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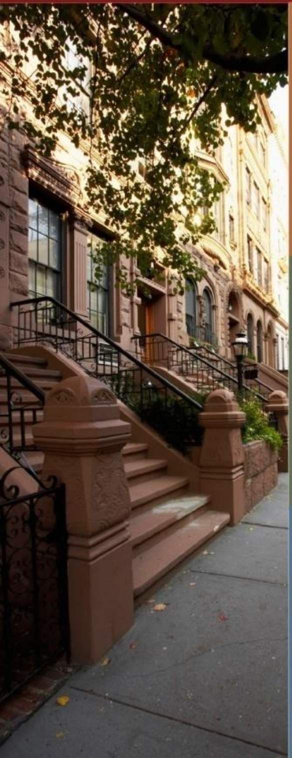
Behavioral Health is Essential To Health



Prevention Works

Treatment is Effective

People Recover

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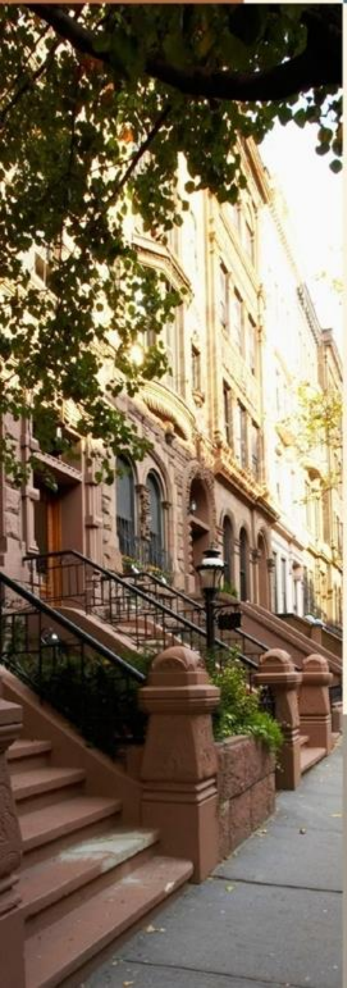

Confidentiality and SAMHSA Participant Protection Guidelines for Family-Run Organizations

January 25, 2018

CARING FOR EVERY CHILD'S MENTAL HEALTH
Systems of Care

THE TA NETWORK
the national technical assistance network for children's behavioral health

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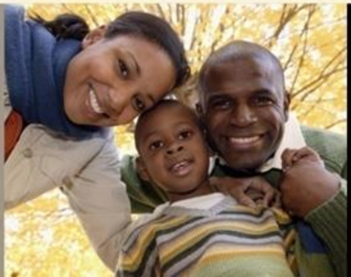

This webinar is hosted by FREDLA, a partner in the National TA Network for Children's Behavioral Health, operated by and coordinated through the University of Maryland.

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Presenters

- Jane Walker, Executive Director, Family-Run Executive Directors Leadership Association (FREDLA)
- Liz Sweet, Project Officer, Child, Adolescent and Family Branch, SAMHSA
- Peggy Nikkel, Project Coordinator, Family-Run Executive Directors Leadership Association (FREDLA)

Purpose

- SAMHSA grantees are required to have safeguards protecting individuals from risks associated with their participation in SAMHSA Projects.
- Family-run organizations that apply for SAMHSA grants are required to have these safeguards in place as well.

Why is participant protection and confidentiality important for family-run organizations?

1. Protecting Clients and Staff from Potential Risk

- Identify any foreseeable physical, medical, psychological, social and legal risks or adverse effects of the project or data collection activities.

Foreseeable Risks to a Training Program

- Discussion of a topic may trigger a memory or post traumatic stress response from a participant.
- By participating in the programs, a family may disclose personal information about themselves to others that they may later regret.
- Families participating in the training may interpret the parent peer support provider's comments as critical of their parenting.

Participant Protection Procedures

- Inform participants in advance that they may leave the group if they become upset and it will not jeopardize their ability to participate at a later date or limit their ability to receive services in the future.
- Have another parent peer support provider available to step outside and stay with the family.
- Have a resource list available.

Participant Protection Procedures (cont.)

- Connect with a community mental health center for additional support.
- Discuss confidentiality at the beginning of the group and do not distribute contact information unless participants give written permission.

2. Fair Selection of Participants

- Describe the population of focus for the proposed project.
- Include age, gender and racial/ethnic background.
- Specify if biological, adoptive and foster families are included as well as kinship caregivers.
- Explain why someone might be excluded from participation.
- Identify barriers to participation and how you will address them in your project.

3. Absence of Coercion

- Explain if participation in the program is voluntary or required.
- Explain any compensation or incentives families may receive for their participation.
- Explain that incentives do not result in undue pressure to participate so that families feel pressured to participate.
- The value of incentives paid for with SAMHSA funds cannot exceed $30.
- A family that choses not to participate in one program does not exclude them from other activities or services.

