

Family-Centered Care Coordination for Children with Neurodevelopmental Disabilities:

An Exploration of Activities and Outcomes

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BACKGROUND

- Pediatric care coordination is defined as a “patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families.”¹
- Research suggests that families who report having adequate care coordination are more likely to perceive their child's care as family-centered, more likely to be satisfied with their services, and more likely to experience a reduction in time spent coordinating their child's care.²
- Activities of the care coordinator include assessment of needs and goals, creation of a shared plan of care, communication with family and providers, and linkage to community resources.³
- In a study of nonreimbursable care coordination activities in general pediatric practices, Antonelli and colleagues⁴ found that telephone contact was the most common care coordinator activity and represented 53% of activities logged.
- While there has been increased interest in care coordination research, there is a paucity of information on the activities, outcomes, and goals of pediatric care coordination.

OBJECTIVES

- Within an interdisciplinary neurodevelopmental outpatient evaluation clinic:
- 1) Describe family goals following neurodevelopmental evaluation and diagnosis.
 - 2) Explore the activities of the care coordinator and time spent meeting family goals.
 - 3) Determine outcomes of family engagement in care coordination following evaluation.

METHODS

- Participants**
- Between September 2017 and June 2018, 53 families were offered care coordination services as part of their child's interdisciplinary neurodevelopmental evaluation. Children ranged in age from 20 months to 13 years ($M = 5.8$, $SD = 2.4$).

Demographics		N	%
Gender	Male	36	67.9
	Female	17	62.1
Race	White	21	80.8
	African American	4	15.4
	Multiracial	1	3.8
	Did not report	27	50
Diagnosis	Other Neurodevelopmental Disorder (e.g., ADHD)	29	54.7
	Autism Spectrum Disorder	15	28.3
	Developmental Delay/Intellectual Disability	9	16.9

Care Coordination Model

- The model of care coordination involves the following steps:
 1. A Shared Plan of Care is pre-populated with information from medical and collateral records prior to the child's interdisciplinary evaluation
 2. Care coordinator meets with families during the initial interdisciplinary evaluation to identify and develop family goals; the Shared Plan of Care is updated.
 3. Care coordinator makes contact following evaluation to continue goal development and update Shared Plan of Care, which is disseminated as appropriate to child's care neighborhood.
 4. Care coordinator engages family and care neighborhood in activities in support of family goals.

Data Collection

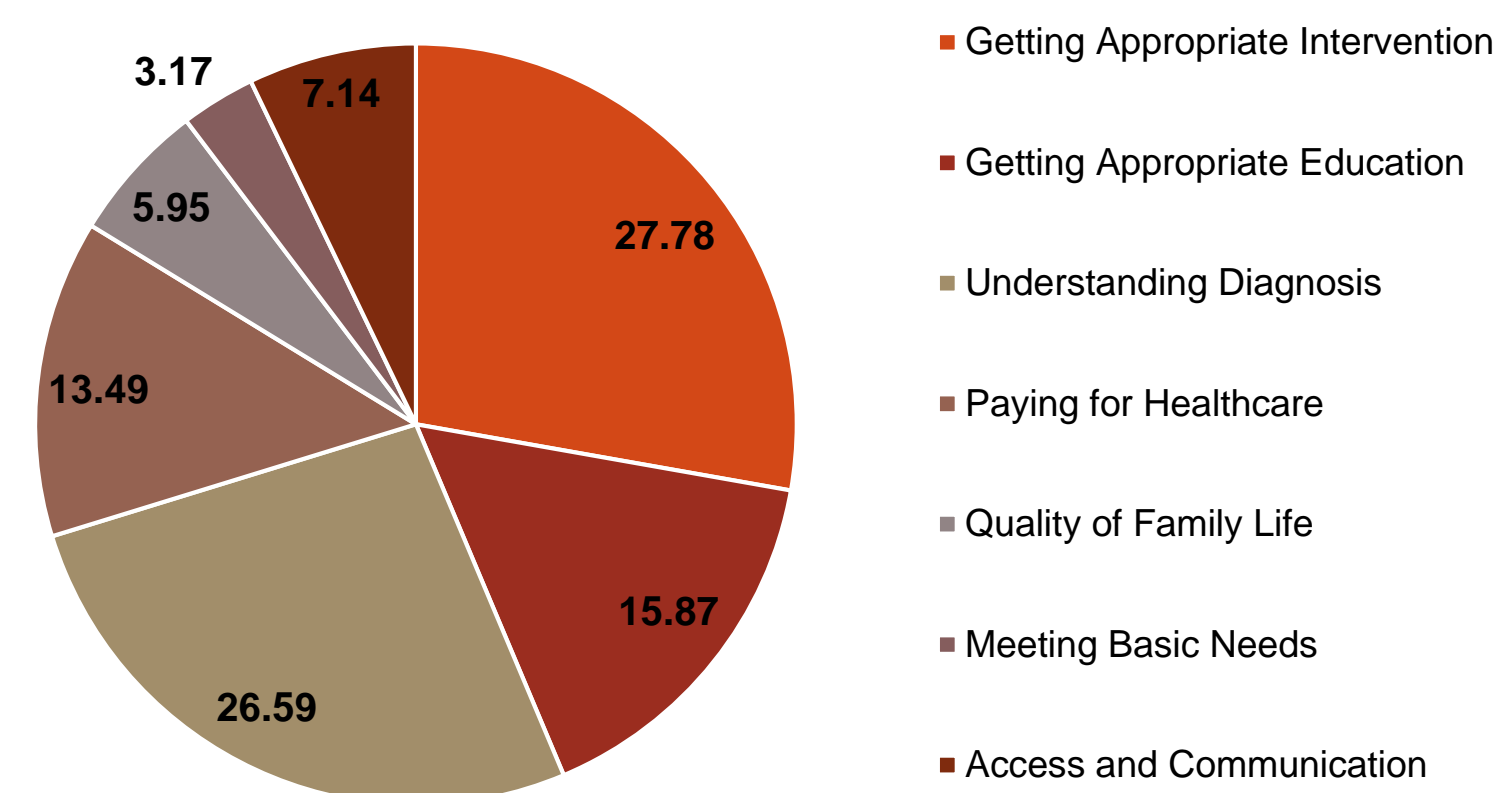
- For a period of 6 months following the family's evaluation, the care coordinator documented activities and time spent supporting achievement of the family goals in a secure research database.
- Variables of interest included goal category, activity type, time spent, and outcome(s) achieved.

