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SCHREYER HONORS COLLEGE

DEPARTMENT OF ELEMENTARY AND EARLY CHILDHOOD EDUCATION

Assessing Social Relationships of Children with Cerebral Palsy in Rural Areas: Family
Perceptions

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ABSTRACT

Individuals with complex disabilities, including children with cerebral palsy, have limited opportunities for social interactions and may rely on alternative and augmentative communication devices, social media, or video games to create meaningful experiences and friendships. The present study sought to use family perspectives to identify and describe the social interactions of children with nonverbal cerebral palsy living in rural areas. One family was interviewed. Through a caretaker's perspective, it was found that an eleven-year-old boy with nonverbal cerebral palsy has limited opportunities for social interaction, has few community resources, and does not rely on the internet or his older sibling for social interaction.

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Chapter 1

Information

Social Interactions of Children with Cerebral Palsy

Children with complex disabilities, such as cerebral palsy (CP), have difficulties participating in everyday activities. They participate in fewer activities than their nondisabled peers, and often these activities are less diverse and less active in nature (Chantry & Dunford, 2010, p. 352). As the disability increases with severity, the gap between these children and their nondisabled peers increases.

Children with cerebral palsy have limited opportunities for social interaction (Borgestig et al., 2017, p. 129). Their limitations in everyday activities can make socializing difficult. Because of this, children with CP often have narrower social networks and have more difficulties making friends compared to their nondisabled peers (Borgestig et al., 2017, p. 552; Raghavendra et al., 2013, p. 553). These children tend to feel more isolated and worry about making friends. They may have fewer reciprocated friendships and can be victimized by their nondisabled peers (Raghavendra et al., 2012, p. 149).

Despite difficulties with social interactions, children with CP still desire friendships and social belonging as much as any other nondisabled child: "Young people with disabilities are likely to have the same aspirations for friendship, participation, and recognition as their non-disabled peers, but those with developmental conditions such as cerebral palsy often have lower social participation due to the ways that individual mobility and communication skills interact

with environmental barriers" (Hynan et al., 2015, p. 5). For children with CP, limited social interactions is not a matter of motivation or desire but rather a complication of limited access due to mobility and communication differences. Given proper access to their peers, children with CP can create meaningful friendships.

Use of Technology for Social Interactions

New technologies are helping individuals with complex communication needs, which often includes cerebral palsy, connect with their peers in three main modes: alternative and augmentative communication (AAC) devices help individuals communicate in place of verbal communication; social media helps to remotely connect individuals; video games may be another source of social connection.

AAC devices allow disabled people to participate in activities and social situations with their nondisabled peers. More high-tech options have become available since the 1990s, including the creation of and ability to use smart phones and tablets for AAC (Myrden et al., 2014, p. 1112). Each individual with disabilities has unique needs, including a wide range of mobility needs for children with cerebral palsy. Technologies are able to offer unique access to each user by offering different requirements for movements, vocalizations, or facial expressions (Myrden et al., 2014, p. 1114). Finding the right AAC device for each individual is a key step in gaining full access to communication with peers with and without disabilities.

Computers are one option to allow children with disabilities to connect with others in a way that is on par with their peers. According to Chantry and Dunford's research (2010), computers aid in academics, allow individuals to showcase skills, and help bridge

communication gaps between peers (p. 355). Computers can also give access to activities that otherwise might not have been available, such as play and learning.

Current research focuses on AAC devices allowing individuals to access social media for social interactions. Hynan et al. (2015) identified that children who use AAC devices, including those with CP, want to use social media to connect with peers (p. 3). Three main barriers to making connections have been identified through research: physical access, literacy skills, and familial assistance, with physical access being the greatest obstacle. “[A]ccess to specialized equipment to aid mobility” is essential for allowing these individuals access to social media (Hynan et al., 2014, p. 181). AAC devices are able to solve one piece of the puzzle to allow individuals with complex disabilities to access social media and participate in social interactions online, giving physical access to the internet. Basic literacy skills are required for these individuals to participate in social media due to the nature of the interactions (Hynan et al., 2014, p. 181; Raghavendra et al., 2013, p. 558). Familial assistance is often needed for these individuals to access social media. Studies have found that collaboration between the individual, parents, siblings, and even friends played a significant role in aiding in social media use (Hynan et al., 2014, p. 182; Raghavendra et al., 2012, p. 159; Raghavendra et al., 2013, p. 553). Family members would assist the individuals with using their AAC devices to access and navigate social media sites. Individuals using AAC devices have expressed the desire for more privacy when interacting with peers, which isn’t always possible with face-to-face interactions due to the presence of caretakers, parents, and other adults (p. 38).

