

Importance of Family Engagement

Presented by: Maria Silva
Chief Operating Officer
Allegheny Family Network



**Allegheny
Family Network**

support • education • advocacy

A little about me!



I am a Family Member!

I have raised 4 biological children, 2 stepchildren and 4 like a sons!

I have their permission to share my story and our journey!

Eldest Son – ADHD (ISP)

Daughter – Bipolar (Anxiety, depression and suicidal attempt/ideologies)

Youngest Son – Prader-Willi Syndrome

Navigating the system was hard! My children did not come with owners' manuals or instructions!



Allegheny Family Network is a “Family Run Organization”

All employees have raised or are raising a child with Emotional, Behavioral, or Mental Health challenges

Mission: Through peer-to-peer support, education and advocacy, we partner with families of children with behavioral health needs to improve their quality of life

- One-to-one Family Support Partners who provide peer support in the home or in the community
 - AFN Provides free:
 - Support Groups
 - Parent/Caregiver Trainings
 - Family Events
 - Adult Education Classes



What we do really well?

ENGAGE FAMILIES!

Our lived experience, shared appropriately with families, helps us engage families!

Clinical Service Providers have their own stories,
but boundaries and professional training often prohibits sharing your story!

Sharing our story and lived experience increases engagement and forms bonds of trust with our unspoken language of connection. There is no judgement, we have taken this journey and continue the path and walk along side families!



The value of Parent/Family Peer Support

- A critical part of the Behavioral Health Team
- Helps improve family engagement and thus improves outcomes
- Piece of the team set apart from clinical care colleagues.

What do you see, think and feel?





Training, Certifications, and Credentialing

- Help us see the big picture (along with visits in the home and community)
- Teach us how to appropriately share our story
- Remind us to leave our bias at the door
- Help us find the unspoken language and commonality to build trust
- Cultural sensitivity keeps us curious and willing to learn each family's differences even within a perceived cultural group.
- We bring all this knowledge and insight to the team! One of our valued principles is TEAM BASED!



- We are NOT Clinical! We need our clinicians!
- Therapeutic but not therapy.
- We promote self advocacy and encourage empowerment
- Uncover barriers and encourage meeting goals
- Share information with all members of the team (with signed Releases of course)!
- Through modeling and education, briefing and debriefing, we help Parents/Families use effective communication to share their concerns



- Strengths-based – help families at their wits end see their own strengths that they may be so stressed they don't acknowledge they have.
- Normalize emotions that Parents/Families may have – we understand the grief, exhaustion, sadness, fear, helplessness and encourage participation, wellness, and offer hope!



Definition of Family Engagement

Commitment to and active participation of family members in the process and empowering families, based on their strengths, to have an active role in determining the services they need and receive.

“The process of identifying, enrolling, and retaining families in treatment services.” (Ong, 2021)

Barriers to Family Engagement



- Misunderstanding of Laws
 - Gabby's Law (ACT 65)
 - Health Insurance Portability and Accountability Act (HIPAA)
- Youth reservation of engaging the family
 - Don't want to burden the family
 - Giving power to a family member
- Family member concerns
 - Blame for the individual's mental illness
 - Prior negative experiences when working with service providers

Translate the information in daily life



Let's think about the majority of parents – not the exception (we have limited time today- that's another training!)

You may not want to give information – but nothing stops you from listening.

A youth who lives in the home and is on medication:

- may need a voice if they become unresponsive

- their parents may need to understand drug interaction with supplements or food

Parents may need to advocate for their child legally or in the education system for medication (think about the medication that might cause aggression and might risk legal ramifications or the need to have IEP adjustments for taking medications during the school day)

Family members

- can aide in promoting accurate information, there are two sides to the story

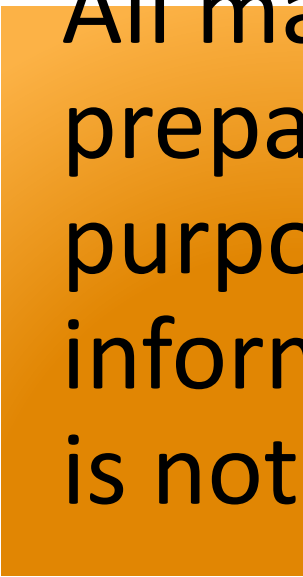
- with information and knowledge parents can understand the diagnosis better and

- understand how the symptoms can appear in the youth and parent with a different approach (their child isn't just mouthy and bad)


- can provide side effects as viewed from the outside in



Disclaimer



All materials have been prepared for general purposes only. The information presented is not legal advice.



Gabby's Law – ACT 65 2020



Consent=
Yes



PA Mental Health Consent Law FAQ

What does "inpatient treatment" mean?

All mental health treatment that requires full-time or part-time residence in a facility that provides mental health treatment.

What makes inpatient treatment consent different?

Once a child has been admitted to an inpatient treatment facility either parent or the child can request a hearing to determine if inpatient treatment is appropriate and necessary. The child will stay at the facility while the judge makes a ruling.

This option does not apply to outpatient treatment.

What about parental disagreement to inpatient treatment?

If a parent who has legal custody rights disagrees with the other parent about consent to a child's inpatient treatment, they can file a petition in the court of common pleas and a hearing will take place within 72 hours of the filing.



