

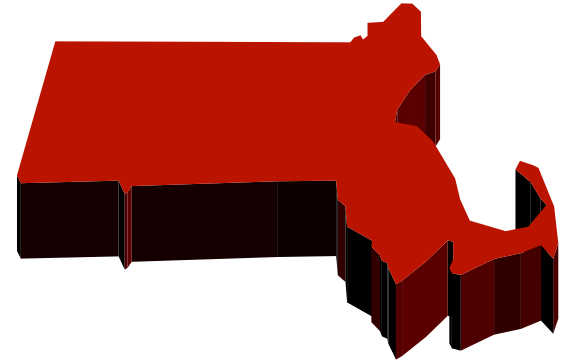
ASKING FAMILIES: HOW DATA FROM FAMILIES CAN INFORM POLICY AND PRACTICE

Lisa Lambert, Executive Director
Parent/Professional Advocacy League
December 19, 2012



PPAL (Parent/Professional Advocacy League)

- A statewide, grassroots, nonprofit, family-run organization in Massachusetts.
- Founded in 1991, PPAL is the state organization of the National Federation of Families for Children's Mental Health and a SAMHSA-funded Statewide Family Network.
- PPAL's goal is to promote opportunities for families to become strong leaders and to ensure that the perspective of families is present in all conversations about children's mental health.



How it started

- It's not enough to use anecdotes--in a sophisticated state
 - Years using anecdotes at hearings, in meetings, in presentations
- Way to push policy, legislation
- Need to grow network
 - Families and youth want to give back
 - Practical value



Frequent surveys

- Began in 2000 with a survey about access
- Families are rarely asked about their experiences and perspectives
- Collecting information in different ways:
 - Through phone log and service data
 - Through surveys—formal and informal
 - Through polls, social media
 - Creating spreadsheet of trainings/workshops
- Promote your data collection at every stage
- Make it easy to read and access

Family Driven Research

- Basic principle: Families must be involved in every stage
 - Developing questions, piloting surveys
 - Distributing tool, collecting data
 - Analyzing results
 - Focus groups
 - Disseminating reports that are family friendly
 - Always thank families
- Partner with others
 - Choose others who value family/youth participation
 - Partners may have questions only families can answer

Paradigm Shift to Family Driven Research

	Researcher Driven	Family Driven
Source of questions	University faculty, graduate students, pharmaceutical companies, providing agencies	Families, school personnel, policy makers, and providers
Purpose	Better understanding of topics of interest to the research community and sponsors – usually to enhance the professional standing of researchers as well	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
Dissemination	Research journals and professional meetings and publications – highly technical language	Newsletters, magazine articles, videos, conferences, public forums, legislative hearings, reports to funding sources – common vocabulary and multiple languages and formats

Adapted from Osher, T.W & Osher, D. (2002). The Paradigm Shift for True Collaboration with Families. *Journal of Child and Family Studies*, 11:1, 47-60

Designing great surveys – the “do’s”

- DO use easy to understand language and short sentences
- Do distribute paper copies
- Do collect demographic information sensitively and consistently
 - “how do you describe yourself”
 - Type of insurance
 - About parent/caregiver AND about child
- Do pre-test your survey
- Do include an open ended question
 - Response rate will be HIGH



DOs

DON'Ts

Designing great surveys – the “don’ts”

- DON'T ask people to check “all that apply”
- DON'T use jargon, acronyms and “loaded” language
- DON'T use grids or tables
- DON'T use 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

