# Understanding the Needs of Siblings of Autistic Individuals and the Role of Online Community Support

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People with autistic siblings often serve as informal caregivers from an early age, and might anticipate taking on a primary guardian role in the future. What are the unique needs of siblings, and what can be done to better support them? Could an online community help? This work aims to understand the experiences of people with autistic siblings through 12 semi-structured interviews with adults, and suggests designs for an online community tailored to them. We find that siblings' lives have three primary phases: living at home with their autistic sibling, living independently, and potentially taking on a role as primary caretaker for their sibling. We focus on adults in the middle stage, who reflect on past and current support needs. A key challenge for community support environments is understanding how to allow an appropriate amount of venting, but prevent members from feeling overwhelmed by negativity. We present design recommendations for a lifelong online community that supports neurotypical siblings in balancing their personal identity with their evolving role as a caregiver, through life-stage sensitive and emotionally supportive interactions. Understanding the need for life-stage sensitive support in this demographic may provide insights into the need for life-stage-differentiated design for other groups.

CCS Concepts: • **Human-centered computing → Empirical studies in collaborative and social computing**.

Additional Key Words and Phrases: Autism, Sibling, Online Community

**ACM Reference Format:**
Hannah Ward, Rohan Kashi Viswanathan, Amy Bruckman, and Jennifer G. Kim. 2026. Understanding the Needs of Siblings of Autistic Individuals and the Role of Online Community Support . *Proc. ACM Hum.-Comput. Interact.* 10, 6, Article CSCW182 (October 2026), 24 pages. https://doi.org/10.1145/3817030

## 1 Introduction

> *I guess I also want to find community. Because I know parents often seek for community and they talk to people, and they they meet up with people who have kids who are neurodivergent… And then when I talk about the situation, I sometimes wonder if I'm making it about myself? Because it shouldn't be about myself, because it's about my brother. Right? -P5*

In raising someone with autism, parents, grandparents, or other trusted adults are often the primary caregivers. However, an overlooked group of contributing caregivers are siblings who both grow alongside and provide care for their autistic sibling throughout their life. From a young age, siblings

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ACM 2573-0142/2026/10-ARTCSCW182
https://doi.org/10.1145/3817030

often watch after their autistic sibling while their parents are gone, prepare meals for them, befriend them, and comfort them [27], and later in life may become full-time guardians when their parents are no longer able to. Having a lifelong responsibility of taking care of their autistic sibling comes with a lot of different emotions, and neurotypical siblings often do not share these feelings, fearing they might create an unnecessary burden on people around them [59]. Instead, they think to themselves that they "shouldn't be having" these feelings [21]. Neurotypical siblings long for community with other people who have siblings with autism [3] and they need outlets to share their emotions with others who better understand their situation.

Online support communities exist for both professional and informal caregivers to help alleviate stress, frustration, and guilt they feel [8] due to a balancing of roles that occur between their personal and caregiving tasks [19, 24]. One way caregivers use these online communities is through venting, and this helps them feel a sense of calmness by expressing emotions during a difficult situation [8]. Caregivers also use these communities to socialize and build relationships with others who are experiencing similar situations [1, 4, 5], as well as to access resources and advocate for the needs of those they care for [1]. While there are similarities that can be drawn between the experiences of an informal caregiver and someone who takes care of their sibling with autism, one key distinction separating them is the timeline of care for siblings. Siblings start caregiving from a young age, and this role can continue for the rest of their life. Gaps in information about their sibling's life can contribute to worry for the future for both themselves and their autistic sibling. This calls for a lifelong community that changes with the needs of neurotypical siblings throughout their life.

In this research, we explore the experiences of neurotypical siblings who serve as informal caregivers and how they use an online platform for support and community with others. We aim to uncover design elements for online communities that meet the desires and needs of neurotypical siblings. To investigate this, we interviewed 12 people who have siblings with autism. Participants in our study describe their relationship with siblings who are verbal but require support with daily life activities, suggesting that our study findings may not represent the experiences of all autistic siblings. We find that our participants' experiences fall into three distinct phases: living at home with their sibling, living independently, and later potentially taking on primary caregiving responsibilities for their sibling when their parents are no longer able. This study focuses on people in the middle stage: living independently. In this middle stage, they are able to reflect back on their needs at a younger age, and also share their questions about how they will fill their possible future role as primary caregiver. We discuss the implications for creating a lifelong online community, and how it can be made more positive and engaging.

## 2 Related Work

The existing literature documents the experiences of professional and informal caregivers and online community design recommendations for this population. We build upon this literature by talking about these existing designs, and applying them to the experiences of people with autistic siblings as they are seldom recognized as informal caregivers.

### 2.1 Online Support Communities for Caregivers

Being a caregiver either professionally or informally has tremendous effects on an individual's physical, emotional, and social self [8, 53]. There are often tasks other than the standard medical ones in caregiving, such as maintaining the patient's quality of life or emotional support for the patient, and caregivers feel a sense of obligation to complete these tasks since it contributes to their patient's care in some way, but this is often done at the cost of their own lives [8].

Many caregivers have familial tasks on top of their caregiving role, making it difficult to manage these different demands. This can result in *role conflict* where their tasks outside of caregiving directly conflict with their tasks as a caregiver [17]. This conflict can lead to *role strain* where the demands of one of their roles ends up not being met [16]. Informal caregiving often involves a person taking care of their parent, child, or spouse, and the caregiver may often feel a conflict between their role as a caregiver and their familial role to the recipient. When it comes to parents caring for their children with special health care needs, for example, parents often have spousal and work-related roles outside of caring for their child which they have to maintain [39], and in taking care of their child, they struggle with balancing their child's medical needs and social development, and not wanting to put much psychological burden on their child through disclosure of health-related information [54]. This results in a "balancing of roles" that has to take place through an internal decision-making process to choose when to act in each role [8, 19, 24].

The balancing act of roles and sometimes not being able to physically maintain them leads to emotional strain, including stress, frustration, and guilt [8, 17]. This guilt stems from caregivers feeling as though they should be doing more than they currently are. The sheer time and effort that caregiving takes allows less time for caregivers to socialize with friends and family, and caregivers oftentimes find it difficult to express their emotions with those close to them, leaving them alone to deal with their negative emotions and stress [8]. These difficulties often go unnoticed by family and friends, and the work of caregivers can feel "invisible" [8, 38, 51, 52], with caregivers ultimately longing for social support [52].

In exploring designs for online spaces to help alleviate the distress that caregivers experience, many encourage the caregiver to offload some of their tasks by sharing with their social network if they're involved in too many tasks [8], or introduce role-segmented systems where parents can separate their different responsibilities for better self-management and visibility for other caregivers involved [39]. Being involved in online support groups is also suggested [45], as venting through an online blog was found to be one way people used technology to express their emotions and feel a sense of calmness in a difficult situation [8]. Online support groups help caregivers feel less lonely in a situation through socializing and building relationships with others with similar distresses [4, 5]. Self-disclosure, the act of revealing emotions or personal information about oneself or their situation, helps people process their emotions and elicits social support, as well as provides social support to someone going through a similar situation [56]. Positive social influence, reciprocity, and trust in an online community contribute to a higher willingness to self-disclose with others online [46], and consistent participation in online support groups can lead to interpersonal relationships and empowerment for individuals [5, 56]. Beyond traditional support groups, CSCW research has also explored how health-related support systems can make care needs and personal circumstances socially visible in ways that foster empathy and support while balancing emotional burden among participants [28–30]

Siblings of autistic individuals as a group may struggle from epistemic injustice: not having enough knowledge to understand their own life experiences [55]. In this research, we seek to understand the challenges they face and what strategies might mitigate them. There is a growing recognition in the HCI research community that forums to support members of marginalized groups must not be deficit oriented, but instead should find ways to foster joy, strengths, and a positive sense of identity [20, 32, 57]. We build on that literature, exploring the need for positive identity construction for siblings.

