



All Theses and Dissertations

2011-07-11

Utilizing Focus Groups to Determine Clinical Perceptions of Assessment Needs

Emily Ruth Smith Putnam
Brigham Young University - Provo

Follow this and additional works at: <https://scholarsarchive.byu.edu/etd>

 Part of the [Psychology Commons](#)

BYU ScholarsArchive Citation

Putnam, Emily Ruth Smith, "Utilizing Focus Groups to Determine Clinical Perceptions of Assessment Needs" (2011). *All Theses and Dissertations*. 2804.

<https://scholarsarchive.byu.edu/etd/2804>

This Dissertation is brought to you for free and open access by BYU ScholarsArchive. It has been accepted for inclusion in All Theses and Dissertations by an authorized administrator of BYU ScholarsArchive. For more information, please contact scholarsarchive@byu.edu, ellen_amatangelo@byu.edu.

Perceptions of Outcome Assessment Needs for
Severely Emotionally Disturbed Children

Emily Smith Putnam

A dissertation submitted to the faculty of
Brigham Young University
In partial fulfillment of the requirements for the degree of
Doctor of Philosophy

Mikle South, Chair
Gary Burlingame
Erin Bigler
Jared Warren
Nancy Howes

Department of Psychology
Brigham Young University

August 2011

Copyright © 2011 Emily Smith Putnam

All Rights Reserved

ABSTRACT

Perceptions of Outcome Assessment Needs for Severely Emotionally Disturbed Children

Emily Smith Putnam
Department of Psychology, BYU
Doctor of Philosophy

There has been a recent trend towards increasing accountability of mental health care providers through the use of treatment outcome measures, in order to reduce spending and improve patient care. This qualitative study utilized focus groups to elicit input regarding the need and possible content involved in creating an improved outcome measure specifically designed for severe emotionally disturbed (SED) children and adolescents. We conducted 60-90 minute focus groups with each of the following three separate constituent groups who are regularly involved in the care of SED youth at the Utah State Hospital (USH), including a) hospital clinical staff, b) affiliated education staff, and c) parents/primary caregivers; as well as clinical staff at community mental health youth outpatient clinic, Wasatch Mental Health (WMH) Youth Outpatient Program. While the groups agreed that a new unified system of tracking outcomes *could* be beneficial as an aid in improving outcomes, their greater concern is about a lack of communication between disciplines and between levels of care. Six broad domains were divided between two sections of Internal versus External Locus of control (Internal: Behavior, Social/Emotional, Academic/Cognitive, and Strength-Based Assessment; External: Collaboration among Care Providers and Family) and 23 subdomains were generated based on themes identified from the focus groups' responses. We also compared these domains and subdomains to ones previously generated by a USH pilot study and found some overarching similarities, but also some notable differences and both should be considered in any future outcome measure created. However, the most prevalent theme we found was a desire for an increase in collaboration and communication between constituencies and throughout levels of care, which is vitally important to improve care and long-term outcomes of SED youth.

Keywords: outcome, severely emotionally disturbed, SED, focus group, collaboration, communication, continuity of care, accountability

ACKNOWLEDGEMENTS

I would like to thank Mikle South for his mentorship, dedication to the completion of this project, and many hours of editing. I am also grateful to Nancy Howes for initiating this research and inviting me to participate in it, and her diligent efforts to recruit so many participants. In addition, I appreciate all of the assistance I have received from other members of my committee, including Gary Burlingame, Erin Bigler, and Jared Warren. I would like to thank all of the participants in the focus groups for their willingness to openly share their experiences and insights and to Utah State Hospital and Wasatch Mental Health for allowing me to conduct this research at their sites. I am also forever grateful to my husband and son for their patience and support, my parents for many years of love and support, and additionally to my parents and sister for their assistance editing this dissertation.

TABLE OF CONTENTS

Introduction.....	1
Study Objectives	4
Fundamental Principles.....	5
Principles for effective outcome measures	5
Principles for child outcome assessment	8
Principles for SED outcome assessment.....	9
Evaluation of Current Assessment Measures	12
Vineland Adaptive Behavior Scales (Vineland ABS)	12
The Child Behavior Checklist/6-18 (CBCL/6-18).....	15
The Behavior Assessment System for Children-2 (BASC-2).....	18
Youth Outcome Questionnaire (Y-OQ).....	20
SED-specific outcome measures.....	24
Focus Group Use in Measurement Development	26
Focus group research design.....	28
Focus group discussion techniques.....	31
Group format.....	32
Data collection and analysis.....	35
Summary of focus groups in measurement development	36
Methods.....	36
Participants.....	36
Mental health professional groups	37
Teachers group.....	37

Parents group	38
Procedure	38
Semi-Structured Group Discussion.....	39
Qualitative Data Analysis	40
Results.....	41
Evaluation of Focus Groups.....	41
Level of Perceived Need for a New Outcome Measure	43
Inpatient clinicians	44
Outpatient clinicians	46
Teachers	48
Parents.....	49
Conceptualization of Domains.....	50
Internal locus of control.....	50
External locus of control.....	71
Comparison of Domains from Focus Groups with USH Pilot Study	83
Discussion.....	88
Level of Perceived Need for a New Outcome Measure	89
Conceptualization of Domains.....	91
Internal locus of control.....	91
External locus of control.....	94
Comparison of Domains from Focus Groups with USH Pilot Study	96
Reflections and Future Considerations	100
Purpose of outcome measures.....	100

Recommendations for an improved SED outcome measure.	101
Current recommendations for improving communication.....	108
References.....	111
Appendix A.....	121

LIST OF TABLES

Table 1. The Relative Number of Comments and Percent Coverage of Comments from each Participant	42
Table 2. Domains and Subdomains with Percent Relative Frequencies and Cover	51
Table 3. Comparison of Items from the USH Pilot Study with Subdomains from the Focus Groups.....	85
Table 4. Suggested Sections, Domains and Subdomains/Items for a New SED Outcome Measure.....	102

LIST OF FIGURES

Figure 1. Common Themes in Child and Adolescent Assessment of Clinical Dysfunction	10
Figure 2. Proposed Likert Scale for New SED Measure.....	105

Perceptions of Assessment Needs in Severely Emotionally Disturbed Children

Due to the high cost of providing mental health services, third party payers such as managed care organizations are demanding increased accountability by requesting that care providers demonstrate evidence of treatment effectiveness (Burlingame, Lambert, Reisinger, Neff, & Mosier, 1995; Meier & Letsch, 2000; Wells, Burlingame, Lambert, & Hoag, 1996). This has led to an increase in outcome measurement research and the development of new assessment tools for mental health patients, such as the Outcome Questionnaire (OQ-45; Lambert et al., 1996) and the Brief Psychiatric Rating Scale (BPRS; Overall & Groman, 1962).

As with other areas of research and treatment, however, development of outcome measures for children has lagged behind that of adults (Greenbaum et al., 1998). There is a particular dearth in outcome research for children classified as severely emotionally disturbed (SED; Behrens & Satterfield, 2006; Greenbaum et al., 1998; Reddy, 2001; Wagner, 1995). There are numerous definitions of SED, but the prevailing definitions are based on clinical diagnosis and functional impairment over a specified time period (Hanson, 2007). For the purposes of this research, the target SED population includes children and adolescents with at least one diagnosis from the Diagnostic and Statistical Manual-IV (DSM-IV) that results in impairment so severe that it creates risk of separation from family and community. SED populations have high levels of involvement in service systems, including mental health, school-based special education, child welfare, juvenile justice, and vocational rehabilitation (Greenbaum et al., 1998). Therefore, tracking outcomes within this population is important throughout treatment and also in follow-up to facilitate intervention as needed and curtail negative functional outcomes.

Measuring treatment outcome is of particular concern for the SED population because a substantial portion of these youth maintain high levels of symptomatology even after intensive mental health services for problems such as emotional disturbances, behavior problems, and substance abuse (Halliday-Boykins, Henggeler, Rowland & DeLucia, 2004). Such treatments frequently involve removing the child from their home environment and placing him or her in long-term residential, hospital, or proctor/foster based intensive treatments. This removal from their natural environment may disrupt normal developmental trajectories, including the development of appropriate social and family relationships. Many of these children and adolescents exhibit a significant decline in adaptive behavior over a period of years, accompanied by decreased academic performance (Greenbaum et al., 1998).

Therefore, beyond the primary focus on symptom reduction captured by most outcome measures of treatment progress in SED populations should also track developmental and cognitive functioning. However, measures currently in use are either (a) focused particularly on adaptive functioning with little measurement of psychiatric symptoms (e.g. Vineland Adaptive Behavior Scales; Sparrow, Balla, & Cicchetti, 1984), (b) adapted from instruments for baseline symptom assessment that lack sensitivity to change over time (e.g. Child Behavior Checklist [CBCL]; Achenbach, 1991 and the Behavioral Assessment System for Children [BASC]; Reynolds & Kamphaus, 1992), c) adapted from the adult model of focusing on symptom reduction while generally ignoring adaptive functioning, such as the Youth Outcome Questionnaire (Y-OQ; Burlingame et al., 2001) or d) do not have sufficiently strong psychometric properties when designed for SED populations (BPRS-C; Overall & Pfefferbaum, 1984 and Child and Adolescent Functional Assessment Scale [CAFAS]; Hodges, 2000).

Because of involvement in so many social service systems and because SED youth frequently move back and forth between multiple levels of care (Marsh & Fristad, 2002), it is likewise important to have a unified way of measuring progress and communicating this progress to other agencies and disciplines. The federally-mandated objective to treat youth within the least restrictive environment possible also contributes to multiple transitions and placements in multiple settings in order to minimize time in higher levels of treatments. A recent trend towards improving the continuity of care has emphasized improving communication between multiple care providers (des Crusier & Diamond, 2004), but a standardized way of communicating current status or progress across providers is lacking. It would also be beneficial to have more accurate ways of predicting when these children are ready to be stepped down to the next, less restrictive level of care; and when they need to be stepped up.

In light of these deficits in current outcome measures for SED populations, the children's treatment team at the Utah State Hospital (USH) conducted a pilot study to generate ideas for a new measure of SED treatment outcome. Through semi-structured interviews with selected mental health staff and professionals at USH, four broad domains were described as vital for inclusion in a new measure of SED treatment success. These four domains consist of:

1. Cognitive Development—skills related to executive brain functioning, such as reason, attention, impulse management, and memory
2. Social Development—behaviors related to interpersonal relationships and ethics
3. Mental Health—symptomatology related to diagnoses of serious mental illnesses, such as psychotic symptoms and mood regulation
4. Well-Being—skills related to functionality across roles, including Activities of Daily Living (ADLs) and identity development

Based on these data, USH staff created a draft instrument that is intended to track progress in each area (the measure is included as Appendix A). However, this measure was created by individual interviews only with mental health staff at USH. Because there are so many other people both within USH and in other treatment settings who contribute to the care of SED youth, the USH treatment team was interested in obtaining input from other relevant groups. This study seeks to include some of these people that interact with youth, including their parents, who have the most extensive experience with these children, teachers, as these children spend a large portion of their time in school and often have poor academic prognosis, outpatient clinicians who interact with these children before admission to USH and after discharge, as well as the mental health professionals at USH.

Study Objectives

This investigation used focus groups to gather information from multiple sources that interact with SED children on a regular basis, including mental health treatment teams, teachers, and parents/caregivers. The specific purposes of this study are to build on the previous USH interviews in three ways:

1. Determine the level of perceived need for a new outcome measure among the various constituencies involved in SED treatment, including child and adolescent treatment teams at USH; teachers at the USH-affiliated school; caregivers of children who are currently receiving treatment at USH; as well as other treatment providers outside of USH.
2. More completely conceptualize the domains (and their dimensions) that should be included in a new measure of treatment outcome in the SED population.
3. Examine the parallels and divergent aspects between the suggestions from the focus groups of treatment providers, teachers and families with those previously generated

domains from the USH pilot study, in preparation for the next revision of the USH measure.

Fundamental Principles

In the following sections, I consider the fundamental principles necessary to successfully complete this project, including (a) delineation of the requirements for making an effective outcome measure; (b) special characteristics needed for outcome measures of children and adolescents, specifically of the SED population; and (c) guidelines for using focus groups effectively for this project.

Principles for effective outcome measures. The 1990s began the era of accountability for practitioners in mental health care, leading to a boom in outcome measure development. Third party payers began pressuring health care providers to document clinical results at the end of treatment (endpoint assessment) and monitor progress throughout treatment to identify and correct any areas necessary (continuous quality improvement [CQI]; Burlingame et al., 1995). After the Joint Commission of the Accreditation of Healthcare Organizations (JCAHO) switched to the continuous quality improvement (CQI) model in 1992, practitioners were required to monitor patient care throughout treatment. By including ongoing tracking throughout treatment, as well as endpoint assessment, practitioners have the opportunity to intervene during treatment if a patient begins to decline. This concern about patient outcomes and treatment success led to the development of many outcome measures (Burlingame et al, 1995), with the majority focused on adult populations. However, quality of outcome measures is not consistent across the board. Burlingame et al. (1995) suggest four major criteria for selecting an outcome measure: (a) psychometric properties (standardization, reliability and validity), (b) usability, (c) suitability for

target population, and (d) sensitivity to change. These criteria are considered in more details in the following paragraphs.

Psychometric properties. The most important requirement for an outcome measure is that it has been standardized in order to provide meaningful comparisons and interpretation of the data. This standardization requires empirical support, including technical vigor in the form of reliability and validity, as well as normative data. For reliability, Burlingame et al. (1995) suggest using measures of internal consistency estimates (i.e., coefficient alphas) to determine homogeneity of the measure; and/or test-retest reliabilities to examine the temporal stability of the measure. Burlingame et al. (1995; see also Durlak, Wells, Cotton, & Johnson, 1995) recommend internal consistency reliability of .80 or above, and test-retest reliability of over .70. It is important to note that if the measure is examining a broad content area, the measure will likely be less consistent. Cicchetti (1994) provides descriptions for a range of internal consistencies: $< .70$ = poor, $.70-.79$ = fair, $.80 = .89$ = good, and $> .90$ = excellent.

Validity, including content, structural, and concurrent, is another technical element that deserves consideration. Burlingame et al. (1995) suggest that concurrent validities, the extent to which the outcome measure agrees with other similar forms of assessments, be at least .50 and above, with .75 being excellent. If a measure does not pass these basic technical requirements, it is not worth pursuing further, as interpretation becomes uncertain.

Usability. The target population must be willing and able to use a measure for it to provide any service as an outcome tool. Burlingame et al. (1995) suggest selecting outcome measures that are “easy to use, score, and interpret and are not costly on a case, clinic or hospital basis” (p. 227). Usability can also include current degree of acceptability among clinicians. Concerns with practicality also include time and effort, and whether the burden is on the client or

clinician. If multiple measures have to be used, this inherently increases the burden and decreases the likelihood of use. Therefore, the design stage of a measure needs to address the usability of assessment and ensure that the target population will be able and willing to administer the new measure. Furthermore, the user must be able to interpret the results of the measure for it to have any practical value, which is especially important if the measure is to track progress throughout treatment and moderate interventions.

Suitability for target population. This criterion focuses on ensuring that the measure is appropriate for the patient population for which it is intended (Burlingame et al., 1995). This can encompass multiple areas, including whether the population will be able to utilize the measure and if it addresses the specific concerns of that population. Content validity, the extent to which it is measuring what it is intended to, is related to this issue of suitability, but suitability also addresses whether this is the most appropriate content to be measuring for the population. This suitability criterion is of particular concern for the population of interest considered here, namely SED children and adolescents.

Sensitivity to change. Sensitivity to change is the degree to which the measure detects and reflects subtle short-term changes, thus enabling the user to track changes throughout treatment. Sensitivity to change is especially important for the CQI portion of accountability, as the capacity to measure subtle changes is crucial for early detection of patients who are declining or not progressing as rapidly as expected. By alerting the clinician early, there is more potential for an effective intervention. Sensitivity to change can also be useful in research, such as in comparing effectiveness of various treatments. Measures with high sensitivity to change are more likely to detect small, but perhaps meaningful, differences. Effect sizes (Cohen's *d*) are often used to demonstrate the extent of change. According to Cohen (1988) an effect size is

considered small when $d = .20$, moderate when $d = .50$, and large when $d = .80$ or greater.

Unfortunately, practitioners often overlook this criterion for both research and clinical purposes, as they continue to use assessment tools that were not developed as outcome measures and lack sensitivity to change, especially to subtle changes.

Principles for child outcome assessment. The above criteria were established for selection and evaluation of outcome measures for adult populations. They may not entirely encompass attributes necessary for a child outcome measure and specific unique aspects of children need to be considered.

Initial progress in research and treatment usually begins in the adult population, with later application for children and adolescent populations. These attempts to apply principles from work with adults to work with children are often inadequate. Achenbach (1995, p. 261) called for a more “independent identity (for child psychopathology) that [is] not merely extrapolated downward from adult models.” Although Achenbach was among the first in the 1970s to recognize the importance of considering competencies of children and adolescents in assessment (Achenbach, 1991), this has not transferred to outcome research (Kazdin & Whitley, 2006). In a field that has its roots in adult populations, it is critical to consider whether the ideas and definitions generated in the adult research are accurate and sufficient for child and adolescent populations.

One of the key definitions that has been carried over from adult to child outcome measures is that of “recovery.” Frequently in adult outcome measures, treatment success, or recovery, is operationalized as reduction of symptoms into the normal range, below diagnostic level. However, unlike adults, children and adolescents have not reached a developmental plateau, but are still maturing. This means that removing symptoms or problems does not

automatically ensure appropriate behavior and adequate development. Therefore, assessing and monitoring levels of developmental progress are important in child treatment and outcome measurement.

Developmental change in children and adolescents over time can also impact the interpretation of problem behaviors and symptoms. The degree of inappropriateness or maladaptiveness of a particular behavior is relative to the developmental stage of the child (Kazdin, 2004). This presents a unique challenge for practitioners treating children and adolescents to determine if a particular behavior deemed problematic is beyond the scope of normal development for the age of the child and, therefore, worthy of treatment. This is a somewhat subjective judgment and can impact assessment of treatment outcome. In addition, whether a particular problem behavior or skill deficit is within normal limits may change through the course of treatment as the child is expected to mature. A measure designed specifically to track the acquisition of developmental gains, as well as symptom reduction, can help address this particular problem.

Kazdin (2005, p. 548) specifically addresses issues in child assessment and identifies six “common themes” that also have application for the more specific field of outcome assessment in children. These are summarized in Figure 1.

Principles for SED outcome assessment. The types and severity of symptoms are different for the SED population than for other client groups and need to be taken into consideration for outcome measures. SED children often experience more severe symptoms and meet criteria for multiple disorders. Moreover, they may exhibit a variety of symptoms simultaneously, even if some are subclinical. In addition, they may experience no symptoms in some areas or even demonstrate strengths while exhibiting severe problems in other areas.

1. There is no "gold standard" to validate assessments. Thus many purported measures of validity are essentially circular.
2. Multiple measures need to be used to capture diverse facets of the clinical problem. Interpretation of data across measures is difficult.
3. Multiple disorders or symptoms from different disorders ought to be measured because of high rates of comorbidity. Even subclinical symptoms can lead to functional impairment.
4. Multiple informants are needed to obtain information from different perspectives and from different contexts. In out-of-home placements, finding consistent raters is especially problematic.
5. Adaptive functioning is as important to measure as functional impairment. It is vital to assess how individuals are doing in their everyday lives in addition to measures of symptoms and disorders.
6. Influences (or moderators) of performance need to be considered for interpreting child assessments, including sex, age or developmental level, culture, and ethnicity, among others.

Figure 1. Common Themes in Child and Adolescent Assessment of Clinical Dysfunction

Note. From Kazdin (2005)

For example, school attendance is one area that could fall on a continuum from extreme problems, such as expulsion or dropping out, to strengths, such as daily attendance and/or excellent grades despite severe problems in other areas. This range of symptom severity and types of symptoms is often lacking in measures designed for other populations. Therefore, there is a need for continuum measurement in each domain, ranging from very severe problems to strengths, to accommodate these unique profiles and adequately assess current status for a wide range of domains, while avoiding ceiling or floor effects.

Consideration of age appropriate development is also important in SED children and adolescents because this population is more prone to being placed in a residential or inpatient treatment setting (Wells, 1991). This removal from a typical home environment can disrupt normal development, and the children and adolescents can experience decline in adaptive functioning (Greenbaum et al., 1998). In addition, intensive treatment may focus extensively on one or a few problematic areas, and other areas, including strengths, may begin to falter. With the focus of outcome measures on symptoms and problem areas, changes in areas of strengths may not be detected. Also, since children are still developing, dramatic focus on a few

developmental areas may be at the expense of normal development in other areas. Therefore, it becomes exceedingly important to assess whether they are making expected developmental progress in non-symptomatic areas as well. Treatment providers need to be held accountable for keeping the child on a suitable developmental trajectory in addition to ameliorating symptoms.

Moreover, because these children often receive intensive treatments outside of their home setting, they frequently lack consistent relationships and/or attachment figures (such as parents and teachers). This limits the type of informants that can be used for gathering information regarding outcome. While it is commonly recognized that self-reports are fallible sources of data (Fernandez-Ballesteros, 2004), this can be further impacted by the severity of pathology, which is problematic with the SED population. Children in general tend to under-report symptoms and are inconsistent with other informants (e.g. parents and teachers), and inpatient SED children tend to under-report symptoms to a greater degree (Kazdin, Esveldt-Dawson, Unis, & Rancurello, 1983). This may be due to poorer insight into their own problems and/or concerns about consequences or longer removal from their home if they report their symptoms accurately. Although their input regarding their current level of functioning and problems is important, it cannot be relied upon as the only source. Nor can parents be relied upon solely, especially if the child is not currently living with them. Kazdin (2005) emphasized the need for multiple sources of information about a child. A more synergistic approach of using an independent rater to combine various sources of data through interviews as well as more objective observations in one measure is one way that has been used to deal with more severe inpatient populations for both children and adults (e.g. the BPRS, BPRS-C, CAFAS).

Clinician-rated instruments are often used in hospital settings as they have an advantage over self-report because of the disabling psychopathology patients exhibit in order to be admitted

to a hospital (Lachar et al., 2001). Especially when first admitted, patients exhibit impairment that negatively affects their ability to complete even a brief self-report measure. However, although using clinician-rated instruments increases accuracy, it also creates a resource drain. The clinician-rated instruments also often require more extensive training to achieve acceptable inter-rater reliabilities.

Overall, the SED population has unique concerns that need to be addressed in an outcome measure. Accurately assessing outcomes in this population is especially important given their high recidivism rates and continued difficulties functioning in society even after intensive treatment. Therefore, developing an outcome measure that takes into account their unique challenges and is able to adequately assess progress is vital. Measures that are currently used for assessing outcome are reviewed and evaluated for their suitability for use in this specialized population.

Evaluation of Current Assessment Measures

Using Burlingame et al.'s (1995) criteria for evaluating outcome measures, as summarized above, I conducted a review of commonly used treatment outcome measures to determine how well the presently available measures address the complexities of this measuring outcome in this difficult population.

Vineland Adaptive Behavior Scales (Vineland ABS). The Vineland Adaptive Behavior Scales (Vineland ABS) is a three point Likert scale, standardized interview or survey form conducted with parents and/or teachers regarding a child's development to determine how well the child is reaching his or her appropriate developmental milestones. It is divided into three broad domains, Communication, Socialization, and Activities of Daily Living, with three

subdomains in each. Although there is not a major focus on negative symptoms, it also has a section regarding maladaptive behaviors.

Design and development. The Vineland Adaptive Behavior Scales (Vineland ABS; Sparrow, Balla, & Cicchetti, 1984) and the revised version (Vineland-II; Sparrow, Cicchetti, & Balla, 2005) were designed to be “applicable whenever an assessment of an individual’s daily functioning is required” (Sparrow et al., 2005, p. 5) and has uses in clinical, educational, and research settings. However, the Vineland was specifically designed for the mentally handicapped and developmentally delayed populations and often exhibits ceiling effects with other populations. Although is not typically used as a short-term tracking outcome measure in the general population, it is considered the gold standard for measuring adaptive functioning, which is important to measure in the SED population.

Psychometric properties. The Vineland-II generally has good to excellent psychometrics. Reliability estimates have a broad range from poor to excellent for children and adolescents: internal consistency (domains: .83 - .95; subdomains: .61 - .93); test-retest ($r = .51 - .81$, or $r_{adj} = .68 - .91$ for adolescents 14-21, $r_{adj} = .77 - .93$ for children 7-13); and inter-rater (interview means: .70 - .74; parent rating means: .70 - .81). The authors attribute the lower reliabilities found in adolescents to two factors (a) this age is more of a transitional period in which they are observed less by parents and (b) adolescents have greater capabilities, so there tends to be greater ceiling effects among adolescents than with children (Sparrow et al., 2005). The validity of the Vineland is strongly supported. Test content and structural validity is supported and matches the underlying theory as correlations between subdomains were moderate to high for children and adolescents (.40 - .89) and the confirmatory factor analysis supported the three-factor model (children $CFI = .96$; adolescents $CFI = .94$; Sparrow et al., 2005). Overall,

the Vineland is well supported psychometrically and, as noted, is the gold standard for measuring adaptive functioning.

Usability. The extensive utilization of the Vineland and Vineland-II by clinicians indicates that it has acceptable usability, both in administration and interpretation. The Vineland-II also includes both an interview form and a parent-rated form for children and adolescents, which allows some flexibility in administration and can ease the burden for the clinician. One difficulty in using the parent-rated form, however, is that the clinician must ensure that the floor and ceiling rules are met, especially if functioning is not close to the child's chronological age.

Suitability for SED population. The Vineland has demonstrated utility in diagnostic realms and in providing some understanding of the child's skills regarding adaptive functioning, instead of focusing solely on symptoms. However, the Vineland was designed specifically to measure deficits in adaptive functioning, particularly among mentally retarded (MR) patients, and is often used to help distinguish between diagnoses (such as developmental disorders and ADHD). There is not much investigation into strengths in adaptive functioning, as noted by the frequent ceiling effects. Furthermore, there is little measurement of behavioral/psychiatric symptoms, especially with regard to the severity of symptoms that are salient in SED children and adolescents. One possible advantage is that the Vineland has both an interview and parent-rated version, which can make it flexible for use in an out-of-home treatment setting.

Sensitivity to change. While the Vineland has been used to evaluate treatment, this is not its most common use and it is not built to measure frequent monitoring over time. When the Vineland is used as an outcome measure to evaluate treatment, it is typically over a long period of years, rather than as a tracking instrument to be used on a weekly basis, and most commonly

used with pervasive developmental disorders and mental retardation (e.g. Magiati, Charman, & Howlin, 2007; Charman, et al., 2005; Magiati & Howlin, 2001; Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002). The Vineland has also been used as an adaptive behavior outcome measure for medical issues, such as head injuries (Fletcher, Levin, Lachar, & Kusnerik, 1996), seizures (Jonas et al., 2004), prenatal exposure to illegal substances (Bada et al., 2008; Phelps & Cottone, 1999), diseases (Bjorkaker et al., 2006). No studies were found in which the Vineland was used as a short or long-term outcome measure with the SED population, although its authors recommend its use for assessment or differential diagnosis in this population (Sparrow et al., 2005). While it may be useful in broad scale changes over significant periods of time, it has not demonstrated usability as a monitoring device to track treatment progress over short-term intervals with the SED population.

The Child Behavior Checklist/6-18 (CBCL/6-18). The Child Behavior Checklist/6-18 (CBCL/6-18; Achenbach, 1991, 2001) is a survey form questionnaire which parents, teachers, and/or the adolescent themselves can rate a combination of competence items and more standardized three point Likert scale questions regarding behavioral and emotional problems over a six month timeframe. It generates scores with clinical cut-offs for nine subdomains regarding external behaviors such as aggression, rule-breaking, and hyperactivity as well as internal problems including anxiety, depression, and withdrawal, among others. It also includes six DSM oriented scales and has a section regarding competencies, including subdomains of activities, social skills, and school performance.

Design and development. Achenbach was one of the early proponents of measuring both strengths and problem behaviors (Greenbaum, Dedrick, & Lipien, 2004). The parent-rated CBCL (along with its corresponding Teacher [TRF] and youth self-report [YSR] measures) is

one of the most widely used parent report forms of child psychological behaviors (Behrens & Satterfield, 2006; Greenbaum et al., 2004; Kazdin, 1994). Although originally designed as an assessment tool, it is now commonly used as an outcome measure (Behrens & Satterfield, 2006; Hatfield & Ogles, 2004). The CBCL (as well as TRF and YSR) is somewhat unique from other assessment and outcome measures in that it was designed to measure competencies as well as problems in children.

Psychometric properties. In addition to its strength in measuring adaptive skills as well as symptoms, the CBCL is generally strong psychometrically (Achenbach & Rescorla, 2004). Internal reliabilities are fairly high overall, but somewhat weaker for the competency scales (.55-.79) than for the problem scales (.71 - .95), likely due to the fact that the competency scale have fewer items. Cross-informant agreement was found to be fairly high between pairs of parents (CBCL, mean $r = .59$) and teachers (mean $r = .64$), but poor between parents and teachers ($r = .27$) and between children and both parents ($r = .25$) and teachers ($r = .20$). Test-retest reliabilities were very high for the composite score over an 8-16 day period (.87 - .95). The validity of the CBCL is well supported empirically and practically by its excessive use. The CBCL was validated using correlations with the BASC-PRS (.24 - .70 for similar scales) and the Conners (1973) Parent Questionnaire (Gladman & Landcaster, 2003) as well as its ability to accurately predict group placement (clinical vs. normative or specific diagnoses) of patients (Achenbach, 1991; Burlingame et al., 2001; Doyle, Ostrander, Skare, Crosby, & August, 1997).

Usability. The acceptability of the CBCL by clinicians is obvious in that the CBCL has been used in numerous studies for assessment (diagnostic), outcome, and comparison purposes (Bérubé & Achenbach, 2006). The CBCL and YSR are two of the most widely used measures of adaptive and maladaptive psycho-social functioning (Behrens, & Satterfield, 2006), underscoring

the popularity and ease of use of the instrument. It is a fairly short questionnaire, requiring about 10-15 minutes to complete and does not increase the burden of the clinician, which makes it appealing to researchers and clinicians.

Suitability for SED population. A strength of the CBCL is that it was specifically designed for children, rather than being adapted from an adult version, and measures competencies as well as problems. However it was not specifically designed for the SED population and lacks the breadth and depth of symptoms and severity of problems. Nonetheless, it has been commonly used as an outcome measure, including with SED populations and in residential type settings.

Sensitivity to change. The CBCL continues to be used as a measurement of treatment effectiveness and has demonstrated significant change results (e.g. Behrens & Satterfield, 2006; Rosenblatt & Rosenblatt, 2002) indicating that it may be valid for detecting the presence of change. However, it is not as sensitive at detecting subtle changes over time (Rosenblatt & Rosenblatt, 2002). Although many studies have used the CBCL as an outcome measure, this may not be the best choice. The CBCL was designed for baseline and diagnostic assessment purposes rather than detecting change; its scales tend to measure more stable phenomena and are less sensitive to change (Greenbaugh et al., 2004). Its narrow response range (only a three-point Likert scale) leaves little room to detect subtle changes. A recent comparison study of the CBCL and BASC-2 to a the YOQ, an instrument designed to measure outcomes using a five-point Likert scale, found that although the CBCL did detect some changes, the slope of change was very shallow compared to the YOQ and the trajectory of change was flatter, and took longer to detect (McClendon et al., 2011). Without evidence of sensitivity to change, the use of traditional assessment measures, such as the CBCL, to assess psychotherapeutic change may be

inappropriate. The lack of sensitivity to change prohibits the measure from demonstrating therapeutic change even when significant change has occurred (Berrett, 1999). Despite the CBCL's limitations as an outcome measure, many continue to use it as such and its authors continue to advocate its use as an outcome measure even though tracking change was not its original intended use.

