysis of their content, provided a unique window into the everyday challenges faced by individuals with autism and their online question-asking behavior. The overall goal of this study was to use this richer, more nuanced understanding of behavior to explore the opportunities for augmenting this kind of online autism forum. I wanted to determine how well the online autism forum served as a social Q&A system for these individuals, and how it might be improved.

I found that the forum was used to receive advice and answers on a variety of life issues. Despite the effectiveness of the forum in providing most answers within a day, it did demonstrate drawbacks: 1) some responses might not be addressed in a timely fashion due to the inherent conversational and social nature of the forum; and 2) some popular question topics and types such as *social skills* and *affirmation* might require socially-appropriate knowledge with a potentially broader perspective beyond the autism community.

The identified drawbacks represent real design opportunities to either improve online autism forums or to create other social networking solutions. Scaffolding of questions through a smart template or natural language critiquing system can better support questions that make clearer the intended form of response. In addition,

crowdsourcing can help users reach out to responders who provide more diverse and needed areas of expertise.

The contributions of this work are three-fold:

- The results of this study reveal the unique Q&A practices of individuals with autism and establish the taxonomy of questions in the autism forum. A detailed analysis of the topics of questions asked in a forum highlights current needs and concerns of the members of the forum. The types of questions present the forms of support the members expected.

- I characterize questions that go answered and unanswered to identify drawbacks of the current autism forum in supporting everyday help and information seeking.

- The identified challenges—unstructured question creation and limited perspectives—open up design opportunities for improving the practice of Q&A that supports the unique needs and experiences of individuals with autism.

CHAPTER 6

SUPPORTING Q&A WITH CROWDSOURCING

In Chapter 5, I described online question and answer behavior of individuals with autism. Many of them satisfy their informational and emotional support needs by engaging in Q&A interactions in autism-specific online forums. However, these forums may present only a limited perspective because of their *in-group* nature. Thus, I hypothesize that obtaining support from *out-group* sources beyond the autism-specific in-group community might prove valuable in addressing a variety of life situations, such as public anxiety and workplace conflicts.

In this chapter, I explore the value of out-group support from crowdsourced responders compared to that of in-group support from members of an autism forum. I develop and conduct a study to explore the potential of eliciting responses using crowdsourcing techniques. Drawing upon the results of the online forum analysis presented in Chapter 5, I sampled questions and answers addressing a variety of everyday life issues in the forum. Using the Amazon Mechanical Turk (MTurk) platform, I generated out-group answers to the questions posted on the forum. I uncovered key differences between the forum answers and the MTurk answers with a panel of evaluators, including researchers, experienced advisors of individuals with autism, and adults with autism. I discuss how these differences can have broad implications in designing new features of a Q&A system for individuals with autism. These implications feed into a new form of social Q&A platform described in Chapter 7.

6.1   Introduction

Some online forums and communities have emerged as social platforms for people on the autism spectrum to self-disclose, vent, and share (Newton, Kramer, & McIntosh, 2009). I characterize these special autism online communities using a notion of *in-group* as mentioned in related work Section 2.3.2. These *in-group* (Tajfel, 1982) communities provide a key benefit by forming communicative relationships with online peer groups and allowing members to share similar experiences or information to address other members' concerns (Massimi & Bender, 2014). However, members of autism-specific in-group communities may lack certain social skills themselves, which, in turn, may affect the nature of their advice.

Crowdsourcing is a common approach for recruiting a diverse set of people to provide information and advice online (Jeong et al., n.d.; M. Morris et al., 2014). Prior research shows perspective-taking through interactions beyond autism peer groups is critical to improve interpersonal relationships and obtain socially appropriate knowledge (Ochs & Kremer-Sadlik, 2004). Using crowdsourcing to generate *out-group* answers may compensate for the limited perspective of in-group members and may augment the existing in-group support for people living with autism. Thus, I explore the potential of a crowdsourcing approach to enable individuals with autism to garner wider and more varied social support from out-group workers in order to cope with everyday issues and frustrations.

In what follows, I begin by following up on a preliminary content analysis of threads characterizing common in-group questions reported in Chapter 6. I examine whether valuable out-group answers to these in-group questions can be generated by a crowdsourcing approach using Amazon Mechanical Turk (MTurk). I present quantitative and qualitative findings about the differing characteristics and values in

answers between groups, including the speed, relative directness, conciseness, informational and emotional support, and perceived helpfulness provided. The findings reported in this chapter come from the systemic evaluation conducted by myself and one other researcher, 6 adults with autism, and 11 individuals (e.g., counselors, teachers) who have worked with individuals with autism. Building upon the findings, I suggest design opportunities that improve existing in-group communities by including user-initiated features to seek responses from an out-group.

6.2   Study Procedure

Figure 6.1 outlines the steps taken in the study. The Analysis procedure starts with the selection of everyday life Q&A threads in an online forum to a randomly selected representative sample of questions that were used to generate crowdsourced out-group answers. The answers were finally judged against examples of in-group answers along a number of quality dimensions. I describe the six steps of data collection and our analysis methods below.

Step 1: Identifying threads initiated by a question throughout community boards.

Step 2: Identifying daily living questions that do not require validation by experts.

Step 3: Classifying questions into nine topical areas and selecting 20 questions.

Step 4: Selecting 5 community responses per question (1 first response + 4 random responses).

Step 5: Generating 20 Mturk responses per question and selecting 5 crowdsourced responses.

Step 6: Evaluating responses using 5 measures. The order is shuffled and the sources are blind.

Figure 6.1: Six Steps of Data Collection for Crowdsourcing Study

6.2.1 Step 1: Identifying question threads

I aim to specifically address day-to-day social struggles, concerns, and challenges that out-group responses could help with, excluding topics that only in-group responses could understand. Thus, the scope of the analysis is the subset of conversations that are "questions" about regular daily challenges. For this study, I used the initial Q&A dataset established through data collection phase presented in Section 5.2.2. I considered a thread as the unit of analysis. For each thread, I viewed the initial post as the question and the subsequent posts as the replies, or in-group answers.

6.2.2 Step 2: Identifying questions for navigating everyday life

From the 1,277 question threads, I wanted to select a random but representative sample of 20 threads that portrayed the variety of everyday life questions the community members were asking. For this fine-grained analysis, I randomly selected threads from Step1. The goal was to create a subset of 20 question threads to feed into the subsequent out-group analysis (Steps 4-6), but I wanted to make sure that questions were relevant to navigating everyday life and did not require too much expert knowledge in autism. With two additional coders, I thoroughly investigated each thread to determine whether the initiating question sought information or advice on how to navigate everyday life. In addition, I excluded confidential and/or sensitive inquiries (e.g., diagnoses, clinical treatments, and medication) that were too specific to autism itself and that required validation by autism experts.

6.2.3 Step 3: Categorizing questions based on established themes

As a initial categorization, I adopted the seven categories of living skills that are necessary for adults with autism to attain independence proposed by Virginia Department of Education (Virginia Department of Education, 2010): 1) grooming/personal hygiene; 2) schedule planning; 3) physical or mental health habits; 4) school, work and professional life; 5) financial planning; 6) household chores management; and 7) leisure and social activity. In order to find example question threads from each of these categories, three coders independently categorized each of the randomly selected 100 question threads accordingly. During this process, two additional categories emerged: 8) communication skills; and 9) initiating and maintaining social relationships. Once the topical categorization was completed, one to three questions were selected from each category so that all topics were covered. This resulted in 20 questions for the crowdsourcing experiment presented in subsequent steps. Table 6.1 shows an example of each of the 9 final question categories that 20 final

question threads fell into. In categorizing the questions into specific areas, I found that social activities overlapped with almost every topic. For instance, the study classifies the "Matching clothes" question in Table 6.1 as primarily a hygiene and grooming question, but it also can be attributed to difficulty in understanding social norms. Rather than create a separate social norms category for this study, and introduce the problem of cross-categorization of questions, I simply point out the overlap between life skills and social skills that are inherent in many questions.

I also identified a distinctive linguistic pattern from our 20 sampled questions. Nine questions included phrases like *"Similar problems?" "Anyone else?"* or *"Is it just me?"* aimed at either gaining empathy or seeking advice. While most question threads were likely to articulate the specific response expected by explicitly asking a question, some of the questions (n=4) appeared to be more in the nature of a self-disclosure. As noted elsewhere, the practice of self-disclosure is an implicit way of eliciting emotional support (Vlahovic et al., 2014). In addition, self-disclosing questions often revealed specific details about the individual's personal problems in an effort to solicit coping strategies from others with similar experiences.

Table 6.1: Example question posts categorized by areas for navigating everyday life. The number next to the category label indicates the total number of questions selected in each category.

Grooming and personal hygiene (2)
Matching clothes: My mom is continuously telling me that the clothes I wear don't match, even though they always look perfectly fine to me. I don't understand how people decide what matches and what doesn't and how they keep track of it. […] Does anybody else have problems with this?
Daily planning (2)
Difficulty starting the day and doing stuff: It has taken me experiencing countless grumpy, irritable, and depressed weekends to realize I do not do well without a schedule or routine. If I don't start doing something within about 1-3 hours, my day is practically ruined. Does anyone else experience this?
Maintaining good health habits (physical / mental) (2)
Sleep and waking trouble: I often have trouble falling asleep. I could sleep through an explosion. I am told I'm rather violent when someone tries to wake me. Apparently I'm a sleep fighter! Any ideas or suggestions? Sleep aids only make this worse.
School, work and professional life (3)
First day back in school: I went to my first college class this summer, and I started having a panic attack even before I got into the classroom. I started pouring sweat and shaking […]. I felt extremely embarrassed about how I must have looked […] If you have any ideas about what to do to make this better, please let me know.
Financial planning and management (1)
Money management: I seriously suck at not just buying useless stuff. […] The only time I don't buy stuff is when I'm depressed. And even then I'll just go out and buy something to try and make me feel happy (I know how materialistic that sounds). I have a $160 monthly allowance and that's usually spent in two days. Does anyone else have an issue like that?
Managing household chores (3)
How do you cope with power cuts?: Just recently I've been having power cuts at my house and I haven't been able to post when I'm at home and I must say, it really sucked that I actually got to the point where I wanted to actually scream, shout or swear and I managed to survive 3 days of it. Anyways, how do you cope with power cuts?
Leisure and social activity (3)
Friend's wedding: I have a friend who's getting married in a couple months and he just asked me today if I'd be one of his Groomsmen. […] I get really anxious in front of a lot of people, even if the focus isn't on me. Does anyone have any hints on how to keep from having a major incident during the wedding? […]
Initiating and maintaining social relationships (2)
Problem with friendships: Ever since I was a child, I've been overly attached to friends I feel very close to. I get jealous when they hang out with other people. I become crushed when they ignore my friend requests for Facebook. […] I don't want to be overly attached to other people anymore. What should I do to have healthier friendships?
Communication and conversational skills (2)
Problem with phones: Does anyone else there have problems with making/receiving phone calls from people they don't know? I can talk on the phone with friends, but anything involving phone calls to unknown people is a major problem for me. […]

6.2.4 Step 4: Selecting representative answers from the forum responses

For purposes of a fair comparison with out-group responses, I wanted to determine five in-group community responses directed to the original question poster. However, the reply structure of this community (i.e., who is replying to whom) can become complex as threads get longer. Following Vlahovic et al.'s approach (Vlahovic et al., 2014), I chose the first response as one of the best answer candidates because it is most likely to be dedicated to the initiating post. I then applied a manual filtering to exclude conversational posts not intending to answer a question as posed. Replies directed to a specific audience by quoting comments or mentioning an audience (@), and follow-up replies generated by the original question asker were also excluded. From the remaining responses, I randomly selected four responses, which I assumed were likely to be answers from community members to the initial question. I used the same procedure for each thread to select five responses (100 responses in total) from the 252 responses generated to the 20 questions.

6.2.5 Step 5: Generating answers through MTurk

I created Amazon Mechanical Turk (MTurk) Human Intelligence Tasks (HITs) to generate out-group crowdsourced answers to the 20 questions garnered from Step 3. Each HIT was generated using the following template as presented in Figure 6.2:

Instructions

Many individuals with autism now turn to online forums or communities to ask questions about issues they are facing when navigating everyday life. We would like to know whether people outside of the specific forums can provide answers for them. A question sampled from a special autism forum will be shown to you.

Please read the question carefully and do following tasks:

- Rate your confidence in being able to answer the question presented.
- Provide the reason for your confidence rating.
- Provide your own answer to the question.

Question title: Friend's Wedding

Question body: Hi everyone, I have a friend who's getting married in a couple months and he just asked me today if I'd be one of his Groomsmen.

This is something I've only been asked once before by a friend, and that time I couldn't make it because of distance. I'm not one for being in front of crowds, especially when it's a lot of people I don't know. I get really anxious in front of a lot of people, even if the focus isn't on me. Does anyone have any hints on how to keep from having a major incident during the wedding? The last wedding where I was part of the wedding party was my sister's wedding, so at least I had a lot of family around, but here, all I have are friends, and only a few know I'm Autistic. Fortunately, 2 friends are also part of the wedding party, and another is the groom. In the coming months, I'm thinking of talking to the other groomsmen who know, and see if they can help me during the downtime to unwind so I don't get so overloaded I need to step out during a part of the reception where I need to be in there.

Rate your confidence in being able to answer this question

○ Not confident at all
○ Slightly confident
○ Somewhat confident
○ Very confident
○ Extremely confident

[Optional] Explain the reason for your confidence rating (e.g., based on your knowledge of the topic or your experience giving advice to this kind of person):

Please provide your own answer to the question, or explain why you cannot answer the question:

[Optional] We'd like to know more about the people who do this HIT. The survey is completely anonymous and takes less than one minute. When you click this link, you will be asked to fill out your demographic information.

