Summary of Consumer Focus Groups

Illinois Department of Human Services/Division of Mental Health (DHS/DMH)

IL DHS/DMH Office of Recovery Support Services with Parker Dennison & Associates, Ltd.

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Executive Summary

Throughout the System Restructuring Initiative, the Department of Human Services/Division of Mental Health (DHS/DMH) has sought to encourage and support participation and input from individuals receiving services (consumers) and families of children and adolescents receiving services (families). This has included outreach and participation of consumers and families for all committees and workgroups, financial support for consumer and family time and travel related to the effort, and other consumer outreach efforts. Recognizing that even best efforts for inclusion of consumers in scheduled meetings were only reaching a relatively small segment of the overall consumer pool, the Services Work Group of the System Restructuring Initiative recommended that consumer focus groups be held state-wide to assist in identifying priorities and service preferences. This report summarizes the process, key findings, and potential impacts of the voices heard in these focus groups.

Process & Participants

Focus groups were organized and facilitated by Recovery Support Specialists through the DHS/DMH Office of Recovery Support Services. Parker Dennison and Associates, Ltd. (Parker Dennison), assisted in the development of targeted focus group issues, development of the focus group script, facilitator training, and summary report assistance.

A total of twenty seven (27) focus groups were held throughout the state with a total of 268 consumer or family member participants. Fourteen (14) focus groups were held for consumers of community agencies, twelve (12) were held for those being served in state operated hospitals, and two (2) were held exclusively for parents of youth being served by DMH funded agencies (family members were also invited to all other groups). A Spanish-speaking group was held and a signing translator was made available for an additional group, targeted toward the deaf/hard of hearing. Efforts to ensure race and ethnic diversity participation were made and the participation data reflect that this was largely successful.

Key Findings

Key findings included:

- Both adult consumers and families of children believe that having input into service choices is critical. Yet the overwhelming majority felt they have little or no input into setting their personal goals on their service plans or service priorities.

- Additionally, the overwhelming majority felt they had little or no input or choice of which services will help them meet their goals.

- Few participants (13%) felt they had any say in the quality of services received.

- Adult consumers most value the relationship and services of their therapist/counselor and/or case manager while families of children served most value therapeutic recreation services for their children.

- Adult consumers would like to see more supported employment, benefits counseling, and budgeting to help them regain control of their own finances (get out of representative payee) while families of children would like to see more recreational activities, summer activities, and respite.
• Both consumer groups highlighted a need for transportation, more flexible service hours, and better access to psychiatrists.

• Both consumer groups indicated that there was not a uniform array of services available.

• Adult consumers do not readily understand or identify a crisis support system and consequently rely most significantly on family members for crisis assistance. Families of children rely significantly on police as first responders and also do not readily identify a crisis system though there is a growing awareness of SASS.

• Both consumer groups indicated a need for more clarity and resource materials about what services are available, how to access services, their rights, and how to get assistance.

• Both consumer groups had specific recommendations for how the system could be improved.

• Both the Spanish-speaking group and the group in which a signing translator was made available echoed the above and emphasized that communication problems exacerbated each issue substantially.

**Impacts from Findings**

Significant results/impacts include:

• New service definitions were written with an increased focus on recovery principles, emphasizing the importance of consumer and family active participation in service choices and self determination.

• The Assertive Community Treatment (ACT) service definition was written to have greater fidelity to nationally recognized Evidence Based models.

• The service of Community Support (Individual, Group, & Team modalities) was added to the taxonomy.

• Definitions for ACT, Community Support, and Psychosocial Rehabilitation (PSR) were drafted to be more inclusive of vocational, educational, and social/recreational language to the extent allowable under Medicaid rules.

• Numerous proposed Rule 132 revisions are directly related to consumer focus group feedback. These include but are not limited to:
  
  o Expansion of benefit coverage prior to completion of an assessment.
  
  o Enhanced emphasis on consumer and family participation in service planning.
  
  o Greater specification in service definitions to enumerate more recovery oriented activities.
  
  o Improved consumer-directed service planning by requiring at least annual updates on assessments of client needs and preferences.
  
  o Improved supervision of minimally trained or credentialed staff.
  
  o Requirement to have a single, coordinated service plan across all programs serving the needs of an individual. This directly addresses concerns voiced by consumers.
• Provider and consumer training topics were identified and will be used to inform training and technical assistance priorities in the coming year.

**Future Development**

As the DHS/DMH continues the system restructuring initiative, the focus group results suggest additional recommendations for further development:

• Continued updating of the taxonomy
• Addition of other services to the taxonomy
• Modification in use of capacity grants
• Focused provider network monitoring
• Consumer and provider training priorities
• Development of consumer handbook & resource guide
• Continued evolution of Office of Recovery Support Services priorities
• Implementation of a Consumer Rights and Choices function
Section 1: Introduction & Purpose

Introduction and Purpose

In an effort to maximize consumer and family participation in the System Restructuring Initiative process and to assure DHS/DMH funded services supported the recovery of individuals being served, consumers and family members have been encouraged to participate in service definition revision activities. Recognizing that even best efforts for inclusion of consumers in scheduled meetings were only reaching a relatively small segment of the overall consumer population, the Services Work Group of the System Restructuring Initiative recommended that consumer focus groups be held state-wide to assist in identifying priorities and service preferences. This report summarizes the process, key findings, and potential impacts of the voices heard in these focus groups. Attachment D provides definitions of key terms used throughout this report.

History of Consumer Involvement in SRI Process

In 2004, the Department of Human Services/Division of Mental Health initiated a conversion of the State’s funding mechanism to community providers from a grants system to a fee-for-service (FFS) system. In July of that year, the Department entered a Memorandum of Understanding (MOU) with the members of the General Assembly and a Memorandum of Agreement (MOA) with the Fee for Service Task Group (a group made up of mental health stakeholders) to form a System Restructuring Initiative (SRI) Task Group. This task group consists of mental health consumers, providers, trade associations, advocates and state agencies and offers advice and comment on the funding change.

In Fiscal Year 2006, the Department of Human Services developed “Community Based Mental Health Services Fee-for-Services Conversion FY2006 Commitment”. The first paragraph of this document states: “Continuing transition efforts shall include a strong consumer voice and be shaped by community needs to promote consumer access and service capacity as a means of minimizing service disruptions. All transition efforts shall be within a recovery philosophy, emphasizing the potential of all individuals to recover from the challenging impact of psychiatric illness through a system that is family/support centered, consumer directed, and encourages independence, integration and a productive role in the community for all individuals.”

A Services Workgroup was created in 2004 to review the then current service definitions and make recommendations to DHS/DMH where improvements were needed. One of the tasks of this group was to articulate a recovery focus in mental health services. Through the collaboration of consumers, community mental health providers, and payors, a “Philosophy of Recovery Oriented Services in Illinois” was developed (Attachment A). This statement identified aspects of the philosophy of recovery, categories of a recovery-oriented service system, and four means of measuring successful outcomes. This document provided the Services Workgroup with a consumer-focused and recovery-oriented direction when developing new service definitions.

In 2005/2006 the Services Workgroup identified specific services that need to be developed in order to improve the service system and comply with federal and state guidelines. These services were Assertive Community Treatment, Psychosocial Rehabilitation, and Community Support services. The Services Workgroup recommended that structured and facilitated consumer focus groups be held throughout the state to elicit input into “what works and what doesn’t work” in mental health services.
Focus On Consumer Needs/Preferences

Based on the experience of Parker Dennison & Associates in other states, consumers often have little interest in technical service definitions, but rather are best able to articulate key results, processes, or supports that they need or prefer. Accordingly, the focus group scripts were not tied directly to the proposed service definitions but rather to more general areas such as service access, care management, crisis access, treatment plan involvement, etc. Responses to these issues/questions were then used to inform the service definitions, proposed policy and/or rule changes, and targeted training/technical assistance in the coming fiscal year.
Section 2: Key Findings

Adults

The key findings of the consumer focus groups have six areas that stand out in terms of consumer's needs and preferences related to mental health treatment, inclusion and services throughout the five regions of the State of Illinois. The six areas are: 1) input into setting goals 2) availability and accessibility of services 3) crisis services 4) connecting to services 5) improvement in the quality of the Illinois mental health service system.