Social media allows a unique avenue for social interaction that may not be possible face-to-face for some individuals with complex disabilities. Interacting online rather than face-to-face allows individuals to communicate without focusing on time constraints, turn taking, or prejudice

(Hynan et al., 2014, p. 176; Raghavendra et al., 2012, p. 553), which may decrease anxiety and increase enjoyment for the individual. Self-representation, such as humor and telling stories about themselves (Hynan et al., 2015, p. 182), which may not otherwise be available to these becomes possible as well. These individuals will be able to participate in social inclusion, make new friends, and strengthen existing friendships through social media use (Hynan et al., 2014, p. 176; Raghavendra et al., 2013, p. 557; Raghavendra et al., 2012, p. 160).

Research is beginning to look at the benefits of playing video games. Chantry and Dunford (2010) studied the social effects of playing video games for children with complex disabilities. Results showed that these children were able to make friends through video games and have social experiences they would likely have otherwise (p. 356). The authors noted that they are unsure if friendships made through video games would encourage social interactions face-to-face, but it may be the first step for these children to begin having a more active role in their own social lives (p. 357). While this study found similar effects to social media use, more research must be conducted to make clear conclusions on the benefits of gaming for individuals with complex disabilities.

Research Question

Children with nonverbal cerebral palsy may have limited opportunities for social interactions due to communication and mobility differences. Despite having the same desires for friendships as their peers, they often feel isolated and have difficulties making friends. Using AAC devices can help a child have more opportunities for social interactions, whether it be face-to-face, through social media, or by playing video games with peers.

The aim of this present study is to use family perspectives to classify the social interactions of nonverbal children with cerebral palsy in rural areas. Rural areas typically have less diverse populations and opportunities for social interactions within a community, and this study seeks to identify how this can be a barrier to a rich social life for these children. Families will report on the types of friendships their children have, how often they are able to see their friends, and how they communicate with their friends.

It is hypothesized that these children will have limited social interactions. The social interactions they do have will rely on internet access due to limited opportunities for peer interactions in their community. They may also rely on mutual friends with their siblings rather than having their own discrete friendships.

Chapter 2

Methods

This study aimed to examine family perceptions of their children's social interactions. Participant families were recruited via word of mouth and by contacting principals of rural schools. Potential participants were given the researchers' contact information and this study's basic methods. Interested participants were to contact the researchers via phone or email for further information and consent forms.

Participants were screened by asking a single question: Do you have a child between 3rd and 12th grade with nonverbal cerebral palsy living in a rural area? If the participant answered "yes", the full methods of the study were discussed, consent forms were provided, and verbal consent was obtained.

This study was conducted with a single interview between participants and the researcher over a Zoom video call (see Appendix A). Part 1 of the interview asked the participant to describe demographic information about their child, and Part 2 asked the participant open-ended questions about their child's social life, discussing details such as access and perceived satisfaction.

The identities of participant(s) will remain confidential. Any sensitive identifying information will be excluded or altered, including the names of the participants and their family members.

Chapter 3

Results

Forty-three principals from rural schools within Venango, Clarion, Jefferson, Clearfield, and Blair counties in Pennsylvania were contacted. Two principals provided the names and contact information for families with a child with nonverbal cerebral palsy, and one family agreed to participate in this study.

In a one-to-one Zoom interview, Jacob's grandmother, Kathy, provided the following information (see Appendix A): Jacob, is an eleven-year-old boy in the fifth grade at a rural school in Central Pennsylvania. Jacob lives with his mother; grandmother, Kathy; and fourteen-year-old brother. Jacob spends time in general education and special education rooms, as well as spending time with occupational and speech therapists. Jacob has no additional diagnosis that Kathy wished to disclose.

Jacob is classified as nonverbal. He speaks in short sentences, but only his family and very familiar individuals are able to understand him clearly. This decreased intelligibility is his greatest challenge with his speech, Kathy reports. She further reported that he stays very positive about having CP, which has made him persistent with his speech, learning to write, and operate his assistive devices.

Jacob is behind two grade levels in school, largely due to his communication challenges. In addition to limited verbal communication, Jacob's fine motor skills make it functionally difficult to write. He has limited mobility in his fingers, so he requires assistance to put a writing utensil into his hand; however, muscle spasms often result in him losing control and throwing it.

He compensates for this challenge by using assistive technology in school. He is able to use the side of his hand and his knuckles to operate a Chromebook and an iPad. All students in his school district are issued a Chromebook, so both the computer and his personal iPad travel from home to school with him. With these devices, he is able to complete school assignments, read digital texts, and play games in his free time. He does use the social media platform Facebook, but he does not use it for any social interactions; he only takes quizzes and looks at the pictures on his feed.

Most of Jacob's social interactions occur during school. Almost all of his classmates are friendly to him and help him with small tasks. Since having his power chair, Jacob is able to participate with his friends during recess and gym class, which gives him social time. He does not see his classmates outside of school, however. His social interactions at home consist of children who live nearby and his brother's friends, who he seldom interacts with due to his older brother's disinterest in sharing friends. This is not an unusual attribute of sibling relationships.