Submit

Figure 6.2: An example screenshot of Human Intelligence Task (HIT) posted to Amazon Mechanical Turk

MTurk workers were provided with brief descriptions of the study objective and the title and body of the question post. They then read the content and provided their own answer to the question or the reason why they could not answer the question. As an optional task, they were asked to rate their confidence in being able to provide an answer and the reason behind the rating. I assigned 20 workers per HIT so that I could collect 400 answers. Each worker was paid $0.20. I refer to the answers generated by these MTurk workers as "out-group crowdsourced answers." In an attempt to determine the demographics of our workers, I sent them a follow-up demographic survey and received responses from 104 workers. As discussed in step 4, I focused on the responses that were intended to answer a question. To build a set of out-group response candidates, I excluded blank responses (n=3), or responses that explicitly stated, "I cannot answer" (n=29). Ultimately, I randomly selected 100 answers (5 per question) from a pool of 368 crowd responses.

Many of the crowdsourced answers arrived very quickly. I paid approximately $90 to collect 400 responses to 20 questions from 149 workers within five hours and nine minutes on MTurk. The first answer arrived within three minutes after I posted the HITs. The demographic information collected on the responding workers. Appendix B describes the MTurk workers demographic information demonstrated that the average age was 33.4 and that 51% of the workers were female. The majority of the workers (76%) were from the United States. Most interestingly, 70% of the workers indicated that they either had experience with autism in their personal or professional life. Seven of them had autism, while 40% indicated they regularly interacted with someone on the autism spectrum. With respect to the definition of out-group in this study, responses from the seven autism workers were eliminated from further analysis because they could be considered in-group. When asked to self-rate their own knowledge about autism (none, a little, a lot), 65% of the workers indicated that they knew a little and 29%

indicated they knew a lot. Only a few workers (6%) indicated that they knew nothing about autism. Seeing that crowd workers could produce answers more quickly than I saw in the online community, I next evaluated those answers to identify key differences between the groups.

6.2.6   Step 6: Evaluating answers

To evaluate the answers from the forum members and the MTurk workers, I defined several outcome measures to define the quality of the answers. I considered the five following subjective outcome measures in our analysis:

- **Directness (Yes/No)**—*whether a response contains a direct answer*—is a primary measure of determining the quality of an answer (Teevan et al., 2011). Regardless of the length of the response and how the topic related to the question, this factor considered whether the response did or did not contain an answer to address the main point of the question.

- **Additional information (Yes/No)**—*whether a response contains any other information (positive or negative) beyond the question*—was examined to identify the existence of extra information, or when viewed from the opposite perspective, how concise the response was.

- **Informational support (Yes/No)** was measured to identify the type of social support provided (Langford, Bowsher, Maloney, & Lillis, 1997). The existence of informational support was determined by checking *whether the response provides advice, suggestions, or knowledge.*

- **Emotional support (Yes/No)** was another measure of social support provision (Langford et al., 1997). Emotional responses *offer empathy, concern, affection, love, trust, acceptance, intimacy, encouragement, or caring*. Both informational and

emotional support measures are often used to analyze health-related discourse in online communities (Wang et al., 2012).

- **Helpfulness (1-5 scale)—**_whether the response helped to address the question_—is used to determine the perceived value of the answer in addressing the issue raised. This was rated was rated on a 5-point scale (1:poor, 2:fair, 3:good, 4:very good, 5:excellent). An excellent answer should convey positive emotions that can relieve a requester's concern as well as provide implementable and useful information.

6.2.7   Participants for the evaluation

I created an evaluation form that includes the original question, 10 randomly shuffled answers from the forum and the MTurk, and the five measures. I recruited a variety of judges who could evaluate the answers along with the measures.

- **Researchers** (n=2)—I exclude myself from the evaluation to avoid the potential bias. Two independent coders who had already participated in the question classification process described above evaluated all 200 answers using the five measures. These research raters were shown the 20 question sets and the sets of ten related community and crowdsourced answers. Answers were shuffled in random order and the answers' origins were not revealed.

- **Autism experts** (n=11)—I also wanted to include raters who regularly interact with someone with autism (i.e., professionals, parents), and to compare how their ratings differed from the other groups' perspectives. I recruited autism experts at an official meeting organized by teachers and staff members who were designing a workplace transition plan for students with autism and other disadvantaged youth in the post-school stage. I created an online evaluation form for rating the helpfulness. Due to the time-consuming nature of the rating

process, autism expert raters were shown only two randomly sampled answer sets (20 answers for two questions). In total, 11 autism expert raters (vocational and transitional specialists (n=4), special education teachers (n=2), job developers (n=3), a behavior analyst (n=1), and a mother of a son with autism (n=1)) completed the online evaluation. I collected their ratings of about 100 answers corresponding to ten question sets.

- **Individuals with autism** (n=6)—Raters self-identified as having high-functioning autism participated in the evaluation process to provide a view of how someone with autism perceives the helpfulness of the responses. To recruit individuals with autism, I sent out recruitment emails to a community mailing list with the objective of the study and inclusion criteria. The letter of recruitment is provided in Appendix C. Note that these raters limited their analysis to the helpfulness measure for two reasons: 1) the first individual with autism that was asked to be a rater reported cognitive fatigue and did not attempt to complete the task. I wanted to lessen the cognitive load during the evaluation; and 2) the other scales were objective measures taken from the literature, so the number of raters from research and experts were enough to trust the results. The most important input from the autism raters was the subjective judgment of helpfulness.

6.3   Results

6.3.1   Quantitative findings

6.3.1.1. Assessing raters agreement

For the Yes/No measures (directness, additional information, informational support and emotional support), I converted Yes=1 and No=0 and calculated an average. Krippendorff's α were calculated in order to determine the multi-coder agreement

(Krippendorff, 2004). Measures appear to be internally consistent (directness: α=0.62; additional information: α=0.48; informational support: α=0.71; emotional support: α=0.44), indicating they are in the range of moderate agreement on additional information and emotional support and substantial agreement on directness and informational support.

Table 6.2: Intra-class correlations for helpfulness between raters.

Raters	Intra-class correlation
Researchers (R)	0.79
Individuals with Autism (A)	0.70
Autism experts (E)	0.67
R + A	0.82
R + E	0.72
E + A	0.75
R + A + E	0.79

To assess agreement on the helpfulness scale, I computed intra-class correlations (ICC). ICC allows us to understand what proportion of the total variance within the measure that is explained by the variance between raters (Bartko, 1966). Table 6.2 shows the ICC values within and between various groups, all indicating strong agreement. I next report on the analysis of scores rated by all evaluator groups.

6.3.1.2. In-group and Out-group characterization

Mann-Whitney U tests (two-tailed, reported with a z score and p-value) were conducted to evaluate the statistical significance of the reported non-parametric differences between in-group and out-group answers. Table 6.3 shows the average score of five measures for the answers from the two sources: in-group community answers and out-group crowdsourced answers. Keeping the high-level findings from the descriptive analysis in mind, I analyzed the qualitatively collected data in order to gain a detailed understanding of the characteristics of the answers in which these patterns occurred.

Table 6.3: Descriptive statistics for the five outcome measures comparing in-group (N=100) and out-group (N=100) answers for 20 questions. The z statistic is the Mann-Whitney U score.

Answer source	Mean (μ)	Median	SD (σ)	Min	Max
	Directness (z=-4.03, p=0.000053)				
In-group	0.69	0.70	0.26	0	1
Out-group	0.97	1.00	0.06	0.80	1
	Additional Information (z=0.28 p=0.777391)				
In-group	0.25	0.20	0.22	0.00	0.80
Out-group	0.23	0.20	0.20	0.00	0.75
	Informational Support (z=-4.34, p=0.000015)				
In-group	0.41	0.35	0.30	0	1
Out-group	0.91	0.90	0.10	0.70	1
	Emotional Support (z=0.25, p=0.797197)				
In-group	0.38	0.35	0.17	0.10	0.80
Out-group	0.36	0.40	0.22	0.00	0.80
	Helpfulness (z= -4.98, p=0.000001)				
In-group	2.18	2.09	0.48	1.43	3.25
Out-group	3.24	3.22	0.26	2.87	3.87

6.3.1.3. Directness and additional information

The out-group responders were more likely to provide direct answers addressing the question asked, as shown in Table 6.3 (z=-4.03, p=0.000053). The out-group directness measures were extremely consistent (σ=0.06), as contrasted with the directness of the in-group answers (σ=0.26). Both the in-group and out-group provided some degree of additional information that might positively or negatively affect the ability to comprehend the answers. No statistically significant differences were found between the in-group and out-group on the additional information measure.

The out-group answers contained fewer words (μ=64.31 words, σ=51.01) than in-group answers (μ=118.49 words, σ=109.39). Regardless of the length of the message, an in-group answer was less likely to contain a direct answer to a question. Our empirical

observation determined that in-group community responses were varied and not necessarily related to the original question posted. These community responses included off-topic discussions, and discussions between responders. Even though I excluded the posts between responders and, for every question, included the first response that was likely to provide a direct answer, the results indicate that the chance of receiving a direct answer for the in-group was lower than from the out-group.

6.3.1.4. The different types of social support

I was interested in whether out-group differed from the in-group as to the form of social support provided. Table 6.3 shows that out-group workers provided more informational value compared to community members (z=-4.34, p=0.000015). The informational value of an in-group answer was dependent on the question at the issue of the question (min=0 to max=1). The groups did not differ statistically in the measure of emotional support. Both groups may equally provide emotional support through their responses, but the results did not present the type of emotional statement (negative or positive) provided. Thus, I revisit this issue by analyzing sampled answers qualitatively in Section 6.3.2.

6.3.1.5. Is the answer helpful?

Helpfulness was rated by investigating whether the response provided a constructive answer that would assist individuals with autism in coping with the challenge identified in the question. For the systematic comparison, I filtered out in-group responses not intending answer a question asked and shuffled the order of responses to be evaluated. Thus, individual and isolated in-group answers are being compared to the individual and isolated out-group crowd ones. However, I further discuss the methodological limitations of this study in Section 6.5.2.

All 15 judges rated the out-group answers as more helpful than the in-group answers (z=-4.98, p=0.000001). Even though the ICC values (Table 6.2) for each group showed substantial and moderate agreement, I separately examined how individuals with autism and the autism experts perceived the helpfulness. The results showed that the rater with autism rated the helpfulness of the out-group higher than the in-group (in-group μ: 2.20 (σ:0.59), out-group μ: 3.10 (σ: 0.30) z=-4.79, p=0.000002); a similar result also holds for the autism experts group (in-group μ: 2.16 (σ:0.54), out-group μ: 3.15 (σ: 0.58), z=-3.20, p= 0.001354).

6.3.2   Qualitative findings

6.3.2.1.   Which Out-group members provide more helpful answers?

While the majority of crowd workers indicated that they were not on the spectrum, many of them (40%) reported regularly interacting with someone with autism. Over one-half indicated that they knew little or nothing about autism. However, I found no correlations between the helpfulness of the response and 1) the crowd worker's confidence in being able to answer the question; 2) his or her level of knowledge about autism; or 3) the crowd worker's personal connection to someone with autism. The results may be due to that most questions requiring autism-specific knowledge were filtered out at the question-sampling stage. Another possible explanation is that the sampled questions likely have common situations occurring in everyone's life, making experience with autism less relevant. One-half of the total crowd responses (n=195) indicated that their past experience was the reason they could answer a question: *"I've overcome spending issues of my own.", "I have moved out to a friend's house before for the first time, and I am in almost the same situation."*

6.3.2.2. Emotional support

The majority of questions often disclosed problems already experienced by the asker and sought feedback from people who have been involved in similar situations, either to receive an opinion or to gain empathy (e.g., *"Last night I went to my school's annual dance. I spent the entire time checking my watch and wanting desperately to leave so that I could go home. There were too many people and too much talking. I felt so overstimulated. Similar problems, advice, anyone?"*). In-group responses to this question appeared to have emotional phrases such as *"I felt like drunk, extremely anxious and my head was empty.", "Never liked dances either. I always found them boring."* These comments could help the asker find people in similar situations who might provide fellowship through shared experiences, a big potential advantage for in-group responses.

Surprisingly, out-group answers contained similar emotional statements: *"I feel this way a lot if I am in a situation where there are too many people."* Almost 30% of the crowdsourced responses (n=118) contained similarly sympathetic messages, and some of them affirmed that the problem was not related to autism, but rather was a general issue for everyone: *"You are not alone having this problem. The only difference is that the percentage of this anxiety.", "It's natural to worry. Everyone worries about loved ones sometimes.", "NO ONE likes going to the dentist! My ex-husband totally freaked out when he had to go and he didn't have autism."*

6.3.2.3. Socially-appropriate coping strategies

Although most in-group answers provided emotional value such as trust and companionship, I found some in-group answers that did not match general social norms and expectations. For instance, in response to a question about dealing with noisy neighbors, one in-group responder suggested: *"Buy a drum kit, wait those neighbors falling asleep, and that's when you practice the living daylights out of that kit. Negotiate with them*

after, say, three or four sessions." However, it is unclear if this type of answer can be attributed to the informal nature of in-group forums or characteristics of autism.

Nevertheless, one of the characteristics for individuals with autism is a difference in social understanding when compared to neurotypicals (Olney, 2000). Their tendency to take things literally would lead them to misunderstand the nuances of a joke or sarcastic phrases. Thus, the nuanced responses may impact them more than it would for others. While some responses from in-group provided no further advice for coping with the problematic situation, I found that many of sampled crowd answers (n=58) contain actionable coping strategies: *"I think that approaching your landlord first, would be a great move. Getting his or her take on the situation will give you another perspective. Also, if you have alerted your landlord with the situation the landlord may be able to do the next steps for you. If this plan is not possible, then I think you should approach the loud people either in passing or in the most non-confrontational way."*

6.3.2.4. Structured social and behavioral prescriptions

I was also surprised to observe that many crowdsourced responses provided step-by-step coping strategies for various social situations (e.g., feeling isolated on Facebook, extreme anxiety when the partner is away, a panic attack at the first class in college). One crowd worker offered the following way of relieving stress when away from a partner: *"First, try talking with your partner about how you feel. […] Talk with him about those worst scenarios you've been imagining. Having a course of action and back-up plan for each scenario will help you both feel more in control. Finally, trust your partner. Try to keep in mind the fact that he's a responsible person who is doing everything possible to keep himself safe."* Many individuals with autism need such assistance in devising explicit rules or strategies for appropriate social behavior (F. A. Boujarwah et al., 2012). I found that crowdsourced responders prescribed remedies for social and behavioral challenges that are well-suited to the needs of individuals with autism.

