RUTGERS
Robert Wood Johnson Medical School

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES
New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service

Parent-led Training about Developmental Screening for Providers at Federally Qualified Health Centers

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The Opportunity

- 1 year project funded by AMCHP
  - Act Early State Systems Grant Project
- Learn the Signs, Act Early campaign
- NJ's state Act Early team
  - Established 2009
- Focus on building collaborations and enhancing Act Early initiatives
  - Community of Care Consortium

Background

- Significant disparities in the identification and treatment of ASD, including later identification as well as misidentification.
  - Poor and minority children later
- Late diagnosis →later enrollment in intervention and →potentially poorer outcomes
- FQHCs

Project Partners

- The Boggs Center, UCEDD
- Statewide Parent Advocacy Network, PTI
- NJ Early Intervention

Project Goal:

- To improve access to developmental screening and referral among underserved children in NJ

- Objectives:
  1. Promote developmental screening using validated instruments at appropriate intervals and referral for diagnosis, Early Intervention, and community services and supports at NJ's FQHCs.

  2. Disseminate Act Early information to community providers that serve families with young children.

  3. Partner with SPAN to provide education to resident physicians about developmental screening and referral.

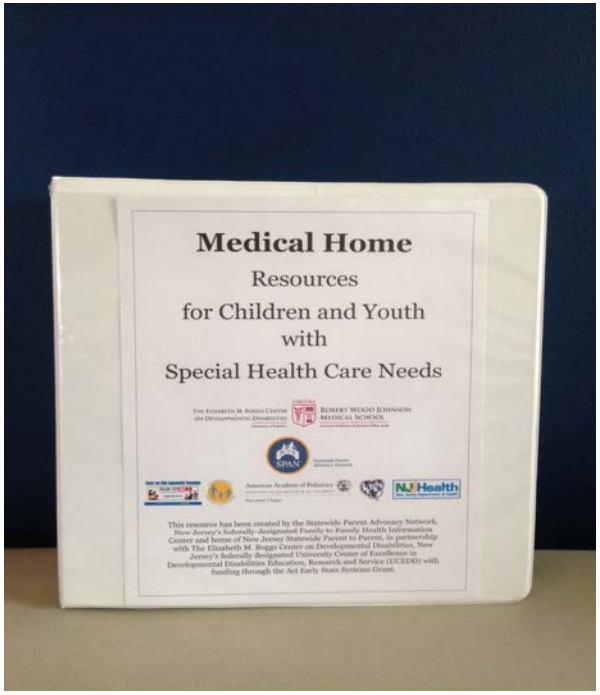
Project Activities

1. Provide a parent-led training about developmental screening for up to 15 FQHCs.

2. Provide 1 webinar about developmental screening, hosted by The Boggs Center and featuring SPAN's parent educators as presenters.

Project Activities

3. Provide each FQHC with a resource binder that contains copies of all Act Early materials, screening guidelines and tools, and other information about community resources and supports for practices and families.