Priority Areas

1. Input into Setting Goals—As noted in the New Freedom Commission Report, “consumer needs and preferences should drive the type and mix of services provided, and... providers should develop customized plans of care in full partnership with consumers”. Sixty-two percent (62%) of the participants surveyed identified the number one priority in their recovery process as “being able to have input into setting their own personal goals and priorities on their treatment plan”. Those present stated that having knowledge of the available services as well as what they need and want for themselves is imperative to maximize the recovery process. Meaningful input and choices into the type of services they can utilize is also important to connect it to the persons’ treatment plan goals. Yet, sixty percent (60%) of participants stated they have “little” to “no input” into setting their own treatment goals and priorities and seventy eight percent (78%) have “little” to “no input” or choice into which services will help them meet those treatment goals. Those surveyed also identified they have “very little” to “no say” (83%) in the quality of the services they receive. Things that were identified as “getting in the way” of having meaningful choices and input regarding the quality of and the types of services one can access included non-supportive staff, symptomology, and lacking the knowledge of what services were offered. Those individuals who felt they are involved in setting goals and priorities of their treatment plan identified having good rapport with staff, reviewing previous treatment goals, having hope, having goals, having a natural support system of family and friends, and staying involved in the treatment planning process.

2. Availability and Accessibility of Services—Being able to choose mental health services from among those the agency has to offer in order to best meet the identified treatment goals and priorities per the individual is imperative in learning/relearning and practicing the skills necessary for the individual to gain, sustain and maintain a healthy quality of life. Services must then be accessible as well as available to the individual who has identified them as a necessary part of his/her treatment. Those surveyed identified counseling as the most valuable service currently being offered in helping them meet their recovery goals, and included such services as Individual Therapy, Dialectical Behavioral Therapy, and Group Therapy. Other services participants identified as valuable in terms of meeting their recovery goals included housing, Medication, and Psychosocial Rehabilitation.

The persons surveyed identified several services they do not receive but would be beneficial in helping them achieve their recovery goals. Services included Supported Employment (Job Support/Vocational), and Benefits Planning/Assistance (i.e. education regarding how employment will affect their benefits). Budgeting was described as a service that would help in achieving recovery goals in that individuals stated that mental health centers often serve as payees and it is difficult to regain power over finances. Some of the services consumers thought would help them achieve their recovery goals included housing, Wellness Recovery Action Planning, Dialectical Behavioral Therapy, Relationship/Grief Counseling, housing, Group Services, Mental Illness Substance Abuse Treatment, GROW. Additionally, transportation was frequently noted as something that would help persons achieve their recovery goals.
3. **Crisis**—Individuals surveyed indicated that crisis services do not meet their overall needs in terms of intervention and stated that there should be a continuum of crisis services to better meet their needs. The results suggest that the majority of consumers do not perceive an obvious crisis response system within the mental health system. A third of the adult consumers reported that they contact a family member if they experience a mental health crisis and 13% contact the mental health provider.

4. **Connecting to Services**—Individuals surveyed identified that getting connected to services is difficult and cumbersome. A Hotline that would inform consumers of what services were available at what agencies was recommended by approximately 25% of participants. Effective communication and respectful, receptive staff attitudes were identified as a way for individuals to more easily connect to services as well as flexibility in appointment times, and more choices in services.

5. **Improvement in the Quality of the Service System**—Individuals were asked to name one thing they would like to improve in the Illinois service system and the survey reflects the top answer was an increase in funding for mental health. Respondents suggested that new funding should be targeted toward staff that are competent, qualified, and who value and elicit client input, more vocational services, client driven treatment, housing, more recovery based services, affordable medications, financial assistance, and better transportation. Individuals identified the above items as key components in finding services to fit their needs and preferences and as a way to positively impact their recovery process.

**Parents – Child & Adolescent Services**

The key findings for Child & Adolescent services from the parent's perspective in the consumer focus groups also have five areas that stand out in terms of needs and preferences related to mental health treatment throughout the five regions of the State of Illinois. Input for this section was garnered primarily from parents who are Family Resource Developers or their child has an Individual Care Grant. The five areas, in terms of priorities, are: 1) input into setting goals 2) availability and accessibility of services 3) crisis services 4) connecting to services 5) improvement in the quality of the Illinois mental health service system.

**Priority Areas**

1. **Input into setting goals**—Twenty percent (20%) of parents stated that having more knowledge about the services that are available and the laws that apply to children and adolescents would help them have meaningful input into treatment plan goals and priorities. Over fifty percent (50%) of the parents surveyed identified several barriers to actively participating in the treatment planning process: “the culture and climate does not invite questions”, there is a lack of knowledge by providers about service options, fragmented services there is no single/unified service system; and “intimidation” by service professionals. Parents who do feel involved in the treatment planning process identified being treated “with respect” by staff, having regular team meetings, staff have a trusting relationship with parents, “labeling” is not used, respite is given and parents are given more time, when necessary, with treatment staff.

2. **Availability and Accessibility**—A common theme identified by parents was the difficulty they have/had in maneuvering the mental health system to obtain services for one’s child because of the many layers of children’s services. Parents surveyed identified Therapeutic Recreational Activities such as equine therapy, art therapy and music as the most valuable service currently being offered in helping their child meet his/her resiliency goals. Other services parents identified as having value in meeting child’s resiliency goals included Therapeutic Behavioral Services, social skills, wrap around services such as life skills, medication management/education, and summer camps. Parents stated there are services their children do not receive that would be beneficial in helping them achieve resiliency goals. Their wish list of services included Therapeutic Recreational Services, life skills training, summer camps, respite/group respite for teenagers, religious services, and social skills group.
In terms of availability, parents did identify that there are times that services are available but inaccessible to their child because of when or where the service/treatment is offered. The following were identified: 1) location(s) where the service is being offered is inconvenient 2) transportation is unavailable, 3) psychiatrist availability 4) limited scheduled evening programs/services, i.e. maybe only open one night per week and 5) special recreation.

3. **Crisis**—Parents of children in service who participated stated that mental health crisis intervention lines do not often meet the need of the parent calling for help and noted that a better system needed to be developed that was more coordinated. Parents who participated in the focus group surveys were asked who they contact first when their child is in crisis. Twenty-five percent (25%) identified the police as the first contact. Other parents identified mental health professionals as people they contact when their child is in crisis such as the child’s therapist, psychiatrist, Screening Assessment Support Service (SASS) worker, and crisis line.

4. **Connecting to Services**—In terms of being able to find resources about what children and adolescent services are available to them; twenty-nine percent (29%) stated that having a hotline/call center available where they could call with questions about what resources are in their area, child therapists/child psychiatrists and local agencies that work with children would be most helpful. They also stated having a variety of brochures, pamphlets, and a manual with information and description of what children and adolescent services include would be helpful. Weighted heavily as having local/regional resource information was having respectful and knowledgeable staff who would treat both their child as well as them with dignity and holistically. Fourteen percent (14%) of parents identified that there is a need for a school social worker in the community in which they live. Other things that would help in getting their child connected to services as identified by parents were: having available and affordable transportation, having a mental health specialist in their pediatrician’s office, and for the agency to have no waiting list. Parents also suggested that the Department of Human Services/Division of Mental Health improve their website to make it more user friendly for consumers and easier to navigate.