6.4   Discussion

This study suggests that crowdsourcing can generate extremely fast, direct, and informational answers from a diverse set of responders with differing perspectives. The crowdsourcing approach shows a potential to provide advice at least as good as that provided by members of a dedicated autism community with no sacrifice in emotional support. In this section, I discuss the implications of these results, focusing on the trade-off between the benefits of in-group Q&A behavior and the potential for including crowdsourced out-group responses as a supplementary source of support.

6.4.1   Implications

6.4.1.1.   Crowds offer quick responses throughout the day

This study reveals that crowd workers are able to provide timely (arguably more timely) answers. For individuals with autism who seek information, the noteworthy speed of crowdsourcing can promise potential support around the clock. This may be particularly helpful since individuals with autism can experience unexpected social situations at any time. In some situations, like contextualized health issues, a support-seeker's satisfaction with provided answers depends on what she is seeking in the first place. If she explicitly asks a question to seek informational support and receives only emotional support in return, the requester is likely to be less satisfied (Vlahovic et al., 2014). If a requester with autism primarily wants prompt, straight answer to cope with a problem, obtaining responses from crowd workers may be more promising than culling the large volume of conversations often provided by an in-group community. Acknowledging that in-group the community demonstrates to seek help, below I propose design directions that enhance the performance of the existing community with the more immediate crowdsourced responses.

6.4.1.2. Crowds *can* answer some of the autism community's questions

The findings of this study suggest that crowd workers are able to answer some of questions asked by individuals with autism, regardless of their knowledge or experience with autism. As I noted, a responder's level of knowledge and experience with autism were not correlated with the helpfulness of the response. While the majority of crowd workers in this study were not on the spectrum, they noted that they have had frustrating situations similar to those that individuals with autism suffer from. About one-half of the crowd workers cited such prior experiences in responding to the questions: *"This definitely happened to me when I've been to a club that I don't want to go to.",* *"While I'm not autistic, I have issues with being touched sometimes", "As a woman, this is based on my own experience going to the salon every 6-8 weeks."* In addition, some crowd workers showed strong confidence in being able to answer a question because of the relationship between the question topic and their current occupation. For instance, a crowd worker noted in a message that *"I work part time in fashion industry"* as the basis for her ability to answer a question on how to match clothes. For a problem involving workplace conflict, one crowd responder provided advice based on her *"experience as a supervisor, years of coaching experience."* Thus, an extended pool of crowdsourced out-group responders may increase the chance to find potential topical experts in various areas of daily living.

6.4.1.3. Crowds provide direct and informational support

The findings suggest that in-group and out-group answers provide different perspectives. In general, the three groups of raters agreed that the out-group answers were more helpful than the in-group answers. One possible reason for this difference may be related to the methodology I used. Given the conversational nature of in-group communities, a collection of answers in a thread may be more valuable than a single post. Unlike the rhetorically-oriented nature of an in-group community, a crowdsourcing platform allows out-group responders to provide isolated and direct

answers (i.e., independent judgment (M. Morris et al., 2014)). Perhaps by virtue of the isolated nature of crowdsourcing, crowd responders are likely to focus on the concerns of the person asking the question.

6.4.1.4. Crowds offer helpful advice without compromising emotional support

Online autism communities are intended to engender interaction with a sympathetic group. One might be concerned about the lack of emotional support from out-group answers. Interestingly, the results suggest out-group answers convey informational value without corresponding loss of the emotional value. I noticed crowd workers sometimes expressed positive emotions, such as empathy and encouragement affirming out-group people experience the same issues. In-group emotional responses were likely to resonate with the poster's suffering, confusion, and frustration (e.g., constantly losing friends, feeling isolated). However, the overexposure to personal, emotionally-laden responses without further helpful insight into their suffering may amplify some negative aspects of life (Massimi & Bender, 2014). If an asker were susceptible to absorbing the negative emotions of the responders, the emotional content in the response would no longer be helpful. Further research should address how individuals with autism perceive the value of emotional support provided by in-group members and out-group members differently.

6.4.1.5. Crowds provide actionable advice with concise language

Out-group answers had less words compared to in-group answers. While length has been found to be a positive indicator of answer quality in general online Q&A forums (Harper, Raban, Rafaeli, & Konstan, 2008), overly verbose answers may not convey greater relevant information. More importantly, out-group answers tended to offer social and behavioral prescriptions such as remedies for extreme anxiety when being apart from a partner, coping strategies in a public presentation, and plans of action for first dates in a structured manner (e.g., numbering, bullet points). This strategy

resonates with a commonly used autism intervention, SocialStories™, in which scenarios guide the person through the sequence of steps needed to carry out a particular task or learn appropriate behavior for social situations. Prior research has shown that crowd workers are effective in generation options that such social script author would choose from (F. A. Boujarwah et al., 2012). The helpfulness ratings by individuals with autism indicate that they find value in concise and structured, playbook-style answers like those generated by out-group responders.

6.4.1.6. Crowds broaden the perspective to the autism community

Crowdsourcing provides a wide variety of perspectives obtained via out-group information that can supplement in-group perspective. I found that a majority of the questions were associated with social skills. The fact that members elicited feedback from others with the same core social challenges may indicate that the current in-group structure presents a limited perspective on problem-solving. The notion of broadening the perspective of individuals with autism is a positive endeavor supported by a study of a social networking service used by young adults with autism in the GroupMe study reported in Chapter 4. This study revealed that members could benefit from obtaining diverse perspectives from a variety of network members, including neurotypical responders such as friends, relatives, parents' friends, and volunteers.

While the results of this study are promising, further research may fill existing gaps identified by other studies related to crowdsourcing advice for everyday decisions. The major concerns include the mismatch between crowd workers and question answerers, differing opinions, decoupling context, trust, and cost (Jeong et al., n.d.; M. Morris et al., 2014). The results suggest an opportunity for improving the question-asking experience through a mixture of in-group and out-group support. Crowdsourcing can serve as a supplemental approach to bridge the gaps in existing support provided by in-group communities.

6.4.2 Design Opportunities

I discuss the design opportunities for existing in-group communities that are being repurposed for question-asking and support-seeking such as the online forum studied in Chapter 5. I also propose the design of interfaces or systems that can maximize the benefit of combining in-group answers with out-group answers.

6.4.2.1. Motivating to seek help from the crowds

This study with crowdsourced responders demonstrates that such a crowdsourcing approach can complement in-group communities by providing rapid, socially appropriate answers that offer a potentially broader out-group perspective.

Thus, the in-group community could be augmented if it is capable of embedding a crowdsourcing mechanism in some situations, such as when a more immediate or methodical response is needed. A simple visual component such as an "Ask Outsiders" button could motivate individuals with autism to consider other answer sources when submitting a question. One can imagine that this feature could serve as a "hotline" in which on-demand online volunteers are ready to respond 24/7. I used Amazon Mechanical Turk for this study, but the notion of a hotline serviced by online volunteers suggests that it might be worthwhile to consider the creation of specialized crowd communities.

6.4.2.2. Supporting delegation of questions

Individuals with autism may find it difficult to determine if and when they should look to in-group or out-group sources to elicit helpful feedback. I found that out-group sources could provide valuable advice on in-group questions in nine areas of daily activity that were not autism-specific. The manual question filtering and classification performed by coders might be replaced by sophisticated natural language processing technique. Algorithms could be trained to learn the topics of questions and the level of

knowledge about autism required for each topic, and suggest a question-asker to consider seeking advice from the crowd as well.

The goal with this work was never to replace online communities, but rather to determine ways to improve upon them. As others have found, I saw a preponderance of Q&A behavior and our manual techniques for determining whether an initial post in a thread is a question or not suggests that it might be useful to simply predict whether a post contains a question at all. Automated techniques could attempt to understand different nuances of a question (e.g., is there an immediate informational need or is emotional support being sought). However, directing a question to the out-group should not be automatic. My suggestion is to augment existing communities by including a user-initiated or moderator-controlled feature to seek responses from crowds.

6.4.2.3. Finding a way to foster trust in strangers

The autism experts working with me initially expressed skepticism about the credibility and safety of consulting anonymous crowd workers. While our results indicate that strangers may be able to provide direct and helpful answers, it still does not mean that those who care for individuals with autism would be comfortable with all of the out-group answers. Thus, it is also important to frame how a question will be presented to the MTurk workers. As presented in the instruction module of MTurk HIT (Figure 6.2) I explained the reason for generating the HIT around autism context to draw attention of motivated workers and manage expectation of the workers. To increase trust in responses from crowd workers, potential workers could be given either a reminder of the "do's and don'ts" of good answers, or gold standard tasks prior to accepting a HIT. The crowd workers in our study represented caregivers (33%) and some autism professionals (4%) without any specific recruiting. These types of crowd workers could also be leveraged to validate answers from other crowd workers. However, this process may inject additional cost and time into the process.

6.5   Limitations

6.5.1   Generalizability of study findings

It is possible that the autism community I sampled is not representative of individuals with autism at large. This issue is mitigated by our empirical observation to characterize several autism communities prior to the study. The observation reveals that these communities share many similarities which impact the pattern of interaction: discussion board structure and topical discussion board (e.g., social skills : social skills and friendships, work and finding a job : education and employment). Such in-group community discussion boards appear to have the same threading structure composed of initiating posts and reply posts. Thus, I picked a community that already generated a vast amount of threads and that were accessible to our research team.

6.5.2   Methodological limitation

The methodology also has shortcomings. First, since out-group membership was critical to our study, I excluded responses generated by crowd workers who stated they had autism.   However, I see studying crowd workers that have autism as an exciting future avenue for leveraging their experience to verify the appropriateness of answers. Second, I recognized the imbalanced comparison between selected community threads from a whole conversation and isolated crowd answers. Future research will benefit from the holistic comparison of MTurk answers and community threads. Thirdly, it is also plausible that the helpfulness rating differences between the groups were simply artifacts of worker self-selection or the nature of being paid. The framing of the HIT introduction on MTurk that was visible to potential workers before accepting the HIT may have drawn more individuals with a relationship to autism than what is characteristic of the broader MTurk community. Indeed, I believe that the explicit presentation of the goals and motivations for our published HITs helped us recruit

crowd workers that were motivated by the task rather than just the monetary value. I will revisit the creation of trusted and cost effective crowds in Section 8.4.

6.6 Conclusion

The goal of this study was to explore the possibility of crowdsourcing answers to garner a wider perspective of information and advice for individuals with autism. The evaluation of in-group and out-group answers illuminated key differences between the groups. The results showed out-group information obtained through crowdsourcing provides added value with its relatively rapid turnaround time, and a wide variety of responses in a concise and structured manner, without loss of the emotional support when compared with the online community's responses. These differences led to a set of design features for augmenting the in-group community support—a nudge to be aware of available answer providers beyond the community, automated question classifier to find better answer source, and a moderating mechanism to foster trust. These implications may also encourage researchers to explore issues faced by other specialized communities whose individuals seek advice to navigate their daily lives effectively. I will revisit the general implications in Chapter 8.

The contributions of this work include:

- An empirical study to crowdsource out-group answers to questions generated in an online autism community, with quantitative and qualitative analysis to determine if out-group answers compare against to in-group answers on a number of important dimensions (directness, additional information, informational / emotional support, and helpfulness).

- The results suggest that crowd workers rapidly provide concise and direct answers offering a broader out-group perspective without loss of emotional support compared to answers obtained within the online community itself.

CHAPTER 7

DESIGNING A SPECIALIZED Q&A SERVICE

In Chapter 3 and Chapter 4, I described design opportunities and challenges around the use of social media to establish support networks with family and friends. In Chapter 5, I discussed the use of an online autism forum—characterized as in-group—to ask questions and obtain answers from people who might not have personal connections. In Chapter 6, I discussed the use of a crowdsourcing platform to provide rapid, direct, concise answers that come from an out-group cohort with a potentially broader and useful perspective. The series of investigations provided me with a better understanding of the problem space of supporting Q&A behavior of individuals with autism through modifications to existing social networking services.

In this chapter, I synthesize the overall design suggestions, gleaned from the results reported in Chapters 3 through 6, to suggest specialized features of a social networking service that supports everyday independence goals of adolescents and adults with autism. For each design feature, I describe where the feature was derived and why the feature was selected for further exploration. With a focus on some of these specialized features, I designed inquir.us—a Q&A platform that combines an online forum structure with a crowdsourcing feature. With this system, I conducted an exploratory study to probe the concept with 8 students and 5 teachers at a school for adolescents and adults with autism. I discuss lessons learned from the exploration and highlight design and methodological limitations that will influence continuing work in this space.

7.1   Design Synthesis

In this section, I address the design guidelines identified earlier and suggest design features associated with the guidelines, and focused features for further exploration.

In Chapter 3, I suggested general considerations for designing a secure social networking service for individuals with autism. I proposed a semi-closed system with a selected set of registered in-group members (e.g., a cohort of individuals with autism and their caregivers) who can view posted questions and provide answers. To establish a trusted network, some caregivers act as moderators to vet the network memberships and monitor the activities, in order to guide the individuals with autism not to disclose too much detail. The involvement of caregivers or autism experts is also necessary to moderate different, or even conflicting, advice. Thus, the main design features derived from this study include: 1) caregiver-mediated network building; 2) secured access control based on pre-existing social relationships; and 3) answer validation by autism experts.

In Chapter 4, a focused communication circle feature in a personal social networking service, GroupMe, was investigated to support the Q&A interaction between an individual and invited members. The shared conversations in a circle allowed communication transparency. However, the group-broadcasting format caused communication overload for the members, particularly for those who are not interested in the topic discussed. To overcome this issue, I proposed a more flexible circle creation feature, focusing on important topic areas or an individual's current interests or concerns reflected in a personal profile. The group members can turn on or off the circle participation temporarily, which can reduce undesired communication traffic. The specialized features to define communication circles—contextual circle formation, profile-mediated help requests, and circle opt-in/out mechanisms—might better support emerging topics of interest as well as keep the online network engaged as a

whole. While these specialized features of communication circles show promise, I have not focused my attention on the design and evaluation of specialized communication circles in this thesis.