dos
&
don'ts

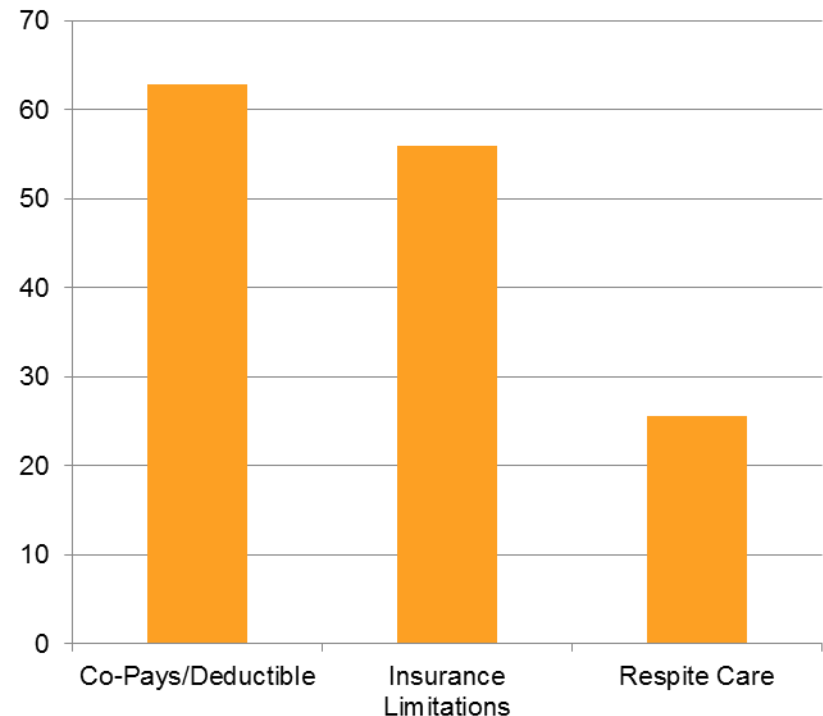
Getting a high response rate

- Post it everywhere
 - Listservs, facebook, newsletters, flyers, support groups
 - Provide the direct link
- Consider a raffle
- Send it on Monday, 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

Valuable information about families

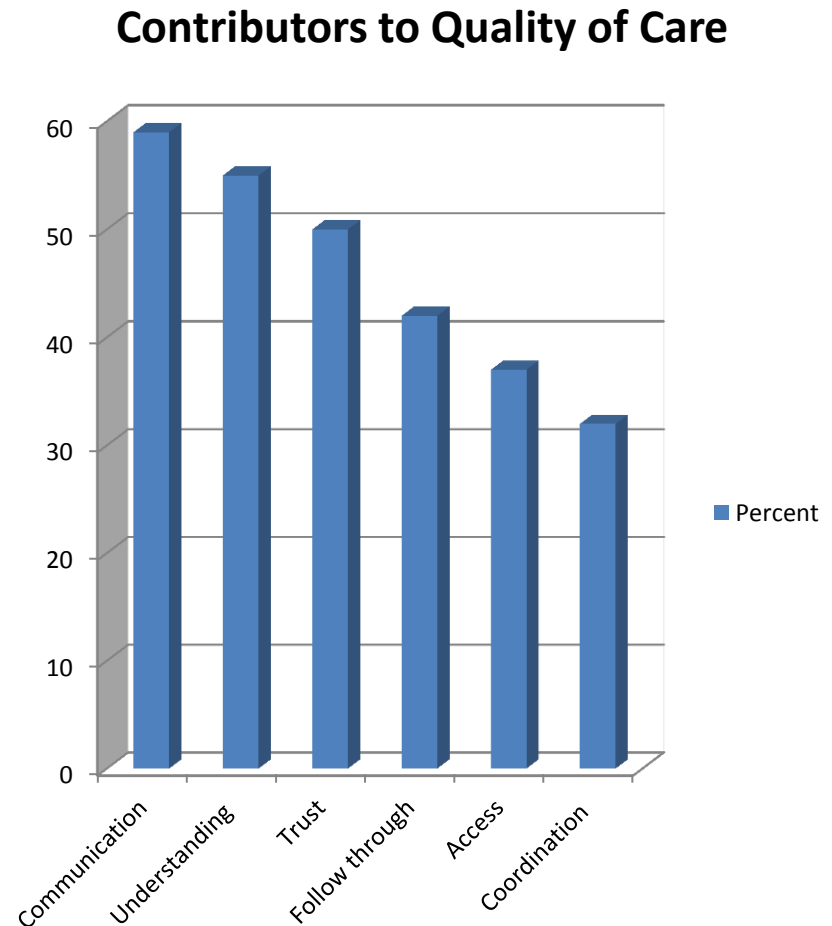
- We ask same demographic questions and compare over time
- Families are more and more eager to answer our surveys – worry about survey fatigue
- We have data about our families no one else has – but they use it!
- We use the data to advocate, put the needs/opinions of families front and center

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



Valuable information about services

- Gather information about system gaps
 - Think strategically about offering services to fill gaps
 - Ask questions about satisfaction
 - Help others understand how families rate services
 - Ask controversial questions--surprises
 - Always ask questions to use to promote your work
 - Example: Answers to Medical Home Survey, 2012



Other ways to use data

- Surveys for legislative testimony
 - Parent-child privilege
 - Status offense reform
- 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.

Working with partners

- Recent request by state to survey families on respite
- Working with pediatricians, state on medical home design
- Collecting specific data for juvenile justice department via call log
- Invited to participate on committees because we have family and youth data
- Working with youth to collect youth data



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

Youth driven research

- Youth topics are very specific
- Youth results can be notable for what is NOT there
- Adult role is “expert” and to ensure professionalism
- Care not to tamper with youth voice
- Greater care with language
- Shorter time frames



Questions?