5. **Improvement in the Quality of the Service System**—Parents were asked to name one thing they would like to improve in the Illinois service system and the survey reflects the desire for all organizations who are involved with the parents and their children to better interface with one another and to fully include the parents, and thus, their children, as full partners in the child’s treatment process. They identified seven areas of needed improvement and rated them equally. Those areas include: 1) improved transition to the adult program, 2) holding school accountable, 3) providers working as a team and including the parent and child on the team, 4) having a central directory of service for easy access, 5) including parents on all levels of the advisory council of the agency/organization, 6) easier access in navigating and getting the services their child needs, and 7) more Family Resource Developers.

**Special Populations**

In addition to the key findings noted above, the Spanish Speaking Group made the following key points:

- The need for more Spanish speaking staff, especially therapists, in order to be able to communicate effectively and better understand their treatment and recovery
- Language barriers contribute to an inability to have meaningful input and choice into the services received
- Having a number or line of communication with a Spanish speaking person to use in the event of a crisis is a service need
Many of the consumers were unsure of who to contact to discuss a question they may have on their treatment plan and felt they had little or no input into setting the goals and priorities or making changes to the treatment plan.

This population also expressed that services were often unavailable to them because of lack of transportation, and the times at which services were offered conflicted with work schedules; night and weekend services were desirable to this population.

The participants also expressed the immediate need for housing assistance.

In addition to the key findings noted above, the session targeted toward the Deaf/Hard of Hearing in which a signing translator was made available, made the following key points:

- The group seemed to consistently agree that they were not given information regarding services that were available to them and where they could go to receive these.
- In order to better connect with services, this population feels it would be helpful to have a consumer handbook clarifying services and their availability to them.
- Most consumers in this group felt they had little or no input into setting goals or priorities on their treatment plan and felt they were not able to receive most of the services they want or need.
- The group also seemed to express a desire to have more employment opportunities, quicker services and more contact with those involved in their recovery process.

Overall, both special populations felt that the language and communication barriers impeded them in their recovery process. They felt that better communication with staff, along with a handbook or document clarifying services that are available and the location of those services, would maximize their opportunity to receive the best treatment and progress in the recovery process.
Section 3: Process

Office of Recovery Support Services

One of the primary functions of the Division of Mental Health (DMH) Office of Recovery Support Services (ORSS) is to ensure that current consumers of mental health services are involved in all aspects of planning, developing, evaluating and delivering services funded by the DMH. Therefore, as part of the System Restructuring Initiative, the ORSS was contacted to coordinate the development of Consumer Focus Groups for the purpose of collecting information on consumer needs and preferences as part of the SRI process.

Preparation

In December, 2005 the members of the ORSS met with SRI project staff and were given an overview of the scope of the Consumer Focus Group project. All members were in support of the ORSS taking leadership for this assignment.

Members of the RSDG were asked to coordinate their efforts by Region, and to identify a minimum of one community agency site in which to host a Focus Group. However, in order to ensure access for consumers, more than one site would be needed per Region. Additionally, the RSDG members unanimously agreed that consumers currently receiving services within state-operated hospitals should also be given the opportunity to participate. Therefore, a date and location for conducting a Focus Group at each of the state hospitals was also identified. Once dates and locations were identified, letters were mailed informing community agencies and state hospitals of the upcoming Focus Groups. These letters also included a description of the purpose of the Focus Groups, and a request that agency staff invite consumers and family of youth to participate.

Training

On January 18, 2006 DMH Recovery Services Specialists participated in three (3) hours of Facilitator Training conducted by Lee Ann Slayton of Parker Dennison. This training, required for any individual who was scheduled to facilitate or co-facilitate one or more of the Focus Groups, covered all aspects of the implementation, including planning for data collection, standard use of survey questions, and alternate sessions for staff participants.

Implementation

A total of twenty-seven (27) Focus Groups were conducted across the state between January 19 and February 10, 2006. Of this total, fourteen were held for consumers of community agencies; twelve were held for consumers being served in state operated hospitals (SOH); and two were held specifically for parents of youth receiving services. Additionally, parents of youth were invited to all community agency focus group sites.

In Region 1, seven separate Focus Groups were conducted on the grounds of either Tinley Park Mental Health Center, Chicago Read Mental Health Center, or Madden Mental Health Center, and four Focus Groups were conducted in distinct geographic locations for community consumers. One of the community sites in Region 1 Central was held specifically for Spanish-speaking individuals. One of the groups held at Chicago-Read Mental Health Center included interpreters for persons who are deaf and hard of hearing.
In Region 2, one Focus Group was held at Singer Mental Health Center and one at Elgin Mental Health Center. **Three** Focus Groups were conducted in distinct geographic locations for community consumers.

In Regions 3 & 4, one Focus Group was held at McFarland Mental Health Center. Four Focus Groups were conducted in distinct geographic locations for community consumers.

In Region 5, one Focus Group was held at Choate Mental Health Center and one at Alton Mental Health Center. Two Focus Groups were conducted in distinct geographic locations for community consumers.

For Child & Adolescent (C&A) Services, two Focus Groups were held specifically for parents of youth receiving services. Additionally, parents of youth were invited to all community agency focus group sites.

**Participants**

For each Focus Group conducted, facilitators and agencies were informed that a maximum capacity of thirty (30) persons would be included, in order to ensure that all persons in attendance were able to participate fully. The overall average participation was 10, with the smallest number being 5, and the largest being 29.

Persons included and invited were from one or more of the following categories:

- Adult consumers currently receiving any of the following services:
  - Supervised Residential (in group homes or other settings)
  - Supported Residential (receiving services in their homes)
  - Assertive Community Treatment (ACT)
  - Psychosocial Rehabilitation (PSR)
  - Case Management

- Parents or family members of children and youth receiving services
  - As part of comprehensive mental health services through DCFS, or
  - Mental health services through DMH-sponsored services. Applicable services include case management, therapeutic behavioral services, skill building and activity therapy.

The categories above were identified in order to ensure that the results of the information collected through the focus group process would be useful in the efforts of the Services Work Group to revise service definitions for Rule 132.

As the survey questions were designed specifically for current consumers of services who did not have knowledge of agency policies/procedure, staff persons or consumers who were also providers were not included in the Focus Groups.
Alternate Sessions for Staff

In addition to the above sessions, recovery-oriented training sessions were offered at no cost at each community site for any staff person who accompanied consumers to a Focus Group. Local facilitators were given the latitude to design these alternate sessions according to one guiding principle—that they would make an effort to ensure that the time would be valuable and recovery-focused for staff persons who attended. Facilitators chose several different approaches for the alternate sessions. For example, some chose to show a video; some enlisted assistance of other local staff to moderate a session on agency needs; some revised the survey questions for the consumer focus groups and held similar focus groups with staff.
Section 4: Summary of Participants

Adult Participants

The total number of adult participants engaged in the survey is 268. Table 1. shows the distribution of age and ethnicity. (Note that the total number of responses to “ethnicity” is less than 268 due to blanks on the data collection sheet.) Participating consumers were engaged in the following services: Case Management 31%, Supported Residential 25%, PSR 25%, Supervised Group Home 11% and ACT 8%. (Note that consumers were engaged in more than one service.)

<table>
<thead>
<tr>
<th>AGE</th>
<th>ETHNICITY</th>
<th>SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>30 11% Caucasian</td>
<td>150 60% Group Home</td>
</tr>
<tr>
<td>25-35</td>
<td>71 26% African American</td>
<td>64 26% Supported Residential</td>
</tr>
<tr>
<td>36-50</td>
<td>110 41% Latino</td>
<td>24 5% Case Management</td>
</tr>
<tr>
<td>Over 50</td>
<td>57 21% Other</td>
<td>12 5% PSR</td>
</tr>
<tr>
<td>Total 268</td>
<td>Total 250</td>
<td>ACT 38 8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other 4 1%</td>
</tr>
<tr>
<td>Total 295</td>
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<td>Total 295</td>
</tr>
</tbody>
</table>

Spanish Speaking Participants

The total number of Spanish speaking participants was 5. These participants were engaged in the following services: PSR 41%, Case Management 33% and ACT 16%. A total of 12 responses were observed in the service category indicating that consumers were engaged in more than one services.