In Chapter 5, I investigated an online forum as a Q&A system. Unlike personal social networking services such as GroupMe, in which communications are restricted to specific circles which each can contain different individuals, the online forum provides access to all members, each being able to observe questions asked by others and answers provided to those questions. The open nature of the online forum allows users to learn from previous interactions produced by others. However, the autism forum I studied demonstrated limitations when it is used as Q&A system: unstructured question creation and limited perspectives. Thus, I considered modifications to the forum structure as a target for further exploration in this thesis. To help a user initiate questions in the forum, two design features—pre-defined topic suggestions and structured question creation process—are provided. In addition, to support the user in receiving a wider perspective on the questions asked, I propose a feature that combines crowdsourcing for out-group responses with the in-group forum responses.

Before designing such a hybrid online Q&A forum, I tested the potential value of crowdsourced out-group responses in Chapter 6. The value of crowdsourced answers is apparent, but their inclusion in a forum warrants some safeguards to address potential risks to safety and privacy. First, seeking responses from a crowd of "trusted strangers" should be user-initiated, i.e., invoked via an explicit action by the question asker or a suitable moderator using an "ask outsiders" button or similar feature. All discussions within the forum are kept safe and secure within the forum, and only specific questions are sent to the crowd of trusted strangers. The crowd is not allowed to see anything else except the question and some motivating context to help them frame a response. In addition, to safeguard against an individual sharing too much information in a question

(e.g., revealing too many personal details such as address or health data), a feature should allow a moderator to hold or modify the question to show the crowd if necessary. To recruit reliable crowd workers, a special crowdsourcing platform containing a pool of trained workers should be considered. To increase the trust in answers provided by the crowd workers, the workers should be informed that the question asker is on the autism spectrum.

Table 7.1 presents design features associated with guidelines derived from previous studies and potential benefits and drawback of each feature.

Table 7.1: Design features for designing the specialized Q&A service

Chapter 3: General considerations for designing a secured social network service	
Scaffolded network building to safeguard the system	
Design features ✓ = Included in inquir.us	**Potential benefits and drawbacks**
Inclusion of moderators in the system (✓)	**Benefits:** Mitigate safety issues by having the moderator review questions to determine that personal details are not disclosed. **Drawbacks:** Additional burden on the moderators; potential violation of an individual's autonomy; increased turnaround time between questioning and answering.
Layering a network by classes of queries for access control	
Access control by the relationship with an individual (✓)	**Benefits:** Only registered in-group members (e.g., autism cohorts and teachers) are allowed to see posted questions and answers within the system. **Drawbacks:** decrease chance to expand the membership beyond pre-existing networks.
Support internal negotiation to avoid conflicting advice	
Answer validation by internal experts (✓)	**Benefits:** Screen different and conflicting advice before it is shown to the individual. **Drawbacks:** Require extra resources and time to gain consensus.
Chapter 4: The use of a focused communication circle for Q&A interaction	
Prompting Temporal and contextual circle formation	
Flexible circle creation based on emerging topics (✓)	**Benefits:** Highlight the topics of interests and requests and encourage the individuals to initiate conversation around those topics. **Drawbacks:** Topics are varied in individuals and contexts.

Requesting and offering help via profile	
A profile presenting an individual's strengths and weaknesses, interests and concerns	**Benefits:** Help network members understand personal context of a question asker and provide relevant answers. **Drawbacks:** Risks of revealing too much information about an individual; added workload on either the individual or caregivers to fill out information. **Notes:** The inquir.us platform supports the profile feature but it was not fully explored in this thesis.
Supporting fine-grained communication control	
A feature that turned off the circle participation temporarily	**Benefits:** Help network members manage their availability to answer questions. **Drawbacks:** A situation that none of responders is not available to answer when an individual has an urgent issue. **Notes:** Not relevant to forum setting.
Chapter 5: The online forum as a Q&A system	
Scaffold the creation of better questions to elicit better answers	
Pre-defined topic suggestions (✓)	**Benefits:** Help a user initiate a question within a focused area. **Drawbacks:** Difficult to develop questions beyond the pre-defined topics.
Topic label and target audience group when formulating a question (✓)	**Benefits:** Provide minimum requirements of a question to elicit relevant answers from appropriate audiences. **Drawbacks:** Impose some constraints on the questions and require burdensome level of detail.
Reaching out to responders outside the in-group autism community	
Crowdsourcing out-group responders (✓)	**Benefits:** Increase the likelihood of potentially diverse, relevant, and quick responses. **Drawbacks:** Financial cost associated with this feature; require an additional process to assess the quality of answers.
Chapter 6: Enhance Q&A experience with crowdsourcing	
Motivating individuals to seek help from the crowds	
A simple button (e.g., "Ask Outsiders") to send question to a crowd of "trusted strangers" (✓)	**Benefits:** Help a user consider other answer sources and submit a question to members outside the community. **Drawbacks:** Financial cost associated with this feature; require assessment module to ensure the quality of answers.
Finding a Way to Foster Trust in Strangers	
Recruit trained workers using a special crowdsourcing service (e.g., CrowdFlower) (✓)	**Benefits:** Increase the likelihood of valid and reliable answers. **Drawbacks:** Inject additional cost and time to find crowds; reduce the chance to recruit people from various backgrounds

Table 7.1 continued: Design features for designing the specialized Q&A service

Provide crowd workers with personal context about the question askers (e.g., the fact that they're on the autism spectrum) (✔)	**Benefits:** Recruit potentially motivated workers who have experiences with someone with autism; help workers provide answers relevant to autism context. **Drawbacks:** Inject additional cost and time to validate answers.

By synthesizing the design features, I suggest the design of a new Q&A forum that is a hybrid of existing online forum structure and user-initiated crowdsourcing features, described next. The system supports the creation and delegation of questions to integrate in-group community support and out-group crowd support. In the next section, I begin by presenting the design goals for inquir.us (based on the features discussed in table 7.1). Then I describe how these design goals are translated into the development of inquir.us.

7.2   The Design of a Hybrid Social Q&A Platform

In this section, I present broad design goals for a hybrid social Q&A forum for young adults with autism. By "hybrid" I mean a Q&A forum composed of a combination of existing in-group resources (e.g., autism cohorts and teachers) and crowdsourced out-group resource.

7.2.1   Design goals

The design of inquir.us was driven by two design goals, which I will discuss in more detail here.

The first design goal (G1) is to support users in generating better questions by scaffolding the creation of questions. Being able to address, or articulate challenges as a form of question-asking is an important step toward increasing independence for the individuals with autism. However, it is a challenge for them to know what to ask, how to ask, and whom to ask. For some of the individuals with autism, motivation is an

important factor. Thus, the biggest challenge can be to get them to want to ask a question. I propose features to encourage and facilitate question creation, including pre-defined topics relevant to their current interests, issues, or demands. However, it is not a primary focus of this thesis to support individuals with autism either who are not necessarily motivated to ask question, or who might not be able to address concerns as a form of question-asking.

Even for the otherwise motivated individuals, such as the GroupMe study participants described in Chapter 4 or the forum users, it is a challenge to create better questions that can elicit effective answers. As I have already discussed in this thesis, it was difficult to address expectations of the audience and target questions to the right set of people either in a focused communication circle (see Section 4.3.2.7), or in an open-ended online discussion forum (see Section 5.4.3). To address this problem, my first design goal was to provide users with information about how to frame questions. In addition, a system needs to support users in articulating what they need while generating a question. I aimed to build a system that scaffolds the creation of a question. The system needs to help users: 1) relate a question to a pre-defined topical category; and 2) enter a question that will be answered by a predefined respondent group.

The second design goal (G2) is to augment in-group online networks with out-group crowd cohorts to provide rapid, direct, and informational answers with a wider perspective. Even though the pre-existing caregiving network provides an important source for advice, it might be unrealistic and undesirable for them to be an individual's only resource. Online autism forums contain a large number of potential responders who could address the issue of over-burdened caregivers. However, such online forums present limitations regarding the speed of receiving answers and the quality of answers (i.e., directness, conciseness, informational and emotional support, and perceived helpfulness) provided by only in-group autism-specific online forum members. I sought

to overcome these limitations by recruiting crowds, large and flexible groups of distributed workers. I showed in Chapter 6 that crowd workers could offer rapid, concise, and socially appropriate coping strategies without compromising emotional support. However, teachers and counselors who care for individuals with autism expressed concerns about the validity of the answers provided by crowd workers and wanted to be a part of the system. Therefore, my design goal is to augment existing communities by including a user-initiated feature to seek responses from crowds. A system needs to motivate individuals with autism to consider "crowds" as a supplementary answer source (a kind of anonymous "hotline") when submitting a question.

7.2.2 inquir.us design and implementation

Based on the preceding goals, I designed inquir.us, a specialized SNS for individuals with autism. Besides being simple to refer to, the name "inquir.us" derives from the overall goal of inquiring into various aspects of everyday life and the nature of various responders in the social networks. inquir.us combines an online forum structure with a user-initiated crowdsourcing feature. I implemented inquir.us as a web-based and mobile Q&A service that facilitates getting quick answers to everyday challenges and frustrations, such as preparing for an upcoming interview or coping with public anxiety (see Figure 7.1). inquir.us was derived from an open source question-and-answer web platform called Discourse.[7] I installed the platform on a cloud server, DigitalOcean. Some inquir.us features and structures mirror those of well-known online Q&A forums, like StackOverflow or StackExchange. I added custom features, such as a topic-oriented view (as presented in Figure 7.1) and a manually integrated crowdsourcing mechanism. I first describe the design of inquir.us and ways in which it supports the goals of

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[7] http://www.discourse.org. The co-founder of Stack Overflow and Stack Exchange, Jeff Atwood announced discourse in 2013.

motivating users to ask better questions as well as getting rapid and valuable answers from crowd workers.
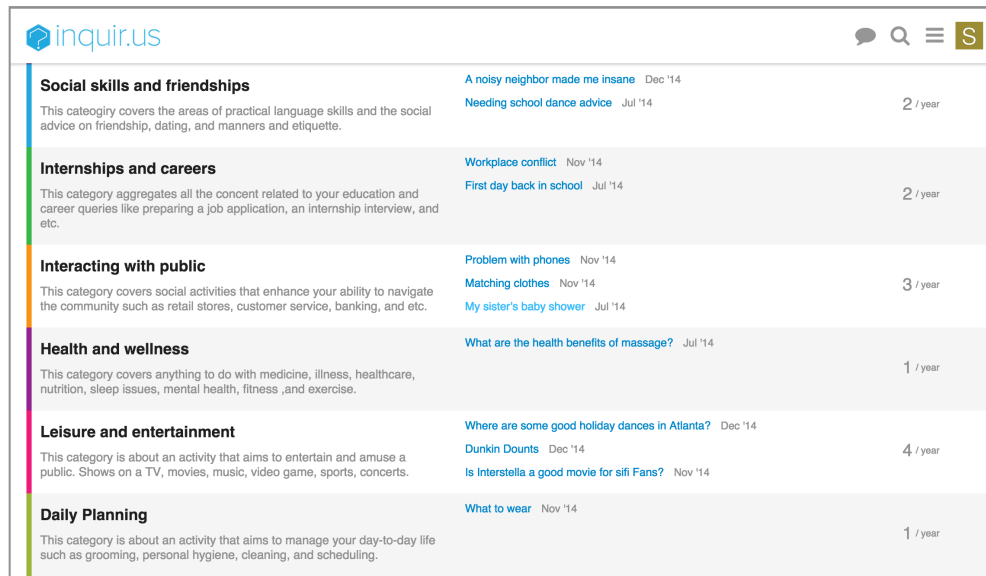
Figure 7.1: inquir.us front page (web view).

7.2.2.1. Prompting question categories

Any registered user can browse the main page displaying others' questions. Once a user clicks "Create a topic" button,[8] the window for the creation is activated. Users are presented with an interface requiring the title of the question, along with a brief summary sentence and then the details of the question itself. Users are also required to apply one of the categories to the question from the dropdown list located next to the

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[8] At the outset of implementation, I attempted to replace the label, "topic" with the more appropriate label "question." However, certain aspects of the pre-packaged interface of Discourse were out of my control as developer. In particular, the system does not allow any changes to the pre-defined button labeling. Hence, I had to use the original term provided by the system. In this system, "topic" refers to "question", and "category" refers to the topical classification of question posts.

question title field (see Figure 7.2). The categories presented in Figure 7.2 were determined based upon the forum question categories reported in Table 5.3. I presented these categories as motivating examples to teachers at a school for students on the autism spectrum, and conducted several rounds of discussion to determine categories that are of real concern. The list and the title of categories are subject to change, depending on deployment experience. For each of these categories, I present several questions that provide individuals with an example of the kind of queries that belong in this category.

