



Towards Digital Independence: Identifying the Tensions between Autistic Young Adults and Their Support Network When Mediating Social Media

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ABSTRACT

We conducted an ethnographically-informed study with 28 participants (9 autistic Young Adults or "YAs" in need of substantial daily support, 6 parents, 13 support staff) to understand how autistic YAs self-regulate and receive mediation on social media. We found that autistic YAs relied on blanket boundary rules and struggled with impulse control; therefore, they coped by asking their support network to help them deal with negative social experiences. Their support networks responded by providing informal advice, in-the-moment instruction, and formal education, but often resorted to monitoring and restrictive mediation when more proactive approaches were ineffective. Overall, we saw boundary tensions arise between Autistic YAs and their support networks as they struggled to find the right balance between providing oversight versus promoting autonomy. This work contributes to the critical disability literature by revealing the benefits and tensions of allyship in the context of helping young autistic adults navigate social media.

CCS CONCEPTS

- Human-centered computing → Field studies.

KEYWORDS

social media, mediation, autism, boundary turbulence

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1 INTRODUCTION

Scholars within the Human-Computer Interaction (HCI) community have confirmed that autistic young adults (YAs) experience amplified risks and challenges when using social media (c.f., [8, 41, 65, 78, 111]). For instance, prior research highlights increased vulnerability to abuse [8], difficulty in navigating complex social dynamics [65], and potential struggles in setting appropriate boundaries [41]. While Page et al. [78] suggests that some of these challenges arise due to autistic YAs perceiving the affordances of these platforms differently than neurotypical users (e.g., taking prompts literally), the literature has yet to examine the role of self-regulation (by autistic YAs) and mediation (e.g., by parents, service providers, and extended family members) in terms of alleviating or facilitating these problems. In order to mitigate harm coming from social media use, it is imperative to understand how autistic YAs, with help from their support network, regulate boundaries on social media to the detriment and/or benefit of autistic YAs.

Meanwhile, researchers in related fields have frequently studied boundary regulation and boundary tensions for adults on social media [52, 55, 102, 122] through the lens of Communication Privacy Management (CPM) [82, 83]. HCI scholars have also studied tensions between self-regulation versus parental mediation in teen populations [25, 32, 121]. This rich body of literature has consistently shown that adults, children, and the interactions between these groups often lead to boundary turbulence and/or privacy violations when using social media. The novel contribution of our study is that we bring these two streams of research together to study boundary tensions between autistic YAs and their support networks, as those on the spectrum (particularly those needing level 2 or 3 support [96, 105]) may need more support than neurotypical YAs. Thus, we undertake a study to explore self-regulation techniques employed by autistic YAs when interacting on social media. However, because autistic YAs have a relatively large support network, including individuals such as parents, caregivers, and service providers who are highly involved in their care [62, 84], we must also seek to understand whether and how their involvement impacts autistic YA's ability to mitigate risks from social media use. While some research has been conducted on parental mediation of social technologies, their findings, focused on children and teens, are not generalizable to neurodivergent groups and their caregivers

[6, 7, 108]. Despite these challenges, there is an opportunity for social technology to bring enormous benefits to these YAs, especially given that national statistics in the U.S. show low social well-being indicators for this group as a whole [86, 101, 114]. We framed our study by asking the following high-level research questions:

- **RQ1:** *What are the roles of a) self-regulation and b) mediation as autistic YAs navigate social media?*
- **RQ2:** *What are the boundary tensions and challenges that arise as autistic YA social media users strive to be independent?*
- **RQ3:** *What are positive outcomes of mediation of social media use for autistic YAs?*

To answer these questions, we interviewed 28 participants (9 autistic YAs in need of substantial daily support, 6 parents, 13 support staff) as part of an ethnographically-informed study to understand social media use, risks, and benefits. We utilized the Wisniewski TOSS (Technology and Online Social Support) framework to identify the mediation approaches utilized by individuals in support networks (RQ1). However, given that it is young *adults* whose usage is being mediated, we also explored privacy and boundary regulation by adopting Communication Privacy Management (CPM) theory to examine the dynamics of boundary turbulence (RQ2). Lastly, we uncovered the benefits of mediating social media use by conducting a grounded thematic analysis of the interviews, drawing on CPM theory for insights (RQ3). Taken collectively, these approaches allowed us to comprehensively address our research inquiries, exploring the role of mediators within the support network and the experiences of autistic YAs on social media.

We found that while autistic YAs engaged in self-regulation, it was not enough to keep them safe. As a result, adults in their support network stepped in to mediate their social media usage. While mediators struggled to strike the right balance between safety and autonomy for autistic YAs, the YAs themselves did not express concerns about their privacy and regularly sought out help from their support network – unless they were concerned about getting punished, in which case they went into defense mode and stopped reaching out for help. Heavy mediation allowed them to be safe online and receive help with socio-emotional regulation and skill building. However, this did little to help them become autonomous social media users. We present these findings and discuss the challenges to overcome as we help autistic YAs work towards digital independence. Based on our findings, we make the following novel research contributions:

- Conducted the first study that deeply examines boundary regulation and tensions between autistic YAs and their socio-ecological support networks of parents, social service providers, and extended family members, who help mediate their social media usage.
- Found that autistic YAs often develop simple rules to regulate their social media interactions with others, but struggle with impulse control during heightened social situations, relying on adult mediators to help them joint troubleshoot problematic situations.
- Uncovered a marked difference between teens and autistic young adults, where the latter did not seek autonomy and privacy from their support network unless they feared being reprimanded for their actions.

- Identified key challenges and benefits of support network mediation of autistic YAs social media use that inform education and design towards helping autistic YAs be more independent and empowered social media users.

Next, we describe the theories and frameworks that ground our research.

2 THEORETICAL FRAMING: A SOCIOECOLOGICAL PERSPECTIVE ON DIGITAL MEDIATION AND BOUNDARY REGULATION FOR AUTISTIC YOUNG ADULTS AND THEIR SUPPORT NETWORK

Autistic YAs who require substantial support in their daily lives (i.e., Level 2 [43, 69]) often rely on the assistance of their parents/guardians/caregivers and advocates such as extended family members and case workers. Thus, we take a socio-ecological perspective, drawing from Bronfenbrenner's Ecological Systems theory which accounts for how social interactions occur within multiple layers of influence, including individual, interpersonal, and environmental factors [12, 13, 106]. As such, we go beyond the relationship between autistic YAs and their parents to explore the role of their broader support network (RQ1), the tensions (RQ2), and benefits (RQ3) arising from mediated social media usage. To do this, we leveraged existing frameworks that were developed specific to parent-child relationships, but include the autistic YA's broader support network. We describe these frameworks below.

2.1 Frameworks for Self-Regulation versus Parental Mediation

2.1.1 Self-Regulation. To understand autistic YAs self-regulation techniques, we first leveraged Wisniewski et al.'s framework [121] of Teen Online Safety Strategies (TOSS), which maps well to our domain. Many autistic YAs, particularly the ones who participated in our study, live with their parents, likely creating similar struggles as teenagers who push for autonomy, while still relying on their guardians for fundamental needs. TOSS highlights self-regulation (self-monitoring, impulse control, and risk-coping) as a key component of safe social media use. *Self-monitoring* describes the ability to apply forethought to one's actions, preventing engagement in risky behavior [99, 100]. *Impulse control* consists of the ability to limit immediate action in order to obtain desired future consequences. Finally, *risk-coping* is how one handles stressful situations after they occur. This could include seeking aide from others, withdrawing, or addressing the issue themselves [23, 27].

2.1.2 Parental Mediation. The theoretical foundations of digital parental mediation trace back to Valkenburg et al.'s [107] early work on parental mediation of children's television viewing. Based on prior literature and their own psychometric analysis, Valkenburg and her colleagues identified 3 mediation strategies. *Restrictive mediation* refers to rule-based practices that set boundaries and limit media use. For example, time limits for viewing or restricting the viewing of specific content are restrictive methods. *Instructive mediation*, also known as active mediation, involves discussing media use and/or viewed media content with one's child. This type of mediation can occur during or after viewing but has more recently

been broadened to include discussions about appropriate behaviors prior to media use [56]. *Coviewing*, reframed more recently as either a form of technology co-use [17, 56] or *passive monitoring*, refers to instances when parents watch media content with their child but do not engage in discussions about that content. These dimensions of parental mediation are still the predominant way in which researchers conceptualize and measure new media parenting [72], including youths' use of the internet in general [57], screens [77], smartphones [47, 121], tablets [11], smart speakers [30], social media [37], and online gaming [53]. As such, we draw from this framework to answer RQ1; yet, given our broader socio-ecological framing, we look beyond parents and include mediation strategies taken by those in YA's extended support network.