The Behavior Assessment System for Children-2 (BASC-2). The Behavior Assessment System for Children-2 (BASC-2) is also a standardized three point Likert scale survey form questionnaire completed by parents, teachers, and/or the adolescent themselves regarding problem as well as adaptive behaviors and generates up to five adaptive scale and up to 10 problem behavior scales.

Design and development. The BASC-2 was designed to “facilitate the differential diagnosis and educational classification of a variety of emotional and behavioral disorders of children and to aid in the design of treatment plans” (Reynolds & Kamphaus, 2004, p. 1). Although this measure was also designed for assessment and recommendations rather than outcome, an asset of the BASC is that it investigates the child's individual strengths and weaknesses, instead of solely focusing on diagnosis (Thorpe, Kamphaus, & Reynolds, 2003). Similar to the CBCL, the BASC-2 can be rated by multiple informants (parents, teachers and youth).

Psychometric properties. Kline (1994) indicated that overall the psychometric integrity of the BASC PRS and TRS scales are generally good. Reliability estimates for the BASC-2 were found to be acceptable across all informants for both composites and subscales. The following reliabilities are provided based on the general norm sample (Reynolds & Kamphaus, 2004) and demonstrate a pattern of higher scores for composites than subscales and the parent

(PRS) and teacher (TRS) reports were higher than self (SPR) report: internal consistency (PRS composite: .90 - .95, subscale: .84 - .88; TRS composite: .93 - .97, subscale: .80 - .86; SRP composite: .88 - .94, subscale: .78 - .83), Test-retest reliabilities (PRS composite: .84 - .91, subscales: .77 - .84; TRS composite: .86 - .90, subscale: .81 - .86; SPR composite: .80 - .90, subscales: .70 - .84), and Inter-rater correlations (PRS composite: .71 - .78, subscales: .69 - .77; TRS composite: .57 - .74, subscales: .53 - .65). Validity is also well supported for the BASC-2 both in structural validity (Reynolds & Kamphaus, 2004) and concurrent validity with the CBCL (total problems score: .73 - .84 and externalizing problems: .74 - .83) and the Conner's PRS-R total indexes (.78 - .79).

Usability. Kline (1994) claims that the items on the BASC are generally clear in meaning, concise (often fewer than 4 words) and refer to specific behaviors. Another useful feature of the BASC is that it includes a few critical items that do not contribute to any scales but alert the clinician to potential problem areas. Scoring and interpretation is also fairly simple and is not an excessive burden on the clinician.

Suitability for SED population. The BASC-2 has a strength in that, like the CBCL, it was designed specifically for children, instead of being extrapolated down from an adult version. In addition, it does include some measures of adaptability, and does not solely focus on impairments and symptoms (Thrope et al., 2003). However, it was designed primarily for differential diagnosis in a general child and adolescent population and not specifically for the SED population. It does include specific norms and profiles for certain clinical groups, including ADHD and learning disabilities (LD), but not for more severe diagnoses (Reynolds & Kamphaus 2004). The four point scale also does not lend itself to a wide range of choices for severity for each item, and the items themselves do not address the breadth and depth of problems

experienced by the SED population. It also does not have a form for outside observer or clinician to rate the child, which can be problematic if the child is in an out-of-home placement and has little contact with traditional parental or teacher figures and must be relied upon as the sole informant.

Sensitivity to change. Although the BASC is newer than the CBCL, it is becoming one of the most popular instruments for clinicians to use and has been adopted as an outcome measure, despite the fact that it was not designed as such. Although the BASC and BASC-2 have been used as outcome measures in many studies, there is not much evidence for this use on the basis of sensitivity to change. A recent study compared the BASC-2, CBCL/6-18, and the YOQ as measures of outcome (Debra Theobald McClendon, 2008, personal communication). Like the CBCL, although the BASC-2 detected some change in patients who successfully completed therapy, they found that the YOQ was most sensitive to change and that the others had very flat slopes. Thus, while statistical change may be found in large studies with numerous subjects, the use of either the CBCL or BASC-2 as a tracking outcome measure for individual clients may not be as useful, given that neither detects small changes rapidly or necessarily produces large effect sizes. For example, another study (Rahill & Teglassi, 2003) used the BASC Behavioral Symptoms Index (BSI) as an outcome measure with children with emotional disorders. Although they found a significant main effect ($F(2, 71) = 3.759, p < .05$) for the BSI, the effect size (eta squared) of the BSI variable was very small (.098). Thus, while the BASC may be able to detect some change over time, it is not sensitive to these changes and the effects are minimal.

Youth Outcome Questionnaire (Y-OQ). The Youth Outcome Questionnaire (Y-OQ) is a 64 item, five-point Likert scale questionnaire completed by parents (there is also a separate

self-report form for adolescents) about current psychological symptoms over a two week period and provides a total score with a clinical cut-off as well as cut-off scores for inpatient and outpatient populations.

Design and development. The Youth Outcome Questionnaire (Y-OQ; Wells, Burlingame, Lambert, & Hoag, 1996) was designed as a measure to track change and hold practitioners accountable for outcome of their child and adolescent patients. It was originally conceived as the child version of the adult OQTM45.2 (Lambert et al., 1996), so there may be some concerns with the idea of extrapolating down from the adult version, but it was changed significantly from the adult version to meet the needs of children. Its conception was designed to fulfill requirements of managed care companies to provide evidence of treatment effectiveness, due to increasing total costs of mental health. The four main objectives in mind during the creation of the Y-OQ, were that the Y-OQ would be: “(1) utilized on a session to session basis to track progress and outcome; (2) brief, requiring less than 7 minutes to complete; (3) sensitive to change over short periods of time; and (4) available at a nominal cost” (Wells et al., 1996). In order to meet these objectives, the measure needed to be sensitive to change while also being fast, simple, inexpensive and convenient for the therapist; thus, it is reasonably quick and simple a client-rated (self or parent) measure, and psychometrically sound (Dunn, Burlingame, Walbridge, Smith, & Crum, 2005).

Psychometric properties. The Y-OQ is strong overall psychometrically. Although it was not designed specifically for the SED population, they were included in normative sampling (Burlingame et al., 2005). The Y-OQ was found to have a very high internal consistency estimate (.97) for the total score, and subscale consistencies ranged depending on the norming sample from .63 - .97 (Burlingame et al., 2005). Total score test-retest reliabilities were strong

(two weeks: $r = .84$; four week: $r = .81$) and subscales ranged from good to excellent ($r = .56 - .82$) with lower values being associated with shorter scales (Burlingame et al., 2005). Validity was supported by correlations with the CBCL total score (normal population: $.75$; inpatient: $.82$) and related subscales (normal: $.56 - .71$; inpatient: $.70 - .73$) and the Conners Parent Rating Scale converging subscales (such as Conduct Disorder: $.71$; Burlingame et al., 2001). The Y-OQ also has some demonstrated predictive validity, such as identifying potential juvenile offenders (Burlingame, Wells, Lambert, & Cox, 2004).

Usability. The Y-OQ was specifically designed to be easy and quick to facilitate routine use, such as on a weekly or biweekly basis. It takes approximately 5 - 7 minutes to complete and is completed by the parent (and/or the self-report form for the youth), so does not add to the burden of the clinician. The interpretation is straight forward, as most clinicians focus on the overall score as a measure of symptoms distress and severity and critical items also alert the clinician to some specific critical problems. It is also inexpensive to use and can be electronically scored allowing almost immediate results for the clinician to use that day.

Suitability for SED population. The Y-OQ was not designed specifically with the SED population in mind. Although it has been used in inpatient settings, the face validity of the items appear to lack the symptom severity and breadth of symptoms often found among the SED population. In addition, the Y-OQ only focused on symptom distress and impairment and does not address adaptive skills or strengths at all. Therefore, although it has been used, it is probably not the most suitable for this population. However, the highly reliable psychometric properties and sensitivity to change makes it very appealing.

Sensitivity to change. This is the Y-OQ's greatest strength over other measures reviewed here. Burlingame et al. (2005) suggest that sensitivity to change, particularly as a result of an

intervention, may be the most important feature of an outcome measure. This was considered in the development of the Y-OQ, as it was specifically constructed as a progress-tracking and outcome measure and not adapted from another purpose. The progress-tracking feature enables users to administer it frequently (weekly or biweekly), which is far more frequent than previous measures reviewed, and is able to detect subtle changes that occur over a short period of time. The Y-OQ has been shown to be stable over short periods of time without intervention, which allows interpretation of any changes to be considered meaningful changes (Burlingame et al., 2005). This can help with determining the specific effects of the intervention being applied.

There are several different ways to operationalize sensitivity to meaningful change however. The simplest, and probably most common, way is calculating the pre-post treatment difference score. Effect sizes can be generated from this method on larger sample sizes. A second measure of sensitivity to change is found by categorizing clients into recovered or significantly changed groups. The *recovered* criterion suggests that the post-intervention score is in the normal range of functioning. The *significantly changed* criterion uses the Reliable Change Index (RCI) to calculate the number of points needed to change to be considered significant. If the client meets both criteria, that their score changed a statistically significant amount and ended in the normal range of functioning, then they can be said to have demonstrated clinically significant change. A third measure of change is the Edwards-Nunnally (EN) method which uses confidence intervals to determine significant change, but is adjusted for regression to the mean.

In a sample of children and adolescents from both outpatient and inpatient settings, sensitivity to change criteria were estimated (Burlingame et al., 2005). All methods of sensitivity to change were used and demonstrated significant change, although each produced a

different profile of patient change. Although there were high rates of agreement regarding number of subjects who improved (93%), there were some discrepancies regarding subjects who were classified as remaining the same (45%) or deteriorating (45%).

In another study of youth changes in a wilderness program, the Y-OQ also demonstrated ability to detect significant changes pre to post treatment. Effect sizes were calculated using Cohen's d and found to be large both when rated by a counselor ($d = .96$) and by parents ($d = 1.5$). The YSR (from the CBCL cluster) was also utilized, but revealed no significant changes, demonstrating the Y-OQ's greater sensitivity to change. Another study (McClendon et al., 2011) also demonstrated the greater sensitivity to change of the Y-OQ compared to the CBCL or BASC-2. The degree of change and rate of change was significantly higher for the Y-OQ than either of the other measures.

SED-specific outcome measures. While there are many other measures that have been used to assess outcome, the ones reviewed above are the most common and have acceptable psychometric properties. The next most important issue then is to consider whether they are appropriate to use in the SED population. There are two measures that were specifically designed to be used with inpatient populations: the Brief Psychiatric Rating Scale for Children (BPRS-C) and the Child and Adolescent Functional Assessment Scale (CAFAS). However, they are fraught with psychometric problems including poor or unknown reliability; questionable content and structural validity, as it is not evident what the theoretical questions are that guided the project; whether the items are most appropriate for their assigned scale; or that the assigned severities are empirically supported. For further discussion regarding their limitations, see Hughes et al. (2001) for the BPRS-C; and Bates (2001) for an excellent critique of the CAFAS.

Brief Psychiatric Rating Scale for Children (BPRS-C). The Brief Psychiatric Rating Scale for Children (BPRS-C; Overall & Pfefferbaum, 1984) is a clinician-rated outcome measure designed to track changes of symptoms of 18 DSM-III disorders in children and adolescents. It is a shorter assessment based on the longer Children's Psychiatric Rating Scale (CPRS) and contains seven factors with three constructs representing each. The BPRS-C was found to be sensitive to change and did not correlate with self-reports of change of adolescents, emphasizing the need for clinician-rated tracking measures (Nelson, Renzenbrink, & Kapp, 1995). The fact that the BPRS-C is clinician-rated, is a strength that the Y-OQ is lacking. However, the BPRS-C does not have the rigorous inter-rater reliability training requirements that the adult version has (BPRS; Hughes, Rintelmann, Emslie, Lopez, & MacCabe, 2001), which reduces the effectiveness of having a clinician-rated scale. In addition, each item is measured on a seven-point Likert scale, but lacks well-defined descriptive anchors for each point or each question. The seven-point scale begins at 0, which means that the symptom is not present, excluding any measurement of adaptive functioning behaviors. A revised version in 2001 added anchors but did not expand the measurement to include assessment of adaptive functioning (Hughes et al., 2001). Only maladaptive psychiatric symptoms are considered on this scale, which is not informative regarding developmental gains or losses. Adaptive functioning is not merely the opposite, or lack, of symptoms and disorders (Kazdin & Whitley, 2006) and therefore needs to be included as part of an outcome assessment.

Child and Adolescent Functional Assessment Scale (CAFAS). The Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 2000) is another clinician-rated measure designed to assess level of impairment. It, too, has been commonly used to assess outcome, particularly with SED populations in mental health facilities across the nation (Bates,

2001; Hodges, Xue, & Wotring, 2004). While an objective, clinician-rated measure designed to assess change in the SED population is appealing, the CAFAS also has some inherent flaws. It has a number of psychometric limitations (Bates, 2001) in addition to a few psychometric strengths. Inter-rater reliability and test-retest reliability were strong using training vignettes and in a research setting respectively, but neither have been measured under actual usage of the CAFAS (Bates, 2001). Internal consistency reliability was low and content and structural validity were non-existent. The CAFAS did provide anchors for determining severity of impairment, but these anchors did not have empirical support for the scaling of severity within and across items (Bates, 2001). While the CAFAS has strengths in targeting the SED population and is clinician-rated, it is not well supported psychometrically as a measure of outcome. In addition, it has the same problem as the Y-OQ and BPRS-C in measuring degree of impairment, or specific symptom reduction, and not investigating adaptive functioning or acquisition of skills.

Focus Group Use in Measurement Development

Focus groups have been used as a means to construct questionnaires and measures for over two decades, particularly in establishing construct validity (e.g., Converse & Presser, 1986; Morgan, 1997; Rossi, Wright, & Anderson, 1983). Although both individual interviews and focus group interviews can be effective in gathering information for test construction, focus groups have the advantage of assessing a “wide range of perspectives in a rather short time” (Morgan, 1997, p. 26). In addition, some researchers suggest that focus groups may be more useful in generating ideas than individual interviews due to the group interaction (Morgan, 1997). Overall, focus groups can be useful not only from a practical viewpoint of gathering large amounts of data quickly, but also can help improve psychometric properties by increasing reliability and validity before the measure enters the qualitative testing phase.

An expert in focus groups, Morgan (1997) suggests three basic ways focus groups can contribute to creation of tests or measures: (a) by elucidating domains that need to be measured, (b) determining the dimensions that make up each of these domains and (c) suggesting specific items or revising item wording to ensure the items effectively convey their intended meaning. Focus groups can help generate a more complete picture of domains than are likely to be thought of by only the researchers due to their biased assumptions and perspectives. Once domains are identified, the set of dimensions that each domain covers needs to be determined and focus groups can help generate a large number of ideas about the categories of items that are necessary to cover each domain. In addition, suggestions for item wording can also help in establishing the dimensions as well as having a practical purpose. This can be especially important for items with anchors or scaled answers to ensure that the items and responses are interpreted the same way by respondents as the researcher intended.

Using focus groups to generate test items and structure can improve three types of psychometric properties (Morgan, 1997). First, determining the necessary domains can help reduce specification error by including more relevant variables than perhaps the researcher initially thought of. Specification error is often a problem in multivariate analyses, when relevant variables are omitted, causing estimate biases in the remaining included variables (Berry & Feldman, 1985). Second, using focus groups to generate items that completely cover a domain can increase validity by ensuring both that the questions cover the content of the domain and that the questions are interpreted the same way by respondents as intended by the researcher. Lastly, focus groups can check and revise item wording to make items more appropriate for a large range of respondents. This can also reduce unreliability as well as increase validity, as it minimizes differences due to interpretation errors. Focus groups thus can be useful not only

from a practical viewpoint of gathering large amounts of data quickly, but also can help improve psychometric properties before the test is finalized, reducing the number of necessary revisions later.

Focus group research design. Focus group design needs to consider several important factors. These include how group members are selected (such as randomly or purposely); how the groups are composed (whether more heterogeneous or homogenous); how structured the group format will be; the size of each group; and the number of groups to include. Some of these variables depend on the types of questions asked, as well as practical consideration, and some factors are more crucial than others.

Group member selection. Morgan (1997) suggests that for focus group research, it is more useful to think in terms of minimizing bias rather than achieving generalizability. Focus groups frequently are conducted with purposively selected samples. Morse (1991) states that qualitative research should follow the principle of appropriateness, using purposeful sampling and “good” informants (i.e. ones who are articulate, reflective, and willing to share with the interviewer). This allows the researcher to gain a deeper understanding of a particular population’s ideas rather than a random assortment of ideas that may or may not be useful. In designing an outcome measure specifically to be used with the SED population, it is important that the informants used in the focus groups actually deal with the SED population. The purpose of this project, and focus groups utilized for measurement development in general, is to add to the researcher’s ideas about what is important to include in the measure as part of the exploratory stage; it is not part of the standardization process, so generalizability is not the criterion of interest.

Focus group composition. Group composition considers both aspects of degree of similarity and familiarity of the participants. Morgan (1997) states that the most important factors to consider in group composition are ensuring that the participants both have something to say about the topic and feel comfortable saying it to each other.

First, the researcher must decide between homogeneous or heterogeneous groups. Homogeneity is often recommended to allow more free-flowing discussions within each group and to be able to compare differences between different categories of groups. However, the most important criterion is the free-flowing discussion, and homogeneity does not guarantee this and heterogeneity does not necessarily prevent it. Wide differences in social backgrounds or lifestyles may be of concern if they create a power differential that can impede group discussions. More important than actual backgrounds though, is whether the participants perceive each other as different and whether they are willing to discuss issues together. An argument against homogeneity is that the researcher typically does not want all members to have the exact same view on the topic, as this can lead to a limited and flat discussion.

The second consideration is whether to use strangers or acquaintances. Acquaintances sometimes have unspoken assumptions, which the moderator may have to push to uncover. On the other hand, strangers may have more difficulties sustaining a free-flowing discussion. Often, focus groups are conducted within organizations where naturally occurring groups are unavoidable and can facilitate discussion because they are used to interacting with each other (Morgan & Krueger, 1993). Morgan (1997) suggests it is more important to consider whether a particular group can comfortably discuss the topic of interest in a way that is useful to the researcher.

In utilizing focus groups to develop an outcome measure for use with the SED population, there are three general categories: parents, teachers, and mental health professionals. While there may be some heterogeneity within these categories, the greatest differences, and potential for power differentials, are between the categories. In addition, there are naturally occurring groups of mental health professionals, such as treatment teams or training meetings, and teachers that can be utilized to facilitate discussions as these groups are used to having free flowing discussions already.

Group structure. The amount of structure in the group process is also a necessary consideration. More structured approaches can be useful when there is a strong, pre-existing agenda and can allow for more rigid comparisons between groups. However, greater structure also forces the moderator to be more involved, and, therefore, to have more influence. Of greater concern, increasing group structure limits the discussion to a narrow set of questions or topics that the moderator/researcher assumes are important instead of allowing for more free-flowing ideas and discussions. Morgan (1997) suggests that less structured approaches are especially useful for exploratory research where the purpose is to generate ideas rather than receive feedback on already produced specific items. When the goal is to learn new ideas from the participants, it is better to allow them the freedom to express themselves.

As this research project is primarily exploratory in nature, a less structured approach allowing participants to generate ideas without excessive influence of the moderator is likely to be most beneficial.

Group size. Small groups may have a difficult time generating a discussion if investment and interest in the topic is low. Conversely, when the participants are both interested in the topic and respectful of each other, small groups can allow for more discussion from each person. The

researcher then has a better understanding of each person's perspective. Larger groups can be more difficult to manage discussions in, thus requiring more moderator involvement, which may increase the effect the moderator has on the group. Groups with 6-10 participants are usually ideal, as it may be hard to maintain a discussion with less than six and it often becomes difficult to manage discussion with more than 10 participants.

Number of groups. Morgan (1997) states that this is the least important factor, as it is mostly up to the researcher to decide how much data they want to collect. Often 3-5 groups are sufficient, as more groups seldom provide meaningful new insights. In other words, when the moderator begins to predict what the next group will say, conducting additional focus groups and collecting more data becomes less useful, having reached a saturation of information. However, variability within each group can affect how many groups are needed before the groups begin generating repetitive ideas. Therefore, research utilizing groups that are composed of more heterogeneous members will likely benefit from having more groups. In addition, less structured groups may also benefit from more groups.

Focus group discussion techniques. Merton, Fiske, and Kendall (1990) suggest four criteria for conducting effective focus group discussions: (a) Range – cover a maximum range of relevant topics, (b) Specificity – generate data as specific as possible, (c) Depth – foster interactions that explore participants' feelings in as much depth as possible, (d) Personal Context – take into account the personal context that participants use in generating responses.

Range. Maximizing range is important for focus groups to discuss not only issues that the researchers already think are important, but also to bring up issues that the researchers have yet to anticipate (Merton et al., 1990; Morgan, 1997). Unfortunately, researchers often narrow

the discussion by having too much structure or by using words or phrases that implicitly narrow a topic.

Specificity. Increasing specificity in focus groups can be accomplished by guiding participants towards concrete and detailed accounts of experiences (Merton et al., 1990) as well as by asking questions about individual experiences with the topic of interest (Morgan, 1997). Specificity can help prevent group member from drifting into ambiguous generalities.

Depth. Depth is a related topic that can also be used to avoid generalities. Depth is particularly important when the group is not as involved in the topic and is less of a problem when participants are highly motivated to share their experiences. Again, an emphasis on sharing personal experiences can generate depth which can draw in more group discussion (Morgan, 1997).

Personal context. The researcher also needs to pay attention to the personal context from which individual remarks arise. This requires the researcher to ask what is it about a particular respondent that lead him or her to express thoughts in a particular way (Morgan, 1997). Individual perspectives may be based in social roles, education, occupation, or individual experiences and can affect an individual's opinion about the topic of interest. Group research is used to bring these different perspectives to light, especially to elucidate implicit assumptions as the interactions may require a participant to explain or defend his or her point of view.

Group format. There are several issues to consider regarding group format, including duration of the group, group topics and style of eliciting group discussion, how to begin a group and organize the discussion during the group.

Group duration and content. Group discussions usually last 1-2 hours (Morgan, 1997; Kagel, May 15, 2008, personal communication,). It is important to maintain focus and not

explore too many topics. Morgan (1997) suggests keeping the discussion for unstructured groups to two broadly stated questions or statements and for more structured groups to, limiting the discussion to 4-5 distinct topics or questions, and having preplanned probes under each major topic. In these structured groups, he suggests following more or less the same order of topics in each group, permitting the moderator to allow a natural progress from topic to topic and creating some compartmentalism. A moderator can also help ensure that each group discusses something about each general topic. Another consideration is whether the topics will be presented as questions or more loosely as topics with an open ended question, such as “what can you tell us about that?” after its presentation. However, even in more structured groups, he suggests that the moderator should not become too rigid. A moderator can allow exploration of new interesting topics by encouraging participant to say more about the new topics. Merton et al. (1990) suggests that it is important to avoid the fallacy of adhering to fixed questions, and allow the moderator to probe more deeply where needed and skip questions about topics that have already been discussed, and follow new topics if they arise. Pretesting can also help discussion flow smoothly from one topic to another. An effective moderator can help encourage and manage discussion without getting in the way of it or influencing the group too much.

Beginning each group. In beginning each focus group, whether high or low structure, it is important to open the session by introducing the topic in an honest, but general way (Morgan, 1997). Beginning with generalities serves two purposes: first, participants may not be able to follow the researcher’s detailed thought processes about the topic, and second, a detailed introduction may influence their thinking and miss new perspectives and ideas. In addition to the introduction of the topic, some basic rules for the group can be established, such as only one person speaking at a time, no side conversations, and each person needs to participate without

one become dominating. Introductions and instructions should be kept short to allow for more open discussions and keep the moderator's participation to a minimum. While it can be useful to state that the purpose of the group is for the moderator to learn from the participants, faking ignorance about the topic completely can lead to a lack of trust, thus inhibiting discussions.

Group discussion organization. To actually begin the discussion, Morgan (1997) and Kagel (May, 15, 2008, personal communication) suggest beginning with a question that can be easily answered by all participants, but more importantly is a topic all participants are interested in. The moderator can facilitate the discussion by reminding the group that the goal is to hear from everyone and make sure each person has a chance to respond to the initial question before moving on (Morgan, 1997). Ensuring that each person makes an opening statement can also help deter group think, which is especially important in groups of acquaintances. Allowing time to write a response to this initial question before sharing can may also help reinforce commitment to contributing each person's own thoughts to the group. What occurs after this initial discussion question depends on the amount of structure and moderator involvement.

In a semi-structured group, the moderator can move to the next topic after everyone has responded. If the topic has already been mentioned by some individuals, the moderator can ask what others think, or if the topic has not been mentioned, the moderator can ask if the group feels this topic is important, since no one mentioned it (Morgan, 1997). Using material that was mentioned previously in the group can help with other transitions as well. In closing the session, the moderator can also ask for a closing summary statement from each participant. This may allow participants to bring something up that was not directly asked about or a topic they may be afraid to be confronted about. In addition, Morgan (1997) suggests that a follow-up phone call a few days after the session as a thank you may allow the participants an opportunity to express

any other ideas that were not discussed during the group or which were thought of after the session.

Data collection and analysis. Another practical concern is gathering the information and recording it for later data analysis. Videotapes are most informative as tone and expression as well as content can be preserved and analyzed later. Although this requires written consent of the participants, using only adults often reduces some of the ethical dilemmas. A backup system is always a good idea, such as using a tape recorder along with a video recording (Morgan, 1997). Short questionnaires can also be used for collecting information, such as who was in the group and some background information, but should not be over-interpreted as these are not the main source of data.

Once the data is collected, it needs to be coded and analyzed. Morgan (1997) suggests that both the individuals that make up the group and the dynamics of the group contribute to the discussions within each focus group. Although the group does influence the individuals, he suggests that this does not mean the group should be the fundamental unit of analysis. This has practical purposes in coding the data. The responses are typically coded in one or more of three ways: (a) number of times a code (topic that is given a code either *a priori* or post-hoc) is mentioned in a group, (b) whether each participant mentioned the code, (c) whether the group mentioned the code. These codes are somewhat nested within each other, but coding only at the group level, misses whether a particular respondent mentioned or did not mention a particular code. In presenting the results, descriptive counts regarding topics can be used to compare groups or simply as an exploratory method of recognizing interest in particular topics. However, utilizing interpretive summaries of the data without counting codes is also common practice. Interpreting data requires distinguishing which topics the participants find interesting and which

they find important. While interesting topics result in lengthy discussions, this does not necessarily mean the group thinks the topic is an important domain for the broader topic of the researcher's interest. Asking the participants during the group can be one way to explicitly determine which topics they find interesting and which they find important, instead of having the researcher try to speculate afterwards. When there are multiple topics of interest or importance, it is sometimes helpful for the participants to rank them.

In reporting the results, focus groups are similar to other qualitative methods in that there is not just one right way. This is partly determined by whether the purpose of the results is exploratory or hypothesis testing, the level of involvement of the moderator, and the type of analysis. Presenting the results can include quotations and/or summarization, and often includes some of both. Morgan (1997) suggests that first separating the topics of greatest importance from those that are less important and then concentrating on a thorough portrayal, including quotes, of the more important topics.

Summary of focus groups in measurement development. Overall, focus groups have demonstrated benefits in questionnaire development and as an exploratory as well as confirmatory tool. Specific designs of the focus groups depend on the researcher's topic and questions, but also need to consider practical concerns. These general guidelines were used to design the methods for this study, while keeping in mind the particular purposes and logistical concerns.

Methods

Participants

Participants were recruited from facilities in Utah County that have involvement with SED populations, including Utah State Hospital and Wasatch Mental Health, the major

community health provider in the county. Volunteer participants from three types of samples participated in one of four groups based on their role. Two groups included mental health professionals ($n = 21$), one group involved teachers of children at Utah State Hospital ($n = 12$), and one group included parents and caregivers of children at Utah State Hospital ($n = 4$). In order to encourage open discussion among all members, all groups were held completely independently.

Mental health professional groups. The mental health professionals group included child psychiatrists, registered nurses and nurse practitioners who contribute to behavioral/psychological medication interventions for SED children and adolescents, as well as neuropsychologists, child psychologists, occupational therapists, and other mental health professionals (such as LCSWs and case workers) who provide therapy and other time-limited (typically 1-3 hours per week) interventions for the SED population. In order to facilitate participation and flow of discussion, focus groups were held at each facility during work hours to reduce the burden on the participants and allow for as many as were interested to participate. For the mental health professionals groups, one group was held at each facility (USH and WMH) with mixed interdisciplinary mental health professionals that work with SED populations on a regular basis.

Teachers group. Teachers were recruited from the Oak Springs School, which is part of the Provo, UT school district but affiliated with USH to provide educational services for the SED children and adolescents that reside in USH. The teacher group was held immediately after school at the school facility in order to be most convenient and allow for maximum participation. The teachers were paid by the school district for their time participating in the group. As teachers have a unique role in these children's treatment and have interests related to, but not

solely focused on mental health issues, , the teacher group was held separately from the mental health professional group at USH, in order to facilitate open discussion.

Parents group. The parent/caregiver focus group included three mothers and one grandmother of children and adolescents currently in treatment at Utah State Hospital. They were recruited individually by researchers, allowing for an opportunity to explain the project and determine level of interest. Interested parents were provided with consent forms that they could complete on their own without pressure from the researcher. Those who expressed interest and completed consent forms were contacted later and invited to participate in a focus group. The group was conducted at a room at USH just prior to a unit-wide family activity, in order to minimize burden on the parents. USH staff and treatment providers were not permitted to attend or observe to ensure confidentiality and allow for as much openness and honesty as possible without fear of repercussions that might affect their child's treatment.

Procedure

Researchers obtained approval from Brigham Young University's Institutional Review Board (IRB) as well as from Utah State Department of Human Services' Institutional Review Board (DHS IRBB). Participants were recruited through individual invitation and all participants signed consent forms approved by the IRB. Participation was voluntary for all mental health professionals, teachers and parents, but the mental health professional and teacher groups were held during working hours for which the volunteers received their regular pay from their respective employers. No other compensation was given to group participants, but light refreshments were provided at each meeting. Video recordings with back-up audio tape recordings were used for the mental health and teacher focus groups with the consent of the

participants. Only audio tape recordings were utilized for the parent focus groups to ensure confidentiality.

Semi-Structured Group Discussion

Two researchers (EP and MS for the three groups held at USH and EP and NH for the WMH group) served as facilitators for each focus group. Each focus group lasted 60-90 minutes. The facilitators used a semi-structured interview approach (Morgan 1997) to ensure that the groups discussed each of the aspects of interest while still allowing for some flexibility for the group to generate new ideas. The main topics of interest follow the primary research goals of: (a) determining whether there is a perceived need for a new outcome measure for the SED population, (b) how the group conceptualizes the domains (and their dimensions) of such a measure, and (c) how congruent these domains are with those generated by the state hospital individual interviews. The main goal of the groups was to determine the domains that the focus groups felt are important in measuring treatment success and tracking progress over time.

The focus groups begin by addressing general issues, including: how participants perceive successful outcomes both in treatment and in a more long-term perspective once the children are released from long-term care; feelings about current outcome measures; and whether a new one is necessary (as appropriate depending on their knowledge of outcome measures). Specific topics included generating ideas about relevant domains to include in a new outcome assessment measure and defining the dimensions of domains they felt were important to be included. In addition, the focus groups addressed issues regarding the design of the measure, including format and raters. Focus groups also brought up additional themes regarding collaboration among treatment providers and parents and these were discussed in depth as well.