What I have described is an explicit *scaffolding* process that is meant to guide the individual in creating a question. I recommended this scaffolding in Chapter 6, without imposing too many constraints, or requiring a burdensome level of details. inquir.us is designed to facilitate asking questions about a variety of life and social issues in two ways: 1) by browsing others' questions classified by pre-determined categories of issues; and 2) by associating a question with an appropriate category. inquir.us's main page displays recently posted questions classified by the pre-determined categories.
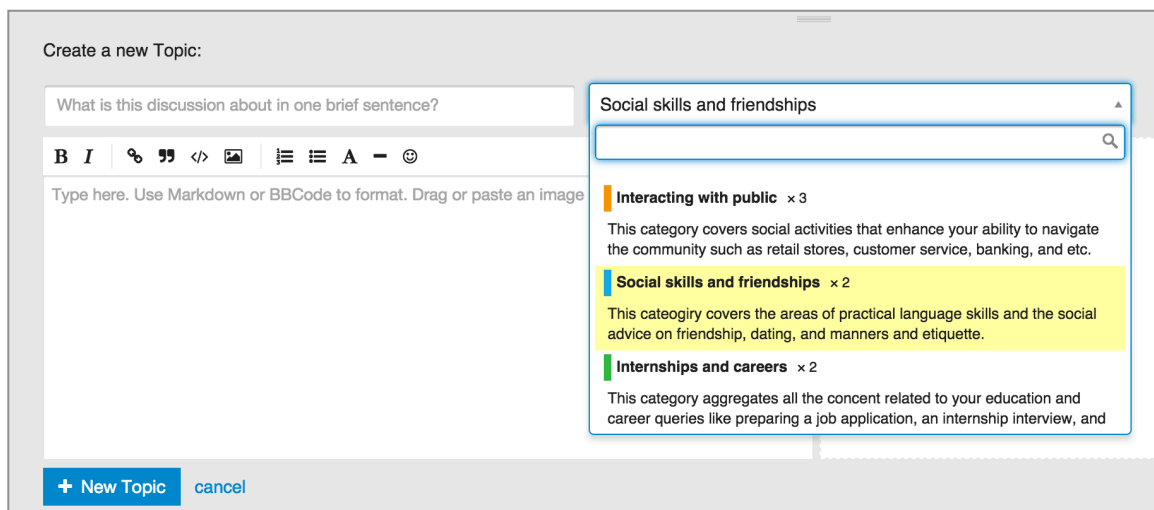
Figure 7.2: The window for creating a question is activated.

7.2.2.2. Mentioning desired responders

inquir.us is a secured service where only invited members can join and generate accounts. In the future deployment, I intend to leverage existing social circles of students and teachers in a class to recruit participants. In inquir.us, the main users, individuals with autism, can reach out to three different classes of responders: 1) peer responders, i.e., other individuals with autism; 2) experts responders, such as teachers or counselors; and 3) crowd responders. I refer to the crowd responders as "**trusted strangers**." Trusted strangers are a moderated group of online responders who are recruited via a crowdsourcing platform. While creating a question, users can search other registered individuals or groups (friends, teachers and trusted strangers) by typing "@" as presented in Figure 7.3. By selecting one or more of these registered individuals or groups, users can explicitly mention whom they want to receive answers from and nudge the desired responders to be aware of the question. The *mentioned* individuals or groups will receive a notification, though everyone in the online network will be able to see the posted question. If a question asker is interested in getting answers from wider and more wide varied social group beyond friends and teachers, or if a quick response is needed, the asker can request responses from the trusted stranger service by *mentioning* @Trusted_Strangers in the question, as presented in Figure 7.4.
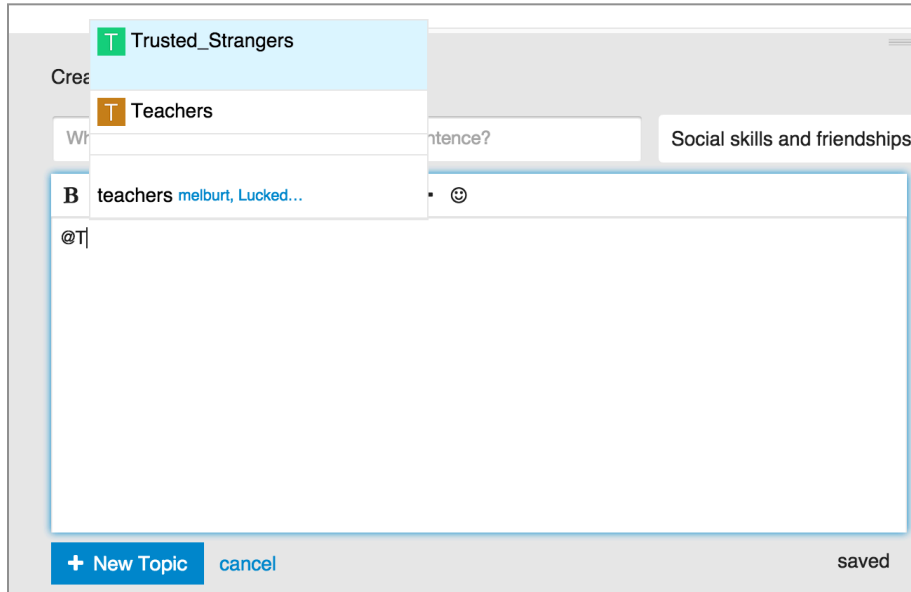
Figure 7.3: In the question creation window, a user can search and mention desired responders
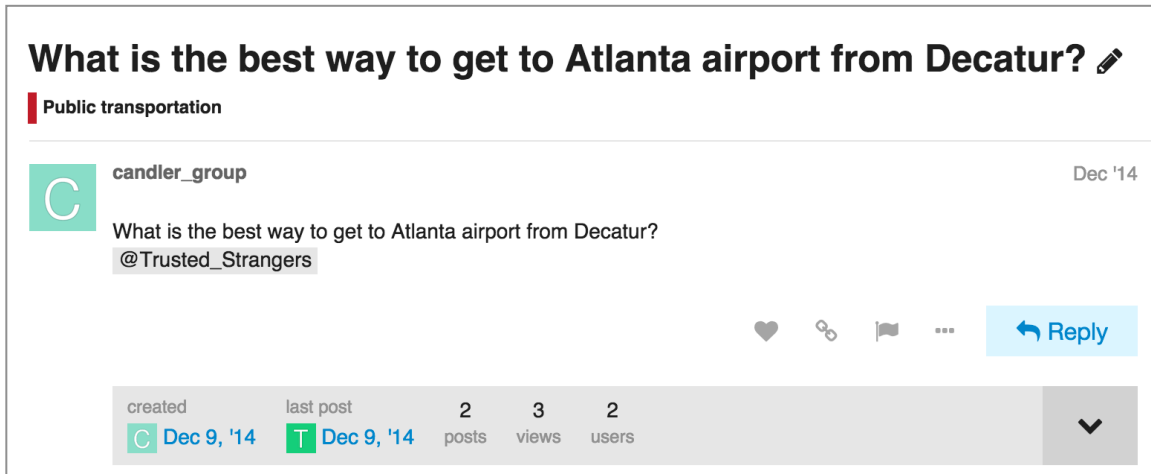
Figure 7.4: In the question creation window, a user can search and mention desired responders

7.2.2.3. Manually-integrated crowdsourcing mechanism

inquir.us features trusted strangers to help users gain rapid and effective answers from credible crowd workers. I used the crowd workers from the Crowdflower[9] service instead of Amazon MTurk, the service used in the study presented in Chapter 6, for several reasons. Crowdflower is a meta-platform that publishes tasks on other crowdsourcing platform like MTurk. What makes Crowdflower different from MTurk is it builds up and trains its own trusted workforces of crowd workers. This "retainer" model of CrowdFlower may keep trained workers around and enhance the credibility of workers. Another interesting feature is a "contributor setting", which is used for recruiting desired workers that meet specific requirements (e.g., geography, language) based on profile information. CrowdFlower also offers features for quality control. For instance, if a worker completes a task in less than 10 seconds, the worker will be removed from the entire job to avoid blank answers. I allowed 5 workers to answer each task (question). Before committing a task, CrowdFlower workers were presented instructions illustrating the neurodiversity of the question askers as shown in Figure 7.5.

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[9] http://www.crowdflower.com
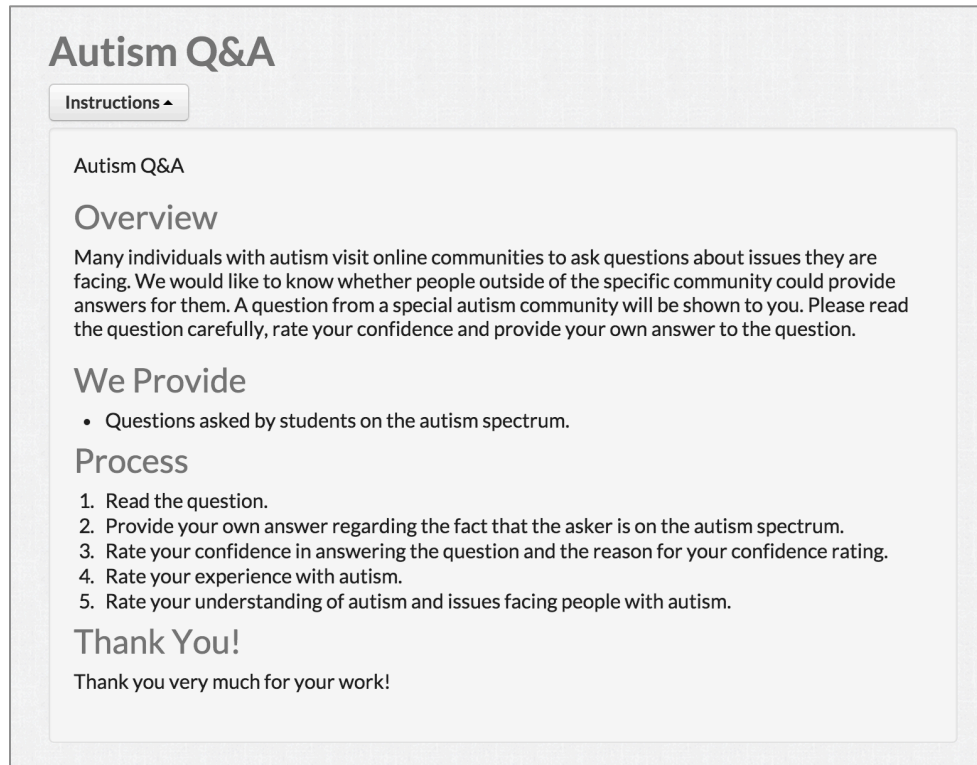
Figure 7.5: Instructions presented to CrowdFlower workers.

In order for the crowdsourcing feature to work on the inquir.us platform, there needs to be a real-time agent (i.e. moderator) to facilitate the process of: 1) reviewing questions mentioning "@trusted_strangers"; 2) directing questions to Crowdflower; 3) selecting reliable answers from Crowdflower; and 4) posting the selected answers to inquir.us. Step 2 requires human knowledge and intelligence. Therefore, I determined that a manually-integrated crowdsourcing mechanism was the easiest solution for any initial deployment studies. In this approach, the human moderator acts as a pipeline for delivering questions and answers between inquir.us and CrowdFlower. The human agent also needs to assess answer quality. To do this, I created an account named "trusted_strangers" for the Wizard of Oz experiment. If a question mentioning @trusted_strangers is posted, it triggers a notification for the human agent (initially me) to delegate the question to CrowdFlower. After collecting 5 responses from the crowd, I

then examined the quality of responses based upon the measures presented in Section 6.2.6. In particular, I posted responses that contain a direct answer (Yes on the directness measure) and provide helpful (above 3:good on helpfulness scale) answer. Figure 7.6 shows some selected crowdsourced responses to a question, *"what's the best way to wrap presents?"* The answer moderation process inevitably introduces a time delay (see results section 7.4).
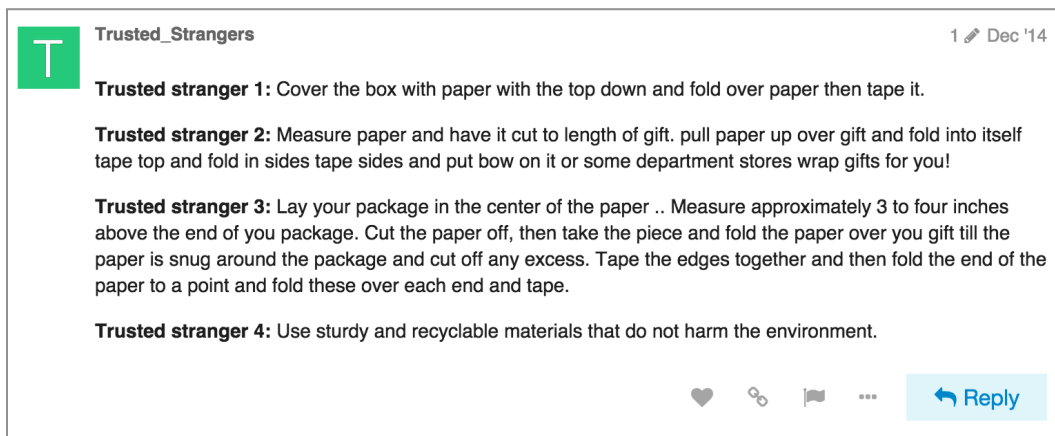
Figure 7.6: Answers generated by workers from CrowdFlower. In this example a human moderator collected answers and posted them in the form of a reply to the original question.

7.3   *Design Exploration*

I created and examined inquir.us as an early functional prototype to serve as a proof-of-concept for the small group of students and teachers in a class. The goal of inquir.us is to facilitate asking questions relevant to everyday social challenges and receiving rapid advice from a variety of responders, including members of existing social networks and crowd workers. For this reason, our participants were a pre-defined circle of people who have personal connections (i.e., students with autism and teachers who facilitate their transition to independent life). Through the initial exploration of inquir.us with the potential stakeholders, I examined the behavior of individuals with autism on this platform, identified the factors that positively or negatively influence the use of

inquir.us, and suggest opportunities for the improvement of the system and further research design.

7.3.1 Recruitment

I targeted a pre-established community providing transition support for young adults with autism. I had established a connection with the executive director of the school for a my previous study (Hong et al., 2012) in Chapter 3. I hoped to leverage those connections when it came time to launch inquir.us and build a stable group of users. I generated interests in inquir.us by explaining that its design was heavily motivated by issues and problems voiced by their former students and staff.