RESULTS

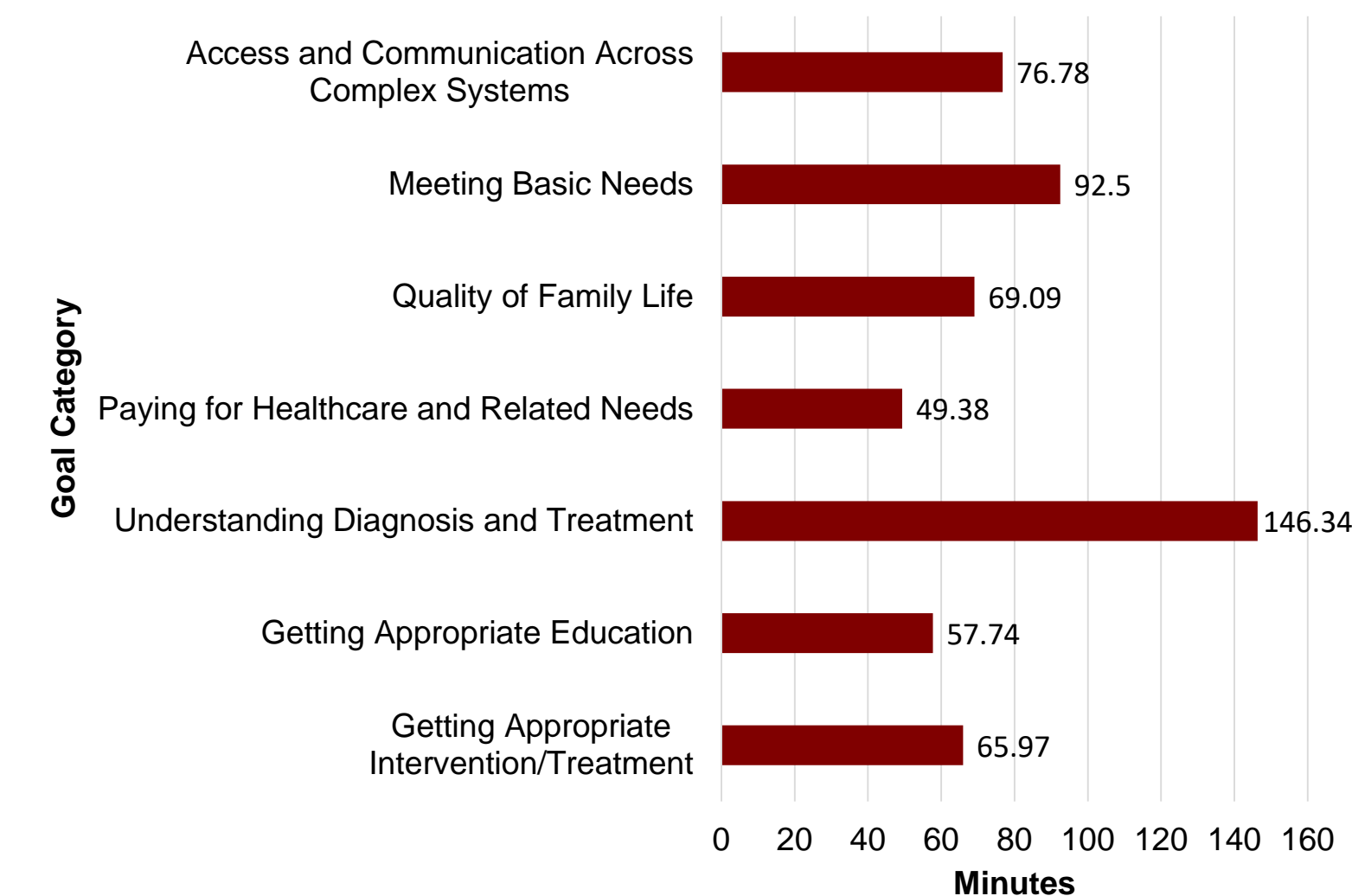
- The care coordinator categorized each family goal into 1 of 7 categories (see McAllister et al., 2018 for method of goal categorization):