Qualitative Data Analysis

The recordings from each focus group was transcribed verbatim to a word processing file, then compared to the audio recording and re-reviewed for accuracy. The transcripts were then analyzed using NVivo 9 (Qualitative Solutions and Research International, 2010) qualitative analysis software package in several stages and supplemented by inspection by two raters (EP and MS). Initially, each transcript was read to identify key words or phrases that represented possible themes. The identification of potential domains for a new measure was a primary goal of these focus groups. Other recurring themes, such as the need for a new measure or suggestions for measure design, were also noted and coded separately, however. Only verbal responses made by participant group members, not facilitators, were coded; nods or other forms of agreement were not coded. After this initial coding, themes and domain categories and subcategories were identified by two non-expert observers and then all reviewed with two of the authors to identify congruence in the themes and domains. Common themes and domains were then organized into categories and subcategories and reviewed with the other primary researchers to affirm the validity of the categorical groups. The transcripts were then recoded according to these categories, into main categories and subcategories. Statements that were too broad to be categorized beyond the general category level were only coded to the umbrella category, and not to any subcategories. NVivo 9 qualitative analysis software package was used to identify which themes and domains were most frequent to determine relative importance. In addition, themes or domains that were unique to a particular group were also identified. The domains that were identified as important in these focus groups were then cross-compared to the domains that were generated by the USH pilot study to determine areas of overlap and congruence. The transcripts from each group were also reviewed to determine the level of perceived need for a new measure

of outcome to be used with SED children, any suggestions regarding the structure of the measure, and who should complete or rate such a measure.

Next, the most frequently identified themes were organized into potential domains and subdomains that were identified as important to consider in a measure of tracking outcomes in SED children and adolescents. The scope of these domains and subdomains were then constructed utilizing the responses from the focus groups. Key responses were used in determining the dimensions of domains and may be used to contribute to future studies that focus further on item generation and modification. Quotes that are representative of these domains and their dimensions were utilized to demonstrate the scope of the domains. The transcripts were also reviewed in light of the other goals of this study to determine the perceived need for a new outcome measure for the SED population and to evaluate congruence between the domains generated from the USH individual interviews and those derived from the focus groups of this study. Specific quotes were utilized to illustrate themes pertinent to the study's aims as well.

Results

Evaluation of Focus Groups

We facilitated four focus groups with parents of clients currently at USH, teachers at the school affiliated with USH, and mental health professions at USH and outpatient clinicians at WMH, which often receives clients after they are discharged from USH and other residential facilities. We had a range of number of participants in each group, with the smallest group being with parent group with four participants and the largest group being the WMH group with 15 participants. The degree of participation varied as well, although facilitators attempted to allow all members who desired to make comments to have opportunities to do so and to limit any one

participant from overrunning the group. The number and percentage of comments from each participant are presented in Table 1.

Table 1

The Relative Number of Comments and Percent Coverage of Comments from each Participant.

WMH			Clinical			Teachers			Parents		
	% #	% Coverage		% #	% Coverage		% #	% Coverage		% #	% Coverage
1	0.9	0.8	1	6.1	13.2	1	18.6	13.5	1	30.2	19.74
2	0.9	0.09	2	32.9	26.7	2	.5	1.4	2	31.9	50.0
3	10.4	10.7	3	10.9	9.4	3	3.76	6.8	3	19.8	10.08
4	7.5	8.6	4	21.1	18.7	4	7.4	8.8	4	18.1	18.37
5	14.1	5.8	5	15.0	12.2	5	11.0	14.9			
6	17.0	33.9	6	8.0	8.35	6	9.6	12.2			
7	1.9	0.8	7	5.7	8.39	7	5.7	12.2			
8	3.8	4.6				8	3.1	8.8			
9	8.5	10.9				9	34.4	21.6			
10	5.7	2.7									
11	9.4	7.3									
12	1.9	2.2									
13	5.7	3.9									
14	1.9	1.1									
15	2.8	1.9									
16	7.5	2.2									

Besides the focus groups that were conducted, we also attempted to organize a focus group of parents of patients who had been in an intensive treatment program outside of the home, such as state hospitalization, for an extensive period of time, but had returned home, as these parents may have different insights. Although the majority of these contacted parents of clients who had been discharged from USH and were in outpatient treatment expressed interest, desire,

and willingness to participate in focus groups, none attended a scheduled focus group, even after many confirmed their plans to attend. In addition, when they were subsequently contacted to arrange individual interviews instead, in order to increase time and location convenience and reduce apprehension about being in a group setting, they again were reluctant to actually follow through with completing the interview. For example, they would state that they were busy or needed to rearrange the time or they simply did not show up or call. Therefore, while the opinions of parents whose children have returned home after intensive out-of-home treatment are potentially valuable in determining areas needing focus in an outcome measure, they were unobtainable for this study. Future studies may want to attempt to include their input as well as a broader base of clinicians and teachers from multiple settings, but we caution concerning the practical difficulty of recruiting some specialized populations for a focus group. As participation is less convenient for these parents and may be more emotionally difficult for parents to share their personal experiences with strangers, they may require additional incentives to be motivated enough to follow through with attending focus groups. We appreciate the participation of the parents of clients who were at USH at the time of this study and their willingness to be open in sharing their feelings and concerns.

Level of Perceived Need for a New Outcome Measure

Each group discussed the need to be able to track progress and determine when a client is ready to be discharged. The clinician groups were specifically asked whether they felt a new outcome measure designed especially for this population was needed and if so, what it would look like, as they have the greatest amount of experience with current tracking measures. In addition, they discussed the current decision process regarding discharge, follow-up after discharge, and the pros and cons of the current system.

Inpatient clinicians. Clinicians at Utah State Hospital responded “Absolutely” when asked “do you feel it would be helpful to develop a new measure to look at outcomes in children who are in state hospital, residential type settings?” They explored some of the potential benefits and design aspects of a new outcome measure specifically constructed for these severely emotionally disturbed children and adolescents.

Clinicians discussed how currently the decision to discharge is ultimately decided by one person (usually the directing psychiatrist), who generally gathers input from other disciplines in a non-standardized way and without any feedback about the clients’ progress or outcomes after they are discharged (besides happenstance anecdotal information). They reported that a measure that continued to be used after discharge to follow-up outcomes would be “invaluable for us, because people ask us all the time what our discharge recommendations are. So when we don’t know what our outcomes are, it makes it really tough.” They also mentioned the importance of being able to apply the results of an outcome measure to treatment, stating “if it is something we could use practically, in a practical setting, like in therapy...that would be really nice.” Overall, they concurred that a new measure could be useful, especially if it continued to be used after discharge.

One of the key design aspects they agreed on was that a new measure would need to incorporate information from multiple disciplines, such as “psychology, neuro[psychology], social work, OT [occupational therapy], RT [recreational therapy]” as well as the client and parents, but it should not rely solely on self-report from the client. They mentioned that each discipline has its “own goals” and they “wonder[ed] what that would look like if it were more collaborative.” They explained that “you need multiple opinions, especially with this population,” as they “have a high level of either personality disorder or head injury or cognitive

problems [and] aren't going to have really good insight...they're not aware that they're dysfunctional." They suggested that it should be only "part self-report" and that similar to an adult outcome measure designed for the inpatient population (the BPRS), it should involve "interviewing the person, but...also making observations, and...taking feedback from staff and chart notes and stuff" and then rating the client on "various domains." However, they also felt that the clients' input was important to obtain; "if only to compare – what did they say when they first came in...what are they acknowledging, a year later; has it changed in any meaningful way?" and to see "are their thoughts consistent with their behaviors" as part of evaluating their progress. Thus, they concluded that information regarding current status and progress should be gathered from multiple informants, including, but not limited to the client, and to engage in a more collaborative approach with the multiple disciplines involved in treatment.

Along with the importance of gathering information from multiple disciplines, they also emphasized the need to have a measure that examines global functionality, including multiple areas of functioning, across multiple situations, and that considers change from the client's personal baseline functioning. Clinicians repeatedly suggested that an outcome measure needs to be somewhat "relative," incorporating "their own baseline," or that "shows improvement from where they were at," rather than solely comparing them to same age peers. In addition, one clinician suggested designing an outcome measure that was somewhat similar to the "BPRS idea," that has "different domains, that cover everything from mood...to psychosis, that are based on a rating scale, and it's based on some criteria." Others agreed and stated that they "would love if this became a more global kind of measure" that considered strengths as well as problem areas and they specified that "the outcome measure needs to be across-situational as well." This focus on all aspects of the clients' functioning across multiple areas of their lives and

situations also reiterated the importance of gathering information from multiple sources that can provide different types of information.

Outpatient clinicians. Outpatient clinicians were most frustrated by the lack of availability of information regarding outcomes and criteria used to discharge clients from inpatient and residential types of settings. They expressed a general lack of knowledge about how residential or inpatient settings tracked outcomes or determined readiness for discharge. They emphasized that they did not receive very much information and what they did receive was generally not standardized, quantified, or explained in a meaningful way to them as the receiving clinicians. Overall, they felt it would be beneficial to have a better understanding of their clients' progress during inpatient treatment and more communication in the transition to outpatient therapy. They also made some suggestions regarding design aspects of a potential new measure, including the importance of not relying solely on self-report and minimizing the burden on the clinician while ensuring its utility in a therapeutic setting.

Outpatient clinicians emphasized the lack of meaningful data that they received from inpatient and residential treatment centers upon discharge. Most outpatient clinicians were unaware of any sort of “standardized measure” that residential treatment centers typically might use although they mentioned that “most residential treatment centers have open economies where they track their clients with point systems, then they show progress week to week...but we never receive that.” In addition, they noted that DCFS case workers sometimes “get a weekly report” or “have a team meeting,” but that this type of information is “not quantified, it’s more ‘this is what we’re doing’.” In addition, they expressed concern that often more information was not always useful or informative, as one clinician noted that he received “16 pages” but that it “was pretty sparse.” He commented that, for him, calling the therapist and discussing the child

for 10 minutes was much more informative and faster. Overall, they were concerned that often this type of unstandardized and treatment center specific descriptive data was generally not useful or informative, in part because the terms and measurements of progress, such as a level system, were often not explained.

They also discussed design aspects, such as the importance of multiple informants, including the client, parents, and therapists, while minimizing the burden on the therapist and maximizing practicality. They expressed concerns about self-report measures, noting that the current outcome measure they used in their outpatient setting (the Y-OQ) often results in large discrepancies between parents and children regarding progress. For example, while a child who was recently discharged from “residential after several months [might claim] everything’s ‘hunky dory,’ you know, they’re happy with life, and Y-OQ scores are consistently lower than even community average; but if you give it to the parents, it’s an entirely different story,” meaning that children and parents can have very different perspectives on the progress and current status of the child and neither should be relied on solely in an outcome measure. However, clinicians felt that including both parent and self-report as part of an outcome measure could “still be important.” While they also all agreed that involving the therapist as an informant in an outcome measure would be beneficial, they also emphasized that they did not want a new measure that would increase the clinician’s paperwork burden. Specifically they mentioned that they wanted it to be “short” and only need to be completed infrequently (not daily or weekly), but still be informative and have therapeutic applicability. A new outcome measure which allows therapists and other disciplines to provide a verbal assessment to an independent rater may help solve this paperwork burden problem while allowing for more standardization and quantifiable results that can be tracked and follow the client through multiple levels of care.

Overall, the outpatient clinicians were most concerned about having access to accurate and meaningful data without increasing clinicians' paperwork burden.

Teachers. Although the teachers group participants have not had as much experience with outcome measures, they did mention that they would like to participate more in, or at least be more informed about, the goal development and decision making process regarding readiness for discharge. They generally felt unaware of the clients' goals, stating, "social work comes in, the doctor comes in, and they come up with a plan on what this kid needs to accomplish before he leaves....I, as a teacher, don't know what that plan is." This was frustrating to them because then they "can't help them achieve their goal. I can't redirect them in the appropriate ways to help them." In addition, one wished that they had "a little bit of a say in [goal development/discharge planning], because the kids will now ask us... 'what do we need to do to get ready for discharge.' I'll say 'It really has no bearing on what you do in school.'" In addition, they expressed some concerns over having to be responsible for discharging the child to the subsequent school, who wants a "guarantee...that they're not going to come down here and do a Columbine" when the Oak Springs School is not involved in the decision process or even informed about how the hospital is determining that the student is ready to be discharged. They stated that they are simply "trusting the hospital" when it comes to determining readiness for discharge, but would appreciate having more information during treatment about their goals as well as progress and discharge planning.

They also mentioned that a staff member from the state hospital attends the school with the students and tracks their behavior qualitatively, but again the teachers are not informed about the results of this tracking and expressed that it would be helpful to be able to discuss these. In addition, they expressed some bafflement at "how they analyze all this text that is produced

every day” and how a standardized quantitative measure would be easier to analyze and communicate about. Overall, they felt a standardized, quantitative measure could be helpful, but mostly they simply wanted to be more informed about whatever process is used to determine discharge readiness and preferably to be more involved in this process.

Parents. Although parents were relatively uninformed about outcome measures and whether a new measure could be helpful, they expressed concerns about their children’s outcomes and wanted to ensure that their children would be adequately prepared for discharge. They too wanted to be involved in the decision process regarding discharge and were quite concerned about being taken seriously in discussions about their child’s progress. They did not want to be ignored or dismissed as not knowing what they were talking about, and instead wanted to be recognized as experts about their child. For example, one parent expressed how “it got to the point where I really felt like I didn’t know what I was talking about, and I started backing off and they starting adding medications, and [then] came the cycle of downhill,” ending with her child being in-and-out of a short term inpatient clinic several times. She felt that her child deteriorated because she was being ignored first by the outpatient treatment providers and then by the inpatient clinicians. Another parent mentioned that she felt that doctors “wouldn’t totally listen to what I was seeing” and felt that this negatively affected their ability to correctly diagnose her son. Being able to continue monitoring a child’s progress or deterioration during treatment as well as after discharge from an inpatient facility seemed important to these parents.

Parents also mentioned changes in grades, either dropping or improving being a sign of progress or deterioration to them. For example, one parent stated “his grades back home were Ds and Fs...but his first semester here at school, they went up to As and Bs...and that’s been a success for him, and that helps him feel better and of course we’re excited for him.” Therefore, a

more global and all-encompassing outcome measure both at the residential/inpatient treatment center and once they return home could be useful to continue to track their progress over time and alert the parents and clinicians to potential problem areas and intervene early.

Conceptualization of Domains

From the focus group discussions, we identified two main areas of concerns regarding client outcomes, namely issues that the clients need to change within themselves (internal locus of control) and issues that could impact the clients' outcomes, but rely on or involve other people or institutions (external locus of control). Within the Internal Locus of Control sections, four broad domains and 12 subdomains were generated based on themes identified from the focus groups' responses. The four main domains include: Behavior, Social/Emotional, Academic/Cognitive, and Strengths. Within the External Locus of Control section, two domains, namely Family and Continuity of Care, and eight subdomains were extracted from the focus group discussions. The subdomains were ranked in order of frequency using NVivo 9 and Table 2 displays the domains and subdomains, as well as the relative percent frequency and relative percent cover of comments about each.

The following will address the scope of each of the sections and the domains and subdomains within them and summarize participants' comments in each.

Internal locus of control. This section primarily involves changes within the clients themselves, or that the client has a significant amount of control in changing, such as learning skills. While the domains and subdomains may involve the clients' interactions with others, they focus on the clients themselves, such as how the client reacts to, responds to, or interacts with others, rather than the dynamic of the relationship.

Table 2

Domains and Subdomains with Percent Relative Frequencies and Cover

Internal Locus of Control			External Locus of Control, Systemic Approach		
Domains/Subdomains	Relative % Number of Comments	Relative % Cover of Comments	Domain	Relative % Number of Comments	Relative % Cover of Comments
Behavior	26.66	21.3	Family	17.15	21.28
Aggression	8.88	10.63	Attachment	1.22	.71
Self-Harm	2.55	3.06	Family Dynamics	4.74	98.04
Addiction	2.07	2.46	Family Interactions	1.34	1.62
Ability to manage behavior in less structured environments	3.89	4.66	Family and Environment Preparedness for Discharge	7.18	9.18
Inappropriate Behaviors	1.70	2.04	Collaboration between Care Providers	17.87	26.21
Self-care	2.67	3.2	Between School and Mental Health Providers	7.18	8.91
Consistency	.73	.87	School Transition	2.55	5.27
Social/Emotional	14.14	13.17	Mental Health Transition	2.92	4.1
Relationship Skills	4.26	5.09	Providers and Teachers to Parents	2.07	3.96
Self-Regulation	4.26	5.09			
Psychiatric Symptoms	3.28	3.93			
Motivation	2.19	2.62			
Academic/Cognitive	17.00	11.39			
Academic Performance	6.45	5.04			
Cognitive Skills	3.89	2.73			
Development	4.01	2.35			
Strengths	7.06	6.68			

Note. Topics not related to specific domains (such as need for a measure or measure design) were not included in calculations for this table.

Behavior. This domain consists of externalizing behaviors that are readily measurable. It includes the subdomains of addiction, aggression, self-harm, other inappropriate behavior or rule-incompliance, self-care, consistency of demonstrating appropriate behaviors, and ability to manage behaviors in less structured environments.

Addiction. The addiction subdomain consists of both substance abuse as well as behavioral addictions such as sexual addictions, which includes pornography and masturbation; electronic addictions, which is comprised of video games as well as other computer, internet, and phone addictions; and self-harm addictive behaviors, such as cutting, burning, picking or other self-mutilating behaviors. Participants comments reflected their concerns that the behavioral addictions sometimes get ignored in treatment, making statements such as “the behaviors addictions are just as significant as the substances, especially for the boy population” and that girls “see their self-harm as an addiction,” although they stated that the girls as well as the boys sometimes also experience the sexual addictions. The state hospital clinical group mentioned that electronic addictions were “one of [the] biggest issues on the unit” and a concern for transitioning home as the state hospital has significantly more control over access to electronics than a home environment where they can “sneak out of bed at three in the morning to use computer all night long.”

Aggression. The aggression subdomain includes physical aggression as well as threats, including both verbal and nonverbal posturing. All of the focus groups mentioned concerns about violence and/or aggression. Focus group participants were concerned about how to quantify aggression, as they considered both quantity/frequency and severity as important: “It depends on the level of aggression...beating someone up severely, even once a week, or once a month, that’s too much, but some of the kids it’s more like horse play ...but it’s still an

aggressive act.” Such statements reflect their concern about both severity and frequency and the difficulty of quantifying aggression.

The teacher focus group also mentioned concerns about the “safe school” law in preparing to transition a child to an outside school when the child is discharged. Often the accepting school wants some sort of guarantee that the child is not going to become violent at their school, which is impossible to give. For example, one participant stated:

I’ve had a principal say to me ‘Whoa, wait a minute when are they coming?’ and I said ‘They’re supposed to get discharged next week, you know.’ They go ‘Can you guarantee me that they’re not going to come down here and do a Columbine?’ and I said, my response was ‘Can you guarantee me that you have someone at that school right now who hasn’t been diagnosed that might do the same thing?’ Dead silence on the other end. But the public’s perception of people with mental illness...is blown way out of proportion.

Parents were also concerned about their own safety as well as the safety of their other children at home, as reflected in comments such as “some of the reasons he is here was he was unsafe at home, he was unsafe with himself, with us. He tried to kill me; he tried to kill his dad.” This can be a barrier for discharge if parents maintain this concern that that their child might “hurt their siblings” and say “hey I can’t have this child, who’s so aggressive, attack my other children.” Overall, this appeared to be a large area of concern for all participants, as they noted that these aggressive acts contributed to probably “75%” of the boys being at the state hospital and therefore are one of the key target behaviors that must be reduced or eliminated for treatment to be considered successful and for the child to be discharged and reintegrated into the community.

Self-harm. The self-harm subdomain includes behaviors such as cutting, burning, picking, or other types of self-mutilation as well as suicidal or pseudosuicidal behaviors, such as overdosing on medications, or demonstrating suicidal ideation or threats. Focus groups mentioned that the only way to be admitted to the state hospital is to be “a danger to themselves or others,” so self-harm behaviors are of great concern in this SED population. Focus group members estimated that “the depressed suicidals [make up] a quarter” of the state hospital population and is particularly common among the females, stating that “they engage in a lot of self-harming things...like cutting and self- mutilation.” They also mentioned an overlap of self-harming behaviors with addictions, noting that the females at least “see their self-harm as an addiction.” However, self-harm and aggression towards others often seem to involve different populations, as they stated that “a fair number of people...have had suicide attempts but they’ve never attacked anybody else.”

Inappropriate behaviors. This subdomain consists of inappropriate behaviors that are not inherently violent towards self or others but are destructive, illegal, or otherwise negative behaviors. These include vandalism, theft, property destruction, disruptive behaviors in the classroom, non-compliance with rules, as well as other inappropriate behaviors, which could include specific “target” behaviors that a particular child is working on. These types of behaviors were of highest concern among teachers, as they have to deal with and track these behaviors in their classroom daily while they are hospitalized. One participant in the teachers group mentioned that this behavior tracking is often correlated with discharge, stating:

Every hour of the day we rate on a scale of one to five for their behavior and their work completion and average that for the day and when kids are discharged they’re pretty

much a top scorer consistently every hour all day long [and] they've been that way for two to three months.

Tracking target behaviors is also of significance, as one participant put it:

Sometimes we have target behaviors; things that we notice that they do all the time and we once had a boy in our children's [classroom] that said 'shut-up' constantly. 'Shut-up, shut-up, shut-up, shut-up' and we would track and tally how many times he did it. So we have the target behaviors that we're actually counting how many times this occurs and when it's an negative behavior and it's decreasing that's how we know [how prepared they are for discharge]. Or if it's a positive behavior and it's increasing, that's how we know.

Therefore, tracking these types of behaviors is important in an outcome measure as well.

Self-care. The self-care subdomain includes behaviors such as hygiene, nutrition, exercise, and medication compliance. Hygiene was a major area of concern, especially for parents who have experienced their child becoming aggressive when they have tried to enforce hygiene as noted in comments such as:

I would like him to do able to do his hygiene without there being aggression, so, yeah, getting his nails clipped. Here they insist on it, they have to force him to do it, but at home, I can't do it because of the younger ones, I'm concerned for their safety. And so I'd like him to do his hygiene without prompting.

They also mentioned concerns about nutrition, both over and under-eating and eating an adequate variety of foods.

All groups also mentioned concerns about medications. The parents were particularly concerned about their children being on the right medications and not overly medicated; making

comments such as “the medications aggravated his system so bad.” The other groups were more concerned about medication compliance and the importance of parents understanding the medications and giving them consistently once their child returned home. One participant noted that:

Recidivism is tied into noncompliance of medications, that’s a factor that we don’t usually look at too much here. We occasionally do have some noncompliance, but it’s a lot tougher on an inpatient setting. But I just know that the second they walk out of here, we no longer have that structure there for them

expressing concern about the parents’ role in medication compliance. However, the parents’ concerns about their children being on the right medications at the best dosage also need to be addressed as they are less likely to be compliant if they disagree with the prescription. This highlights the importance of having the parents involved throughout treatment and listening to their opinions and educating them about medications in order to maximize medication compliance.

Consistency. This subdomain emphasizes the importance of consistency in appropriate behaviors across time and settings as a measure of when a child might be ready for discharge. Parents were concerned about their child regressing into past behaviors again once they came home and clinicians were concerned about maintaining gains across settings (home, school, dorm) as well as for a significant period of time. For example, one participant stated that they need to:

Be consistent across different [settings]...dorm, at school, in groups, in therapy, in recreation, with OT, and for a consistent period of time as well, it’s not just two weeks

and they're doing fabulous, but that it's for an extended period of time that they've shown improvement in several different areas.

However, they were careful to emphasize that the amount of required consistent time might vary depending on the child, making comments such as “at some point you start being happy that if it used to be that they couldn't hardly go a week and now they can go a month... but for most of the kids, a month is not enough” or “if we know they only do it once every few months, that person has to go 6 months before you can feel confident.” Therefore, consistent positive behavior and lack of negative behaviors both across settings as well as over time appears to be an important area of concern.

Ability to manage behaviors in less structured environment. This transition from a controlled environment to a less structured environment was a concern for all groups, as reflected in comments such as wondering if they were “doing enough to prepare people for all of these different situations versus the controlled environment.” Teachers noted that the students tend to behave better in their classrooms due to the “structured environment here, that a lot of times they behave much better than what we've been hearing,” but were concerned about transiting back to less structured classrooms. All of the parents specifically expressed concerns about their children's difficulties with transitions and wanting to have them be prepared as much as possible for this transition, including being able to deal with the lack of structure and being able to handle “some boredom.” Parents also mentioned what signs to look for in their children to evaluate whether they are prepared to come home, including “how does he treat us, how does he talk to us, how does he respond when we ask him to do things... If we keep getting a positive things coming, than we know discharge is coming closer.” Groups also mentioned concerns about being able to handle more responsibilities as well.

Social/emotional. This domain investigates the social and emotional functioning of the children and adolescents, including relationships skills, such as communication, psychological symptoms and diagnoses, and self-regulation abilities, including coping skills and ability to transition.

Relationship skills. This subdomain evaluates each client’s social skills and ability to relate to and communicate with others, especially their peers, in an appropriate and effective manner. All group recognized this area as important. For example, teachers emphasized that even they are “trying to improve social skills” and not just academics. Another teacher explained that the one thing that “every one of our students is receiving on a daily basis or should be receiving is social skills and how to respond in certain situations and how to socially interact with each other in a classroom and in public” noting that it is “their social interaction and their behaviors that get them red-flagged and get them in here.” Clinicians also emphasized the importance of social skills, particularly for the girls, stating that when they evaluate their readiness for discharge, they consider “where are they in terms of their *interpersonal* skills.” Specifically, they reported wanting to ensure that “she can communicate effectively and she knows when she needs to talk to somebody or not, or how to handle this or that with family members and peers.” Outpatient clinicians agreed that “social integration is pretty important” and that “the children that have improved the most and been able to maintain those gains are the ones that have some sort of social skills and social understanding and they’re able to develop good supportive peer networks.” The parents were also concerned about their children learning social skills, noting that their children were “socially...very behind,” Therefore, tracking their acquisition of social skills can be quite informative in helping determine readiness for discharge.

Psychological symptoms. This subdomain includes acute psychiatric symptoms, such as mania and hallucinations, as well as internal emotional symptoms, including depression and anxiety. In addition, this subdomain incorporates exposure to trauma and reactivity to triggers relating to this trauma. Lastly, this subdomain considers the importance of correctly diagnosing the clients and the effectiveness of medications.

Clinicians noted that an important domain to include is “mental health...include[ing] the symptoms that they came in [with]...why did they come in and are those remitting, and includes psychotic symptoms as well as mood regulation.” This emphasizes that certain psychiatric symptoms do need to be monitored and tracked over time. However, as one clinician stated “symptoms kind of takes a back seat to functioning,” even for fairly severe symptoms such as hallucinations, noting that “if their auditory hallucinations haven’t improved at all but they’re able to function well, then that’s a very different thing,” although “there are certain specific symptoms that...have to be better.” Therefore, monitoring both mental health symptoms, such as mood, anxiety, hallucinations, mania, as well as functioning provides a more global assessment of the individual’s progress.

Clinicians also noted the importance of trauma, as one commented that measuring “how they are doing with their trauma...and where they are at with reactivity, nightmares, all that stuff” is really important for treatment outcomes. Another emphasized the impact trauma can have on their emotions and behavior, stating that “we talk a lot about triggers and trauma, ‘how has your trauma impacted your mood today and how you’re behaving today, and the choices you’re making, and your perspective on the world and why you don’t trust this person’.” Mood disorders in general were also of concern to clinicians, especially working with adolescent girls.

Clinicians and parents were particularly concerned about having the correct diagnosis, as they felt this affected treatment, including medications, and therefore likelihood of successful outcomes. For example, one clinician stated “the number one thing I see is correct diagnosis” and went on to explain for one of his clients the “correct diagnosis....was the key for his success.” Parents were also concerned about medications and diagnoses, as one stated the “medication...sent him into a violent rage” when she believed he was given an incorrect diagnosis and therefore incorrect medications.” Another parent expressed her frustration and the importance of diagnosis for treatment noting that when she would try to tell the doctors about her concerns, with issues such as “aggravation” and “anxiety” that often the “doctors would just change his medications, ‘Oh well let’s try this ADD medication, it’s a new one’” and that his symptoms did not seem to improve until he was given another diagnosis with a different medication. Thus, considering specific symptoms as well as diagnoses and possible responses to medications are an important part of measuring treatment success.

Self-regulation. This includes a client’s ability to regulate their emotions and reactions to difficult situations, such as adjusting to changes and transitioning, being able to cope with stressful situations, delaying gratification, and inhibiting impulses. This ability to use coping skills to identify their moods and be able to use words, instead of becoming aggressive or engaging in self-harm, seemed to be an important theme in all of the groups.

For example, one clinician stated the importance of “self-regulation, just being able to understand where they are at and then try to adjust, and try to meet their [own] needs...understanding themselves and then being able to meet their own needs.” Another clinician described this as “stress-tolerance, being aware of how things affect them,” being able to say “‘I’m mad right now,’ and ‘I’m mad, because’ and then the social, or the coping skills,

would come in ‘so I’m going to do this’.” This clinician stated that often when clients first arrive at the state hospital, “they didn’t even know why they’re mad, [and] really they’re sad,” so to be able to recognize their own emotions and identify that they are feeling and why can be very helpful and can impact outcome success, so it is important to measure. Another clinician emphasized the importance of developing “the internalized ability to cope with stress, stress coping skills, problem solving skills...to not, fall back into those acute symptoms that maybe brought them here in the first place, whether it’s self-harming, or aggression, or whatever it might be” when stressful even happen in the future.

Parents also emphasize the importance of these coping skills, stating “I’d really like to see him be able to deal with those things better that he is *not* successful at...to learn the coping skills and coping mechanisms to be able to function in a[n] average society,” such as taking the time to stop and think before reacting in an inappropriate way. Another parent noted the need to learn to recognize signs from their environment, especially regarding changes “so they can internalize and say, ‘ok, something’s changing I need to take a minute and breathe so I can deal with the next step’.” A third noted the progress she is already seeing in her child, “he would go to his room to calm down and then come back and *always* apologize, which never happened before, never...he’s learning to work with his anger and to manage his anger a little bit better.” Thus, learning to recognize, identify and then deal with their negative emotions in an appropriate way appears to be quite important.

Motivation. The focus groups discussed two aspects of motivation: motivation in general to change their behaviors, thoughts, and feelings, and motivation specifically regarding discharge.

Clinicians were particularly concerned about a client’s motivation and distinguishing

between volition and motivation, noting that it is important to consider whether a client is “able to do something, but just plain won’t or don’t want to unless the situation is this, A vs. B.” In addition, they mentioned the importance of considering the motivation behind particular behavior and considering the situation of a particular behavior, stating that they “wish there was a way to kind of tease that apart, because, to me that looks way different. The motivation is different. I mean a lot of the things up here look way different depending on what’s happening in the environment at the time.” This suggests the need to include intentions and circumstances in interpreting and evaluating behaviors.

Secondly, this subdomain also considers their motivation and perception of readiness for discharge in particular. Clinicians were concerned about the clients’ own subjective feelings of readiness for discharge and belief that they will be successful and the degree to which clients feel safe in the environment they are to be discharged. Several comments expressed how some children want to return to residential type of settings, such as “she keeps wanting to go back because she feels more safe in the hospital than at home” and “man I wish I was back there, cause I loved it up there, it’s boring at home.” Therefore, considering all aspects of a client’s preparedness to transition, including looking at their perspective of the situation can provide some insight into their likelihood for success.

Academic and cognitive functioning. This domain examines the academic and cognitive functioning of the client, including academic performance, cognitive abilities and appropriate development. Encompassed within cognitive abilities are neuropsychological functions such as impulsivity, attention, executive functioning, memory, processing speed, comprehension and verbal expression. All groups emphasized the importance of academic progress and the necessity of considering cognitive capabilities in understanding each client and generating an

appropriate treatment plan and individualized expectations for their level. This domain includes subdomains of academic performance, cognitive skills, and development.

Academic performance. This subdomain includes academic performance, current grade level, credits, and preparation for the future, such as college. All of the focus groups emphasized the importance of school and academic performance for these children and adolescents.