7.3.2 Study settings

The school offers a young adults transition program for students who will attend or have completed high school. The program includes vocational and transition support, college support, independent living skills, wellness, and relationship development support. Students meet twice weekly with teachers to strengthen specific aspects of transition skills. For the Fall 2014 semester, the program offered independence classes of varying kinds that included career/internships and social outings. Also, other aspects of living independently were addressed, such as money management and transportation. These are very similar to the topics that I wanted to support. Thus, the director was excited to integrate the inquir.us system into the curriculum of those independence classes. More specifically, he wanted to support students in submitting questions and processing responses in the context of a class. Using several communication channels, including phone calls, emails, and an in-person school visit, I planned out the study with the director and teachers. In total, I was able to recruit 4 teachers and 8 adolescents/adult students (between 14 to 24 years old) with high-functioning autism (6 men and 2 women) for the pilot study.

7.3.3 Study procedures

The study was designed as a probe to enhance my understanding of how the primary stakeholders perceive and use inquir.us. It served mainly as a feasibility study to determine that the system would actually work and reveal what barriers to adoption still exist. This is an essential step before conducting any hypothesis-driven deployment study. Before engaging with inquir.us, students and teachers took part in a kick-off meeting and tutorial, during which I explained and demonstrated how the system could be used. I also seeded a couple of questions that exemplified what they could ask: *"What to wear: Can I wear black shoes with blue pants?"*; and *"Is Interstellar a good movie for SiFi Fans?"* I then highlighted the way of designating a desired responder group, such as friends, teachers, and trusted strangers, when submitting a question.

Over the course of a week, participants were asked to use inquir.us to generate questions and answers. Data from the inquir.us system was collected during this period. Teachers were asked to encourage their students to generate questions related to what they have learned during the independence classes. The focused areas of training, in this study period, were navigating the city with public transportation and interacting with the public. The classes were usually held twice a week, and inquir.us was actually used as part of the training classes. Students were encouraged to post a question related to what they learned in a given class to inquir.us during the class session, and they were not encouraged to use it outside of the training classes. During the study, teachers and the executive director observed the students' reactions and reported the results to me via email. The data was collected through my observations of students at the kick-off meeting, system logs data, and the director's email briefs.

7.4   Results and Discussion of Design Exploration

The inquir.us design exploration with students and teachers helped me to gain an understanding of the unique Q&A behaviors of the students in the class context and the

barriers to adoption of the system. It also gave me information about the inclusion criteria that individuals with autism would have to meet to participate in future deployments.

7.4.1 Results of the design exploration

Requiring teachers' promotion. In the classes, students were generating questions in consultation with teachers. Thus, students' question-asking behavior was perhaps strongly dependent on the theme of classes and the guidance of teachers. For the majority of students, one-on-one intensive consultation was needed to comprehend the questionnaire items. Instead of generating each participant's response, the director provided information about students. With respect to the willingness of participation, students in the classes were encouraged to use the system regardless their age. Thus, the age span of students (14–24) was much more varied than expected. Although the director reported that all students are on the autism spectrum, students exhibited varying levels of functioning and language ability. Because the system relies on participants' ability to describe their situation in order to receive a relevant answer, it was very challenging for many of the Community School participants as compared to the cohort in the GroupMe study or the online forum users.

Complex registration steps for safeguarding the students led to sacrifice in ease of registration. Even though 12 participants (8 students and 4 teachers) expressed interest in the study, I noticed that only one teacher (the director) and two students registered on inquir.us. Only one of the two students created a question. After a couple of days, the director emailed me to report this issue. The director reported that the class was clearly not at the place where they could manage the inquir.us account independently. He noted that this was because of the complexity of the registration process. In order to activate one's inquir.us account, users needed to click on a secured link sent to a registered email account. Many of the students have email accounts, but don't check

them regularly. This extra step for registration was inevitable for keeping users safe, but served to discourage users from immediate participation. The director suggested a work around where we would create a single account (called Candler Group) for the class and use it to post questions.

Asking short and localized questions without describing the context. Using the shared account, students generated in total five questions presented in Table 7.2. I found that participants used the same text for the title of the topic/question as in the body. There was no further detail added to the body. The five questions were simply soliciting opinions about various situations. In particular, four of the questions were specific to locations where students often navigate (e.g., menu choice in a restaurant located in the southern part of USA).

Table 7.2: Questions generated by students in a class for a week.

Question	Category	Expected responder	Number of answers passed the quality assessment	Time for crowd sourcing five answers	Time from when posted and when answered by a human moderator
Where are some good holiday dances in Atlanta?	Leisure and entertainment	@trusted_ strangers	0/5	8m	N/A
What Dunkin Donuts is closest to Decatur?	Leisure and entertainment	Unspecified	N/A	N/A	N/A
What is the best way to get to Atlanta airport from Decatur?	Transportation	@trusted_ strangers	2/5	8m	2h:56m
What is something good to order at Waffle House?	Uncategorized	@trusted_ strangers	4/5	4m	2h:57m
What's the best way to wrap presents?	Uncategorized	@trusted_ strangers	4/5	12m	1h:02m

Questions not directed to specific responders. Figure 7.7 presents an example of a question asked by a student using the shared account and the answer provided by CrowdFlower workers. None of the students or teachers answered Question 2, which did not specify any expected responders. For those questions directed to trusted strangers (1,3,4,5), it took, on average, 8 minutes to collect five answers through CrowdFlower, including only the time for the crowdsourcing. The total average time to manually handle the question, including moderation, was 2.5 hours.
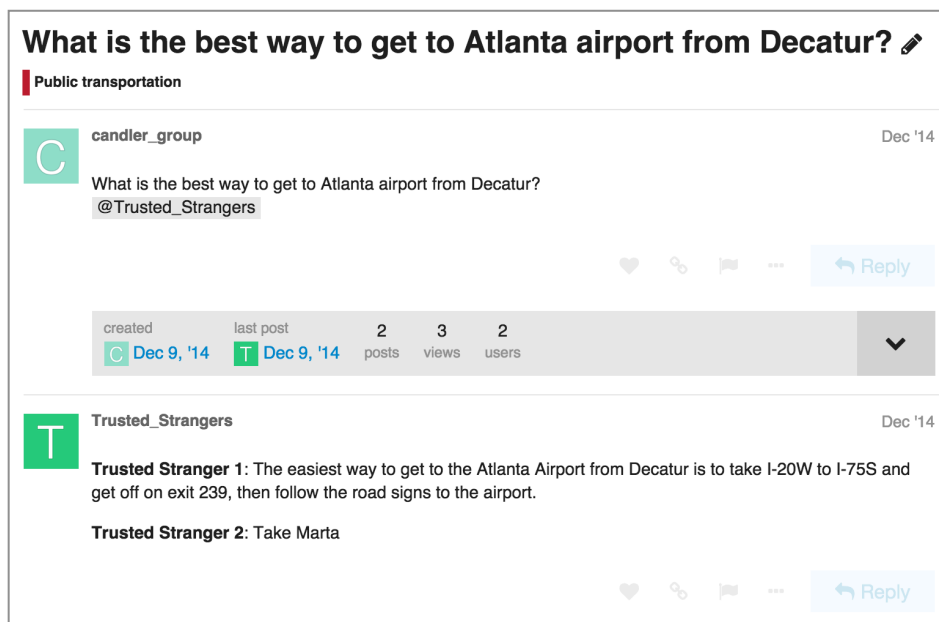
Figure 7.7: A question asked by a student in the Community school during the study and answers generated by CrowdFlower workers.

7.4.2   Understanding Limitations

7.4.2.1. The desire of teachers to increase offline peer-interaction

There was dual usage of the system that I had not anticipated nor designed for. I designed a system to be used by individuals who would understand how it works and would want to use it to ask questions. The online forum users studied in Chapter 5 might fit into this category. However, the Community School teachers wanted to use the

system to train their students to understand why they would want to do this. Teachers reported that they liked the idea of asking of online networks, but it seems less useful in their class context, where there are friends and mentors around for people to get help from in-person. Also, questions generated in the class might not reflect an immediate concern a student was actually facing. The director reported: *"We prefer that participants be using their in-person social skills. In general, we prefer that participants be using their in-person social skills, so going to the Internet doesn't make as much sense in our context. For us, we're trying to strengthen the critical skill of asking for help, so we want our participants to be seeking each other out."* The desire to increase offline peer-support in a class setting could discourage students from asking question using online networks.

7.4.2.2. Limited technology accessibility

Unlike online autism forum users experienced in interacting with others online, our students diverged widely in their technical ability to create and manage an account. As the director addressed, most of students (n=6) were not able to manage their account independently due to the extra step for the registration combined with an email confirmation. Since email is rarely used by most of the participants, it discouraged immediate participation. A single, shared account was alternatively provided to remove this accessibility barrier. Afterwards, four questions were generated in a week. Providing an easy access to the students could increase the participation, but it did not significantly impact the activity of question-asking.

According to the director, at the outset of the study students exhibited interest in asking questions using this system. However, it was necessary to provide students with time to build a routine via constant prompts. The director noted: *"I actually think that a number of the students were engaged, or would have gotten engaged, with more time to acclimate. The short span of the trial didn't leave much time for the system to become a part of our routine. […] Over time, though, I think it could have had more of an impact."* Regardless of

an individual's technical capability, lowering some hurdles requiring knowledge about existing SNS infrastructure (e.g., registration via an email account) is critical to enhance accessibility of the system. Also, having this population of students work with a relatively complex social computing system requires several rounds of tutorials and trials prior to the actual study.

7.4.2.3. Limited language ability in describing the context of a question

I found that the five questions generated in the class were shorter and less detailed compared to questions generated by the online forum users. As with the broader spectrum of autism, our students were also diverse in language ability, making it difficult to accurately and completely describe their situation in order to get relevant answers. The director described that students had difficulty in explaining a richer context of a question: *"They don't always think to include relevant context. For example, if someone wants help with what to wear to an internship, they might simply ask "What should I wear today?" and not include the necessary context? Our staff had to support participants in providing enough detail in the questions to make them useful."*

One of the main design ideas—scaffolding the creation of question—helped users identify what to address. However, it was a challenge for them to know whether and how to address the context of the question. One might consider an advanced scaffolding interface that provides a reminder of the minimum requirements of a question, as described in design consideration section later.

7.4.2.4. Increased burden on a moderator

In the informal discussion with teachers prior to the field study, teachers expressed concerns about the credibility of information provided by crowd workers and the influence it has. They also mentioned privacy concerns and the potential negative results of putting personal information online. Thus, deciding which questions should be

directed to internal members, and which questions could go to trusted strangers independently, might be a challenge for the individuals with autism. To ameliorate this issue, teachers were asked to guide students to identify a desired answer source while generating a question. To ensure the credibility of crowd answers, this study used a human to moderate question delivery and answer investigation. Ultimately, this process could be done by teachers in the network. However, involving human moderator(s) may create a tension between ensuring safety and increasing extra work (e.g., answer judgments). Furthermore, manual selection and curation of crowd responses generated a bottleneck that reduces the speed of receiving response. The director said: *"The impossibility of getting instant answers is also a weakness from the students' point of view, as once a question has been raised, it generally needs to be answered quickly. For the most part, our students are not "holding" information for a long period of time nor are they able to wait on distant information before continuing on."* Even though the overall answer generation time was 7.5 minutes, it needed much more time, almost 2.5 hours, to investigate the generated answers by a moderator. Thus, a real-time agent that includes human judgments is necessary to address the speed of crowd answers.

7.4.2.5. Lack of awareness

Seeding conversation and keeping the students engaged were two major challenges reported by teachers. Teachers needed to nudge them to consider asking the system a question in class. The director noted: *"Since many of our participants struggle to initiate tasks and generate new ideas, it was hard for them to begin calling on the system unless we actively prompted it."* Active prompts provided by champion users (i.e., teachers) should play a key role in research with individuals with autism. The director asked if both teachers and students could receive a notification that a question has been asked and answered without logging into the system. To do so, the system sent a real-time email

notification as well as an email digest at the end of the day. However, students did not check email regularly making it difficult to be aware of real-time Q&A interaction.

7.4.3   Future design and research considerations

A week's exploratory study allowed me to identify potential issues of using a hybrid Q&A forum with crowdsourcing feature for the students who have limited technology ability. The participants required intensive support in creating an account and then generating questions containing enough details. In this section, I discuss further design considerations to support individuals like the students I studied. In addition, I discuss considerations for further research including facilitating account creation, and defining the inclusion criteria to recruit the right audience who can independently use a system like inquir.us and benefit from the specialized social Q&A forum.

7.4.3.1. Design considerations

Balancing Independence in Account Management: The initial account registration turned out to be too difficult for all but 2 of the 8 students. To lessen the burden of account creation for each student, a single e-mail account was shared among the students, but one person (the director) was typically responsible for this e-mail account that might affect the practice of question-asking. Ultimately, a student needs support for creating and managing his own account, but this may cause feeling of being "watched" while they receive online account support. The system could better support privacy by more clearly presenting to users what kind of information is being monitored and how privacy setting changes can be easily made.

An advanced scaffolding interface is needed to support these students. While users create a question, the interface could examples or guidelines to scaffold the creation of a good question. A question of the day feature, for example, could be presented to demonstrate good question-asking practices, particularly if it points out what is good. Another option is a structured interface eliciting minimum requirements

of a question (e.g., title, body that should be different from title, the reason why you ask a question, expected responder, and expected timeline to receive an answer). However, again such practices might present challenges for language-impaired individuals. A voice recording of a question as an alternative to typing could be helpful for some people.

User-generated hashtags: inquir.us could be a tool that supports reflective thinking by asking questions that are relevant to what students learn from classes or workshops. To motivate users to consider asking questions, a revised system could support flexible topic category generation, reflecting a program curriculum or the growing interests of students. The current system asks users to find a topic from pre-defined categories, but it could be improved by adding features like hashtagging that allows user-generated tags.

Automating the crowdsourcing and moderation mechanism: A single human moderator is not an ideal solution. Manual question and answer delivery and validation increased the expected time to receive crowd-supplied answers. In the future, one of the major technical challenges is to build (semi-) automated agents to mediate between inquir.us and CrowdFlower. Using the CrowdFlower API or other crowdsourcing platforms, I hope to build a real-time delivery mechanism embedded into inquir.us. Also, I hope to utilize crowd workers not only as answer generators but also answer quality judges to increase the speed of answers.

