SED Definition Review Survey:
Thoughts from families, Family-Run Organizations, and colleagues from the Children's Mental Health field
May 2014
Compiled by
The Family-Run Executive Director Leadership Association (FREDLA)

The Center for Mental Health Services (CMHS) is in the first stages of reviewing the definition of Serious Emotional Disturbance (SED) to: 1) assess the current definition's strengths and challenges, 2) determine if there is a need for revision or change, and 3) identify implications of changing the definition. The definition was first introduced in 1993 and has not changed in more than 20 years.

The definition reads: "Children with a Serious Emotional Disturbance" are persons:

- From birth up to age 18
- Who currently or at any time during the past year
- Have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R (and subsequent revisions)
- That resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities.

This definition is used in conjunction with Community Mental Health Services Block Grant funding to the states. Please note, this review of the definition is not related to the definition of SED used in special education. Both the U.S. Department of Education and Center for Mental Health Services use the same terminology, Serious Emotional Disturbance. Each agency has a different definition and eligibility criteria. At this time only Center for Mental Health Services is reviewing the definition of SED. This review will not have an impact on the definition in IDEA.

While constituents were able to provide individual input into the process through an online Information Exchange set up by SAMHSA, FREDLA felt it was important to develop a short, eight question survey in an effort to facilitate a collective response from the field. In doing so, we believe this has resulted in a more unified and stronger family voice on potential changes to the SED definition. It is crucial that the voice and expertise of family members, leaders of Family-Run Organizations, and other colleagues from the Children's Mental Health field be heard.

CMHS has emphasized that this is the first step in a lengthy process that could include changes to federal statute and regulations. Due to this, we do not expect changes any time soon. FREDLA will try to keep you apprised each step of the way as this process continues.

The survey was distributed to over 200 family-run organizations and children's mental health colleagues. A total of 64 individuals participated in the survey. We hope the information contained in this report will support your individual and collective efforts to elevate the importance of family and youth voice and the enormously positive impact Family-Run Organizations play in their lives.

Summary of Findings:

A diverse group of individuals responded to this survey. Approximately one-third of the respondents were Parent Support Providers/Partners. Others included clinicians, advocates, consultants, parents, founders of Family-Run Organizations, and siblings.

The sixty-four individuals who participated came from twenty-four different states and represented a variety of organizations including: family-run organizations, mental health provider agencies, and independent consulting corporations.

- While the majority of respondents agreed with keeping a DSM diagnosis, many families also raised two concerns: 1) Emphasis should be placed on the child's ability to function, across life domains and 2) the definition should accommodate children who have not yet been diagnosed.
- While respondents to the survey were split on using a one-year timeframe for the definition of SED, several people pointed out the issue of having children wait for a "year of failure" to become eligible for services that could benefits them sooner.
- The majority of respondents felt that the definition should be changed to include substance abuse and developmental disabilities.
- Respondents overwhelmingly agreed that the terminology should be changed. The three top choices for more acceptable terminology were: Serious Emotional & Behavioral Disorder, Serious Behavioral Health Condition, or Significant Emotional Impairment. Several people objected to using the term "behavioral" and others felt the word "serious" should be removed from the terminology.
- Three-fourths of the respondents felt the age should be increased from age 18 to 26 years noting that for many youth there is a delay in maturation when youth are coping with mental health disorders.
- Respondents were split about whether recovery orientation should be included in the definition. Many respondents felt it was important for the definition to clearly communicate that children and youth can recover from mental health conditions and go on to live productive and fulfilling lives.

**Note: not all participants answered every question. Due to this, you will notice different numbers throughout the survey report.*

Question #1

The current definition of Serious Emotional Disturbance requires that a child have "a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the DSM-III-R (and subsequent revisions)." Do you agree with using a DSM diagnosis as a core component of the definition?

Yes = 74.14% (43 respondents) **No = 25.86% (15 respondents)**

Key Concepts:

Many respondents agreed that a DSM diagnosis does create the ability for a healthcare professional to quantify the challenges a child or youth is experiencing, however, the definition should also be able to accommodate those who have not yet been diagnosed. Many felt the definition should focus on the functionality of the individual across life domains such as home, school and community.