2.2 Communication Privacy Management and Boundary Regulation

In addition to analyzing mediation strategies, we wanted to investigate the tensions that may arise as a result of this negotiation between self-regulation and mediation. As has been done in prior work to uncover mediation tensions between parents and teens desiring autonomy [18, 25], we draw on Petronio's Communication Privacy Management theory (CPM) to characterize the decision-making tensions around information disclosure on social media [82, 107]. According to CPM, a person feels ownership over their personal information. They have the right to determine how and whether this information is shared. In other words, they have their own privacy rules around sharing this information. However, when this information is shared with others it becomes *co-owned* with that group of individuals. The privacy rules around further sharing this information are then negotiated between the co-owners. Unfortunately, *boundary turbulence* occurs when privacy rules aren't effectively negotiated or are violated [81, 82]. Using CPM, we identify who becomes co-owners over information posted on social media by the autistic YA, when they become co-owners, the privacy rules used, boundary turbulence, as well as benefits that arose from such mediation.

3 RELATED WORK

Our work focuses on social media usage by autistic young adults. Below, we motivate our work based on existing literature, then pinpoint the research gaps addressed by our work.

3.1 Studying Social Media Use of Autistic Individuals

This growing body of literature emphasizes the difficulties autistic users face using social media. These include harrassment, cyberbullying, relationship damage, as well as financial, mental, and physical harms [33, 73, 78, 104, 109]. Researchers also point out how autistic social media users are more susceptible to harm than the general population. This includes being much more likely to experience privacy, safety, and other online risks [60, 92] as well as harassment both on- and offline [19, 29]. Much research takes a deficit-based framing by emphasizing unhealthy social media practices that lead to physiological, cognitive, social, emotional, legal, and safety issues [26, 36]. Nonetheless, the research is mixed regarding whether autistic youth's high engagement with social media

has a negative impact on their overall well-being [36, 64, 65, 89, 110]. Some work even shows higher levels of happiness for autistic social media users over non users [113]. Recent scholarship focuses on the opportunities presented by social media given the different characteristics of autistic individuals [16, 35]. Such research suggests that social media can help autistic users better control their social interactions, connect with a community, and be their authentic selves [33, 73, 109].

While most of the work on autism and social media focuses on children [60, 90, 91] and teens (e.g., [36]), researchers have started exploring social media usage among young autistic adults [9, 10, 78]. Recent work by Page et al. reveals how autistic YAs perceive the affordances of social media differently than the general population [78]. Literal interpretations of social media interface elements result in adverse outcomes such as heightened social anxiety, social exclusion, inadvertent social relationship harm, and financial and physical harm. Barros et al. uncovered social media's deficiencies in addressing the sensitivities and social requirements of neurodiverse users [9]. They highlight how mainstream platforms offer insufficient user control, inadequate mechanisms for conveying tone and intention, and too much emphasis on superficial interactions. Baylor et al. identified issues related to online safety, digital literacy, and the disruptive influence of advertising content for autistic YAs with Intellectual Disabilities, a sub population whose social media use is even less studied [10]. These recent studies all highlight deficiencies in the design of social media for neurodiverse users. We extend this line of research by investigating how autistic YAs self-regulate their social media use. Furthermore, we include both those with and those without intellectual disabilities.

3.2 Investigating Allyship and Mediation in the Context of Social Media Use

We focus on YAs on the autism spectrum, a stage of life that is under-investigated [80] and where social support is greatly lacking [78]. Social media studies of autistic YAs often involve those who are attending college and relatively independent (e.g., [93]). However, many autistic YAs do not fit this profile as many are dependent on their support network for their day-to-day needs [44, 84]. In fact, enabling them to perform tasks of daily living creates care giving demands that grow more complex over time and increase feelings of caregiver burden [63]. Parents, thus, often need to form support networks to ensure the support needs of their autistic children are met even into adulthood [62].

In contrast to prior disability work that relies solely on indirect reports from parents or caretakers, we actively involve the target population (autistic YAs) in the research process [15, 20, 28, 125]. Furthermore, while much accessibility research aims to assist individuals in a way that they can perform tasks independently, we emphasize the importance of allyship and the integral role of the support network of the individual [39, 45, 71]. As such, our research takes a critical disability perspective by focusing on inclusion, empowerment, and allyship [61, 68, 97]. Especially in context of autistic individuals, a community of support can be the key to enabling access [120], rather than insisting that the individual must act completely independently. While the critical disability literature emphasizes the importance of caretaker networks, little is known

about how this manifests for social media and autistic YAs. Past research has focused on other media contexts (e.g., television and video game use [54] and mitigating the effects of cyber victimization [123]). Furthermore, past research has focused on autistic adolescents (rather than autistic adults whose goals and values diverge more from parents [98]) and parental mediation rather than the broader support network. Thus, our work extends this literature by investigating a wider support network beyond parents, in the unexplored context of social media, and with the different relationship tensions in play when mediating technology usage of autistic YAs.

4 METHODS

Critical disability studies emphasize the importance of building relationships with the community to better understand how to support and engage with them, and to shape research study plans [39, 59, 118]. Ethnographically-informed field work has been recognized as an effective approach to more deeply understand and build relationships with a study population [31, 79]. We engaged in ethnographically-informed field work which allowed us to become aware of the personal, social, structural, and material factors that shape the daily behaviors of autistic YAs, including their technology usage. Through this field work, we discovered that close family and service providers played a very large role in assisting and guiding the actions and choices made by autistic YAs. This led us to broaden our interview sample and include individuals within the YA's daily support network who mediate social media usage of the YA. We were also able to anticipate many of the issues that YAs and their support network face, which shaped the interview protocol to probe on these issues. Our field notes served as additional data points and insights to reinforce and contextualize what we found through subsequent interviews. Finally, all authors on this paper have extended personal experience with this community, whether it be family members who are diagnosed as autistic, or extensive experience working for or volunteering in community organizations serving this population. This insight proved to be invaluable during analysis of the data and allowed for reflection upon the researchers' own similar lived experiences and that of their family members or clients. Here, we describe this initial field work which helped us shape the subsequent interview and recruitment process.

4.1 Ethnographically-Informed Field Work

We worked with two service providers (that we will refer to as "Alpha" and "Beta") located in metropolitan areas in the Northeastern United States. These organizations provide day services for adults on the autism spectrum such as life skills development, job preparation, and social enrichment. Clients must have a verified diagnosis of being on the autism spectrum in order to receive services from these organizations. Alpha serves clients with IQ above 70 who tend to go to the facility a few times a week. Beta serves clients with IQ below 70 who come to Beta's facilities every weekday and participate in a full day of programs. The last author engaged in field work to observe various workshops and programs sponsored by Alpha and Beta as well as other community organizations to help autistic individuals and their families learn about resources, receive training, and connect with others. These community programs covered a wide array of topics ranging from independent living to

navigating government benefits and accommodations to emergency preparedness. A key learning from participating in these programs was that families, service providers, educators, and others in the individual's support network needed to provide extensive support and scaffolding to enable individuals to live more independently and navigate a world built on neurotypical needs and norms. The researcher was additionally invited to present interactive workshops about online safety at a number of these facilities. During these engagements, she directly interacted with YAs on the autism spectrum and individuals in their support networks, sensitizing her to key challenges and priorities in technology use. Support networks constantly described the difficulties YAs faced using social media, and shared their attempts at mediation. These experiences shaped our research questions as well as the semi-structured interview protocol. Next, we describe how we used interviews to probe on challenges with social media usage and the involvement of the support network.

4.2 Semi-Structured Interviews

We relied on Alpha and Beta to advertise the study to their clients and their clients' support networks, including family members and staff at their facilities. We also were introduced to and interviewed some staff unaffiliated with these organizations (Gamma is also a day program, Delta is a school with a transition program for autistic YAs). Alpha and Beta helped potential participants and their families understand the goal of the study and the procedures involved. In Fall 2018-2019, we conducted 28 interviews consisting of 9 YAs on the autism spectrum, 6 parents of autistic YAs, and 13 staff working at Alpha or Beta or another service provider. All of our autistic YA participants lived at home with their parents and needed substantial support in their daily lives, most relying heavily on Alpha and Beta for their transportation needs. Participants were formally diagnosed as being on the autism spectrum, had used social media, and most were not their own guardians. They received disability benefits from the state and were limited in the number of hours they could work since exceeding an earnings threshold would lead to permanently losing disability benefits. Because prior literature shows that caregivers of autistic adults also share in the responsibilities of managing the individual's social media account, we included parents in our study [84]. Based on the observations from our field work, we also interviewed service providers, who played an integral role in supporting the daily activities of YAs. Note that many parents and staff also had personal experience with another autistic child, sibling, or relative and spoke from that perspective as well. The characteristics of our participants are described in Table 1.