Siblings are seldom recognized in the literature as a caretaker for their sibling and the responsibilities that come with that role. A sibling's role is unique in that caretaking begins from a very young age and continues into adulthood, with their entire life involving caring for another individual. As a result, the existing designs for caregivers' distress alleviation typically do not address the unique needs of siblings. There are existing support channels for both children and adults who have siblings with special needs. For children between the ages of 8 to 13 who have siblings with special developmental needs, Sibshops provides support to meet one another, talk about their experiences as a sibling, and do fun activities together [13, 36]. Through these locally run and in-person events, neurotypical siblings have opportunities to talk with other siblings about the positive and negative aspects of having a sibling with special needs, and for many, this is the first time they are able to share these emotions [13]. For adults, there are Facebook groups where people who have siblings with special needs can interact with one another and share their experiences. However, these spaces have not been studied in detail.

## 2.2 Experiences of Individuals Who Have Autistic Siblings

Sibling relationships are typically the longest lasting relationships one can have. Research on the developmental tasks of typical sibling relationships across the life cycle are separated into three stages by Goetting [15]: childhood and adolescence, early and middle adulthood, and old age. The childhood and adolescence stage is the most intense and formative years for the sibling relationship as they are in consistent daily contact with one another. In this stage, siblings confide in and provide friendship to one another, form sibling coalitions to deal with parents and provide resources to each other in the event of parental ineffectiveness. Older siblings typically take on some form of caretaking tasks for their younger siblings, which is similar to the relationship neurotypical and autistic siblings have with one another [27]. In early and middle adulthood, siblings each develop their own lives and usually provide passive support to one another, and are typically reunited once again when they turn to one another in support to manage the care of their elderly parents. In old age, once siblings are post-retirement, their bond is strengthened once again even though interactions are still infrequent, as they are able to reminisce with each other and validate each other's life experiences [15].

Siblings of people with autism or other conditions of people who need support in daily life have unique experiences in that they often begin to care for their sibling from a young age. Some of these caregiving tasks include looking after their sibling while their parents are away, cleaning up after them, helping them talk to or be understood by other people, befriending them, providing comfort for them, preparing meals, and reminding them to take their medication [27]. Prior HCI and CSCW work has also explored technology-mediated approaches for supporting autistic young adults' participation in everyday social settings, including systems that scaffold life-skill practice and social interaction [23]. Our work highlights opportunities for supporting interpersonal and communicative participation, which may complement the informal communicative support that siblings often provide in daily life. This informal caregiving and general experience of growing up with a sibling who requires attention result in both positive and negative effects on the individual. The positive impacts of having a sibling with autism include the neurotypical sibling's desire to promote acceptance of people with autism in broader society and feelings of empathy towards their sibling with autism and others around them, as well as giving the neurotypical sibling a sense of accomplishment and well-being when helping their sibling [6, 18, 59]. On the other hand, the responsibilities of taking care of their sibling often lead to changing their own plans in both small and big ways [10], and might involve things that are above what would be expected of someone at that developmental stage, such as protecting their sibling from being bullied or taking over caregiving duties to provide their parents a break [59]. Additionally, siblings of individuals with autism have been shown to exhibit higher levels of internalizing behaviors, such as anxiety or depression, and externalizing behaviors, which are outwardly directed problem behaviors like aggression [49, 50].

Siblings sometimes find it difficult to express their feelings regarding their autistic sibling, with both their friends and family members, even telling themselves that they "shouldn't be having" certain feelings [10, 21, 25]. Neurotypical siblings feel as though they will add an unnecessary burden to those around them if they are to share their feelings, or that they would be invalidating the struggles of their parents [21, 59]. Guilt is a commonly unexpressed emotion felt by siblings, for example wanting to spend time outside of the family home but feeling a loyalty to their sibling, or for not being able to consistently support their sibling as they lead independent lives and accomplish things that their sibling could not [21]. The bottling up of these emotions can sometimes make siblings feel alone and isolated [10, 42, 49]. Prior research has explored technologies that support understanding of neurodivergent experiences and more balanced neurodivergent–neurotypical interactions [31, 32]. However, neurotypical siblings can often find themselves navigating these interactions without comparable support and feel invisible in their social interactions with others, including their family members and other adults. Participants in a study with people who have siblings with autism recounted how everyone often asked how their sibling was doing, but never asked how they themselves were doing, leading to feelings of neglect [21].

A lack of information for siblings regarding how to best support their autistic sibling later in life presents a unique design opportunity to address this need. While there are online groups and resources for people who are currently caregivers, siblings who are not primary caregivers when living independently might constantly anticipate the day when they take on the role of a primary caregiver. In a systematic review of literature regarding adults having siblings with autism, it was found, similar to adolescents dispositions, that adults expect to be a primary caregiver and live with their autistic sibling in the future, however a small percentage actually turned out to follow through with those plans of co-residing with their sibling [22]. The expectation that they will be residing with them in the future still causes a considerable amount of worry for adults before they become a primary decision-maker for their sibling. Greater communication with their family increased siblings' satisfaction with future plans and combats the worry they feel [22]. In a study with adult siblings regarding their support needs, it was found that neurotypical siblings yearn for more support from other people who have a sibling with special needs, with participants saying they hadn't felt "normal" until coming into contact with an online group of other siblings [3]. Other desires from participants include wanting to be apart of conversations dealing with their sibling's needs before they become the sole guardian, help with future planning and system navigation, and a general system improvement in formal care for their sibling [3].

Online communities and support groups typically exist for specific circumstances and may be participated in only for the duration of that experience. However, siblings' circumstances are lifelong. From childhood to adulthood, the responsibilities and relationships of the neurotypical sibling evolve, and unique design opportunities for an online group arise from this. As the neurotypical and autistic sibling grow together, their relationship with each other generally tends to develop into a more positive one [22], and it typically involves more emotional support rather than direct caregiving [44]. In a literature review on siblings of individuals who have autism, a lifespan developmental perspective was taken, and at a young age, siblings tend to spend a considerable amount of time with each other when they live together. However, when neurotypical siblings start to lead a more independent lifestyle, lower levels of engagement between siblings is observed. Despite this, as mentioned previously, the sibling relationship tends to improve, potentially due to the decreased influence of parents on adults, and the ability for adults to have developed more effective coping strategies [44].

There is a clear desire from siblings of those with autism to be connected to others with similar life experiences [3, 21]. While many papers suggest that there needs to be an intervention for individuals who have siblings with special needs, whether that be in the form of online or formal support [3, 6, 10, 21, 22, 25, 59], there is little research into how a lifelong intervention should be designed past childhood. This research seeks to understand the specific design details for an online community for people who have siblings with autism in an effort to connect them in a meaningful way across their lifespan.

