Come In & Take a Seat & Please Stay! Sustaining Family Advisors

System of Care Learning Institute | June 21, 2016 Julie DiAngi', Sylvia White, Wendy Luckenbill



Workshop Expectations

- Participants will have an opportunity to learn about & discuss:
 - The evolving work of embedding families' voice into the programs and systems that serve them and their children
 - Real world accounts of what works and what doesn't when bringing and keeping families at the table from families with advisory experience
 - Big picture ideas around families as advisors
 - 30 years since CASSP was created to address the United States' "Unclaimed Children"

Participant Expectations

- Are you in the right workshop?
- What did you come here to learn?
- What would you like to leave with?

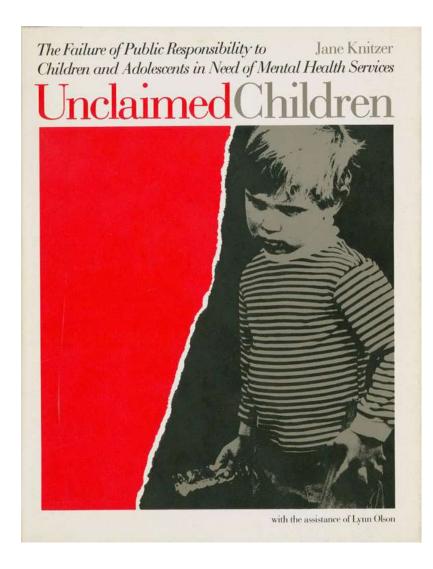
Families: Not Part of the Solution

Until the 1980s, families sat in waiting rooms while clinicians met with their child or children were sent away to institutions for treatment





Children's Behavioral Health Reform



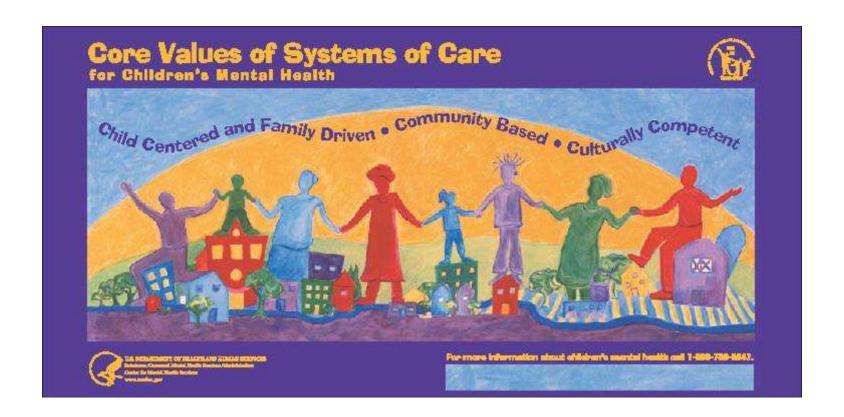
- 1982- Resulted in creation of CASSP- Child and Adolescent Service System Program
- Recommendations include:
 - Target new funds or reallocate old ones for intensive *nonresidential* services
 - Treatment & treatment planning should *involve*, as much as possible, the child's or adolescent's family & others important in the child's life

Children's BH Reform

- 1983: National Institute of Mental Health funds CASSP across states & territories
- 1984 Present: PA CASSP principles developed by families & practitioners & implemented in services
 - Child-centered
 - Family-focused
 - Community-based
 - Multi-system
 - Culturally competent
 - Least restrictive/least intrusive



Children's BH Reform: 1986 – Present



Family Advisors: Personal Stories

- Stuck in Time: The Tragedy of Childhood Mental Illness by Lee Gutkind (1993)
 - Includes story of PA family
 - Online sample chapter, "The Scanlons"

What's working?

Seeking Family Advisors: Credentialed by Lived Experience



- Assure confidentiality
 - Reinforce consistently that while you have invited families to give their perspective and advice on issues, you do not expect them to provide specific details of their experience
- Be supportive
 - Make sure families are connected with resources including each other and other peer support to resolve any immediate and longer term problems they are facing. Give out contact info for local and family advocacy resources

Offer hope

– Let families know that you are part of a change process that rejects blaming family and is committed to partnering with them to achieve positive change, and that they are being invited as crucial partners in this transformative work to make things better so that people will have healthier lives in healthier communities

Give perspective

- Let families know that people come to human services to do good, but that too frequently they are not given the information and tools to truly achieve the objectives they are responsible for, and again this is something you are asking them to join in helping to resolve

- Validate system experiences
 - Acknowledge that past and current practice from all the agencies, including JJ, CW, BH, and ED, may have done harm to them and their children, but that we are evolving effective practice and policies, and it is only within the last decade that we have really been applying evidence and accountability vs. local practice and gut feelings to decision making
- Follow-up
 - Identify how they can be informed about how things will be changing and a variety of ways they can be involved with this change, based on their own availability

- Concretely recognize member contributions
 - Reimburse for travel, child care, time, and other resources including training and conferences, information on how to help their children, etc.

• Affirm

 Affirm their heroism in living lives with multiple challenges and being willing to participate with you in making things better

- These questions ask how well community Care supported your ability to serve as a member of the FAB:
 - Was there enough support from staff to help you prepare to participate in meetings?
 - Were meeting topics presented in ways that allowed you to understand & provide input on them?
 - Were you supported to get to know & learn from other FAB members?
 - Did you get enough support for your attendance & travel?

- These questions ask about the FAB meetings:
 - Did FAB meeting topics relate to your own experiences & concerns?
 - Were you able to provide your input on the discussed topics?
 - Do you think Community Care valued your input & the input of other members?
 - Did Community Care provide enough follow-up on how FAB members' feedback was used?

- These questions ask what you have learned from being a FAB member:
 - Did you gain a better understanding of Community Care?
 - Did you gain a better understanding of child & youth behavioral health services?
 - Did you gain a better understanding of how to access & use services for children & youth?
 - Did you gain a better understanding of how to improve your community's behavioral health services?
 - Did your membership give you opportunities for your own personal growth?

Additional Comments!

• Giving room for the unknown, the hidden, the wisdom & the heart of family experience

Commitment Checklist

•	I will support family input into my community/agency/group/	
•	Assure Confidentiality	
•	Be Supportive	
•	Offer Hope	
•	Give Perspective	
•	Validate System Experiences	
•	Follow-up	
•	Concretely Recognize Member Contributions	
•	Affirm	



More Information

- Handouts (on SOC Inst. website)
 - Does my child need help? Community Care
 - Family Engagement Suggestions Advisory Work Wendy Luckenbill, 2011
 - Checklist: Your commitment to enhance family advisory activities - Community Care
- Resources (available on Amazon)
 - Unclaimed Children, Jane Knitzer, 1982
 - Stuck in Time, Lee Gutkind, 1993
 - Books by Charlotte Des Jardins, 1993
 - How to get Services by Being Assertive
 - How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies
- Contact: Wendy Luckenbill *luckenbillwl@ccbh.com*