Semi-structured interviews were conducted by the last author on site at Alpha and Beta with a staff member present for adults who were not their own guardians (as recommended by Alpha and Beta). No staff assistance turned out to be needed during the interviews. Staff and parents were interviewed in person or via phone based on their preferences. Alpha and Beta facilitated distributing and having participants sign the informed consent form well ahead of the actual session. Those who were not their own guardians signed an assent form, while their guardian signed the consent form (a practice also used to empower adolescents to understand and give assent to participating). Verbal consent/assent was verified at the

beginning of each interview. Interview questions probed on benefits and dealing with challenges with using social media. This broad framing of questions allowed us to identify mediation strategies (whether successful or not) utilized by individuals in their support network to address or prevent issues. It also allowed us to note when mediation was not needed because the individuals dealt with the problem on their own. Interviews averaged 40 minutes (ranging from one unusually short interview at 13 minutes, and up to 75 minutes). All interviews were audio recorded and professionally transcribed for later analysis, with identifying information removed. At the recommendation of Alpha and Beta, participants were not compensated to avoid potentially putting clients at risk of becoming ineligible for disability benefits due to additional income. This study was approved by Alpha and Beta's governing boards in addition to being IRB-approved by the last author's institution.

4.3 Data Analysis Approach

For the analysis of RQ1, we analyzed self-regulation by applying the Wisniewski TOSS (Technology and Online Self-Regulation in Students) framework which encompasses three dimensions: 1) self-monitoring, 2) impulse control, and 3) risk-coping. We then used Valkenburg's Mediation framework to code for mediation strategies, including: 1) restrictive mediation, 2) instructive mediation, 3) and passive monitoring. These frameworks guided us towards a rich understanding of the strategies employed by autistic YAs and their support network. The codebook for self-regulation can be found in Appendix A and the codebook for mediation can be found in Appendix B. For RQ2, we analyzed the data through the lens of Petronio's Communication Privacy Management (CPM) framework to identify data co-owners, privacy rules, and boundary tensions that might emerge as a result of mediation resulting in the codebook in Appendix C. For RQ3, we performed a grounded thematic analysis which resulted in Appendix D.

The first author led the qualitative analyses with the assistance of two undergraduate research assistants. The two last authors, who are experts in qualitative HCI research, oversaw the analyses. For RQ1 and RQ2, transcripts were coded using a theory-driven approach based on the Wisniewski et al.'s TOSS framework [121], Valkenburg et al.'s Parental Mediation strategies [107], and Petronio et al.'s Communication Privacy Management (CPM) framework [81, 82]. The first author drove the analysis, working with the research assistants to code all transcripts, discussing and building consensus on all of the coding. For RQ3, we used a thematic analysis grounded in the data. The first author and research assistants first explored the data and formulated initial codes independently. Then, the first author led the research team to iterate and merge the codes to finalize the codebook, complete the data analysis, and identify cohesive themes. Given that we used an iterative consensus building process throughout the final stages of analysis, as McDonald et al. suggests [66], there was no need to calculate IRR.

4.4 Ethical Considerations

This study received IRB approval and was conducted in accordance with the ethical guidelines set by the Institutional Review Board (IRB). We also took many additional precautions to help our participants feel comfortable with the process as described in our

methodology. We are committed to serving the community long-term rather than engaging in isolated research studies. We continue to work with these and other organizations to develop solutions based on this initial research. This has included giving free online safety training and sharing our findings with the community in publicly accessible ways.

5 RESULTS

We first describe the self-regulation techniques used by autistic young adults on social media and how these techniques were not enough to keep them emotionally, socially, and physically healthy and safe. We also identify the various mediation techniques employed by their social networks in an attempt to help them be safe online. Finally, we share the results of analyzing boundary turbulence coming from mediation, uncovering relatively little turbulence perceived by the young adults. We elaborate on the benefits and drawbacks of employing such mediation.

5.1 Self-Regulation of One's Own Social Media Activities (RQ1a)

In this section, we delve into instances where autistic YAs demonstrated self-regulation approaches to managing their social media usage. These approaches encompassed self-monitoring, impulse-control, and risk-coping strategies. These proactive techniques shed light on how autistic individuals independently navigate the complexities of online interactions, demonstrating their capacity for self-regulation in the digital realm. By examining these strategies, we aim to provide insights into the innovative ways in which autistic adults engage with social media while striving for personal autonomy and well-being.

5.1.1 Self-Monitoring. For many of the autistic YAs we interviewed, negative encounters online led to their creating rules that helped them self-monitor their social media usage. One participant explained that they only accept Facebook friend requests if they have mutual friends: "[When I receive a friend request,] I look at their profile first, and I wanna see if they have any friends of mine that I know. So if they have friends of mine, fine. But if they don't have any friends, then I'm not gonna accept it...sometimes I won't [accept friends with mutual friends requests], because I don't feel comfortable" (Participant6). Other times, YAs internalized guidance from others without knowing the reasoning behind the rule. As one participant shared, her rules for navigating social media was based on what her parents had taught her: "I just don't want people to know where I live so [I don't post my address]...I was just told by family members not to post stuff on Facebook, and I just haven't since" (Participant6). While further questioning did not lead to insights about why people shouldn't know where she lived, following the rule was her method of accepting her family's safety guidelines. Other boundary rules included refraining from engaging in online conflicts, disengaging with bullies, blocking individuals who harassed them online, and not giving money to anyone online. However, we did observe that rules were often too simple and lacked needed nuance. One participant shared how they checked the veracity of friend requests: "There's a lot of people that either friend me, but I always make sure the account is legit first" (Participant8). While this was a good rule to follow, the YA checked legitimacy by directly responding to the

Table 1: Participant Descriptions

ID	Gender	Org	Description/Title
Participant1	M	Beta	Facebook user; Part-time job at a grocery chain
Participant2	F	Beta	Facebook/Instagram user; Participates in group work programs
Participant3	F	Beta	Facebook/Instagram user; Participates in group work programs, Part-time job at hotel chain
Participant4	M	Beta	Facebook/Instagram/FaceTime/YouTube user; Participates in group work programs
Participant5	M	Alpha	Facebook/Instagram/Twitter/SnapChat/Badoo user; Part-time job at grocery chain
Participant6	F	Alpha	Facebook/Instagram/Snapchat/Dating Website user; Recently lost part-time job at grocery chain, looking for work
Participant7	M	Alpha	Facebook/Twitter/SnapChat/MeetMe user
Participant8	M	Alpha	Facebook/Twitter/Reddit/Instagram/SnapChat user
Participant9	M	Alpha	Facebook user, currently working an internship
Parent1	F	Alpha	Mother client at Alpha, Facebook non-user, Child diagnosed with ASD, communicates with child's therapist and psychiatrist
Parent2	F	Beta	Mother of a client at Beta, Facebook user
Parent3	F	Alpha	Mother of a client at Alpha, Facebook user
Parent4	M	Beta	Father of a client at Beta, child lives at home, Facebook non-user
Parent5	F	n/a	Nurse who cares for many family members on the spectrum, Facebook user
Parent6	F	Alpha	Mother of client at Alpha, child works internships
Staff1	F	Alpha	Program Coordinator, supervises case managers, conducts workshops
Staff2	M	Alpha	Program Director, oversees staff and programming, works with clients
Staff3	F	Alpha	Adult Support Coordinator, Case Manager, works with individuals age 19-50 years old, assists with job coaching services
Staff4	M	Beta	Case Manager, plans and teaches day programs, works at group-supported employment sites, has son with ASD, Facebook non-user
Staff5	F	Beta	Case Manager, leads curriculum based activities, occupational coach, provides both individual and group training, Infrequent Facebook user
Staff6	F	Beta	Case Manager, Job Coach, leads group and individual sessions, visits jobs sites, Facebook user
Staff7	F	Beta	Relief Staff and Employment Case Manager, leads offsite activities, attends work sites, leads curriculum based activities, Facebook user
Staff8	F	Beta	Case Manager, community employment specialist, works at group-supported employment sites, teaches curriculum, Facebook user
Staff9	M	Beta	Residential Staff, Facebook non-user
Staff10	F	Beta	Assessment Manager, job coordinator, provides employment training and job placement
Staff11	F	Beta	Residential Staff, reviews technology use of residents, works closely with guardians
Staff12	M	Gamma	Site Managers, oversees program coordinators, leads group programs, offers employment and advocacy services
Staff13	F	Delta	Employed at publicly funded private school for students who can't be serviced within the local district

requester about how they knew each other or why they were reaching out. Taking those answers at face value was unfortunately not enough to provide a safeguard.

5.1.2 Impulse Control. Autistic interviewees often expressed difficulties in self-regulation where they felt unable to pause and reflect before posting or responding. One participant ascribed their struggles on social media to their impulse control saying,

"I had tried to follow this girl that I liked, and it was a little much. I realize that now. And she had blocked me. That was the first time I had really been blocked like that. I could probably put up more with it now more

than I could then. But it hurt me at the time that I was being blocked. I'm like, 'This doesn't make any sense.' So I sat there and then I obsessed about that. And that wasn't very healthy either...I have little problems with impulse control. And I don't wanna jump on and make people uncomfortable" (Participant7).