### 2.3 Positionality Statement

We recognize that this research is influenced by the distinct perspectives and experiences of the authors. Three of the four authors have siblings with autism. One of these three authors currently lives with their sibling, while the other two have transitioned to living independently. These authors have previously engaged in existing online groups which are aimed at connecting adult siblings of people with disabilities and other developmental and health concerns.

## 3 METHODS

This study aims to understand the experiences of people who have siblings with autism by focusing on their relationships with their sibling(s) and their experiences with existing online platforms designed for people in similar situations. To do this, we conducted semi-structured interviews with 12 participants who have a verbal sibling with autism requiring support with daily life activities.

People with different kinds of disabilities have different needs for support, and the needs of their support networks vary correspondingly. For example, supporting a blind sibling requires different mechanisms than supporting a sibling who is a wheel-chair user. There is a rich variety of people who need assistance with activities of daily life. To focus our research, we have chosen to focus on people who have verbal siblings with autism but require support with daily life activities. This is both a methodological choice (we wish to understand one group in depth) and a personal one (three of the four authors have verbal siblings with autism). The support needs of verbal and non-verbal people with autism are somewhat different, and we have chosen to focus on verbal siblings for clarity. In future work, we would like to study people with non-verbal siblings with autism, and also people with other challenges.

Table 1. Participants Demographics including their living situation and autistic sibling information

| ID | Age | Gender | Living Situation | Sibling Context |
|---|---|---|---|---|
| P1 | 19 | Male | Currently a student (Living context was not specified) | Oldest sibling, younger sister has autism |
| P2 | 26 | Female | Does not currently live with sibling with autism | Middle child, one older sister, younger brother has autism |
| P3 | 29 | Female | Does not currently live with sibling with autism | Oldest sister, one younger sister, youngest brother has autism |
| P4 | 26 | Female | Lives independently from their family | Oldest sister, younger brother has autism |
| P5 | 18 | Female | Is in college, lives independently from their family | Oldest sister, younger brother has autism |
| P6 | 20 | Female | Is in college, lives independently from family, moved back home and took a semester off from school to help family move and get brother used to new living situation | Twin brother has autism |

| | | | | |
|---|---|---|---|---|
| P7 | 19 | Female | Is in college, lives independently from family | Youngest sibling, has two older brothers with autism |
| P8 | 18 | Female | Is in college, (Living context was not specified) | Youngest sibling, older brother has autism |
| P9 | 21 | Male | Is in college, lives independently from family | Oldest sibling, two younger sisters, one younger brother with autism |
| P10 | 18 | Male | Is in high school, lives with their family and sibling with autism | Younger sibling, older brother has autism |
| P11 | 21 | Female | Currently lives with family and sibling with autism | Older sibling, younger brother has autism |
| P12 | 20 | Female | Is in college, lives independently from their family | Not specified if autistic sibling is younger or older |

### 3.1 Interview Participants

Participants for this study were recruited from February 2024 to April 2024. We targeted individuals aged 18 years old or older who have at least one sibling with autism who is verbal. These participants may be able to understand their sibling's experiences better through communication with their verbal sibling which is why we decided to focus on this population. A total of 12 participants were recruited with an average age of 21. Participants were recruited by word-of-mouth and snowball sampling. Due to our sampling methods, all of our participants were located in the United States, with a majority coming from the Southeast. The authors reached out to people who had access to potential participants and were referred to them. Recruitment was mainly conducted via email and sometimes text message. We also used snowball sampling, asking each participant whether they knew anyone else who might fit the participant criteria. We reached out to moderators of existing Facebook groups for siblings of people with autism, but received no reply. As a result, we did not study those groups directly; however, we do report the experiences of two of our participants who belong to such groups. Other participants had not tried Facebook groups for support as a sibling.

This study was approved by the authors' institution's Institutional Review Board. Due to the sensitive nature of some content, identifying information of participants or their families was removed from this work to ensure their privacy. Compensation was not provided for participating in this study.

### 3.2 Interview Procedure

During the recruitment of participants, those interested were sent an online consent form in which they could agree to be interviewed for this study. If they agreed, a later time was set up to conduct the interview. All interviews took place with one of the first two authors via the online video calling platform Zoom. Interviews lasted between 30 to 90 minutes, and were recorded with consent from participants. There are six major themes of questions that were asked:

(1) Family Dynamics: Each interview began by asking each participant to tell us about their family and their sibling, and how their relationships have evolved over time.

(2) Support: Participants were then asked to describe how they and their family support their sibling, and any challenges that may arise in administering this support. We also asked participants about whom or where they looked to for answers about caring for their sibling, and anything they wished they knew more about to help better support their sibling.

(3) Role as a Sibling: We asked participants what support they feel they receive at home, if any. We also wanted more insight into how the challenges of their sibling have impacted the

participant directly, and if there was anything they wish they knew more about to better take care of themselves.

(4) Online Support: Participants were then asked to recount their experiences with existing online communities geared toward family members of those with special needs. If participants have been a part of an online group previously, they were asked to give reasons why they searched for these communities, what they expect to gain from these communities, who typically participate in these communities, and whether they have learned something new by participating in these online forums. All participants were then asked if they have connected with other people who have siblings with special needs outside of online forums.

(5) Online Community Design: We then asked participants to describe what their ideal online community for people with neurodiverse siblings would look like, what content or type of discussion they would find valuable, and how they would balance informational versus emotional support on the platform. Participants were also asked how they might structure the platform knowing that people come from many different backgrounds including age and caretaker statuses.

(6) Demographics: Participants' age, highest level of education, occupation, and gender identity were also gathered, with the option to decline to answer any of these questions.

### 3.3 Analysis

Otter.ai was used to transcribe all interview recordings, and reflexive thematic analysis [7] was used for the coding process. The first two authors started by coding one of their own interviews, as well as the same one the other author coded. They then came together to decide on codes for the remaining interviews, with each researcher coding their remaining interviews individually. The researchers came together again once finished and spoke about commonalities across interviews. Major overarching themes were then decided on, and interview quotes were selected to support each theme.

## 4 RESULTS

We report three key findings from our interview analysis. First, participants perceive themselves as a "third parent" to their autistic siblings, facing unique support opportunities while balancing personal life goals. Second, we detail how these tensions vary across different life stages. Finally, we describe participants' needs for online community designs that could support the identified challenges.

### 4.1 Feeling Like a Third Parent

One of the most commonly mentioned characteristics of our participants' experiences involves feeling like a "third parent" to their autistic sibling. This "third parent" role was also tightly coupled to siblings' verbal communication. Participants often acted as translators or social advocates for their autistic siblings because they were the ones who often best understood their autistic siblings' verbal communications. Therefore, they frequently mediated communication between their siblings and others. In this section, we explore the tension of being "third parents," highlighting how our participants find themselves in a unique position to offer support to their autistic siblings, yet also encounter the challenge of balancing this responsibility with their own personal life goals. We further explore this tension in the discussion section, offering design insights into how online communities can address the balance between these opportunities and challenges.

