

*Evaluating Parent VOICE:
Building Family Organization
Sustainability Through Family-
University Collaboration*

Ryan P. Kilmer, Sheila Wall-Hill,
James R. Cook, Nancy Kothandapany,
and Laura J. Weber

A 'Roadmap' for Today

- Brief introduction to Parent VOICE
- Background regarding the partnership and the need for technical assistance and evaluation
- The evaluation's multi-method approach... and a few early findings
- Discussion of issues and barriers encountered
- A consideration of the 'big' picture

What is ParentVOICE?

- A grassroots family support organization serving families and youth with mental, behavioral, and/or emotional health concerns and their siblings in Mecklenburg County, NC.
- Staffed by trained parents and caregivers of children with the above concerns.

ParentVOICE: What We Do

- Provide trainings for caregivers, youth, and siblings, as well as professionals
- Provide regular support and education for parents, caregivers, family members, and youth
- Role model effective advocacy for parents and assist parents in advocating for themselves
- Inform caregivers and youth of their rights and responsibilities

Parent VOICE: What We Do - II

- Explain and recruit for MeckCARES
- Provide information and referrals
- Participate on boards and committees
- Collaborate with professionals and policy-makers
- Represent parents and families in the community

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- Parent VOICE is a project of the Exceptional Children's Assistance Center, and is funded via a multi-year system of care (SOC) grant to our home county, Mecklenburg County, NC, as well as state funds.
 - That SOC initiative is known as MeckCARES.

Why Partner with University Faculty?

We recognized the need to demonstrate, *with data*, our effectiveness in helping families, as we work towards long-term sustainability.

We needed to be able to have evidence of our impact.

What Else Led to this Partnership?

- We also wanted to:
 - Assess the degree to which our efforts were improving family-centered practice; and
 - Track the evolving roles of family members over time, as they participated in the system.
- Parent VOICE could collect and track certain data, but could not access or address others.