Of those interviewed that struggled with impulse control, many of these individuals found themselves repeatedly facing similar difficult situations. One staff member shared,

"Our clients are able to talk about a mistake they made on social media or an incident that happened. And they're really able to reflect back on it, but they can't

in the moment change that behavior the next time it comes. So it's interesting. A lot of our individuals are very able to talk about their challenges and their disabilities in striking detail. But in the moment of a social interaction or whatever it is, they can't manage those behaviors in the moment" (Staff2).

This struggle against impulse control was common amongst many participants. During our field visits, parents and service providers also were often discussing situations where they had to help autistic YAs trouble-shoot the negative consequences of impulsive behavior. However, when individuals in the support network consistently reinforced principles of self-control, progress could be made. One staff member shared that they teach their clients to pause and assess the situation and say to themselves, "Do I need to have my mentor, my mom or us at the [day facility] look at something beforehand?" (Staff2). With persistent teaching, individuals in the support network felt autistic YAs were moving towards internalizing these rules and self-regulation.

5.1.3 Risk-Coping. Every interviewee had experienced negative interactions while using social media. Indeed, during field visits, it became clear that parents and service providers were at a loss for how to help their autistic YAs; those who used social media had many negative experiences. Some had more coping mechanisms than others. One participant explained how they dealt with bullying and negativity online by simply removing the other individual from their social network: "All I do is unfriend 'em. If they get on my nerves, I just simply block 'em" (Participant8). This blocking technique was commonly reinforced by staff to allow YAs to remove themselves from stressful situations. Other coping mechanisms involved recovery after the YA had inadvertently damaged relationship ties. One staff member described this recovery period for a participant in saying, "She's super intelligent, so it was really about developing, once she was able to get past the, 'They unfriended me and we're not going to be able to change that' part of the therapy, she had to accept that. Then moving on it's coming up with coping strategies" (Staff2). Helping them develop emotional resilience was vital for autistic YAs to deal with inevitable friction online. However, this was an exceedingly difficult outcome to achieve and required a lot of support over a long period of time. One parent observed that "when people that are autistic make a mistake, it takes a long time for them to forgive themselves...they remember, and they repeat that again and again to themselves saying, 'Oh, no. I said that, and that's not right'" (Parent3). One interviewee shared how this constant struggle with impulse-control and risk-coping led them to abandon social media:

"At the end of the day, my mental health is more important. I'm sure people sometimes wonder where I am because I did used to communicate with people who moved out of state and stuff... And believe me, yeah, when all of a sudden I'm gone, people are probably absolutely like, 'Where'd he go?' But like I said, at the end of the day, it's more important that I'm okay because that stuff used to bother me, it used to eat at me. Let's just put it this way. You can drive yourself crazy if you're focusing on that all the time because there's other stuff that, at the end of the day, matters more

than waiting for...worrying about why somebody won't respond or this and that and whatever. Facebook is just not for everybody" (Participant7).

This YA recognized how using social media triggered extreme anxiety as he struggled to regulate his interactions and to interpret the meaning behind other people's (non) reactions online.

5.2 Mediating Social Media Use of Young Autistic Adults (RQ1b)

Upon seeing challenges with self-regulation and impulse control that autistic YAs faced, individuals in their support network were motivated to mediate their technology usage. We describe these mediation strategies below.

5.2.1 Instructive Mediation. Similar to Valekenburg's "Instructive Mediation," we saw that verbal communication was by far the most commonly used. Mediators explained the nuances of distressing situations, provided advice or instruction, and discussed possible solutions with the YA. This manifested in four distinct ways, as described below.

Immediate. This approach involved employing instructive mediation when an issue arose. It was almost always utilized by parents since YAs were typically at home when they used social media. This was regardless of the parent's philosophy on being involved in their child's social media use (a few didn't feel social media was problematic, other parents were deeply involved in the everyday details). One parent explained how they engaged in frequent conversations with their child about being cyberbullied: "He'll get online and so and so is saying this about that, or [insult], Or whatever, and I [tell my child], 'just don't respond to it, just ignore it all and it'll go away. They're just looking to see if they can start trouble or get a rise out of you or whatever'" (Parent4). Here the parent can provide an interpretation of the situation, and give explicit directives on how to proceed. This same parent shared that "He gets an email from [a suspicious source] and he'll get [scam calls]. [He will] mention to us, 'This person keeps calling...' which, I think it was phishing scams and things like that, and, [I said] 'if you don't know exactly what you're talking to or who it is, you don't give them any information'" (Parent4). Because YAs voice their confusion or concern when they encounter a problem, the co-located parent can weigh in right away, sharing specific rules about how to deal with such situations now and in the future.

Delayed. Delayed instructive mediation occurred long after the problematic incident. This approach was widely utilized by staff members who often had clients come into the program upset by something that happened the night before: "[We] encourage [them] to block... and we encourage just shaking it off. They'll come up and find me and show me [bullying on social media]. We have to redirect them. Did you block her? Did you do this?" (Staff5). While damage control was a common form of advice to clients being harassed, several staff explained that this was ineffective: "There's only so much that I can say and so many times I can say the same thing. If you're not going to listen to that, the same thing keeps happening...the verbal's not really helping" (Staff8). Another common type of delayed instructive mediation occurred when clients wanted help interpreting a situation: "I think things get misinterpreted a lot

here...There's another girl [with autism] here, and she'll always [ask me], 'So and so said this...Is that mean?'" (Staff8). While this client sought guidance, the staff member went on to explain that "mostly they'll only show me things if there's some sort of assumption of a problem", where they have decided there's an issue already. In those cases, they turn to staff for advice on dealing with the issue:

"One of the girls always comes in. She'll come in and say, 'I don't understand why she's not answering me' or 'She doesn't want to be my friend anymore and I don't get it. I just want to talk to her, but she's not answering me when I call her, [or] when I message her,' and we're like, 'You have to give her space'. It happens over and over, so it's hard to kind of learn the lesson from it" (Staff7).

This example underscores how staff try to advise on coping skills after-the-fact, but it does not prevent the issue from happening again. Finally, staff also assisted autistic YAs to understand one another:

"[One] girl who was here was showing me texts between [her and my client]. My client was like, 'I'm going to bed, it's like 11:00 at night. Bye'. And the girl was like, 'That's so rude. Why would she say it like that?' So it's like both ways where maybe you don't say 'bye' when you're going to bed, but you don't think that's rude either. So, it goes both ways" (Staff8).

Here, an unexpected use of "bye" by an autistic YA may not have been an issue on its own, but became problematic when combined with the other autistic YAs interpreting "bye" as offensive.

Technology-Mediated. Sometimes autistic YAs wanted to reach out to someone who was not co-located. We especially observed that they reached out to extended family, such as adult siblings and cousins. One YA shared how he reached out to his sister for help: "Well, I just went to message my sister about why [the cyberbullying] happened, and she said, 'Don't worry about that, you still have friends that wanna' be your friend'" (Participant1). Here his sister was able to address his concern despite no longer living in the same household. However, technology-mediated mediation could also be a source of anxiety if the extended family member did not respond right away. One parent shared how their autistic child would "text like three more times like 'Why aren't you answering me?'" when the sibling did not respond immediately (Parent2).

Formal. We observed much interest in online safety sessions by the support networks at our field sites, as well as in the community in general. The more commonly expressed need was around social media education. Because of the issues coming from using social media, various service providers developed structured educational curriculum around online safety. Lessons were accompanied by training material such as visual aides or hands-on activities. We observed one in a series of online safety classes where Beta invited a police officer to teach an online safety course since they felt autistic YAs would be more likely to heed an authority figure than the staff: "It just seems to have a difference when we have an officer explain it, because I think that the guys take it more seriously" (Staff1). Even though the caseworker had planned the whole curriculum, they wanted to make a lasting impression by having it delivered by the officer. While this session was highly memorable (and mentioned

by many staff and autistic YA interviewees), it did not bring about immediate change. One staff member explained that it was part of a long-term plan: "We teach curriculum on [social media]. We've had so many meetings and we're trying to teach it so that it will stick" (Staff7).

While courses were taught to groups of YAs, some occupational therapists engaged in one-on-one education:

"I'll spend most of my time with people reflecting on their journey and all the challenges they've had, and then helping them to look at the things that they've learned and how they apply it, and so that they can have those conversations. When someone says, 'What's your biggest challenge?' They can say, 'I used to really struggle understanding nuances, but I've become a lot better.' They're learning to turn their challenges into positives and to be able to talk about it" (Staff10).