> *I definitely feel like I grew up a lot faster. And not in a bad way, just things that typically people who don't have siblings with special needs don't necessarily grow up that fast... just felt like I grew faster... maturity wise. -P3*

*Opportunities to provide unique support as siblings:* Participants feel they understand their autistic sibling in ways their parents do not. This often meant decoding jokes, sarcasm, and peer norms, which aligned with evidence that siblings can shape communication trajectories. Sharing the same or similar generational perspective allows them to understand their siblings in navigating social situations and guides them through various schooling experiences. Through this, they are more than just taking care of their sibling's physical needs, they are providing emotional support for them as well:

> *He definitely comes to me with things a lot more than he goes to my parents with... I feel like I understand his needs better than they do. -P12*

Neurotypical siblings often find themselves in settings, such as school, where their parents are not present, giving them unique opportunities to better understand and support their autistic sibling. The distinctive opportunity particularly arises when the autistic sibling is verbal. Because they can speak, others expect them to be able to respond in conversations, even though autistic siblings may struggle to find the right words or to respond in real time. In these moments, neurotypical siblings often step into a "voice role"—not replacing their sibling's communication, but mediating it so others can understand what their sibling is trying to convey. This is a role unique to siblings of verbal autistic children, since the expectation of speech itself creates the need for immediate, situational support:

> *I'm kind of like a voice for him. In certain scenarios, like in a school setting, if someone were to approach him and ask him a question, he wouldn't exactly know how to respond. Whereas I was right near him, I would kind of verbally relay what he's trying to communicate, even though he can't form the words. -P8*

*Struggles to balance multiple roles:* As a third parent, participants take on various caregiving roles. They sometimes drive their sibling to day programs, help them finish household chores, take them to therapy sessions, help calm them down, and generally be in charge of their sibling and the house while their parents are away. These habits often occur from a young age of participants, when their autistic sibling is born, and continue potentially for the rest of their lives. In many cases, even a younger neurotypical sibling takes on a caregiving role for an older autistic sibling. Participants have to balance this role as a third parent with their role as a sibling. This balancing act results in participants seeing a difference between their sibling relationship and the sibling relationships their peers experience:

> *I sometimes joke about this, and I'll say like, oh, I'm his third parent... Definitely, when you start growing up faster than maybe a friend, you definitely notice that this is your role in the family. And it's like your job to be a good sister, but also lead the ropes and like teach them the ways. -P11*

Participants took on the role of a third parent for two main reasons. Some participants did so to actively try and make their parents' lives easier. Many participants stated that they tend to take on tasks related to their sibling in order to alleviate some of the stresses their parents have in taking care of their sibling. However, other participants expressed feeling pressure from their parents to step into a caregiver role for their sibling. In fact, some participants believed that they were expected to change their future life plans to be able to provide for their sibling in the long run:

> *I also sometimes get a lot of pressure from my parents trying to tell me that because my younger brother isn't always going to be capable of doing things... I need to always be grindier. -P5*

Below, we describe how our participants navigate and manage the opportunities and challenges of taking on the unique role of a third parent while balancing their own life experiences and plans at different stages of their lives. These insights can inform the design of lifelong online communities that address the evolving needs of siblings of people with autism.

## 4.2 Stages in the Life of an Individual with an Autistic Sibling

We identified three major stages in the life of individuals who have a sibling with autism, which are similar in age range to the life cycle stages of typical siblings defined by Goetting [15]. Stage 1 describes the time when participants are living at home with their family during their adolescent to young adult life. In Stage 2, participants are leading a more independent lifestyle, potentially away from their family. Finally, Stage 3 describes how a sibling may have caretaker status over their autistic sibling later in life when their parents can no longer be the primary caretakers. We describe below the different characteristics of each stage.

*4.2.1 Stage 1: Living with Family Phase.* In this stage, as we mentioned above, non-autistic siblings often take on the role of interpreters and protectors, helping their autistic sibling communicate with teachers, peers, and extended family. Because their sibling was verbal and able to express needs directly, participants frequently felt responsible for responding to those needs rather than attending to their own. This dynamic aligns with previous research showing that when autistic siblings use more language, it may foster greater responsibility-taking and emotional involvement in non-autistic siblings [9].

*Tension Between Early Responsibility and the Formation of One's Own Identity:* Participants described about taking on caregiving, interpretive, and protective roles for their autistic siblings. While these responsibilities allowed participants to develop empathy, maturity, and a strong sense of familial commitment, as shown in previous literature [47, 58], they also shaped their identities in ways that sometimes de-prioritized their own needs. Participants explained that while growing up, their autistic sibling would often get more attention from their parents since their care needs would typically require more attentiveness. While participants acknowledged their siblings might need more assistance, they also expressed that their needs and emotions often felt overlooked by their parents, with their feelings ultimately being unaddressed:

> *We joke about that I was the normal one now, but like back in the day, they didn't say that, but that I was the one that they had to like worry about less essentially. So it was like 'Okay, I understand that.' But at the same time I'm like, I need help too. You know, just because it seems like I'm fine doesn't mean that I am. –P2*

Some participants spoke about how there were times when their parents couldn't help them with their homework, and this made them feel as though their parents didn't love them as much as their siblings since attention was not being given to them. This sense of being overlooked sometimes shaped how participants came to view their own worth within the family.

> *I felt like I was being forgotten about... that played a big part with the whole like she needs us less kind of thing. –P2*

Parents not making the neurotypical sibling's needs a priority might instill in them that their needs are not as important as those of other family members. There is a consistent theme across participants' experiences in that they tend to put the needs of their family members above their own. Going back to the idea that they become third parents in order to alleviate the stress on their parents, participants sometimes decide to hide their own feelings from their parents because they feel as though they would burden them more:

> *[My parents] offer to talk to me if anything's going on but I honestly don't really do that too much. Because if I started telling them all the things... all the problems that I have,*

> *they'll probably get way more stressed. Like that's not worth it. So I don't do that too much. -P1*

When it comes to their autistic sibling, participants also tend to think of their sibling's needs first and worry about their own needs later. This dynamic may be amplified by the fact that their autistic siblings were verbal, able to directly express their wants and challenges, which participants often felt compelled to address by stepping into a "voice role" from an early age. However, the parental role participants take on leads them to feel some sense of sacrifice they need to make in order to cater to their sibling:

> *I took a semester off from school actually my sophomore year to help my family... with the move and like having my brother transition and that sort of thing. -P6*

This pattern––being positioned early as the responsible sibling, being perceived as self-sufficient, and consequently suppressing one's own emotional needs to protect parents from additional stress–– reflects a central tension in participants' identity development. Some participants even go as far as stating that they are doing well only if their sibling is doing well, and will put their own life on hold to ensure their sibling has what they need. While this reflects a deep sense of care and responsibility, it also reveals an identity shaped around self-sacrifice rather than balance:

> *My well being is fulfilled if my brother's well being is fulfilled -P9*

This quote captures a dual reality: participants' identities are positively shaped by love, commitment, and advocacy for their sibling, yet they often lack models or guidance for understanding how to care for themselves alongside this responsibility. This consistent thought process of putting their family's needs above their own ultimately shapes participants' decisions for the future. Many participants reflect on the fact that their sibling and their abilities are at the forefront of all their decision-making. Taken together, these accounts highlight a critical gap in support. Participants rarely encountered role models, narratives, or informational resources that demonstrate how caregiving responsibility can be balanced with personal autonomy and care for themselves:

> *It becomes the center of your life, it is the center of our family. It's the thing that everything revolves around, all our decisions, all of my decisions. It's just the biggest thing, it's become the biggest thing. -P12*

*Struggling to Balance Caregiving, Belonging, and Emotional Well-being:* The constant dismissal of participants' needs, both by their family members and themselves, takes an emotional toll. Participants communicated some difficulties that come with keeping up with their sibling's care and needs. They have a consistent responsibility to their sibling which can be draining emotionally:

> *Because [my brother] has to be entertained, he has to be the priority... I think that can get pretty exhausting when your life is expected to revolve around someone that's not you. -P12*

These challenges were especially visible in social settings, where participants felt responsible for monitoring and managing their sibling's behavior, as a part of their "voice role" responsibility, limiting their ability to relax or feel fully present:

> *So we can't really go out as often... like when people call us over, we have to take turns keeping an eye on [my brother]. And he makes it kind of hard to sometimes enjoy the time. -P5*

Beyond caregiving demands, participants highlighted how growing up without peers who also had autistic siblings shaped their sense of identity. Many described feeling isolated, not because of their sibling, but because they lacked opportunities to see their experiences reflected in others. Many don't have an outlet to express these feelings with others who might understand what they're going through:

> *As far as I know, I'm the only person I know... that had a sibling with special needs. –P1*

These minimal connections to other people who have siblings with autism leaves participants feeling alone in their situation, like they are living an abnormal life:

> *I've always just thought that I'm an exception, like everyone else has siblings that are... so called regular. -P9*

This absence of shared experience often influenced how participants navigated friendships. Participants were cautious about introducing their sibling to peers because others might not understand or be able to handle the situation:

> *When I was younger, I had friends I never brought around. They'd never come to my house, I'd go to their house, because either didn't trust him, them to handle him, or want to keep that side of my little, not hide it but, more on acceptance issue... I had to be careful with friends that I would bring around. Not because I was embarrassed of him. I was more I couldn't. It was more them, if that makes sense. I knew they couldn't handle what came with being around him. -P3*

Participants also described the emotional labor of the "voice" role, repeatedly explaining their sibling's behavior to others. While they strongly rejected the notion that their sibling was something to apologize for, the constant need to contextualize their family dynamics reinforced feelings of being different.

> *It is something that I find myself I have to explain almost to people constantly. Oh, like I'm sorry, my brother is special needs. I don't want to keep apologizing and I don't think he's someone I should apologize for. I don't think he should be apologized for I think he's fine. - P12*

*4.2.2 Stage 2: Living Independently Phase.* Because their sibling was verbal, some participants were able to maintain direct connections even at a distance, for example, through receiving texts, calls, or conversations where their sibling shared feelings, thoughts, or updates about daily life. At the same time, this verbal ability could also intensify guilt. When autistic siblings expressed disappointment or sadness about their non-autistic sibling moving out, participants experienced tension between personal goals and caregiving responsibilities. On one hand, they wanted to pursue their own life goals; on the other, they worried about abandoning their sibling's needs and stepping away from the "voice role" they had carried since childhood. We describe about this in more detail below.

*Changing relationships:* When entering Stage 2, participants see a change in their relationship with both their sibling and their parents. Participants are no longer involved first-hand with the care of their sibling as they once were when living at home. They instead stay connected by talking and texting over the phone, relying on their parents for information about their sibling, since they are generally not as involved:

> *Before I would consider myself one of the main caretakers for them – that's not really how it is anymore... When I go home, I still drive them places and I still kind of fall back into that older role. But yeah, now... I'm kind of separate from the home life. -P7*

In addition to the physical care aspect changing, the way participants view their relationship with their sibling has changed. Participants are no longer the main caregiver for their sibling, thereby taking a step back from their third-parent role when living away. When receiving their own space, participants see an evolution and potential improvement in their relationship:

> *Going to college has significantly changed... my relationship with my brother, we get along more, things like that. And it's mostly me moving away and having my own personal space away from home. -P12*

Participants reflect on that evolution, and some have close relationships with their sibling, where they have developed fun activities to do with one another:

> *As [my brother] grew older, we definitely formed that bond that I think is very special, we have a very close relationship, we have different hobbies that we like doing together, like baking, cooking, playing tennis... -P11*

*Personality shaped by adolescent experiences and relationship with sibling:* Many participants reflect on how their experiences throughout their adolescent life within their family and with their sibling have had a significant impact on their personality and how they interact with others. Some say they have become more understanding of others' struggles as a direct result of having a sibling with autism:

> *I've become more outspoken, more including, and can understand people's struggles and speak out about them, which if my brother wasn't the way he was, I don't think I would have that personality. -P8*

Others say they have become more empathetic and selfless as a result of putting their sibling's needs above their own as they were growing up:

> *I think it's made me a little more selfless of a person... you are kind of in a position where you're forced to help them on a daily basis and forced to kind of go outside of yourself... I think it's made me a little more assertive... it's also given me a lot more empathy. -P4*

*Guilt associated with changing relationship:* In Stage 2, for one of the first times in participants' lives, they are pursuing their own life goals rather than catering to the needs of their sibling or family first. Because of this, participants expressed feelings of guilt associated with their changing relationship with their sibling. Being a third parent to their autistic sibling, helping them grow throughout their childhood, then taking a step back from that caregiving role as they enter into Stage 2 leads to feelings of guilt for participants, like they're doing less than they should be to help their sibling:

> *I was there at the beginning... while he was learning how to cope with being neurodivergent, but now I'm not in the loop about anything anymore. So I don't know how he's doing in school. I'll see these changes when I come back from college and whatnot. And I'll be like, Oh, that's so cool. But I feel a little guilty because I'm not really there to experience it. -P5*

Participants' siblings are of course affected by this change in their relationship as well, and may react poorly in their confusion. Negative reactions from their autistic sibling to participants moving forward in their life stick with participants and also contribute to the formation of guilt:

> *I do remember a couple conversations with my brother where he wasn't super excited about me leaving, and I don't think he actually was upset with me about it, but the way kind of his reactions came off were like, why are you leaving or like she's leaving us forever and all that stuff. So that was difficult... it did kind of feel like me choosing to leave them. So I struggled with that a little bit. -P7*

*4.2.3 Stage 3: Sibling May Become Primary Guardian.* When parents are no longer able to take care of their child with autism, the neurotypical sibling may take on the role as the primary caregiver. In other instances, their autistic sibling may live in a home, the caregiving responsibility is shared among multiple siblings, or they are just not closely involved. Although none of our participants were currently in Stage 3, all of them expressed concerns about entering into this stage, particularly the possibility of taking on a future guardian or "voice" role. These expectations and concerns align with prior research showing that non-autistic adult siblings often worry about the future well-being of their autistic brother or sister [11, 43, 47]. By outlining participants' concerns about

Stage 3, we surface the types of information and support that non-autistic siblings seek before entering this stage.