Teachers were particularly concerned with ensuring that the adolescents were on track to graduate from high school, which involves determining what credits they have and helping them earn the ones they need. For example, one teacher stated that this is especially important for high school students “so when and if they do leave they can go back to a place and not be so far behind that they feel like that can’t do it; so that is critical.” Another teacher pointed out that often youth in custody are considered “at risk” and sometimes their intelligence is over looked and how important it is for treatment programs and schools to determine their academic levels and keep them on track, as they had a “student that came in working on college credits and has a placement waiting for them.” They noted the importance of communication with previous and subsequent schools and their frustration with not having current records, but also emphasized the importance of accurate academic placement. In addition, they mentioned how some clients are high school seniors and how they need to coordinate with their home school to find out graduation requirements if “they [are] going to get discharged...around graduation time...and see if they’ve met those” and how some “students that have actually gone on to college after being here.” This emphasizes the importance of keeping adolescents on as normal of a developmental trajectory as possible and preventing mental health treatment from interfering with their life overall, such as academic achievement.

Clinicians also indicated that a decline in academic performance can be a sign of other problems as well and can impact treatment. For example, with one client “the first thing that started, her parents recognized her grades started to fail, she had been always been an ‘A’ student or suddenly she didn’t want to go to school or things like that,” which clinicians noted is fairly typical. They also stated that knowing a child’s academic progress is “critical” for their treatment. Parents also mentioned concerns about school, as they connected academic success to life-long success and happiness. For example, one parent stated that she wanted her son to be able to find a “direction toward something that would help him, make him happy, a technical school [or] something where he can find something that would make him happy.” Another parent mentioned that “my big thing is I want him to graduate from high school...That’s my biggest concern. I want him to be able to hold a job and to keep an apartment.” They also noted how success or difficulties in school can affect other areas, such as mood, as one parent commented that when school has “been a success for him...that’s helps him feel better and of course we’re excited for him.” Likewise, when there are problems at school, this can also lead to other difficulties, as when “they have all these learning disabilities...and it just is chaotic, they get suspended, they get kicked out of school, there’s nowhere for them to go, so they’re at home, the parent gets frustrated.” On the other hand, one clinician explained how when his client was diagnosed correctly with a learning disability and was able to have “a learning coach that taught him ‘you learn this way,’ and it really helped him understand himself that he wasn’t stupid,” whereas before “he would get really frustrated in school...[he] calmed down...his social skills improved...so that was the key for his success.” This ties the importance of considering both the academic and mental health aspects together as they can affect each other and both have implications for long-term success in life.

Cognitive skills. This subdomain includes various cognitive skills, such as ability to focus, time required to complete tasks, problem-solve, inhibit impulses, process information, processing speed, speech and language skills as well as considers learning disabilities and brain damage. Clinicians mentioned that they see “a lot of cognitive disorders” at Utah State hospital and suggested that “impulsivity would be a good area to look at.” In addition, they were concerned about clients’ ability to maintain attention and stated that “their ability to stay in the classroom successfully would be a huge” indicator of improvement. Teachers also mentioned “ability to focus” and “time on [a] task” as important indicators to measure. Parents were particularly concerned about their children’s ability to process information and their speed of processing and how this affected them. They mentioned that some of their children have “very low processing” or processed different types of stimuli differently, and needed accommodations for this, such as “put[ting] a picture [up] would help instead of just the note on the door.” One clinician emphasized how cognitive disorders and brain damage can affect treatment, as a client can have “a lot more challenges than another one” because “his brain is damaged and he has a lot harder time.” They also expressed concern about how clients with “cognitive problems...aren’t going to have really good insight...they’re not aware that they’re dysfunctional.” Another clinician noted how frustrated some clients become due to their cognitive impairments and how this can lead to negative behaviors, but understanding the cognitive impairments and learning disabilities and receiving specific interventions for these also helped improve mood and behavior.

Development. This subdomain includes examination of age appropriate development and considers the effects of developmental disorders. Clinicians specifically mentioned that “development should be up there” as a potential domain on a measure of treatment progress and

outcome, and explained that examining the discrepancies between chronological age and emotional and cognitive development are important. For example, they mentioned concerns about clients who are “chronologically 16, but she acts like an 8 year old” and “when girls are physically mature, but emotionally” are not as mature. They mentioned how sometimes it can be difficult to separate “the dysfunctional stuff from the normal developmental stuff.” In addition they recognized that “development has to be a huge factor” in having realistic expectations of clients, as they “aren’t going to expect any 7 year-old to be able to say, ‘I’m right now feeling angry because, mom and dad fought last night.’” This emphasized the importance of planning individualized treatment plans and individual measures of progress as expectations will vary for each client and by age and developmental level. They also mentioned some concerns about preparing clients with developmental disabilities for discharge as when “you send them out of the hospital back into the real world, the real world tends to put them in their chronological age.” Clinicians also noted a gender discrepancy in developmental disorders, commenting that there are “a lot more developmental [disorder] boys than...girls.”

In addition, clinicians were concerned about how being in an institution rather than a typical family environment may interfere with development, as reflected in comments such as “developmentally, I don’t think it’s a good place to be here. I don’t think normal development progresses while they’re here, they don’t have the same experiences that you get in the real world.” However, clinicians also noted that “the other side to that...if they’re having these behaviors that are so severe out in their home environments, how quote on quote of a normal of a life are they living anyway.” Thus, it is important to track their developmental progress to try to ensure that they are not falling significantly behind developmentally while they are in these types of inpatient settings.

Parents also expressed concern about development and cognitive delays. For example, several mentioned a desire to see more treatments specifically designed for children and adolescents with developmental disorders, such as autism, as exemplified in comments such as “I would like to see...more socialized work for specific things like...autism,” including interventions such as “more assistive technologies [and] maybe some assessments done in that area.” Overall, there were concerns about having appropriate expectations based on developmental levels, accurate assessment of developmental progress, and specific interventions for developmental delays.

Strengths. All of the focus groups emphasized strengths as an important domain to be included in an outcome measure. However, they discussed this in broad and somewhat vague terms rather than generating specific subdomains. Therefore, this section describes a strength based domain as a whole rather than specific subdomains.

The groups discussed the value of recognizing areas that children are successful in and not solely focusing on symptoms or areas of weakness. For example, teachers emphasized that it is “important for these kids to experience success.” One participant stated that some parents have been told that their child was a “throw-away child that they’d never accomplish anything.” He responded:

How can they say that about a kid? You look at these kids here and there’s not one student that comes in here that you can’t find something positive about. And then you start building on that positive thing and their little successes and you watch the little successes grow and as the little successes grow, the weeds of the negative behaviors get chucked out and they disappear.”

Teachers recognized that success may look different for the students at the state hospital, but to focus on the positives and find relative improvements. For example, one participant indicated that “other schools measure success by getting on the honor roll” whereas at USH it might be a student that success is when they “sat at their desk for fifteen minutes straight...because when they first got here a month, month and a half ago they couldn’t do a minute or two minutes.” They also stressed the importance of reinforcing these positive behaviors to the child so they “start internalizing” them, but being careful to do it in a manner they can receive it, such as just stating the good progress “and walk away” so they don’t have time to react negatively or be embarrassed.

Clinicians at the state hospital also recognized how imperative it is to consider the positive as well as the negative in evaluating a child’s progress. Clinicians specifically proposed “strength-based assessment, rather than just let’s look at all the bad stuff” and that measures of progress need to be more than “tallying all their bad marks.” Another commented that they “need to highlight sometimes some of their achievements and look at that as far as assessments go” and a third specifically stated that “including strengths in there would be a very important piece of getting a full picture.” They also gave some specific examples. One participant wondered about weighing the positives with negatives, noting a specific incidence in which she had to “gave [a client] three prompts with time in between, yet he shared with his peer, he helped his peer calm down,” and that she felt these positive behaviors need to be considered and not overlooked. She reflected that “if the parent has to prompt the kid three times, but the kid’s not strangling the 3 year-old brother anymore, did we do our job?...is that the outcome that we were looking for and the family?” Another suggested that they consider the positive as well as the negative in discussing progress, noting that the positive are “worth something...‘they were able

to do this,' or 'they had a chance to do something and they actually didn't'," referring to the ability to inhibit a target behavior may also be a sign of success for them.

Outpatient clinicians also mentioned specific areas of strengths that they thought might be useful to measure. For example, one stated, "self-esteem would be a good area to look at." In addition, another mentioned that being able to measure if "their support systems were actually growing in a quantitative way, that would be really helpful," while someone else countered that it is really "their perception of social support that they see, because that's been shown in the literature to be kind of the most salient thing," rather than a strict numerical count of supportive people. Another clinician suggested "finding what are their strengths before [discharge], in the residential placement that they're in afterwards, because if we have their strengths, we have something to build off of." They also emphasized that anything that the client considers a strength should be utilized. Thus, the variety and specific areas of strength were not as clear as the recognition that considering and acknowledging strengths in these children and adolescents is vital.

Parents also recognized the importance of "progress." Some parents emphasized that their child is "doing positive things again" and how crucial it is for them "to be happy and feel good about who he is and what he does." They noted that "happiness would be to see success, he feels good when he can succeed at something...you know when he succeeds and when he does something that's positive, he absolutely, you can just see the glow and he just is happy." They also specifically mentioned "probably self-esteem for one" as an important area to include in measuring strengths and that they would "like to see him have a higher self-esteem of himself." In addition, they also felt that "see[ing] success in education...get him in a direction toward something that would help him, make him happy," which is important in overall mental

health. Another parent suggested that she “would love to see the success and the self-confidence come out,” and would “like to see him be able to deal with those things better than he is *not* successful at, that he does not excel at or is not happy with” and “learn the coping skills and coping mechanisms to be able *to* function in an average society.” In addition, she mentioned the importance of having “higher expectations, with the knowledge that he has limitations, but he can still do it and let him know he’s expected to try.” Therefore, recognizing strengths and focusing on increasing the positive and not just focusing on the negative appears to be important to the parents of these children and adolescents.

Overall, all of the groups agreed that considering strengths is a vital part of the total assessment of a child’s functioning and needs to be included in an outcome measure. However, they were less specific about potential subdomains that should be included in such a domain. A review of the literature and other strength based assessments revealed some areas that have been included in other assessments and may be worth evaluating for use in a potential new measure. For example, the Devereux suite of assessments (DECA -I/T, DECA, DESSA; LeBuffe & Naglieri, 1999), the Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2007), or the Behavioral and Emotional Rating Scale, Second Edition (BERS-2; Epstein, 2004) are strength based measures that may include potentially useful domains. The Devereux suite of assessments (DECA -I/T, DECA, DESSA; LeBuffe & Naglieri, 1999), includes the following eight subdomains that might be considered in a strengths domain: (a) Self-Awareness, (b) Social-Awareness, (c) Self-Management, (d) Goal-Directed Behavior, (e) Relationship Skills, (f) Personal Responsibility, (g) Decision Making, and (h) Optimistic Thinking. The Resiliency Scales for Children and Adolescents (RSCA; Prince-Embury, 2007) measures three areas of strengths and/or vulnerability that appear to be related to psychological resilience: (a) Sense of

Mastery, which involves measuring optimism, self-efficacy, and adaptability; (b) Sense of Relatedness, which measures trust, support, comfort, and tolerance; and (c) Emotional Reactivity, which measures sensitivity, recovery, and impairment. The Behavioral and Emotional Rating Scale, Second Edition (BERS-2; Epstein, 2004) includes six subscales of potential use: (a) Interpersonal Strength, (b) Family Involvement, (c) Intrapersonal Strength, (d) School Functioning, (e) Affective Strength, and (7) Career Strength. These areas represent potential subdomains to be considered under an overall strengths domain, but are not considered all-encompassing or exclusive.

External locus of control. This section focuses more on issues that may affect the client and their potential for long-term success, but are at least in part outside of the client's control and involve other people or institutions. In addition, these areas are likely more difficult for a hospital or residential treatment center to treat directly, so may not be the most representative of treatment effectiveness but should be considered in trying to predict and prepare for long-term outcomes.

Family. This domain involves various aspects of the client's family, including a systematic view of family dynamics, the client's interactions with and responses to their family members, the client's attachment to their family, and the home environment, which is broader than just the family.

Family dynamics. This subdomain incorporates a systems approach and considers the complexities of the family dynamics that might affect a child's behavior, mood, potential for success after discharge, and timing of discharge.

Several groups mentioned concerns about the siblings of the child in treatment and the need for these siblings to be prepared for transition, especially if they had been traumatized by

their experience with the SED client. For example, one mother stated that her daughter was “very scared to express her feelings about how he’s doing, because he still has his boundary issues...he comes up and hugs her and grabs her and it scares [her].” Another parent mentioned that “family therapy would be a good thing and include everybody if you need to.” Overall, parents were quite concerned about the family dynamics and readjusting to having the child come back home.

Clinicians expressed concerns about families that lack involvement in their children’s lives or have issues of neglect or trauma. They mentioned concerns about “kids who have a lack of parental...care, organization, involvement” or who have “a lot reactive attachment, some disruptive parenting/poor parenting, neglect, abuse, trauma.” They were also concerned about families that are secretive, stating that “some families are very cooperative and you feel you have a good handle on it and some families seem [to be] shrouded in secrecy...the really tough ones,” emphasizing the importance of the role of families in the successful outcomes of patients. In addition, clinicians were concerned about the reintegration of the child with the family, the added stress on the family in having to readjust when the client returns home, and how the parent’s stress, own pathology, and multi-generational trauma can impact the client.

Family interactions. This subdomain specifically looks at the client’s interactions and communication with his or her family members. This is different from the family dynamics subdomain, which considers the entire family as a systematic unit, whereas this subdomain specifically looks at how the client is relating and reacting to his or her family members. This includes how clients “communicate with their families at some level so that everyone can get their needs met” and their ability to “communicate day in and day out” versus “communicating with [their] family here at the hospital where everything’s controlled or for a 2 hour home visit.”

It also includes their ability to “find solutions to the problems with [their] family” and “get along with siblings.” Clinicians noted that watching this interaction with siblings is important during treatment “so when there’s a conflict, then conflict can be more successfully addressed while they’re there, so it’s not a big surprise when they come home, and conflict occurs and nobody really knows how to resolve it successfully.” Family therapy was emphasized as important primarily by the parents, but all groups discussed its role in successful treatment outcomes. In addition, issues such as “attachment and then trust” were also considered important aspects for treatment and in preparing for discharge. Overall, this subdomain primarily evaluates clients abilities to communicate effectively with their families, their abilities to appropriate solve conflicts and overall ability to interact appropriately with their family members.

Attachment. This subdomain specifically considers a client’s attachment to his or her family. Clinicians noted emphasized that “attachment and then trust” are important areas to consider and that there is “a lot of reactive attachment” among the clients at USH, especially among the younger clients. Attachment has long-term effects on a person’s ability to interact with others and form appropriate relationships throughout his or her life, so it is a particularly salient area to look at specifically. Clinicians also discussed how clients can become attached to care-givers at long-term care facilities and that this needs to be dealt with judiciously in preparing for discharge and suggested having a smoother transition, allowing the client more connection to care providers after discharge. Specifically, they suggested having a system that “helps them maintain what’s they’ve established, especially if it attachment, if they’ve lost a parent, and they’ve identify somebody in that residential setting that has taken on that role and now that person’s gone.” They noted the need to reduce further trauma and sense of loss and to build healthy attachments.

Family and home environment appropriateness/preparedness for discharge. This subdomain considers the broader environmental perspective and how prepared a family is for discharge, including receiving training and education about their child’s diagnoses, medications, and how to respond to certain situations with their child. This environmental aspect of where the children are to return upon discharge and the differences between a hospital type of setting with extensive structure and a more traditional home environment were of concern to all of the groups. Participants mentioned concerns about clients being able to deal with some of the negatives in their environments and having less structure and fewer “activities.” Clinicians were concerned about the appropriateness of the client’s environment, exposure to negative or unsafe environments, and wanting to ensure that the parents were appropriately educated and trained about how to handle their child. Parents were also concerned about differences in responsibilities, chores, and enforcing rules as well as difficulties in providing as much structure or as many activities as the hospital and desired to be more informed as well as consulted about their child.

Clinicians emphasized concerns about the safety and stress in some home environments. One clinician at USH noted that while the children are at USH, they seem to “make more progress” in part because “the cops aren’t coming at night to arrest parents or to bring parents’ home or to solve a domestic dispute or to arrest them...we know that they have clothes to wear, we know that they’ve eaten.” They also felt that providing the children with a feeling of safety is crucial to their potential for successful outcomes and noted that “for some kids, coming to this school [and hospital] will be the safest environment that they will ever see even in their whole life.” They were also concerned about “discharging someone back into a negative situation” and how this could impact their outcomes. They noted how the home environment affects and

shapes a child's development and behavior, and questioned whether some of the children were "getting exposed to the appropriate environment that can shape those behaviors at home."

Following a systems approach, some clinicians were concerned about the chances of success for a child "where you're placing the child back in that environment, where not a lot has been changed." They also noted that removing the child from their home environment can be informative and has advantages over an outpatient setting as it "reduce[s] the number of variables that we are trying to control, so we're trying to determine if it's an environmental influence...stress versus internal etiology" whereas in "outpatient it's hard to determine if it is internal or environmental or a mix of both of them." They expressed hope that "if we can improve the internal functioning, we can help them progress back to the environmental stressors," but noted the importance of considering environmental stressors.

All groups, clinicians, teachers, and parents were concerned about transitioning from a very structured environment with rewarding activities at the hospital to a less structured typical home environment with fewer fun activities. They explained that the children have "been in a structured environment, they have had a lot of really fun activities" and parents felt that they "can't compete with that, I have to work...I can't provide the structure, I don't have the money to take them on activities," "I can't afford it," and "we don't have the means to go to a movie every other day." Clinicians and teachers were concerned that a child's behavior might improve in the structured environment at USH, but that they might return to their previous negative behaviors when discharged to a less structured setting. For example, they commented how at "the state hospital, everything was controlled" and then when they are discharged the parent has to be "the state hospital, [they] have to maintain that stability, and a lot of parents [are not] prepared for that, well willing in a lot of cases, but even those who are willing, they're not

exactly sure what to do.” All parties recognized how much harder it is to provide structure in a home environment compared to the state hospital or treatment programs and the importance of preparing parents as much as possible, noting that to “a degree the family has to learn how to deal with their particular needs.”

Parents were also concerned about the difference in responsibilities at the state hospital compared to at home, as well as more difficulty in enforcing rules. They were concerned that “they don’t have chores [on the unit]; they don’t have any responsibilities” or very minimal, such as “they have to make up their bed, but good heavens they have a camp cot and a blanket...that doesn’t require...much discipline.” Parents worried about transitioning back home where there are often more chores, “wondering is he going to be to the point that he doesn’t like to do chores anymore and he won’t be willing to help.” They were also concerned about the transition of following rules both at the hospital and home, stating “this is dorm, this is home, rules still apply, but it’s a different atmosphere and you’ve got to adjust” and being unsure how to facilitate that transition.

Collaboration between care providers. This domain consists of issues of collaboration and communication between different constituencies at the same treatment level and during transitions between levels of treatment. This was one of the most frequently mentioned domains, reflecting its importance in designing a new measure. The Continuity of Care domain includes the subdomains of collaboration between the school system and mental health system, , school transitioning, mental health transitioning, and the service organizations communication with the client’s parents or guardians..

Collaboration between school system and mental health system. This subdomain considers the amount, quality, and effectiveness of communication between the child’s school

and mental health professionals and case managers as appropriate. It consists of communication between disciplines during residential or inpatient treatment as well as planning with subsequent caregivers to prepare for discharge. Academic and mental health treatment efforts need to be coordinated in these children and adolescents as both are important for their progress and consume a large portion of their time daily. Unfortunately, however, there appears to be a lack of communication and coordination between disciplines, which could be detrimental to the child's long-term successful treatment outcome. Both the clinician and educator focus groups recognized and emphasized the importance of having communication with each other, they also expressed a concern about the lack of communication. In addition, mental health professionals and educators specifically mentioned feeling restricted as to the type of information that could be readily shared due to confidentiality requirements.

Teachers addressed some of their concerns about the break-down in communication with the hospital (USH) feeling that clinicians did not appear to be making an effort to participate in meeting with them or provide them with information. Teachers reported that they valued the input of the hospital staff, especially in informing them of things such as medication changes that may affect behaviors. The teachers explained that a "Core Team meeting is where the hospital and the school sit down and discuss the progress, academically, [and] behaviorally of these students." However, they reported that "sometimes no one shows up" to these core team meetings until the client is almost ready to be discharged and were concerned that "very seldom [does the treatment team] know the grade or the [educational] classification of their patient." They did note that "the children's unit...[is] very consistent [and is] a cohesive team and they're pretty successful," with the social worker, nursing directions, unit director, classroom staff and teacher all meeting together. Some of the teachers were also concerned that in "most cases they

have no idea what a patient's treatment track is; they have to kind of guess and...hope that whatever they're doing in school lines up with that treatment track." Another commented that they "can find out what treatment tracks they're on...but what we don't know is the measurement of it or how they're doing" and reported that the hospital staff that tracks the children's behavior in school has told them they cannot share their observations "because of HIPAA rules," even though parents have signed releases to allow communication between the hospital and school. Teachers were also concerned about not having access to information about details of a child's life that might affect their behavior or performance in school. One teacher gave an example:

One time I found out from a student that his parents were going through a divorce. I went to the social worker and I said 'can you tell me?' and they said 'I don't know if I should share that with you,' I said 'I have him six hours a day, his mother and father just got divorced, I need to know what's going on here.'

Overall, teachers were concerned both about sharing information with and receiving from the hospital treatment team and how not having critical information negatively affects their ability to effectively teach the students or help address behavioral concerns or other relevant goals.

Clinicians also expressed concerns about the lack of communication between the school and hospital, with one stating that "it would be nice to know academic progress, that's one of the things I'm not super happy about here." They explained that "partly because the school is separate from the hospital...when they first come in, sometimes I get some testing results" but then reported that they did not receive periodic updates regularly. Another clinician stated "it is my impression that the school is hold[ing] back a lot of information...they won't even invite us to the IEP, unless the parent requests that the psychologist be invited...very strange,"

emphasizing the lack of communication. Overall, both teachers and clinicians were concerned about the lack of communication and access to records, being two separate entities that do not have a shared filing system. This means that every piece of information has to be shared individually and there appears to be concerns about maintaining confidentiality and not violating HIPAA laws. One clinician desired more collaboration, stating that in “addressing synchronization between school and hospital I’ve often wondered what would the schedule look like if one person was in charge of a child’s whole day schedule.”

Overall, both sides acknowledged and were concerned about the lack of communication and collaboration and recognized that it was likely affecting the effectiveness of treatment. One teacher stated that she felt the USH mental health team was “only being sixty percent effective; if we worked as a team then we’ve got twenty-four hours a day of working together as a team, working towards the same goal, but I’ll do it from the education point and they’ll do it from the medical point.” This emphasizes that a more collaborative team-work approach could be beneficial for the long-term outcomes of the child.

School transition. This subdomain considers the transition of the child between a school outside of inpatient/residential treatment and the school setting in inpatient/residential. It incorporates concerns about transferring records back and forth, obtaining the necessary information to provide education at the appropriate level, ensuring that the child is achieving credits, getting or keeping them on track for graduation, and preparing the subsequent school for discharge. This may include meeting and developing a specific behavioral plan with the subsequent school, not just sending records regarding their academic standing and credits.

The teachers group specifically mentioned some frustration with the amount of time it typically takes to receive records from previous schools and the lack of communication and

preparation transitioning in and out. For example, they noted that sometimes it would take several months before they receive records and then they would have to readjust their academic curriculum or levels. They reported that they are often not given much warning about when a client will begin school with them, or information about the student, stating that “sometimes we have advanced notice of a couple of weeks, sometimes its they are coming in tomorrow and then...we have to track down their school records and...we find many times that the school records are very scarce.” They commented that the subsequent school also often feels ill-prepared without much warning, sometimes only being told a week before the child is to be discharged, but the teachers felt they have little control of that as the hospital side determines discharge dates.

There was also a related theme of fear regarding the anticipation of the client both at the school affiliated with USH as well as at the subsequent school. The teachers reported that their fear is often based on negative information they receive about the child before admission, whereas at the public schools, there is generally a basic fear of a child who has severe enough psychopathology to warrant a stay in the state hospital. For example, one teacher commented that “sometimes in my class I would read the file and I will be like ‘I do not want this kid in my class’... [but after] five, six months and the kid ...never displayed any violent behavior in my classroom,” noting that often the fears are unfounded. Likewise, they stated that “we will hear all kinds of nightmare stories...[but] because it’s such a structured environment here that a lot of times they behave much better than what we’ve been hearing.” However, the subsequent school also has fears of receiving these children and “always wants to know ‘how do you know they’re ready to transition back into the community’” and that the teachers feel ill-informed to answer that question because they “have never seen any form of discussion or written information that

tells [them] how the hospital measures progress so [the teachers] don't know what kind of a yard stick they're using.”

In addition, the teachers mentioned concerns about the child doing well in the very controlled and structured classrooms at the state hospital, but being concerned that the child may regress and their “behaviors [will] become less than positive” when they transition. As one participant stated, “in residential placements, education is so controlled” but when they transition to another school and “have all these learning disabilities...it just is chaotic, they get suspended...the parent gets frustrated...and that's a huge problem when they come out.” Thus, preparing for this transition to avoid these types of problems is essential to successful outcomes. The importance of tracking academic progress and success was mentioned repeatedly in multiple groups, especially as children and adolescents spend much of their time in the school setting and success in education affects multiple areas of their lives throughout their lives; thus smoothing the transition and preparing everyone involved for this transition is of utmost importance.

Mental health provider transition. This subdomain involves transitioning to a subsequent outpatient or step-down treatment and the communication between the hospital or residential placement and the next treatment provider. Outpatient clinicians expressed some frustration with a lack of accurate or informative records from inpatient/residential treatment centers. Clinician noted “documentation information from [the client's residential] therapist...didn't include anything,” or even if they “got 16 pages...it was kind of sparse” and did not explain the information it in, such as how they were measuring progress. Another therapist was concerned about the lack of communication, commenting that “we're measuring things, residential is measuring things, and we're not communicating well.” Overall, the outpatient clinicians felt that they were not receiving much preparation or information prior to the transition of the client.

Outpatient clinicians suggested some potential solutions, as one cited that “by far the most helpful thing...was to call the residential place and talk to therapist on the phone,” and another suggested a face to face “meeting when they transition.” This idea of a meeting rather than completing more paperwork or having to rely on existing paperwork that the next treatment provider won’t necessarily understand appeared to be quite popular among outpatient clinicians. This also underscores the importance of standardized and easily understood outcome measures if they are to be used. Regardless of how the information is transferred, preparing for this transition can help reduce the chances of a child falling through the cracks when they are discharged and gives the next treatment provider more well-rounded and hopefully accurate ideas of the issues to work on prior to beginning treatment.

Communication with parents. All of the groups also expressed concern about collaboration with parents. Clinicians were concerned that “some of the parents are really involved while their child is in the state hospital, but some of them aren’t and the child is discharged to those parents with very little understanding of what the treatment program actually was.” Parents emphasized their desires to be included in their children’s treatment and to have their opinions respected. One parent noted that she appreciated that “the staff here [at USH] have actually listened to me” compared to other experiences at different inpatient facilities where she stated that “they made me feel like I didn’t know anything.” Parents also emphasized a desire to be informed about and included in treatment so that the family could be prepared for transitioning, noting that “it’s the entire household that needs to be included in not only what they’re learning while [they’re] inpatient, but how to transition that to home as a family.” Overall, all the groups wanted to ensure that parents were involved and informed about treatment so they could be more prepared for the transition to the home environment.

Comparison of Domains from Focus Groups with USH Pilot Study

The USH pilot study generated four broad domains and 23 total items within these domains, each of which is rated on a five point Likert scale ranging from severely impaired to above average. The domains consisted of: Cognitive Development, Social Development, Mental Health, and Well-Being. This study generated six broad domains, divided into two overarching sections, and 22 subdomains. The six broad focus group domains included: , Behavior, Social/Emotional, Academic/Cognitive, and Strengths in the Internal Locus of Control section and Family and Collaboration among Care Providers in the External Locus of Control section. The broad domains generated by both the USH pilot study and those extrapolated from these focus groups were fairly similar, but also had some important differences as well. In addition, the organization of ideas or subdomains/items was somewhat different, such that both studies might have generated a similar idea, but placed them in different domains.

Although the focus of comparison is on the narrower subdomains or items rather than the broad domains in order to address this issue of differences in organization, the broad domains are briefly compared. The Cognitive Development and Academic/Cognitive both included the cognitive aspect, but the focus groups emphasized academics more, whereas the USH study focused more on basic cognitive skills. Likewise, both studies emphasized the importance of social relationships, but these were placed in their own domain, Social Development, in the USH study and combined with emotional functioning in this focus group study. Mental health symptoms were given their own domain in the USH study, whereas these were included as a subdomain under the Social/Emotional domain in the focus group study. Well-Being was its own domain in the USH study and some, but not all aspects of this domain were included in other domains of the focus group study. Conversely, behavior was given its own domain in the

focus group study and only certain types of behaviors were included under the Mental Health and Well-Being domains in the USH study. Lastly, the Strengths, Collaboration among Care Providers, and Family domains were unique to the focus group study, although some ideas within these were included elsewhere in the USH study.

Some subdomains and items were almost identical, whereas others were similar but divided or organized differently in each (see Table 3). A few of the areas of most overlap included a domain labeled “safe behaviors” in the USH pilot study, which was broken down into “aggression” and “self-harm” in the focus group study; the “coping mechanisms” versus “self-regulation,” which includes coping skills, as well as “motivation” and “self-care.” Both the focus groups and interviewees from the pilot study mentioned all of these specifically and extensively.

Another area of similarity also included social skills, which were divided into “social communication” and “relationships with peers and associates” in the USH pilot study and “interpersonal relationships” in the focus group study. Likewise, family relationships, which consist of the pilot study subdomain “attachment to family” and the focus group subfamily domain and specifically the attachment subdomain, were considered important in both studies. In addition, the pilot study separated “sustained attention and task focus” and “impulse management,” into distinct subdomains and while these were specifically mentioned by the focus groups, they were combined under the “cognitive skills” subdomain in the focus group Academic/Cognitive domain. Motivation was also a prevalent idea in both studies, but was given its own subdomain in the USH draft measure and was subsumed under the “client preparedness for discharge” subdomain generated from the focus groups. There were also several

Table 3

Comparison of Items from the USH Pilot Study with Subdomains from the Focus Groups

Very Similar		Some Commonalities		USH Items Not Mentioned by Focus Groups, but Subdomains They Could be Included In		Unique Focus Group Domains/ Subdomains
USH	Focus Groups	USH	Focus Groups	USH	Focus Groups	Focus Groups
Social Communication	Interpersonal relationships	Motivation	Motivation	Affect	Psychological Symptoms	Addiction
Relationships with Peers and Associates	Interpersonal relationships	Sustained Attention and Task Focus	Cognitive skills	Anxiety	Psychological Symptoms	Academic Performance
Safe Behaviors	Aggression	Impulse Management	Cognitive skills	Somatic Manifestations		Strengths
Safe Behaviors	Self-Harm	Learning Skills	cognitive skills/ academic performance	Physical Development	Development	Consistency
Self-Care	Self-Care	Language	Family interactions/ Interpersonal Relationships	Respect for Norms and Conventions	Inappropriate Behaviors	Family and Environment Preparedness for Discharge
Coping Mechanisms	Coping Skills	Achievement	Academic performance/ Strengths	Memory	Cognitive Skills	Collaboration among Care Providers
Attachment to Family	Attachment to Family	Rule-governed behavior	Inappropriate Behaviors			Collaboration between school system and mental health system
		Mood	Psychological Symptoms			School Transition
		Reality Orientation	Psychological Symptoms			Mental Health Provider Transition
		Values	Strengths			Communication with Parents
		Identity Development	Strengths			

subdomains that involved overlapping ideas and that both groups at least implicitly or explicitly mentioned, although they were not as directly correlated. The pilot study generated a subdomain entitled “learning skills,” which is somewhat similar, but not identical, to both the “cognitive skills” and “academic performance” subdomains from the focus group. Although learning disabilities were specifically mentioned in the focus groups, learning skills was not. A subdomain “language” was also mentioned in the USH pilot study, and the broader concept of communication was emphasized by the focus groups, but included within interaction/relationship subdomains such as “relationships skills” and “family interactions” instead of a separate subdomain. In addition, “mood,” “affect,” “anxiety,” “reality orientation,” and “somatic manifestations” were all distinct domains in the USH pilot study, but were could be subsumed under the subdomain “psychological symptoms” in the focus group study, and only mood was discussed extensively and hallucinations, which are part of being oriented to reality, were mentioned briefly. Lastly, the pilot study produced a subdomain labeled “rule-governed behavior,” which may be somewhat similar to the subdomain “inappropriate behaviors” which includes rule compliance generated by the focus groups, but the idea of self-governance was not specifically dwelt on in the focus groups. Also, while the pilot study included “identity development” and “personal values” as separate subdomains, values and identity were mentioned only passingly by one participant and may ultimately fall under the Strengths domain, but were not assigned specific subdomains in the focus group study.

