

NAMI

National Alliance on Mental Illness

*The Family Perspective on
Measurement and Information Needs*

Presented by: Darcy Gruttadaro
Director, NAMI Child & Adolescent Action Center

A Snapshot: C&A with MI

- § Number of C&A with MI? Depends on who you ask.
- § What kinds of services and supports are C&A getting and from what systems? Not always clear.
- § Are we achieving positive outcomes for C&A in the services delivered? Not sure.
- § Consequences of lack of services and/or ineffective services? School drop out (50% - highest rate of any disability group); JJ involvement (70% of youth with psychiatric illnesses ~ 20% with serious impairment) and youth suicide (CDC - 3rd leading cause of death); and loss of critical developmental years.

What Do We Really Want to Know?

- § Prevalence of existing and emerging MI in children, youth and transition-age young adults – how many children and their families need MH services?
- § How are systems performing in MH screening, assessment and diagnosis?
- § Are we identifying children early and linking them with effective MH services?
- § What systems are providing MH services to children and their families?
- § Are we providing effective MH interventions and achieving positive outcomes ?

What Do We Really Want to Know?

More on effective interventions ...

- § We cannot improve the quality of MH services if we do not measure our performance or stated differently ...
- § We can improve the quality of MH services and increase accountability in the delivery of services if we measure and publically report on outcomes.

What Do We Really Want to Know?

NAMI asked families about outcomes important to them ~ here is what they said:

- § Improved ability and skill to manage behaviors;
- § Improved family and peer relationships;
- § Improved school attendance and performance;
- § Reduced self harm and suicide related behaviors;
- § Decreased out-of-home placement (hospital, residential, and others); and
- § Reduced contact with law enforcement and reduced substance use.

What Do We Really Want to Know?

When it comes to the provision of MH services, we want to be able to answer the following...

Are children reaching their educational and functional goals, are they developing the social and life skills they need, and are they avoiding unnecessary out-of-home placements as a result of MH services and supports?

What Is the Current Capacity to Provide This Information?

- § SAMHSA should make the collection of data on children's MH a priority and should allocate resources to support states in collecting standardized data.
- § The CDC should collect epidemiological data related to prevalence and the services provided to children with emerging and existing MI.
- § Systematic analysis of Medicaid claims data to be done for children and ensure we capture the right data – early identification, links to effective interventions and outcomes.

What Are the Critical Gaps?

- § Data are not standardized within or across states on MH services and outcomes making comparisons extremely difficult.
- § Lack of national meaningful outcome measures and good data reporting by state mental health systems on children's MH.
- § Lack of integrated data systems across child-serving systems and lack of coordination in care across states and communities.
- § Fragmentation across child-serving systems including PC, MH, education, CW, and JJ/Courts.

How Do or Could Family Advocates Use the Information?

- § Advocating for investments in what works and to reinvest in more effective interventions.
- § NAMI's Grading the States Report for Adults – similar report in the works for children.
- § Use data combined with family stories to advocate for an investment in and reform to improve MH services at the federal, state and local levels to produce better outcomes.

What Are the Challenges In Generating Better Information?

- § Services are delivered in multiple child-serving systems and fragmentation runs deep.
- § Federal leadership is needed to develop meaningful outcome measures and in enforcing good data reporting by state mental health systems.
- § Investment needed for states and communities to collect data and to build the infrastructures they need.
- § Lack of consensus in children's MH in many areas (diagnosis, age of onset and more).

How Would Families Make Use of Additional Information?

- § Data would be used to advocate for improved outcomes and continuous quality improvement in the delivery of MH services;
- § Increased transparency and accountability because the data would speak for itself;
- § Increased national focus and investment in those states and communities that require attention to improve the identification of children with MI and access to effective services.

Final Thoughts ...

Families would like increased transparency and accountability in the services that are provided to children.

They would also like to know that the services and supports that their child receives are effective and produce positive outcomes.

There is momentum with states interested in collecting outcomes data ...

Contact Information

Darcy Gruttadaro, Director
NAMI Child & Adolescent Action Center.
darcy@nami.org, 703-516-7965