Some harms were addressed by individualized trainings, such as "*Understanding Sexual Abuse Among Individuals with Developmental Disabilities training*" (Staff8), a training specifically for those whose online experienced merited it, while others were more generalized to a group.

5.2.2 Restrictive Mediation. Restrictive mediation consists of measures that physically limit access to social media. We observed that restrictive measures were primarily invoked as a reaction to autistic YAs perpetrating harmful behavior through social media (e.g., irresponsibly giving money, issuing public threats, sharing nude photos, defaming co-workers or employers, and harassing others).

Removing Access Entirely. Day programs and employers commonly banned all phones and technology from being used in their facilities. One autistic employee shared, "*I leave my phone at home [if] I'm working*" (Participant3). Another similarly shared, "*I can't look at it at work because they get upset if you do*" (Participant1). Staff explained how this was an attempt to maintain a professional atmosphere and curb the distraction of social media for employees. When it came to their jobs, autistic YAs seemed very clear about these rules and adhered to them at work. While the day programs also restricted usage to "*during breaks or in emergencies*", YAs did not always follow the rules: "*If they're supposed to leave their phone at home, they'll try to then come in and use somebody else's...whose ever phone it is can get frustrated with the person, saying, 'This is mine. I don't want you using it.' Or just an issue in general, because they're not supposed to be using one, and they're going to outside sources*" (Staff1). Here YAs may technically follow the rule to leave their phone behind, but it does not achieve the higher level goal envisioned by the staff.

Partial Restriction. We saw more nuanced restriction rules implemented by parents at home. A common type of restriction was time-based: "*I know she's only allowed her electronics I think it's from 6-8 or something, for a few hours at night. I don't know that it's strictly monitored, but I know that there is a time gap*" (Staff5). Still others focused on setting boundaries on social interactions. One parent explained that their autistic YA's "*account is private*," and that "*she only has people in her account that we approve of, and if she gets a friend request, she's required to ask us*" (Parent2). While the YA can still fully use social media, the parent restricts who can see and interact with the YA. Other parents opted for limiting the device:

"He doesn't have a smartphone, we won't go that route, but he's got a cellphone" (Parent4). While this addressed inappropriate access on the go, this parent had to restrict usage time at home: *"We've recently attempted [rules about tech use], 'cause he's been staying up too late and he has issues with the seizures if he gets over tired. So, we're trying to say, '10:00 you're done with it'"*. Setting boundaries was a reaction to insufficient self-regulation.

Enforcing restrictive mediation was a challenge. One parent would deactivate her child's Facebook account when the YA started harassing others in her day program, only to find out the YA had gotten around the restriction: *"We didn't even know, as parents. The kids said, 'She has two different accounts.' Because they'd block her, and she's opened another account"* (Parent2). We saw that low digital literacy such as this, was often a barrier for parents who did not grow up with technology and many times did not even have a social media account themselves. Another mother would take away her daughter's devices when there was inappropriate online behavior: *"[W]hen those things happen, then she loses [access to her devices]...she can't use them at all, and that tortures her,...but that's what we have to do. So she'll lose them like, for two days and that's like, torture"* (Parent2). An unintended consequence of this was that her daughter later shared with her caseworker an unsafe social media incident, but begged the caseworker not to tell her mother since she believed her technology would be taken away. While the mother's use of restriction removed an immediate source of danger, it had unintended consequences for the transparency between parent and child.

5.2.3 Passive Monitoring. Adult mediators sometimes chose to monitor social media accounts in order to detect problems before they occurred, or to check when they had reason to believe there might be an issue. Interviewees spoke about two types of monitoring.

Manual Inspection of Social Media Use. This approach was used by almost every parent, as well as some family members. They monitored social media activity by actively following the YA's posts on social media, or physically taking the device and looking through messages or posts. Several parents did this ad hoc, checking *"periodically...I'll look every now and then"* (Parent3). Most would check when a problematic incident had occurred offline or they were tipped off: *"I would get an email or a call from [someone], or something like that"* (Parent2). Once notified, she and her husband would start to look at the group chats to understand what was going on *"until it settles down"* (Parent2). While this did not prevent issues, the family could directly observe what was happening and give specific feedback on potential solutions. These parents also were much more in tune with the stressors and dangers their YAs face.

Some mediators were much more proactive. One staff member, who was also a sibling, would often look through her autistic brother's phone *"just if he [leaves] it out"* explaining, *"When he's bored he's just on his bed just scrolling through and messaging girls the exact same thing over and over. 'Get you coffee.' Like that's his favorite line...there might be some girls that will jump at it and be like, 'Oh, this guy is going to get me a free coffee' or whatever"* (Staff 6). She further explained her concern for him and his financial well-being: *"He has had girlfriends that just want his money. And even though*

he doesn't make a lot, he's on Social Security, but they know when the first of the month is and they'll hang out with him those times [but not later in the month]." She offered that *"he doesn't care [that I'm manually monitoring his phone] so it's not like I'd be sneaking to look at it"* (Staff 6).

Manual monitoring was reportedly used by staff at residential facilities where it was part of their care-giving duty. Staff at a day program observed, *"At residences it seems to be more regulated, whether it even is just staff checking in to say, 'Hey, what's going on? What are you doing?' Kind of thing, because staff are required to know what individuals are doing in the house"* (Staff 1). This staff member went on to observe that autistic YAs who live at home get into more trouble because, *"[they] have more freedom for using either computer or iPads or their phone, where at residences, it seems to be more regulated"* (Staff 1). Monitoring in residences was regular and systematic. Instead of reacting to dangers, monitoring was preventative which seemed to curb unsafe online behavior early.

Software-Based: Unused but Desired. While no one reported using software-based monitoring, some mediators really wanted to have software that could monitor and help YAs remain autonomous while protecting them from phishing, sexual predation, and cyber-bullying. One parent wanted *"something that [they] could have on social media, an exclamation point would come up or something [before posting], something that they would see that would maybe question them [and give them] pause"* (Staff2). Similar to other suggestions, this solution could help strike a balance between autonomy and privacy.

5.3 Boundary Tensions between Autistic Young Adults and their Support Network (RQ2)

After identifying the types of technology mediation employed by adults in the YA's support network, we drew on Petronio's Communication Privacy Management theory (CPM) to explore what boundary turbulence may result from such mediation. When a mediator becomes aware of information posted on social media by a YA, they become co-owners of that information with the YA. This means they (perhaps implicitly) take on the joint responsibility for defining rules around how that information should be used and shared. Boundary turbulence can result when co-owners perceive different rules and/or those rules are violated. Here we share when/how mediators become co-owners, how rules are established, and the resulting boundary turbulence. We saw from our field notes that support networks very much realized that they were co-owners of autistic YA's social media content, but struggled to understand how they should best mediate social media usage to keep YAs safe.

5.3.1 Becoming Co-Owners of Private Information. Here we describe how co-ownership was triggered when (1) the YAs invited individuals in their support network to weigh in, (2) a parent is informed by someone else about something problematic online, and (3) the autistic YA's account is proactively monitored by someone in their support network.

The most common trigger for co-ownership was when YAs asked individuals in their support network for help. They often sought instructional mediation or emotional support, and felt very comfortable sharing their private information openly with many in their

support network. One caseworker explained that for *"the most part, my caseload's very open with me and comes to find me and just tells me"* regardless of whether the YA's actions would be seen as appropriate (Staff8). This openness with parents, staff, and siblings was a common refrain amongst interviewees. Autistic YAs explained that their mediators *"are the only one[s] that would listen,"* (Participant1) and that *"they help me out a lot"* (Participant4). Similarly, an autistic man shared a lot with his brother because *"[they're] real close"* (Parent4).

In other cases, mediators became co-owners when notified of an issue by someone else in the YA's support network. Friends, siblings, therapists, psychiatrists, occupational therapists, caseworkers, and other autistic YAs were the source of notifications. Most often, the parents were notified. Occasionally the caseworker or other staff members were notified by *"the family"* in hopes that issues could be addressed in their social skills programs (Staff7). One parent described how this relieved a lot of the burden. His wife was *"friends with enough people that we don't have to watch it, 'cause we would be alerted to something that popped up if we weren't on regular checkups"* (Parent4). We observed many instances where parents were notified by others regarding an issue their autistic child was facing online.

However, the most effective approach for keeping autistic YAs safe was when parents or siblings in the YA's support network become co-owners by proactively manually monitoring, sometimes in conjunction with the previous two methods. A parent described how her autistic daughter will post *"something that the girls, like my other daughters, feel is not appropriate, they'll pick up the phone and they'll call her. ...get that off right now"* (Parent3). Their sister would heed their advice. This was also helpful in cases where mediators did not try to change the autistic YA's behavior. One YA described how he messaged and then called his sister to understand an online situation: *"[She] answered and she said that, 'I see you have a problem with somebody,'"* (Participant1). She was able to help her brother process the incident in part because she had already been manually monitoring his social media. He regularly invited his sister to be a co-owner and turned to her for advice.

