

REPORT ON TRANSITION-AGE YOUTH

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An Examination of Current Data Collection Procedures and Target Population Definitions Relevant to the Quality and Accessibility of Services for the Transition-Age Population

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EXECUTIVE SUMMARY

This study was designed to examine two state policies as they relate to the quality and accessibility of services provided by Community Mental Health Centers (CMHC) to Transition-Age youth in Kansas. Transition-age (TA) youth are defined as the population of mental health consumers, ages 16 to 26, who have needs for intensive community based support services in order to maintain stability during the period of transition from childhood to adulthood. The policies under review were

- **AIMS** (Automated Information Management System) data collection procedures along with the resulting CSR (Client Status Reports) and
- **Target Population definitions** for youth with serious emotional disturbance (SED) and adults with severe and persistent mental illness (SPMI).

The study focused on TA youth as a separate and distinct consumer population with unique service needs and treatment goals. Emotional/behavioral disorders or psychiatric symptoms create significant barriers for these youth as they negotiate the already challenging developmental tasks of transition to independence. TA youth are at increased risk of critical life disruptions such as: dropping out of school, facing unemployment, and lacking stable housing. The most effective programming for a TA population includes access to flexible and intensive community-based supports for the duration of the transition period. Development of independent living skills and acquisition of stable housing, employment or education, and needed social supports are key factors in maintaining stability for TA youth.

The primary research for this study consisted of a set of focused interviews with program staff at five CMHCs chosen for their interest in providing specialized transition services as well as demographic characteristics representing urban and rural communities across the state. Interview questions focused on the usefulness of AIMS data/CSRs for evaluating services to the TA population and the effect of SED and SPMI target population definitions on services to this group of consumers.

CMHC program staff interviews consistently indicated that the two state policies under review are problematic for use with designing high quality services that are accessible to Transition-Age consumers.

- AIMS data collection procedures are designed to track service quality through measurement of certain performance outcomes for the state's child and adult target populations. However, TA consumers' service needs and expected outcomes span both the child and adult data sets and neither of these adequately captures the specific data needed to assess suitable performance outcomes for the TA population.
- The disparity between the broadly defined SED criteria and the narrowly defined SPMI criteria is viewed as creating a significant service eligibility gap. As TA youth

age out of SED eligibility at age 18 or 22, they face the more restrictive SPMI criteria which can result in a denial of adult target population status and a resulting loss of Medicaid coverage for intensive supports just as they reach the critical time of transition to independence.

- The current Child and Adult CSR's were reported to have little value for local program improvement efforts for services to TA youth although that is one of the stated purposes for the data management system. A majority of CMHC staff indicated a desire for reports to include individualized data to allow tracking of outcomes for specific consumers, case management caseloads, or specific program caseloads.

Based on conclusions developed through a review of the pertinent policy documents and information gathered through interviews of CMHC program staff, the following recommendations were provided for consideration. The recommendations are presented as possible next steps in the process of developing strategies for supporting the provision of high quality services for Transition-Age youth in Kansas.

RECOMMENDATIONS REGARDING AIMS/CSR & TA YOUTH

1. Revise the AIMS data set to incorporate a set of "Client Status Fields" specific to Transition-Age consumers.
2. Develop a new CSR (Client Status Report) with a set of performance outcome measures specific to TA consumers.
3. Develop an AIMS/CSR training package to be provided to CMHC program staff to assist in the understanding and interpretation of CSR results and development of techniques for using the data for program improvement efforts.
4. Develop a data management program (such as "Workbench") allowing manipulation of individual consumer data to be made available for use by CMHC program staff with both children's and adult services.

RECOMMENDATIONS REGARDING SED/SPMI DEFINITIONS

1. Conduct a review of state policy relative to target populations' eligibility criteria for other states with records of high quality service to TA youth in order to identify alternative approaches to maximizing service accessibility and positive outcomes.
2. Establish an advisory council that would review the possibility of revising SED and SPMI target population definitions in order to ensure adequate service accessibility for transition-age consumers who are in need of intensive support services.

SECTION I. INTRODUCTION

This paper presents the results of a study designed to assess the value and appropriateness of state mandated data collection procedures and target population definitions utilized by Community Mental Health Centers (CMHCs) providing services to Transition-Age (TA) youth in Kansas. Transition-Age youth are defined here as the population of young mental health clients who have needs for intensive community based support services and who are at an age of transition from childhood to adulthood. The ages typically referred to throughout this study ranged from 16 to 26.

Transition-Age youth with serious emotional disorders or severe psychiatric illnesses have long been identified as a difficult to serve population. Information from youth and families, service providers, and literature reviews (see Appendix A) indicates that TA youth form a separate and distinct population with unique service needs and treatment goals based on their developmental needs at this stage of their lives.

- **TA youth face significant barriers in negotiating the already challenging developmental tasks of transition due to the limitations caused by their emotional and behavioral disorders or psychiatric symptoms.**
- **During the transition period, TA youth are at increased risk of critical life disruptions such as dropping out of school, facing unemployment, and lacking stable housing.**
- **In order to effectively address the needs of a transition-age population, services must include flexible and intensive community-based assistance with key developmental tasks such as developing independent living skills, completing educational goals, acquiring stable housing, obtaining employment, and developing needed social supports.**

The effects of state information management procedures and target population definitions on the quality and accessibility of specialized services for the TA population were the focus of this study. **The state's Automated Information Management System (AIMS) is designed to track service quality through measurement of certain performance outcomes for the two state target populations:** children with serious emotional disturbance (SED) and adults with severe and persistent mental illness (SPMI). Data collected for these two populations is separated into two unique sets of data fields determined to be appropriate for each population (See Appendix B). However, TA consumers' service needs and expected outcomes are likely to span both the child and adult data sets. Therefore, neither of the existing target population data sets may adequately capture the data specifically needed to assess performance outcomes for the TA population. This study undertook a review of this data collection and management issue.

Accessibility to transition focused services can also be problematic for TA consumers due to the disparity between eligibility criteria for the two “targeted populations”. The state’s definitions for Serious Emotional Disturbance (SED) for children and Severe and Persistent Mental Illness (SPMI) for adults (see Appendix B) define the target populations eligible for Medicaid coverage of intensive support services such as case management, psychosocial rehabilitation groups, and community-based wrap around services. The SED criteria are considered to be much more broadly defined than SPMI, resulting in a large gap in service eligibility between the two target populations. State policy sets the time of expiration of SED eligibility based on age rather than on the developmental needs of the youth. As they age out of SED service eligibility, TA youth face the more restrictive SPMI criteria which can result in a denial of eligibility for the adult target population and a resulting loss of intensive supports just as they reach the critical time of transition to adulthood. This study included a review of the effects of the current SED and SPMI definitions on the availability of appropriate services for the TA population.

SECTION II. RESEARCH ACTIVITIES

The two primary research activities utilized in this study were: 1) a review of the state documents pertinent to this evaluation, and 2) interviews with CMHC program staff to obtain their views regarding the strengths and weaknesses of the state's target population policy and information management procedures relative to their provision of service to TA youth. Previously completed literature reviews (See Appendix A) were also utilized for this study in order to identify the particular risks, needs, service barriers, and other issues common to the provision of service to a transition-age population.

DOCUMENT REVIEWS

The documents reviewed for the study were the state's Automated Information Management Systems (AIMS) Manual, the Children's and Adult Client Status Reports (CSR) produced quarterly by the University of Kansas based on AIMS data, and the state's "target population" definitions for Serious Emotional Disturbance (SED) and Severe and Persistent Mental Illness (SPMI) included in Appendices E and F of the AIMS Manual (See Appendix B). The AIMS/CSR review included an analysis of the volume and relevance of the information that is currently collected and reported specifically to assess service quality for the TA population. A comparison of the SED and SPMI definitions was conducted in order to assess their policy implications for continuous service accessibility for the transition-age population.

