How Family Driven Research Takes Family Voice and Impacts Policy and Practice in Three States

Lisa Lambert, Parent/Professional Advocacy League
Gail Cormier, North Carolina Families United
Laura Wallis, Parent Network

31st Annual Research and Policy Conference on Child, Adolescent and Young Adult Behavioral Health
March 5, 2018
Family Driven Research

Family driven research works to capture the experience of families whose children have behavioral health and/or other special needs

- Topics are chosen which are important to families
- Families collaborate in developing the questions and choosing the language
- Families can be involved in distributing the tool and collecting data
- Families are involved in evaluating results
- Findings are disseminated in media that are accessible to families
- Results are often used to advocate for changes that benefit families and youth
- Families can be involved in developing advocacy goals and steps
- Families are partners and shown appreciation and thanks
Unique Ability of Family Run Organizations

• Network of families connected to social media
• Families want to participate and give back
• Family run orgs have credibility
• Families are rarely asked about their opinions and experiences in a way that matters to them
• Family run orgs know how to speak to families (jargon free, neutral terms)
• Use results to make positive change in policy and practice
### Paradigm Shift to Family Driven Research

<table>
<thead>
<tr>
<th></th>
<th>Researcher Driven</th>
<th>Family Driven</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Source of questions</strong></td>
<td>University faculty, graduate students, pharmaceutical companies, provider agencies</td>
<td>Families, school personnel, policy makers, and providers</td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
<td>Better understanding of topics of interest to the research community and sponsors – usually to enhance the professional standing of researchers as well</td>
<td>Advocacy tool for system change higher academic achievement, and improvement in quality of life for children and families and continuous quality improvement in school system operations and outcomes</td>
</tr>
<tr>
<td><strong>Dissemination</strong></td>
<td>Research journals and professional meetings and publications – highly technical language</td>
<td>Newsletters, magazine articles, videos, conferences, public forums, legislative hearings, reports to funding sources – common vocabulary and multiple languages and formats</td>
</tr>
</tbody>
</table>

Expanding forms of data collection

• Stories and anecdotes
  – Illustrated experiences, barriers
  – Limits include number of scope of problem

• Themes and trends
  – Shows emerging issues, helps project future impact

• Focus groups
  – In the wheelhouse of family orgs
  – Limited number of participants, time intensive

• Quantitative data such as surveys, evaluations
  – Data gathering software became user friendly
  – Collect information from larger number of participants
How Family Run Organizations Collect Data

Data collection methods

1. Online survey tools (c,d)
2. Quick polls such as polldaddy (d,e)
3. Google tools (c,d,e)
4. Paper surveys (d,e)
5. Focus groups (a,b,e)
6. Interviews: structured, semi-structured, informal (a,b,d,e)

Considerations

a. Some methods better at gathering experience and opinion
b. Some are more/less time consuming to implement
c. Some gather larger number of responses
d. Some match needs or style of families
e. Some are more/less expensive
Choosing a Research Partner

• Must share values about families and family involvement
• Comfortable with families taking the lead
• Practice participatory research
• Have needed expertise
• Interested in the long haul
• Comfortable with involving the community
Working with Partners

• Partner with others
  – Choose others who value family/youth participation
  – Partners may have questions only families can answer

• Partner with mental health and medical professionals

• Partner with academic institutions

• Partner with state agencies including mental health, education, child welfare, juvenile justice

• Partner with other consumer or family run organizations

• Working with youth to collect youth data
Goals of Family Driven Research

• Collect and amplify family voice and experiences
• Use the responses of families and their children to define needs, barriers and experiences
• Create improvements at practice and policy level
• Quantify the needs of families and their children
• Involve families as partners
• Create acceptance of and appetite for family driven studies and data
• Connects data to individual experience
Impact and Results

• New partnerships, new ways to partner
• Use of family organization data by partners to go after funding, create change
• Use of findings to create new practice approaches
• Including family input into research becomes standard practice
• Demystify concepts of data and research for families
• Shift to the satisfaction of services away from claims data, demographic data and process measures
Gail Cormier Executive Director
FREDLA president/Co-Founder
Learning Objectives

• Describe the process of family driven research and its unique ability for obtaining valuable data from families
• Understand how data highlighting the experience of families directly shapes policy solutions
• Through discussion, participants will learn how family organization data can augment their formal evaluations
• Give examples of the range of research conducted by family run organizations
Some Highlights

- 1996 Pen PAL in 3 counties
- FACES- 5 counties
- Child Welfare- 3 Counties
- MECKCARES
- Alamance Alliance
- SOC Expansion- statewide
The Evolution of Research with Family Members as Partners

- **1996 Pen Pal**
  - Parents were asked to sit on an advisory committee. 2 Parents helped the data collection team by calling families served and asking satisfaction questions designed by University staff.