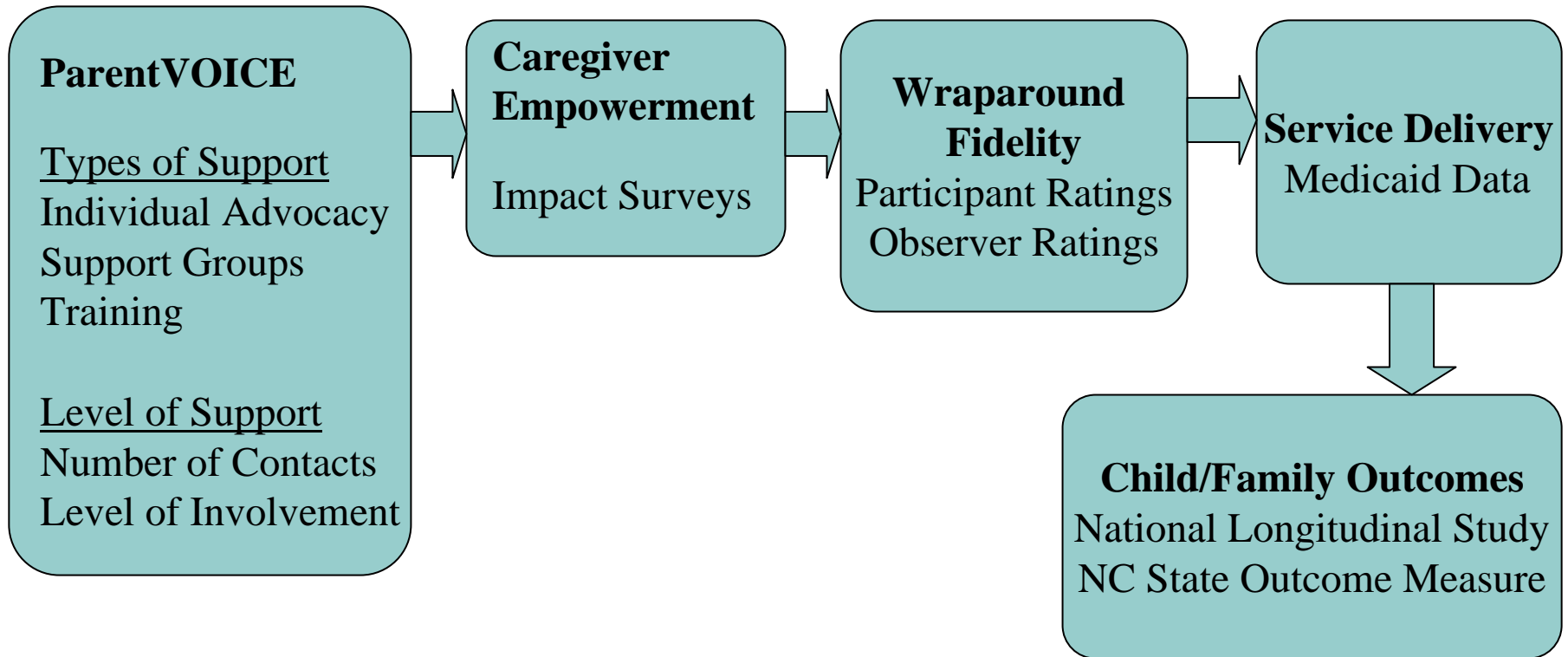
The Nature of the Partnership

- Family members have always been full partners in the evaluation's development.
- Family and university partners have worked to identify goals to ensure that the data collected would address questions of interest to ParentVOICE.
- All parties have recognized the need to develop a process that was family-friendly and would minimize staff workload.

Brief Overview of the Process: What Steps Have Been Involved To Date?

- Multiple discussions regarding ParentVOICE's goals and the nature of their questions
- Assessed information being tracked
- Recordkeeping and data management support (i.e., modified contact sheets, revamp database)
- Developed plan/logic model
- Identified/developed measures and methods – informed by logic model
- Collected and analyzed pilot data
- Identified actions to take... e.g., modified consent process

Picturing These Linkages: A Theory of Change



Tracking Parent VOICE's Impact - 1

- Parent VOICE provides support and services (e.g., parent education; empowerment groups for parents, youth, and siblings; advocacy).
 - How Assessed: Modified recordkeeping and data management to track nature and intensity of services and supports.
- These activities are expected to relate to changes in parent perceptions of themselves and their ability to advocate for their families.
 - How Assessed: Impact Survey Data.