AIMS: The state of Kansas developed AIMS through the assistance of a federal MHSIP (Mental Health Statistics Improvement Program) grant designed to assist states to develop comprehensive information management systems for use in evaluating mental health services. AIMS is a resource utilized by both the state and CMHCs for many purposes, including quality improvement. The state's AIMS process was finalized and data collection began in September 2002. The current version of the AIMS Manual, "AIMS_V3.0," was reviewed for this study. The AIMS data set includes 85 data fields. Information designed to assess specified critical outcomes for the state's child and adult target populations is incorporated within the sections titled "client status fields" (See Appendix B). The AIMS data set also includes a general section for demographic information and a "service encounter/screening data" section capturing service use data. An AIMS Oversight Committee continues to meet to advise the state regarding operation of the AIMS process. A set of revisions to the AIMS data set recommended by this committee were implemented in 2005.

CSR: Information from the two target population sections of the AIMS data set ("Adult Client Status Fields" and the "Children/Youth [SED] Client Status Fields") is utilized in the preparation of Client Status Reports (CSR). Data extracted from these sections are forwarded quarterly to the KU for preparation of two reports describing statewide and individual CMHC results relevant to a set of specified outcomes. State policy sets performance outcome goals deemed appropriate for each target

population. The CSRs present CMHC results for the targeted outcome categories and include statewide averages for comparison purposes.

SED and SPMI target population definitions: The state sets criteria for determination of “target population” status for two groups of mental health consumers considered to be most at risk for substantial disruption of normal life activities without the assistance of an intensive array of community-based supports. SED criteria are age-based and restrict SED eligibility to children under the age of 18 or under the age of 22 if they have been receiving mental health services prior to the age of 18 that must be continued for optimal benefit. The SED definition is based on broad diagnostic and functional criteria that include a large array of mental, emotional, and behavioral disorders. In contrast, the adult SPMI definition is based on strict diagnostic criteria limited primarily to a small set of psychotic and mood disorders as well as restrictive functional criteria that additionally limits eligibility (See Appendix B).

CMHC STAFF INTERVIEWS

A set of interviews was conducted with program staff at five selected CMHCs in order to gain their perspective regarding the study questions. The CMHCs included in the interviews were selected based on demographic characteristics as well as their interest in providing specialized transition services. Three of the CMHCs were located in larger urban communities and two in smaller more rural communities. Geographic regions included northeastern, southeastern, central, and western areas of the state. Two of the large programs provide a formal set of transition services through their adult community support services (CSS) programs. The other three programs provide transition services through less formal approaches but do identify staff members whose duties include a focus on the needs of TA youth in their children’s community-based services (CBS) and/or CSS programs.

CMHCs selected the program staff to be interviewed based on their relation to the provision of formal or informal transition services provided at each agency. Staff at the following levels participated: program director, supervisor and direct service. Interview questions were designed to elicit information about the service providers’ use of the documents and procedures described above and their perspectives regarding the value of those documents as it pertains to their work with TA youth. Interviews were conducted in the winter and spring of 2006. **Interview questions fell into the following categories:**

1. How are AIMS data and CSR reports currently being used by staff involved with transition-age services at your agency?
2. What problems have you encountered with the use of AIMS and CSRs for the TA population?
3. What changes are needed in the AIMS data set and/or the CSR reports to make them more useful for the transition-age population?
4. What service or administrative problems have you encountered with the use of the SED and SPMI target population definitions in working with TA youth?
5. In what ways would you like to see the SED and/or SPMI definitions changed to make them more helpful in serving the TA population?

SECTION III. RESEARCH RESULTS

This section describes the opinions and recommendations obtained from CMHC program staff during the interview process. The information obtained is grouped into categories relevant to each of the interview questions described above. A number of themes consistently emerged from interviews conducted across the state as well as some opinions that seemed to be more specific to one or two agencies or individual staff. The major themes are presented below. Any opinions that were specific to only a few interviewees are identified by language in the text. *(Note: Information from the document review analyses is included within the discussion of conclusions in Section IV of this report.)*

1. HOW ARE AIMS DATA AND CSR REPORTS CURRENTLY BEING USED BY STAFF INVOLVED WITH TRANSITION-AGE SERVICES AT YOUR AGENCY?

The majority of program staff interviewed indicated that the primary use for AIMS (Automated Information Management System) data and CSRs (Client Status Reports) is to review their agency's compliance with state contract requirements for performance outcomes.

- Interviewees indicated that CSR results are primarily reviewed by program managers or supervisors and most often are not distributed to case managers, although one large urban agency did report routine discussion of the CSR at the case management team level. The majority of staff interviewed described the CSR as not being useful at the direct service level because it does not allow tracking of individual consumers' progress.
- A number of interviewees expressed the opinion that the AIMS data system is driven by state contract requirements rather than program needs. Many staff indicated that CSRs have limited value for local quality improvement efforts although that is listed in the AIMS Manual as one of the data collection purposes (See Appendix B).

Management and supervisory staff gave mixed reviews as to the usefulness of CSRs as a management tool.

- In general, the smaller rural programs without a formal TA (Transition-Age) services program did not indicate use of the CSR for any specific management purposes relative to this population.
- About half of the staff interviewed at larger urban agencies with more formalized TA services programs reported using CSRs for one or more evaluation purposes at the management level. One large agency reported use of CSR results to focus the development of program improvement plans in a specific outcome area related to the general population of adults, not specifically to TA consumers.

- Program supervisors and team leaders reported that CSRs would be more useful if information was available at the team level as opposed to the agency as a whole. CSRs that are not specific to TA consumers were not viewed as being useful.
- Some program managers expressed appreciation for the opportunity the CSR affords to compare their agency's outcomes to those of other agencies and to state averages. These comparisons were reported to assist with identification of areas in need of improvement.
- A few programs indicated a desire for more education and training regarding the interpretation of and use of CSR reports in their own program development and evaluation efforts.
- Several supervisory staff indicated that while they do not view the agency-wide CSR reports as useful to case managers, they do see the process of entry of AIMS data as being a good opportunity for a monthly status check on important indicators for each consumer. At many programs, case managers either entered their own caseload AIMS data or met with their team to update AIMS data together. These monthly team data entry meetings allow for updates and discussion about the current consumer statuses and service needs.

2. WHAT PROBLEMS HAVE YOU ENCOUNTERED WITH THE USE OF AIMS DATA AND CSRs FOR THE TRANSITION-AGE POPULATION?

Program staff identified a number of difficulties reporting and using AIMS data for Transition-Age youth. Reporting for these consumers is complicated by the fact that they are sometimes included within the children's AIMS data set and sometimes within the adult category.

- Programs housed within adult CSS services often had to complete different AIMS forms for youth on their caseloads depending on their age. Since the child and adult AIMS client status data sets are different, this poses problems for coherent analysis of the resulting reports as they relate to TA consumers.
- For programs housed within children's services, generally only children's AIMS client status data is reported since TA youth leave children's services at age 18 or 22. However, there were several issues consistently identified as problematic with the children's AIMS data set as it applies to older youth. Several staff expressed the opinion that some adult AIMS client status fields would be more appropriate for TA youth.

A majority of programs reported difficulty in using CSR information that refers to the entire agency's child or adult service programs and is not specific to Transition-Age youth.

- Due to the unique role changes and developmental tasks specific to this age group, TA consumers are viewed as having service needs and indicators of success that are different than those of younger children or older adults. Therefore, neither the

Child nor Adult CSR was viewed as being particularly useful for this population. Although the Child CSR has limited TA information, it is not viewed as sufficient.

It was widely reported by interviewees that a number of data categories on the Child AIMS data set are of questionable value for TA youth.