Deaf/Hard of Hearing Participants

The total number of participants engaged in the survey was 20. A low number of participants responded to the service section. Only 1 individual indicated that they received Supported Residential services, and 2 individuals indicated that they obtain case management services. No consumers attested to living in a group home, or receiving PSR or ACT services.

Children, Adolescent & Families

The Children and Adolescent Attendance Profile listed the number of attendees at the two consumer focus group sessions that were held specifically for parents of children receiving mental health services or the child or adolescent themselves. There were a total of 19 attendees at the ICG focus group, and 10 attendees at the Family Resource Developer focus group. The participants were not asked to identify their age, ethnicity or services that their child/adolescent was receiving at the time of the survey.
Section 5: Impact & Implications

Short Term Impacts

The feedback from the consumers who participated in the Focus Groups contributed immediately to priorities and decisions made during the recent development of new service definitions, Rule 132 modifications, and planning for FY 07 training and technical assistance. It is anticipated that the consumer feedback will continue to impact priorities and policy decisions throughout the coming months, including the development of a DMH Provider Manual.

Significant results/impacts include:

1. New service definitions were written with an increased focus on recovery principles, emphasizing the importance of consumer and family active participation in service choices and self determination. Whereas past service definitions passively allowed these activities, new service definitions enumerated specific intervention expectations and examples that provide more recovery-oriented operational specifics.

2. The Assertive Community Treatment (ACT) service definition was written to have greater fidelity to nationally recognized Evidence Based models. This model is recognized by the federal Substance Abuse and Mental Health Services Administration (SAMSHA) as embracing recovery concepts and affording the most significantly ill individuals the best supports for success.

3. The service of Community Support (Individual, Group, & Team modalities) was added to the taxonomy. The definition delineates activities that directly address consumer feedback including supporting and teaching consumers to actively participate in choices, service planning and identification of preferences; emphasizing the involvement of consumers’ natural support systems including families and significant others; focusing on teaching, enabling, and supporting the development of consumer competencies and skills leading to independence rather than ‘doing for’ consumers and fostering dependence; and requiring a majority of activities to be delivered in consumers’ natural environment improving access and affording greatest learning opportunity.

4. Definitions for ACT, Community Support, and Psychosocial Rehabilitation (PSR) were drafted to be more inclusive of vocational, educational, and social/recreational language to the extent allowable under Medicaid rules. Given the documented importance of ‘work’ in the recovery from serious and persistent mental illness, as well as the clear message from the focus groups, DMH is enhancing the non-Medicaid taxonomy to place more emphasis on supported employment services.

5. Numerous proposed Rule 132 revisions are directly related to consumer focus group feedback. These include but are not limited to:
   
   o Expansion of benefit coverage prior to completion of an assessment and service planning. This will allow providers to spend more time (billable) to ensure active engagement by the consumer and their families in the identification of needs, preferences and choices. Previously, only ‘emergency’ case management could be provided.
   
   o Enhanced emphasis on consumer and family participation in service planning.
   
   o Greater specification in service definitions to enumerate more recovery-oriented activities.
Improved consumer-directed service planning by requiring at least annual updates on assessments of client needs and preferences.

Improved supervision of minimally trained or credentialed staff.

Requirement to have a single, coordinated service plan across all programs serving the needs of an individual. This directly addresses concerns voiced by consumers.

6. Provider and consumer training topics were identified and will be used to inform training and technical assistance priorities in the coming year. See Attachment B.

Future Development

As the DHS/DMH continues the system restructuring initiative, the focus group results suggest additional recommendations for further development:

1. **Continued updating of the taxonomy**—As recommended previously, the entire mental health system could benefit from incorporating and enumerating the operationalization of recovery and resiliency principles.

2. **Addition of other services to the taxonomy**—Not all of the priorities expressed by the consumer groups are fully covered under the current taxonomy. Some priorities are difficult to cover under Medicaid requirements. As DMH reviews non-Medicaid services, priority should be placed on those things identified by consumers and families in this feedback process.

3. **Use of capacity grants**—As DMH considers how capacity grants should be allocated and how those dollars can be used synergistically with Medicaid and non-Medicaid fee-for-service funding, consumer and family priorities delineated through these focus groups should be considered, including crisis intervention and related systems.

4. **Focused provider network monitoring**—In its stewardship role for consumers and families who are the beneficiaries of the mental health system, DMH should ensure contractual expectations and the associated consistent monitoring of those aspects most important to constituents. These focus group results suggest that monitoring of timely access, consumer choice, consumer input, and consumer self determination are key values and deserving of performance expectations and accountability.

5. **Consumer and provider training priorities**—Though the concepts of recovery and resilience are not new to the Illinois provider network, consumer focus group results suggest that additional consumer and provider training is indicated. Attachment B provides some suggested topics.

6. **Consumer Handbook & Resource Guide**—Feedback from consumers and their families was uniform in asking for more information—service options, their rights, responsibilities, and resources to help them make choices. DMH should considering developing a Consumer Handbook and Resource Guide and make it available to all consumers.

7. **Office of Recovery Support Services priorities**—Consistent with their mission and growing impact, ORSS should consider the results from this consumer focus group project in setting its priorities and deployment of resources. The FY 2006 priorities (below) were very consistent with the findings and serve as a good foundation for FY 2007:
a. **Consumer-Operated Services Development:** Encouraging the growth of new and existing consumer-run organizations throughout the state in order to broaden access to peer support and increase available resources for persons in recovery.

b. **Recovery Program Expertise / Implementation:** Providing leadership for the implementation of recovery-oriented, evidence-based/emerging best practices, Wellness Recovery Action Plan, Integrated Dual Diagnosis Treatment, Illness Management and Recovery (IMR), Supported Employment Programs, Certified Recovery Support Specialist (CRSS), and Trauma Awareness and Advocacy.

c. **Positive Intervention Alternatives:** Encouraging the use of those interventions which increase consumer choice, empowerment and self-determination.

d. **Recovery Specialists Classification System:** Ensuring that individuals who are trained to share their knowledge, skills and personal experiences of recovery are employed at all levels of the public mental health system.

e. **Implementation of Legislation:** Providing leadership and expertise in projects related to the implementation of consumer-driven legislation, such as Olmstead, ADA, Treatment Preference Act and Psychiatric Advance Directives.

8. **Consumer Rights and Choices Function**—Currently, other than for a very narrow range of Medicaid related benefits issues, consumers have no recourse beyond their provider should they have unresolved concerns. These results suggest that a substantial majority of consumers do not feel they have the level of input or control of their treatment that they would desire. It is recommended that the DMH establish and authorize a policy to ensure that consumer rights are protected and consumer freedom of choice is not unfairly limited. This policy should encourage resolution of grievances at the lowest possible level. It shall focus on the mediation and resolution of issues as soon as possible after they arise.
Attachments
Attachment A—Philosophy of Recovery Oriented Services in Illinois
A Philosophy of Recovery Oriented Services In Illinois (2-14-05)

A philosophy of recovery:

- Emphasizes the potential of all individuals to recover from the challenging impact of psychiatric illness.
- Is a recovery-oriented system of care that is consumer directed, family/support centered,
- Encourages independence, integration and a productive role in the community for all individuals.
- Identifies and uses of consumer strengths
- Skillfully integrates ‘natural supports’ (friends, family, support groups, other community resources) with professional supports
- Delivers professional services in the consumer’s natural environment where healing and re-learning can be maximized.
- Balances resources, consumer needs (per the individual’s request) and best practice models with wellness and recovery principles defined by the person regarding their personal capacity and potential, to achieve quality services with accountability.
- Provides incentives to both consumers and providers to embrace and/or deliver recovery-oriented services at the individual’s pace.