*Tension Between Caring for a Sibling's Future and Living One's Own Life:* Consistent with prior research [11, 47], our participants expressed concerns about their brother or sister's future access to appropriate services, such as residential care facilities or in-home aides, as well as the type and level of care that may be needed over time. At the same time, participants described an underlying tension between this anticipated caregiving role and their own life trajectories. The prospect of entering Stage 3 introduces substantial uncertainty, as participants imagine assuming greater responsibility as a guardian while also managing their own lives. Participants might be married, have children, live far from their sibling, have full-time jobs that require a lot of attention, so many factors that will play a role in their transition into Stage 3. As a result, caring for their sibling's future is not considered in isolation, but in direct relation to how it may constrain, reshape, or compete with their own personal goals, relationships, and sense of stability:

> *There are these sorts of moments where [my mom] will be like, we don't know how [my brother] will be in the future. And she's always worried about the future, which makes me worried about the future. [...] And I'm always worried about my future. But then she starts talking about my brother and our family dynamic and how my brother's gonna get older. And then I start getting scared because now somebody else's future to worry about, and it's just a whole lot. -P5*

*Uncertainty at the Transition into Stage 3 due to Reduced Involvement in Stage 2:* There's also somewhat of a gap of knowledge when participants enter Stage 3 that is a product of Stage 2. As participants become less directly involved in their sibling's day-to-day care during this stage, they increasingly rely on infrequent interactions with their sibling and secondhand updates from parents. These updates are often irregular and incomplete, leaving participants without a continuous or holistic understanding of their sibling's needs, services, and care arrangements. Therefore, our participants expressed concerns about their brother or sister's future access to appropriate services, such as residential care facilities or in-home aides, as well as the type and level of care that may be needed over time, consistent with prior research [11, 47]. One participant described how their understanding of their sibling's care depended largely on sporadic parental updates, highlighting the fragility of this information flow:

> *My mom calls me, she tells me about things, like she'll tell me about a certain day at therapy or at school. And that works, it's just we don't call or talk enough times about it to keep me updated on that. -P5*

Again, this uncertainty can evolve into worry since there is no clear picture of what the future holds.

### 4.3 Online Support Needs

Considering the feelings and experiences outlined above, participants have some real support needs that could be addressed through an online community of other siblings. Participants are generally striving to feel understood by someone, especially in Stage 1 of their life. When asked about how they might accomplish this, they felt that having an online community of other siblings could help to accomplish this goal:

> *[An online community] would have been helpful just to know of any other people who are going through what you're going through. -P4*

*4.3.1 The Need to Balance Venting Spaces and Positive Spaces.* Participants detailed different aspects they might like to see in an online community for people who have siblings with autism, one being a space to vent:

> *I think a safe space to vent if there are any issues that you're having -P4*

Some participants expressed wanting to be able to vent about their situation without getting advice from others, essentially a way to get their feelings out there and then being able to move on:

> *I think [venting] can be helpful. Because if it's like a sibling who's genuinely going through something emotional that they just want to talk about, they probably know the logical part to it. But they just want to feel a little bit better in the moment -P11*

While venting may help someone alleviate stress in the moment, the constant reading through and intake of negative sentiment can take a mental toll on other community members. Two of our participants have been involved in existing online communities geared towards people who have siblings with special needs. P3 recounts how the existing communities they have participated in can become "depressing" when all that is being posted is about someone's sibling in the hospital or their setbacks. While understanding that people are going through something, it can still make participants sad and not as likely to participate in an online group, even pushing them away from participating at all:

> *I feel like people will post stuff and they're upset in the moment and stressed... you know, get it out. But I think that's one of the reasons I don't participate that much in [the communities] is because it just makes me sad. -P2*

Recognizing the toll constant negativity can take on community members, one participant suggests having a day dedicated to community members posting encouraging content:

> *Having a day where it's good news day or update day to help drown out some of the other not so fun conversation. -P3*

*4.3.2 Coping With a Changing Role.* As mentioned above, there are different emotions, including guilt, that might come with the changing role participants are taking. Trying to reconcile these feelings with participants' decisions about their own goals and desires is difficult. Having the ability to talk about these feelings with older siblings who have been through a similar scenario could be beneficial. In Stage 1, when neurotypical siblings are still young, and their own identities are forming, our findings suggest that guidance and positive role models are important. These supports can help siblings learn how to balance their caregiving and advocacy roles for their autistic siblings with their own lives. As one participant expressed: *I don't know how to always support him without getting drained -P12*

Being able to talk to others about what's going on in their current situation can also make participants feel validated. Participants want a space to be able to ask older individuals whether or not what they are going through is normal and how they got through it in the past:

> *Is this normal? Yes or No? I think a space where you're like how do you handle this? I think that would be helpful -P4*

In Stage 2, when neurotypical siblings live independently, participants want to get advice from others and wonder how people before them have created a life for themselves while also keeping their family in mind:

> *How are other people staying connected and helping their family in the best way they can while also developing their own interests and goals and reaching for those things? -P7*

Hearing experiences can also give participants a clearer picture of what the future might hold for them and their sibling. Participants want to know what life in Stage 3 looks like:

> *I think themes like what they would be doing in the future or what the future holds for our special needs siblings would really help people. Because a lot of people are anxious about what their special needs siblings or child would do in the future -P10*

Participants also desire the ability to speak with people about different resources they used to help both them and their sibling. Many participants suggested being able to talk to others who are in a geographically similar area, acknowledging that resources can vary from place to place:

> *Grouping by... people that are either in your same state, your same country, because obviously the resources that you have vary a lot from country to country -P1*

In addition to hearing from past experiences, participants could benefit from talking to other siblings who are at the same stage in their lives. One participant expresses the need for siblings to be able to talk about personal things in their life with others from the same generation who have more of an immediate understanding of their current situation:

> *These 20 year olds are coming to us with dating things, but there's sixty year olds on here, they don't relate to what it was like dating when they were younger versus nowadays... In order to benefit more sibs and make them more comfortable to talk about what's going on in their life, trying to make a page here towards their age groups -P3*

## 5 Discussion: Designing a Life Stage Specific Online Community Supporting Both Personal Identity and the Sibling Role

Previous research has shown that adult informal online caregiving communities offer valuable emotional and social support for caregivers [4, 5]. Similarly, neurotypical siblings of autistic individuals can benefit from seeing and connecting with others in similar situations, which can help them better understand and process the complex emotions they have toward their sibling and family [4, 5, 56]. However, many participants in our study shared that they did not personally know anyone else with a sibling on the autism spectrum, which often made them feel isolated or as though their experiences were uncommon.

Our study findings contribute to the design of online communities by identifying the distinct and evolving needs of neurotypical siblings across different life stages. Specifically, **we highlight the importance of life stage–focused, positive online spaces that support individuals navigating both their personal identity and their role as a sibling caregiver.** This goes beyond prior work on online caregiving communities [4, 5], which has largely focused on adult caregivers seeking emotional support. By showing that siblings' needs shift as they transition from childhood to adulthood, our findings surface design features of online communities that can adapt to these developmental changes.

We also found a unique challenge for siblings of verbal autistic children. The "voice role," in which non-autistic siblings mediate communication because others expect their sibling to respond verbally, but they often cannot do so effectively in real time. Prior online caregiving research has not considered this kind of situational, peer-to-peer mediation, which is distinct from the more traditional caregiving responsibilities of siblings of non-verbal autistic children. Designing online communities that acknowledge the "voice role" is crucial, as it validates siblings' unique experiences, provides resources for navigating these high-stakes interactions, and offers identity-affirming spaces where siblings can process the responsibility of speaking on behalf of their autistic brother or sister.