- CBCL (Child Behavior Check List) scores were often viewed as being cumbersome to obtain and of limited relevance for TA consumers.
- Residential status definitions such as “permanent home” were viewed as being a poor fit for older youth who may be living independently.
- AIMS fields related to school information were often reported to be of limited value for older youth who are not in school or may be involved in post secondary educational activities that are not specified on the child AIMS data set.
- The child AIMS data set does not report vocational information other than supported employment. It was reported that many TA youth are working at independent jobs and this information is not captured in the children’s data set.
- Contacts with law enforcement are included on the Child AIMS data set, but are not reported in the same manner in the adult data collection and are not part of adult performance outcomes.

There were several problems identified with the CSR report format and process.

- A number of staff indicated that the CSRs come too late to be useful for internal program purposes. *(Note: AIMS data is reported to The Consortium by CMHCs monthly, but the data is transferred to KU quarterly for the preparation of CSR reports. The CSR generally reaches CMHC program director staff near the middle of the following quarter.)*
- Interviewees at several agencies indicated that CSR reports are difficult to understand and that education and training are needed to assist staff to interpret and use CSR results.

A majority of staff interviewed indicated a desire for the reports to include more specific or individualized data. Interviewees who were familiar with the development of the “Workbench”¹ concept expressed a desire to have that data management capability available to their programs.

¹ “Workbench” is a data management program developed by the University of Kansas for mental health center staff who use AIMS data. The Workbench program allows staff to manipulate AIMS data to answer questions related to individual consumers or specific groups of consumers. It has only been developed for use with the Adult AIMS data set at this point and is not yet in use at most CMHCs. Updated information for use with the Workbench is distributed to all Kansas CMHCs quarterly. However, KU is currently in negotiations with SRS to supply CMHCs with updates on a monthly basis.

3. WHAT CHANGES ARE NEEDED IN THE AIMS DATA SET AND/OR CSR REPORTS TO MAKE THEM MORE USEFUL FOR THE TRANSITION-AGE POPULATION?

There were two large themes emerging from the program staff interviews that were consistent across all programs:

- **Staff at all of the programs interviewed indicated a need for a separate CSR specific to Transition-Age consumers.** Some interviewees reported they would still like to receive the current Child and Adult CSRs but would like an additional report that pulls pertinent information together from each of those reports for the TA population. However, a number of staff indicated a need for changing and/or adding new AIMS data fields to create a set of information relevant to TA youth that is not currently captured through existing data. This implies that a new section of data specific to TA youth would need to be developed for AIMS. It was recommended that criteria for inclusion in the new section should be age in the transition range rather than a “Chronicity” category of SED or SPMI. The ages recommended for inclusion in the TA definition ranged from 14 to 16 at the low end, to 25 or 26 at the upper end.
- **A second desire for change that was consistently reported at all programs was the need for a data management and reporting process that allows tracking of individual consumer information.** Staff stated repeatedly that the AIMS data would be much more useful at the program level if it could be reported back to them in such a way that case managers could track progress of individual consumers on their caseloads. Supervisors and program managers also reported that an ability to review trends and answer specific questions related to individual caseloads under their supervision would be more useful to them than the general program-wide information they currently receive through existing Child and Adult CSRs.

In addition to the two overall themes described above, there were a number of recommendations for changes and additions to the existing AIMS fields in order to more closely capture the information relevant to a TA population. The changes described were based on the existing AIMS fields in the SED child and SPMI adult client status field categories.

Recommendations from a majority of programs interviewed included items relevant to the goals of independence in four major outcome areas seen as critical for TA youth:

- **Employment** – The current Child AIMS data set does not include employment information other than whether or not the child participates in “supported employment.” Interviewees reported that many TA youth still in children’s services are independently employed, and they would like to see a vocational status field for the TA population that includes all of the options currently included in the Adult AIMS “current vocational status” field regardless of where they are receiving services. One program also recommended that “work/study” be added as a vocational status category.

- **Residential** – Currently the AIMS residential fields for children and adults are different. The “current residential setting” categories listed for children include “permanent home” (meaning the child lives with their parents) as the preferred outcome. However, many interviewees reported that TA youth still receiving SED services may more appropriately fit into the residential categories for adult AIMS where “independent living” is the preferred status. It was suggested that development of a new residential status category for the TA population could include a range of options encompassing both child and adult statuses that are relevant.
- **Education** – Many TA youth are no longer in regular K-12 education, which is the focus of a number of AIMS fields included in the Child CSR. Several interviewees recommended the option to skip those fields for TA youth for whom they do not apply. The Adult AIMS field of “current educational status” which includes vocational training and additional post-secondary educational categories more closely fits the TA population. Some programs also recommended additional categories such as computer based high school diploma programs.
- **Social Supports** – The majority of program staff interviewed indicated that social supports are a critical factor in helping TA youth to maintain stability, yet there are no AIMS fields currently addressing this issue for either children or adults in the target populations. Program staff at several agencies recommended that a category capturing the number of social supports available and some idea of frequency of social contacts be added to AIMS for this population.

A number of other additions to the AIMS data set were suggested by individual program staff. Some of the recommended changes related to data that is currently collected through the AIMS process but is not included in Adult or Child CSRs.

- Several program staff indicated they would like to receive service utilization and diagnostic data in order to compare service use, diagnosis, and outcomes and track trends in associations between these categories. *(Note: Diagnosis data is presently collected in the demographic section of the AIMS data set and service utilization data is collected through the service encounter section, but this data is not reported through CSRs.)*
- Some program staff stated they would like to be able to track the number of crisis interventions and hospital diversions for the TA population. *(Note: While this information is not reported through the CSR process, it may be available to CMHCs through other channels such as reports prepared by The Consortium, the agency managing the AIMS data set.)*
- Some program staff indicated a desire to track information regarding the reasons that TA youth leave service. *(Note: The existing Child CSR format includes a section regarding “Exit from Case Management Statistics” that reports “Reason for Case Management Stop”. The Adult CSR format also reports “Reason for CSS Stop” each*

quarter. It is unclear whether this information is not considered to be sufficient or whether interviewees were unaware that it is currently included in CSRs.)

- Other additions to AIMS recommended by a few staff included tracking use of resources such as natural supports or other community program services utilized by TA consumers. Examples mentioned included income resources such as SSI, transportation resources, and other disability services such as MRDD service. Some staff also mentioned wanting to track the need for specific services such as alcohol/drug services or money management skills training. *(Note: While this information is likely to be included on individual treatment or goal plans, it is not currently being captured through AIMS.)*
- A final desire expressed by a number of program staff was for more information in CSRs tracking trends over time. Recommendations ranged from two to six quarters. Interviewee suggestions indicated that this type of information would be useful both at the program and the individual consumer level. *(Note: While the Child CSR cover memo includes some trend information and individual mental health center comparisons to the previous quarter, this is apparently not viewed as being sufficient to meet the program needs.)*

4. WHAT SERVICE OR ADMINISTRATIVE PROBLEMS HAVE YOU ENCOUNTERED WITH THE USE OF THE SED AND SPMI TARGET POPULATION DEFINITIONS IN WORKING WITH TRANSITION-AGE YOUTH?

It was consistently reported across all programs interviewed that the current state target population definitions for Serious Emotional Disturbance (SED) and Severe and Persistent Mental Illness (SPMI) pose barriers to appropriate service provision to the population of TA youth.

- The SPMI definition is considered to be much more narrow and restrictive than SED. It was reported by one large urban children's service program that only about 25% of children in their program are expected to meet eligibility criteria for SPMI when they age out of SED services.
- Program staff indicated that the need for case management and other intensive services is expected to continue beyond the SED age limits for many TA youth. Since eligibility for Medicaid reimbursement for these intensive services is dependent upon meeting target population criteria, this means that many children lose medical coverage for their most needed services just as they reach a critical age of transition.