Recovery-oriented service systems coordinate funding streams to offer a comprehensive array of rehabilitation service categories including but not limited to:

- Interviewing focusing on individual’s purposeful strengths and needs
- Service planning that emphasizes personalized care plans that promote resilience, self-determination, and full participation in the design, implementation, and evaluation of treatment and service plans
- Cost efficient Medication services and supports
- Basic living skills training and supports
- Social skills training and supports
- Housing and residential support services
- Employment support services
- Education related support services
- Social and recreational services
- Peer services and supports
- Family and natural support system education
- Integrated co-occurring/substance abuse services
  - MISA
- Symptom and disability management
- Coordination of treatment for individuals with both physical and mental health conditions (i.e. diabetes)
- Advance directives and self management supports
- Service and care coordination
- Coordination of treatment with individual’s faith community
- Outreach and linkage
- Crisis intervention and stabilization (including crisis respite and acute inpatient)
- Trauma Recovery

Successful outcomes will be measured by:
• People having the ability to live as independently as possible
• People reporting an improved quality of life
• People having access to peer services and support
• People exercising their right to make autonomous choices about their own financial, social, personal and employment or community involvement goals.
Attachment B—Provider and Consumer Training Topics
## Consumer/Provider Training

<table>
<thead>
<tr>
<th>Consumer &amp; Family Training</th>
<th>Provider Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to use a Crisis Line as part of an overall crisis plan.</td>
<td>How to respond to a person who calls the Crisis Line when the person’s crisis does not fit the Crisis Line guidelines.</td>
</tr>
<tr>
<td></td>
<td>How to set up a Personal Assistance Telephone Hotline (PATH) system</td>
</tr>
<tr>
<td>How to find community based resources and services that are outside of the agency of which you are a client.</td>
<td>How to promote services that matches those for which a person is looking (even if those are outside of the agency that employs you.)</td>
</tr>
<tr>
<td>Vision of Recovery Training</td>
<td>Vision of Recovery Training</td>
</tr>
<tr>
<td>• New Freedom Commission</td>
<td>• New Freedom Commission</td>
</tr>
<tr>
<td>• Foundational Principles of Recovery</td>
<td>• Foundational Principles of Recovery</td>
</tr>
<tr>
<td>• What Are Consumer Driven Services?</td>
<td>• What Are Consumer Driven Services?</td>
</tr>
<tr>
<td>Empowerment Training</td>
<td>Sensitivity Training</td>
</tr>
<tr>
<td>• How to Participate in Your Treatment Planning</td>
<td>• Motivational Interviewing</td>
</tr>
<tr>
<td>• How to Collaborate with Health Care Providers</td>
<td>• How to collaborate with clients</td>
</tr>
<tr>
<td>• How to talk with the doctor; case manager; benefits representative</td>
<td>• How to encourage without taking over</td>
</tr>
<tr>
<td>• How to say what you need and find what you want.</td>
<td>• How to Use the Foundational Principles of Recovery</td>
</tr>
<tr>
<td>• How to Use the Foundational Principles of Recovery</td>
<td></td>
</tr>
<tr>
<td>What Are Evidence Based Practices and What Do They Mean to Me?</td>
<td>What are Evidence Based Practices and How Do We Use them in a Fee-for-service Environment?</td>
</tr>
<tr>
<td>How to Find Services that are Recovery Oriented</td>
<td>How to Provide Services that are Recovery Oriented</td>
</tr>
<tr>
<td>What are the Services Available to a Person Pursuing Mental Health Recovery? Where To Go To Get Them.</td>
<td>What are the Services Being Requested by Persons Pursuing Mental Health Recovery?</td>
</tr>
<tr>
<td>Wellness Recovery Action Plans</td>
<td>WRAP for Working Wellness for Mental Health Professionals - How to Stamp Out Burn-Out</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Time Management for Mental Health Recovery</td>
<td></td>
</tr>
</tbody>
</table>
Attachment C—Full Summary of Results
<table>
<thead>
<tr>
<th>Question</th>
<th>Adult Answers</th>
<th>Child/Parent Answer</th>
</tr>
</thead>
</table>
| Who do you call or contact if you (or your child) have a crisis? | 31.3%-Family Member  
12.28%-Doctor  
11.2%-Mental Health Center Staff  
9.8%-Friends or Peers  
9.8%-Hospital/E.R.  
9.8%-911/Police  
7.3%-Spiritual Resources  
2.4%-AA Hotline  
1.9%-Probation Officer/Lawyer  
1.4%-MHC Crisis Team  
<1%-Homeless Shelter  
-Guardian  
-GROW  
-TTY Hotline | 25%-Police  
18.7%-Therapist  
12.5%-Psychiatrist  
12.5%-Crisis line  
12.5%-SASS-2  
6.2%-Friends  
6.2%-ER  
6.2%-Parent Liason |
| Who do you call or contact first (or most often) if you have a question or concern about your services? | 84%-MHC Staff  
5%-Miscellaneous(NAMI, Members counsel, AA)  
2.9%-Family  
2.5%-Friend  
2.1%-Spiritual Resource  
1.2%-Crisis Line  
<1%-No one  
-Family/Patient Advocate  
-Other consumers | 25%-Caseworker  
25%-SASS  
25%-Community Residential Service Authority  
25%-No one |
| What about if you have a question or suggestion about your treatment plan? | 88.5%-MHC Staff  
2.7%-Friend  
2.2%-Family  
2.2%-No one/Unknown  
1.8%-Miscellaneous(WRAP, pharmacist)  
1.3%-Spiritual Resource  
<1%-Family/Patient Advocate | 50%-Staff  
25%-Therapist  
25%-Case Manager |
| Who do you call when you have a concern about your recovery or progress toward recovery? | 67.3%-MHC Staff  
13%-Friends  
13%-Family  
2%-GROW  
2%-Misc(AA, God, Crisis Line, etc.)  
1.3%-WRAP  
1%-No one | 33%-Psychiatrist  
33%-Therapist  
16%-Nurse  
16%-Program Manager-1 |
| When you think about how you currently connect to services, what might be different that would make it easier or more helpful for you? | 18.4%-Better communication  
17.7%-New information phone number/hotline  
11.9%-Assistance with finances  
11.2%-More availability with MHC staff contact  
9.8%-Better means of transportation  
6.4%-More receptive staff attitude  
5.8%-Improving my attitude/patience  
4.7%-More assisted living  
3.7%-Job services  
3%-More flexible appointment times  
2%-More choices in services  
2%-More flexible appointment times  
2%-More bilingual staff and doctors | 28.5%-Hotline/resource to services (brochures, pamphlets, manual, callcenter)  
28.5%-Respectful/Knowledgeable staff  
14.2%-School Social Worker  
7.1%-No waiting list  
7.1%-Transportation  
7.1%-Mental Health Specialist in Pediatrician’s Office  
7.1%-Better DMH website |
### DHS/DMH CONSUMER FOCUS GROUP FINAL DATA
Adult & C&A Condensed Version

<table>
<thead>
<tr>
<th>1.7% - Less staff turnover</th>
<th>1% - Staff Consistency</th>
</tr>
</thead>
</table>

#### Question Two

<table>
<thead>
<tr>
<th>How much input do you have into setting the goals and priorities on your treatment plan?</th>
<th>34.3% - A lot/90-100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>What specific things help you have meaningful input into and choice about your treatment plan goals and priorities?</td>
<td>33.3% - None</td>
</tr>
<tr>
<td>20% - Some/50-90%</td>
<td>12.3% - Very Little/10-50%</td>
</tr>
<tr>
<td>39.2% - Good rapport with staff</td>
<td>12.8% - Review of previous treatment goals</td>
</tr>
<tr>
<td>10.4% - Having hope</td>
<td>9.6% - Having goals</td>
</tr>
<tr>
<td>9.6% - Misc (God, past events, nurse, transp.)</td>
<td>8% - Supportive family and friends</td>
</tr>
<tr>
<td>7.2% - Keeping involved in the treatment plan</td>
<td>3.2% - Nothing/Unknown</td>
</tr>
</tbody>
</table>