5.3.2 Creation of Privacy Rules and Setting of Privacy Boundaries. Once individuals in the support network became co-owners of information posted by an autistic YA, we observed that it was always the mediators who would establish privacy rules. Often it was through instructive mediation: *"[I] would say to [my autistic son], 'you can talk about yourself, but you can't talk about other people on Facebook. It's not appropriate'"* (Parent1). Whether YAs agreed and accepted those rules varied tremendously. Parents and staff felt it was not so much a matter of disagreeing, but of remembering and being able to recognize that they were posting the same type of information where the same rule should be applied. A mother shared how she knew her daughter was finally adopting some of these privacy rules because she would say, *"I was going to post something, mom, but I decided not to because I don't think that I learned my lesson"* (Parent3). Here we see that this YA accepted the privacy rules proposed by her mother, recognized that it was a situation where those privacy rules apply, and decided not to engage in that online activity because she still needed time to develop her socio-digital skills. Overall, parents seemed to be more

successful in setting privacy rules that YAs would agree to than staff; they felt their efforts were futile. This could be due to staff opposition to getting *"too involved with what constitutes appropriate behavior online"* (Staff8). Rather, they only mediated retroactively when approached by the YA, which is less effective than proactive mediation.

While many mediators used instructive mediation to set privacy rules, others stepped in to enforce rules without the YA's input: *"I was going through a panic attack that day...and I didn't know what to do...So, I kind of had to get my mom involved. My mom said, 'no contact between both of them for a while because I don't like the way you treated my son...'"* (Participant5). One staff declared, *"if I hear about [problems on social media], I'll stop it, immediately intercede"* (Staff4). Another parent established a process for such intercession with her daughter: *"She knows now if someone says something, in social media or in person, to get a job coach or [someone] in charge, and discuss it with them. She's not to handle it herself"* (Parent2). Given the harm and risks that many of their autistic children faced, intervention was their preferred option over risking things going terribly wrong.

5.3.3 A Unique Approach to Boundary Turbulence: Privacy, Independence, and Restriction. The most striking observation was that autistic YAs seldom resisted co-ownership of their data and rather sought outside advice and were accepting of mediator's suggestions and enforcement of privacy rules. Turbulence was instead traced to restrictive mediation and fears of losing access to social media. One mother shared that her mediation strategy of closing social media accounts when her autistic YA was sending messages others perceived as hurtful was ineffective. If *"you shut down her Facebook, she'll open another one,"* thus denying her mother of co-ownership and making it difficult for her to mediate (Parent2). Such restrictive mediation often led to YAs avoiding co-ownership with their parents. One parent had to be persistent to find out about a troubling incident online since her daughter feared she would *"tell her to give it up"* (Parent1). A staff member similarly shared that her restrictive mediation made open dialog difficult. She explained that YAs at Beta were *"not communicating"* about the issues they were facing online, *"probably because I'm overly controlling of it"* (Staff10).

Instances when restrictive mediation was not used were conducive to co-ownership, perhaps because these autistic YAs did not have the same privacy expectations as their neurotypical support network. Rather, privacy expectations were externally valued by mediators and taught to autistic YAs. One mother would correct her daughter *"every once in a while"* not to post certain things (Parent2). *"That's private. You don't really have to tell everybody that."* Similarly, staff had difficulty explaining that other people have privacy boundaries, such as when taking a picture, *"other people in the background, those people aren't giving permission to have their picture... it's hard to really explain it"* to autistic YAs (Staff1). Even in describing appropriate content to post, one autistic YA described how she doesn't *"post about [friend], me, and a lot of different stuff that's private between us, and I don't want [that person] to get mad at me about it"* (Participant4). The reason for not posting private information was not internally driven, but externally driven by not wanting to upset her friend.

In fact, mediators were much more concerned about boundary turbulence because they felt YAs were not establishing appropriate privacy rules independently and so mediators needed to be continually involved. Yet, being involved as co-owners of what YAs post was a lot to add on top of the *"exhaustion"* that parents of autistic YAs feel from all that they need to do to care for their YA: *"The last thing they can do is monitor [their] young adult on social media"* when their child has so many other needs and is technically an adult (Staff2). The staff member continues to explain that *"even if they're a very organized parent"* who would be willing to monitor the account, they may not because they are *"just trying to respect their child's adulthood because they're going through a very difficult time in their life and they want to pick their battles."* In fact, he asserts that taking *"their kids off social media completely"* would be simpler, but unrealistic in the long run. This staff member similarly explains:

"...because the goal is really, I think, to help them live independently. And, you know, ... what I hear a lot is just, the parents are really worried, you know, because they're kind of the ones who have to monitor or, you know, intervene. And then especially as they get older... the underlying thought is, oh, my goodness, what's gonna happen when I'm not around and my adult child still has to deal with these issues, you know, how is that going to happen? And even just when they are still around, it's, you want them to live independently" (Staff13).

This concern was overwhelmingly expressed by parents in every aspect of the autistic YAs lives, not just social media.

Staff felt a different tension in being unable to establish privacy rules despite being exposed to private information:

"As far as my other client who meets men a lot online, that's really hard because she's very high-functioning, but she still has an intellectual disability that seriously prohibits her range of thinking. So I would never want her to have restricted access online, but I also want her to be safe all the time. So it's hard to find that balance. Because she lives with her parents, I feel that's more of her parents' responsibility to be teaching that at home as well. Because we're told here for the most part that this is a workplace, so I wouldn't go to work, and work wouldn't lecture me about social media" (Staff1).

This caseworker recognized the trade-off between online access and safety, but felt that becoming a mediator would violate a professional boundary.

5.4 Positive Outcomes from Mediation (RQ3)

While we observed boundary turbulence, we also found several benefits of mediation. We describe them here.

5.4.1 Collective Ownership Reinforces Safety and Mediation Efficacy. We observed that each position within the support network offered unique capacities, strengths, and limitations. While parents tended to be the most accessible in the support network and hold the most authority to teach and mediate good use of social media, they also tended to be the least digitally literate and have the least amount of bandwidth to mediate. On the other hand, staff members were often proficient in using digital technologies and were often uniquely

privy to their clients' online, private information. However, even when they were invited to become co-owners and co-managers of their clients' private information, they did not feel they had the authority to mediate. The siblings were not usually co-located, but provided extra support to their parents in mediating and to their autistic siblings in social situations. Their mediation methods were well-received.

Generally, the most effective support networks were the ones who acted collectively to support the autistic YA's online behavior. For example, one case worker described how *"reinforcement's one of the main routes we go through because... it's really hard to address in the moment. But stuff like team meetings and where families are involved...If there's issues with residents where there's a plan where they need to know... once they're not here for the day program anymore, it's kind of out of our hands"* and up to the family to reinforce at home (Staff1). This case worker recognized that support needed to continue at home and so family involvement is key to aligning mediation strategies since they are more readily available when YAs used social media. Service providers and siblings who were often more tech savvy realized they could help parents become aware of risks and know how to deal with them: *"A lot of parents are older, so I feel like maybe they aren't really aware of what actually goes on. They kind of know but-they don't really, know. And that's scary, too, because they can't help if they don't know"* (Staff6). This, in turn, even increased digital literacy for YAs who learned from their parents at home and staff at day programs. By leveraging the unique strengths of each member of the support network, they were better able to keep autistic YAs safe.

5.4.2 Helps with social emotional co-regulation. A benefit of having the YA's support network monitor their social media account is that they are more aware of how the YA is feeling and can offer emotional support. One autistic YA felt more comfortable expressing difficult feelings online. A parent shared how *"sometimes if she's depressed or something, she may just say certain things like, 'If you're feeling down in the dumps, and you're . . . I don't know, some things like that. 'Let me know if you're feeling the same way,' ...I think she puts her feelings out there because she knows that she can now"* and her support network will see it (Parent3). Another parent emphasized that the autistic YA's connectivity with his sibling helps *"when he's got a question"* (Parent4). Even when not explicitly moderating social media, siblings were often reported to be places of support to just talk about challenges being faced on social media and offer consolation.

6 DISCUSSION

6.1 Balancing Caregiver Mediation with Self-Regulation of Social Media Use (RQ1)

Our findings indicate that autistic YAs struggled with intuiting appropriate and safe behaviors on social media. However, even when they did understand online social skills, they still struggled with impulse control. Thus, approaches such as Applied Behavior Analysis, which focus on incentive-driven and intentional behaviors, would not help them navigate such impulsive behavior online [67, 94]. Instead, we recommend teaching mindfulness and coping

skills for when impulsive behaviors inevitably occur [14, 51]. This could allow autistic YAs to gain more self-control [24, 117].

