

SHARED DECISION-MAKING IN CHILD PSYCHIATRY: INSIGHTS FROM PHILADELPHIA'S FAMILY PEER SUPPORTS

Shared decision-making is a clinical approach in which the experience and expertise of the prescriber, patient, and family are regarded as equally important. Shared decision-making is characterized by collaboration, flexibility, and information-sharing that is initiated and sustained over time by the clinician.

Why Does This Matter?

Clinician/parent disagreement has been linked with treatment dropout¹, whereas shared decision-making has been associated with greater treatment satisfaction². Discussion of patient and family member preferences is associated with achieving agreement in decision-making³.

The following are recommendations to clinicians from family peer support specialists in Philadelphia. This input is based on experiences of peer support specialists when seeking care for family members within the CBH network of providers.

Getting Started and Setting the Tone

- ➔ Explicitly identify collaboration as a necessary component for effective treatment: *"We are a team."*
- ➔ Acknowledge the parent/caregiver's expertise: *"You know your child best."*
- ➔ Highlight the importance of the parent's role in making a decision that works for their family: *"It's important that you share your perspective so that we can find a plan that really works for you and your family."*
- ➔ Acknowledge that treatment is a process: *"We're going to make decisions together and adjust as needed."*

Prescribing Medication

"I feel like a Guinea pig."

When considering medication, families may wonder:

- ➔ *What's in it?*
- ➔ *Why is this needed?*
- ➔ *What are the side effects?*
- ➔ *Will my child get addicted?*
- ➔ *Will my child become like a zombie?*
- ➔ *What is the effect of medication on my child's developing brain?*

¹ Decker, LB et al. "When Parents and Clinicians Disagree: Consequences for High-Risk Youth Receiving In-Home Family-Based Psychiatric Treatment." *Children and Youth Services Review*. 121 (2021): n. pag. Web.

² Butler, Ashley M, Bridget Weller, and Courtney Titus. "Relationships of Shared Decision-Making with Parental Perceptions of Child Mental Health Functioning and Care." *Administration and Policy in Mental Health*. 42.6 (2015): 767–774. Web.

³ Fukui, Sadaaki et al. "Predictors of Shared Decision-Making and Level of Agreement Between Consumers and Providers in Psychiatric Care." *Community Mental Health Journal*. 50.4 (2014): 375–382. Web.

When starting medication:

- ➔ Explain the diagnosis.
- ➔ Explain options for treatment.
- ➔ Identify specific goals or milestones to achieve with medication.
- ➔ Provide written information to the family.
- ➔ Encourage family members to do independent research.
- ➔ Allow the family to make an informed decision.
- ➔ Be flexible.

When changing medication:

- ➔ Explain why a dose adjustment is needed.
- ➔ Share the expected timeframe for medication to be continued.
- ➔ Reinforce the importance of therapy and other supports alongside medication.
- ➔ Recommend that families work with the prescriber to follow a taper rather than discontinue medication abruptly.

Family Culture and Medication

“My extended family did not think my child should take medication, and it was a really hard decision for me to make.”

Get curious!

- ➔ Ask the parent: *“Were you ever on medication? How did that go?”*
- ➔ How do other family members feel about mental health treatment?
- ➔ What are the family’s past experiences with the medical system?
- ➔ What else is the family managing currently?
- ➔ What are the family’s natural and professional supports?

Recommendations:

- ➔ Involve others from the treatment team, such as the child’s therapist.
- ➔ Prioritize building trust with families.
- ➔ Take time to understand how the parent and other family members feel about treatment.

Care Systems

“I didn’t know how the system worked.”

- ➔ Families may not understand how to navigate administrative processes in order to advocate for a child’s needs to be met in school
- ➔ Past experiences accessing mental health treatment may have been negative for parents and children.

Recommendations:

- ➔ Inform families if making a Childline report is necessary. Make the report with family present, if possible.
- ➔ Assist families with resources to address identified safety needs at school and at home. Validate the challenge and offer contact information for [Philadelphia Family Voices](#) (484-228-1229) as a resource for system navigation.
 - » *“It can be really tough, but you’re not alone. Here’s the number for an organization of parents and caregivers like yourself, who understand and would like to help.”*

Parenting

“I felt like the doctor was saying my child’s behavior problems were my fault.”