#### Answers to 2A, 2B, 2C

- 20% - Parents need more knowledge about services/laws available
- 13.3% - Staff that respects parents
- 13.3% - Regular team meetings
- 13.3% - Trusting relationship with parents
- 6.6% - Transportation
- 6.6% - Child/Parent Friendly Language
- 6.6% - No labels
- 6.6% - Respite
- 6.6% - Staff consistency
- 6.6% - More time with treatment staff
### DHS/DMH CONSUMER FOCUS GROUP FINAL DATA
#### Adult & C&A Condensed Version

| How much input and choice do you have about which services you receive to help you meet those treatment plan goals and priorities? | 51.3% - Very little/10-50%
21.7% - A lot/90-100%
16.4% - Some/50-90%
10.5% - No choice |
| --- | --- |
| What specific things help you have meaningful input and choice about your services? | 32.9% - Knowing what you want/need
29.1% - Knowledge of available services
17.2% - Good rapport with staff
5.9% - Peer support
4.8% - Misc (Positive atmosphere, problem solving skills)
3.7% - Family support
1.6% - Spiritual resources
1% - Learning English |
| What specific things get in the way? | 16.3% - Non-supportive staff
15.8% - Symptomatology
10.9% - Lack of knowledge about services
8.7% - Lack of transportation
8.7% - Not enough staff time
7.1% - Limited understanding of services/illness
6% - Non-supportive family friends
6% - Lack of individually tailored services
5.4% - Lack of finances/benefits
5.4% - Time services are offered
4.3% - Stress
2.1% - Physical problems/limitations
2.1% - Not being seen as an equal
1% - Length of time until services available |
| How much input do you have into the quality of the services you receive? | 59.8% - Very Little/None
22.7% - Some/A little | 100% - None |
<table>
<thead>
<tr>
<th>Of the services you receive now, which are the most valuable in helping you meet your recovery goals?</th>
<th>18.1% Counseling (Therapist/Counselor, Case manager)</th>
<th>25% - Therapeutic Recreational Activities (Equine therapy, art therapy, music)</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.9% - Residential</td>
<td>15% - Therapeutic Behavioral Services</td>
<td></td>
</tr>
<tr>
<td>10.2% - Medication</td>
<td>15% - Social skills-3</td>
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<tr>
<td>8.8% - PSR</td>
<td>10% - Summer camps-2</td>
<td></td>
</tr>
<tr>
<td>5.1% DBT</td>
<td>10% - Medication-2</td>
<td></td>
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<tr>
<td>4.6% - Social Activities/Socialization</td>
<td>5% - Wrap around services</td>
<td></td>
</tr>
<tr>
<td>4.6% - Group therapy</td>
<td>5% - Mentoring</td>
<td></td>
</tr>
<tr>
<td>4.1% - Life skills development</td>
<td>5% - Life skills</td>
<td></td>
</tr>
<tr>
<td>3.7% - MISA</td>
<td>5% - Job Coach</td>
<td></td>
</tr>
<tr>
<td>3.2% - Job skills Training/Vocational</td>
<td>5% - Special Education</td>
<td></td>
</tr>
<tr>
<td>2.7% - Substance Abuse Treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.7% - Medical Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.7% - Relaxation/Fitness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.7% - Family/Peers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.7% - WRAP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.8% - Spiritual Resources</td>
<td></td>
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<tr>
<td>1.3% - Transportation</td>
<td></td>
<td></td>
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<tr>
<td>1.3% - Nothing</td>
<td></td>
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</tr>
<tr>
<td>1.3% - ACT</td>
<td></td>
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</tr>
<tr>
<td>&lt;1% - Education/College</td>
<td></td>
<td></td>
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<tr>
<td>- GROW</td>
<td></td>
<td></td>
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<tr>
<td>- Weekend Services</td>
<td></td>
<td></td>
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<tr>
<td>- Art Therapy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
DHS/DMH CONSUMER FOCUS GROUP FINAL DATA  
Adult & C&A Condensed Version

<table>
<thead>
<tr>
<th>Are there some services you wish you could receive that would help you achieve your recovery goals?</th>
<th>16.7%-Job Support/Vocational</th>
<th>28.5%-Therapeutic Recreational Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14.1%-Budgeting</td>
<td>21.4%-Life Skills</td>
</tr>
<tr>
<td></td>
<td>10.4%-Benefit Assistance</td>
<td>14.2%-Camps</td>
</tr>
<tr>
<td></td>
<td>8.3%-Substance Abuse Services</td>
<td>14.2%-Respite</td>
</tr>
<tr>
<td></td>
<td>8.3%-Housing</td>
<td>7.1%-Religious services</td>
</tr>
<tr>
<td></td>
<td>4.1%-Education</td>
<td>7.1%-Social skills group</td>
</tr>
<tr>
<td></td>
<td>4.1%-WRAP</td>
<td>7.1%-Group respite for teenagers</td>
</tr>
<tr>
<td></td>
<td>3.6%-DBT</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.1%-Relationship/Grief Counseling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.1%-Residential</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.6%-Group Services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.6%-Parenting/Daycare</td>
<td></td>
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<tr>
<td></td>
<td>2%-MISA</td>
<td></td>
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<td></td>
<td>2%-Transportation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.5%-Case Management</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.5%-GROW</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.5%-Legal Services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&lt;1%-Rep Payee,PSR,Doctor services,Legal services,Drop in center,Community support ,ACT,Anger management,Peer support</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question Four</th>
<th>15.9%-Fitness</th>
<th>50%-Transportation</th>
</tr>
</thead>
<tbody>
<tr>
<td>First, are there some services that are available now but you cannot receive them because of when or where they are offered? What are they?</td>
<td>14.4%-Therapy/Counseling</td>
<td>12.5%-Psychiatrist</td>
</tr>
<tr>
<td></td>
<td>11.5%-Trauma Groups</td>
<td>12.5%-More evening services</td>
</tr>
<tr>
<td></td>
<td>8.6%-Recreation</td>
<td>12.5%-Locations inconvenient</td>
</tr>
<tr>
<td></td>
<td>8.6%-PSR</td>
<td>12.5%Special recreation</td>
</tr>
</tbody>
</table>
If you have had the experience of getting better and getting more involved in school, work, or community, were the services you needed still conveniently available? How or how not?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>77.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>22.8%</td>
</tr>
</tbody>
</table>

83%-Services only available during working hours
16.6%-Not enough night and weekend services

Question Five

Imagine it is next January and you have been making progress toward your recovery goals. What would it look like for you in:
Your living arrangements/at home?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent living in own house/apartment</td>
<td>54.1%</td>
</tr>
<tr>
<td>Residential Home Living</td>
<td>6.3%</td>
</tr>
<tr>
<td>Own a vehicle</td>
<td>5.7%</td>
</tr>
<tr>
<td>Out of state hospital</td>
<td>5%</td>
</tr>
<tr>
<td>Stable on medicines</td>
<td>5%</td>
</tr>
<tr>
<td>Mre Enthusiasm</td>
<td>4.4%</td>
</tr>
<tr>
<td>Reunite with family</td>
<td>4.4%</td>
</tr>
<tr>
<td>More money</td>
<td>3.8%</td>
</tr>
<tr>
<td>Out of Public Housing</td>
<td>3.1%</td>
</tr>
</tbody>
</table>

Answers to 5A,5B,5C

50%-Still in services
16.6%-No longer need services
16.6%-Still on medication
16.6%-Involved in community activities
### DHS/DMH CONSUMER FOCUS GROUP FINAL DATA
#### Adult & C&A Condensed Version