There were several issues that were consistently cited by program staff at all agencies as being problematic with the SPMI eligibility criteria for TA youth needing intensive supports.

- Many youth aging out of SED services (usually between ages 18 and 22) have behavioral or developmental diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), or Pervasive Developmental Disability (PDD) that are specifically excluded from meeting the SPMI definition.
- Diagnosis can be particularly difficult to assess for transition-age youth since they are just entering the typical age of onset for many SPMI eligible diagnoses. Youth at this age are also generally entering a very stressful period of significant life transitions that can exacerbate existing behavioral or emotional problems and can further complicate diagnosis.
- Functional and risk factor criteria - required in addition to a Category B diagnosis in order to meet the SPMI definition - are difficult for TA youth to meet. If the TA consumers who have been receiving intensive SED services have not been hospitalized or incarcerated in the past six months, they will not receive the necessary points to meet risk factor criteria. The criteria do not take into account the risks associated with discontinuing intensive services and supports that may be lost as the TA consumer ages out of SED service.

5. IN WHAT WAYS WOULD YOU LIKE TO SEE THE SED AND/OR SPMI DEFINITIONS CHANGED TO MAKE THEM MORE HELPFUL IN SERVING THE TRANSITION-AGE POPULATION?

Staff at several programs interviewed reported that they continue to serve TA youth who have aged out of SED services without reimbursement for as long as they can to attempt to help them reach a point of stability. However, these are viewed as stop gap measures that cannot adequately address the problem of limited access to the most appropriate services for TA youth who do not meet SPMI criteria. Interviewees at all programs reported this is a significant point of failure of the current system configuration.

The following measures were suggested by program staff to address the service accessibility gap for TA consumers:

- Functional and risk factor criteria that are specific to the unique circumstances and needs of TA youth aging out of the SED target population could be added to the SPMI definition.
- Behavior disorders could be included in the “Category B” diagnoses on the SPMI definition.
- The age limits for meeting SED criteria could be expanded beyond age 22 as this age is often premature for making SPMI diagnoses.
- The state could change target population definitions so that youth who have been members of the SED target population as children could automatically qualify as

members of the adult target population if they still need intensive support services when they reach the age of transition.

SECTION IV. CONCLUSIONS

This study confirmed that in Kansas, as well as nationwide, the population of Transition-Age (TA) youth with serious emotional disorders or severe and persistent mental illness is recognized by service providers as a distinct population with unique service needs. It is widely reported that failure to adequately respond to these needs can result in an array of social problems and significant life disruptions for this population. Study participants expressed strong opinions regarding the effects of two state policies - AIMS and target population definitions - on the quality and accessibility of specialized services for their TA consumers.

- **Focused interviews with staff at five rural and urban CMHC programs across Kansas yielded a set of consistent themes. The results clearly indicate a pervasive dissatisfaction with target population policies as they relate to services for Transition-Age youth, specifically the limitations of the current SED and SPMI definition. In addition, the current data reporting processes are seen to be of limited use with the TA population.**

CMHC program staff recognized that AIMS data collection and reporting is necessary for the state to track compliance with CMHC performance contracts and is also a useful measure for comparison of their own general program outcomes to statewide results. A number of staff interviewed also indicated that their own AIMS data entry process is a valuable opportunity for a monthly status check on important indicators for each of their consumers. However, the AIMS data set configuration and Client Status Reports (CSR) prepared from AIMS data were reported to have little value for program managers responsible for evaluating the quality of their services targeted to TA consumers.

Target population definitions for SED and SPMI were also reported to be problematic and were viewed as posing a barrier to service accessibility for SED youth who are aging out of children's services. The majority of SED youth are believed to need intensive support services during their transition to adult status and independence. However, the age limits on SED eligibility and the restrictive nature of adult target population criteria are thought to severely limit the percentage of SED youth who can qualify for the continued intensive supports that they need in order to maintain stability through their transition process.

The major themes emerging from the CMHC interview responses are summarized below and are followed by conclusions based on the interview results and analysis of the relevant policy documents.

AIMS/CSR & TA Youth

SUMMARY OF MAJOR RESPONSE THEMES

- The majority of CMHC staff interviewed did not view AIMS data and CSRs as being useful management tools for evaluating or improving their services to TA youth.
- The current configuration of AIMS data into Child (SED) and Adult (SPMI) sections for “client status” evaluation was consistently reported to be problematic and inadequate for appropriately assessing the status of TA consumers who are in an age range that spans both populations.
- Due to their unique developmental tasks and service needs, the lack of a CSR with outcomes specific to TA consumers was reported to be a significant barrier to the effective use of AIMS/CSR data for local program purposes.
- A majority of staff interviewed expressed a desire for reports that display data specific to individual consumers, something that the current CSR process cannot provide.
- Interviewees consistently recommended a revision of the AIMS data set to incorporate fields that would more closely capture the information most relevant to a TA population.

CONCLUSIONS

- 1. A review of the AIMS Manual and CSR report process supports the position that these information management procedures are not effective as management tools for the purpose of development of high quality services specific to the needs of TA consumers.**

The majority of TA youth meeting the target population definitions are being served through Children’s SED services. Data collection for these TA consumers is required through the “Children/Youth (SED) Client Status Fields” in the AIMS data set. However, the focus of the SED fields is often not appropriate for older youth who are transitioning out of children’s home and school settings.

The SED client status fields are heavily focused on K-12 educational statuses and a family focused residential outcome. The Children’s CSR currently reports performance outcome measures related to the goals of “permanent home” (with family), “A, B, or C grades,” and “Regular Attendance” (at K-12 school). However, TA youth (typically ages 16 to 22) in children’s services are generally in the process of leaving the K-12 school system and are in transition to post-secondary educational experiences, vocational training or employment, and independent living. As a result, the AIMS data reported through the Children’s CSR have limited value for tracking the outcomes that would be appropriate indicators of success for the TA population.

- 2. Adequate assessment of program performance for TA youth is dependant on the collection and reporting (e.g., CSR) of AIMS data specific to the TA age group. The Transition-Age CSR should incorporate a set of outcome measures relevant to the employment, residential, education, and social support goals reported by CMHC program staff to be critical for this population.**

The Children's CSR currently provides an outcome measures table specific to "Transition Age Children (Ages 16 and Over)"; however, this table reports the same outcome measures as the other children's services tables and is not an adequate measure of success for TA consumers. The Adult CSR does report outcomes measuring more appropriate levels of independence in residential, vocational, and independent living statuses, but it does not include the social support outcomes recommended by CMHC program staff and it does not report outcomes specific to TA consumers. Therefore, neither of the CSR formats currently available is suitable for use in evaluating program performance specific to the TA population.

SED/SPMI

SUMMARY OF MAJOR RESPONSE THEMES

- All programs participating in the interviews reported that the disparity between state target population definitions for SED and SPMI poses a significant barrier to provision of appropriate services to youth in transition.
- Program staff indicated that the majority of youth aging out of SED service would continue to need intensive supports, such as case management, in order to make a successful transition to adulthood; however, estimates of the percentage of these youth who would meet criteria for the adult target population were as low as 25%.
- SPMI eligibility criteria are reported to be problematic for TA youth due to several factors:
 - Many SED youth have behavioral or developmental disorders that are specifically excluded from SPMI criteria.
 - Diagnosis can be particularly difficult to assess for TA youth as they are just entering the typical age of onset for many of the SPMI eligible diagnoses. SED upper age limits (18 to 22) are considered to be too low as this age is premature for making an SPMI diagnosis.
 - Youth who have been receiving intensive SED services may have difficulty meeting the SPMI functional criteria requiring recent hospitalization or structured residential care.

CONCLUSIONS

A review of the SED and SPMI definition criteria supports the CMHC staff assessment that the two definitions do not utilize a uniform standard of impairment for target population eligibility among the child and adult criteria.