There were also some areas of divergence between the (sub)domains generated by the USH pilot study and those from the focus groups. For example, the USH subdomain “memory” was not mentioned by the focus groups. In addition, although focus groups mentioned the importance of tracking rule compliance, they did not discuss specifically ideas consistent with

“respect for norms and conventions.” or subdomains. Likewise, while development, especially mental development was discussed by the focus groups, and they recognized how mental/emotional development might be conflicting with physical development, the focus groups did not specify the importance of measuring or tracking physical development on an outcome measure, whereas it was its own subdomain in the USH study. Lastly, as mentioned above, many areas that could be included in the focus group subdomain “psychological symptoms,” such as affect, anxiety, and somatic manifestations, were not specifically mentioned by the focus groups.

Conversely, there were ideas that lead to subdomains in the focus group study that were not explicitly included in the subdomains generated by the pilot study. These include domains of Collaboration of Care, Family, and Strengths, and several subdomains within these as well as a few others. All of the subdomains within the Collaboration of Care domain were unique, including “collaboration between school system and mental health system,” “school transition,” and “mental health transition,” and “communication with parents.” Within the Family domain, “family dynamics” and “family and environment preparedness for discharge” were also unique and broader than the USH pilot’s focus on “attachment” with regards to family. The subdomain of “addiction” was also unique to the focus group study. There were also subdomains that were somewhat similar, but also slightly different, such as being broader or narrower in scope, and these include “development,” which is broader than the USH pilot subdomain of “physical development,” “academic performance,” which is similar to, but different from “learning skills,” and “consistency,” which may have been included in other domains as specific to that area, but not as its own separate subdomain. Lastly, the idea of “strengths” was addressed somewhat differently between the pilot study and the focus groups, as the pilot study involved a rating scale

that allowed for an “above average” rating for each subdomain, whereas the focus groups emphasized the importance of recognizing areas of strengths that might be entirely separate from the other subdomains. Thus, there were many areas of direct correlations between the two studies as well as many ideas that overlapped even though they might be slightly different, but there were also several areas of discrepancy.

Discussion

The primary purpose of this study is ultimately to improve treatment and long-term outcomes for SED youth. This involves increasing accountability of treatment providers and being able to accurately track progress and outcomes of the children and adolescents receiving interventions. Besides being in the best interest of the children and adolescents that receive services, third party payers are also demanding increased accountability, because providing intensive services is quite costly. In addition, these youth often have involvement with multiple service organizations besides mental health treatment facilities, including juvenile justice, welfare, school-based services, and vocational rehabilitation. Thus improving outcomes could reduce long-term costs for many service organizations, benefitting the community as a whole.

The specific aims of this study were to a) to determine whether there is a consensus regarding the need for a new outcome measure; b) elucidate the areas that different groups who interact with these SED youth feel are important measure with respect to treatment and progress in these SED children; c) and then compare these domains with the ones generated by the initial USH pilot study. This study utilized four focus groups comprised of various constituencies that interact with SED youth, namely inpatient and outpatient mental health professions, teachers, and parents. This is one of the few studies that incorporated multiple groups of people involved

with these SED youth besides treatment providers, such as parents and teachers, to determine what areas are important to consider with respect to long-term outcomes of SED youth.

The overall results of this study with respect to the initial aims are briefly reviewed here and then will be evaluated in detail. While the groups agreed that a new unified system of tracking outcomes *could* be beneficial as an aid in improving outcomes, their greater concern is about lack communication between disciplines and between levels of care. The groups suggested that *if* a new unified measure would help facilitate communication without increasing the paperwork burden on treatment providers then it would be useful. Two main sections, Internal and External Locus of Control, divided into six broad domains (Internal: Behavior, Social/Emotional, Academic/Cognitive, and Strength-Based Assessment; External: Family and Collaboration) and 22 subdomains were extrapolated from themes discovered in the focus group discussions. We compared these domains to ones previously generated by a USH pilot study and found overarching similarities, but also notable differences. The findings of both the pilot study and this research should be considered in the development of any potential improved outcome measure as well as in improving treatment of this specialized SED population. One of the most prevalent themes we found, however, was a desire for an increase in collaboration and communication between constituencies and throughout levels of care, which is vitally important to improve care and long-term outcomes of SED children and adolescents.

Level of Perceived Need for a New Outcome Measure

The focus groups concurred that a new outcome measure could be beneficial, but expressed greater concern regarding other aspects of the current treatment process, including evaluation of progress, determination of readiness for discharge, and preparation for discharge. The area of greatest concern, however, was about communication among disciplines, such as

educators and mental health providers, and between levels of care, such as between inpatient and outpatient care providers. The groups also provided specific suggestions for the design of such a potential new measure.

The most frequent theme of the focus groups—independent of the need for a new formal measure—was that participants in all groups simply want to be more informed about the children’s progress in all aspects of treatment, including qualitative feedback and quantitative data from current measures that are used to determine progress (mental health and academic) and discharge. Beyond that, participants expressed interest in a possible new standardized measure if it would allow for that information to be conveyed more easily, more clearly, and would be more available to all treatment participants without adding an additional paperwork burden on any of the treatment providers. The groups also agreed that it would be helpful to have a measure that would continue to be used after discharge to provide continuity, especially if the results could be made available to all levels of care in order to allow caregivers (inpatient and outpatient treatment providers, teachers/school personnel, and parents or primary caregiver) to receive and provide feedback about the child’s continued trajectory after discharge. Parents and teachers also expressed a desire to be more involved in the treatment process and planning. They wanted their input about the children to be considered and valued by the treatment teams and to receive information about the child’s treatment plan, progress towards goals, and preparing for discharge. Overall, participants agreed that (a) the current system does not seem to fulfill their desires for better communication and (b) that a new, standardized measure designed for this SED population, if done well, *could* help facilitate and integrate the flow of information and input across caregiving and treatment settings.

All groups agreed that the design of an SED-specific measure should include the client's perspective, but that it should not rely solely on the client's self-report. Input from multiple sources is necessary, including parents, teachers, and all disciplines within the treatment team, not solely clinicians. Clinicians also requested that a new measure be designed in such a way that it would not increase their paperwork burden, but be relatively quick to complete with a moderate time interval between evaluations, stating that daily or weekly would be too often. Clinicians expressed hope that a new measure could be used with the clients in a therapeutic setting, such as to increase client awareness regarding their own progress, motivate change, or help facilitate discussion about therapeutic issues. Besides general design suggestions, participants also provided input about specific areas or domains they think are important, and all groups specifically emphasize the importance of considering the child's strengths as well as problem areas.

Conceptualization of Domains

Two main sections, Internal and External Locus of Control, were divided into six broad domains (Internal: Behavior, Social/Emotional, Academic/Cognitive, and Strengths; External: Family and Collaboration among Care Providers) and 22 subdomains based on themes generated from the focus group discussions.

Internal locus of control. This includes domains focused on changes primarily within the client.

Behavior. This domain incorporates a number of areas including aggression, safety, self-harm, addiction, inappropriate behaviors, self-care, consistency, and ability to handle less structured environments. As the state hospital criteria includes a mandate that the client must pose a danger to themselves or others to warrant that level of care, aggression tends to be an

issue for many of the clients, with clinicians estimating that about 75% of clients meet the *endangering others* criterion and about 25% meet the danger-to-self criterion. These behaviors appear to set this SED population at the state hospital (USH) apart from other clients that are maintained in lower levels of care and therefore are critical to address in treatment and effectively track as part of measuring progress. There is also a strong gender basis with more males being a threat to others, and females being a threat to themselves. There also appears to be a gender difference in addictive behaviors as well, with a far greater tendency for males to have electronic and sexual addictions whereas females often view their self-harm behavior as an addiction. Focus groups also stressed that the behavior changes need to be stable across time and situation, although the frequency and severity permissible may vary by child depending on their capabilities and baseline functioning. Self-care, including hygiene and medication compliance among daily living skills, was also considered important to all participants. Understanding age and developmentally appropriate behaviors as well considering gender appear to be important within this Behavior domain.

Social/Emotional. All groups indicated concern about clients developing coping skills to be able to appropriately handle stressful situations in the future once they were discharged. Some of their specific concerns included the ability to transition, adjust to changes, manage their own behaviors, inhibit impulses, regulate their emotions, and find appropriate solutions to problems. Clinicians emphasized gender differences in this domain as well, noting how peer relationships and relationship skills are particularly important for the females. In addition clinicians recommended that youth, particularly girls, learn to navigate conflicts with peers and build positive support networks, and that the perception of a support network is vitally important in outcomes for all youth, but especially girls.

Clinicians also noted how trauma affects many other areas, such as emotional functioning and trust and relationships, and that girls particularly are vulnerable to experiencing trauma and reactivity. They recommended regularly assessing how clients are doing with their trauma and reactivity and using this assessment to focus treatment. Emotional symptoms, such as depression and anxiety, as well as other psychological and psychotic symptoms also need to be evaluated and tracked, but the focus groups place more emphasis on functioning, how these symptoms might be affecting other areas, such as relationships or behaviors or school performance, rather than dwelling on the symptoms as isolated entities. In addition, they discussed concerns about ensuring that the child is given the most appropriate diagnoses and medications.

Academic/cognitive. The Academic/Cognitive domain specifically and directly considers the role of school, including academic performance, attendance, and behavior, in the child's life as well as other cognitive and developmental aspects. Often the mental health profession sees their impact and role in children's lives as being separate from academics, but school is such an important part of children's lives that everything else in their lives, including mental health and behavior or emotional problems, are connected to it. School both affects and is affected by children's psychological and emotional well-being and, therefore, cannot be ignored or considered trivial in any evaluation of overall progress in a child's life. Cognitive functioning, such as ability to inhibit impulses and delay gratification, directly affects many areas of functioning, including relationship skills and the ability to engage in the mental processing necessary to stop an impulse such as an aggressive act and find a suitable alternative to achieving one's needs. Evaluating these basic cognitive skills can help aid and guide treatment as well as help evaluate readiness for discharge. Removing children from their primary environment to place them in an intensive treatment center, such as a state hospital, may affect

their normal developmental trajectory, so it is imperative to track whether they are making expected progress in academic, cognitive, and other development realms while they are away and once they return. However, it is also interesting to note that while clinicians express concerns about how removing a child from their home and a more natural environment may affect development as they are having fewer normal experiences, they also suggest that children with such severe symptomatology are likely not having “normal experiences anyways.” Developmental disorders, such as autism, can profoundly impact a child’s life and abilities and therefore needs to be considering in treatment and evaluation.

Strengths. Lastly, all focus groups stressed the importance of considering the concept of strengths for each client on an individual bases. Although these focus groups did not provide specific suggestions about what areas should be included in a measure of strengths, they emphasized the individuality of strengths, stating that anything the client considered a strength should be considered a strength, even something like eating green beans. Feelings of success can be beneficial for long-term outcomes and therefore should be assessed in treatment as well as an outcome measure. Focus groups also suggested that the balance of positive and negative behaviors also needs to be considered as several small negative behaviors might be weighted lower when there are also positive behaviors, or strengths, compared to when positive behaviors are absent. A focus on building positive strengths, instead of simply reducing negative behaviors, can improve long-term outcomes as well when negative behaviors are replaced and not just repressed during treatment. Therefore, we recommend that strengths be evaluated as part of treatment for these SED youth and be included in an outcome measure of progress.

External locus of control. This section involves a more systematic approach to understanding how external factors may affect the long-term success of clients.

Family. Family relationships, including the client's ability to interact appropriately with his or her family, the client's attachment to his or her family, and the greater family dynamics, are crucial for positive long-term outcomes. Parents were particularly concerned about their SED child's relationship with his or her siblings, who are often affected by, even traumatized by, what has happened in their home prior to the primary client's removal. How the client interacts with his or her family as well as how the family is responding to him or her are both important to treat and measure in working with SED youth. While males tend to engage in more aggressive interactions with their families, females tend to experience more trauma, sometimes from family members. Clinicians need to address these issues and establish a plan to keep all family members safe from further trauma.

However, clinicians also stressed incorporating a systems approach that evaluates the family as a whole and considers the home environment, stating that children cannot be viewed and treated as an entity separate from their family and environment. The family dynamics, including issues such as psychopathology of the parents, and unsafe or otherwise negative environments can also significantly affect the client. The entire family and environment need to be considered and included both in treatment as well as in the evaluation of readiness for discharge as they can have enormous effects on outcomes once the child is discharged. Clinicians also need to evaluate whether the family is ready and appropriate for the client as well as ensuring that the client has made progress before reunification should happen .

Collaboration among care providers. The fact that every group mentioned concerns about communication between treatment and care providers and about transitions between levels of care, both inpatient to outpatient and between the home environment and inpatient, suggests that this is a vital area to consider in improving treatment of SED youth. Regardless of whether

a new measure is created to facilitate the flow of information, communication and access to information must be improved. Parents and teachers have crucial input about the children's progress and areas of decline that treatment teams need to consider and value. But parents and teachers also want to be informed about the treatment goals and strategies that are being implemented as well as progress, so that they, too, can assist in treatment in any way possible. In addition, if they are more informed about the treatment process, they can provide more salient input. Since children spend quite a bit of time both in the academic setting and home environment, receiving accurate and informative feedback from these groups could be very useful to treatment providers in planning and assessing the effectiveness of treatment. Subsequent schools and outpatient treatment providers of course could also benefit from receiving information from inpatient providers to help plan transition and prepare for the SED youth. In addition, outpatient clinicians and parents especially emphasized the importance of involving parents in treatment more so that they can be more prepared for discharge and have a smoother transition

Comparison of Domains from Focus Groups with USH Pilot Study

There are many overarching similarities between the results of the USH pilot study and the domains generated from the focus groups, but there are also some notable differences. Areas of agreement consist of the importance of safety, both of self and others, relationships and communication, attachment, mental health symptoms, coping mechanisms, motivation, ability to engage in self-care, and cognitive functioning, including learning, impulse control, and attention. However, there are also some areas that are unique to one or the other study and both need to be considered and evaluated prior to the generation of potential new measure to ensure that all relevant aspects are included.

In comparing the two cognitive domains, the USH pilot study has a fairly extensive focus on cognitive skills with an entire domain entitled Cognitive Development, which is divided into six subcategories, whereas these are combined into one subcategory, Cognitive Skills, under the broader Academic/Cognitive domain in this study. In addition, memory is unique to the USH study and was not mentioned by focus groups in this study. Conversely, the focus groups elucidated the importance of including academic performance and achievements specifically, beyond basic cognitive skills necessary for academic achievement, in considering overall progress of a child in treatment. The education aspect should not be ignored or trivialized in either treatment or an outcome measure as it is a central and critical component to every child's life and needs to be treated as such.

Both studies agreed that social relationships and communication are vital aspects in treatment and in determining progress. The USH study also suggested that respect for norms and conventions as well as personal values may be important to include in examining a child's progress, whereas these were not emphasized by the focus groups. Family interactions and attachment. The focus groups, on the other hand, pointed out that both a child's interactions with his or her family as well as the overall family dynamics and the home environment need to be considered in measuring readiness for discharge in a more comprehensive systems approach. While client's *attachment* to his or her family were included as an item within the USH study, many aspects of the Family domain are unique to this study. Future studies may wish to evaluate which of these, or all of these, are most related to successful outcomes and warrant attention in treatment and inclusion in an outcome measure.

In addition, both studies concurred that mental health or psychological symptoms are an important aspect for both treatment and in evaluating progress. They both agreed that mood and

safety are important, although the focus groups discussed safe behaviors as separate from emotional mental health symptoms and emphasized a distinction between aggression towards others and self-harm. The USH draft measure also divides mental health symptoms into six subcategories, with three that are not mentioned at all by the focus groups, namely affect, anxiety, and somatic manifestations. Although hallucinations are the only aspect of reality orientation that were mentioned even fleetingly by the focus groups, both are likely important enough symptoms, although rare, to warrant inclusion on any measure of outcome. Coping skills or mechanisms were recognized by both studies as important to treatment and their acquisition was considered necessary for successful long-term outcomes.

As mentioned above, the focus groups placed an emphasis on measurable behaviors separate from emotions, feelings, or even thoughts. Besides safety behaviors including aggression and self-harm, the focus groups pointed out addictions as an important area to consider in treatment and long-term outcomes, which are not included in the USH draft measure. Addictions are a common contributing factor in removing an adolescent from the home environment, such as being placed in intensive substance abuse treatment programs and need to be considered in evaluating progress in treatment and long-term potential for success. Likewise, illegal or otherwise inappropriate behaviors that may not be directly harmful, such as destruction of property, can also be severe enough behaviors that they could contribute to the removal of a child from his or her home and it is recommended that these be included in an outcome measure especially designed for SED youth. Consistency, across both time and situation, is a theme that the focus groups highlighted and warrants consideration in an outcome measure; future studies will need to determine whether it should be included as its own subdomain or as part of each of the other categories. In addition self-care, or the ability to engage in basic self-care activities,

including taking care of hygiene and medications, was considered important by both studies although it was placed in different domains in each.

While there are quite a few similarities or overlaps between the domains of each study, there are two domains generated from the focus groups that are quite unique from those from the USH pilot study, namely the Strengths and the Collaboration among Care Providers domains.

Both studies agreed that adaptive functioning is an important aspect to consider in developing children and adolescents, but this idea was conceptualized differently by each. The USH draft measure addressed this idea by including a broader range of functioning for each area or subdomain. Instead of only including several levels of impairment and then a level of “no impairment” in each area, the draft measure expands the Likert scale to include a level of above average functioning for each. The focus groups, on the other hand, specifically suggested including a separate domain for strengths that can include additional types of strengths besides ones that might be encompassed by positive functioning in other domains, such as sports, music, helping others, or even eating green beans.

The Collaboration among Care Providers domain reflects the strongest and most prevalent theme of all of the focus groups, with emphasis on communication between disciplines at each level of care (e.g. the hospital and school), between levels of care, (e.g. the hospital school and the subsequent school), and between treatment providers and parents or families.

Besides warranting consideration in any future measure of preparedness for discharge, the idea of Continuity of Care also deserves attention now in terms of improving treatment. All disciplines can make greater efforts to communicate with other disciplines, increase availability of information, and streamline or create a unified system to access information. Although the hospital and school are technically separate entities, both claim that parents sign consent forms to

share information when the child is admitted, so conceivably there should be a way that allows both organizations greater access to information, such as one system, possibly electronic, that both have access to, and more collaboration between disciplines. Focus groups also recommended having face to face meetings with subsequent care/treatment providers before discharge, such as with the next teacher/school and therapist (although these could be separate meetings) to inform and prepare the subsequent providers. This will allow for increased continuity of care, which is currently being recommended in the literature (des Crusier and Diamond, 2004), and better potential long-term outcomes.

Reflections and Future Considerations

There are many potential benefits of having an improved outcome measure that incorporates the most salient domains pertinent to SED youth and increases accountability of treatment providers. One measure that can communicate information about progress in a relatively simple, straightforward, and standardized manner and that follows the client through levels of care, providing feedback back to previous levels of care has the potential to improve outcomes. Treatment providers at the next level can continue tracking progress and identify a decline earlier and therefore modify interventions. It also allows for the collection of data regarding long-term outcomes, which can help validate or nullify the effectiveness of particular treatment interventions, ultimately leading to better care in the long-term.

Purpose of outcome measures. The two primary potential purposes for outcome measures are: a) to test treatment efficacy, thus improving accountability and b) to predict functional success. These two goals, efficacy and prediction are not entirely mutually exclusive, but are not inherently congruent either and the design of an outcome measure is affected by which of these goals the developers are most focused on. For example, while the focus groups in

this study stressed the importance of collaboration between treatment providers at various levels during transitions and the necessity of considering the home environment in predicting long-term success, these are issues external to changes within the client and may be less reflective of treatment efficacy. Therefore, both goals are appropriate in outcome measurement development, but affect the design and need to be considered and weighed at the outset.

Since focus groups can be used at both an exploratory and confirmatory level in designing measures, future studies may wish to again utilize focus groups in subsequent steps of this project. Morgan (1997) suggests three basic ways that focus groups can be used to contribute to creation of tests or measures: (a) to elucidate domains that need to be measured, (b) determine the dimensions that make up each of these domains and (c) suggest specific items or revise item wording to ensure the items effectively convey their intended meaning (Morgan, 1997). These initial focus groups have provided suggestions for potential domains and some of the dimensions of these domains and subdomains. Subsequent studies will need to generate a specific design for the measure and more specific questions and anchors for each domain and subdomain if a new measure is to be created. Once a draft measure is complete, focus groups from a broader audience, still including parents, teachers, and treatment teams, but outside of USH may be useful in evaluating this measure. Focus groups may also suggest revisions of wording that clarify the meaning of questions or broaden or narrow the dimensions of domains.

Recommendations for an improved SED outcome measure. We suggest incorporating both purposes, but in separate sections of a new SED measure, having one section focused on changes within the client (Internal Locus of Control), which could be used to determine *client* preparedness for discharge and treatment efficacy, and another that utilizes a more systematic approach and considers the preparedness of family, home and all constituencies

involved in treatment to help predict long-term success (External Locus of Control). This would allow both for accountability of treatment providers to adequately prepare the client for discharge as well as to evaluate whether the environment the client is to be discharged to is appropriate and make adjustments as necessary. For example, if the client has reached an acceptable level to be discharged but the family is not yet ready, a step-down to a lower level placement with a goal of focusing on family interactions may be appropriate. The following table (Table 4) details suggestions for sections, domains, and subdomains/items for such a measure.

Table 4

Suggested Sections, Domains and Subdomains/Items for a New SED Outcome Measure.

Internal Locus of Control		External Locus of Control, Systemic Approach	
Domain	Explanation	Domain	Explanation
Behavior	Includes unsafe and inappropriate behaviors, considering severity, frequency and consistency of appropriate behaviors	Family	Includes attachment, interactions, family dynamics
Aggression	Aggressive behaviors towards others. Considers severity and frequency	Attachment	Degree of Attachment to family
Self-Harm	This includes self-harm behaviors such as cutting, burning, picking, banging head against a wall, as well as suicidal and pseudosuicidal behaviors such as overdosing.	Family Dynamics	A systems approach looking at the family dynamics and home environment as well as the degree to which the family is prepared or feels prepared for the discharge and transition. This also includes parent or other family member pathology that needs to be considered as it could impact the child's success after discharge.
Addiction	Substance abuse and behavioral addictions, including electronic and sexual	Family Interactions	This includes communication and relationships with family members

Internal Locus of Control		External Locus of Control, Systemic Approach	
Domain	Explanation	Domain	Explanation
Inappropriate Behaviors	Property destruction, rule-breaking, target behaviors	Family and Environment Preparedness for Discharge	This subdomain evaluates the preparedness and appropriateness of the current family and environment situation for the client after discharge
Self-Care	The client's ability to engage in age appropriate self-care, including hygiene, medication compliance and activities of daily living.	Collaboration between care providers	Considers the communication and collaboration between all constituencies involved with caring for and treatment SED youth
Social/Emotional	Includes social and communication skills, relationships, emotional and behavior regulation, and mood and psychiatric symptoms	Between School and Mental Health Systems	This includes communication, or lack thereof within and between MHP agencies and schools. This includes within state hospital/residential placements
Relationship Skills	Ability to communicate, interact, respond appropriately to others	School Transition	Includes communication between hospital/residential school and previous and subsequent schools to ensure level appropriate and adequate education is occurring in an atypical school setting as well as set up any necessary aids to minimize risk of failure when discharge.
Self-Regulation	Ability to respond to stress and transitions appropriately, self-regulate emotions and behaviors	Mental Health Transition	This includes setting up subsequent outpatient or step-down treatment prior to discharge and communication between the hospital or residential placement and the next treatment provider.
Motivation	Evaluates the client's general motivation to make changes in his or her life and the degree to which the child feels ready to transition or be discharged. This includes the degree to which the feel safe in their next environments, perception of support after discharge, and considers any self-sabotaging behaviors.	Providers and Teachers to Parents	Evaluates the communication between treatment providers and teachers with parents and the degree to which the parents are being adequately prepared for discharge
Psychiatric Symptoms	This includes emotional regulation, degree of reactivity to trauma, acute psychiatric symptoms such as hallucinations, and internal emotional symptoms such as depression and anxiety		

Internal Locus of Control		External Locus of Control, Systemic Approach	
Domain	Explanation	Domain	Explanation
Academic/ Cognitive	Includes academic performance, and cognitive, physical and overall development		
Academic Performance	Includes academic performance, credits, whether they are at grade level or above or below.		
Cognitive Skills	This includes ability to attend, sustain focus, time required to complete tasks, problem-solve, process information, processing speed, speech and language , memory as well as considers learning disabilities brain damage		
Development	This includes examination of age appropriate development and considers the effects of developmental disorders.		
Strengths	Incorporates a broad range of positive attributes and skills of the client		
Self-Esteem/Self-Confidence	This includes positive feelings about the self as well as self-confidence or the degree to which they believe they will succeed.		
Coping Skills	Degree to which they possess appropriate coping skills to handle life's stresses and disappointments		
Goal-Directed Behaviors	Degree of goal-directed behaviors and thoughts, such as planning for college or a career		
Responsibility	Responsibility they demonstrate or accept, such as chores, jobs, initiation of responsible behaviors, and independence or self-reliant behaviors		
Self-Awareness	Degree of insight into their own selves, motivations, strengths and weaknesses		
Successes	Degree to which the client feels successful in his or her endeavors		

In addition, clinicians suggested having a relative rating system which would compare a child's progress to their own baseline, emphasizing the importance of considering relative progress. We suggest incorporating this relative improvement on a Likert scale for each item (see Figure 2) as well as following the USH pilot study's suggestion of including above average functioning in each area.

Severe	Moderate	Mild	Significantly improved	No Impairment	Above
0	1	2	3	4	5
Impairment	Impairment	Impairment	although still relatively impaired (perhaps approaching personal capabilities)		Average

Figure 2. Proposed Likert Scale for New SED Measure.

The focus groups, especially the mental health professional groups, provided specific suggestions for the design of a new measure which we advocate incorporating into a potential new measure. Both inpatient and outpatient clinician groups specifically admonished receiving input from multiple informants from multiple disciplines for any outcome measure used with SED youth. Although they concurred that the client is a valuable resource and should be included as one of the informants, the client should not be solely relied on, as they sometimes lack insight into their dysfunction, are motivated to exaggerate their symptoms in a call for help or deny problems in hopes of an earlier release, or simply are poor historians. Besides the client and parents, focus groups suggested including input from teachers, psychologists, neuropsychologists, social workers, occupational therapists, and recreational therapists, as they can provide valuable insights into the client's current functioning. Therefore, we advocate using a system that would incorporate input from multiple constituencies that are involved with the child and can provide observations and not relying solely on self-report.

Since clinicians and teachers were also particularly concerned about ensuring that they have access to the results in order to best focus their interactions with that child, we recommend

allowing all constituencies to both provide their observations and opinions in the evaluation and receive feedback about progress from such a measure. This can help improve communication across disciplines as well as potentially improve outcomes for these SED children. Several studies have demonstrated that providing feedback to therapists at least about the on-going progress or decline of their clients improves outcomes (Harmon et al., 2006; Hawkins et al., 2004; Lambert et al., 2001; Lambert et al., 2002; Whipple et al., 2003). Therefore, it is likely that providing feedback to other mental health disciplines as well as teachers could also help improve outcomes. If such as global measure is designed to measure progress in all areas of functioning SED clients' lives, future potential research could help determine whether providing feedback about global functioning to particular constituencies, such as teachers, actually does help improve outcomes.

Besides relying on multiple informants, clinicians were concerned about increasing their paperwork burden and requested that any new measure be fairly quick and straightforward to complete or administer and score. Independent raters, separate from the client's clinician, might help solve both this concern as well as including multiple informants, as they could utilize observations of the client as well as interviews with the client, treatment providers, parents, and teachers in an unbiased approach of measuring progress without increasing the clinician's paperwork burden. Administering such a measure every 90 days instead of once of week or every day would decrease the frequency burden, and using an independent rater to interview them rather than completing qualitative data forms would likely reduce the time burden on the clinician. However, there is the question of who the independent raters would be and the need to ensure inter-rater reliability. Alternative to using an independent rater, several groups suggested having a transition meeting; likewise it could be beneficial to have a meeting every 3-

6 months during treatment as well as a transition meeting prior to discharge with all constituencies involved, including the parents and child, Various scoring methods could be utilized at such a meeting, such as having one person, perhaps an independent rater, calculate a final score, or voting for each item's score or taking an average of all participants' scores per item. Regardless, we recommend that anyone who scores such a measure undergo training that includes practice scoring in order to maximize inter-rater reliability.

In addition, we recommend having specific anchors for each age at each level of impairment for each item to improve inter-rater reliability and reduce confusing and time spent on such a measure by people providing inputs and evaluating progress. Clinicians mentioned some concerns about the difficulty distinguishing functional from dysfunctional behaviors, especially after extensive interactions with children and adolescents that have many impairments. Likewise, they mentioned the need to consider what would be developmentally appropriate for children of a particular age, so specific anchors by age would be particularly beneficial to take this into account, ensure that all raters have the same view of what would constitute level of impairment, and reduce time and confusion about each item. Without specific anchors for each impairment level, people are likely to be more arbitrary or subjective in their ratings.

Overall, we recommend incorporating the suggestions for domains, subdomains and items from parents, teachers, and mental health professionals; including all of these constituencies as well as the client in gathering information in order to evaluate progress; provide feedback about progress (allow access to results) to all parties involved, and design the measure in such a way as to enable both prediction of successful outcomes as well as evaluate effectiveness of treatment interventions. In addition, we recommend incorporating training,

including practice and evaluations of rating, for the measure and age-based anchors within the measure to maximize inter-rater reliability.

Although, not directly related to the design of such a measure, we also recommend continuing follow-up after discharge in order to monitor long-term effectiveness of treatment about evaluate the measure's ability to accurately predict long-term success. This also relates to the broader need to improve communication among care providers at each level of care and between levels of care, especially during transition periods.

Current recommendations for improving communication. We were gratified by the interest, enthusiasm, and participation received from treatment providers and teachers. They clearly care deeply about improving treatment and accountability, even of themselves. However, although both sides identified weaknesses in the current system and desired greater correspondence between the two sides, neither has made substantial efforts to change the status quo, and appear somewhat resigned to the current broken system although there is desire for improvement. Regardless of whether or when a new outcome measure is created, we highly recommend policy, administrative, and any practical changes necessary in order to improve communication across discipline lines and between previous and subsequent treatment providers, including schools. Ideally, patients' files could conveniently follow them throughout levels of care and they, or their parents, could specify who they want to have access to what specific parts. An electronic filing system may help facilitate this as access to various types of information could be granted to particular individuals or groups and could be made available to multiple service organizations and/or levels of care. Besides increased access to relevant information, there also needs to be increased collaboration within and among disciplines, including between the treatment team and school, as well as with the parents and patient themselves. Improving

continuity of care has been touted in the literature, but practical recommendations of how to actually implement this are still sparse, especially in maintaining compliance with privacy laws, such as HIPAA.

