



Implementing a Caregiver Support Group for Children with Intellectual or Developmental Disability

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ABSTRACT

- Caring for pediatric patients with intellectual or developmental disability is both a rewarding and challenging task. We performed a needs assessment with the RHA-Howell Tar River staff to determine the potential use of a caregiver support group. From this, we developed a support group that would provide both educational resources and various forms of support to caregivers.

INTRODUCTION

- Children with disabilities are twice as likely to be in a home that is under financial stress and 3.5 times as likely to live with caregivers with both financial stress and high levels of psychological stress when compared to children who display typical development.¹
- Caregivers also display a high degree of sleep deprivation, which has negative implications on their respective lives and relationships.²

METHODS

Location and Population

- RHA-Howell Tar River in Greenville, NC. Participants will come from parents/caregivers of the patients at the RHA-Howell Center Tar River as well as from surrounding clinics (ECU Pediatrics or C5 clinic). Virtual and in-person format.

Group Facilitators

- Multidisciplinary – nurses and RHA Howell Tar River support staff, pediatricians, respiratory therapists, nutritionists, chaplains, and child life specialists.

Qualitative Evaluation

- Needs Assessment to determine how to best assist this population.
- Surveys to assess effectiveness.

RESULTS

Needs Assessment Findings:

- There are immense challenges for new parents of patients with intellectual disability, developmental disability, or complex medical care needs.
- There needs to be better forms of support for these parents as they navigate their new roles as caretakers.
- A multi-purpose support group that can achieve the education of caretakers on pertinent topics as well as provide a community of support is needed.

First Meeting Implementation Outcomes

- The first meeting was hosted by Dr. Caitlin King from ECU Health who talked about the topic, “What to Expect If Your Child Goes to the Hospital.”
- There were no in-person attendees.
- While there was ample interest for the online format for the first meeting, group moderators encountered technical difficulties trying to get the online meeting platform link to work. This meeting has been rescheduled.

JOIN OUR NEW SUPPORT GROUP

For Families of Children
Living with an Intellectual
& Developmental Disability

MEETING TOPIC:
What to Expect if Your Child Goes to the Hospital

PRESENTER:
Dr. King from ECU Pediatrics

RHA Health Services and ECU are partnering to launch a support group for families of children living with an intellectual and developmental disability. Experts will cover a new topic at each meeting.

When:
April 5, 2025
2:00 p.m. EST

Join Virtually:
rhahealth.org/CaregiverSupport

Join In Person:
RHA - Tar River
500 Sean Dr.,
Greenville, NC 27834

Please RSVP by April 2:
rhahealth.org/SupportRSVP
or call 252-758-1101
(ask for Christine)

Future meeting topics may include CAP C, community resources, hospice and end-of-life care, and taking your loved one home. If you have ideas for topics, email Spencer at cookes21@students.ecu.edu.

To learn more, visit: rhahealth.org/ChildGroup
Check this site for new meeting information in the future.

DISCUSSION

Collaboration Outcomes and Limitations

- Support groups are caregiver-centered, low-cost, relationship-based, and inclusive.
- Through this project, the RHA Howell Center Network and individuals from the Brody School of Medicine and ECU Health were able to form useful partnerships. This enables better communication and coordination of care for patients and their families.
- Certain barriers may have prevented people from showing up to the in-person portion of the meeting – language, distance, scheduling, and communication barriers. Technical barriers certainly prevented the online option from happening.
- Future meetings will need to minimize these barriers as well as consider ways in which we can make it easier for this population to both learn about the event and come to it.

REFERENCES

- 1.Goudie A, Narcisse MR, Hall DE, Kuo DZ. Financial and psychological stressors associated with caring for children with disability. *Fam Syst Health*. 2014;32(3):280-290. doi:10.1037/fsh0000027
- 2.McCann D, Bull R, Winzenberg T. Sleep deprivation in parents caring for children with complex needs at home: a mixed methods systematic review. *J Fam Nurs*. 2015;21(1):86-118. doi:10.1177/1074840714562026