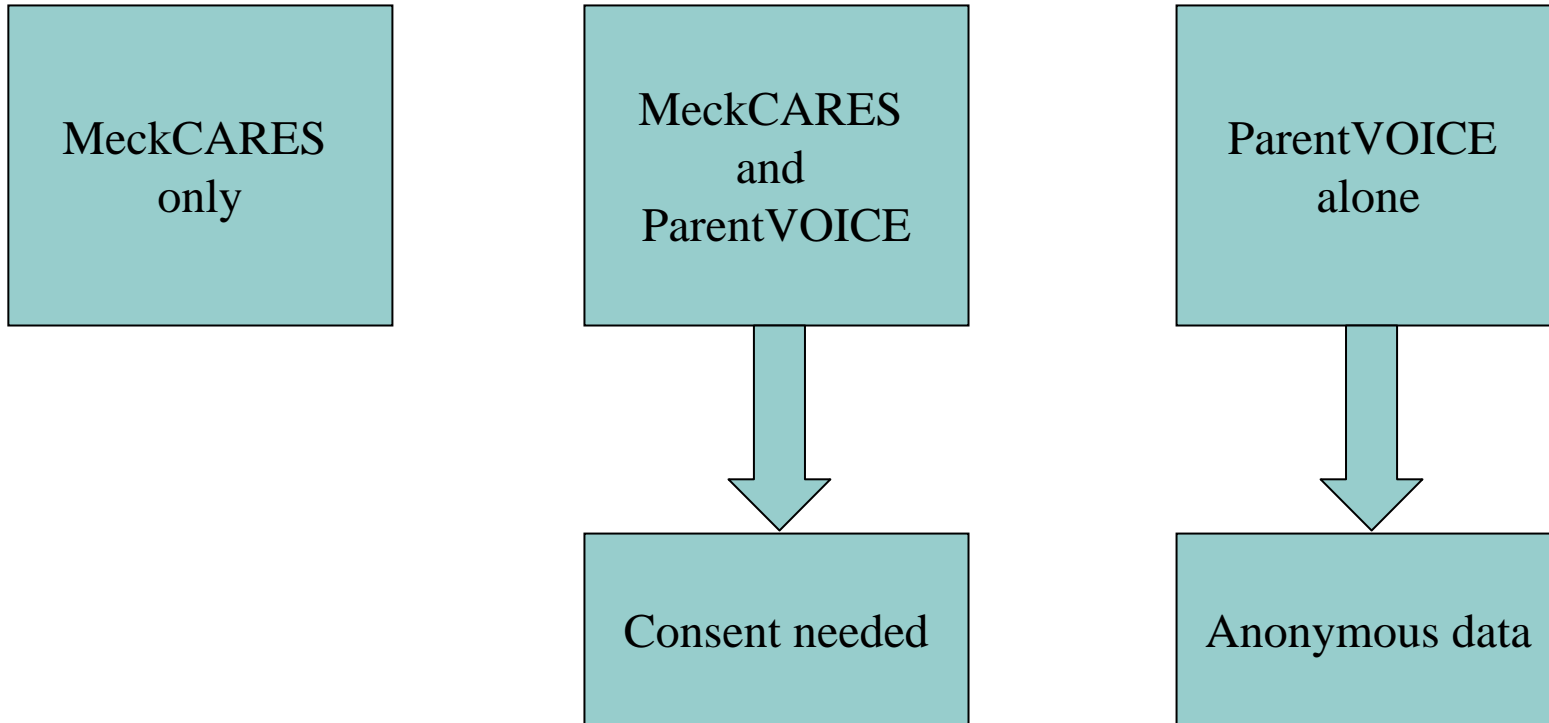
Tracking Parent VOICE's Impact - II

- Caregiver support and change are expected to contribute to improved wraparound processes used with their families.
 - How Assessed: Fidelity of wraparound assessed through local evaluation efforts for MeckCARES and for the Area Mental Health Authority.
- Improved wraparound fidelity would be expected to result in more services and less restrictive services (and/or an initial increase but later decrease in services).
 - How Assessed: Access to Medicaid service data.

Tracking Parent VOICE's Impact - III

- Better wraparound service planning and greater/more effective service provision should potentially result in better outcomes for children and families.
 - How Assessed: More broadly via the NC state outcome measure and for MeckCARES youth through the national longitudinal study.

Considering Informed Consent and Confidentiality



Data Tracking and Collection: Where We've Been

- Before:
 - 'Database' was the mailing list
 - Everything was tracked and tallied manually
 - Inefficient, not collecting information needed to demonstrate impact

Data Tracking and Collection: Where We Are and Where We're Going

- Now:
 - Revised contact sheets to reflect needed fields
 - Customized database in Access
 - Mixed success in documentation
 - Learning the ropes, i.e., growing pains with the new database
- In the Future:
 - All staff will be consistent in documentation
 - Increased ability to manipulate the database and produce reports

How Those Data Get Used

- Summaries of efforts to funders and system administrators
- For example, during the last quarter:
 - ParentVOICE received 20 new referrals for MeckCARES
 - 461 contacts made for information and referral
 - Empowerment Groups: 41 attendees, 13 for the first time
 - Staff members attended 44 meetings with families as a support person
 - Youth support/training: 135 contacts with youth, 21 new to the program; 70 youth (total) attended the 3 support groups
 - 120 contacts with siblings, including activities, mailings, leadership team meetings, and outreach activities

How Those Data Get Used

- For evaluation, we are tracking those served, reasons for the contacts, actions taken, etc., so that we can assess relationships between these factors and various outcomes

Beyond Changing the Way We Track Our Activities: Procedures for Pilot Impact Survey

- In May, 2007, attempted to contact by phone 63 parents/caregivers who had a minimum of 3 contacts with ParentVOICE since January, 2007.
- Completed surveys from $n = 34$; 6 refusals
- Eight-item survey, with responses on 1 (strongly agree) to 5 (strongly disagree) scale
- Three open-ended items at end
- Averaged less than 5 minutes in total

Pilot Impact Survey: Some 'Early Returns'

On the basis of their experiences with ParentVOICE (i.e., information, support, etc.) caregivers reported:

- Being better able to access services and supports [$M=1.40$; $SD=.74$].
- Having used the information and support provided by ParentVOICE to improve services for their families [$M=1.37$; $SD=.81$].
- Being more effective advocates for themselves and their child(ren) [$M=1.53$; $SD=.99$].
- Using the information about their child's rights to help him/her in school [$M=1.82$; $SD=1.10$].