7.4.3.2. Considerations for further research

It was fortunate that I could work with an established program that values question and answer behavior of students with autism. However, this design exploration with small samples of potential users revealed a variety of challenges students who have limited technical and language ability face when using an unfamiliar SNS. Some actions needed for managing the SNS (e.g., registration) created hurdles for adoption among these

students. Cross-platform registration using a user's preferred channel could be one solution. Instead of following a traditional account model, a champion user could spend the time in advance to set up accounts for a specific group of users with autism.

In addition, the exploration motivated me to reconsider the inclusion criteria of the study. The desired participants would be like the autism forum users who possess technology and language fluency. Even through the participants were reported as people with high-functioning autism, they presented a wide spectrum of behaviors and abilities. Being able to elicit challenges and relevant context with a computer was a challenge for these students. Thus, I suggest gauging potential participant ability with the inclusion criteria (Appendix C), and a screening questionnaire asking the participants to provide what they posted on the social media as an exemplar. The adult autism rater who participated in the answer quality judgment study reported in Section 6.2.7 could be an example of the right population for the further study.

7.5   *Summary*

In this chapter, I presented the design and evaluation of a specialized Q&A forum for individuals with autism. Based upon my two design goals—supporting users in generating better questions and receiving rapid and wider perspective answers, I built inquir.us to augment what existing online communities provide with crowdsourcing.

The pilot study aimed to investigate how design features of inquir.us would be used in the context of training classes. I attempted to integrate the system into the existing social circles. I studied the system with students in a transition program at a school for individuals with autism in Atlanta for a month. The transition program teachers were willing to integrate the system into their classes, and to motivate students to ask the system questions about life and social issues. The pilot study suggested that some students were able to ask questions and receive answers by using the system, but the

overall engagement was fairly low. One of the explanations for this is due to the population mismatch between the target users who have technology and language fluency and the participants who have limited ability. Thus, I suggested reconsideration of inclusion criteria for recruiting appropriate audiences who can benefit from inquir.us. This design exploration revealed interesting insights for advanced design features for designing a hybrid social Q&A forum augmented by crowdsourcing that I intend to pursue in future work.

CHAPTER 8

CONCLUSIONS

Autism diagnoses have increased rapidly in recent decades, with the CDC now estimating that 1 in 68 American children have the condition (CDC, 2014). Children from that generation are beginning to the transition to adulthood. However, the characteristics and needs of adolescents and adults living with autism are understudied. They may face unique challenges during adolescence and as they transition to adulthood. One of the significant issues these adolescents encounter is accessing appropriate services and gaining social support beyond a primary caregiver. This work in this thesis is targeted towards adolescents on the high end of the spectrum who require continuing social support in their struggle for an independent life. The rise in social networking services (SNS) has spawned new opportunities to serve these individuals in generating online social networks that supplement primary direct caregivers, who are often overburdened.

The goals of my thesis are to better understand challenges and opportunities to support individuals with autism in navigating everyday life, and to design special features of a variety of SNSs—from an existing social networking application to an online community and to a hybrid Q&A platform—that may be able to address some of the challenges faced by these individuals. Through the research explored for this dissertation, I have found that *SNS can* support some adolescents and adults with autism in increasing independence by *1) facilitating the asking of a variety of online networks, while reducing participation of a primary caregiver;* and *2) allowing acquisition of rapid, direct, and informational advice with crowdsourcing.* However, the use of a specialized

Q&A service built on an existing SNS platform appeared to be less practical for some students, which leaves spaces to consider further in the future how to improve technical details of the SNS and research process with and for individuals with autism or other mentally challenged users. In this final chapter, I summarize and synthesize the overall findings of this dissertation, as well as describe areas for future research directions.

8.1   A Summary of Prior Chapters

The thesis has discussed ways of specializing social networking services to support the independence of individuals with autism.

In Chapter 2, I defined **independence**, especially for the young adults with autism, as "being able to request help to navigate a variety of life situations with the minimal aid of a primary caregiver" and "being able to reach out to a supportive social network to fully integrate into society by operating effectively." In this light, I brought up ways to promote independence: 1) building connections with both off-line and on-line networks; and 2) facilitating question-and-answer interaction to receive effective advice from the network members. I identified the gap between what traditional assistive technologies provide and what individuals with autism need. I argued that different kinds of social networking services—personal social networking sites, online communities, Q&A sites, and crowdsourcing platforms—could address the needs related to independence.

In Chapter 3, I addressed the first research question—what are the current needs and concerns for attaining independent life for young adults with autism and caregivers? Understanding current caregiving practice for young adults with autism helps designers learn challenges and opportunities in this area. Through field observations and in-depth interviews, I identified key challenges characterized as prompt-dependent, less contextualized instruction, and over-reliance. To address these issues, I suggested preliminary design considerations: 1) motivating to engage in self-care activities; 2)

embedding advice in the context of the day's events; and 3) leveraging a natural network of individuals and caregivers. These guidelines were instantiated as a design concept, SocialMirror, a device capable of online social networking that allows an individual to ask questions and receive answers. The focus group discussion with a video prototype of SocialMirror identified the potential benefits (e.g., increased motivation to ask for help, distribution of caregiving, and social connectivity) and risks (e.g., privacy and safety, conflicting advice, diffusion of answering responsibility, and tension between a young adult and a caregiver) when SocialMirror might be deployed in the real world. I identified design considerations for specializing SNS toward better supporting the work of establishing trusted support networks vetted by strong-ties of family and friends.

In Chapter 4, I investigated how existing SNSs can support individuals with autism in generating online networks and initiating communication or requests for help. I focused on a special feature of a SNS, a focused communication circle, which allowed users to direct conversations to a set of people. I conducted a four-week exploration of a SNS, *GroupMe*, with three individuals with autism and their pre-defined social network of family and friends to whom the individuals could reach out about everyday life issues and questions. The use of GroupMe was investigated using a mixed-methods approach combining multiple sources of quantitative (usage logs, questionnaires) and qualitative (pre- and post-interview, coded logs of conversations) data. Over four weeks, GroupMe motivated each participant to communicate with this trusted circle of members and reduce reliance on his or her primary caregiver. However, a unified and pre-defined membership might not always be suitable for discussing some sensitive questions and could hinder receiving a wide perspective of answers. These challenges therefore allowed me to understand what is missing in existing SNSs and expand the

research agenda to generating a broad range of answers outside of an individual's pre-existing personal networks.

In Chapter 5, I expanded the research agenda addressing the design of a social Q&A system capable of generating effective answers to navigate everyday demands and challenges. While I devoted Chapter 4 to identifying some individuals' patterns of initiating help or advice, I dedicated Chapter 5, to uncovering the general Q&A behavior of a large number of autism forum users who seek advice beyond strong-ties of family and friends. I conducted a content analysis of threads in an online autism forum to characterize the forum users' Q&A behavior. The results showed the majority of threads were initiated by asking a question where users sought opinions or suggestions for coping with a variety of everyday social challenges. However, the study also revealed several drawbacks of this forum: 1) delayed answers, due to unstructured questions created in an open-ended nature; and 2) questions that needed a potentially broader perspective beyond the autism community. I identified opportunities to improve the community-based Q&A forums or suggest new Q&A systems that have: 1) a scaffolded question creation feature; and 2) crowdsourced responders to elicit relevant and rapid answers.

In Chapter 6, I suggested and evaluated crowdsourcing as a means to eliciting valuable answers to the autism forum questions. I used the terms, *in-group* and *out-group* to define the property of social membership for autism forum users and crowd workers. Using Amazon Mechanical Turk, I generated out-group answers to the in-group questions and evaluated them with a panel of judges, including researchers, experienced advisors of individuals with autism, and adults with autism. The results revealed that crowds offered rapid, concise, and potentially broad coping strategies without compromising emotional support. Building upon the findings, I suggested design opportunities that improve existing in-group communities by including: 1) a feature to

remind of the out-group answer source; 2) an automated question classifier; and 3) a moderating mechanism to foster trust.

In Chapter 7, I designed and evaluated inquir.us, a specialized Q&A platform combining in-group and out-group members that could address questions asked by individuals with autism. I had two design goals for inquir.us, which were drawn from prior work. The design goals were: 1) to support users in generating better questions by scaffolding the creation of questions; and 2) to augment in-group online networks with out-group crowd cohorts in order to provide rapid, direct, and informational answers from a wider perspective. The inquir.us system was derived from an open source question-and-answer web platform called Discourse, and included customized features (e.g., topic-oriented view and manually-integrated crowdsourcing via @Trusted_Strangers account). For the design exploration, I leveraged a young adults transition program offered by a school to train students to ask questions using inquir.us. This exploratory study revealed a variety of challenges that students who have limited technical and language ability face when using an unfamiliar SNS. Challenges included the complexity of account management, difficulty in describing the context of a question, delayed answers caused by a human moderator, and lack of awareness to Q&A interactions. Several key lessons and technical and methodological implications were identified from the initial exploration.

8.2 A Summary of Contributions

In this thesis research, I made contributions to the interdisciplinary fields of human-computer interaction, social computing and assistive technology design. I contend that this thesis has opened up an important discourse for *socially-augmented assistive technology*. Socially-augmented assistive technology refers to a system that garners support from a variety of social relationships across family, friends, and crowd

workers. I have investigated the combination of social media and crowdsourcing to provide information or advice to empower individuals with autism in everyday problem solving. My dissertation work illuminates structures and features of social computing systems that leverage various social ties, including: 1) direct support provided by local strong ties; 2) remote support provided by weak ties online; and 3) crowdsourced support provided by a large number of online volunteers.

My dissertation offers the following major contributions:

- **A rich description of challenges and design considerations on the way to attaining independent life.** The formative study revealed challenges as follows: 1) it is difficult for individuals with autism to keep up with everyday tasks spontaneously; 2) pre-programmed interventions are not related to an individual's personal context; and 3) primary caregivers become burdened due to the tendency of over-reliance. To address these issues, I suggested preliminary design guidelines for motivating individuals with autism to ask help and receive support from existing support networks. I also identified implications for designing SNSs that support secured and strong-tie connections to mitigate privacy and efficacy issues.

- **Empirical findings of the impact of SNS for individuals with autism.** The four-week exploratory study of GroupMe's focused communication circle revealed the circle actively engaged and shared the responsibility for responding to the queries of an individual with autism. The positive online interactions in the circle led to real-life interactions between the individuals and their circle members, relieving the concern of over-reliance on a primary caregiver. The results may encourage autism specialists to consider SNS as a special

intervention tool to teach everyday life skills in real world and break the trend of social isolation that impedes attaining successful independence.

- **A rich and nuanced description of online Q&A behavior of individuals with autism.** The analysis of a number of threads in an autism forum revealed unique Q&A practices of individuals with autism and established the taxonomy of Q&A. A detailed analysis of the topics and types of questions asked in a forum highlighted common needs and concerns of the members of the forum. I also identified pitfalls of the forum as a Q&A system where individuals with autism seek immediate and diverse support.

- **An empirical evaluation of a crowdsourcing approach to generate effective advice for individuals with autism.** I conducted **a** study to crowdsource out-group answers to questions generated in an online autism forum, with quantitative and qualitative analysis to determine how out-group answers compare against to in-group answers on a number of important dimensions (directness, additional information, informational / emotional support, and helpfulness). The results suggest that crowd workers rapidly provide concise and direct answers, offering a broader out-group perspective without loss of emotional support as compared to answers obtained within the online community itself.

- **Design guidelines to augment existing SNSs facilitating Q&A interactions**. Drawn from the exploratory GroupMe study (Chapter 4), the online Q&A thread study (Chapter 5) and the crowdsourcing study (Chapter 6), I demonstrated the limitations of each service as a Q&A system and discussed the design opportunities for improving the practice of Q&A. The discussed opportunities include: 1) supporting users in generating better questions by scaffolding the

creation of questions; and 2) augment in-group online networks with out-group crowd cohorts to provide rapid, direct, and informational answers from a wider perspective.

- **The development of a specialized Q&A platform.** I showed a hybrid social Q&A platform combining existing in-group resources (e.g., autism cohorts and teachers) with crowdsourced out-group resources that facilitate receiving fast, direct and informational answers. The initial design exploration study revealed several technical and procedural suggestions to improve the platform to better support students with autism. The suggestions include: 1) balancing independence in account management; and 2) integrating Q&A interaction into everyday life with the moderation of champion users (i.e., teaching staff), scaffolded question creation, and voice-activated question asking. To increase the speed of Q&A turnaround, the need for an automated agent mediating the Q&A platform and crowdsourcing is discussed. I also suggested the possibility of crowd workers as answer quality judges.

8.3   *Methodological Recommendations*

I combined qualitative and quantitative investigations, design, and the deployment of existing or novel technology as a way to identify future design directions. This dissertation presented empirical research based on multiple sources and methods of data collection and analysis. I triangulated the data (e.g., SNS logs and questionnaire) for a deeper understanding of user behavior and rationale.

More importantly, I made methodological contributions on engaging users with autism in a variety of research phases from the exploration of future systems, on the rapid deployment of an existing service, and on the design exploration study of a suggested platform. A number of researchers and designers, including myself, have

focused on working for the neurodiverse population and involving such individuals in technology design process (Benton, Johnson, Brosnan, Ashwin, & Grawemeyer, 2011; Benton, Vasalou, Khaled, Johnson, & Gooch, 2014; Hayes et al., 2010; Porayska-Pomsta et al., 2010). The development of research methods requires careful consideration for balancing an individual's strengths and weaknesses. Some of difficulties (e.g., social and communication skills) and strengths (e.g., visual thinking, exceptional talents and interests in very specific areas) typically define the autism condition. However, these characteristics can be viewed as either a difficulty or a strength depending on the situation or the lens through which they are viewed. Technology designers should direct their attention to autistic individual's strengths, while supporting their difficulties. From these experiences, I provide designers with the following methodological considerations that guide them in conducting formative and summative research with the neurodiverse population.