While mediation did help autistic YAs stay safe, a combination of methods must be used. Passive Monitoring combined with Instructive Mediation was the most effective combination that we observed. Moreover, autistic YAs often exhibit Pathological Demand Avoidance (PDA) [76], which necessitates declarative language and positive (rather than restrictive) parenting approaches. Thus, when engaging in instructive mediation, it is important for mediators to make statements about what the autistic YA will do to address issues. Leaving it open-ended would be ambiguous. Such mediation also needs to happen when autistic YAs are not in defense mode, shut down and unable to hear what others have to say since they are too overwhelmed [103]. They need to be regulated and ready, in other words, in control of their emotions and ready to listen [75].

6.2 Balancing Tensions between Promoting Autonomy and Needed Support (RQ2)

We saw a marketed difference in boundary regulation between autistic YAs and their adult mediators compared to what the adolescent online safety literature has consistently found between teens and their parents [34, 54, 124]. Unlike teens from prior studies, autistic YAs often had very open boundaries and communication with their support network, especially when a problem arose on social media. In contrast, teens often fought for their privacy and evaded their parents' oversight. Teens and autistic young adults only converged at the point when sharing about their online behaviors meant getting punished. In these cases, autistic YAs also closed their privacy boundaries to their adult mediators as a protective mechanism. A key take-away from these comparisons is that autistic YAs are not the same as teens and should not be treated as if they have the same developmental needs as younger neurotypical youth.

The challenge, therefore, lies in finding a nuanced solution that transcends the binary choice of either permitting unrestricted use or prohibiting it altogether. In terms of *who* provides support, our findings indicate that autistic YAs were relatively open about accepting support, but with a preference for positive support that facilitated joint troubleshooting [74]. However, it was crucial for this support to be constructive and devoid of criticism or punitive measures. Instances where support was declined typically revolved around autistic YA's anticipation of negative consequences, such as getting into trouble or losing access to their devices. The timing of support emerged as a pivotal factor. Proactive teaching of boundary regulation best practices and in-the-moment assistance when boundaries were violated were found to be the most effective approaches. Transparency was highly valued, and tension arose primarily when autistic YAs felt that support was driven by punitive motives. While privacy boundaries were not a motivating concern for autistic YAs, we observed that cases of overprotective support treating autistic YAs as children hindered the promotion of self-regulation and autonomy. In some cases, co-owners wielded excessive power, further exacerbating the imbalance.

The *how and what* of boundary rules were often shaped by the support network rather than by the individual, except in cases where individuals in the support network adopted a hands-off approach, leaving the responsibility solely on the autistic YA. Our

observations revealed that mediation strategies varied between being reactionary and preventive. Some strategies served as immediate responses to online incidents, while others concurrently mitigated future conflicts. This duality highlights the complexity of balancing autonomy and support in the context of social media use by autistic YA. In summary, addressing the complexities surrounding autonomy and support in the realm of social media use by autistic YAs calls for a multifaceted approach. It necessitates the provision of constructive and positive support, aligned with autistic YA's preferences for joint troubleshooting. It also demands a shift from reactionary to proactive mediation, emphasizing transparency and respect for autistic YA's autonomy. Striking the right balance is essential to ensure that the rewards of social media use are harnessed while mitigating potential risks effectively.

6.3 Implications for Education, Training, and Awareness

In light of our findings, several implications for education, training, and awareness emerge, aiming to foster a healthier and more autonomous approach to social media use among autistic YAs. Firstly, there is a pressing need for a more formalized educational curriculum, designed and delivered by experts, to equip autistic YAs with essential skills for navigating social media platforms effectively. This curriculum should encompass not only technical aspects but also address the interpretation of social cues, a vital component of online interactions for autistic YAs. The emphasis should be on preventing future conflicts by providing participants with the knowledge and resources necessary to identify and handle suspicious online encounters independently. Collaborations with professionals who are perceived as authoritative to teach courses on online safety can greatly increase acceptance by the YAs and be instrumental in achieving this goal. Current internet safety courses taught by these organizations do not focus on social media.

Additionally, education and training should not be confined to one-time interventions but should extend to on-going, contextualized support. Regular, short sessions (e.g., half an hour per week) can help autistic YAs address in-the-moment issues and reinforce their skills continually. This approach aligns with the need for practical, on-demand support, considering the busy and often stressed lives of autistic YAs. Furthermore, parents play a crucial role in supporting autistic YAs in their social media use. As some studies have shown, including parents in joint training sessions and educational programs have improved generalization and maintenance skills for individuals in the support network [48, 49]. Our results similarly point to how parents could make a more lasting impression on autistic YAs. To facilitate a positive and autonomy-driven approach, parents should receive training in digital literacy and positive parenting strategies tailored to this context. This training could include a class that autistic YAs could take with their parents to help create joint understanding on their boundaries. Courses should be easily accessible and user-friendly, acknowledging the demanding schedules and responsibilities that parents typically contend with. Given the limited technical expertise of many parents in navigating social media, they should be provided with resources and guidance, rather than being burdened with the responsibility of creating or teaching formal curricula. Recognizing the fatigue experienced by parents

in mediating their children's social media use, it is imperative to explore avenues for offloading some of this responsibility. Other studies have shown that increasing parent education can reduce anxiety, improve coping ability, and increase quality of life [85], although it can be difficult to implement [21]. Allocating resources for expert support personnel within organizations can help distribute the caregiving load more evenly and provide parents with much-needed respite.

Finally, the concept of the proverbial "village" becomes especially pertinent. Engaging the entire support network, including staff, extended family, and friends, in the constant monitoring of autistic YA's social media activities can create a more comprehensive safety net while also more effectively handling stressors for the family [115]. Collaborative efforts across various stakeholders can help address the unique challenges posed by the intersection of autism and social media, ultimately promoting a healthier, more autonomous digital experience for autistic YAs.

6.4 Implications for Design

Our results reveal design opportunities to empower and assist autistic YAs by both supporting their self-regulatory needs and helping their support networks collaboratively mediate when extra support is needed.

6.4.1 Designing to Empower Autistic Young Adults by Supporting Self-Regulation. Our autistic YA participants often turned to their support networks when they needed help interpreting and contextualizing nuanced social cues (e.g., sarcasm, anger, concern), struggled with impulse control, or when boundary rules for appropriate behavior on social media were not clear cut. Yet, it is possible to use technology to support some of these needs in ways that offer more independence to autistic YAs so that they do not have to rely so heavily on their support networks. For instance, some autistic YAs have found recent developments in large-language models and conversational agents (i.e., ChatGPT) critical in disentangling nuance in neurotypical communications and providing practical support and advice [42]. Similar to this premise, designers could develop social media features that help autistic YAs take into account multiple contextual cues when interpreting content or deciding on their course of action. Importantly, such features would need to be non-judgmental and non-prescriptive – suggesting possible courses of action and helping autistic YAs weigh the trade-offs of different decisions, while using declarative (e.g., "you could...") instead of imperative language (e.g., "you should...") that supports executive functioning [38]. Similarly, automated approaches, which detect emotions such as sarcasm (e.g., [95]) could be utilized to help autistic YAs understand the intent of a message, although further development of such tools would be required to account for differences in communication style based on culture or even neurodivergence itself.

Alternatively, designers could support autistic YAs by supporting their stated struggles with impulse control. For instance, researchers in other contexts have designed visual cues to curb impulsivity [4], wearable technologies to help improve emotional regulation [119], as well as impulse control interventions that rely on the assistance and cooperation of others [22]. Furthermore, research in the autism community [46, 116] found the use of self-monitoring videos as

a feedback mechanism helped increase autistic individuals' self-awareness, which fostered a stronger sense of independence in their daily lives. Moving forward, designers could help by designing to encourage autistic YAs to pause before acting. This might take the form of detecting emotion-filled messages (e.g., characterized by anger, anxiety, or frustration) and prompting to have them take a break or talk to a person in their support network before taking an action they may later regret [112]. Beyond social media features that foster independence, other researchers have advocated for social media platforms and other collaborative support tools specifically designed for autistic users to improve their life skills and facilitate a collaborative and distributed care network that can help them build agency as they transition into adulthood [40, 58]. Similarly, we advocate for sociotechnical support tools that allow autistic YAs to safely and meaningfully navigate social media with *and without* the help of their support network.

6.4.2 Designing for Collaborative Mediation to Facilitate Support and Allyship. While designing to assist in self-regulation is important, the complexities of navigating social interactions cannot be fully addressed through self-regulation alone. As is the case for their offline social interactions, autistic YAs desire support from their network on interpreting and contextualizing their online interactions. Our research aligns with findings from previous critical disabilities studies in other contexts [120] where allyship is crucial to enabling access. Namely, the support network plays a key role in enabling access for autistic YAs. Moreover, our research uncovers that this allyship must extend far beyond the allies often identified in prior research and, instead, include a much larger pool of allies (i.e., parents, adult siblings, extended family, and service providers). The intense need for caregiving and support requires a village to lighten caregiver burden and to take advantage of the unique strengths of various individuals in the support network. Parents can provide consistent, personalized support and reinforcement over time and are the ones who are around when autistic YAs are using their social media (usually at home). Trusted relationships with siblings who are less likely to take punitive actions and who are more technically savvy are vital to getting actionable advice. Finally, service providers are more likely to see offline cues that something is going wrong and have a larger understanding of the social context since they work with many of the individuals with which the autistic YAs are interacting on social media. These various perspectives and strengths combine to create the support network.