> *"I have mixed feelings but lean more toward using a definition that focuses more on the impact of the disorder on daily functioning, than on a specific DSM diagnosis."*
>
> *"The definition should be based on significant functional impairment across life domains."*
>
> *"Using the DSM allows providers to quantify and qualify children that meet the criteria. Labels, perhaps unfortunately, are necessary to receive appropriate treatment and educational services. However, I feel that some parents either would not seek a diagnosis because of stigma or because of socioeconomic reasons, and how do we ensure that those children aren't discounted because they lack a DSM diagnosis?"*

Question #2

Children with substance abuse and developmental disorders are excluded from the definition of SED unless they also have a co-occurring diagnosable mental health disorder. Please comment on whether you think this exclusion should be changed or remain the same.

Remain the same = 35.71% (20 respondents) **Should be changed = 64.29% (36 respondents)**

Key Concepts:

The majority of respondents felt that the definition should be changed. Of those who commented, several mentioned the cross over between substance use, developmental, and mental health disorders. Comments highlighted youth with mental health challenges who self-medicate with substances and children and/or youth with developmental disorders who frequently present with behavioral manifestations, depression, and anxiety. Inclusion of substance use and developmental disorders may allow for a more holistic approach to treatment.

> *"It should be expanded to include children with both SA and DD. Children with SA abuse disorders almost always are manifesting serious emotional disturbance which us often masked by the substance use problem. Children with dev. delays often and usually express severe and pervasive behavioral issues. The fact that a dev. condition exists frequently excludes these children from treatment."*

> *"Many children with developmental disorders also have a mental, emotional, behavioral health component or diagnosis that results in complex behaviors."*

> *"Experience has shown us that most of our youth that self-medicate have an underlying mental health challenge. The "chicken" and "egg" scenario (What came first) prevents many youth from accessing and/or engaging in appropriate interventions in a timely manner."*

Question #3

The current definition requires that the diagnosis result in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities. Functional impairment is defined as difficulties that substantially interfere with or limit a child or adolescent from achieving or maintaining one or more developmentally-appropriate social, behavioral, cognitive, communicative, or adaptive skills. Functional impairments of episodic, recurrent, and continuous duration are included unless they are temporary and expected responses to stressful events in the environment. Children who would have met functional impairment criteria during the referenced year without the benefit of treatment or other support services are included in this definition. Please comment on whether you think functional impairment should be changed or remain the same.

Remain the same = 78.85% (41 respondents) Should be changed = 21.15% (11 respondents)

Key Concepts:

Most respondents felt the functional impairment language should remain the same, however, many of the comments focused on recognizing that the child and/or youth's level of impairment may be influenced by the formal and informal supports that may be in place. Another area of concern was around the need to ensure that children and/or youth experiencing challenges at home, school, or

community have access to treatment earlier in the process rather than waiting until the level of impairment has reached a 'substantial' level.

"While I appreciate the depth of the above description, it doesn't seem to go far enough. Why must we wait for a year of failure before classifying SED?"

"Often times strong families put semi-effective interventions into place, so that, their child is functioning and does not qualify for SED or services related to SED. Once the parent gets worn out or the current services move on, then the child is labeled SED. It seems to me that we should have a definition that works for these children instead of having to wait for their symptoms to worsen."

"Suggest that 'substantially interferes' be removed. I have seen even when there are minimal functional impairment that impacts the child relationship in these different arenas.

Question #4

The definition of SED requires that the child has had the diagnosis currently or at any time in the past year. Do you agree with using a one-year timeframe for the definition of SED?

Yes = 53.85% (28 respondents) **No = 46.15% (24 respondents)**

Key Concepts:

Responses were split on whether the one year time frame should remain. Respondents emphasized the need for the definition to be inclusive, to not require a child/youth to 'fail' for a year to receive needed services and supports, and the need to not penalize children, youth and families by removing supports if the child/youth improves as a result of accessing needed services and supports.

"Many programmatic structures require SED definition be met before providing intensive services and supports. I don't like 'waiting a year' and a child experiencing continued failure for that year. Not only is that dollar foolish, we're now in deep end services, the resulting human cost is priceless. Requiring a model that is based on a year of failure before eligibility for intensive services is not ok."

"There needs to be some reference to the fact that the diagnosis may not be applicable due to current supports or treatments that are in place, and that if the supports/treatment were discontinued, the diagnosis may again apply."

"Should be changed to currently or at any time in the past and then another question to specify the date/year of diagnosis."

Question #5

Do you think the term "Serious Emotional Disturbance" should be changed?

No = 6.25% (3 respondents) **Yes = 93.75% (45 respondents)**

Question #6

If you think the language should be changed, please rank your top three choices to replace SED.