Want to learn more or read the law yourself? Click here or scan this QR code.

<https://www.paparentandfamilyalliance.org/mental-health-faq>

What about children under the age of 14?

Parental consent is required for children under age 14 to receive mental health treatment.

Who can consent to a minor receiving mental health treatment?

- Parents or legal guardians
- A minor between the ages of 14-17

I Agree

Can a parent refuse to allow treatment once a child (age 14-17) has consented?

no

Can a child (age 14-17) refuse treatment once a parent has consented?

no

Can a parent say no after another parent already said yes?

no

What happens if a child (age 14 - 17) takes away their consent?

The treatment will be stopped **UNLESS** a parent or legal guardian gives their consent; in that case the treatment will continue.



We understand because we've been there.

The Parent Alliance support parents anywhere in the state of PA who have children who are struggling with social, emotional, behavioral or mental health challenges including substance abuse.

Give us a call @ 570-664-8615 or visit our website.

This document updated March 2022

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HIPAA Privacy Rule and Minors



Generally, a parent or guardian of a minor child is regarded as what the HIPAA Privacy Rule calls the “personal representative” of the minor child. Per the HIPAA Privacy Rule, a personal representative is authorized to exercise the HIPAA rights of the individual whom he or she represents, on that person’s behalf. Therefore, a parent who is a personal representative can exercise a minor’s HIPAA Privacy Rule rights with respect to protected health information (PHI), consistently with state law

When a physician or other covered entity reasonably believes that an individual, including an unemancipated minor, has been or may be subjected to domestic violence, abuse, or neglect by the personal representative, or that treating a person as an individual’s personal representative could endanger the individual, *the covered entity may choose not to treat that person as the individual’s personal representative, if in the exercise of professional judgment, doing so would not be in the best interests of the individual.*

Prevent imminent harm. A healthcare provider may release PHI as necessary to prevent a serious imminent threat to the health or safety of a person or the public. However, the provider should disclose the minimum amount of information necessary and only disclose PHI to someone capable of reducing the risk of harm, such as the target of the harm or law enforcement personnel.



- We are great at engagement and use that skill to encourage and promote Engagement with the whole team!
- Do For, Do With, Cheer On!
- Engagement is promoted through prep before appointments and helping the family in the comfort of their own home to formulate sharing of information
- Voice and Choice principle is paramount to our engagement – but it comes with responsibility and accountability!
- We can normalize the journey with our lived experience. The parent is NOT alone!

What parents don't know and fear!



Age of onset of types of disorders in children



Age 6

median age
of onset

**Anxiety
Disorders**



Age 11

median age
of onset

**ADHD and
Behavior
Disorders**



Age 13

median age
of onset

**Mood
Disorders**



Age 15

median age
of onset

**Substance
Use**

*Child Mind Institute Children's Mental Health Report, 2015

Transition – Part of Normal Development



We remind the Parent/Family of their own teen years. Normalize that development, validate their concerns, encourage them to seek assistance from our Clinical Partners.

It's a teenager's job on the road to independence to want separation from their family and have their autonomy.

Outside systems have power to either give credibility to a parental role or to destroy it. A parent has a history with the youth, understands their illness from that historical perspective and may have more information. The struggle a parent has is the duality of wanting their child to fly and knowing they don't have wings. They could have genuine concerns or the inability to understand the possibilities.

Systems have to be careful during this time and promote a healthy and appropriate separation while maintaining the family's connection. Understanding normal part of child development and how mental illness of the youth can interfere with the ability to make this transition and develop plans that are achievable.

Remember that the family is the connection that individuals will come back to long after systems leave.

Let's first do no harm!

Benefits of Family Engagement



Family and patient psychoeducation has been shown to significantly reduce relapse and rehospitalization rates in patients with mental illness and reduce the burden and stress level of carers. (Santoso, 2021)

- Historical information
- Support with outcomes, improved accountability and self-monitoring
- Earlier detection of warning signs
- Support the individual in recovery
- Healing generational trauma
- What are some of the benefits you see?

Its hard enough to be a teenager, let alone be a teenager transitioning into adulthood and having to navigate the mental health system. Families can help!

“Parents are their child’s lifelong safety net.” (Johnson-Walburn 2023)



- Because this is our specialty and the unique position we have – we can promote and help engagement of the rest of team.
- Engagement of the Parent/Family improves participation, promotes honesty, helps break down barriers and formulate possible resolution, teaches effective communication



Our unique services

- Meet families where they are – not just figuratively – but literally!
 - Going into the family home
 - Ability to engage extended family
 - Coordination of services and plans (not service coordination)
 - Attendance of school, court, and other services
 - Prep Parents/Families
 - Debrief Parent/Families

What Sets us Apart – Why are we different?



Use our lived experience through the engagement process to build trust and encourage the trust of the whole team!

Share our story appropriately that promotes engagement, encourages trust, and yet maintains boundaries.

Those home visits provide a unique view of the family and home interactions that can be helpful to other providers!

Able to engage “Natural Supports” and others that live in the home



Use our lived experience through the engagement process to build trust and encourage the trust of the whole team!

We are mandated reporters, but we have no power over – just shared experiences and deep understanding

Truth with Respect! Easily accepted

Thank you!



**Thoughts
Questions
Needs**

Thank you for your participation!