From Research to Real Life: Increasing Visibility and Use of Family-to-family Centers

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The Study Team

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Introduction

• Support
  • Grant R40MC 17176 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services

• Study Goals:
  • Understand the characteristics of information-seeking by African American and Hispanic families of CYSHCN
  • Develop and evaluate a communications intervention to increase use of Centers as a source of information and support by these families
  • Disseminate the project findings to provide Centers in all states and territories with a tested, evidence-based approach to increasing family access to information and support through their organizations
Background

- Children from ethnic/minority families report that a lack of information about where and how to find services and supports is a key barrier to access (NS-CSHCN 2009/2010)
- To address this need for information and support, federally-funded Family-family centers were created within states
- However, when seeking information and help in raising their children, families tend to turn to interpersonal, not federal or state organizations (Halfon, 2002)
Diffusion of Innovations:
Providing the framework to address information seeking of families

• Rogers (2003) defines an innovation as an idea, practice or object that is perceived as new

• We used this framework to guide us in understanding and developing ways to present the innovation to maximize its adoption. Rogers calls this process diffusion
Stages of Diffusion

- Knowledge
- Persuasion
- Decision
- Implementation/Confirmation
What people think about when deciding to try something new

- Relative Advantage
- Compatibility
- Complexity
- Trialability
- Observability
- Re-invention
Participatory Research

• Multi-site study with data collection and intervention at three Family-to-family Centers:
  • Parents’ Place of Maryland (PPDM)
  • Exceptional Children’s Assistance Center (ECAC) in North Carolina
  • Parents’ Reaching Out (PRO) in New Mexico
• Georgetown coordinated the study, oversaw the design and implementation of study activities, provided data management and analysis
• Partner between GU and Center staff on producing the products for dissemination
Methodology

- Target population: African American and Hispanic families of CSHCN
- Focus groups with families
- Interviews with medical home providers and community service providers
- Focus groups and interviews were recorded, translated if necessary, transcribed, and analyzed.
Findings: Focus Groups

- 15 focus groups
- 105 participants
  - 55 families with previous experience with Centers
  - 50 families without previous experience with Centers
  - African American: 40 participants
  - Hispanic: 65 participants
  - English-speakers: 35 participants
  - Spanish-speakers: 30 participants
Focus Group Findings: Knowledge

- Where do families turn for information and resources about their children?
  - Pediatricians
  - Teachers
  - Internet
- When do they seek information and support?
  - When their child has a new diagnosis
  - When their child is having school-related difficulties

“Because usually if you’re getting that diagnosis at that age, you’re overwhelmed. And the school is really focused on the educational piece for your child, but the support piece of it for your family is not talked about.” – African American Family
Focus Group Findings: Knowledge

- How do they like to receive information?
  - One-to-one

“Contact using technology would be easier but it’s best to get the information we need in person. Technology is good, but it is not personal, you need to personalize it and that cannot be done.” - Hispanic/Latino Family

“For those of us that are on even lower end of technology; I can’t afford an internet. I can’t afford a computer. ... I know I’m not the only one out there that just can’t afford to keep up with technology. So I think it’s important to be able to reach those of us that are below the economic abilities to even check Facebook.” - English Speaking Hispanic/Latino Family
Focus Group Findings: Persuasion

- Relative advantages of using centers
  - Centers are assumed to have well-trained and knowledgeable staff—parents “like me”
  - Services free of charge
  - Center teaches parents how to advocate for their child

“What’s better about [the Center] is that you all live it every day, as we do. And, church, family members, other people in the community may not.”
- African American Family
Focus Group Findings: Persuasion

- Compatibility
  - Families liked that staff at center are like them
  - Offer services in Spanish
  - Family barriers to seeking services

- Complexity
  - Using center and their services is convenient and easy

- Trialability
  - Families didn’t feel pressured to continue receiving services from the Center if it was not right for them
Differences Between Groups

- Hispanics who spoke Spanish mentioned the following:
  - Use of ethnic specific community support/development organizations
  - Doctors in Mexico (NM group)
  - Limited access to internet and not able to use English language sites
Difference Between Groups

- Rural African Americans turned to government agencies
- Urban African Americans more often noted turning to health care professionals and non-profit organizations
- Urban African Americans noted prayer or God
Findings: Interviews