- ➔ Ask questions to understand family dynamics.
 - » *“What have you tried?”*
 - » *“What would happen if the child’s behaviors were addressed differently?”*
 - » *“What led up to the behaviors?”*
- ➔ Encourage parents to discuss behaviors and consequences with children.
 - » *“How did we get here?”*
 - » *“What do you think your consequence should be?”*
- ➔ Don’t use schoolwork as a punishment.
- ➔ Build on the child’s strengths and functional skills.
 - » *“What has helped in the past?”*
 - » *“How does the child calm or soothe themselves?”*
 - » *“What could be positive behaviors we want to see continue or increase?”*
- ➔ Teach the caregiver effective de-escalation techniques that can be used at home.
- ➔ Involve the parents in the children’s treatment to encourage them to begin therapy.

Importance of Family Peer Supports

“I’ve been there.”

How can Philadelphia families connect with peers?

Peer supports help parents navigate the system and identify resources.

- ➔ 25 School District of Philadelphia schools have family peers.
- ➔ 15 peers are part of [Philadelphia Family Voices](#) (PFV), a group of caring family members who assists families in obtaining the proper services required for their children.
 - » 841 E Hunting Park Avenue, Suite 204, Philadelphia, PA 19124
484-228-1229 | philadelphiasupport@philadelphiafamilyvoices.com
 - » Any Philadelphia resident can use PFV as a service, regardless of insurance status.

- ➔ There is currently one Youth Peer Navigator available through [NAMI Philadelphia](#). This service is specifically intended for youths 12-17 years old stepping down from higher levels of care to the community.
 - » NAMI Philadelphia Warmline: 844-PHL-HOPE

How can my agency hire a family peer support specialist?

- ➔ The Department of Behavioral Health and Intellectual disAbility Services' (DBHIDS) [Peer Support Toolkit](#) offers a broad roadmap to agencies looking to effectively integrate family peers.
- ➔ Resources to support implementation alongside the toolkit include PFV and the [PA Parent and Family Alliance](#), a statewide organization.

Additional Resources

- ➔ [Shared decision-making interventions for people with mental health conditions](#) | Cochrane Library
- ➔ [Relationships of Shared Decision-Making with Parental Perceptions of Child Mental Health Functioning and Care](#) | National Institutes of Health (NIH) National Library of Medicine
- ➔ [When parents and clinicians disagree: Consequences for high-risk youth receiving in-home family-based psychiatric treatment](#) | Children and Youth Services Review
- ➔ [Predictors of Shared Decision-Making and Level of Agreement Between Consumers and Providers in Psychiatric Care](#) | NIH National Library of Medicine
- ➔ [An integrative model of shared decision-making in medical encounters](#) | Patient Education and Counseling
- ➔ [The SHARE Approach — Essential Steps of Shared Decision-making: Expanded Reference Guide with Sample Conversation Starters](#) | Agency for Healthcare Research and Quality (AHRQ)

Please share these member-friendly educational resources with your clients and their families/caregivers.

[CBH Website: Pharmacy Education and Resources for Members](#)

Includes medication guides, tip sheets, and other valuable tools and resources to get informed about and properly use medications you may be prescribed

[National Alliance on Mental Illness \(NAMI\) Mental Health Medication Information](#)

For questions or support, please contact cbh.pharmacyinitatives@phila.gov.

Share Checklist

Step 1: Seek Your Patient's Participation

- I invited my patient to participate in the decision-making process.
- I explained the importance of my patient's role in the decision-making process.
- I discussed the essential issues about my patient's condition.

Step 2: Help Your Patient Explore and Compare Treatment Options

- I presented all the reasonable treatment/intervention options to my patient.
- I discussed the risks and benefits of each option with my patient.
- I asked my patient to review relevant decision tools (e.g., booklets, videos, websites).
- I asked my patient to teach back what was discussed.
- My patient demonstrated an understanding of the options.

Step 3: Assess Your Patient's Values and Preferences

- I encouraged my patient to talk about what matters most to them.
- I listened actively to my patient and asked open-ended questions.
- I asked my patient how their decision might impact their daily life.
- I acknowledged and agreed with my patient on what matters most to them.

Step 4: Reach a Decision With Your Patient

- I asked my patient what option they preferred.
- I asked my patient if they needed additional information or wanted to consult others before making a decision.
- My patient and I agreed on the decision.

Step 5: Evaluate Your Patient's Decision

- My patient and I made plans to review their decision in the future.
- I worked with my patient to help them manage barriers to implementing their decision.

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