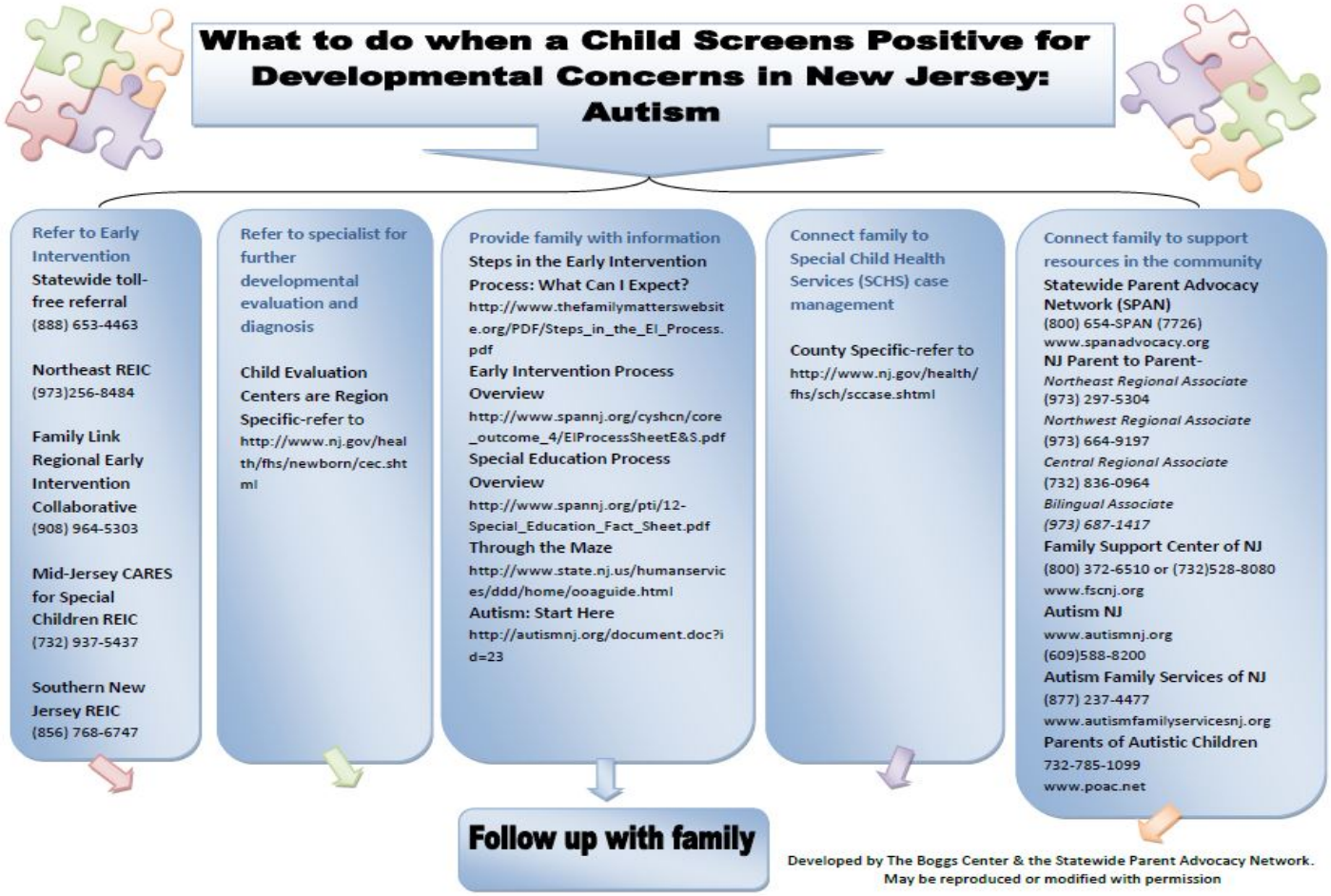


Project Activities

4. Provide the Act Early "Milestone Moments" booklets to FQHCs to be shared with patients and families.

Project Activities

5. Create flow charts for each FQHC to illustrate next steps when a child screens positive for a developmental concern.



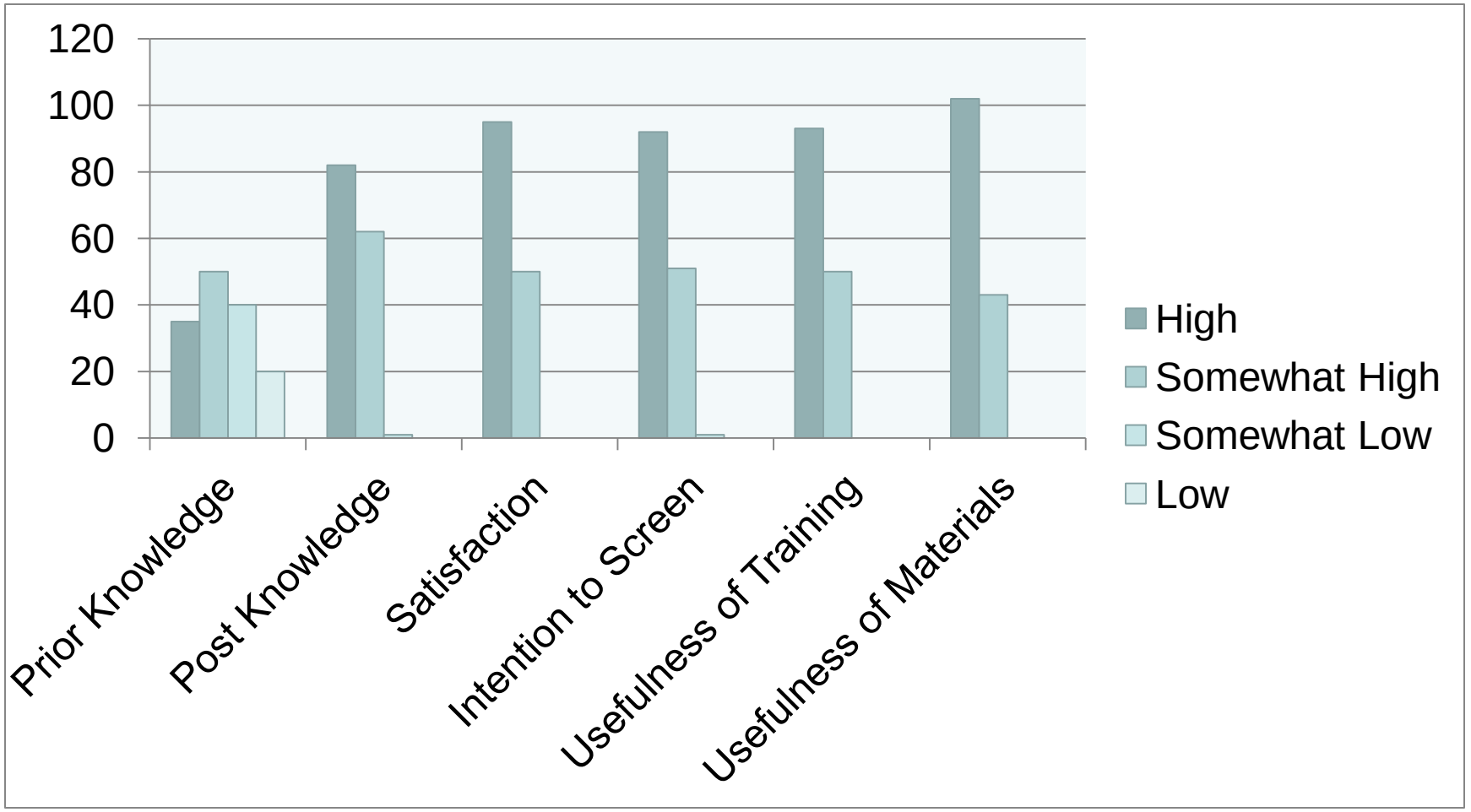
Project Activities

6. Provide training about developmental screening and referral at a noon conference for RWJMS pediatric residents.

Progress

- 15 parent-led presentations
- 195 participants
- 1500 Milestone Moments Booklets disseminated
- 15 community-specific resource binders disseminated
- 15 site-specific and 15 New Jersey flow charts illustrating next steps once a child screens positive for any kind of developmental concern disseminated