Due to the limited number of eligible diagnoses and more restrictive functional criteria, the SPMI definition establishes a much higher threshold of impairment than the more broadly defined SED criteria. While the SED definition allows inclusion of virtually any mental, behavioral, or emotional disorder in the DSM (excluding substance abuse), SPMI criteria is primarily limited to psychotic or major depressive disorders. Behavior disorders which are extensively represented in the SED population are specifically excluded from SPMI criteria. In addition, diagnostic assessment for SPMI can be particularly difficult for transition-age youth as they are just entering the typical age of onset for some of the primary diagnostic categories.

In addition to the restrictive list of eligible diagnoses, SPMI criteria requires the existence of a severe level of impairment as evidenced by meeting a detailed set of functional and risk factor criteria. These criteria can be difficult for TA youth to meet if they have been receiving intensive SED services and have not been hospitalized or incarcerated in the past six months. SED functional impairment criteria state that children who would have met functional impairment criteria without the benefit of treatment or other support services are included in the definition. However, the SPMI criteria do not take into account the risks associated with discontinuing intensive supports that may be lost as the TA consumer ages out of eligibility for SED service.

SECTION V: RECOMMENDATIONS

Based on the conclusions described above, the following recommendations are presented for consideration. It is understood that the procedures for revision of state policy are complex and must take into account an array of financial, political, and resource limit factors that were not reviewed in the context of this study. The recommendations outlined below are presented as possible next steps in the process of developing strategies for supporting the provision of high quality services for transition-age youth in Kansas.

AIMS/CSR & TA Youth

- 1. Revise the AIMS data set to incorporate a set of “Client Status Fields” specific to Transition-Age consumers.** Completion of the “TA fields” would be based on age in the transition range in addition to “Chronicity” status. Development of the new TA field set and parameters for its use should be accomplished with the assistance of an advisory group composed of CMHC program staff and others with expertise in the provision of appropriate services to TA youth.
- 2. Develop a new CSR (Client Status Report) with a set of performance outcome measures specific to TA consumers.** The new TA – CSR would be based on data from the fields determined to capture the information most relevant to TA youth. Development of the new report format should be accomplished with the assistance of the advisory group described above.
- 3. Develop an AIMS/CSR training package to be provided to CMHC program staff.** The training would be designed to assist in the understanding and interpretation of CSR results as well as techniques for the effective use of AIMS and CSR data for program improvement efforts.
- 4. Develop a monthly data management program (such as “Workbench”) to be made available for use by CMHC program staff with both children’s and adult services.** The data management program would allow manipulation of AIMS data for review of individual consumer progress and other functions useful for program improvement efforts.

SED/SPMI Definitions

1. **Conduct a review of state policy relative to target populations' eligibility criteria for other states with records of high quality service to TA youth.** Such a review could inform state policymakers about alternative approaches to maximizing service accessibility and positive outcomes for TA youth.
2. **Establish an advisory council that would review the possibility of revising SED and SPMI target population definitions in order to ensure adequate service accessibility for transition-age consumers who are in need of intensive support services.** The advisory council should include CMHC program staff and others with expertise in the provision of appropriate services to TA youth. The research results outlined in this and other pertinent studies could be utilized as a resource for advisory council deliberations.

APPENDIX A

**Literature Review
from**

**Transition-Age Youth in the Kansas Mental Health System:
An Examination of Services, Programming, & Policy**

University of Kansas School of Social Welfare
Office of Child Welfare and Children's Mental Health

Gail Zukav-Ross, M.S., Young Joon Hong, Alexander Barket,
Ronna Chamberlain, Ph.D, & Susan K. Corrigan, Ph.D.
June, 2006

Transition-Age Youth in the Kansas Mental Health System: An Examination of Services, Programming, & Policy

LITERATURE REVIEW

The Transition-Age (TA) group is unique and distinct from either childhood or adulthood in its essential characteristics of changeability. Embedded within the TA population is an additional developmental period which is distinctly neither adolescence nor adulthood. This unique developmental period between the ages of 18 and 25 had been termed “emerging adulthood” by Arnett (2000). This period is marked by profound change, a time when, “...many different directions remain possible, when little about the future has been decided for certain, when the scope of independent exploration of life’s possibilities is greater for most people than it will be at any other period of the life course” (p. 469). It is a time during which experimenting with social roles, which began in adolescence, continues and intensifies. By the time youth have reached their mid-twenties, most have made life choices that carry enduring ramifications, and when adults look back at the more important and pivotal events of their lives, they often name ones that took place during these years (Martin & Smyer, 1990)

Due to the experimental and exploratory quality of emerging adulthood, it is the only period in life for which there are few demographic norms (Rindfuss, 1991; Wallace, 1995). This fact carries powerful implications for flexibility in philosophies of service delivery, programming, funding, and characteristics of service providers who wish to work successfully with this population. Arnett (2000) agrees indicating, “*Amidst this diversity, perhaps the unifying feature of the residential status of emerging adults is the instability of it*” (p. 471).

Youth with SED or SPMI face many challenges as they transition from childhood to adulthood (Pullman & Koroloff, 2004). They are at high risk for dropping out of school (Blackorby & Wagner, 1996; Pullman & Koroloff, 2004) and are more likely to face unemployment (Blackorby & Wagner, 1996), criminal involvement (Davis & Vander Stoep, 1997), depression (Reinherz, 2003), anxiety, and substance abuse (Davis & Vander Stoep, 1997). Additionally, difficulties developing independent living skills may be compounded for youth who do not complete their education and do not have work experience (Davis, 2003). When youth with emotional and behavioral difficulties are able to obtain jobs, their earnings tend to be slightly more than minimum wage and employment is often less than fulltime, which leaves them in poverty (Davis & Vander Stoep, 1997). In addition, this population has difficulty accessing stable housing (Collins, 2001), health services, mental health services, and other supports that could promote their successful transition into adult roles. Without financial self-sufficiency, transition age youth are at great risk of homelessness and dependency on public assistance once they leave the school system (Davis & Vander Stoep, 1997; Doren, Bullis, & Benz, 1996; Way et al., 1997).

As in other stages of life, it is reasonable to expect that needs which emerge during the transition from childhood to adulthood may find expression in problematic behavior if they are not met. According to Walker (2001) and Davis (2003), if transition needs cannot be met through family and/or community services, they will be met through the justice system and the welfare systems in far more expensive ways in terms of human and financial costs.

With somewhere between one to three million youth of transition age in the U.S. (Davis & Sondheimer, 2005), this problem is not an insignificant one.

Kansas is not alone in its struggle to provide adequate services to its TA population. Specialized assistance for youth with disabilities, who are transitioning from all public service systems, has been quite limited (Davis, 2003). More recently, Davis and Sondheimer (2005) reported that our state child mental health systems and/or special education services fail to prepare many youth for the tasks of adulthood. Historically, youth who age out of children's systems have reported nation-wide that the services they require are unavailable or undesirable (Evans, Huz, McNulty & Banks, 1996; Greenbaum, 2000, Silver, 1995).

Nationally, neither the child nor the adult public mental health system is designed to provide the support needed by TA youth as they move toward independence (Davis, 2003). Referencing Knitzer's 1982 term for children with emotional or behavioral difficulties, "unclaimed children," Vander Stoep, Davis, and Collins (2000) state that a *"major oversight continues to be the plight of those children at the upper age range of childhood who are about to lose their entitlement to participate in these improved systems of care. Transitional youth are today's unclaimed children"* (p.22).