- **2000 FACES – 5 Counties**
  - 6 Family Members sat on Advisory Committee. Several were asked to be part of an evaluation sub-committee to design questions for parent satisfaction. 3 Family Members paid to call families to collect the data. 4 Family Members hired as faculty at the University to co-teach SOC and family involved data collection.

- **2004 Child Welfare**
  - The State Family Organization (NCFU) contracted to oversee and conduct satisfaction calls.

- **2005 MECKCARES**
  - The grant funds a local family organization to help support data collection. This includes parent satisfaction surveys, involvement in research, design and analysis of data and inclusion in written documents.

- **2009 Alamance Alliance**
  - Family Organization is contract to have staff on evaluation committee to design and implement. 3 Family Members hired to conduct door to door surveys using design questions. 1 Data Family Data Specialist hired to conduct NOMS, and satisfaction calls. Families analyze and publish reports based on data. Data shows Families do better with Peer Support. Pushes Family Partner Peer Support into mainstream. Family Organization triples staff contracts for Family Partners.
2014NC System of Care Expansion (SOC XP)

NC DMHDDSAS PI

Flo Stein & Walt Caison

State & Family Partner Organization Project Oversight

Eric Harbour, NCDMHDDSAS

Gail Cormier, NCFU

Project Management Team

Terri Grant State SOC Coordinator
Petra Mozzetti Implementation Specialist

Terri Reichert Project Manager
Lisa Lackman UNC

Laura Muse NCFU Family/Youth Director

NC State Collaborative for Children Youth and Families (State Advisory Board)

Joann Scaturro Co-Chair

Stacy Justiss Co-Chair
Families partner in SOC EX Governance

Families partner as grant administrators

Families and Youth doing direct service peer support work
2014 SOC EX Partnership

• NC Families United brought grant idea to state partners
• NC Families United co-wrote application
• NC Families United oversees, contracts, supervises Evaluation team.
• Families included on team
• Family and Youth collect NOMS and all data
The co-partnership has been recognized nationally and statewide.

- SAMHSA site visit May 2017 – strongest family partnership
- Best trained Family and Youth Peer Support
- Excellent State Collaborative
- Wraparound Innovations Award for state and family partnerships in SOC sites
- Well developed State and local YouthMove Chapters
PIT FALLS
and
Steps Backward

• Still need to involve more families and youth in evaluations
• Youth still not part of process
• Evaluators did not understand why Cost Effectiveness for Peer Support should be part of evaluation
Final Thoughts from North Carolina

• Family Organization and state grew stronger partnerships
• Because of successful data Family Peer support written into in lieu definition
• State B3 is designed to include family partner peer support (not approved yet)
• NC DHHS MEDICAID feels we need stronger data to support position B3 may not pass 😞
Laura Wallis, P.E.

- Mom
- Volunteer
- Engineer
- Advocate

The Parent Network promotes a children's mental health care system in Idaho where parents are viewed as valuable experts on their children, and treated as full and supported partners while having access to appropriate community based mental health care services and supports.
Youth Empowerment Services (YES) is the result of the Jeff D. Class Action Settlement Agreement

The impacted agencies include:

- Department of Health and Welfare
  - Division of Behavioral Health
  - Medicaid
  - Family and Community Services (Child Welfare)
- State Department of Education
- Department of Juvenile Corrections
The **Parent Network** is actively involved with the creation of the State of Idaho’s new children’s mental health system of care, **Youth Empowerment Services** (YES).

We participate by contributing parent perspective to:

- Task Specific Workgroups
- Messaging and Training
The Parent Network contributes parent perspective to YES by:

- Creating parent surveys to gather statewide data
- Collecting stories from families

That information is then shared with YES workgroups to inform project decisions.
The Parent Network partnered with other children’s advocacy groups to extend our survey’s reach.
Data collected from the **Parent Voice** surveys allows policy makers to see how the system is currently working.
How do you define a crisis?

Collecting stories from families also helps policy makers understand how families view important topics.

“We learned that crisis services **MUST** be available to support families with aggressive kids.”

“Any situation that escalated to a level where as a parent I can no longer ensure the safety of my child or others around my child.”