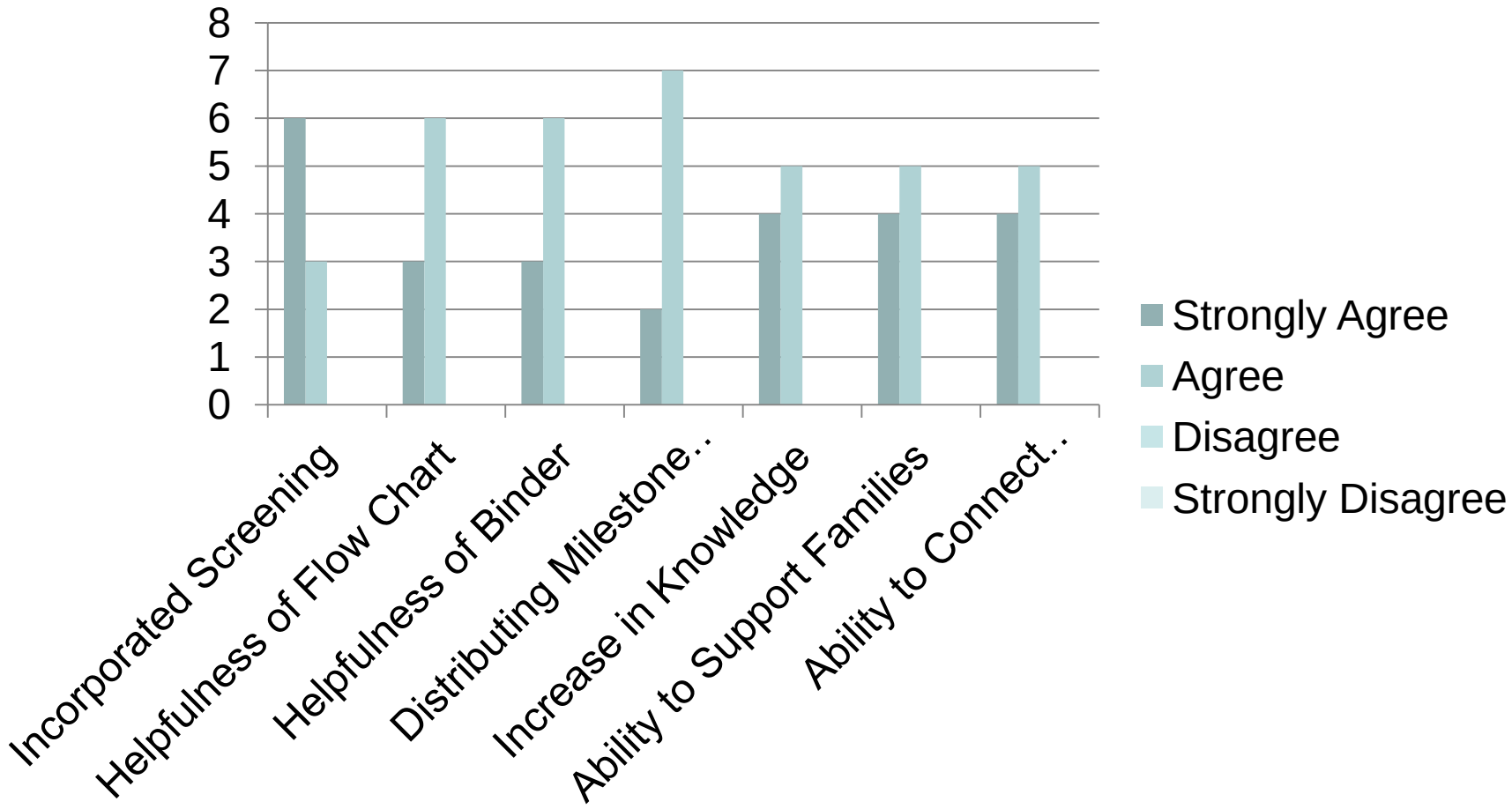
Outcomes – Quantitative Results



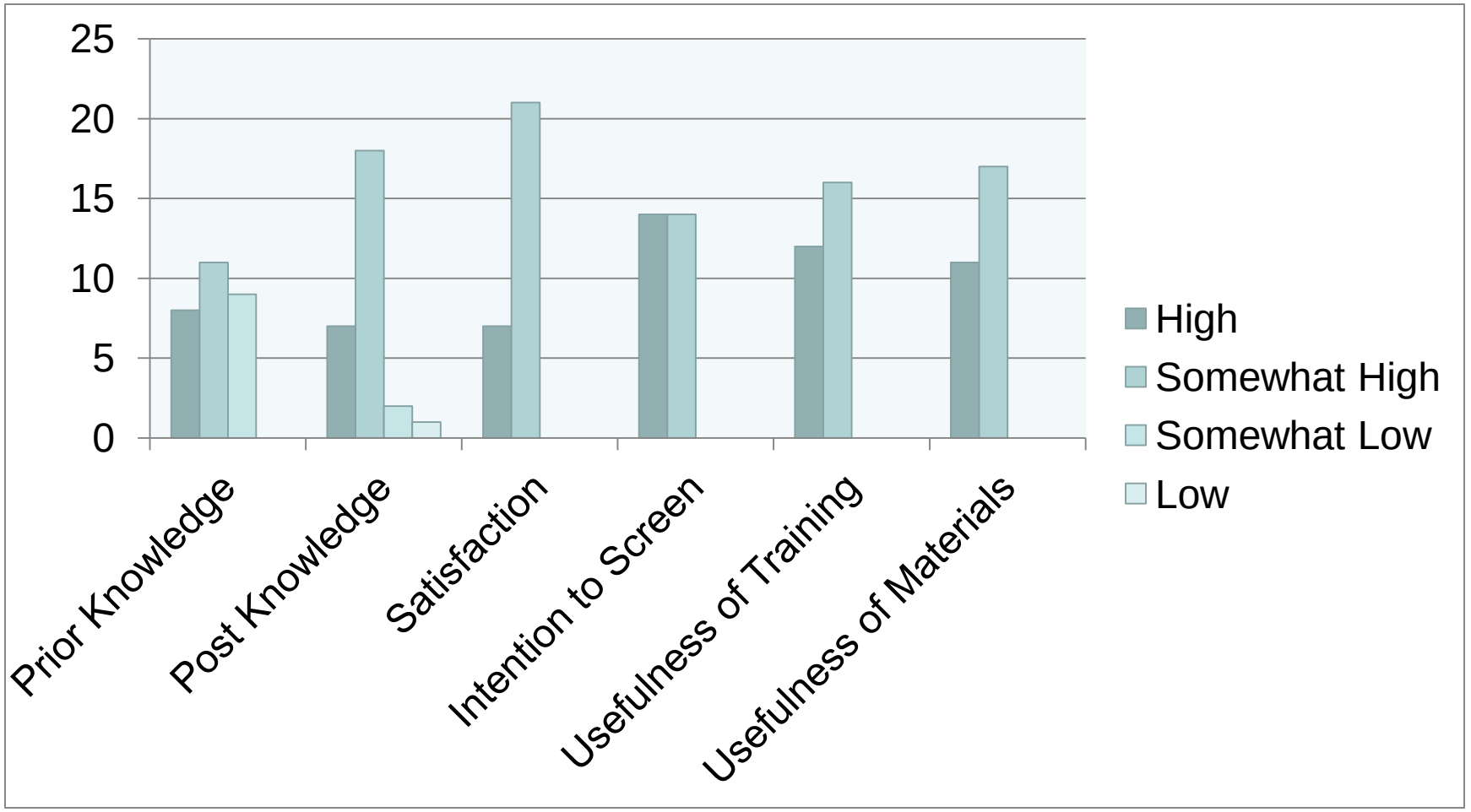
Outcomes – Qualitative themes

- Qualitative Themes
  - *Awareness of Resources for Referral*
    - one participant commented on learning about "multiple resources that I never knew existed even as a healthcare provider and as a parent with a child with autism spectrum disorder"
  - *Sensitivity*
    - "having someone who understands and can support is priceless"
  - *Importance of Early Screening and Intervention*
  - *Distributing Information to Parents*
  - *Referral Processes and Procedures*

Outcomes – Follow up



Outcomes - Webinar



Response & Feedback

- Parent stories very effective
- Appreciate that all FQHC staff were invited to participate
  - Physicians, nurses, medical assistants, receptionists, etc.
- Frustration with evaluation wait times
  - Happy to have resources to refer families to in the mean time

Project Challenges

- Scheduling trainings with exceedingly busy staff at FQHCs
  - Despite consistent outreach to FQHC staff, we were unable to schedule any training sessions for FQHCs in the southern region of the state.
- Completion of follow-up evaluations
- Difficulty in scheduling noon conference for Robert Wood Johnson Medical School pediatric residents