Several groups also suggested having more transitional meetings to facilitate this. In addition, having one person who maintains a role of monitoring care of children as they move through different levels of various systems could help ensure that children do not fall through the cracks after discharge as well as help facilitate feedback back to previous treatment providers. Although case managers somewhat fulfill this role for children in state custody, a comparable role for children who are not in the state's is lacking. In addition, children that are released from state's custody also often lack continued follow-up and monitoring.

In addition, smoothing the transition for the client so that it is not so sudden could help the client and their families adjust and monitor if there are any setbacks. Perhaps continued check in with at least one person, such as a therapist for 3-6 months after discharge could help facilitate this process. Clinicians noted that sometimes clients become attached to individuals at residential centers, so a continuing some contact post discharge may be beneficial. Somewhat related to this issue, families and teachers also expressed some concerns about the institutional feel of a hospital compared to a home environment and felt that having more staff consistency and personal interactions, even allowing for some attachment, could be helpful for the children. Lastly, as families also complained about the difficulty providing activities on their own after discharge, perhaps family outpatient groups designed to aid in these types of transitions and allow for families to support each other could be useful.

Overall, in order to improve care and long-term outcomes of SED children and adolescents, there must be an increase in collaboration and communication. Creating a

standardized and unified way of tracking outcomes and increasing accountability may be able to facilitate this process, if all parties are able to provide input into the measure and receive feedback about the results. Besides improving the quality of life of these youth, improving outcomes and reducing recidivism can decrease the overall long-term cost of care across multiple service organizations, and is in the best interest of the client, their families, third party payers, and the community of tax-payers contributing to these services.

References

- Achenbach, T. A., & Rescorla, L. A. (2004). The Achenbach System of Empirically Based Assessment (ASEBA) for ages 1.5 to 18 years. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcome assessment* (3rd ed., Vol. 2). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Achenbach, T. M. (1991). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington: University of Vermont, Department of Psychology.
- Achenbach, T. M. (1995). Empirically based assessment and taxonomy: Applications to clinical research. *Psychological Assessment*, 7, 261-274.
- Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin*, 101(2), 213-232.
- Achenbach, T.M. (2001). *Manual for the ASEBA School-Age Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, and Families.
- Bada, H. S., Langer, J., Twomey, J., Bursi, C., Lagasse, L., Bauer, C. R.,...Maza, P. L. (2008). Importance of stability in early living arrangements of behavior outcomes of children with and without prenatal drug exposure. *Journal of Developmental & Behavioral Pediatrics*, 29(3), 173-182.
- Bates, M. P. (2001). The Child and Adolescent Functional Assessment Scale (CAFAS): Review and current Status. *Clinical Child & Family Psychology Review*, 4(1), 63-84.
- Behrens, E. & Satterfield, K. (2006). Report of findings from a multi-center study of youth outcomes in private residential treatment. *Proceedings of the 114th Annual Convention of the American Psychological Association*.

- Berrett, K. M. S. (1999). *Youth Outcome Questionnaire (Y-OQ): Item sensitivity to change*. (Doctoral dissertation, Brigham Young University 1999/2000). Dissertation Abstracts International, 60, 4876.
- Berry, W. D., & Feldman, S. (1985). *Multiple regression in practice*. Beverly Hills, CA: Sage.
- Bérubé, R. L., & Achenbach, T. M. (2006). *Bibliography of published studies using ASEBA* (2006 ed.). Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families.
- Bibby, P., Eikeseth, S., Martin, N. T., Mudford, O. C., & Reeves, D. (2002). 'Progress and outcomes for children with autism receiving parent-managed intensive interventions: Erratum. *Research in Developmental Disabilities*, 23(1), 79-104.
- Bjoraker, K. J., Delaney, K., Peters, C., Krivit, W., & Shapiro, E. G. (2006). Long-term outcomes of adaptive functions for children with mucopolysaccharidosis I (Hurlers Syndrome) treated with hematopoietic stem cell transplantation. *Journal of Developmental & Behavioral Pediatrics*, 27(4), 290-296.
- Burlingame, G. M., Lambert, M. J., Reisinger, C. W., Neff, W. M., & Mosier, J. (1995). Pragmatics of tracking mental health outcomes in a managed care setting. *Journal of Mental Health Administration*, 22(3), 226-236.
- Burlingame, G. M., Mosier, J. I., Wells, M. G., Atkin, Q. G., Lambert, M. J., Whoolery, M., & Latkowski, M. (2001). Tracking the influence of mental health treatment: The development of the Youth Outcome Questionnaire. *Clinical Psychology and Psychotherapy*, 8, 361-379.

- Burlingame, G. M., Wells, M. G., Lambert, M. J., Cox, J. (2004). Youth Outcome Questionnaire: Y-OQ. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcome* (3rd ed.). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Burlingame, G. M., Wells, M. G., Lambert, M. J., Cox, J., Latkowski, M., & Justice, D. (2005). *Administration and scoring manual for the Youth Outcome Questionnaire (Y-OQ.2.2)*. Salt Lake City, UT: American Professional Credentialing Services.
- Charman, T., Taylor, E., Drew, A., Cockerill, H., Brown, J. A. and G. Baird, (2005). Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time, *Journal of Child Psychology and Psychiatry*, 46, 500–513.
- Cicchetti, D. V. (1994). Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. *Psychological Assessment*, 6, 284-290.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Conners, C. K. (1973). Rating scales for use in drug studies with children. *Psychopharmacology Bulletin: Psychopharmacology with Children*. Washington, D. C.: U. S. Government Printing Office.
- Converse, J. M., & Presser, S. (1986). *Survey questions: Handcrafting the standardized questionnaire*. Thousand Oaks, CA: Sage.
- des Crusier, A. & Diamond, P. M. (2004). An exploration of social policy and organizational culture in jail-based mental health services. *Administration and Policy in Mental Health and Mental Health Services Research*, 24(2), 129-148.

- Doyle, A., Ostrander, R., Skare, S., Crosby, R. D., & August, G. J. (1997). Convergent and criterion-related validity of the behavior assessment system for children-parent rating scale. *Journal of Clinical Child Psychology, 26*(3), 276-284.
- Dunn, T. W., Burlingame, G. M., Walbridge, M., Smith, J., & Crum, M. J. (2005). Outcome assessment for children and adolescents: Psychometric validation of the Youth Outcome Questionnaire 30.1 (Y-OQ 30.1). *Clinical Psychology & Psychotherapy, 12*(5), 388-401.
- Durlak, J. A., Wells, A. M., Cotton, K. J., & Johnson, S. (1995). Analysis of selected methodological issues in child psychotherapy research. *Journal of Clinical Child Psychology, 24*, 141-148.
- Epstein, M. H. (2004). *Behavioral and Emotional Rating Scale (2nd ed.)*. Austin, TX: PRO-ED.
- Fletcher, J. M., Levin, H. S., Lachar, D., & Kusnerik, L. (1996). Behavioral outcomes after pediatric closed head injury: Relationships with age, severity, and lesion size. *Journal of Child Neurology, 11*(4), 283-290.
- Gladman, M., & Landcaster, S. (2003). A review of the behaviour assessment system for children. *School Psychology International, 24*, 276-291.
- Greenbaum, P. E., Dedrick, R. F., Friedman, R. M., Kutash, K., Brown, E. C., Lardieri, S. P. & Pugh, A. M. (1998). National adolescent and child treatment study (NACTS): Outcomes for children with serious emotional and behavioral disturbance. In M. H. Epstein, K. Kutash & A. Duchnowski (Eds.), *Outcomes for children and youth with emotional and behavioral disorders and their families: Programs and evaluation best practices* (pp. 21-54). Austin, TX: PRO-ED.

- Greenbaum, P., Dedrick, R., & Lipien, L. (2004). *The Child Behavior Checklist/4-18 (CBCL/4-18). Comprehensive handbook of psychological assessment : Personality assessment* (Vol. 2, pp. 179-191). Hoboken, NJ US: John Wiley & Sons Inc.
- Halliday-Boykins, C. A., Henggeler, S. W., Rowland, M. D., & DeLucia, C. (2004). Heterogeneity in youth symptom trajectories following psychiatric crisis: Predictors and placement outcome. *Journal of Consulting and Clinical Psychology, 72*(6), 993-1003.
- Hanson, C. A. (2007). *Effects of intensive in-home treatment for children with severe emotional disturbance*. Unpublished doctoral dissertation, Marquette University. Retrieved June 16, 2008 from Dissertations and Theses database.
- Harmon, S. C., Lambert M. J., Smart, D. W., Hawkins, E. J., Nielsen, S. L., Slade, K., & Lutz, W. (2007). Enhancing outcome for potential treatment failures: Therapist-client feedback and clinical support tools. *Psychotherapy Research, 17*, 379-392.
- Hatfield, D. R., & Ogles, B. M. (2004). The use of outcome measures by psychologists in clinical practice. *Professional Psychology: Research and Practice, 35*, 485-491.
- Hawkins, E. J., Lambert, M. J., Vermeersch, D. A., Slade, K., & Tuttle, K. (2004). The effects of providing patient progress information to therapists and patients. *Psychotherapy Research, 31*, 308-327.
- Hodges, K. (2000). *Child and Adolescent Functional Assessment Scale*. Ypsilanti: Eastern Michigan University.
- Hodges, K., Xue, Y., & Wotring, J. (2004). Uses of the CAFAS to evaluate outcome for youths with SED served by public mental health. *Journal of Child and Family Studies, 13*, 325-339.

- Hughes, C. W., Rintelmann, J., Emslie, G. J., Lopez, M., & MacCabe, N. (2001). A revised anchored version of the BPRS-C for childhood psychiatric disorders. *Journal of Child and Adolescent Psychopharmacology*, *11*(1), 77-93.
- Jonas, R., Nguyen, S., Hu, B., Asarnow, R. F., LoPresti, C., Curtiss, S.,...Mathern, G. W. (2004). Cerebral hemispherectomy: Hospital course, seizure, developmental, language, and motor outcomes. *Neurology*, *62*, 1712-1721.
- Kazdin, A. E. (1994). Psychotherapy for children and adolescents. In A. E. Bergin & S. L. Garfield (Eds.), *Handbook of psychotherapy and behavior change* (4th ed., pp.593-594). Oxford: John Wiley & Sons.
- Kazdin, A. E. (2004). Psychotherapy for Children and Adolescents. In M. J. Lambert (Ed.), *Bergin and Garfield's handbook of psychotherapy and behavior change* (5th ed.). New York: Wiley.
- Kazdin, A. E. (2005). Evidence-based assessment for children and adolescents: issues in measurement development and clinical application. *Journal of Clinical Child Adolescent Psychology*, *34*(3), 548-558.
- Kazdin, A. E., & Whitley, M. K. (2006). Comorbidity, case complexity, and effects of evidence-based treatment for children referred for disruptive behavior. *Journal of Consulting and Clinical Psychology*, *74*(3), 455-467.
- Kazdin, A. E., Esveldt-Dawson, K., Unis, A. S., & Rancurello, M. D. (1983). Child and parent evaluations of depression and aggression in psychiatric inpatient children. *Journal of Abnormal Child Psychology*, *11*, 401-413.
- Kline, R. B. (1994). Book review: New objective rating scales for child assessment, I. parent-teacher-informant inventories of the behavior assessment system for children: The Child

- Behavior Checklist, and the Teacher Report Form. *Journal of Psychoeducational Assessment* 12, 289-306.
- Lachar, D., Bailey, S. E., Rhoades H. M., Espadas, A., Aponte, M., Cowanm K. A.,... Wassef, A. (2001). New subscales for an anchored version of the Brief Psychiatric Rating Scale: Construction, reliability, and validity in acute psychiatric admissions. *Psychological Assessment*, 13(3), 384–395.
- Lambert, M. J., Hansen, N. B., & Finch, A. E. (2001). Patient-focused research: Using patient outcome data to enhance treatment effects. *Journal of Consulting and Clinical Psychology*, 69, 159-172.
- Lambert, M. J., Hansen, N. B., Umphress, V., Lunnen, K., Okiishi, J., Burlingame, G. M.,...Reisinger, C. W. (1996). *Administration and scoring manual for the Outcome Questionnaire (Q-45.2)*. Wilmington, DL: American Professional Credentialing Services.
- Lambert, M. J., Whipple, J. L., Bishop, M. J., Vermeersch, D. A., Gray, G. V., & Finch, A. E. (2002). Comparison of empirically derived and rationally derived methods for identifying clients at risk for treatment failure. *Clinical Psychology and Psychotherapy*, 9, 149-164.
- LeBuffe, P. A., & Naglieri, J. A. (1999). *Devereux Early Childhood Assessment Program (DECA)*. The Devereux Foundation. Lewisville, NC: Kaplan Press.
- Magiati, I. & Howlin, P. (2001). Monitoring the progress of preschool children with autism enrolled in early intervention programmes. *Autism*, 5, 399-406.
- Magiati, I., Charman, T., & Howlin, P. (2007). A two-year prospective study of community-based early intense behavioural intervention and specialist nursery provision for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 48, 803-812.

- Marsh, D. T. & Fristad, M. A. (2002). *Handbook of serious emotional disturbance in children and adolescents*. United States of America: John Wiley & Sons, Inc.
- McClendon, D. T., Warren, J. S., Green, K. M., Burlingame, G. M, Eggett, D. L., & McClendon, R. J. (2011). Sensitivity to change of youth treatment outcome measures: A comparison of the CBCL, BASC-2, and Y-OQ. *Journal of Clinical Psychology, 67*, 111-125.
- Meier, S. T., & Letsch, E. A. (2000). What is necessary and sufficient information for outcome assessment? *Professional Psychology: Research and Practice, 31*, 409-411.
- Merton, R. K., Fiske, M., & Kendall, P. L. (1990). The focused interview. *American Journal of Sociology, 51*, 541-557.
- Morgan, D. L. & Krueger, R. A. (1993). When to use focus groups and why. In D. L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art*. Newbury Park, CA: Sage.
- Morgan, D. L. (1997). *Focus groups as qualitative research (2nd ed.)*. Thousand Oaks, CA: Sage Publications.
- Morse, J.M. (1991) Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue*. Newbury Park, CA: Sage.
- Nelson, W. M., Renzenbrink, G. & Kapp, C. J. (1995). Sensitivity of clinically hospitalized adolescents' self-report measures to change over time. *Journal of Clinical Psychology, 51*, 753-760.
- NVivo qualitative data analysis software; QSR International Pty Ltd. Version 9, 2010. Doncaster, Victoria, Australia: Qualitative Solutions and Research International Pty Lrd.
- Overall J. E, & Gorham D. R. (1962). The brief psychiatric rating scale. *Psychological Reports, 10*, 799-812

- Overall, J. E. & Pfefferbaum, B. (1984). A brief scale for rating psychopathology in children. In Keller and Ritt (Eds.). *Innovations in clinical practice: A source book*. (Vol. 3). Sarasota, FL: Professional Resource Exchange.
- Phelps, L., & Cottone, J. W. (1999). Long-term developmental outcomes of prenatal cocaine exposure. *Journal of Psychoeducational Assessment*, 17, 343-353.
- Prince-Embury, S. (2007). *Resiliency Scales for Children and Adolescents: Profiles of personal strengths*. San Antonio, TX: Harcourt Assessments.
- Rahill, S. A. & Teglasi, H. (2003). Processes and outcomes of story-based and skill-based social competency programs for children with emotional disabilities. *Journal of School Psychology*, 41, 413-429.
- Reddy, L.A. (2001). Serious emotional disturbance in children and adolescents: current status and future directions. *Behavior Therapy*, 32, 667-691.
- Reynolds, C. R., & Kamphaus, R. W. (1992). *Behavior Assessment System for Children*. Circle Pines, MN: American Guidance Service.
- Reynolds, C. R., & Kamphaus, R. W. (2004). *Behavioral Assessment System for Children*, (BASC-2; 2nd ed.). Circle Pines, MN: AGS Publishing.
- Rosenblatt, A. & Rosenblatt, J. A. (2002). Assessing the effectiveness of care for youth with severe emotional disturbances: Is there agreement between popular outcome measures? *The Journal of Behavioral Health Services & Research*, 29, 259-273.
- Rossi, P. H., Wright, J. D., & Anderson, A. B. (Eds.). (1983). *Handbook of survey research*. New York: Academic Press.
- Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland-II: Vineland Adaptive Behavior Scales*, (2nd ed.). Circle Pines, MN: American Guidance Service.

- Sparrow, S.S., Balla, D.A., & Cicchetti, D.V. (1984). *Vineland Adaptive Behaviour Scales*. Circle Pines, MN: American Guidance Service.
- Thorpe, J., Kamphaus, R.W., & Reynolds, C.R. (2003). The Behavior Assessment System for Children. In C. R. Reynolds & R. W. Kamphaus (2nd ed.) (Eds.), *Handbook of psychological and educational assessment of children* (pp. 387-405). New York: The Guilford Press.
- Wagner, M. (1995). Outcomes for youth with serious emotional disturbance in secondary school and early adulthood. *The Future of Children*, 5, 90-112.
- Wells, K. (1991). Eagerly awaiting a home. Severely emotionally disturbed youth lost in our system: A personal reflection. *Child & Youth Care Forum*, 20, 7-17.
- Wells, M. G., Burlingame, G. M., Lambert, M. J., & Hoag, M. J. (1996). Conceptualization and measurement of patient change during psychotherapy: Development of the Outcome Questionnaire and Youth Outcome Questionnaire. *Psychotherapy: Theory, Research, Practice, Training*, 33, 275-283.
- Whipple, J. L., Lambert, M. J., Vermeersch, D. A., Smart, D. W., Nielsen, S. L., & Hawkins, E. J. (2003). Improving the effects of psychotherapy: The use of early identification of treatment failure and problem solving strategies in routine practice. *Journal of Counseling Psychology*, 58, 59-68.

Appendix A

USH Pilot Study Draft Measure:
Child Treatment Outcome Scale**COGNITIVE DEVELOPMENT****Attention/Executive Function**

1. Sustained Attention and Task Focus: Ability to maintain alertness to important environmental stimuli over time, to filter out unimportant sensory information, and to selectively shift or alternate focus as needed
 - 1 Severe Impairment or Deficiency**
The child is unable to sustain mental effort or maintain focus, even with adult assistance, for more than five minutes on anything but a limited set of novel or passive stimuli (television, video games, computer-generated images, favored toy or object, etc.). Efforts to direct the child's attention and reinforcements to maintain attention have little or no effect.
 - 2 Moderate Impairment or Deficiency**
The child's attention can be directed to a specific non-passive stimulus or task (educational toy, craft project, school assignment, household chore, etc.) for a short time (5-10 minutes) by another individual, but the child is highly vulnerable to even minor distractions. Vulnerability is manifested by disrupted listening, looking away from the task, and/or efforts to physically approach, touch, or grab the distractor.
 - 3 Mild Impairment or Deficiency**
The child can selectively focus attention on a specific stimulus or task without assistance, and appears to be attending most of the time, but loses information or pauses frequently in task completion due to attentional lapses.
 - 4 No Impairment**
The child can selectively focus and maintain attention on a specific stimulus or task until the task is finished or it is time to switch to a different activity.
 - 5 Above Average**
The child can independently plan and organize unstructured time and can carry out plans in order to achieve a desired objective or to experience an intrinsic reinforcement.
2. Impulse Management: The ability to inhibit premature, incorrect, socially inappropriate or destructive immediate responses to stimuli and situations and to delay activity until a more adaptive response can be formulated.

1 Severe Impairment or Deficiency

The child is unable to inhibit even destructive immediate responses that are (a) grossly out of proportion to precipitating stimuli **and** (b) create a situation of clear danger (physical attack, property damage, threatening/provoking verbal outbursts, running away, self-injury, physical tantrums).

2 Moderate Impairment or Deficiency

Destructive impulses are not prominent, but the child experiences frequent accidents, losses, or social or physical discomfort resulting from carelessness or acting without thinking (daredevil behavior, unintentional breakage of desired possessions, horseplay, overspending money, intruding on others' physical space, stomachache from overeating, etc.)

3 Mild Impairment or Deficiency

The child is unable to delay social actions. This is manifested by interrupting conversations, blurting out answers without being called upon, pushing ahead of others, not waiting his or her turn, and/or beginning tasks or activities before the instructions are finished. The child is not usually aware of behavioral infractions, but they are noticeable to others.

4 No Impairment

The child can respond to social cues for timing of actions and can effectively contain destructive or unwise impulses.

5 Above Average

The child effectively contains destructive or unwise impulses and anticipates future wants and needs, using planning, saving, problem-solving, or negotiation to obtain a desired outcome that cannot be achieved immediately.

Thinking and Problem-solving

3. Learning Skills: A set of attitudes, behaviors, and mental procedures that support the creation of problem solutions or the acquisition of new information.

1 Severe Impairment or Deficiency

The child is uninterested in new information and skills and is unreceptive to or actively resists teaching efforts and learning situations. Verbal encouragements and reinforcements for engaging in a learning situation have little or no effect.

2 Moderate Impairment or Deficiency

The child initially resists or refuses to engage in learning activities but can be encouraged to do so for brief periods of time requiring the use of prompts, reinforcements, and/or individual assistance.

- 3 Mild Impairment or Deficiency**
The child is interested in learning activities and is initially cooperative with teaching efforts but becomes frustrated and gives up quickly if not immediately successful.
- 4 No Impairment**
The child is interested and cooperative in learning situations and asks for assistance or tries a new problem-solving approach if not immediately successful. The child engages in the learning activity until it is completed or the desired skill is mastered.
- 5 Above Average**
The child independently seeks out new information or learning opportunities in areas of interest and engages in skill practice, study, or learning activities without adult direction.
4. Memory: The ability to encode, store, and retrieve information.
- 1 Severe Impairment or Deficiency**
The child recalls less than 25% of either (a) verbal information (instructions, simple stories, vocabulary words, explanations, etc.) **and/or** (b) visual/spatial information (locations of rooms or objects, demonstrations of procedures, appearance of people, objects, or designs, etc.) after 24 hours despite adequate exposure, repetition, or practice and despite the use of hints and cues for recall.
OR
The child scores more than two standard deviations below the mean on an individually administered, standardized measure of verbal **and/or** visual-spatial learning **and/or** delayed recall.
- 2 Moderate Impairment or Deficiency**
The child recalls only 25% to 50% of either verbal and/or visual-spatial information after 24 hours, but requires much more exposure, repetition, or practice to learn the material than do same-age peers, and recall is dependent upon verbal or visual hints and cues.
OR
The child scores between 1 ½ and 2 standard deviations below the mean on an individually administered, standardized measure of verbal **and/or** visual-spatial learning **and/or** delayed recall.
- 3 Mild Impairment or Deficiency**
The child recalls 50% to 75% of learned verbal and visual-spatial information after 24 hours but requires more exposure, repetition, or practice than do same-age peers, and recall is dependent upon verbal or visual hints and cues.
OR

The child scores between 1 to 1 ½ standard deviations below the mean on an individually administered, standardized measure of verbal and/or visual-spatial learning and/or delayed recall.

4 No Impairment

The child recalls more than 50% (but less than 75%) of learned verbal and visual-spatial information after 24 hours without needing more exposure, repetition, or practice than same-age peers working with comparable material. The information can be recalled without the aid of hints or cues.

5 Above Average

The child regularly recalls 75% or more of learned verbal and visual-spatial information after 24 hours without needing more exposure, repetition, or practice than same-age peers working with comparable material, and the information can be recalled without the aid of hints or cues

AND

The child has sometimes demonstrated verbatim or photographic recall of small amounts of information (lines from movies or books, words or melodies of musical compositions, complex graphic designs, a sequence of mechanical procedures, a mathematical formula, etc.) at 24 hours or more after only one exposure.

5. Language: The ability to both comprehend and express thoughts, ideas, and information through speech or signing.

1 Severe Impairment or Deficiency

The child communicates mainly with single words or short phrases with no use of complex sentences; vocabulary is severely limited for age, and/or comprehension of verbal material is restricted to brief, concrete communications such as routine social phrases, one-step directives, familiar nouns and verbs, etc.

OR

The child scores more than two standard deviations below the mean on an individually administered, standardized measure of comprehensive receptive or expressive language functioning.

2 Moderate Impairment or Deficiency

Child communicates in short phrases and brief, simple sentences; language is concrete and mostly bound to stimuli in the immediate environment, with minimal vocabulary for expressing abstract ideas such as feelings, reasons, or logical arguments; and/or comprehension of simple verbal concepts or instructions often requires repetition and use of visual supports or demonstrations. There is evidence that verbal expression or comprehension

requires an uncomfortable level of effort, such as word finding problems, long speech latencies, outbursts of frustration while speaking or listening, or complaints of problems with understanding.

OR

The child scores between 1 ½ and 2 standard deviations below the mean on an individually administered, standardized measure of comprehensive receptive or expressive language functioning.

3 Mild Impairment or Deficiency

Child speaks fluently and with adequate vocabulary, but is difficult to understand because of mispronunciations, misuse of words or phrases, odd or immature grammar, vague speech, or low speech content; and/or the child makes frequent mistakes due to misunderstanding instructions and explanations or missing the main point or important details in communications.

OR

The child scores between 1 and 1 ½ standard deviations below the mean on an individually administered, standardized measure of comprehensive receptive or expressive language functioning.

4 No Impairment

Speech is fluent and the child can use complex sentences with predominantly correct grammar and word usage. The child's ability to comprehend and express abstract ideas and feelings, and to appreciate verbal humor, is comparable to that of most same-age peers.

5 Above Average

Speech is articulate, coherent, and logical with a large technical, descriptive, or socially sophisticated vocabulary. The child is sometimes sensitive to inferences, innuendoes, or implications that are present but not directly stated in communications. The child is often successful at using language to persuade, negotiate, rationalize, or entertain.

6. Achievement: The ability to manage mental resources and capacities to produce identifiable accomplishments or work products.

1 Severe Impairment or Deficiency

Even with adult assistance, encouragement, and reinforcement, the child completes less than 25% of school assignments, developmentally appropriate household responsibilities, **and/or** extra-curricular activities (piano, baseball, or martial arts practice, cub scout participation, etc.)

2 Moderate Impairment or Deficiency

The child completes between 25% and 50% of school assignments, developmentally appropriate household responsibilities, **and** extra-curricular activities (piano, baseball, or martial arts practice, cub scout participation, etc.), but requires nearly constant adult assistance, encouragement and reinforcement.

3 Mild Impairment or Deficiency

The child completes between 50% and 75% of school assignments, developmentally appropriate household responsibilities, **and** extra-curricular activities (piano, baseball, or martial arts practice, cub scout participation, etc.), with regular (every 30-60 minutes) but not continuous adult assistance, encouragement, and/or reinforcement.

4 No Impairment

The child requires only occasional (3-4 times per day) adult encouragement or monitoring to complete between 50% and 75% of school assignments, developmentally appropriate household responsibilities, **and** extra-curricular activities (piano, baseball, or martial arts practice, cub scout participation, etc.).

5 Above Average

The child completes more than 75% of school assignments, developmentally appropriate household responsibilities, **and** extra-curricular activities (piano, baseball, or martial arts practice, cub scout participation, etc.) independently, without adult monitoring or assistance, and may appreciate, but does not require, adult encouragement or reinforcement.

SOCIAL DEVELOPMENT

Social Interaction Skills

1. Social Communication: Ability to both send and interpret verbal and nonverbal messages about motivations, intentions, and emotions.

1 Severe Impairment or Deficiency

The child is seldom able to correctly verbally identify his/her own feelings, intentions, or motivations, and either does not notice or has no response to the social communications of others. Facial expression is unchanging or incongruent with the child's statements or situation and the child has few, if any meaningful gestures. Neither expressions nor gestures are directed toward other people for the purpose of communicating affect. The child almost never initiates a conversation.

- 2 Moderate Impairment or Deficiency**
The child is occasionally able to correctly verbally identify his/her own feelings, intentions, or motivations but has little or no response to the social communications of others. Facial expressions are directed at others only to communicate emotional extremes and gestures are seldom used. The child initiates conversations, but tends to “talk at” other people about objects, preoccupying concerns, or his/her own interests. There is little or no conversational give and take.
- 3 Mild Impairment or Deficiency**
The child is often able to correctly verbally identify his/her own feelings, intentions, or motivations. If prompted, he/she can sometimes identify those of other people and think of an appropriate response, but this is almost never spontaneous. Facial expressions and gestures are directed at others, but are qualitatively odd, restricted, or difficult to interpret. Reciprocal, give and take conversations happen only rarely or only in certain settings.
- 4 No Impairment**
The child is often able to correctly verbally identify his/her own feelings, intentions, or motivations. Additionally, he/she can identify those of other people, nearly always generates an appropriate response with prompting, and occasionally generates an appropriate response spontaneously out of empathy or shared enjoyment. Conversations have a give-and-take quality and demonstrate clear interest in the feelings, intentions, and motivations of the other person.
- 5 Above Average**
The child can expressively describe his/her own feelings, intentions, and motivations and accurately predict those of other people who are in a familiar circumstance. Usually, he/she does not require prompting to respond appropriately to the situations of others, but realizes his/her limitations and may seek counsel of a more experienced person in a complex or unfamiliar situation. Conversations have a give-and-take quality, and the child has the capacity to suspend his/her own concerns or interests in order to focus full attention on another person.
2. Respect for Norms and Conventions: Ability to demonstrate an understanding and use of social etiquette in the individual’s predominant culture.

1 Severe Impairment or Deficiency

Child/adolescent uses predominantly rude, invasive, or sexually suggestive/aggressive overtures to initiate interaction with others. Interactional style violates social expectations for age and tends to cause others discomfort (stands too close or far away, touches without permission,

excessively loud or too quiet, etc.). Clothing, grooming, or language is offensive to a significant number of associates.

2 Moderate Impairment or Deficiency

Child's/adolescent's social overtures are frequently inappropriate, awkward, or embarrassing to him/herself or others. While she/he usually responds to prompts for maintaining appropriate physical and verbal boundaries with others, consistent supervision and reminders are necessary for this to occur. Child/adolescent often misperceives others' feelings about him/her and either believes that others like him/her much more than they actually do, or interprets neutral and friendly interactions negatively.

3 Mild Impairment or Deficiency

Child/adolescent is hesitant and self-conscious in situations where interaction is expected. Often depends upon adults or more sophisticated peers to initiate and maintain social exchange or activity. Social discomfort is not continuously obvious but does result in reduced participation and enjoyment of social activities.

4 No Impairment

Child/adolescent routinely demonstrates a knowledge and use of basic predominant cultural formulas for showing respect and interest in others (appropriate titles, manners, greeting customs etc.). Child/adolescent manages everyday casual or business interactions with parents, teachers, peers, and siblings fairly automatically and without obvious discomfort or escalation of conflicts. Physical and verbal boundaries are maintained most of the time without conscious effort. Child/adolescent is sensitive to strong or obvious social cues in other's facial expressions, body language, tone of voice, etc.

5 Above Average

Child/adolescent adjusts interactional style and social formulas to the age and characteristics of others with whom he/she is interacting **and/or** child/adolescent demonstrates social facility in more than one culture. Child/adolescent is usually able to accurately assess how others feel about him/her and is often sensitive to subtle social cues in facial expressions, body language, tone of voice, etc.

Attachments and Relationships

3. Attachment to Family: Pervasive desire to be around family members, loyalty to family standards and customs, concern about the well-being of others in the family unit.

1 Severe Impairment or Deficiency

Child/adolescent consistently expresses active contempt, dislike, or complete indifference toward **all** family members. He/she never expresses a desire or makes plans to see family members. Interactions with family

members when they are present are minimal, unpleasant, and/or forced. Child/adolescent never relates pleasant experiences with family members.

2 Moderate Impairment or Deficiency

Child/adolescent claims some liking or fondness for at least one family member but these feelings are based mainly upon the person's usefulness in providing material goods or privileges. He/she prefers being with a favored family member to being alone, but would be attracted to a stranger who could offer desired goods or privileges. Child/adolescent resents and may attempt to harm others who claim a favored family member's time or attention.

3 Mild Impairment or Deficiency

Child/adolescent expresses strong liking for or attachment to more than one family member but it is primarily based upon recognition of dependency. He/she is mildly clingy or possessive of these individuals, and often feels unable to accomplish certain tasks without their assistance. Child/adolescent trusts certain family members to meet his or her needs but does not recognize a reciprocal obligation to consider the needs of other family members.