“Raging and destroying property in our home, becoming physically aggressive with others, threatening suicide with a plan.”

“Out of control meltdown, extreme depression”
There are 4 main ways that the Parent Network uses the information collected from surveys and their own lived experiences to help the State.

1. Parents participate on (and even chair) task specific workgroups which produce project deliverables.

2. Parents assist the state in creating project messaging that is relevant and useful to families.

3. Parents help develop services to be family friendly.

4. Parents deliver trainings to state employees, providers, and other parents.
How do you get PARENT input into your system?

1. Recognize the value of these “SYSTEM USER EXPERTS.”

2. Find CHAMPIONS in all areas of your system that have the authority to add parents to the process.

3. Invite parents to PARTICIPATE EVERYWHERE!

4. RESPECT your parent team members the same way you respect your employees.

5. Add them to your PRESENTATIONS and your TRAININGS.
As a **PARENT**, how do you get involved?

1. Recognize that you bring the voice of a “**SYSTEM USER EXPERT.**”

2. Find the **CHAMPIONS** that already exist in your system and work to build the relationships needed to create more.

3. Ask to **PARTICIPATE EVERYWHERE** and learn more about the areas you are involved in.

4. **RESPECT** your project team members as they work hard every day to improve the system.

5. Ask to help with **PRESENTATIONS** and **TRAININGS** because your voice is unique.
When thinking about the impact of parent voice in the process of changing our current systems of children’s mental health care, I want you to remember one thing...

Together our voices are strong!
Introducing Parent/Professional Advocacy League (PPAL)

- A statewide, grassroots family-run organization based in Boston and Worcester Massachusetts
- Founded in 1991, PPAL is the state organization of the National Federation of Families for Children’s Mental Health and a founding member of FREDLA
- PPAL’s goal is to promote opportunities for families to become strong leaders and to increase and sustain parent and youth involvement at all levels of the system
- PPAL is the only organization in Massachusetts representing the interests of families whose children and youth have mental health needs
Why we started collecting data

- It’s not enough to use anecdotes--in a sophisticated state
- Way to push policy, legislation
- It’s part of our mission
- Parents are the Amazon reviewers, the Consumer Reporters and the mystery diners of the children’s system
- Way to grow network
  - Families and youth want to give back
  - Some families can’t testify, speak publicly, but can do fill out surveys, polls
Collecting data is essential to us

• Began in 2000 with a survey about access
• Families are rarely asked about their experiences and perspectives
• Collect information in different ways:
  – Through phone log and service data
  – Through surveys—formal and informal
  – Through quick polls, social media (pose questions)
  – Evaluations
• Surveys receive 200-500 respondents
• Promote our data collection at every stage
• Make it easy to read and access
How we do it and what we know

Ways we collect data

• 14 surveys since 2000
  – 2 more underway
  – 3 pop up surveys
• 120 monthly quick polls on website
• Targeted questions to use in testimony, at hearings or to answer questions posed by funder
• Satisfaction survey underway for justice involved families
• Youth led focus groups and youth-adult collaboration on surveys

What we know

• 85% of families say child in on IEP or 504
• About 60-65% are on Medicaid
• Race/ethnicity of parent follows census
• Race/ethnicity of child is sometimes not the same as parent
• Parents of young adults want to be included in data
• Parents have strong opinions
## Research topics

<table>
<thead>
<tr>
<th>Topic</th>
<th>Date</th>
<th>Responses</th>
<th>Topic</th>
<th>Date</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to care</td>
<td>2001</td>
<td>301</td>
<td>EHRs &amp; privacy</td>
<td>2015</td>
<td>203</td>
</tr>
<tr>
<td>Medications</td>
<td>2006</td>
<td>274</td>
<td>Co-occurring disorders</td>
<td>2015</td>
<td>115</td>
</tr>
<tr>
<td>Youth Initiative</td>
<td>2009</td>
<td>n/a</td>
<td>Access – Pop Up</td>
<td>2016</td>
<td>102</td>
</tr>
<tr>
<td>Parent Priorities</td>
<td>2010</td>
<td>471</td>
<td>Medications – Pop Up</td>
<td>2016</td>
<td>150</td>
</tr>
<tr>
<td>Medical Home</td>
<td>2011</td>
<td>171</td>
<td>Stigma - Pop Up</td>
<td>2016</td>
<td>78</td>
</tr>
<tr>
<td>Training Needs</td>
<td>2012</td>
<td>322</td>
<td>ED Waits</td>
<td>2017</td>
<td>411</td>
</tr>
<tr>
<td>Respite Care</td>
<td>2013</td>
<td>280</td>
<td>Disparities</td>
<td>2018</td>
<td>402</td>
</tr>
<tr>
<td>Care Coordination</td>
<td>2013</td>
<td>442</td>
<td>SBIRT and Youth</td>
<td>2018</td>
<td>ongoing</td>
</tr>
</tbody>
</table>
Designing great surveys – the “do’s”