<table>
<thead>
<tr>
<th>Topic</th>
<th>Percentage</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.9% - More time w/ children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1% - Driving</td>
<td></td>
<td></td>
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<tr>
<td>- Better clothes</td>
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<tr>
<td>- Off medicine</td>
<td></td>
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<tr>
<td>- Job, Free Time</td>
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<tr>
<td>- Church</td>
<td></td>
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<tr>
<td>- Save money</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Relationship w/ others</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Your school or work?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51.6% - Have a job/trade</td>
<td></td>
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<tr>
<td>38.7% - Pursue education/College</td>
<td></td>
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<tr>
<td>5.5% - Recovery Support Specialist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.3% - Working in Mental Health Field</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.8% - Volunteering</td>
<td></td>
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<tr>
<td><strong>Your treatment and services?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.4% - Doctor services-14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.2% - Medical services-11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.7% - Medicine compliance-7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.7% - Services reduced/no services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.3% - Treatment compliance-6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.3% - Therapy-6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.9% - No longer need payee-5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.9% - Meds reduced/off meds-5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.1% - PSR-3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.7% - Services match goals-2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.3% - Trust in services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.3% - Group home,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.3% - Case management</td>
<td></td>
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</tr>
<tr>
<td>1.3% - More services</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Question Six

If you could wave that magic wand and get just one thing that improve the Illinois service system for you or your child, what would it be?

<table>
<thead>
<tr>
<th>18%</th>
<th>Increase funding for mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.4%</td>
<td>More staff</td>
</tr>
<tr>
<td>10.5%</td>
<td>More peer counselors</td>
</tr>
<tr>
<td>7.4%</td>
<td>More vocational services</td>
</tr>
<tr>
<td>6.8%</td>
<td>Client driven treatment</td>
</tr>
<tr>
<td>6.2%</td>
<td>Reduce stigma</td>
</tr>
<tr>
<td>6.2%</td>
<td>Residential homes</td>
</tr>
<tr>
<td>5.5%</td>
<td>Caring/Qualified staff</td>
</tr>
<tr>
<td>3.7%</td>
<td>More recovery services</td>
</tr>
<tr>
<td>3.1%</td>
<td>Input valued</td>
</tr>
<tr>
<td>3.7%</td>
<td>Better transportation</td>
</tr>
<tr>
<td>2.4%</td>
<td>Financial Assistance</td>
</tr>
<tr>
<td>1.8%</td>
<td>More social/recreational activities</td>
</tr>
<tr>
<td>1.8%</td>
<td>Affordable meds</td>
</tr>
<tr>
<td>1.8%</td>
<td>Substance Abuse Treatment</td>
</tr>
<tr>
<td>1.2%</td>
<td>Daycare services</td>
</tr>
<tr>
<td>1.2%</td>
<td>Improved meds</td>
</tr>
<tr>
<td>1.2%</td>
<td>More psychiatric services</td>
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<tr>
<td>1.2%</td>
<td>Improved family education</td>
</tr>
<tr>
<td>&lt;1%</td>
<td>Respite center</td>
</tr>
<tr>
<td></td>
<td>Prevention services</td>
</tr>
<tr>
<td>14%</td>
<td>Improved transition to adult program</td>
</tr>
<tr>
<td>14%</td>
<td>Holding schools accountable</td>
</tr>
<tr>
<td>14%</td>
<td>Providers work as a team</td>
</tr>
<tr>
<td>14%</td>
<td>Central directory of services</td>
</tr>
<tr>
<td>14%</td>
<td>Parents on all levels of advisory counsel</td>
</tr>
<tr>
<td>14%</td>
<td>Easier access</td>
</tr>
<tr>
<td>14%</td>
<td>More Family Resource Developers</td>
</tr>
</tbody>
</table>
Attachment D—Definition of Terms/HUH Booklet
Department of Human Services/ 
Division of Mental Health

This dictionary was developed by the Consumer Empowerment Project in July 1994 and updated in January 2005. It is provided to help you better understand the Vocabulary of the Mental Health System of Care.
ACT: The acronym for Assertive Community Treatment.

ADA: The acronym for the Americans With Disabilities Act.

Accreditation: A process establishing that a program or hospital complies with nationally-recognized standards of care. All hospitals and community programs in Illinois are accredited. The following organizations set standards of care:

Accreditation Manual for Hospitals (Joint Commission on Accreditation of Healthcare Organizations (JCAHO), One Renaissance Blvd., Oakbrook Terrace, Illinois 60181, 1993);

Manual for Agency Accreditation (Council on Accreditation of Services for Families and Children (COA), 520 Eighth Ave., Suite 2202B, NY, NY 10018, 1992);

Mental Health Standards (Joint Commission on Accreditation of Healthcare Organizations (JCAHO), One Renaissance Blvd., Oakbrook Terrace, Illinois 60181, 1993);

Standards for Services for People with Developmental Disabilities (Accreditation Council for Services for Developmentally Disabled Persons (Council), 8100 Professional Place, Suite 204, Landover, MD 20785, 1990);


Acronym: A word created by taking the first letter or letters of a few words in a phrase or title. For example: COC stands for Continuity of Care. This is a type of professional short-hand that can save time, but may confuse those not familiar with the acronym. Always explain any acronym you use or ask for clarification if you don’t understand the speaker.

Acute: A sudden, serious or emergency-type situation or condition that isn’t expected to last long. An acute illness or situation is the opposite of a chronic one.

Acute Care: The services and treatment provided to a person in an emergency or crisis situation.

Acute Care Facility: A place that provides emergency or crisis services, such as an emergency room or respite care beds.

Adulthood: An individual who is 18 years of age or older or a person who is emancipated pursuant to the Emancipation of Mature Minors Act [750 ILCS 30].

Advance Directives: A consumer’s choice to designate treatment options which may be needed in the future.

Advisory Council: A group formed to give advice, feedback and ideas to people who make the decisions. There are many different kinds of advisory councils. There is a statewide Advisory Council and an Advisory Council serving each Comprehensive Mental Health Network.
Advocate: A person who works to ensure that consumers receive the kinds of services and treatment they need.

Agenda: A written list of topics to be discussed during a meeting. An agenda should be provided ahead of time to the meeting members so they can be thinking about ideas they wish to discuss. If you want to have something discussed that isn't on the agenda, you should call the person in charge of the meeting and ask to have your topic included.

Allocation: Money set aside to be used for a specific purpose. See Budget.

Americans With Disabilities Act (ADA): A civil rights law for people with disabilities. ADA requirements cover (a) employment practices by units of state and local government, (b) programs, services, and activities of state and local government, and (c) public accommodations and commercial facilities.

Array of Services: These are the different types and levels of mental health service that may be available to consumers. A person may select the ones that best meet his/her needs.

Assertive Community Treatment (ACT): ACT is a special program to provide assertive case management and other services to selected individuals. It is a unique treatment model in which the majority of direct services are provided internally by the ACT program in the client’s regular environment. This program is available only in areas which have received ACT grants.

Baseline: Information collected about what’s going on now. This information is then used to plan for the future.

Bill: An idea or a suggestion for a new law that is being discussed by the legislature.

Board: A group of people who is responsible for making decisions. A mental health agency usually has a Board of directors to make policy and budget decisions for that agency. Other important boards are 553 Boards and 708 boards.

553 Board: A county public health department board. Not all counties have such boards, but in those who do, many mental health services are funded and monitored by this board.

708 Board: A governmental board formed in some communities to fund mental health services through taxes. See also Mental Health Authority.

Budget: A plan for spending money. See also capital budget, line item and operating budget.

Bureau of the Budget: The State agency responsible for coordinating state funds under the supervision of the governor.
CAFAS: The acronym for Child and Adolescent Functional Assessment Scale.

C&A: The acronym for Children and Adolescent.

CARES:

CARE: The acronym for Certification and Accreditation of Rehabilitation Facilities.