The terms with the highest ranking were:

- Serious Emotional & Behavioral Disorder (26 respondents)
- Serious Behavioral Health Condition (24 respondents)
- Significant Emotional Impairment (23 respondents)

Additional comments:

"Classifying any mental health condition with the word "behavior" implies to society that there is control and willfulness. We should eliminate behavior from the diagnostic labels."

"Serious Mental Health Condition (do not like the term "behavioral" - behavior is a result of the disorder, not the disorder itself."

Question #7

Age: The current definition is restricted to persons up to age 18 years. Some states extend this age to persons less than age 22. Do you think the age range should be changed?

No = 23.40% (11 respondents) **Yes = 76.60% (36 respondents)**

Key Concepts:

Participant comments indicated that as a result of the youth's mental health challenges, their social, emotional, and behavioral skills are not necessarily age appropriate. Due to this, most felt the age range should be extended. The age range suggested was from 21 to 26 years of age.

"Since research indicates that the brain is not fully developed until at least 25 years of age, it makes sense to me that the upper limit should be 25 years of age."

"Though our children become legal adults at the age of 18, those of us that are parents know that their emotional, social, and behavioral function is often behind that of their peers. I would like to see this definition include transitional-age young adults to 26."

Question #8

Should recovery orientation (e.g. resiliency, responsiveness to services) be included in the definition?

No = 51.06% (24 respondents) **Yes = 48.94% (23 respondents)**

Key Concepts:

Respondents were split about whether recovery orientation should be included in the definition. Many respondents felt it was important for the definition to clearly communicate that children and youth can recover from mental health conditions and go on to live productive and fulfilling lives.

"The antiquated notion that mental illness dooms the diagnosed individual to a diminished life must change. People can and do recover, and go on to live fulfilling and productive lives. We must promote hope, wellness, resiliency and recovery, and support when our illness recurs."

"Giving anyone hope makes a difference to those receiving the diagnosis and encourages the family to continue to grow and be educated in the recovery model."

Question #9

Additional comments submitted regarding the current definition of Serious Emotional Disturbance?

"The words 'emotional' and 'behavioral' do nothing to promote wellness and recovery."

"There should be an alignment with the education definition for IEPs and Section 504 plans."

"The word 'disturbance' continues to stigmatize the child, the child's family and beyond."

"The term 'serious' needs to be removed. The functional aspects should be emphasized when doing assessments and the data should come from multiple sources (preferably reliable ones). Responsiveness to treatment or stabilization as a result of successful treatment should not lead to disqualifying a child from continuing to receive the services that are being effective."

"The current title adds to stigma attached to the diagnosis and prevents openness to receiving services."

ABOUT FREDLA

The Family-Run Executive Director Leadership Association (FREDLA) is a dynamic, new association to support those in leadership roles of family run organizations. FREDLA's mission is to: ***Empower and strengthen executive leaders of family-run organizations focused on the wellbeing of children and youth with mental health, emotional or behavioral challenges and their families.***

Each core member of FREDLA is the executive director of a state or local family-run organization. While many family-run organizations are funded through a SAMHSA Statewide Family Network grant or System of Care grant, this is not a requirement for FREDLA membership.

FREDLA is a partner in the Technical Assistance Network providing technical assistance and consultation for family-run organizations to: strengthen family leadership, build organizational capacity, and work with system of care communities and agencies to foster the true meaning of a family-driven system of care. Technical Assistance and consultation is provided through a peer-to peer model by experienced Executive Directors from local and state family-run organizations. Technical Assistance and consultation is tailored to the unique needs of the individual state and local communities and incorporates the cultural values and beliefs of families.

FREDLA offers a range of programs to build leadership and organizational capacity including:

- A network of peers to call upon for resources and expertise
- A one-day Leadership Camp for directors and emerging leaders of family and youth run organizations
- Webinars tailored to the unique needs of family-run organizations in a changing health care climate. Topics include: Certification Options for Family/Parent Support providers; Accreditation for Family-Run Organizations; and Family-Run Organizations Becoming Medicaid Providers
- Workshops on "Models of Family-Run Organizations: One Size Does Not Fit All" and "The Affordable Care Act: What Families and Family Run Organizations Need to Know"
- Diverse Leaders Scholarship Program

To learn more about FREDLA and become a member, visit FREDLA's website at www.fredla.org for membership information and additional resources.

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