1. Accessing Interventions and Treatment
 - Occupational Therapy, Physical Therapy, Speech Language Therapy, Applied Behavior Analysis
2. Accessing Appropriate Education
 - Early intervention
 - Educational planning and school advocacy
3. Understanding Diagnosis and Treatment
 - Helping family and friends accept diagnosis
 - Provision of resources
4. Healthcare Financing & Related Needs
 - Insurance and related funding needs
5. Quality of Family Life
 - Recreational & social activities
 - Respite care
 - Sibling supports
6. Meeting Basic Needs
 - Food, shelter, transportation, safety
7. Complex Care Access & Communication
 - Communication across providers
 - Relationship with primary care

Percentage of Goals by Category



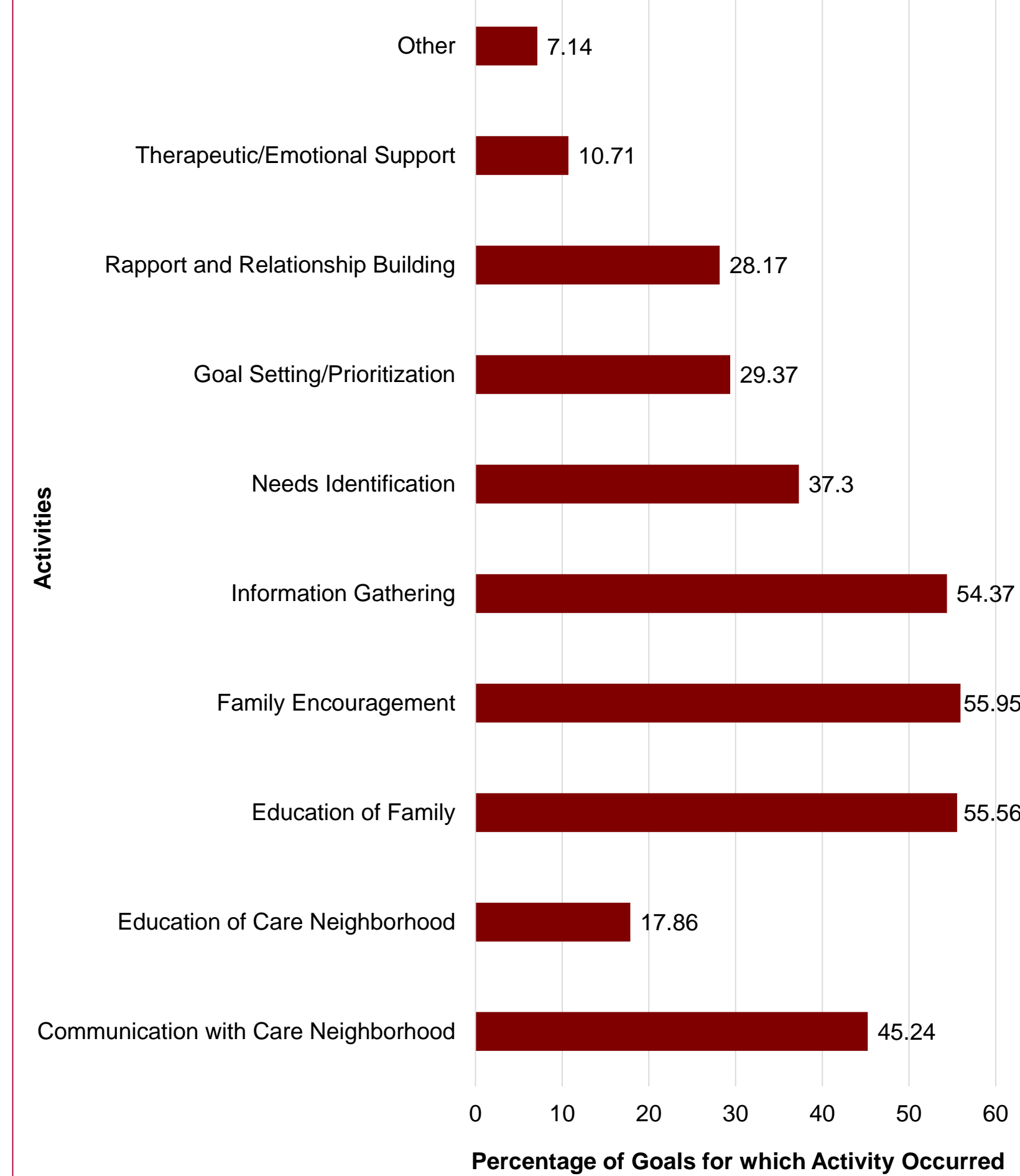
Mean Time Spent Per Goal Category



Mean time spent on care coordination per child was 346.71 minutes (approximately 5.77 hours).

