



Summer Camp- Addressing the special care needs of rural children

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RESEARCH BACKGROUND & METHODS

“Camp Gizmo” is a collaborative effort funded by the WV Department of Education [Office of Special Programs], the WVDHHR [Bureau for Public Health/Office of Maternal, Child and Family Health] and the WVDHHR/Bureau for Children and Families. In-kind support is provided by WVATS, WVU Center of Excellence in Disabilities, WVU, National Seating and Mobility, and Assistive Technology Works, Inc. Each year 25 “focus families” are identified as needing support with responding to the complex developmental challenges faced by their child. Families selected have at least one child under the age of 8 years with AT needs spanning two or more areas of function. Preference is given to families from rural areas without regular access to AT specialists. The data for this study is drawn from historical records of intake data interviews completed for families planning to attend the West Virginia Department of Education’s Camp Gizmo. This a retrospective qualitative content analysis analyzes parent reports of the focus child’s child functional abilities and their goals for their child at camp.

Demographic information was gathered from separate intake data interviews of 25 separate focus children and their families purposively drawn from Camp Intake files 2013 - 2017. Of the 25 children, the average age of the focus children involved in this study was four. The children’s diagnoses included various types of cerebral palsy, visual impairment, neonatal abstinence syndrome, and a variety of genetic conditions.



DATA ANALYSIS

Qualitative content analysis was utilized to code the data and statements to questions related to priorities and concerns, difficult daily routine situations, parental goals, adaptation and modification issues, and adaptive development of the child were the focus of the data analysis. The established unit of analysis involved individual themes derived from words or statements taken from the intake interviews that reflected an emotional tone or perception regarding the child with complex medical challenges (e.g., positive, negative, frustrated, etc.) The coding scheme was derived from the data; inductive reasoning was used to condense the data into themes based on valid inference and interpretation of emotional tones and perceptions. Our analysis yielded four themes reflecting parent goals and concerns that were named verbatim using the parent’s own words. The themes are: *participate in everything possible, trying to get her not to fight so much, and he needs assistance with everything.*

EMERGENT ISSUES

Embedded in this data were some families stories that include the experiences families living below the poverty level, of custodial grandparents caring for children who had been born addicted, parents who had to relocate due to the severe flooding in the state in 2016, and families living in remote areas trying to gain an understanding of the needs and supports available for their child with a rare condition.

Gaining insight into caregiver perceptions both of the challenges they face and of the types of support they prefer offers practitioners of all disciplines a valuable tool to illustrate how policy impacts families and individuals with disabilities. The bulk of the families in study currently receive services through the ACA Medicaid expansion and will be impacted by upcoming health policy changes. Issues that seem unrelated to child health care, such as the opioid epidemic and natural disasters will also be shown to have a direct impact on the families’ perceptions of their needs and challenges as they support their special needs children.

Custodial Grandparents

The Grandparents*

- 19,310 grandparents are the householders and are responsible for their grandchildren living with them. Of these:
 - 93% of the grandparents are White and not Hispanic, 4% are Black/African American, and 1% are Hispanic/Latino, and may be of any race.
 - 47% have no parents of the children present in the home.
 - 65% are under age 60.
 - 23% live in poverty.**
- 366 grandparents in Huntington, 175 grandparents in Wheeling, and 164 grandparents in Charleston are the householders and are responsible for their grandchildren living with them.

*Comparable data are not currently available for homes where other relatives are the householders.

**100% of poverty level.

U.S. Census Bureau 2005-2009 American Community Survey 5-Year Estimates, Detailed Table B09006 and Subject Tables S1001 and S1002

- Ellis and Simmons (2014) report that 57 percent of the roughly 33,430 Mountain State grandparents who live with their grandchildren are responsible for those grandchildren. These authors note that West Virginia ranks third among all states in the percentage of grandparents responsible for their grandchildren. Of these custodial grandparents about 68% are 50 years of age or older, and most have one or more chronic disease.
- Based on the family stories from camp, Grandparents were positive about their grandchildren with developmental disabilities and cherished their role with them, but were more likely to focus on the child than to care for their own health
- Physical handling and transportation of the children seems to be far greater problem for grandparents than younger biological parents
- Grandparents seem to have better community supports and are less likely to report social isolation than the younger biological parents

2016-17 Floods

In 2016, Camp Gizmo occurred shortly after the dramatic floods in WV that made the national news. There were also significant, but more geographically limited flood shortly before the 2017 camp session. Though data collected for camp annually did not address issues related natural disasters, families reported significant challenges dealing with housing for their family with special needs.

- In 2017 families who had been impacted by floods described difficulty associated with transportation, child-care and the relocation of public schools as especially challenging
- The re-establishment of family routines was especially challenging for families, even as much as a year after the flooding event



THE TAKE-AWAY

Families were inconsistent/incomplete reporters of child functional ability through interview prior to camp. Parent/guardian reports seemed to draw out much detail about diagnosis and impairment but resulted in generalizations about actual functional abilities. Families with the greatest accuracy in functional reporting were also the families with well established family routines. Routines were identified as essential in dealing with the unexpected.

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