- **Video prototyping served to elicit discussion.** It was a challenge to keep participants with autism focused on the topics of discussion and give them clear opportunities to express their opinions in the meetings. Also, it was a difficult task for them to envision intangible concepts of future technology. In the development of SocialMirror concept, I used a video prototyping method inspired by invisible design (Briggs et al., 2012) and video prompts for older adults (Lindsay, Jackson, Schofield, & Olivier, 2012). Video prototyping has dual purposes: 1) illustrating usage scenarios without a fully-developed prototype in the early stage of the concept development; and 2) engaging potential users who are familiar with visual thinking in focused discussion around technology. Participants were presented with the video prototype illustrating several scenarios which they might face and discussing a fictitious intervention for the problem domain. I found that the video prototype helped participants speculate

on possible uses or misuses of the system, and that the speculation led to novel design solutions.

- **Rapid deployment studies of an existing SNS.** Building a stand-alone SNS requires considerable energy and time. The nature of cross-platform interactions (e.g., text message, mobile, web) makes the development of an application complicated. One can consider using traditional HCI prototyping and evaluation methods (e.g., a Wizard of OZ study with a low fidelity screen mockup) to reduce the cost. However, this approach largely focuses on interface interaction at a moment rather than longer trace of social interactions. Thus, it was not suited to work with "groups" and for observing experiential aspects of the technology. Furthermore, of particular interest to the study presented in Chapter 4, I was to identify design opportunities through shortcomings of an existing SNS that provides core functionalities of social networking. Using GroupMe, a cross-platform social networking application, I was able to establish secured and private online communication circle leveraged by existing offline connections. This study presents an opportunity to take advantage of deploying an existing social networking platform before design and engineering commitment. Designers should be aware of research goals and target populations to find the best social platform to study.

- **Research-through-design with special needs population.** This thesis work involves groups of students with autism directly in each phase of the research process, from the formative design studies to the evaluation of inquir.us. Also, it is important to include members who have psychological knowledge to best engage the students. The involvement of enthusiastic members of teaching staff, who "champion" the project idea, played a critical role throughout the research process. In the case of the inquir.us study, I targeted a pre-established

educational community, including students with autism and teaching staff, and introduced inquir.us as a tool to educate how to ask for help. Teaching staff members I worked with were able to embed inquir.us into their educational sessions and improvise the sessions where necessary. They also provided students' interests and concerns with the aim to integrate them into research design (e.g., tasks appropriate for the student's ability), and system configuration (e.g., pre-defined topical categories). The case study of inquir.us presents an opportunity to improve reflective thinking by asking questions relevant to what students learn from the educational sessions. However, it is particularly a challenge for some students with limited technical and language ability to use the system, which might increase the teachers' burden. Thus, designers should have knowledge of the educational environment settings, and of the characteristics of each student they will study. Several rounds of tutorials, focusing on capitalizing on students' strength while supporting identified difficulties, are required prior to the deployment study.

8.4   *Opportunities for Future Work*

Many interesting ideas for future work build on the findings of this thesis. One of the most exciting parts of the work was the crowdsourcing approach for generating advice on everyday social challenges that individuals often face. There are several avenues that ought to be explored related to this approach.

There are approaches I am interested in for developing crowd-powered support systems that are more accessible in everyday life. For example, how might we support crowds making a "hotline" in which online volunteers are ready to respond 24/7? I used paid crowdsourcing mechanisms such as Amazon Mechanical Turk and CrowdFlower to recruit workers, but the notion of a hotline serviced by online volunteers suggests that

it might be worthwhile to consider the creation of specialized crowds that should be cost effective and trustworthy. To address the cost issue, I hope to explore the possibility of a "philanthropic turk," where online volunteers provide answers not because they are being paid, but because they want to help others in need. This exploration will reveal the motivation and reward structure to make the online micro-volunteer practices successful. In the crowdsourcing study presented in Chapter 6, crowd workers were told that the person who asked the question is on the autism spectrum. I believe that it is important that crowd workers know the neurodiversity status of the question askers. It will be interesting to explore how the framing of the HIT affects the recruitment of crowd workers and the creation of answers. Is there any difference between the workers knowing the nerodiversity status of the question askers or not knowing it? What any other context about the person should be presented to the workers to provide more relevant answers? All of these are questions that would be useful to explore in future work.

The work with MTurk responders in Chapter 6 introduces socio-ethical issues related to the use of a crowdsourcing labor force that is global. One potential drawback is the lack of cultural sensitivity to localized questions about daily living that may often require a nuanced understanding of particular social worlds (e.g., conventions around landlords and apartment rental). To account for cultural contexts and social norms, I envision the creation of specialized crowd communities by leveraging local volunteers who are familiar with the particular contexts of a question asker. I assume that volunteers are recruited by and from a credible group, such as a campus or a professional service organization. In such a scenario, registering as potential responders could provide a digital micro-volunteering opportunity for college students who wish to contribute to community service. It is important to understand the nature of volunteer work and to develop recruitment practices that adapt to the specific motivations and

needs of volunteers. Beyond the intrinsic motivations (e.g., altruism and reputation), interpersonal factors (e.g., affiliation requirements, personal benefit such as earning service hours) could also be motivations for volunteer work. How should the system provide extrinsic incentives to match intrinsic motivations? Do volunteers equate answering questions asked by individuals with autism to doing volunteer work?

As I noted, conclusive evidence that inquir.us actually impacted the Q&A behavior of individuals with autism is lacking, due to the nature of the initial exploration. There are several avenues that ought to be explored with an advanced system based upon the design considerations, such as voice-activated Q&A interactions and the use of an API to automate crowdsourcing. Beyond the technical advances, one question that would be important to address in future study is about what makes "trusted strangers" actually "trusted" for the individuals with autism. What is the interpretation of individuals with autism? Do they trust that the answers are of high quality? Further research should address how individuals with autism perceive the value of answers provided by their peers/teaching staff members and by trusted strangers differently. Do they trust that the strangers will keep information from the questions private? Can they decide which question is appropriate or not to ask of trusted strangers? If the system somehow empowers guardians or teaching staff to delegate a question to the crowd, they could achieve a nice balance between the speed and power of the crowd and the comfort of responsible professionals. The future system should help individuals balance between control and independence, and should consider privacy and safety.

Ultimately, I look forward to identifying challenges, guidelines, and trade-offs for the design of the next generation of social networking and crowdsourcing systems to support advanced interfaces for assisting individuals as well as groups to become more knowledgeable, more productive, and more creative. In my future work, I hope to reveal important considerations for generating valuable insights from crowds, such as

integrating offline and online crowds and fostering trust in crowd workers. I will investigate design patterns and best practices for crowd computing in greater depth. In addition, the discoveries can inform ethics and privacy issues surrounding crowd computing.

APPENDIX A

GROUPME QUESTIONNAIRES

Skills and Confidence Questionnaire

a. Based upon your experience, what is the most important skill for you?

Please rank the following topics according to their importance. Please write "1" next to the topic that is most important, a "2" next to the topic that is next most important, and so on. Remember, no two topics can have the same rank.

Topic	Rank
Maintaining good hygiene & wearing neat, clean clothes	
Staying on schedule	
Good health habits (e.g., cooking, exercise)	
Work and professional life	
Financial management	
Leisure and social activities	
Cleaning the house & managing household chores	

b. In addition, how confident are you in completing the following tasks?

Please rate your confidence.

Topic	Confidence				
	Not confident at all, always need help	Slightly confident, often need help	Moderately confident, sometimes need help	Very confident, seldom need help	Completely confident, never need help
Maintaining good hygiene & wearing neat, clean clothes	o--------------------o--------------------o--------------------o--------------------o				
Staying on schedule	o--------------------o--------------------o--------------------o--------------------o				
Good health habits (e.g., cooking, exercise)	o--------------------o--------------------o--------------------o--------------------o				
Work and professional life	o--------------------o--------------------o--------------------o--------------------o				
Financial management	o--------------------o--------------------o--------------------o--------------------o				
Leisure and social activities	o--------------------o--------------------o--------------------o--------------------o				
Cleaning the house & managing household chores	o--------------------o--------------------o--------------------o--------------------o				

Social Network Questionnaire

Existing and Potential Support People: Please list the people who have helped you in the following categories. You can put one person into multiple categories, or multiple people in one category. In addition, please list people who you may not have contacted, but who would also help you if you asked. (For example, you may never have contacted one or more classmates often, but you could contact them for help on your homework.) Please keep their contact information (e.g., email or cell phone number) if you know it so that we can send them an invitation to participate in this study and a questionnaire during the first interview.

Topic	Network Members
Maintaining good hygiene & wearing near, clean clothes	Name: _____ Relationship: _____ Name: _____ Relationship: _____ Name: _____ Relationship: _____
Staying on schedule	Name: _____ Relationship: _____ Name: _____ Relationship: _____ Name: _____ Relationship: _____
Good health habits (e.g., cooking, exercise)	Name: _____ Relationship: _____ Name: _____ Relationship: _____
Work and professional life	Name: _____ Relationship: _____ Name: _____ Relationship: _____ Name: _____ Relationship: _____
Financial management	Name: _____ Relationship: _____ Name: _____ Relationship: _____ Name: _____ Relationship: _____
Leisure and social activities	Name: _____ Relationship: _____ Name: _____ Relationship: _____ Name: _____ Relationship: _____
Cleaning the house & managing household chores	Name: _____ Relationship: _____ Name: _____ Relationship: _____ Name: _____ Relationship: _____

Pre and Post Questionnaire (Individuals will answer each questionnaire for each caregiver)
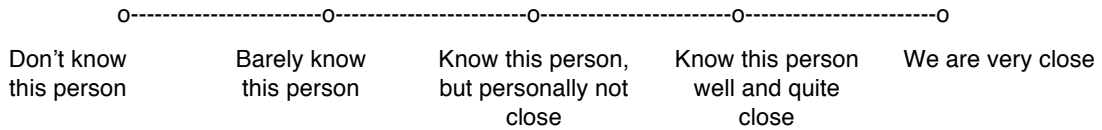
Participant _____   Caregiver _____

1. How do you know this caregiver? (Choose all that apply)

a) I know this person. (Relationship: _____)

b) I personally do not know this person, but my parents know this person.

c) I personally do not know this person, but my teacher knows this person.

e) I do not know this person at all.

2. How long have you known this person?

a) I do not know this person.

b) I have known this person since _____

3. How strong is your relationship with this person?

o----------------------o----------------------o----------------------o----------------------o

| Don't know this person | Barely know this person | Know this person, but personally not close | Know this person well and quite close | We are very close |

4. What is the most frequent communication mode between you and this person?

____ Phone call   ____ SMS/Text   ____ Email

____ Face-to-face   ____ Other (_____)

5. How often do you get help from this person (frequency) and how helpful would be this person (helpfulness)?

We define 'help' as a broad range of activities that support you to live independently. People may provide practical advices such as life skill instructions, schedule management, social skills support. Emotional support can also be considered as providing 'help.'

		Never helps me	Barely helps me	Helps me if I ask	Never helps me	Always helps me
Overall	Frequency	o----------------o----------------o----------------o----------------o				
	Helpfulness	o----------------o----------------o----------------o----------------o				
Maintaining good hygiene & Getting dressed well	Frequency	o----------------o----------------o----------------o----------------o				
	Helpfulness	o----------------o----------------o----------------o----------------o				
Staying on schedule	Frequency	o----------------o----------------o----------------o----------------o				
	Helpfulness	o----------------o----------------o----------------o----------------o				
Good health habit (e.g., cooking, exercises)	Frequency	o----------------o----------------o----------------o----------------o				
	Helpfulness	o----------------o----------------o----------------o----------------o				

Work and professional life	Frequency	o----------------o----------------o----------------o----------------o
	Helpfulness	o----------------o----------------o----------------o----------------o
Financial management	Frequency	o----------------o----------------o----------------o----------------o
	Helpfulness	o----------------o----------------o----------------o----------------o
Leisure and Social Activity	Frequency	o----------------o----------------o----------------o----------------o
	Helpfulness	o----------------o----------------o----------------o----------------o
Cleaning household & Managing chores	Frequency	o----------------o----------------o----------------o----------------o
	Helpfulness	o----------------o----------------o----------------o----------------o
Other Areas of Support (_____)	Frequency	o----------------o----------------o----------------o----------------o
	Helpfulness	o----------------o----------------o----------------o----------------o

APPENDIX B

MTURK WORKERS DEMOGRAPHIC INFORMATION

Total number of assignments received	**400**
Total number of assignments providing an answer to a question	**311**
Mean length of answers (words)	**60**
Time elapsed to collect 400 answers	**21 hours and 7 minutes**
Average time that workers spent to complete an assignment	**3 minutes 35 seconds**
Total cost	**$88 ($0.2 / HIT)**
Total number of workers	**98**
Total number of workers provided demographic information	**68**
Age (Mean)	**31.5**
Nationality	**American (45), Indian (8), British (1), Canadian (1), Filipino (1), Haitian (1), Irish (1), Slovenian (1), Vietnamese (1), Unspecified (8)**
Gender	**Female (37), Male (30)** **Other (1)**
Autism diagnosis	**Not on the spectrum (61)** **Self-diagnosed (3)** **First diagnosed by clinician as an adult (3)** **Awaiting clinical diagnosis (1)**
Know someone with autism?	**Total: 50** **Relationship:** **Friend (26), Relative (10), Client/Student (7), Acquaintance (6), Colleague (4), Child (3), Parent (2), Sibling (1)**
Regularly interact with them?	**28**
Level of knowledge about autism	**Nothing (4)** **A little (42)** **A lot (21)**

APPENDIX C

LETTER OF RECRUITMENT

Are you an adult on the autism spectrum?

Researchers at Georgia Tech are running a survey to examine the value of online advice that supports the everyday life of individuals with autism.

We have collected a large number of questions asked online by individuals with autism and answers provided by other online responders.

You will be asked to judge the helpfulness of each. The online survey (we can provide a printed version if preferred) takes 20~30 minutes to complete, and participants will receive $20 compensation for study.

 Eligible participants must:

• be at least 18 years old;

• have some experience with social media (e.g., Facebook, Twitter, Online communities like wrongplanet.net); and

• be able to read English

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