Purpose of Data Collection

- Documentation demonstrating funding is being used for intended purpose
- Documentation of program effectiveness
- Ongoing CQI – make recommendations about program improvements

4. Data Collection

- Data can be collected in a variety of ways:
  - Surveys
  - Questionnaires
  - Participant sign-in sheets
  - Program evaluations
  - Focus groups

- Types of data:
  - *Quantitative* describes information in numbers
  - *Qualitative* describes information in words

4. Data Collection (cont.)

- Describe the data that will be collected.
- Who will be collecting the data?
- How will the data be collected?
- Provide data collection tools that will be used.
- Use validated measurement tools.
- Will data be used in aggregate or will individual measurement be used?

What Families Need to Know About Their Data

Explain to families:

- What data is being collected
- Why the data is being collected
- How information is protected
- How/where it will be stored
- Who will see it
- When it will be destroyed and how

5. Privacy and Confidentiality

- More accountability for confidentiality and patient protection was required with the passing of the key Health Insurance Portability Accountability Act legislation (HIPAA).

Code of Federal Regulations: 45 CFR Part 160 and Subparts A and E of Part 164

Privacy Rule

The Standards for Privacy of Individually Identifiable Health Information also known as the **Privacy Rule**.

Protects all "*individually identifiable health information*" held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral.

i.e. "*protected health information (PHI).”*

Protected Health Information

Individually identifiable health information is information, including demographic data, that relates to:

- the individual's past, present or future physical or mental health or condition,
- the provision of health care to the individual, or
- past, present, or future payment for the provision of health care to the individual,
- and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual.
  - Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, social security number).

Confidentiality Violation or Breach

- According to the Breach Report 2015:

  A total of 1,437 large breaches of protected health information (PHI) affecting over 150 million patients have been reported to the Secretary of Health and Human Services (HHS) since 2009.

(Redspin Breach Report, 2015)

Strategies to Avoid a Confidentiality Violation

- Staff training
- Staff confidentiality statement
- Consents to release/obtain information
- Client release of confidential information
- Policies and procedures for safe handling of client confidential information
- Protecting electronic information.

Consent to Release Information

Consent to release information must include:

- The parent/guardian’s name
- Purpose of the disclosure
- The name of the program making the disclosure
- The recipient of the information
- The specific information to be released
- The process for a patient to revoke this consent
- Expiration date of the consent

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Consent to Obtain Information

Consent to obtain information must include the same information as the consent to release form.

- The parent/guardian’s name
- Purpose of the disclosure
- The name of the program making the disclosure
- The recipient of the information
- The specific information to be released
- The process for a patient to revoke this consent
- Expiration date of the consent

6. Adequate Consent Procedures

Consent procedures must include:

- Whether participation is voluntary
- A family's right to leave at any time without problems
- Possible risks from participation in the project
- Plans to protect families from risks

Obtaining Consent

Use multiple methods to ensure that families understand everything they are consenting to:

- Forms should be:
  - written in language that is understandable
  - written in the family's first language
  - reviewed by a staff member before asking the family to sign
- Invite questions
- Reassure there is no coercion and it is the family's decision
- No negative repercussions

7. Risk/Benefit Discussion

Minimizing risk:

- Participation is voluntary
- Families retain the right to leave at any time
- There are no negative consequences if families decide to leave or not to participate in the program
- Procedures are in place for unforeseen risks

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Maximizing Benefit

- For Families:
  - information and support,
  - access to resources,
  - families are empowered
- For Systems:
  - data is used to increase awareness of the challenges for families and youth with complex mental health needs and ultimately to improve systems of care for children.

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Final Thoughts

- Patient protection and confidentiality is critical for family-run organizations and it is our hope that this presentation has assisted in preparing you to better address these important issues.

- A final section will include *Resources* discussed in this presentation.

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Q & A

Resources: Sample Forms

- Staff Confidentiality Statement
- Client Informed Consent
- Consent to Release Information
- Consent to Obtain Information

*Sample templates can be downloaded from this webinar or accessed on FREDLA's website:

www.fredla.org/resources

Other Resources

- Summary of HIPAA Privacy Rule
  https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html?language=es

- List of Identifiers Protected Under HIPAA

https://privacyruleandresearch.nih.gov/pr_08.asp

- Your Rights Under HIPAA
  https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html?language=es

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Coming Up

Next Learning Community for Family Leaders:

Family Engagement in Juvenile Justice

February 22, 2018

Thank You for Participating!

Join the Family Leadership Learning Community Closed Facebook Page:
https://www.facebook.com/groups/familylearningcommunity/

Contact **FREDLA** if you are in need of technical assistance or have thoughts on how we can improve the Learning Community for Family Leaders!

sratliff@fredla.org

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