There are several policy issues and system barriers to providing transitional services to youth. Eligibility is often based on age rather than developmental needs, and services are often available only after failure has occurred (Vander Stoep et al., 2000). The divergence between the child and the adult mental health systems, especially in regard to eligibility, can lead to significant problems. According to Vander Stoep et al. (2000), *the strict diagnostic eligibility criteria for access to adult mental health services bar entry of the majority of youth with emotional or behavioral difficulties who are cared for in the children's mental health services system* (p.21). In addition, neither the adult system nor the children's system receives funding specifically for this population. The children's system does not have the comprehensive services in place for moving to adulthood and the adult system is focused on serving those with the most severe needs. Moreover, while the adult system may have services that the children's system does not; the focus is on rehabilitation versus habilitation. In addition, the programming in which the supports are provided is often not appealing to young adults (Vander Stoep et al., 2000).

Based on the developmental needs of this population, the most effective services are relevant to the age group and allow young adults to develop their identity and balance their need to take responsibility while recognizing their limited skills and knowledge (Davis, 2003). Bridgeo, Davis, and Florida's (2000) guidelines for engaging the TA population include an approach which

- respects the youth's individuality,
- encourages choice,
- is flexible,
- is based on a firm understanding of the adolescent developmental state,
- encourages autonomy and the development of responsibility,
- engages youth at their convenience and on their turf,
- encourages staff to become advocates and teach self-advocacy,
- promotes family involvement while respecting young adults' choices, and
- focuses on the positive and stresses a sense of humor.

Based on effective practices used by a number of promising transition programs, Clark, Deschenes, and Jones' (2000) developed a framework for service provision for TA youth. The Transition to Independence Process (TIP) includes four transition domains: employment, education, living environment, and community life. The authors also developed guidelines for work with TA youth. Under the TIP program, services and supports are

- person-centered and driven by the young person's interest, strengths, and cultural and familial values,
- tailored for each youth individually and encompass all above mentioned transition domains,
- coordinated to provide continuity from the young person's perspective,
- a safety net provided by the young person's team,
- designed to enhance the youth's competencies, which results in greater independence, and
- outcome driven.

The guidelines cover a number of skills and areas of intervention that should be included in services for TA youth. The skills development areas include work with social problem solving, daily living skills, and relationship skills. Areas of focus for intervention include health, regulation of emotions and behavior, and substance abuse. Finally, areas of focus for increasing knowledge include sex education, safety, community resources, transportation, cultural/religious resources, and leisure.

Overall, effective services focused on both the developmental and clinical needs of TA youth. From the review of the literature on young adults in transition, the following services were noted to be necessary for a comprehensive transition program: mental health services, case management, housing, employment, vocation and educational services, independent living skills, social needs and relationship skills, recreation, crisis services, advocacy, and substance use/abuse services (Davis & Vander Stoep, 1996; Davis & Vander Stoep 1997; Delman & Jones, 2002).

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APPENDIX B

Selections from the AIMS_V3.0 Manual Published June 27, 2005

- **Introduction to AIMS**
- **AIMS Data Requirements Based on Registration Enrolled/Targeted Reporting Population**
- **Appendix E – Criteria for Serious Emotional Disturbance (SED)**
- **Appendix F – Method to Define Adults with SPMI**

INTRODUCTION to AIMS

The **Automated Information Management System (AIMS)** is a succession of processes that result in a comprehensive data set comprised of 85 data fields that reflect demographic, client status, and encounter data for the mental health consumers served by local Community Mental Health Centers (CMHCs) in Kansas. SRS has used data generated through the AIMS since September 2002 in federal and state quality improvement reports and to monitor CMHCs' Mental Health Reform Contracts. The CMHCs' business arm, the Association of Community Mental Health Centers in Kansas, uses AIMS data for legislative reporting and lobbying. The CMHCs use AIMS data for local quality improvement efforts. AIMS is, therefore, a collective resource for the Kansas public mental health system.

Beginning September '02, CMHCs' performance measures are collected solely through the AIMS. CMHCs' Adult Community Support Services Performance Reports and Children's Community Based Services Performance Reports are accessible through the Kansas Mental Health Information Website at the following web addresses:

<http://www.srskansas.org/hcp/MHSIP/AdultReports.html>

<http://www.srskansas.org/hcp/MHSIP/ChildrenReports.html>

This manual is designed to guide AIMS users at the local level in recording and submitting accurate AIMS data. The manual is organized in three sections. These sections detail the data reporting requirements for clients on the basis of the person's registration (AIMS Field 9) and chronicity status (AIMS Field 19). What follows are the AIMS_V3.0 definitions for registration and chronicity.

Registration (AIMS Field 9)

Registration, reflects a person's enrollment status. There are three enrollment statuses:

1. **Enrolled:** The client (enrolled) is a person seen face-to-face for a clinical service by a member of the center staff.
2. **Not Enrolled:** The client (not enrolled) is a person seen face-to-face for a clinical service, but the center staff anticipates no further contact. Potentially a billable service. Must be closed at this time.
3. **Pending:** The client (pending) is a person seen face-to-face for a clinical service, but the center staff is not sure if there will be further contact. Potentially a billable service. Must be closed within 30 days. This registration value is only chosen for people who have been seen face-to-face at the CMHC. Do not enter this value for people who are "pending" in terms of being scheduled for an appointment.

**AIMS DATA REQUIREMENTS BASED ON REGISTRATION
ENROLLED/TARGETED REPORTING POPULATION**

* Updates are reflected with a C for demographic fields that are updated when they change or at least annually and an M for client status fields that are updated monthly and at discharge.

* Children/adolescents can stop case management without being discharged from CMHC services. Therefore, CMS (case management stop) designates when fields are entered in children/adolescent's last month of case management.

* Adults cans stop CSS without being discharged from CMHC services. Therefore, CMS (case management stop) designates when fields are entered in adults last month of case management.

* Fields that are required at discharge are reflected with a D.

DEMOGRAPHIC FIELDS					
Field #	Data Field	Page Number	Admit.	Discharge	Update*
0	Global Status Review Date	10	A	D	C
1	Community Mental Health Center Number (CMHC)	10	A	D	C
2	Unique Client Identifier	10	A	D	C
3	Medicaid Beneficiary ID	11	A	Enter for customer's whose payment source becomes Medicaid after admission	
4	Initial Contact Date	11	A		
5	Scheduled Appointment Date	11	A		
6	Appointment Time Lapse: Initial Contact Date and Scheduled Appnt.	11	A		
7	Admission Date (Open Date)	12	A		
8	Appointment Time Lapse: Initial Assessment and Next Service Offered	12	A		
9	Registration	13	A		
10	Acuity	13	A		
11	Most Recent Hospitalization	14	A		C
12	DOB	14	A		
13	Gender	15	A		
14	Ethnicity	15	A		
15	Race	15	A		
16	Primary Diagnosis	15	A		C
17	Secondary Diagnosis	16	A		C
18	Functional level	16	A		C
19	Chronicity: SPMI (Adults) And SED (Children/Adolescents)	16	A		C
20	Enter the date that chronicity (field 19) was entered or changed	16	A		C
21	Payment Source(s)	17	A		C

Field #	Data Field	Page Number	Admit.	Discharge	Update*
22	SED WAIVER Stop Reason	17	Report when a child/adolescent is no longer served through the SED Waiver because of a change in payment source or discharge.		
23	Annual Income	18	A		
24	Eligibility Regarding Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI)	18	A		C
25	Resident County	18	A		C
26	Responsible County	19	A		C
27	Admission Referral Source	19	A		
28	Client's Highest Level of Education	21	A		C
29	Closing Date	21		D	
30	Last Contact Date	22		D	
31	Discharge Reason	22		D	
32	Primary Diagnosis at Discharge	22		D	
33	Secondary Diagnosis(es) at Discharge	22		D	
34	Functional Level at Closing	22		D	
ADULT CLIENT STATUS FIELDS					
Field #	Data Field	Page Number	Admit.	CSS Stop	Update
35	Report Period	23	A	CSS stop	M
36	Client status review date	23	A	CSS stop	M
37.01	Supported housing	23		CSS stop	M
37.02	Supported employment	23		CSS stop	M
37.03	Integrated treatment for Co-Occurring disorders	23		CSS stop	M
38	Current educational status	24	A	CSS stop	M
39.01	(DAYS) Psychiatric hospital ward	25		CSS stop	M
39.02	(DAYS) General hosp. psyche. ward	25		CSS stop	M
40	Total number of psychiatric hospitalizations during the reporting period	26		CSS stop	M
41	Current residential arrangement	26	A	CSS stop	M
42	Current vocational status	28	A	CSS stop	M
43	Total number of arrests	30		CSS stop	M
44	Number of convicted felonies other than 45 & 46	30		CSS stop	M