The voice role is also aligned with prior HCI and CSCW literature that explains how adult caregivers routinely engage in communication-oriented caregiving work, such as speaking on behalf of care recipients in everyday contexts and conveying care-related needs to other family members, clinicians, and institutions [8, 14, 24, 37, 40]. Prior work has shown that caregivers' intimate, long-term knowledge of care recipients positions them as key intermediaries who translate, coordinate, and negotiate information across the care ecosystem [8, 14]. This communicative labor is often described as part of caregivers' invisible work, requiring them to balance caregiving responsibilities with other life roles, including work, family, and personal well-being [8, 24, 37, 40]. Similar to these adult caregivers, siblings in our study also described the need to continuously juggle caregiving-related voice work with their own educational, social, and personal activities.

However, our findings extend this literature by surfacing proxy-mediated voice work within a group whose caregiving role begins early in life, at a time when their own identities and social positions are still in formation. While prior CSCW research has largely examined caregiving voice and role management among adults with relatively established identities and role repertoires [8, 24, 40], siblings in our study began enacting the voice role during childhood or adolescence. This early onset reveals not only struggles and emotional burden, but also the importance of helping siblings meaningfully interpret and positively process their caregiving experiences as part of their developing sense of self. Our findings point to the need for online communities that go beyond providing emotional support, by offering perspectives that help siblings reflect on their role, reframe their experiences, and navigate identity-related tensions over time.

By foregrounding the "voice role," our work shows how online communities can move beyond general emotional and informational support to address the nuanced, identity-shaping forms of work that siblings of verbal autistic children undertake. In doing so, these communities can help reduce isolation, foster solidarity, and create design frameworks that recognize siblings not just as caregivers, but as individuals balancing complex, evolving roles across their life course. Below, we further discuss how our findings extend online caregiving research by presenting design guidelines for online community platforms that can not only provide emotional relief, but also foster positive identity development and prepare siblings for evolving roles across the lifespan.

### 5.1 Design Guidelines for Online Spaces Supporting Both Self-Care and Identity

Our findings revealed that neurotypical siblings of autistic individuals navigate complex tensions between their personal identities and roles as caregivers across three distinct life stages. Participants expressed a strong need to see how others manage these dual identities and cope with the guilt that often arises from prioritizing themselves. These findings underscore the importance of an online community that explicitly supports neurotypical siblings in nurturing their personal identity in a positive manner. **Therefore, drawing on the positive design framework [12, 57], we propose designing online communities for neurotypical siblings that highlight the positive aspects of their identities and support their personal growth, rather than feelings of guilt**. This contribution goes beyond prior research on online caregiving communities, which has mainly emphasized emotional relief and sharing burdens [4, 5]. Our findings highlight that siblings—who are simultaneously caregivers and peers—require spaces that foster personal identity development and positive growth, not only emotional catharsis. By supporting siblings' flourishing identities, online communities can mitigate guilt and help sustain engagement over the long term.

To guide the development of online spaces that intentionally promote positive identity formation [34], Lyu et al. employed the framework with three core elements—pleasure, personal significance, and virtue. Below, we explore how each element of this framework can inform the design of online communities for neurotypical siblings of autistic individuals.

*Virtue* involves deriving happiness from morally and ethically meaningful actions [12]. Lyu et al. emphasize that online communities can foster virtue by encouraging prosocial behavior [34]. In the context of sibling communities, this could include features that recognize acts of kindness, inspiration, or encouragement to promote a culture of engagement and positive reinforcement. For example, the virtue construct can help surface how siblings understand their caregiving—particularly the "voice role"—as meaningful rather than burdensome. Prior research on siblings of autistic individuals has shown that non-autistic siblings' caregiving and advocacy experiences, such as mediating conversations, advocating in public spaces, and developing attentiveness to others' needs, have positively shaped their professional trajectories, interpersonal skills, and sense of self-concept [2, 35]. However, participants in our study reported having limited exposure to peers or older siblings who had framed these experiences as positive assets in their lives or had successfully integrated them into their personal or professional identities. This absence made it difficult for younger siblings, especially those in early stages of caregiving, to envision how their current efforts might contribute to a meaningful and fulfilling future. Designing online communities that support the sharing of such lived trajectories can help address this gap. By enabling siblings to share how their caregiving and "voice role" experiences later contributed to their lives, communities can help younger siblings recognize the meaning and value of their current roles. At the same time, sharing these stories can offer older siblings a sense of fulfillment and affirmation, as their experiences may support others in similar situations. In this way, online communities can function as spaces for cultivating virtue by helping siblings collectively reinterpret caregiving as a morally meaningful practice with enduring positive impact.

*Personal significance* focuses on enabling individuals to reflect on their progress and share meaningful achievements [12]. For neurotypical siblings, this construct is particularly important as our findings showed the tension between early responsibility and the formation of one's own identity. Neurotypical siblings often assume caregiving and "voice" roles from a young age, which fosters maturity and empathy but simultaneously de-prioritizes their own emotional needs and personal aspirations, shaping an identity oriented around self-sacrifice rather than balance. For example, online community design can respond to this tension by explicitly creating spaces that validate personal growth as distinct from, yet compatible with, caregiving responsibilities. For instance, role-separated storytelling features can allow siblings to reflect on achievements and challenges related to their own lives without having to frame them through their sibling's needs, counteracting the internalized belief that self-focused narratives are inappropriate. Life stage–based milestone tracking can further surface personal progress across transitions (e.g., leaving home or pursuing independent goals) helping siblings reinterpret these moments as meaningful achievements rather than moral conflicts.

*Pleasure* refers to enhancing positive emotions or reducing negative ones [12, 26]. For instance, prior research on BlindTok found that TikTok features like voice-over acting, audio effects, and duets allowed blind users to share moments of joy, humor, and self-expression, helping them connect through playful engagement rather than solely focusing on their disability identity [34]. In our study, many siblings described experiences of guilt and emotional pressure that limited their ability to experience positive emotions in caregiving contexts. For example, participants who took on the "voice role" from an early age often felt responsibility in social settings, such as monitoring their sibling's behavior or mediating conversations, which made it difficult to relax or enjoy time with others. Also, feelings of guilt when participants began pursuing independence further reduced opportunities for positive affect. From a pleasure perspective, these findings suggest a design opportunity for sibling-focused online communities to intentionally create space for positive, low-pressure interaction. Incorporating features like meme-sharing or lighthearted creative prompts could help siblings connect with one another through humor and shared interests, extending beyond their caregiving roles. This kind of design is especially important for younger siblings just beginning to take on the "voice role," as it ensures their early advocacy experiences are not defined only by pressure, but also by opportunities for joy, play, and affirmation.

While designing these communities to support personal growth, it is also important to acknowledge the emotional challenges of neurotypical siblings. Many participants expressed a desire for dedicated spaces to vent, with the option to choose whether they wanted feedback or simply a listening ear. This aligns with Oladeji et al.'s findings on Discord venting channels [41], where mismatched expectations around receiving advice often lead to frustration. Aligning with the previous research findings [41, 60], our participants also described how constant exposure to negativity in existing online sibling support groups led them to disengage. Continuous emotional venting without balance can drain community members and diminish long-term engagement. To create a more sustainable and supportive environment, we recommend structuring the community into distinct emotional zones — one for venting and emotional release, and another for encouragement, celebration, and personal updates. This dual-space model can offer respite from difficult conversations while still validating users' complex emotional experiences. Positive emotional expressions can help maintain long-term participation and create a more resilient, self-sustaining community [60].

