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"Patient Perspectives on Primary Care"

A presentation June 2, 2020 for
The National Academies of Sciences, Engineering, and Medicine

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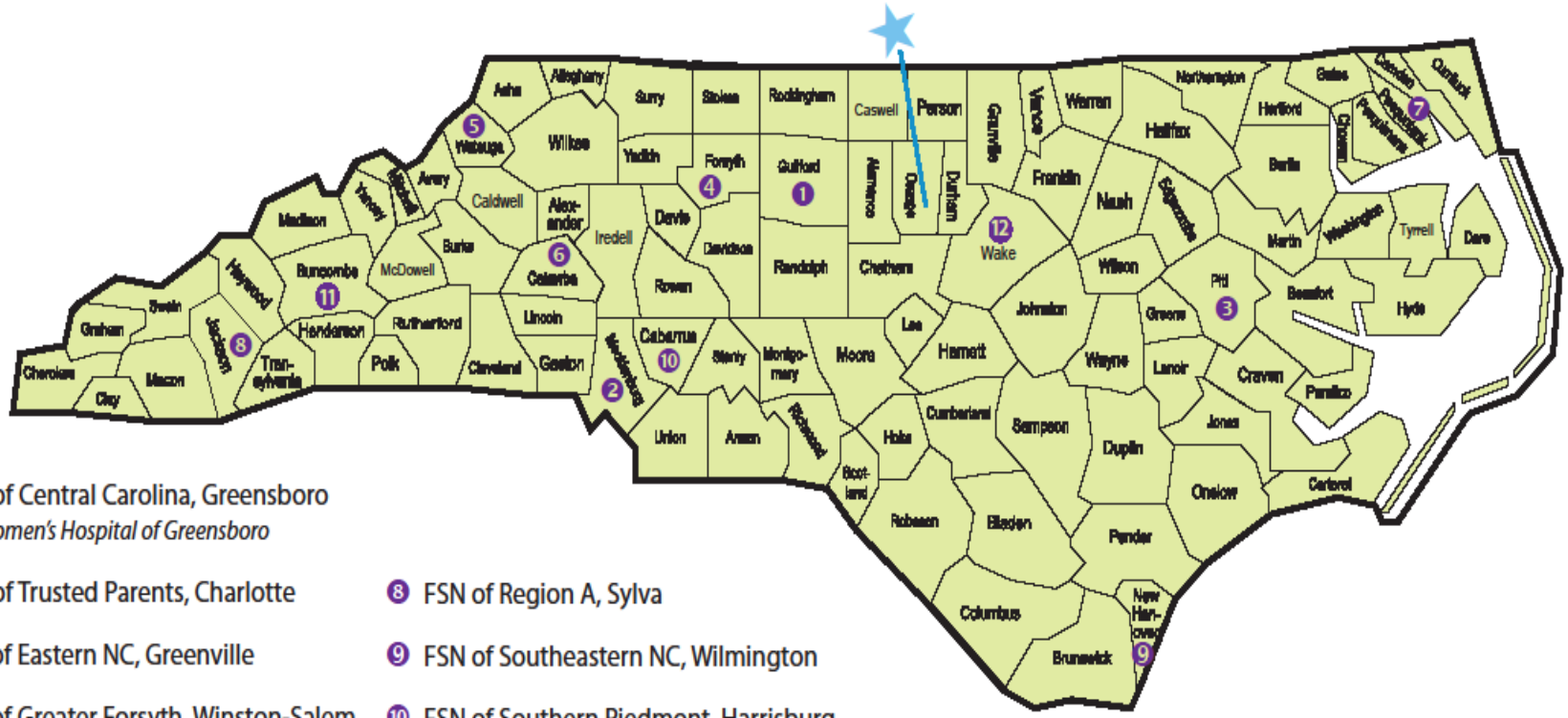
Mission of the Family Support Program at UNC-CH School of Social Work

"To promote and provide support for families with children who have special needs."