• Take your time during design phase
• DO use easy to understand language and short sentences
• Do distribute paper copies, translate if possible
• Do collect demographic information sensitively and consistently
  – “how do you describe yourself”
  – Type of insurance
  – About parent/caregiver AND about
• Do pre-test your survey
• Do include an open ended question
  – Response rate will be HIGH
Designing great surveys – the “don’ts”

• DON’T ask people to check “all that apply” willy nilly
• DON’T use jargon, acronyms and “loaded” language
• DON’T use grids or tables
• DON’T encourage skip patterns
• Limit the number of qualifying questions
• DON’T have a long list of questions
• DON’T forget to thank everyone both in the survey and in the report
Getting a high response rate

• Social media matters so post it everywhere
  – Listserves, Facebook, newsletters, flyers, support groups
  – Provide the direct link
• Consider a raffle
• Send it on Monday or Thursday, with a cool subject line
• Tell people why you need them to respond
• Do a weekly e-news update
  – adding respondents
  – announcing raffle winner
  – quote of the week
• Tell people how long/how many questions
• Be clear about participant privacy
Many families from diverse cultures will not initiate contact with us or other services

Our team is bilingual/bicultural

Outreach to Somali, Asian, Brazilian, Columbian, Cape Verdean and many families who speak Spanish

Approach requires individual connection, respect for religion, understanding of how family views mental health

Responses from diverse cultures are important and often differ from white, suburban families
Consistent demographic questions

- Parent questions: gender, race/ethnicity, education level, years advocating
- Child questions: gender, race/ethnicity, insurance, diagnosis or problem, special education
- Changes over the years: dual insurance, how information is found
Promote the HECK out of results

- Deliver paper copies with cover letter to the VIPs
- Write a press release and send to your e-list
- Bring copies to every meeting; get on agenda
- Send to the research geeks nationally
- Get it in newsletters, media, social media
Our partners and funders

Partners
- State agencies including mental health, juvenile justice
- Research organizations
- Other family organizations
- Other advocacy organizations
- Children’s Mental Health Campaign
- Youth MOVE Massachusetts
- Pediatricians, psychiatrists, school nurses

Funders
- State agencies
- Private foundations
- Campaigns and their funders
- SAMHSA SFN grant
- HRSA medical home grant
Quick polls

- Monthly polls on web page
- Topics tie into projects or current issues
- Promoted via Facebook, Twitter and newsletter
- Answers often mirror similar answers in surveys
Valuable information about families

- Families are more and more eager to answer our surveys – we worry about survey fatigue
- We have data about our families no one else has – and they use it
- We use the data to advocate, put the needs/opinions of families front and center
- Ways we use data:
  - legislative testimony
  - grant writing
  - policy discussions
  - to change practice
  - workshops and trainings
  - media stories

Which out of pocket expenses are a barrier to getting the services your child needs?

- Co-Pays/Deductible
- Insurance Limitations
- Respite Care
Other ways to use data

• Surveys for legislative testimony
  – Parent-child privilege
  – Status offense reform
  – Phantom networks
• Quick polls on topical issues
• Use quotes from open ended questions
• Use family demographic information often

Quote from a family partner

As a matter of fact, since becoming a family partner, I have told many relatives and friends of the joys, rewards, heart-wrenching issues, heart-breaking stories, and dilemmas of what my community is enduring behind closed doors.
Unintended (but great) consequences

- Families thank us for asking their opinion
- Families put their contact info in and ask to help more
- Families bring up stigma, even if we don’t ask
- High response rate to open ended questions – 15-50%
- Families say they learn from taking the surveys (example: EHR survey)
- Our policy partners are VERY interested in the results
- The more we do this, the more people ask us, What do families think?
Questions?

Any Questions?
Contact info

Lisa Lambert, Executive Director
Parent/Professional Advocacy League
llambert@ppal.net

Gail Cormier, Executive Director
North Carolina Families United
gcormier@triad.rr.com

Laura Wallis
Parent Network, Region 7 Representative
PNRegion7@gmail.com