Field #	Data Field	Page Number	Admit.	CSS Stop	Update
45	Number of convicted felonies for property crimes	30		CSS stop	M
46	Number of convicted felonies for crimes against persons	30		CSS stop	M
47	Number of convicted misdemeanors	31		CSS stop	M
48	Reason for CSS Stop	31		CSS stop	
CHILDREN/YOUTH (SED) CLIENT STATUS FIELDS					
Field #	Data Field	Page Number	Admit.	Case Manage. Stop	Update
21	Payment Source	Fields 21 and 22 are demographic/admission fields that must be updated and accurately maintained in order for CMHCs' Children's Client Status Reports to be accurate.			
22	SED WAIVER Stop Reason				
49	Report period	32	A	CMS	M
50	Client Status Review Data	32	A	CMS	M
51	Custody Status	33	A	CMS	M
52.01-52.06	Admission CSR risk factors	33	A		
53.01-53.06	CSR risk factors	33		CMS	M
54.01	Supported housing	34		CMS	M
54.02	Supported employment	34		CMS	M
54.03	Integrated treatment for Co-Occurring disorders	34		CMS	M
55	Current educational placement	34	A	CMS	M
56.01	Is child identified on an IEP?	35	A	CMS	M
56.02	IEP Exceptionality	35	A	CMS	M
56.03	Is child identified on 504 Plan?	35	A	CMS	M
57.01	Number excused absences	35		CMS	M
57.02	Number unexcused absences	35		CMS	M
57.03	Currently charged/found truant?	35		CMS	M
58	Average academic performance	36		CMS	M
59	Grade level or estimation by age	36	A	CMS	M

Field #	Data Field	Page Number	Admit.	Case Manage. Stop	Update
60	Number of <u>days</u> for in-school suspension	37		CMS	M
61	Number of <u>days</u> for out-of-school suspension	37		CMS	M
62	Residential setting	37		CMS	M
63	Current residential setting	39	A	CMS	M
64	Total number of NEW foster care placements	39		CMS	M
65	Foster care contractor	39	A	CMS	M
66	Total number of arrests	40	A	CMS	M
67	Number of adjudicated felonies	40	A	CMS	M
68	Number of adjudicated felonies for property crimes	40	A	CMS	M
69	Number of adjudicated felonies for crimes against persons	40	A	CMS	M
70	Number of adjudicated misdemeanors	41	A	CMS	M
71	Law enforcement contact	41	A	CMS	M
72	Total Competence	41 & 42	A	UPDATE FIELDS 72-75 at six-month intervals (new reports can be reported between 5 & 7 months from the report of the last set of scores).	
73	Total Problem	41 & 42	A		
74	Internalizing	41 & 42	A		
75	Externalizing	41 & 42	A		
76	Reason for CM stop for children	42		CMS	
SERVICE ENCOUNTER/SCREENING DATA					
Data Field		Page Number			
77	Service Code	43			
78	Date of Service	43			
79	Units of Service	43			
80	Where Service Occurred	43			
81	Practitioner or person providing service	43			
82	Screening Disposition Value for Reform	43			
83	Screening Disposition Value for Medicaid	44			
84	Screening Disposition Value for Level VI	44			
85	Diverted To	44			

APPENDIX E

DRAFT July '03

Kansas Criteria for Serious Emotional Disturbance (SED)

The term serious emotional disturbance refers to a diagnosed mental health condition that substantially disrupts a child's ability to function socially, academically, and/or emotionally.

Complete the following checklist to determine if the youth has SED.

Name of Youth

Name of Agency

Evaluator Signature

Date

Check yes or no on #1 - 3 to determine if the youth has SED:

YES NO

1. AGE:

___ ___

The youth is under age 18, or under the age of 22 and has been receiving mental health services prior to the age of 18 that must be continued for optimal benefit.

YES NO

2. DURATION and DIAGNOSIS:

___ ___

The youth currently has a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet the diagnostic criteria specified within the most current DSM.

Disorders include those listed in the most current DSM or the ICD - 9 equivalent with the exception of DSM - IV "V" codes, substance abuse or dependence, and developmental disorders, unless they co-occur with another diagnosable disorder that is accepted within this definition.

Diagnosis _____

(1)

YES NO

— —

3. FUNCTIONAL IMPAIRMENT

The disorder must have resulted in functional impairment which substantially interferes with or limits the youth's role or functioning in family, school, or community activities.

Functional impairment is defined as difficulties (internalizing and externalizing) that substantially interfere with or limit a youth from achieving or maintaining one or more developmentally-appropriate social, behavioral, cognitive, communicative, or adaptive skills. Functional impairments of episodic, recurrent, and continuous duration are included.

Youth that would have met functional impairment criteria without the benefit of treatment or other support services are included in this definition.

Which of the following functional areas has been disrupted as a direct result of the child's mental health condition? (**Examples are not intended to be all inclusive, and more than one can be marked**).

- School (for example: exhibiting behaviors that interfere with the child's ability to perform such as inattentive in class, unable to sit in one place, unable to concentrate, withdrawn at school to the point that the child's ability to function at school is impacted, accumulating sick days as a result of being overwhelmed/depressed which places the student at risk for truancy, in-school suspension, out-of-school suspension)

Describe _____

- Family (for example: at-risk of out-of-home placement, physical aggression at home, suicidal, isolative and withdrawn to the point that youth is not engaging in day to day family activities)

Describe _____

(2)

- Community (for example: impairment necessitates law enforcement contact such as youth is running away due to delusional symptoms;

unable to or serious difficulty participating in regular community and/or peer activities due to behavior, isolating from peers)

Describe _____

EXCLUSIONS: Functional impairment does not qualify if it is a temporary response to stressful events in the youth's environment. Functional impairment also does not qualify if it can be attributed solely to intellectual, physical, or sensory deficits.

Youth meets the criteria for SED: YES _____ NO _____

(3)

APPENDIX F

Docking State Office Building
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Appendix 3

METHOD TO DEFINE ADULTS WITH SPMI **FINAL DRAFT**

PURPOSE: To insure that adults with Severe and Persistent Mental Illness (SPMI), or who are most at risk of developing SPMI, are promptly and accurately identified.

To insure that those most in need are offered the full array of community- based mental health services necessary to successfully manage their illness, support their recovery process, and live meaningful lives in their community.

APPROACH: Apply two main areas of assessment to determine an individual's status as meeting criteria for SPMI: (1) diagnostic criteria, and (2) functional and risk criteria.

STEP ONE: Apply diagnostic criteria to determine an individual's identification as meeting initial criteria for the CSS target population. To meet diagnostic criteria for SPMI, individuals must be assessed to determine whether they have a principal diagnosis in either Category A or Category B.