4 No Impairment

Child/adolescent expresses a strong attachment, loyalty, or devotion to his/her family as a unit, even though he/she may have current conflicts with specific family members. The child/adolescent can identify role models within the family that he/she admires for specific strengths and occasionally imitates desired characteristics or behaviors of family members. The child/adolescent conforms behaviorally to several family values (behavior standards, religious practices, achievement criteria, etc.)

5 Above Average

The child/adolescent expresses a strong attachment, loyalty, or devotion to all members of his/her immediate family despite an understanding of their personal shortcomings and limitations. The child/adolescent is actively attempting to gain skills, knowledge, or personal attributes that he/she believes are important to the family or will increase the family's pride in him/her. There is expressed awareness and concern for the welfare of other family members and some attempt to assist family members with achieving personal goals.

4. Relationships with Peers and Associates: Ability to gain the friendship or good will of others.
 - 1 **Severe Impairment or Deficiency**
Child/adolescent has no friends and is actively avoided by acquaintances due to displays of aggression, coercion, bad temper, bullying, and/or rudeness. Child/adolescent is often feared by others.
 - 2 **Moderate Impairment or Deficiency**
Child's/adolescent's friendships and social relationships are usually brief and superficial and often end in conflict. Child/adolescent alienates friends and associates with bossiness, demands, tantrums, and/or refusals to share or change plans to accommodate others.
 - 3 **Mild Impairment or Deficiency**
Child/adolescent maintains one or two friends outside of immediate family. Friendship or association is based more on a shared interest or activity than on a mutual liking or trust. Associations do not usually end because of conflict but tend to fade due to changing interests or locations.
 - 4 **No Impairment**
Child/adolescent has one or more close friends with whom he/she shares common interests, values, and behavioral standards. Child/adolescent is on congenial terms with most peers and other-age associates and expresses empathy and shared enjoyment with close associates and concern for the welfare of friends who may be in stressful circumstances.
 - 5 **Above Average**
Child/adolescent has one or more close friendships based upon mutual trust and positive regard. Child/adolescent demonstrates an awareness and concern for the feelings and needs of more peripheral members of his/her social group/community and has at least once demonstrated independence or courage in addressing these feelings and needs.

Ethical Development

5. Rule-governed behavior: Ability to understand and respect the laws of societies and rules of social institutions.
 - 1 **Severe Impairment or Deficiency**
Child's/adolescent's behavior is governed by immediate desires and needs. Rules are obeyed only if it is convenient to do so or if fear of punishment is high. There is little or no evidence of an internal code of conduct. The child/adolescent will intentionally harm others, damage property, or use terroristic threats if it is to his/her advantage in obtaining gratification. He/she usually gives no evidence of remorse.

2 Moderate Impairment or Deficiency

The child/adolescent has a minimal behavioral standard that prohibits intentional violence (attempted murder, animal cruelty, terroristic threats, arson, sexual aggression, etc.), but he/she frequently engages in unethical acts that are less immediately destructive (deception, conning, petty theft, etc.). He/she often lies to avoid responsibility and mentally minimizes the consequences of unethical acts. Child/adolescent may verbally express remorse if caught but does not curtail the behavior.

3 Mild Impairment or Deficiency

The child/adolescent obeys rules most of the time. There is a rudimentary recognition of the value of laws to maintain social order, but the child's/adolescent's obedience is mainly motivated by a desire to avoid negative consequences. He/she is easily influenced into rule-breaking behavior by strong-willed peers or group consensus. Usually, there is some evidence of sincere remorse, but only after the harm to others has been pointed out by someone else.

4 No Impairment

The child/adolescent obeys laws and rules most of the time due to recognition of the necessity of rules to regulate behavior and maintain social order/safety. He/she has, at a minimum, internal behavioral standards for nonviolence, honesty, and trustworthiness. Although these standards may occasionally be violated in a moment of weakness or poor judgment, sincere remorse is usually spontaneously evident and he/she is almost never influenced by others to change or abandon standards.

5 Above Average

The child/adolescent generally obeys laws and rules and recognizes the need for such to maintain social order, but in one or more behavioral domains, holds themselves to a higher standard than laws or rules demand. He/she regularly considers fairness to others and the welfare of others when making behavioral decisions and spontaneously feels remorseful and attempts to make restitution if he/she violates rules or laws. The behavioral decisions of others have little or no effect on his/her rule-governed decisions.

6. Personal values: An internal set of ideals, standards, and convictions created by the individual to both encompass and supercede externally applied behavioral controls.

1 Severe Impairment or Deficiency

Child's/Adolescent's values are entirely self-centered. Ideas of right and wrong are determined almost exclusively by what is desirable or undesirable to him/her. There is little or no acknowledgment of the rights or needs of others. Concepts of moral conduct are entirely concrete – if the child/adolescent does something others want him/her to do, he/she expects to get something back in return and can justify retaliation if others do not behave

as he/she expects. Child/adolescent expects to profit from conflict and views force as an acceptable means of controlling other people and situations.

2 Moderate Impairment or Deficiency

Child/Adolescent bases values on conformity to the norms of a restricted and not necessarily ethical social group to which he/she belongs or wishes to belong (gang, cult, school clique, criminal family or organization, etc.). Ideas of right and wrong are determined by the approval or disapproval of the other members of the social group. There is little or no attempt on the part of the child/adolescent to assess the fairness or justice of the group's value system. Child/adolescent can justify violence and use of force by group members against outsiders, and prejudices against outsiders are prominent.

3 Mild Impairment or Deficiency

Child's/Adolescent's values are based on external societal rewards and punishments. Right actions reap tangible rewards and wrong ones earn punishments or costs. Interpretations of laws and rules are extremely literal. The child/adolescent believes that everyone should be subject to the same laws and rules that he/she is (have the same type of government, religious beliefs, classroom or household rules, behavioral expectations, etc) regardless of age, sex, nationality, culture, or handicapping condition. Concepts of right and wrong tend to be rigid and invariant regardless of individual differences or extenuating circumstances. Force is acceptable to make others conform to rules.

4 No Impairment

Child's/Adolescent's values are in a dynamic state and are being derived from experience and from observation of multiple significant cultural role models (family members, religious figures, community/world leaders, etc.) whose ideas have withstood trials in the child's/adolescent's life or reliable tests of time. Interpretation and application of laws and rules is somewhat flexible based upon individual differences. Child/adolescent may be biased in favor of his/her own ideas of right and wrong but acknowledges the right of others to their own viewpoint. Persuasion and negotiation are used to influence the behavior of others, in preference to physical force, which is a last resort for protection or defense.

5 Above Average

Child's/adolescent's values are in a dynamic state and are being formulated not only upon experience and observation, but also upon an internal sense of justice, integrity, and responsibility. There is recognition of some obligation, to humanity or to a higher power, to improve the human condition if possible. Child/adolescent acknowledges his/her ultimate responsibility for actions and decisions and has more than once relied on his/her own conscience as the final determinant of behavior. Child/adolescent is able to consider the value systems and perspectives of others when making ethical decisions.

MENTAL HEALTH

Mood

Pervasive, sustained emotional presentation that colors the person's perception of the world and interactions within the social milieu.

1. Severe Impairment

The child's mood significantly impacts his/her ability to perform age appropriate tasks and social functions such as attending school, completing assignments, engaging in age appropriate play activities, communications with friends and family and general outlook towards life most days, most waking hours of the day for at least a two week period. Efforts to alter the child's mood have little to no effect.

2. Moderate Impairment

The child's mood moderately impacts his/her ability to perform age appropriate tasks and social functions such as attending school, completing assignments, engaging in age appropriate play activities, communications with friends and family and general outlook towards life more days than not, most waking hours of the day for at least a two week period. Efforts to alter the child's mood have minimal effect.

3. Mild Impairment

The child's mood has some impact on his/her ability to perform age appropriate tasks and social functions such as attending school, completing assignments, engaging in age appropriate play activities, communications with friends and family and general outlook towards life. The child remains generally able to function in important life activities, but is not able to do so at an optimal level.

4. No Impairment

The child's mood is generally euthymic and is able to perform age appropriate tasks and social functions such as attending school, completing assignments, engaging in age appropriate play activities, communications with friends and family and general outlook towards life.

5. Above Average/Realistic Optimism

The child's mood reflects an optimistic approach to age appropriate tasks, social functions, completing assignments, leisure activities and communications with friends and family that results in a positive outlook in most areas of life and a confident approach to challenging situations.

Affect

Fluctuating changes in behavior which includes facial expressions, tone of voice, and general demeanor resulting from subjective experiencing of emotional states such as sadness, elation or anger.

1. Severe Impairment

Extensively limited range of affective expression (flat to blunted affect) resulting in absence or near absence of any signs of affective variation, or, conversely, grossly labile affect with extensive variability as evidenced by repeated, rapid and abrupt shifts in emotional presentation. Additionally, this criterion is also met by inappropriate affect exemplified by discordance of affective expression in the context of current circumstances, content of speech or ideation.

2. Moderate Impairment

Limited range of affective expression (blunted to restricted affect) resulting in reduction of affective variation, or, conversely, labile affect with moderate variability as evidenced by abnormally frequent shifts in emotional presentation.

3. Mild Impairment

Range of affective presentation is restricted as indicated by a mild reduction in the range and intensity of emotional expression, or conversely, mild affective lability as evidenced by occasional abnormal shifts in emotional presentation.

4. No Impairment

Normal range of emotional expression that is consistent with circumstances, content of speech or ideation.

5. Above Average/Positive Affect

Consistent affective presentation marked by confidence, even in the face of minor setbacks and challenges. Verbally expresses hope for success in completing tasks and generally displays a cheerful demeanor.

Anxiety

Excessive worry (apprehensive anticipation) accompanied by subjective distress which is not well managed by the individual. Worry may coexist with symptoms of restlessness, fatigue difficulty concentrating, irritability, muscle tension and disturbed sleep. Somatic symptoms (heart palpitations, sweating, trembling, shortness of breath, chest pain, nausea, dizziness etc.) and dysphoria may also be present.

1. Severe Impairment

Extreme worry accompanied by multiple somatic symptoms which significantly impacts the individual's social, occupational (academic) and emotional functioning most waking hours. The person is unable to control or manage the worry on their own.

2. Moderate Impairment

Marked worry accompanied by some somatic symptoms which creates some impairment in the individual's social, occupational (academic) and emotional functioning during at least some of their waking hours. The person, with sustained effort, is able to carry out some functions on their own despite ongoing discomfort.

3. Mild Impairment

Worry and apprehension are present at least part of the day without accompanying somatic symptoms. The person is able to perform functions with mild discomfort.

4. No Impairment

Minimal reality-based concerns may be present, however such concerns do not impact the person's ability to perform important functions. Anxiety related somatic symptoms are not present.

5. Above Average/Feeling of Wellbeing

Person's general presentation may be described as calm, relaxed, content and as presenting a sense of wellbeing.

Reality Orientation

Ability to accurately perceive the external world, develop realistic conceptualizations of perceptions and to present perceptions and associations in a linear, logical and goal-directed manner consistent with the individual's environment and cultural context.

1. Severe Impairment

Hallucinations and/or delusions are consistently present and significantly impact the person's ability to perform age-appropriate activities. Speech reflects thought processes that are illogical, tangential, loosely associated, and/or circumstantial. Person's ability to accurately track time, place, identity and circumstances are significantly impaired.

2. Moderate Impairment

Hallucinations and/or delusions are present much of the time and have some impact upon the person's ability to perform age-appropriate activities. Speech sporadically reflects thought processes that are illogical, tangential, loosely associated, and/or circumstantial. Person's ability to track time, place, identity and circumstances may be impaired in one of these domains.

3. Mild Impairment

Hallucinations and/or delusions are present some of the time, yet have minimal impact upon the person's ability to perform age-appropriate activities. Speech is generally coherent with minimal evidence of thought process impairment. Person is oriented to person, place, time and circumstances.

4. No Impairment

Absence of hallucinations and/or delusions, able to perform age-appropriate activities, thoughts are linear, logical and goal-directed. Person is fully oriented.

5. Above Average/Adaptive Creativity

Person is able to utilize abstract reasoning to develop novel, adaptive solutions to life's challenges, is able to multi-task in an appropriately prioritized manner and is highly productive within their environmental and cultural context.

Safe Behaviors

Management of behaviors which are directly dangerous to self or others, as well as risk-taking behaviors which place the individual in a likely position of physical harm.

1. Severe Impairment

Person engages in self-harming behaviors, or significant risk-taking behaviors or aggression towards others which pose a risk of substantial bodily injury or death at least twice per month. These behaviors have a high likelihood of resulting in injuries which require emergency medical care. Self-harming may include extensive cutting or deep cutting in critical areas, extensive self-inflicted burns, swallowing metal or other hard, potentially dangerous non-edible objects or toxic chemicals, head-banging on hard surfaces, use of weapons upon self etc. Risk-taking behaviors may include jumping from a high place onto a hard surface with no protective measures, driving recklessly and/or at excessive speeds, Russian Roulette etc. Harm to others which result in injuries requiring medical attention and may include choking, biting, hitting, kicking, striking with objects, stabbing, use of weapons etc.

2. Moderate Impairment

Person engages in self-harming behaviors, or risk-taking behaviors or aggression towards others which poses a risk of bodily injury at least twice per month. These behaviors are likely to result in injuries which require medical care. Self-harming may include superficial cutting, scratching, minor burns, swallowing digestible non-food items (e.g. small pieces of paper), minor head banging etc. Risk-taking behaviors may include attempting or mimicking sport activities typically performed by highly trained and practiced athletes (e.g. X Games Events) without adequate safety measures, training and practice. Harm to others may include poking, hitting, slapping, striking with small or softer objects, kicking, hair pulling etc.

3. Mild Impairment

Person engages in self-harming behaviors, or risk-taking behaviors or aggression towards others which may pose a risk of bodily injury at least one time per month. These behaviors result in very minor injuries which require minor to no medical attention. Self-harming may include very superficial scratching, striking self with limited force, picking at scabs, etc. Risk-taking behaviors would include participating in activities which have some potential for harm without protective gear (e.g. riding a

bicycle without a helmet, not wearing seat belts in an automobile). Harm to others may include pushing, minor slapping or hitting resulting in only minor discomfort etc.

4. **No Impairment**

Person is free from self-harming behaviors and aggression towards others, posing a risk of bodily injury. Mild, socially-acceptable, risk taking behaviors with protective gear are acceptable (e.g. participation in school athletic activities, driving with seatbelt secured, skate boarding with adequate protection).

5. **Above Average/ Vigilance**

Person is not only free from self harming behaviors and aggression towards others, but is aware of and attempts to assist those demonstrating various degrees of unsafe behavior. The person is vigilant with regard to mild, socially acceptable risk-taking behaviors with protective gear. Safety is a main theme as risk-taking behaviors are well thought out and planned, resulting in the decreased likelihood of bodily injury (e.g. thoroughly planned camping trip with compass, first-aid kit, insect repellent, flare).

Somatic Manifestations

Clinically significant physiological complaints resulting in medical treatment (e.g. taking medication, receiving physical therapy etc.) that cannot be fully explained by a known medical condition and include a clear psychological component, resulting in significant impairment in social, occupational (educational), or other important areas of functioning.

1. **Severe Impairment**

Child exhibits one or more chronic physiological complaints with acute exacerbations for at least two weeks, requiring medical attention. Social and educational functioning is severely impaired most of the day, significantly impacting the child's ability to perform age appropriate tasks and engage in social functions to include attending school, completing assignments, engaging in age-appropriate play activities, and communicating with family and friends.

2. **Moderate Impairment**

The child reports one or more somatic complaints for at least 1 week, resulting in the need for medical attention. Social and educational functioning is moderately impaired for at least part of the day, impacting the child's ability to perform age appropriate tasks and engage in social functions to include attending school, completing assignments, engaging in age-appropriate play activities, and communicating with family and friends.

3. **Mild Impairment**

The child presents with one or more somatic complaints for at least 1 day, resulting in the need for medical attention. The child's social and occupational functioning is only mildly impaired, meaning the child is generally able to function in important life activities, but is not able to do so at an optimal level.

4. No Impairment

The child does not voice any somatic complaints. The child is able to perform age-appropriate tasks and engage in social functions to include attending school, completing assignments, engaging in age appropriate play activities, and communicating with family and friends.

5. Above Average/ Physiologically Healthy

The child communicates a physiologically healthy attitude, engages in physical and nutritional activities which promote wellness and expressing an improvement in physiological functioning from baseline. The child denies any somatic complaints and participates in important life activities to a greater degree than most children.

WELL-BEING

Self Care

Ability of the child to engage in independent, age-appropriate self-care and activities of daily living to include dressing, grooming, hygiene, ability to prepare simple meals such as breakfast cereal, soup etc.. Ability to communicate essential personal needs such as hunger, injury, need to eliminate waste etc

1. Severe Impairment

Person is unable to provide age-appropriate care for themselves and engage in activities of daily living without substantial assistance from others. Appearance is unkempt with poor hygiene and grooming. Food preparation and cleaning skills are minimal to non-existent, age-appropriate communication of needs, and simple self-care skills are significantly underdeveloped. The individual's level of independence is considered to be very minimal to nonexistent.

2. Moderate Impairment

The child is able to engage in some age-appropriate self-care and activities of daily living with assistance from others. The child demonstrates some awareness of appearance and initiates minimal efforts to manage own hygiene and grooming. With minimal assistance is able to prepare age-appropriate foods and perform basic cleaning. Child engages in some age-appropriate communication of needs. Self-care skills are underdeveloped and level of independence is minimal.

3. Mild Impairment

The child is able to engage in most age-appropriate self-care and activities of daily living with prompts or other forms of minimal assistance. The child is aware of appearance and generally manages own hygiene and grooming with prompts such as checklists, verbal prompts etc. Child is generally able to engage in age-appropriate communication of personal needs. Self-care skills are slightly underdeveloped and level of independence is moderate.

4. No Impairment

The child is able to engage in age-appropriate self-care and activities of daily living without assistance. The child is aware of appearance and manages own hygiene and grooming. Child engages in age-appropriate communication of personal needs. Self-care skills are adequately developed. Level of independence is age-appropriate.

5. Above Average Self-Care

The child demonstrates above average/well-developed self-care. Activities of daily living are easily accomplished and at a level that exceeds age-appropriate expectations. The child communicates personal needs and plans ahead to make sure needs are met. Level of independence is similar to that of a well-functioning older child.

Physical Development

Child's ability to engage in age-appropriate physical activities that include play, gross and fine motor skills, coordination, visual-motor performance, motor speed, flexibility, strength and endurance.

1. Severe Impairment

Child is grossly unable to independently engage in age-appropriate physical activities without active compensatory assistance. Child demonstrates poor gross and/or fine motor skills, coordination is significantly below average for age, and/or visual-motor performance, motor speed, flexibility, strength or endurance are well below age-appropriate levels.

2. Moderate Impairment

Child demonstrates moderate difficulties engaging in age-appropriate physical activities without a degree of assistance. Child's gross and/or fine motor skills, coordination and/or visual-motor performance, motor speed, flexibility, strength or endurance are below age-appropriate levels to a noticeable degree.

3. Mild Impairment

Child is able to independently engage in age-appropriate physical activities with mild impairment in gross and/or fine motor skills, coordination and/or visual-motor performance, motor speed, flexibility, strength or endurance. These areas of physical development are somewhat below age-appropriate levels.

4. No Impairment

Child is able to independently engage in age-appropriate physical activities with no impairment in gross and/or fine motor skills, coordination and/or visual-motor performance, motor speed, flexibility, strength or endurance. These areas of physical development are at age-appropriate levels.

5. Above-Average Physical Development

Child independently engages in physical activities at a level beyond what would be expected for their chronological age. Superior gross and/or fine motor skills, coordination and/or visual-motor performance, motor speed, flexibility, strength or endurance are evident.

Coping Mechanisms

Coping mechanisms are reflective of the child's utilization of adaptive behavioral and cognitive strategies to manage interpersonal, intrapersonal, environmental, social and physical stressors. Maladaptive coping mechanisms include: sexual acting-out, drug abuse, overly dependent attachments compulsive rituals, improper use of nutrition, etc.

1. Severe Impairment

Child utilizes grossly maladaptive behavioral and cognitive strategies to manage stressors. These strategies require external interventions due to their disruptive and potentially dangerous nature. Conversely, the child may demonstrate a marked inability to manage stressors to the degree that they are overwhelmed and unable to engage in age-appropriate activities.

2. Moderate Impairment

Child periodically utilizes maladaptive behavioral and cognitive strategies to manage stressors. These strategies, at times require external interventions due to their disruptive and potentially dangerous nature. Conversely, the child may, at times, demonstrate an inability to manage stressors to the degree that there is clear interference with the performance of age-appropriate activities.

3. Mild Impairment

Child occasionally utilizes maladaptive behavioral and cognitive strategies to manage stressors. These strategies are utilized infrequently and typically do not require external interventions. Conversely, the child at times, utilizes adaptive coping skills in managing stressors thereby limiting the impact of stressors on the performance of age-appropriate activities.

4. No Impairment

Child consistently utilizes adaptive coping mechanisms to manage stressors and is able to generally perform age-appropriate activities with no more than minimal, occasional disruption.

5. Above Average Coping Ability

Child not only consistently utilizes adaptive coping mechanisms in their own life, but is also able to assist others in managing their stressors. Child consistently performs activities at a level that is beyond age-appropriate expectations despite the presence of stressors.

Motivation

The child's intrinsic or extrinsic drive to accomplish age-appropriate tasks, work towards a desired goal, or engage in self-improvement activities without prompts or assistance from others. The child self-initiates activities and performance of required tasks such as school work, cleaning living area etc..

1. Severe Impairment

The child fails to demonstrate the motivation, or age-appropriate intrinsic/extrinsic drive, to work towards a desired goal. He or she is not goal-oriented and requires continuous prompting, encouragement and assistance to accomplish basic tasks and activities of daily living. Rewards and positive reinforcement offered to the child result in limited constructive behavior change.

2. Moderate Impairment

The child demonstrates little motivation, or age-appropriate intrinsic/extrinsic drive, to work towards a desired goal. He or she requires prompting and encouragement to accomplish most daily tasks (e.g. ADL's, homework, demonstration of appropriate social behavior). Rewards and positive reinforcement have some constructive impact on behavior change.

3. Mild Impairment

The child demonstrates a moderate level of motivation, or age-appropriate intrinsic/extrinsic drive, in some situations, to work towards a desired goal. He or she requires little prompting and/or encouragement to accomplish daily tasks and is generally able to demonstrate behavior consistent with identified goals. Rewards and positive reinforcement generally have an overall positive impact on behavior.

4. No Impairment

The child consistently demonstrates a level of motivation, or age-appropriate intrinsic/extrinsic drive, in most all situations, to work towards a desired goal. Prompting and encouragement to accomplish daily tasks or goal-directed activities is generally unnecessary. The child is able to demonstrate behavior consistent with identified goals. Additional rewards and reinforcement methods targeted at modifying behavior are typically not needed as the child finds activities to be inherently rewarding.

5. Above Average Motivation

The child consistently demonstrates a level of intrinsic motivation beyond developmental years. The child generally operates autonomously to accomplish desired goals, with a proven track-record of success. Prompts, rewards, and encouragement from others do not appreciably increase goal-directed behavior.

Identity Development

The process of developing a distinct and persisting set of age-appropriate personality and behavioral characteristics (conduct, temperament, values, goals, emotional reactivity, and

social relationship skills) characterized as unique to the child. Individual characteristics are generally consistent across environmental settings and are representative of the child's sense of self.

1. Severe Impairment

The child has a poorly developed sense of self, rapidly shifts behavior, goals, emotional reactions etc. based upon current environmental influences and interests. The child demonstrates a lack of consistency regarding associations, ambitions, life direction and reactions to external events. The child is very easily swayed by peer modeling with very limited comprehension of the motivations for their current behaviors.

2. Moderate Impairment

The child demonstrates some consistent interests and reactions to life events, but remains developmentally unstable in terms of persisting interests, goals, sense of self and values. The child is relatively easy to influence by peers to engage in behaviors and adopting attitudes espoused by others.

3. Mild Impairment

The child generally demonstrates consistency in interests, goals, values and style of reacting to life events. However, the child remains somewhat easily influenced by others such as peers and given adequate pressure, will alter behavior and attitudes to conform with those of the peer group.

4. No Impairment

The child maintains an age-appropriate sense of self, consistency in reactions to life events, and espoused goals, values and interests. The child appreciates peer perspectives which are divergent from their own, but only accommodates such perspectives after careful consideration.

5. Above Average Identity Development

The child's sense of self and characteristic responses are developmentally advanced for their chronological age. The child has persisting values which are not swayed by even extensive peer pressure. The child appreciates perspectives which are at variance with his/her own beliefs, but is not influenced by such perspectives to alter their own goals, interests, beliefs and values.



Executive Summary

Perceptions of Outcome Assessment Needs for Severely Emotionally Disturbed Children

By: Emily Putnam, Mikle South, Ph.D., and Nancy Howes, Ph.D.

Effective treatment for severely emotionally disturbed (SED) children requires the integration of multiple disciplines and levels of care both within and beyond mental health systems. Care for these children is extremely expensive, and marked by high rates of recidivism in which children return for intensive treatment on multiple occasions. The ability to accurately track progress and outcomes of the children and adolescents receiving interventions is therefore an essential foundation for planning and modifying treatment goals and techniques to best help each child. The current climate of health care service likewise demands reliable measurement of treatment outcomes from treatment providers at every level of care to increase accountability. However, reports from treatment providers of SED children suggest frustration about the lack of comprehensive, functional measures that adequately capture the complexity of treating this population.

This executive summary reviews the major findings from our qualitative study utilizing focus groups designed to elicit input regarding the need and possible content involved in creating such measure. We conducted 60-90 minute focus groups with each of the following three separate constituent groups who are regularly involved in the care of SED youth at the Utah State Hospital (USH) child and adolescent treatment programs, including a) hospital clinical staff, b) education staff, and c) parents/primary caregivers; as well as clinical staff at the Wasatch Mental Health (WMH) Youth Outpatient Program that provide transitional care for youth going into and out of the USH programs. We asked each group about whether an SED-specific outcome measure could be beneficial, how it might be designed, and what content areas would be most useful to include in such a measure. The first section of this summary details the main findings from that project.

During the course of this project, several major consistent themes became apparent relating to obstacles that challenge the current system of treatment coordination both within and beyond USH. These include 1) feelings of isolation across the three constituent groups at USH, so that each group feels “out of touch” with the others; 2) concerns about continuity of care after leaving USH, including trepidation from USH and WMH focus groups about transitions to mental health, school, and social/criminal justice services; and 3) limited understanding of what criteria are used for planning and evaluating treatment goals and discharge from care. Thus, after reviewing our findings related to the building of a new measure, we discuss these current challenges, and finally end with recommendations for how these challenges might be addressed with a new SED-specific measure.

Treatment of SED Youth

Youth with severe emotional disturbances often have involvement with multiple service organizations besides mental health treatment facilities, including juvenile justice, welfare, school-based services, and vocational rehabilitation. Thus, improving outcomes could reduce long-term costs for many service organizations, benefitting the community as a whole. In addition, because these children and adolescents are frequently moved between more and less intensive levels of care and are involved in multiple service organizations, communication between all treatment and care providers is extremely important.

There is a recent trend towards improving the continuity of care which has emphasized improving communication between multiple care providers (Cruser and Diamond, 2004), but a standardized way of communicating current status or progress across providers is still lacking. In particular, research on outcome measures for children has lagged behind the adult research and there is a notable dearth in outcome research for children classified as SED (Behrens &

Satterfield, 2006; Greenbaum et al., 1998; Reddy, 2001; Wagner, 1995). This lack of accurate progress assessment tools is especially detrimental for children because treatment often involves intensive interventions that require removing the child from their home environment, which can interfere with typical developmental trajectories. That is, this type of intensive intervention of children interacts with ongoing development, making frequent, specific measures of the effectiveness of treatment all the more critical.

Perceptions Regarding a New Outcome Measure

Level of Perceived Need for a New Outcome Measure

While the groups agreed that a new unified system of tracking outcomes *could* be beneficial as an aid in improving outcomes, their greater concern was about a lack of communication between disciplines and between levels of care. The groups suggested that *if* a new unified measure would help facilitate communication without increasing the paperwork burden on treatment providers then it could be useful. All groups agreed that multiple disciplines, including mental health treatment providers, but also teachers, parents and clients need to be included as informants of such a measure and that any new outcome measure for SED youth should not rely solely on self-report.

Inpatient clinicians (clinicians at Utah State Hospital) responded “Absolutely” when asked if a new outcome measure designed specifically for SED youth in residential or state hospital types of settings was needed. They described how currently they rely on informal, non-standardized gathering of information from each discipline. They felt that a standardized measure that continued to follow the clients after discharge and provided feedback to the hospital would be “invaluable” in helping track recidivism and determine treatment effectiveness. In addition, they stressed the importance of focusing on global functionality across disciplines, not

just symptom reduction, and suggested considering a relative approach, incorporating the client's own baseline in measuring progress.

Outpatient clinicians were most concerned about receiving information regarding progress and discharge planning for clients when they are in inpatient care and preparing to transition to outpatient, whether at USH or other intensive, residential programs. These providers agreed that *if* a new, improved outcome measure could convey this information in a simple, unified, easy to understand way, then such a measure could be helpful. Importantly, they did not believe that this would necessarily require a formal outcome measure. They reported that currently they rarely receive any type of information, especially standardized information, regarding progress or discharge criteria and what information they do receive, such as the current "level" a client is on, is not typically explained in any meaningful way. They felt that even having a short phone call or a sit down meeting and receiving some qualitative data and having the opportunity to ask questions could be useful. This group requested that any new standardized outcome measure not increase their own paperwork burden, stating that a daily or weekly measure would be too arduous.

School staff echoed these sentiments. They explained that a significant portion of the children's time at the hospital is spent in school, and they felt it would be beneficial to be more informed about the children's treatment goals in order to better help them. They were in favor of a new standardized outcome measure that would be more available to them and included aspects of the clients' educational experience, performance, and behaviors, meaning that the teachers are able to provide input into such a measure.

Parents were relatively unfamiliar with current procedures for measuring outcomes and determining discharge, but also desired to be more informed about and included in this process.

They wanted their input considered, especially in diagnoses and medications, but in general about the client's progress, and to be more prepared for transitioning before discharge.

Conceptualization of Content Areas

From the focus group discussions, we identified two main areas of concerns regarding client outcomes, namely issues that the clients need to change within themselves (internal locus of control) and issues that could impact the clients' outcomes, but rely on or involve other people or institutions (external locus of control). Within the Internal Locus of Control sections, four broad domains and 12 subdomains were generated based on themes identified from the focus groups' responses. The four main domains include: Behavior, Social/Emotional, Academic/Cognitive, and Strengths. Within the External Locus of Control section, two domains, namely Family and Continuity of Care, and eight subdomains were extracted from the focus group discussions. The subdomains were ranked in order of frequency using NVivo 9 and Table 1 displays the domains and subdomains, as well as the relative percent frequency and relative percent cover of comments about each.