Family Support Network™ of North Carolina

A statewide network providing parent to parent matching, support parent training, support groups, information for parents and providers, workshops, Sibshops™, Neonatal Intensive Care Unit (NICU) programs, social events, lending libraries and opportunities for parent leadership. Services vary by location.



1. FSN of Central Carolina, Greensboro
   - *Women's Hospital of Greensboro*
2. FSN of Trusted Parents, Charlotte
3. FSN of Eastern NC, Greenville
4. FSN of Greater Forsyth, Winston-Salem
   - *Brenner Children's Hospital and Forsyth Medical Center*
5. FSN of the High Country, Boone
6. FSN/HOPE, Hickory
   - *Catawba Valley Medical Center*
7. FSN of Northeastern NC, Elizabeth City
8. FSN of Region A, Sylva
9. FSN of Southeastern NC, Wilmington
10. FSN of Southern Piedmont, Harrisburg
    - *Jeff Gordon Children's Hospital at Carolina's Healthcare System Northeast*
11. FSN of Western NC, Asheville
    - *Mission Children's Hospital*
12. FSN of the Greater Triangle, Raleigh

★ FSN-University Office, Chapel Hill - provides statewide information and referral, technical assistance and program evaluation.

- *NICU program*

For more information, visit our website at fsnnc.org or call 1-800-852-0042

Updated 11/2018

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Primary Care Parent Perspective

Brief survey to family organizations across the state:

- Family Support Network™ of North Carolina Regional Affiliates
- NC Family2Family Health Information Center
- Parents of Adult Children with Disabilities
- NC Council on Developmental Disabilities

Responses (n=22):

- Parents and caregivers
- Self advocates
- Family advocates

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Three Questions

- What does primary care mean to you as a caregiver of a child, adolescent or young adult with special needs?
- How can primary care better support children with special needs and their caregivers/parents?
- If you could make one recommendation for improving primary care, what would it be?

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What Does Primary Care Mean?

Basic level of routine care that includes:

- A medical doctor (PA, NP) who oversees any medical issues; a gatekeeper of information
- Coordinated care among all of my child's specialists
- Health promotion, disease prevention, health maintenance
- Identify and address potential issues before they become critical
- Diagnosis and treatment of acute and chronic illness

Patient and caregiver education and information

- Information and education about conditions or diseases
- Referral to specialists, community resources, and other supports

Health care advocate

- Addresses the whole child and related issues (medical, emotional, educational, life skills)
- Teaches parents skills to help and support their child's well-being

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How Can Primary Care *Best* Support Children with Special Needs and their Families?

- Team-based approach - share medical records, consultation with other specialists to promote and support wellness
- Co-locate specialists to deal with co-occurring conditions and complex needs of child (mental health, social work, etc.)
- Learn more about IDD, DD and other special health care needs *("I shouldn't have to be the one who explains common symptoms of my child's disability to the pediatrician.")*
- Take a comprehensive approach to dealing with the disability *(awareness of and addressing complications, side effects)*

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How can Primary Care *Better* Support Children and Families?

- Listen to caregiver concerns and be responsive
- Be more flexible – length of appointment, sensory issues, etc.
- Provide referrals to other specialists, supports, and resources
- Partner with parents to address child's educational needs
- Offer training on topics of importance (feeding tubes, healthy eating, developmental milestones, child behavior, coping, etc.)
- Talk to the child instead of just to the parent ("After all, *he* is the patient.")

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Recommendations

1. Train all practice staff on best practices in caring for children and youth with I/DD and special healthcare needs.

2. Use a checklist and pre-appointment forms to be more efficient and focus on current concerns.

3. Be flexible to accommodate child's unique needs.

4. Fully engage child and family in partnership to promote well-being and positive outcomes.

5. Adjust vocabulary so that child (and parents) understand the diagnosis, condition, and treatment plan.

6. Follow through on what you said you would do between appointments.

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Thank You!