Category A Diagnoses:

- 295.10 **Schizophrenia**, Disorganized Type
- 295.20 Schizophrenia, Catatonic Type
- 295.30 Schizophrenia, Paranoid Type
- 295.60 Schizophrenia, Residual Type
- 295.70 **Schizoaffective Disorder**
- 295.90 Schizophrenia, Undifferentiated Type
- 296.34 **Major Depressive Disorder**, Recurrent, Severe, with Psychotic Features
Bipolar I Disorders that are Severe, and/or with Psychotic Features
- 298.9 **Psychotic Disorder** NOS

Category B Diagnoses:

All Other Bipolar I Disorders, not listed in Category 1

- 296.89 **Bipolar II Disorder**
- 296.23 **Major Depressive Disorder**, Single Episode, Severe, Without Psychotic Features
- 296.24 Major Depressive Disorder, Single Episode, With Psychotic Features
- 296.32 Major Depressive Disorder, Recurrent, Moderate
- 296.33 Major Depressive Disorder, Recurrent, Severe, Without Psychotic Features
- 296.35 Major Depressive Disorder, Recurrent, In Partial Remission
- 296.36 Major Depressive Disorder, Recurrent, In Full Remission
- 297.10 **Delusional Disorder**
- 300.21 **Panic Disorder** With Agoraphobia
- 300.3 **Obsessive-Compulsive Disorder**
- 301.83 **Borderline Personality Disorder**

Category C Diagnoses:

The following diagnoses (as a principal diagnosis) are excluded from those defining an individual as having SPMI or being most at risk of SPMI.

Anti-Social Personality Disorder

Behavior Disorders

Developmental Disorders

Neurological/General Medical Disorders

Substance Abuse Disorders

Psychotic Disorder [Substance-induced only]

DSM-IV-R “V” Codes

STEP TWO: To meet functional criteria for SPMI, persons with a primary diagnosis in Category A or B must, as a result of their qualifying diagnosis, demonstrate impaired functioning through use of the following assessment. For those with a primary diagnosis in Category A who **do** meet the functional criteria listed below, no further assessment is needed to determine eligibility for CSS. Those with a primary diagnosis in Category B must meet these criteria as well as criteria outlined in Step 3.

Impaired functioning¹ is evidenced by meeting at least one (1) of the first three criteria, **and** at least three (3) of the criteria numbered 4 through 9 that have occurred on either a continuous or intermittent basis over the last two years:

- 1. Required inpatient hospitalization for psychiatric care and treatment more intensive than outpatient care at least once in her/his lifetime;
 - 2. Experienced at least one episode of disability requiring continuous, structured supportive residential care, lasting for at least two months (e.g. a nursing facility, group home, half-way house, residential mental health treatment in a state correctional facility);
 - 3. Experienced at least one episode of disability requiring continuous, structured supportive care, lasting at least two months, where the family, significant other or friend of the consumer provided this level of care in lieu of the consumer entering formalized institutional services. (In this case, the intake assessment must fully document the consumer's level of severe disability and lack of functioning that required the family or other person to provide this level of care).
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- 4. Has been unemployed, employed in a sheltered setting, or has markedly limited skills and a poor work history;
 - 5. Requires public financial assistance for their out-of-institutional maintenance and is unable to procure such financial assistance without help;
 - 6. Shows severe inability to establish or maintain a personal support system, evidenced by extreme withdrawal and social isolation;
 - 7. Requires help in instrumental activities of daily living such as shopping, meal preparation, laundry, basic housekeeping, and money management;
 - 8. Requires help in attending to basic health care regarding hygiene, grooming, nutrition, medical and dental care, and taking medications. (*Note: this refers to the lack of a basic skill to accomplish the task, not to the appropriateness of dress, meal choices, or personal hygiene*);
 - 9. Exhibits inappropriate social behavior not easily tolerated in the community, which results in demand for intervention by the mental health or judicial systems (e.g. screaming, self-abusive acts, inappropriate sexual behavior, verbal harassment of others, physical violence toward others).

STEP THREE: For individuals with a primary diagnosis in Category B, eligibility for CSS **always** depends upon a more detailed determination of risk and functional impairment (through face-to-face assessment). Only those with a Category B diagnosis who also meet these additional criteria in Step Three are guaranteed eligibility for Community Support Services (CSS) through a CMHC.

¹ Adults that would have met functional impairment criteria during the referenced time period without the benefit of treatment or other support services are included here.

Individuals with a primary diagnosis in Category A do not need to meet the additional criteria in Step Three **unless** they failed to demonstrate impaired functioning as evidenced by the criteria outlined in Step Two.

SRS will make available a tool for CMHC staff to use in making this determination.

RELATED POLICIES:

1. The emphasis on diagnostic categories is for purposes of determining eligibility for CMHC/CSS services only, and is not in any way a recommendation to rely on a person's diagnosis to determine specific treatment approaches or service modalities. It remains a policy of SRS/MHAAPS to reinforce a practice approach that is based on each individual's unique strengths, characteristics, life situation, desires, and resources.
2. CMHC/CSS staff qualified to make determinations regarding a person's SPMI status must meet QMHP statutory criteria as defined by the State of Kansas. It remains the right of the CMHC to make a determination of a person's SPMI status for the purposes of being found eligible for CMHC/CSS services.
3. It is the responsibility of any CMHC/CSS staff performing an SPMI determination to fully explain to the individual the purpose of the determination, the process involved, and their rights/appeal process.
4. The access standards as outlined in CMHC contracts with SRS/MHAAPS apply to the process of determining an individual's status in meeting the target population definition criteria.
5. During determination of an individual's status as having SPMI, the person shall have access to a basic package of CMHC services, including medication management, crisis case management and crisis services, substance abuse treatment, and outpatient treatment. For those individuals who do not meet the criteria for SPMI status, but who do need some mental health intervention, they shall continue to have access to this basic package of CMHC services.
6. If a person's status is SPMI at termination of CMHC/CSS services or upon transfer to another CMHC, the person's status shall continue as SPMI upon re-enrollment or transfer.
7. Once an individual is determined to meet SPMI status and is receiving CMHC/CSS services, periodic review of the intensity and frequency of the services being provided will be done with the consumer by the CMHC at least every twelve (12) months, and may be done more frequently as determined by SRS/MHAAPS, the CMHC, or at the consumer's request. SRS QE staff will monitor CMHC/CSS performance in completing these reviews during licensing visits or periodic site visits. Documentation of this review with consumers must be kept in each person's CMHC/CSS records.
8. SRS QE staff will monitor CMHC/CSS performance in accurate application of the process used to determine individuals' SPMI status during licensing reviews or periodic site visits.

Documentation of SPMI status demonstrating a person's eligibility to receive CSS services must be kept in each person's CMHC/CSS records.

9. As of September 1, 2001, all CMHC's will use this approach to determine a person's SPMI status and eligibility for CSS. For new enrollees the determination process will be included at intake. For current CSS consumers the determination process will be completed no later than her/his second 90-day review. For those receiving medication services only, the determination process will be completed no later than her/his third 90-day review.
10. For consumers who have been receiving CSS services for more than 6 (six) months prior to September 1, 2001, who have been found that they do not meet the new eligibility criteria, a process of exemption can be made:
 - (a) The CMHC will provide through its quality assurance and utilization review process documentation explaining how the level of treatment being provided matches the unique conditions and situation of the consumer, AND how the consumer is actively being transitioned to naturally-occurring community supports;
 - (b) The CMHC's Quality Enhancement (QE) staff person will, as a part of her/his licensing visit or periodic site visits, review a portion of consumers' records for whom an exemption to this eligibility determination has been made; and
 - (c) The CMHC will report quarterly (in written form) the number of individuals comprising exemptions to the new target population definition process. This report will be made to the CMHC's assigned QE staff person, or to MHAAPS central office if the CMHC lacks a QE assignment. Corrective action may be taken with CMHC's who are making an inordinately large number of exemptions to the new target population definition process.

NOTE: Six to nine months after implementation of this new target population definition procedure, MHAAPS will conduct a review to determine its effectiveness. Adjustments may be made in any or all sections of the definitional approach depending on results from the review process. To that end, CMHC's will need to be prepared to report data to MHAAPS or its contracted agent concerning implementation of this approach to defining the target population.