As the state hospital criteria includes a mandate that the client must pose a danger to themselves or others to warrant that level of care, aggression and self-harm behaviors appear to set this SED population at the state hospital (USH) apart from other clients that are maintained in lower levels of care such as outpatient and therefore are critical to address in treatment and effectively track their reduction as part of measuring progress. There is also a strong gender basis with more males being a threat to others, and females being a threat to themselves. There also appears to be a gender difference in addictive behaviors as well, with a far greater tendency for males to have electronic and sexual addictions whereas females often view their self-harm behavior as an addiction. In addition clinicians noted that social relationships appear to be more

Table 1

Domains and Subdomains with Percent Relative Frequencies and Cover

Internal Locus of Control			External Locus of Control, Systemic Approach		
Domain/Subdomain	Relative % Number of Comments	Relative % Cover of Comments	Domain/Subdomain	Relative % Number of Comments	Relative % Cover of Comments
Behavior	26.66	21.3	Family	17.15	21.28
Aggression	8.88	10.63	Attachment	1.22	.71
Self-Harm	2.55	3.06	Family Dynamics	4.74	98.04
Addiction	2.07	2.46	Family Interactions	1.34	1.62
Ability to manage behavior in less structured environments	3.89	4.66	Family and Environment Preparedness for Discharge	7.18	9.18
Inappropriate Behaviors	1.70	2.04	Collaboration between Care Providers	17.87	26.21
Self-care	2.67	3.2	Between School and Mental Health Providers	7.18	8.91
Consistency	.73	.87	School Transition	2.55	5.27
Social/Emotional	14.14	13.17	Mental Health Transition	2.92	4.1
Relationship Skills	4.26	5.09	Providers and Teachers to Parents	2.07	3.96
Self-Regulation	4.26	5.09			
Psychiatric Symptoms	3.28	3.93			
Motivation	2.19	2.62			
Academic/Cognitive	17.00	11.39			
Academic Performance	6.45	5.04			
Cognitive Skills	3.89	2.73			
Development	4.01	2.35			
Strengths	7.06	6.68			

Note. Topics not related to specific domains (such as need for a measure or measure design) were not included in calculations for this table.

more aggressive interactions with their families, some of which may be perceived as traumatic by siblings, females tend to experience more trauma, sometimes from family members; clinicians need to resolve this and establish a plan to keep clients and siblings safe from further trauma before reunification can happen.

Often the mental health profession sees their impact and role in children's lives as being separate from academics, but school is such an important part of children's lives that everything else in their lives, including mental health and behavior or emotional problems, are connected to it. School both affects and is affected by children's psychological and emotional well-being and, therefore, cannot be ignored or considered trivial in any evaluation of overall progress in a child's life.

Clinicians also noted that removing children from their primary environment to place them in an intensive treatment center, such as a state hospital, may affect their normal developmental trajectory. However, it is also interesting to note that they also suggest that children with such severe symptomatology are likely not having normal experiences anyways. In addition, they expressed concern that sometimes it is difficult to distinguish dysfunctional problems from "normal teenage" difficulties.

All of the focus groups emphasized strengths as an important domain to be included in an outcome measure. However, they discussed this in broad and somewhat vague terms rather than generating specific subdomains. The groups discussed the value of recognizing areas that children are successful in and not solely focusing on symptoms or areas of weakness. For example, teachers emphasized that it is "important for these kids to experience success." One participant stated that some parents have been told that their child was a "throw-away child that they'd never accomplish anything." He responded:

How can they say that about a kid. You look at these kids here and there's not one student that comes in here that you can't find something positive about. And then you start building on that positive thing and their little successes and you watch the little successes grow and as the little successes grow, the weeds of the negative behaviors get chucked out and they disappear

Participants recognized that success may look different for the students at the state hospital, but to focus on the positives and find relative improvements. They also emphasized that anything that the client considers a strength should be utilized. Thus, the variety and specific areas of strength were not as clear as the recognition that considering and acknowledging strengths in these children and adolescents is vital. While measurements of strengths is not common or detailed in the literature or current outcome measures, there are a few measures that focus on strengths. For example, the Devereux suite of assessments (DECA -I/T, DECA, DESSA), the Resiliency Scales for Children (RSC), or the Ages and Stages are strength based measures that may include potentially useful domains.

Comparison of Domains from Focus Groups with Existing USH Pilot Measure

USH previously created a pilot measure based on individual interviews with select clinical staff. That measure included four broad domains and 23 items within these domains, each of which is rated on a five point scale ranging from severely impaired to above average. The USH domains consisted of: Cognitive Development, Social Development, Mental Health, and Well-Being. There are many overarching similarities between the results of the USH pilot study and the domains generated from the focus groups, but there are also some notable differences (see Table 2). Areas of agreement consist of the importance of safety, both of self and others, relationships and communication, mental health symptoms, coping mechanisms,

motivation, ability to engage in self-care, and cognitive functioning, including learning, impulse control, and attention. However, there are also some areas that are unique to one or the other study and both need to be considered and evaluated prior to the generation of a potential new measure to ensure that all relevant aspects are included.

The USH pilot study domains are more focused on specific cognitive skills, detailed mental health symptoms, identity development and internalization of social rules and norms whereas the focus group comments reflect unique themes of academics, addictions, family dynamics from a systems perspective, consistency across situation and time, strengths, and collaboration among care providers.

Current Obstacles to Coordinating Care

Communication Across Constituencies

While all focus groups, including educators, mental health professions, and parents recognized and emphasized the importance of having communication with each other, they also expressed concerns about the lack of communication. Unfortunately, however, there appears to be a lack of communication and coordination between disciplines and caregivers, which could be detrimental to the child's long-term successful treatment outcome. Academic and mental health treatment efforts especially need to be coordinated in these children and adolescents as both are important for their progress and consume a large portion of their time daily. Mental health professionals and educators specifically mentioned feeling restricted as to the type of information that could readily be shared due to confidentiality requirements, while parents emphasized concerns about being listened to and informed and prepared regarding transition to their home environment. Treatment is enhanced when all systems coordinate efforts to work on common goals and conversely, patient outcomes suffer when there is a lack of corroboration.

Table 2

Comparison of Items from the USH Pilot Study with Subdomains from the Focus Groups

Very Similar		Some Commonalities		USH Items Not Mentioned by Focus Groups, but Subdomains They Could be Included In		Unique Focus Group Domains/ Subdomains
USH	Focus Groups	USH	Focus Groups	USH	Focus Groups	Focus Groups
Social Communication	Interpersonal relationships	Motivation	Motivation	Affect	Psychological Symptoms	Addiction
Relationships with Peers and Associates	Interpersonal relationships	Sustained Attention and Task Focus	Cognitive skills	Anxiety	Psychological Symptoms	Academic Performance
Safe Behaviors	Aggression	Impulse Management	Cognitive skills	Somatic Manifestations		Strengths
Safe Behaviors	Self-Harm	Learning Skills	cognitive skills/ academic performance	Physical Development	Development	Consistency
Self-Care	Self-Care	Language	Family interactions/ Interpersonal Relationships	Respect for Norms and Conventions	Inappropriate Behaviors	Family and Environment Preparedness for Discharge
Coping Mechanisms	Coping Skills	Achievement	Academic performance/ Strengths	Memory	Cognitive Skills	Collaboration among Care Providers
Attachment to Family	Attachment to Family	Rule-governed behavior	Inappropriate Behaviors			Collaboration between school system and mental health system
		Mood	Psychological Symptoms			School Transition
		Reality Orientation	Psychological Symptoms			Mental Health Provider Transition
		Values	Strengths			Communication with Parents
		Identity Development	Strengths			

Specifically considering communication between the school and the hospital during treatment, there appears to be somewhat of a break-down in communication. For example, teachers explained “that Core Team meeting is where the hospital and the school sit down and discuss the progress, academically, behaviorally of these students.” Teachers reported that they valued the input of the hospital staff, especially to inform them of things such as medication changes that may affect behaviors. However, the teachers reported that “sometimes no one shows up” to these core team meetings until the client is almost ready to be discharged and were concerned that “very seldom [does the treatment team] know the grade or the classification [educational classification] of their patient.” They did note that “the children’s unit it’s very consistent [and is] a cohesive team and they’re pretty successful,” with the social worker, nursing directions, unit director, classroom staff and teacher all meeting together. Some of the teachers were also concerned that in “most cases they have no idea what a patient’s treatment track is; they have to kind of guess and...hope that whatever they’re doing in school lines up with that treatment track.” Another commented that they “can find out what treatment tracks they’re on...but what we don’t know is the measurement of it or how they’re doing” and reported that the hospital staff that tracks the children’s behavior in school has told them they cannot share their observations “because of HIPPA rules,” even though parents have signed releases to allow communication between the hospital and school. Teachers were also concerned about not having access to information about details of a child’s life that might affect their behavior or performance in school. One teacher gave an example:

One time I found out from a student that his parents were going through a divorce. I went to the social worker and I said ‘can you tell me?’ and they said ‘I don’t

know if I should share that with you,' I said 'I have him six hours a day, his mother and father just got divorced, I need to know what's going on here.'

Overall, teachers were concerned both about sharing information with and receiving from the hospital treatment team and expressed how not having critical information negatively affects their ability to effectively teach the students or help address behavioral concerns or other relevant goals.

The mental health professionals groups also expressed concerns about the lack of communication between the school and hospital, stating that "it would be nice to know academic progress, that's one of the things I'm not super happy about here." They explained that "partly because the school is separate from the hospital...when they first come in, sometimes I get some testing results" but then reported that they did not receive periodic updates regularly. One clinician stated "it is my impression is that the school is hold[ing] back a lot of information...they won't even invite us to the IEP, unless the parent requests that the psychologist be invited...very strange," emphasizing the lack of collaboration. Another complained that it is "like pulling teeth to get information, and to me that's critical," as school performance both affects and is affected by emotional and mental well-being. One clinician desired for more collaboration and cooperation, stating that in "addressing synchronization between school and hospital I've often wondered what would the schedule look like if one person was in charge of a child's whole day schedule." Both teachers and clinicians were concerned about the lack of communication and access to records and being two separate entities that do not have a shared filing system, this means that every piece of information has to be shared individually and there appears to be concerns about maintaining confidentiality and not violating HIPPA laws.

Overall, both desired to be more informed about the goals and progress of the other entity so that they can best help meet these goals and work as a collaborative in the best interest of the child.

However, as frustrating as the current process of communication at USH is, outpatient mental health professionals reported that they have even less communication with schools of their clients, and are less informed about their clients' lives, stating:

when you're in an inpatient setting, a residential setting, kind of everyone knows what's going on with that particular child, there's a lot better communication, more regular meetings, more informal meetings that take place, but in the outpatient settings, I find it a lot more difficult to get a lot of relevant information, especially from adolescents, who may or may be telling me the truth. Sometimes you get a lot of disinformation in outpatient settings that gets caught in inpatient settings, because there's more ears around to hear.

They reported that they liked it when schools have an electronic on-line system that they can check "the child's attendance and grades anytime...I just need their permission and a code and that information is available."

All of the groups also expressed concern about collaboration with parents. Clinicians were worried that "some of the parents are really involved while their child is in the state hospital, but some of them aren't and the child is discharged to those parents with very little understanding of what the treatment program actually was." Parents emphasized their desires to be included in their children's treatment and to have their opinions respected. One parent noted that she appreciated that "the staff here [at USH] has actually listened to me" compared to other experiences at different inpatient facilities

where she stated that “they made me feel like I didn’t know anything.” Parents also emphasized a desire to be informed about and included in treatment so that the family could be prepared for transitioning, noting that “it’s the entire household that needs to be included in not only what they’re learning while [they’re] inpatient, but how to transition that to home as a family.” Overall, all the groups wanted to ensure that parents were involved and informed about treatment so they could be more prepared for the transition to the home environment.

Continuity of Care

All constituencies expressed concerns about transitioning between levels of care. The teachers group specifically mentioned some frustration and concerns with transitioning into and out of the school associated with the state hospital, specifically with the amount of time it took to receive records from previous schools and the lack of communication and preparation for transitioning in and out. For example, they noted that sometimes months passed before they receive records and then they would have to readjust their academic curriculum or levels. They also were frustrated that they typically are not given much warning about when a client will begin school with them or information about the student, stating that “sometimes we have advanced notice of a couple of weeks, sometimes its they are coming in tomorrow and then...we have to track down their school records and...we find many times that the school records are very scarce.” They commented that the subsequent school also often feels ill-prepared without much warning, sometimes the following week, but they felt they have little control of that as the hospital side determines discharge dates. Teachers also expressed mixed feelings about how much input they or the hospital should have in providing recommendations to

the subsequent school. Some indicated that education “classification...it’s not a hospital concern...don’t try and dictate and force them to do something.” Others reported that they have “transition meetings” with the subsequent school in which they provide recommendations and were concerned that:

Some of the things that we’ve told them to try, the teacher refuses to do and the next thing you know...this student is headed back to the state hospital. Why?...did they try an intervention that we suggested at the transition meeting, ‘Well, no that teacher wouldn’t do it.’ It’s like ‘well there you go.’

Overall, teachers appeared to be concerned with preparing both the student and the subsequent school for the transition, but were very concerned about the outcome for the child if the transition does not go well.

Outpatient clinicians expressed some frustration with a lack of accurate or informative records from inpatient/residential treatment centers. Clinician noted “documentation information from their [residential] therapist...didn’t include anything,” or even if they “got 16 pages...it was kind of sparse” and did not explain the information in, such as how they were measuring progress. Another therapist was concerned about the lack of communication, commenting that “we’re measuring things, residential is measuring things, and we’re not communicating well.” In general, the outpatient clinicians felt that they were not receiving much preparation or information prior to the transition of the client. Outpatient clinicians suggested some potential solutions, as one cited that “by far the most helpful thing...was to call the residential place and talk to therapist on the phone,” and another suggested a face to face “meeting when they transition.” This idea of a meeting rather than completing more paperwork or having to

rely on existing paperwork that the next treatment provider does necessarily understand appeared to be quite popular among outpatient clinicians. This also underscores the importance of standardized and easily understood outcome measures if they are to be used. Regardless of how the information is transferred, preparing for this transition could help reduce the chances of a child falling through the cracks when they are discharged and gives the next treatment provider more well-rounded and hopefully accurate ideas of the issues to work on prior to beginning treatment.

Elucidating Criteria for Treatment Planning and Discharge

Teachers, parents, outpatient clinicians, the clients themselves and even some inpatient clinicians seemed somewhat unsure about the criteria used to determine when a client is ready to be discharged or even how progress is measured throughout treatment.

One teacher related when she's asked the treatment team about how they know when a client is ready to be discharged:

I said what's the standard what is the treatment plan what are we hoping for, what's the objective? At what point do we know that he's safe to leave?

Well...we don't really know, we haven't really decided. Well I can't work on 'haven't really decided.' I mean how do you measure 'haven't really decided.'

They generally felt unaware of the clients' goals, stating, "social work comes in, the doctor comes in, and they come up with a plan on what this kid needs to accomplish before he leaves....I, as a teacher, don't know what that plan is." This was frustrating to them because then they "can't help them achieve their goal. I can't redirect them in the appropriate ways to help them." In addition, one wished that they had "a little bit of a say in [goal development/discharge planning], because the kids will now ask us... 'what do

we need to do to get ready for discharge.’ I’ll say ‘It really has no bearing on what you do in school.’” Another commented that teachers “can find out what treatment tracks they’re on...but what [the teachers] don’t know is the measurement of it or how they’re doing”

Teachers also reported that the subsequent school often has fears about receiving these children and “always wants to know ‘how do you know they’re ready to transition back into the community’” and that the teachers have felt ill-informed to answer that question because they “have never seen any form of discussion or written information that tells me how the hospital measures progress so I don’t know what kind of a yard stick they’re using.” In addition, they expressed some concerns over having to be responsible for discharging the child to the subsequent school, who wants a “guarantee...that they’re not going to come down here and do a Columbine” when the school was not involved in the decision process or even informed about how the hospital was determining that the student was ready to be discharged. They stated that they were simply “trusting the hospital” when it comes to determining readiness for discharge, but would appreciate having more information during treatment about their goals as well as progress and discharge planning.

Parents expressed concerns about their children’s outcomes and wanted to ensure that their children would be adequately prepared for discharge, but were not really sure how their children’s progress was being measured or when they would be able to be discharged. They too wanted to be involved in the decision process regarding discharge and were quite concerned about being taken seriously in discussions about their child’s progress. For example, one parent expressed how at a different inpatient facility “it got to

the point where I really felt like I didn't know what I was talking about, and I started backing off and they starting adding medications, and [then] came the cycle of downhill," ending with her child being in-and-out of a short term inpatient clinic several times. She felt that her child deteriorated because she was being ignored first by his outpatient treatment providers and then by the inpatient clinicians. They were concerned that their children also did not seem to understand what was required for them to be discharged, as one parent stated "he comes home, and he thinks he's on vacation, and we're trying to pound into his head, this is your trail for discharge, if you can't come home and follow the rules and boundaries...then you have to go back and then we'll try again next week." Another parent stated that her son is "working to get out now that he's realized he can't just sit back and wait 6 months...at first he thought he could just sit here for 6 months... and do whatever he wanted and they'd let him go home," demonstrated that lack of understanding clients seem to have about what is required to be discharged.

Outpatient clinicians indicated that while they thought that inpatient and residential treatment centers probably have their own ways of measuring progress, these are not often provided or explained to the outpatient clinicians as reflected in statements such as "I know that most residential treatment centers have open economies where they track their clients with point systems that they show progress week to week and they're able to map that...but we never receive that." They also reported that they "might know their level, like level 5, but we have no reference for" what that means.

Even inpatient clinicians had difficulty articulating the exact procedure for how they determine when a client is ready to be discharged. For example, they indicated that there are some external pressures that appear to have little to do with a client's actual

progress or current status such as “I mean we can only keep someone for so long...I start to feel pressure about at the one year mark” partly because they feel that “developmentally, I don’t think it’s a good place to be here. I don’t think normal development progresses while they’re here, they don’t have the same experiences that you get in the real world.” While they agreed that aggression was one of the key behaviors that needs to be reduced, they did not have a set standard stating “certain kids are held at a higher standard than others, some boys if they can go a week, we’re real happy, and others, 3 months. It varies” but when asked how they decide “who needs to go a week and who needs to go 90 days?” they simply shrugged and shook their heads. One therapist stated: “ultimately,.. it would be [the psychiatrist, the psychologist and the social worker] that decides if a client can be discharged “but we all have our own goals too. We all have objectives, for what we’re working on, so I just kind of wonder what that would look like if it were more collaborative.” The psychiatrist explained that she has a “template” that “each discipline fills out certain parts of it. And they can write anything they want to in there, but there are some things that I say, I do need to know this. Because I think they answer different questions.” However, this is not a standardized or quantifiable measure and other disciplines seem somewhat unsure about how she ultimately decides if a client is ready and some expressed interest in having “a more global kind of measure” that is standardized that they can all provide input into.

Reflections and Future Considerations

There are many potential benefits of having an improved outcome measure that incorporates the most salient domains pertinent to SED youth and increases accountability of treatment providers. One measure that can communicate information

about progress in a relatively simple, straightforward, and standardized manner and that follows the client through levels of care, providing feedback back to previous levels of care has the potential to improve outcomes. Treatment providers at the next level can continue tracking progress and identify a decline earlier and therefore modify interventions. It also allows for the collection of data regarding long-term outcomes, which can help validate or nullify the effectiveness of particular treatment interventions, ultimately leading to better care in the long-term.

Purpose of outcome measures. The two primary potential purposes for outcome measures are: a) to test treatment efficacy, thus improving accountability and b) to predict functional success. These two goals, efficacy and prediction are not entirely mutually exclusive, but are not inherently congruent either and the design of an outcome measure is affected by which of these goals the developers are most focused on. For example, while the focus groups in this study stressed the importance of collaboration between treatment providers at various levels during transitions and the necessity of considering the home environment in predicting long-term success, these are issues external to changes within the client and may be less reflective of treatment efficacy. Therefore, both goals are appropriate in outcome measurement development, but affect the design and need to be considered and weighed at the outset.

Since focus groups can be used at both an exploratory and confirmatory level in designing measures, future studies may wish to again utilize focus groups in subsequent steps of this project. Morgan (1997) suggests three basic ways that focus groups can be used to contribute to creation of tests or measures: (a) to elucidate domains that need to be measured, (b) determine the dimensions that make up each of these domains and (c)

suggest specific items or revise item wording to ensure the items effectively convey their intended meaning (Morgan, 1997). These initial focus groups have provided suggestions for potential domains and some of the dimensions of these domains and subdomains.

Subsequent studies will need to generate a specific design for the measure and more specific questions and anchors for each domain and subdomain if a new measure is to be created. Once a draft measure is complete, focus groups from a broader audience, still including parents, teachers, and treatment teams, but outside of USH may be useful in evaluating this measure. Focus groups may also suggest revisions of wording that clarify the meaning of questions or broaden or narrow the dimensions of domains.

Recommendations for an improved SED outcome measure. We suggest incorporating both purposes, but in separate sections of a new SED measure, having one section focused on changes within the client (Internal Locus of Control), which could be used to determine *client* preparedness for discharge and treatment efficacy, and another that utilizes a more systematic approach and considers the preparedness of family, home and all constituencies involved in treatment to help predict long-term success (External Locus of Control). This would allow both for accountability of treatment providers to adequately prepare the client for discharge as well as to evaluate whether the environment the client is to be discharged to is appropriate and make adjustments as necessary. For example, if the client has reached an acceptable level to be discharged but the family is not yet ready, a step-down to a lower level placement with a goal of focusing on family interactions may be appropriate. The following table (Table 4) details suggestions for sections, domains, and subdomains/items for such a measure.

Table 4.

Suggested Sections, Domains and Subdomains/Items for a New SED Outcome Measure.

Internal Locus of Control		External Locus of Control, Systemic Approach	
Domain	Explanation	Domain	Explanation
Behavior	Includes unsafe and inappropriate behaviors, considering severity, frequency and consistency of appropriate behaviors	Family	Includes attachment, interactions, family dynamics
Aggression	Aggressive behaviors towards others. Considers severity and frequency	Attachment	Degree of Attachment to family
Self-Harm	This includes self-harm behaviors such as cutting, burning, picking, banging head against a wall, as well as suicidal and pseudosuicidal behaviors such as overdosing.	Family Dynamics	A systems approach looking at the family dynamics and home environment as well as the degree to which the family is prepared or feels prepared for the discharge and transition. This also includes parent or other family member pathology that needs to be considered as it could impact the child's success after discharge.
Addiction	Substance abuse and behavioral addictions, including electronic and sexual	Family Interactions	This includes communication and relationships with family members
Inappropriate Behaviors	Property destruction, rule-breaking, target behaviors	Family and Environment Preparedness for Discharge	This subdomain evaluates the preparedness and appropriateness of the current family and environment situation for the client after discharge
Self-Care	The client's ability to engage in age appropriate self-care, including hygiene, medication compliance and activities of daily living.	Collaboration between care providers	Considers the communication and collaboration between all constituencies involved with caring for and treatment SED youth
Social/Emotional	Includes social and communication skills, relationships, emotional and behavior regulation, and mood and psychiatric symptoms	Between School and Mental Health Systems	This includes communication, or lack thereof within and between MHP agencies and schools. This includes within state hospital/residential placements
Relationship Skills	Ability to communicate, interact, respond appropriately to others	School Transition	Includes communication between hospital/residential school and previous and subsequent schools to ensure level appropriate and adequate education is occurring in an atypical school setting as well as set up any necessary aids to

Internal Locus of Control		External Locus of Control, Systemic Approach	
Domain	Explanation	Domain	Explanation
			minimize risk of failure when discharge.
Self-Regulation	Ability to respond to stress and transitions appropriately, self-regulate emotions and behaviors	Mental Health Transition	This includes setting up subsequent outpatient or step-down treatment prior to discharge and communication between the hospital or residential placement and the next treatment provider.
Motivation	Evaluates the client's general motivation to make changes in his or her life and the degree to which the child feels ready to transition or be discharged. This includes the degree to which the feel safe in their next environments, perception of support after discharge, and considers any self-sabotaging behaviors.	Providers and Teachers to Parents	Evaluates the communication between treatment providers and teachers with parents and the degree to which the parents are being adequately prepared for discharge
Psychiatric Symptoms	This includes emotional regulation, degree of reactivity to trauma, acute psychiatric symptoms such as hallucinations, and internal emotional symptoms such as depression and anxiety		
Academic/Cognitive	Includes academic performance, and cognitive, physical and overall development		
Academic Performance	Includes academic performance, credits, whether they are at grade level or above or below.		
Cognitive Skills	This includes ability to attend, sustain focus, time required to complete tasks, problem-solve, process information, processing speed, speech and language , memory as well as considers learning disabilities brain damage		
Development	This includes examination of age appropriate development and considers the effects of developmental disorders.		
Strengths	Incorporates a broad range of positive attributes and skills of the client		

Internal Locus of Control		External Locus of Control, Systemic Approach	
Domain	Explanation	Domain	Explanation
Self-Esteem/Self-Confidence	This includes positive feelings about the self as well as self-confidence or the degree to which they believe they will succeed.		
Coping Skills	Degree to which they possess appropriate coping skills to handle life's stresses and disappointments		
Goal-Directed Behaviors	Degree of goal-directed behaviors and thoughts, such as planning for college or a career		
Responsibility	Responsibility they demonstrate or accept, such as chores, jobs, initiation of responsible behaviors, and independence or self-reliant behaviors		
Self-Awareness	Degree of insight into their own selves, motivations, strengths and weaknesses		
Successes	Degree to which the client feels successful in his or her endeavors		

In addition, clinicians suggested having a relative rating system which would compare a child's progress to their own baseline, emphasizing the importance of considering relative progress. We suggest incorporating this relative improvement on a Likert scale for each item (see Figure 2) as well as following the USH pilot study's suggestion of including above average functioning in each area.

Severe	Moderate	Mild	Significantly improved	No Impairment	Above
0	1	2	3	4	5
Impairment	Impairment	Impairment	although still relatively impaired (perhaps approaching personal capabilities)		Average

Figure 2. Proposed Likert Scale for New SED Measure.

The focus groups, especially the mental health professional groups, provided specific suggestions for the design of a new measure which we advocate incorporating into a potential new measure. Both inpatient and outpatient clinician groups specifically

admonished receiving input from multiple informants from multiple disciplines for any outcome measure used with SED youth. Although they concurred that the client is a valuable resource and should be included as one of the informants, the client should not be solely relied on, as they sometimes lack insight into their dysfunction, are motivated to exaggerate their symptoms in a call for help or deny problems in hopes of an earlier release, or simply are poor historians. Besides the client and parents, focus groups suggested including input from teachers, psychologists, neuropsychologists, social workers, occupational therapists, and recreational therapists, as they can provide valuable insights into the client's current functioning. Therefore, we advocate using a system that would incorporate input from multiple constituencies that are involved with the child and can provide observations and not relying solely on self-report.

Since clinicians and teachers were also particularly concerned about ensuring that they have access to the results in order to best focus their interactions with that child, we recommend allowing all constituencies to both provide their observations and opinions in the evaluation and receive feedback about progress from such a measure. This can help improve communication across disciplines as well as potentially improve outcomes for these SED children. Several studies have demonstrated that providing feedback to therapists at least about the on-going progress or decline of their clients improves outcomes (Harmon et al., 2006; Hawkins, Lambert, Vermeersch, Slade, & Tuttle, 2004; Lambert, Hansen, & Finch, 2001; Lambert et al., 2002; Whipple et al., 2003). Therefore, it is likely that providing feedback to other mental health disciplines as well as teachers could also help improve outcomes. If such a global measure is designed to measure progress in all areas of functioning SED clients' lives, future potential research could

help determine whether providing feedback about global functioning to particular constituencies, such as teachers, actually does help improve outcomes.

Besides relying on multiple informants, clinicians were concerned about increasing their paperwork burden and requested that any new measure be fairly quick and straightforward to complete or administer and score. Independent raters, separate from the client's clinician, might help solve both this concern as well as including multiple informants, as they could utilize observations of the client as well as interviews with the client, treatment providers, parents, and teachers in an unbiased approach of measuring progress without increasing the clinician's paperwork burden. Administering such a measure every 90 days instead of once of week or every day would decrease the frequency burden, and using an independent rater to interview them rather than completing qualitative data forms would likely reduce the time burden on the clinician. However, there is the question of who the independent raters would be and the need to ensure inter-rater reliability. Alternative to using an independent rater, several groups suggested having a transition meeting; likewise it could be beneficial to have a meeting every 3-6 months during treatment as well as a transition meeting prior to discharge with all constituencies involved, including the parents and child, Various scoring methods could be utilized at such a meeting, such as having one person, perhaps an independent rater, calculate a final score, or voting for each item's score or taking an average of all participants' scores per item. Regardless, we recommend that anyone who scores such a measure undergo training that includes practice scoring in order to maximize inter-rater reliability.

In addition, we recommend having specific anchors for each age at each level of impairment for each item to improve inter-rater reliability and reduce confusing and time spent on such a measure by people providing inputs and evaluating progress. Clinicians mentioned some concerns about the difficulty distinguishing functional from dysfunctional behaviors, especially after extensive interactions with children and adolescents that have many impairments. Likewise, they mentioned the need to consider what would be developmentally appropriate for children of a particular age, so specific anchors by age would be particularly beneficial to take this into account, ensure that all raters have the same view of what would constitute level of impairment, and reduce time and confusion about each item. Without specific anchors for each impairment level, people are likely to be more arbitrary or subjective in their ratings.

Overall, we recommend incorporating the suggestions for domains, subdomains and items from parents, teachers, and mental health professionals; including all of these constituencies as well as the client in gathering information in order to evaluate progress; provide feedback about progress (allow access to results) to all parties involved, and design the measure in such a way as to enable both prediction of successful outcomes as well as evaluate effectiveness of treatment interventions. In addition, we recommend incorporating training, including practice and evaluations of rating, for the measure and age-based anchors within the measure to maximize inter-rater reliability,

Although, not directly related to the design of such a measure, we also recommend continuing follow-up after discharge in order to monitor long-term effectiveness of treatment about evaluate the measure's ability to accurately predict long-term success. This also relates to the broader need to improve communication among

care providers at each level of care and between levels of care, especially during transition periods.

Current recommendations for improving communication. We were gratified by the interest, enthusiasm, and participation received from treatment providers and teachers. They clearly care deeply about improving treatment and accountability, even of themselves. However, although both sides identified weaknesses in the current system and desired greater correspondence between the two sides, neither has made substantial efforts to change the status quo, and appear somewhat resigned to the current broken system although there is desire for improvement. Regardless of whether or when a new outcome measure is created, we highly recommend policy, administrative, and any practical changes necessary in order to improve communication across discipline lines and between previous and subsequent treatment providers, including schools. Ideally, patients' files could conveniently follow them throughout levels of care and they, or their parents, could specify who they want to have access to what specific parts. An electronic filing system may help facilitate this as access to various types of information could be granted to particular individuals or groups and could be made available to multiple service organizations and/or levels of care. Besides increased access to relevant information, there also needs to be increased collaboration within and among disciplines, including between the treatment team and school, as well as with the parents and patient themselves. Improving continuity of care has been touted in the literature, but practical recommendations of how to actually implement this are still sparse, especially in maintaining compliance with privacy laws, such as HIPAA.

Several groups also suggested having more transitional meetings to facilitate this. In addition, having one person who maintains a role of monitoring care of children as they move through different levels of various systems could help ensure that children do not fall through the cracks after discharge as well as help facilitate feedback back to previous treatment providers. Although case managers somewhat fulfill this role for children in state custody, a comparable role for children who are not in the state's is lacking. In addition, children that are released from state's custody also often lack continued follow-up and monitoring.

In addition, smoothing the transition for the client so that it is not so sudden could help the client and their families adjust and monitor if there are any setbacks. Perhaps continued check in with at least one person, such as a therapist for 3-6 months after discharge could help facilitate this process. Clinicians noted that sometimes clients become attached to individuals at residential centers, so a continuing some contact post discharge may be beneficial. Somewhat related to this issue, families and teachers also expressed some concerns about the institutional feel of a hospital compared to a home environment and felt that having more staff consistency and personal interactions, even allowing for some attachment, could be helpful for the children. Lastly, as families also complained about the difficulty providing activities on their own after discharge, perhaps family outpatient groups designed to aid in these types of transitions and allow for families to support each other could be useful.

Overall, in order to improve care and long-term outcomes of SED children and adolescents, there must be an increase in collaboration and communication. Creating a standardized and unified way of tracking outcomes and increasing accountability may be

able to facilitate this process, if all parties are able to provide input into the measure and receive feedback about the results. Besides improving the quality of life of these youth, improving outcomes and reducing recidivism can decrease the overall long-term cost of care across multiple service organizations, and is in the best interest of the client, their families, third party payers, and the community of tax-payers contributing to these services.