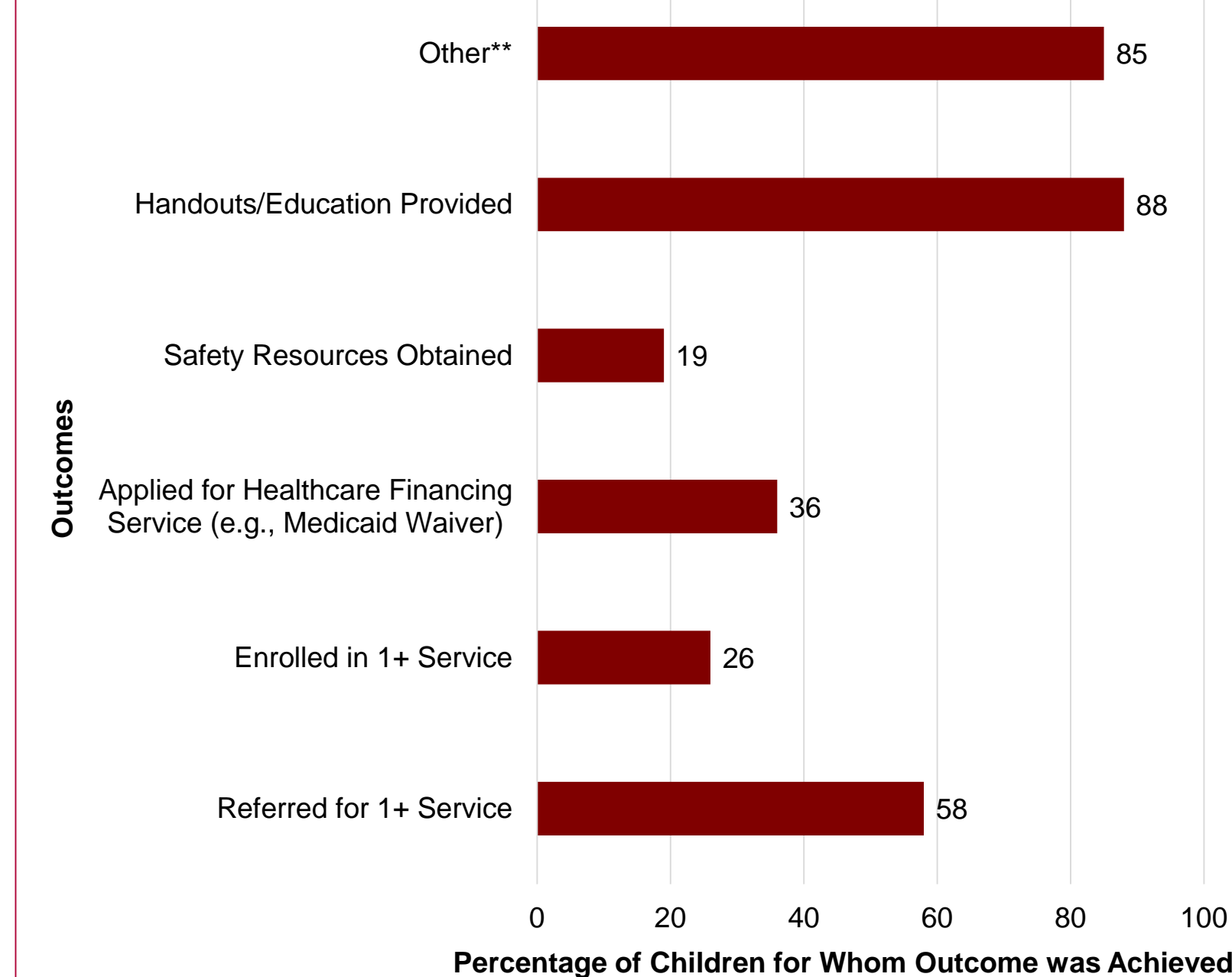
RESULTS

Care Coordination Activities



*Other activities include visits to the Riley Safety Store, composition of special education request letter, administrative tasks (e.g., documentation)

Care Coordination Outcomes



**Other outcomes include completion of a formal request for special education evaluation, increased parent understanding of diagnosis, and obtaining needed medication.

CONCLUSIONS

- Care coordination can provide families with needed support and assistance to ensure that families understand their child's diagnosis and have access to necessary services. In the present study:
 - Families most frequently identified goals centered around getting appropriate intervention and understanding the child's diagnosis.
 - The majority of care coordination time was spent on helping families understand their child's neurodevelopmental diagnosis and related interventions.
 - Most frequent care coordinator activities included providing education and encouragement to families and gathering information through record review, discussion with other providers, and locating helpful resources for the family.
 - The most frequently reported care coordination outcomes to date included providing support, developing goals, providing family psychoeducational materials, assisting families with healthcare financing, and referring the child to needed neurodevelopmental services.
- Results suggest that clinical assumptions about what the family might need and benefit from most may not match what families prioritize as goals following their child's neurodevelopmental diagnosis. Our care coordinator spent a large portion of time helping families process and understand their child's diagnosis and treatment. This highlights the crucial importance of an identified person with whom the family feels comfortable discussing their questions and concerns as a first step to meeting their child's neurodevelopmental needs following evaluation.
- Care coordination can assist children and families with effective advocacy for services and supports needed for optimal development and quality of family life. Oftentimes, this includes the goal of maximizing inclusion in the child's community (e.g., providing support related to special education and the least restrictive environment).