- 63 Key Informant Interviews
  - 30 Medical Home Provider Interviews
  - 33 Community Service Provider Interviews
Interview Findings: Knowledge

• How do they like to receive information?
  • One-on-one
  • Online/email
  • Written

“Well, I think what I would love to do is have you come to our agency and talk to us, for one... I can have you come and talk to all the managers at our meeting. I’m sure they would be happy to set up stuff for you to come and talk to their staff as well.”
- Community Service Provider
Interview Findings: Knowledge

• How do they provide information to parents?
  • Written
  • One-on-one

• When do families seek their services?
  • When there is a new diagnosis
Interview Findings: Persuasion

• Observability (positives)
  • Encouraged that Centers are run by family members of CSHCN
  • Services are free of charge
  • Centers provide workshops and training
  • Families have an advocate and are given the skills to be their child’s advocate
  • Families served by Centers get their needs met
Interview Findings: Persuasion

- Observability (negatives)
  - Contextual and perceived barriers prevent families from reaching out
  - Location of Center/transportation issues
- Observability (misconception)
  - Centers are believed to focus solely on school-related concerns
Interview Findings: Confirmation

- Re-invention
  - In few cases where services from Centers did not meet client’s expectations, the problem was found to be rectified
Next Steps

• Next phase of study:
  • Work with marketing specialist to develop marketing plan tailored to one population for each site
  • Evaluate impact of marketing plans

• Deliverables:
  • Briefs for Centers in all states
  • Articles
Overall Marketing Approach

- Develop materials that are consumer-centered not organization-focused
  - Don’t put your mission statement and photo of your staff on the cover of the brochure
  - Put a picture of people you serve and tell them what you can do for them
- Make client benefits visible – put them front and central
  - “Confidence, strength and knowledge to advocate for your child”
  - “Free services offered by people like you”
  - “You don’t have to have all the answers. We are here to help”
Overall Marketing Approach

- Promote organization as a whole, as opposed to individual “practices” – use holistic approach
  - Clients don’t need to know that you have 20 different programs supported by 20 different organizations. They want to know that you can offer help in education, healthcare and advocacy
- Let clients tell your story: Use testimonials and storytelling approach
- Meet clients where they live, play and pray
- Activate and cultivate volunteer base: use systemic approach
Marketing Approaches

- North Carolina
  - Worked with marketing specialist to develop a strategy
  - Identified community and key stakeholders reaching out to community agencies that provide services to the families of the area to form partnerships
- Direct mailing
- Offering workshops and leadership skill-building opportunities
- Health Care Coaching Peers Pilot Site
- Building of volunteer network using HCCP supported by monthly calls and site visits
Marketing Approaches

- New Mexico
  - Redesigned materials to better attract target population
  - Reached out to non-traditional recruiting locations (Laundromats, dentists, child protective offices, SSA, Income Support Divisions, etc.)
  - Reached out to previous volunteers. Through one-on-one conversations enlisted their help in promoting services and workshops
  - Contacted local radio stations and newspapers
Marketing Approaches

- Maryland
  - Focusing on one community more intensely; identified demographics & target population
  - Using face-to-face appointments in non-traditional locations; using existing networks to reach out
  - Redesigning materials
  - Using volunteers to reach out in communities; mentoring
  - Contacting local media
Implications

- Organizational implications
  - How Centers run their programs
  - Budgetary issues
- Policy implications
  - Emphasis on technology
- Research implications
  - Expanding use of theory: DOI
  - Move research closer to the community: participatory research
Participatory Research: Centers’ Perspective

• Benefits
  • Knowledge learned from families
  • Participation increases centers’ research capacity and skills
  • Participation assure that the family perspective informs the questions, the methods and the analysis

• Challenges
  • IRB training is very time consuming
  • Recruiting is not a passive process, families have to be reached personally
  • Conducting interviews was difficult: time-consuming to fit into other people’s schedules
Participatory Research: Research Perspective

• Benefits
  • Centers are in the community and tend to know the best methods to recruit and who the key players are
  • The community is familiar with the Center and comfortable making referrals to their focus groups and interviews
  • Centers collect their own data and therefore more “bought in” to the intervention before it takes place

• Challenges
  • Collecting data is out of the research team’s hands
  • Timelines are different
    • Funders do not recognize that participatory research takes longer
  • Different priorities
For More Information

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Wrap Up/Discussion

- Questions?
References