Next Steps

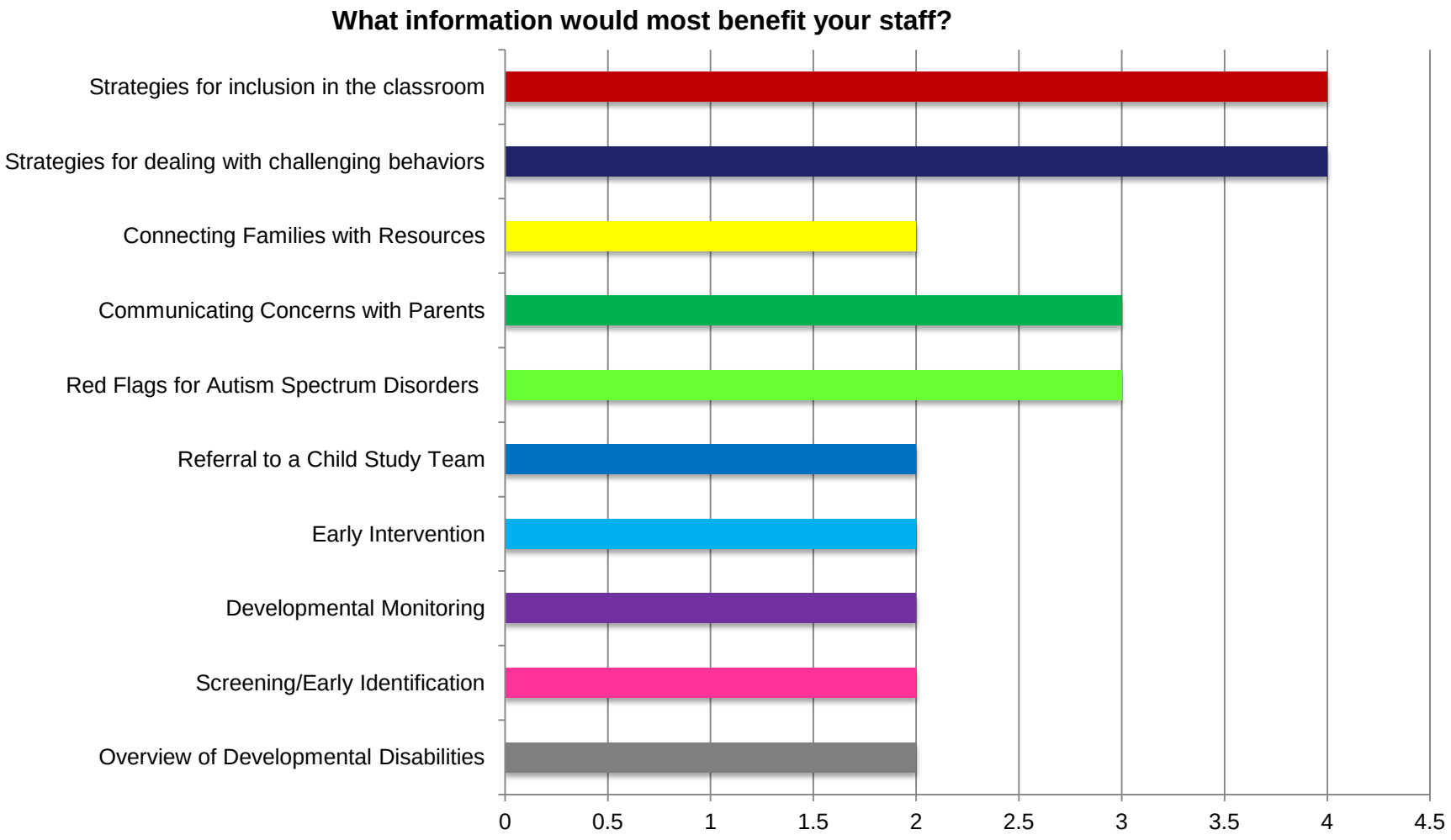
- Awarded a second grant to provide training to Head Starts and Early Head Starts
- **Project Goals:**

1. Assess training and resource needs among early childhood educators and care providers
2. Use these results to develop new materials and disseminate existing Act Early information to early childhood educators and related professionals at up to 20 Head Starts.
   - Priority for selection of training sites will be given to Head Start/Early Head Start programs that have not benefitted from currently or previously funded initiatives in the state.