## 5.2 Life-Stage Specific Online Support for Neurotypical Siblings Preparing for Caregiving Roles

While having a space to care for neurotypical sibling themselves is important, neurotypical siblings still desire an online space where they can better prepare for their evolving roles as caregivers. In this section, we describe the types of support that online communities can offer to help siblings prepare for caregiving across the different stages of their lives — helping them anticipate what lies ahead and learn from one another.

This life-stage approach extends existing caregiving research, which has primarily examined adult caregivers in stable roles. Our findings show that siblings' needs evolve across developmental stages, requiring community design that adapts over time—from childhood identity support, to young adulthood independence, to adult caregiving. Online communities that mirror these transitions can scaffold siblings' readiness in ways current caregiving platforms do not.

In Stage 1, when neurotypical siblings are still young and beginning to form their personal identities, participants expressed a strong need to focus on themselves, as they often already feel pressure to take on a caregiving role. Online communities for this stage can benefit from facilitating peer connections and emotional expression. For example, participants shared that talking with other siblings about both the positive and challenging aspects of having a sibling with special needs allowed them to express emotions they had not previously shared. This echoes the spirit of Sibshops, in-person programs designed for children, typically between ages 8 and 13, to meet other siblings of children with developmental disabilities and engage in activities and conversations in a supportive environment [13, 36]. Translating these ideas into an online setting, communities can encourage members in this stage to share activities they do with their siblings, helping foster engagement, connection, and a sense of validation during the early life stage of neurotypical siblings. For siblings of verbal autistic children specifically, these communities can also provide scenario-based role-play or discussion prompts to help them reflect on when they serve as their sibling's "voice" in peer or school contexts—an aspect not captured in broader caregiving research.

In Stage 2, neurotypical siblings often begin living independently, and their caregiving responsibilities become more distant. Participants described relying on their parents to receive updates about their autistic sibling, typically through texts and phone calls, and the occasional first-hand experience when they meet up with their sibling. During this time, many participants, in line with previous research [22], anticipate taking on full guardianship of their autistic sibling in the future. However, they often lack critical information about their sibling, what their future options are, and how their life might change again once the time comes to be a full-time caregiver, and this contributes heavily to feelings of worry for the future. Online communities can play a critical role by allowing members to share how they maintain involvement with their families, gather updates, and mentally and practically prepare for future caregiving roles [33]. These shared experiences can help reduce uncertainty and build a sense of readiness. For siblings in the "voice role," this stage also requires guidance on how mediation shifts from school-based interactions to supporting autonomy and self-advocacy in adulthood, a dimension that is often absent in current online caregiving designs.

In Stage 3, neurotypical siblings may begin assuming full or partial caregiving responsibilities for their autistic siblings. Our participants expressed significant concerns about the future, including uncertainty around legal guardianship, finances, housing, care activities, and long-term planning. To support siblings in this phase, online communities should provide both peer support and practical information-sharing. Participants wanted to hear from others who had navigated legal and logistical systems—such as applying for guardianship, choosing care homes, or managing finances—to help set expectations and make informed decisions. For siblings with a history of serving in the "voice role," this stage may also involve navigating how much to continue advocating versus encouraging their autistic sibling's independent voice—an area of tension that deserves explicit design attention. Furthermore, as their autistic siblings can voice their priorities, thoughts, and needs, it is possible that these are not always aligned with the non-autistic siblings' plans and expectations, which can surface conflicts [9]. These stories can help siblings manage their expectations about their role in the future and build their confidence for what lies ahead [5, 56].

Across all stages, participants noted that available resources vary widely based on location. Therefore, creating geographically organized subgroups (e.g., by city or state) within an online community can enhance both emotional connection and access to relevant support. This builds on prior findings that location-based communities strengthen bonds [30, 48]. However, our findings extend them by applying the principle to siblings who often lack awareness of geographically specific caregiving resources. By organizing members into location-based groups, an online community could also cultivate a sense of shared identity and purpose [30]. These localized communities could further allow siblings to discuss regional services, legal requirements, and other context-specific concerns while increasing their attachment to and participation in the broader community.

Many groups of people need support. Like Taylor's study of bisexual people and To et. al.'s study of BIPOC individuals, siblings of people with autism need support that is not just deficit-oriented, but fosters a positive sense of identity for individuals and the group, and provides opportunities for joy–joy in who they are, and what they contribute to their families [55, 57]. This particular group has strong lifestyle stages, and support needs that evolve through the stages. In this research, we characterize those stages. Generalizing beyond the situation of siblings of people with autism, we suggest that many types of people in need of support may also need different kinds of support throughout the lifecycle. Thus, building stage-differentiated support for neurotypical siblings may provide a roadmap for evolving support for members of other groups.

## 6 Limitations and Future Work

Our work is subject to a few limitations. First, two of our participants shared their thoughts on existing online communities for people with siblings with autism and found those sites not fully satisfying; however, we have been unable as yet to gain entrée to analyze those sites in detail. We hope to do so in future work.

Second, our study also did not include participants who are in Stage 3 of their life, where siblings might have a primary caregiver responsibility over their autistic sibling. Future work should include experiences from siblings who are in Stage 3 in order to understand their distinct needs and be able to make design suggestions based on those needs.

Third, our focus here is exclusively from the siblings' perspective. We accepted our participants' accounts at face value, and did not attempt to tease out tensions and contradictions within them. We have no access to how either their parents or their autistic siblings perceive their efforts to support the family. The reality of how selfless/selfish they are may differ from their perception. Future work could productively engage with entire families, to find ways that they can all better support one-another.

Finally, we used snowball sampling to reach our participants, and as a result, a majority of our participants were from the southeastern portion of the United States. As mentioned, resources can vary based on where someone lives, and people in different locations may have varying experiences in receiving support. In the future, participants from many geographical locations, including other countries, should be interviewed to determine potential differences and similarities in experiences of siblings across locations.

## 7 Conclusion

Through this study, we have shown people with autistic siblings to be a group in need of support. Siblings typically take on a caregiving role early in life, and as their role changes over time, so do their challenges and support needs. We have explored some of these challenges through interviews with participants, and have presented design recommendations for a lifelong online community that is both positive and engaging. We envision online communities for neurotypical siblings that highlight the positive aspects of their identities and support their personal growth. However, this research is only scratching the surface as to what meaningful support might look like for siblings. Siblings need a safe space to engage with other people in similar situations, and the details of this community matter. More work in this space is essential to understanding exactly how to best support people who have siblings with autism.

## 8 Acknowledgments

This work was supported by the National Science Foundation under Grant No. 2444572, the Industrial Technology Innovation Program (P0028404) of the Ministry of Industry, Trade and Energy of Korea, and the internal fund/grant of Electronics and Telecommunications Research Institute (ETRI) [25YD1100].

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Received 13 May 2025; revised 13 January 2026; accepted 17 March 2026