Given the importance of this constellation of individuals in the support network, we urge designers to consider how to go beyond supporting parental mediation of children and teen's technology. For example, Facebook, Messenger, and TikTok have all recently released ways for parents to mediate their teen's social media usage [1, 2]. Some of these features are extremely useful in the context of young autistic adults: seeing who is on the friends list can allow support networks to assist in discerning bad actors. Yet, most existing parental control software is designed for younger children [50, 70], which may unintentionally infantilize autistic YAs and, therefore, be unsuitable for this population. In addition, a majority of families with autistic YAs have not had any experience with

control software specifically designed for neurodivergent or cognitively disabled individuals [87]. Therefore, we recommend that designers create online safety software that is tailored to the specific needs of autistic YAs. One way to do this would be to conduct co-design sessions with autistic YAs and their parents to conceptualize needed features and privacy mechanisms for encouraging autistic YAs to self-regulate, but give them reassurance that their parent or guardian is available to help when needed. Importantly, this active monitoring should not be used to police or punish autistic YAs, as we saw this often led to the most boundary turbulence between autistic YAs and their parents.

Features around monitoring and limiting screen time on a teenager's app follow a more paternalistic approach and may even result in autistic YAs rejecting to use these types of apps because they perceive them as punitive and restrictions on their autonomy. Rather, we advocate for designers to provide features that facilitate easily connecting YAs with their support network to trouble-shoot together. For example, often context of what was said earlier in a conversation is needed for an ally to help the autistic YA interpret a given message. Service providers could provide more relevant advice when autistic YAs show them their phones and asked for help trouble shooting. Technologies could be designed to magnify the support network's ability to help. One design could be to facilitate remote support by enabling autistic YAs to send whole segments of conversations and other relevant information along with a query to siblings and close family members who are not co-located. To help autistic YAs and support networks be alerted to situations that require attention, researchers could explore automated risk detection methods [3, 5, 88]. While these methods should not be the only mechanism for identifying issues, they could potentially alleviate some of the burden of constant monitoring as well as assist when support networks are less aware of online risks themselves.

6.5 Limitations and Future Research

We focused on a population of autistic YAs living with their parents, attending day programs, and in need of substantial support in their daily lives. Therefore, our findings should not be generalized to other autistic YAs, who may have different needs. Future research should study other autistic YAs given the enormous diversity of individuals on the autism spectrum. While we were able to identify a number of mediation strategies, triggers for co-ownership, and sources of boundary turbulence, our assessment of their effectiveness should be treated as a starting point and future research should probe more deeply on these mediation tactics and the associated outcomes for additional groups of participants. Future work could more systematically examine effectiveness of the different types of mediation as our study is exploratory in nature. Furthermore, future research should investigate mediation in different cultural and sociopolitical contexts, as the social norms and laws for supporting autistic YAs can vary across these contexts.

7 CONCLUSION

A key struggle within the autism community is when to advocate versus when to empower autistic YAs to be independent, especially when they may require significant support in other aspects of their lives. Overall, our position is that there is an opportunity to educate

families (i.e., both autistic YAs and their parents) on appropriate social media use, as well as when to hold on tight versus when to let go. However, a prerequisite to this transition into adulthood is the need for formal training programs that disambiguate the social nuances of technology-mediated communication, as well as meaningful redesign of social media platforms to cater to the unique needs of autistic users. Until then, autistic YAs will continue to benefit from joint troubleshooting on how to properly regulate their social media boundaries with the support from their extended support networks.

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A AUTISTIC YOUNG ADULT SELF-REGULATION STRATEGIES CODEBOOK (RQ1A)

Table 2: Wisniewski et al.'s TOSS Framework

TOSS Dimension	Description	Exemplar
Self Monitoring	Creating rules to behavior to direct actions online.	<i>"Now, like, when a guy friend requests me, I don't accept it, because sometimes it could be ... you know, because I already have a boyfriend."</i> (Participant 3)
Impulse Control	Using knowledge of past experiences and previous mediation to create impulse blockers to improve online experience.	<i>"So I immediately blocked her. I told my mom."</i> (Participant 4)
Risk Coping	Creating patterns to calm strong emotions and gain resilience towards online stressors.	<i>"I actually went out for a walk and it calmed me down right away because those people that are just, they don't wanna be your friend."</i> (Participant 1)

B ADULT MEDIATION STRATEGIES CODEBOOK (RQ1B)

Table 3: Valkenburg Parental Mediation Framework

Mediation Strategies	Codes	Description	Exemplar
Instructive	Immediate	Immediate verbal assistance in the moment of need.	<i>"We'll be sitting at the dinner table and his phone's just binging, binging, binging, binging, and she just won't quit. So we'll kinda counsel him on how to handle it." (Parent 4)</i>
	Delayed	Providing verbal instruction, explanation, and counseling after the problematic situation.	<i>"She has this weekly check in with her life coach. They talk about it a lot. We've got a good enough relationship where I can kind of be, I speak brutally honest." (Staff 2)</i>
	Technology-Mediated	Using technology to seek help from those who were not co-located.	<i>"So I called [my sister] and she answered, and she said, 'I see you have a problem with somebody,' and I said, 'Yeah I do. I don't know how to get out of it.' Then she said, 'Maybe it's just that they don't wanna be your friends, you know?' And I said, 'Oh, okay.' " (Participant 1)</i>
Restrictive	Formal Education	Curated curriculum, workshop, or activities hosted by day facilities to formally teach online safety.	<i>"We do run our own curriculum groups on that to focus on bullying and cyberbullying, but we are planning on having police officers in and also explain it." (Staff 1)</i>
	Partial Restriction	Rules that place partial restrictions on technology access.	<i>"Well, she has to put her stuff in the kitchen counter when she's not using it, so we know she doesn't have it...She has an area that she hangs out, and she doesn't have access to internet so she can't do Facebook on her computer." (Parent 2)</i>
	Absolute Restriction	Rules that prohibit technology use.	<i>"She's not allowed to have her phone out when she's here. She's supposed to be offsite being busy." (Staff 5)</i>
Passive Monitoring	Manual	Manually checking social media accounts to verify behavior is safe and appropriate.	<i>"Most of the stuff that I see that she posts when she does are okay. Just every once in a while I have to maybe say to her, 'That's private. You don't really have to tell everybody that.' " (Parent 3)</i>
	Software	Using software to notify a social network about potential issues online.	<i>"I'd love to be able to actually go and look and see what their activity looks like or see how these people friended them, and how they got them into these dangerous situations or, just to understand how can we detect these situations, and what types of situations should we be triggering." (Parent 5)</i>

C BOUNDARY TENSIONS AND CHALLENGES (RQ2)

Table 4: Boundary Tensions Themes

Themes	Exemplar
Co-Ownership with Network	<i>"Mostly friends or family, like with my mother or my dad, or with some relatives of mine, like aunt, uncle or cousins"</i> (Participant 9)
Privacy Rule Creation	<i>"Because usually if it's a picture that I posted of [my girlfriend] and me, and they say something rude about it, I just type onto it and say 'If you don't like it don't say anything.'"</i> (Participant 4)
Privacy Boundary Assertion	<i>"If it's something that's not nice, and has to do with bullying, I don't say a word. My fingers are off the phone."</i> (Participant 3)
Boundary Turbulence	<i>"Yeah. So I look at her phone and like my nephew, who's, you know, he's we just had to finally take his device away from him, because he was the one that was kind of addicted to the number of friends he could get on Facebook. "</i> (Parent 5)

D BENEFITS OF MEDIATION THEMES (RQ3)

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Table 5: Benefits of Mediation Themes

Theme	Exemplar
Collective Ownership	<i>"Oftentimes, what we will do is we'll sit down in a meeting with the teacher and the parent and maybe a counselor...[and have] a meeting to talk about like 'How How can we present this to the student? How can we share that this is an this is unexpected.'...And then come up with a plan going forward to sort of help teach that student what is expected of them and sort of help them troubleshoot through that."</i> (Staff 13)
Social emotional co-regulation	<i>"I was going through a panic attack that day because I was thinking of other things like Facebook, this and that and that got me under a lot of stress and I didn't know what to do. I didn't know how to react to that. So, I kind of had to get my mom involve"</i> (Staff 8)