Kathy notes that there are very few child-centered activities, especially for a child with a disability. Social interactions at home are infrequent and brief.

Jacob's favorite times to socialize are during community events that occur three to four times a year. Summer craft shows and holiday events are easily accessible to him, as they are mostly outside, allowing space to operate his power chair. At these events, Jacob is able to socialize with classmates and adults. Just before COVID-19 started, More regularly, Jacob signed- up to play the drums in band and drama club at school. He is looking forward to that opportunity after COVID restrictions lift.

Jacob is very family-oriented. He loves taking walks with Kathy and spending time with his uncle camping, fishing, and hunting. Kathy says he has a very adventurous spirit and will often get himself into trouble by doing tricks on his power chair. One of his favorite activities with his younger cousins is to give them rides up and down his street.

Kathy knows that Jacob has a very positive attitude surrounding his disability, but he wishes for more social interaction with his peers. Jacob is always happiest when he gets to interact with his peers and do things they get to do. He knows he cannot do everything other kids his age can, which sometimes frustrates him. Kathy's biggest concern for him is that as he and his classmates grow up, cliques will form and Jacob will no longer have a place.

Chapter 4

Discussion

The results from this case study align with the results of previous studies. Children with nonverbal cerebral palsy have limited opportunities for social interactions. Based on Kathy's

reports, Jacob's limitations may be more significant due to the few social opportunities in rural communities. Considering the challenges he faces for speech and writing, Jacob has limitations when interacting with his peers. He has friends at home and at school, but he does not appear to have any deep friendships.

Without rich social interactions in his community and internet use for socialization, Jacob is left with very few opportunities to create meaningful friendships. He does not actively participate in social interactions through the internet does not share friends with his older brother. Aside from occasionally participating in community events and seeing local children, Jacob's primary avenue of social interaction is school.

The present findings are relevant to any teacher or caretaker within a rural community. Smaller communities mean less opportunities for social interactions outside of school for all children, but especially for children with complex disabilities such as cerebral palsy. Being aware of the social challenges brought on by a child's disability and their limited communities creates a moment for a teacher or caretaker to acknowledge the challenges and begin to work towards helping these children form meaningful friendships and make connections to their community.

Opportunities for Further Research

Further research may be conducted to find correlations between a lack of community opportunities in rural areas and socialization outside of school. As Kathy suggested, all children struggle in her town, not just children with disabilities. Options utilized by nondisabled peers to generate social opportunities are less available to Jacob.

Future studies may also continue to look the use of the internet to increase social interactions for children with nonverbal cerebral palsy because virtual interaction provides sufficient time for children like Jacob to formulate their responses. In natural conversational settings, the additional time is rarely offered by nondisabled peers. The internet also provides opportunities for social interactions when community activities are limited.

Additional studies may be conducted to specifically analyze the changes in social interactions as children with cerebral palsy age. Kathy fears Jacob will lose friendships with his peers as cliques are formed, and an additional study may focus on tracking these changes and their repercussions. Age may also be a contributing factor to in sibling relationships between children with and without disabilities.

Appendix A

Interview Questions

1. Demographic Questions

- A. What is your child's name?
- B. What is your child's gender?
- C. What is your child's birth date?
- D. What grade is your child in?
- E. What school does your child attend?
- F. What classrooms are your child in throughout the school day? Examples would be a special education room, general education room, or life skills room.
- G. In addition to cerebral palsy, does your child have any other diagnosis that you would like to disclose?
- H. How many siblings does your child have and what are their ages and genders?

2. Open-Ended Questions

- A. Tell me about your child's speech. What are their strengths and challenges?
- B. How do your child's reading and writing levels compare to his or her grade level in school?
- C. What assistive devices does your child use at school? Do they bring it home with them?
- D. How would you describe your child's circle of friends? How did they meet these friends?
- E. Does your child interact with their friends outside of school? How and how often?

- F. Does your child participate in any school or community structured groups, clubs, or programs?
- G. Does your child's school offer programs designed to promote social interaction between students with and students without disabilities?
- H. What recreational activities does your child participate in?
- I. Is your child satisfied with their social interactions?
- J. Do you have any concerns about your child's social relationships?
- K. Are there any other details or information you would like to give us regarding your child and their social life?

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- **Nittany Lion Reads Federal Work-Study** | The Pennsylvania State University | On-Site Location: The First Church of Christ | Altoona, PA | February, 2018 - Present
Responsibilities: providing childcare, assisting with classroom activities, prepping activities and events, substitute teaching in emergencies
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Professional Development

Certifications

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- **OSHA, 10-Hour** | 2016

Clearances

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- **Child Abuse History (Act 151)** | February, 2018

Publications

- **"She Had a Father" Poem** | *Hard Freight* Online Literary Magazine | Fall 2019 Issue
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