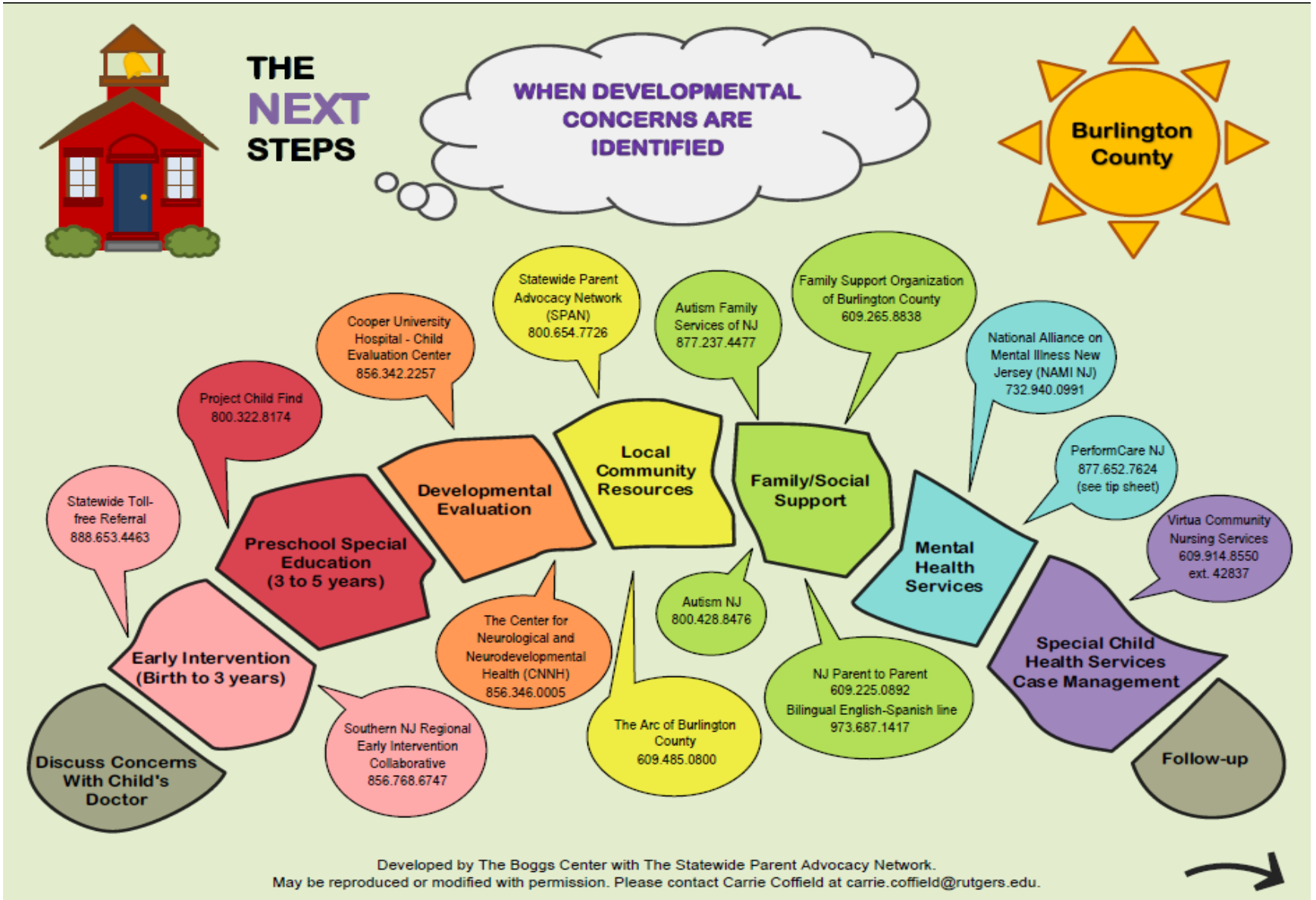
Head Start/Early Head Start Training and Resource Needs Survey

- Capture the topics and resources that would be most relevant and helpful to include in training for Head Start staff as well as to determine the time of day and format that works best.
- To date, the survey has been distributed electronically to some Head Start/Early Head Start Directors.
  - 4 responses have been obtained.
- Subsequent dissemination will be undertaken as the school year begins, to ensure completion by programs that do not operate over the summer months.

Survey Results



New Flow Charts



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Additional Resources – Burlington County Tip Sheet

Discuss Concerns with Your Child's Doctor

If you or your child's primary caretaker has noticed that your child has not reached age-appropriate milestones, ask your child's doctor or nurse practitioner for a referral to a specialist. During your appointment, you should also bring up any vision, hearing, or dental concerns.

Contact NJ Early Intervention (Birth to 3 years old)

The Early Intervention System is the primary point of entry for health and social services. The statewide toll-free number listed on the chart will connect you to someone who will guide you through the enrollment process.

Contact Preschool Special Education (3 to 5 years old)

Your local school district can give you information on transition planning, school placement, and more.

NJ Department of Education – Office of Special Education Programs
609-292-4469

Schedule a Developmental Evaluation

An evaluation team will assess your child for developmental delays, make a diagnosis if needed, and recommend a treatment plan.

Connect with Local Community Resources

Community resources include advocacy groups, parent workshops, and recreational programs. In addition to the Local Community Resources listed on the flow chart, you may also contact:

Parents of Autistic Children (POAC)
732-785-1099

Parents of Autistic Children Together (PACT)
856-278-0798

Find Family/Social Support

Consider joining a support group to share experiences and resources.

Family Support Center of New Jersey
800-372-6510

New Jersey Self-Help Clearinghouse
800-367-6274

Mom2Mom
877-914-6662

Contact Mental Health Services

PerformCare NJ connects children and their families to a variety of behavioral health and developmental disability services.

Contact Special Child Health Services Case Management

Your county's Special Child Health Services (SCHS) Case Management Unit will coordinate family-centered care for your child.

Follow-up

Keep in touch with your child's pediatrician, case manager, child care provider(s), and teacher(s).

Contact Info:

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