More Early Impact Survey Findings

On the basis of their experiences with ParentVOICE (i.e., information, support, etc.) caregivers reported:

- A better understanding of their child's mental health issues [$M=1.88$; $SD=1.17$].
- Feeling more confident talking to professionals about their child's needs [$M=1.53$; $SD=.93$].
- Being actively involved in the decisions involving their child [$M=1.32$; $SD=.81$].
- A greater sense of hope regarding their child's future [$M=1.71$; $SD=1.19$].
- Overall across 8 items: [$M=1.57$; $SD=.99$].

Additional Survey Findings

In response to open-ended items, some themes emerged, including a desire to see ParentVOICE:

- Increase involvement with their child[ren]'s schools;
- Offer more opportunities targeting grandparents as caregivers; and
- Provide transportation for those eager to participate in groups but without the means to attend.

Also, 100% of respondents said they would be willing to complete a similar survey again.

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- The impact survey with families is a good start – and an important feedback mechanism – but that’s not enough. We need multiple methods...
 - Tracking data regarding their contacts – going to link with outcome data

Strengths and Assets of the Partnership

- Parent VOICE director's investment and recognition of the need for data to support their efforts
- Diverse make-up of those involved in the evaluation's development
- All parties have a voice
- Openness, willingness to listen, and style of the university evaluators in shaping an approach that will yield useful, 'actionable' information
- The team's commitment to the collaboration

Issues and Obstacles Encountered

- Family group members and evaluators often speak different languages
- ParentVOICE staff are sufficiently burdened with their regular responsibilities; the evaluation is not (and cannot be) their top priority
- This process takes time; family groups' scope of work does not typically include or fund evaluation
- Family groups often do not see the value of evaluation

After Months of Work Together... Chalking Up the 'Little Victories'

- Developed a clear understanding of the mutual benefits of working together and trusting each other
- Shared expertise re: Systems of Care and family support generally (UNCC) and the needs and expectations of families and the types of changes seen in families (ParentVOICE)
- Identified data to be collected and developed mechanisms for collecting and managing the data

More 'Little Victories'

- Identified questions that, if answered, can help ParentVOICE better serve families and document its impact for funders (and have a broader relevance for policy and practice).
- Have begun to develop methods to address these questions.

Considering the Larger Picture: Conclusions, Implications, and Next Steps

- Only such partnership in the state
- Can serve as a model for other groups...
- In fact, it is: grant proposal in process
- Where do we go from here?

Sustainability Planning Has Begun

- Advisory Committee identified (made up of staff, professionals, local family members, and family members who have experience in family-run organizations around NC); 4 meetings over 4 months with consultant
- Evaluation data will play key role

Take-home Points

- Evaluation (i.e., documenting impact) a key sustainability issue.
- The process is incremental and iterative... there will be ‘baby steps’...
 - And sometimes with every 2 steps forward, you’ll take two back...
- Sound evaluations of family support organizations require multiple methods.

Contact Us at ParentVOICE

Sheila Wall-Hill, Director

Nancy Kothandapany, Data Coordinator

ParentVOICE

3430 Wheatley Avenue

Charlotte, NC 28205

Phone: 704-336-7128

E-mail: parentvoiceSWH@aol.com
parentvoice01@aol.com

www.charmeck.org/Departments/MeckCARES/ParentVOICE.htm

Contact Us at UNC Charlotte

Ryan P. Kilmer, Ph.D. & James R. Cook, Ph.D.

Associate Professors of Psychology

Department of Psychology

UNC Charlotte

Charlotte, NC 28223-0001

Phone: 704-687-3689 / 704-687-4758

E-mail: rpkilmer@uncc.edu / jcook@uncc.edu

Contact Laura Weber

Laura J. Weber

Technical Assistance to Parent VOICE

Training and Consulting Services

3803 Pershing Court

Greensboro, NC 27408

Phone: 336-288-9264

E-mail: ljweber40@aol.com