 - 36% of children were supported in accessing healthcare financing programs, which include application for the Medicaid Waiver and other related programs which can provide community-based services and support inclusion.
 - While not captured in our pre-determined outcomes, our care coordinator helped many families navigate the process of advocating for their child's legal rights with regard to appropriate special education services and the least restrictive environment (captured under "Other" outcomes).
- The current study was limited by the use of one care coordinator. It would be beneficial to have multiple care coordinators in the future to determine whether other care coordinators from different disciplines would demonstrate similar results. Additionally, activities, outcomes, and time for only the first six months of care coordination were tracked; however, the family's need for care coordination may ebb and flow through a multitude of child and family transitions and further research is needed to better understand these processes.
- Future research would benefit from a comparison of care coordinator outcomes with reported family outcomes to determine whether family and professional perceptions of the experience differ.

REFERENCES

¹American Academy of Pediatrics Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. (2014). Patient- and family-centered care coordination: A framework for integrating care for children and youth across multiple systems. *Pediatrics*, 133(5), 1451-1460. doi:10.1542/peds.2014-0318

²Turchi, R. M., Berhane, Z., Bethell, C., Pomponio, A., Antonelli, R., & Minkovitz, C. (2009). Care coordination for CSHCN: Associations with family-provider relations and family/child outcomes. *Pediatrics*, 124, 428-434. doi: 10.1542/peds.2009-1255O.

³Schultz, E.M., & McDonald, K.M. (2014) What is care coordination? *Journal of Care Coordination*, 17, 5-24. doi: 10.1177/2053435414540615

⁴Antonelli, R.C., Stille, C.J., & Antonelli, D.M. (2008). Care coordination for children and youth with special health care needs: a descriptive, multisite study of activities, personnel costs, and outcomes. *Pediatrics*, 122(1), 209-216. doi: 10.1542/peds.2007-2254.

McAllister, J. W., McNally Keehn, R., Rodgers, R., Mofu, P. B., Monahan, P. O., & Lock, T. M. (2018). Effects of a care coordination intervention with children with neurodevelopmental disabilities and their families. *Journal of Developmental and Behavioral Pediatrics*, 39(6), 471-480.