CARS: The acronym for the Consolidated Accounting and Reporting System.

CASSP: The acronym for the Child and Adolescent Service System Program.

CBHA: The acronym for the Community Behavioral Health Association.

CCSN: The acronym for Comprehensive Community Service Networks.

CGAS: The acronym for the Children's Global Assessment Scale.

CHIPS: The acronym for Community Hospital Inpatient Psychiatric Services.

CMHC: The acronym for a Community Mental Health Center.

CMS: The acronym for Central Management Services.

COCA: The acronym for Continuity of Care Agreement.

CQI: The acronym for Continuous Quality Assurance

CQI: The acronym for Continuous Quality Improvement.

Cap: To put a limit on how much money can be spent.

Capital Budget: The plan to spend money for new equipment, property, buildings and improvements to buildings.

Capitation: Providing money or funding based upon the number of clients who are receiving services.

Care Management: Making sure that an individual receives the appropriate kinds of services they need. These services include direct support services as well as coordination of services, treatment planning and monitoring. This includes choosing from the full range of case management services available.

Case Management: This is not a service but a group of services which provide linkage, support and advocacy for persons with mental illnesses who need multiple services and require assistance in gaining access to and in using mental health, health, social, vocational, educational and other community services and resources.

Central Management Services (CMS): A State agency which provides a broad range of programs and services to other State agencies and to the general public, ranging from personnel and employee benefits to management of numerous properties around the state.
Certification: This is a process whereby an agency applies to an accrediting body who surveys the agency to assure that they meet the standards, requirements of that licensing body. An agency may be certified by one or more of several accrediting bodies. (e.g., CARF, JCAHO) All mental health providers who receive funds from the Division of Mental Health must be certified by an acceptable national organization. Some mental health professionals may be licensed also.

Child and Adolescent (C&A): For the Department and DOC, an individual who is 17 years of age or younger. For DCFS, an individual who is 17 years of age or younger, except for an individual 18 years of age but less than 21 years old, who was receiving child welfare services from DCFS prior to his or her 18th birthday and continues to receive such services following his or her 18th birthday.

Child and Adolescent Functional Assessment Scale (CAFAS): An assessment tool used to evaluate a child’s functioning in the home, school, and community.

Chronic: A situation or illness that lasts for a long time. See also acute.

Client-centered consultation: A mental health service which provides individual, patient-focused professional communication between DMH community agency staff, or staff of other agencies, or with others (including family members) who are involved with providing services to persons with mental illnesses for the purpose of implementing or evaluating the treatment plan.

Coalition: A group of people who are working together to reach a special goal.

Collaborate: To work together.

Committee: A group of people within an organization who are responsible for a specific task - example: The “housing committee” is in charge of any issues about housing. See also subcommittee.

Community Behavioral Health Association (CBHA): A statewide trade organization that keeps member mental health agencies informed about issues affecting their programs and helps advocate for mental health and mental health agency concerns.

Confidentiality Act: The Mental Health and Developmental Disabilities Confidentiality Act [740 ILCS 110].

Consensus: A decision or agreement made by a group of people through discussion and compromise rather than taking sides and voting.

Consolidated Accounting and Reporting System (CARS): An accounting and reporting system used by the Department of Human Services (DHS).

Consortium: A group of people from different organizations who work together to reach goals they all have.

Consumer: A person who uses or has used mental health services or resources. See also Primary consumer and Secondary consumer.

Consumer Provider: A mental health service provider who is or has also been a consumer of mental health services. Sometimes referred to as a prosumer.

Consumer Representative (Consumer Rep): A consumer who has been chosen by a group of other consumers to speak for them at official meetings such as the Steering Committee or Advisory Council meetings.

Consumer Services Specialist: A person who uses or has used mental health services or resources who works for the Division of Mental Health in the role of change agent. They recommend policy changes, insure the consumer voice is heard, provide staff training on recovery and other consumer issues, provide peer support and serve on various committees.
Continuity of Care Agreement (COCA): An agreement between providers of mental health services to work together when a person is being transferred from one provider to another. This is most often discussed as an agreement between a State Operated Hospital and a community agency.

Contract Manager: DMH staff who work in each of the Regions whose primary responsibility is to help community mental health agencies implement DMH policies and procedures. These persons help the flow of information between networks, State Operated Hospitals and community agencies. You are encouraged to share your questions and concerns with them!

Cost Effective: Getting your money’s worth!

Crisis-Emergency Services: Service provided according to Division of Mental Health guidelines to ensure consumers have access to psychiatric services during a crisis or emergency. Crisis services provide a rapid response to person in a mental health crisis. Services may include: 24 hour telephone response, a mobile crisis team, crisis residential beds.

Decisions Depend on You!

DASA: The acronym for the Division of Alcoholism and Substance Abuse.


DD: The acronym for developmental disability.

DDD: The acronym for Division of Developmental Disabilities.

DHS: The acronym for the Department of Human Services.

DMH: The acronym for the Division of Mental Health.

DPA: The acronym for Department of Public Aid.

DRS: The acronym for the Division of Rehabilitation Services.

DSM-IV-R: The acronym for the fourth edition, revised, of the Diagnostic and Statistical Manual.

Dx: The medical abbreviation for diagnosis.

Data: Information, facts and figures.

Deflection: Finding appropriate treatment and services for a person in his/her community so that unnecessary hospitalization is avoided.

Department of Children and Family Services (DCFS): State agency which provides child welfare services.

Department of Human Services (DHS): State agency dedicated to helping families and individuals move toward self-sufficiency and maximum independence.
Department of Public Aid (DPA): State agency that provides income support to persons below the poverty level. This agency also regulates Medicaid.

Diagnostic and Statistical Manual (DSM): A guidebook used by mental health professionals to make and classify a diagnosis of a mental illness.

Division of Alcoholism and Substance Abuse (DASA): The State agency responsible for regulating alcoholism and substance abuse services throughout the state.

Division of Developmental Disabilities (DDD): State agency which provides services and supports for individuals with developmental disabilities to achieve as much independence as possible and to live in their home communities with families and friends.

Division of Mental Health (DMH): The State agency responsible for funding and regulating mental health services throughout the state.

Division of Rehabilitation Services (DRS): The State agency responsible for regulating rehabilitation services throughout the state.

Dually Diagnosed: A person who has two significant conditions which need treatment. This most often means a person who has either a mental illness and a developmental disability (MI/DD) or one who has a mental illness and a substance abuse problem (MISA).

Experience Empowerment!


Emergency Psychiatric Services (EPS): State funds for inpatient psychiatric treatment for children, adolescents, and adults in private hospitals who are indigent.

Entity: An organization, usually a service provider or funder.

EPS Banker: The agency responsible for the funds for Emergency Psychiatric Services.

Find Out!

FFP: The acronym for Federal Financial Participation.

FSQ: The acronym for Family Satisfaction Questionnaire.

FY: The acronym for fiscal year.

Facilitate: To help something to happen such as a meeting, class or group therapy. The person who facilitates is...
called a facilitator.

**Facility**: A place that provides some kind of service.

**Family Counseling**: A mental health service in which one or more mental health staff meets with a person with a mental illness and his or her available family members or with his or her family members on their behalf in ongoing periodic formal sessions to deal with daily living issues associated with the client's emotional, cognitive or behavioral problems which are significantly impacted on by current family interactions. This counseling approach uses a variety of supportive and re-educative techniques.

**Family Therapy**: A mental health service in which one or more professionals deliberately establish a relationship with a person with a mental illness and his or her immediate family or with his or her family on the their behalf in ongoing periodic formal sessions when the client's problems are perceived to be substantially due to impaired relations within the family. The goal is to modify family relationships which will help reduce the client's symptoms of emotional, cognitive or behavioral disorder.

**Feasible**: Able to be done or accomplished. See also **Feasibility Study**.

**Feasibility Study**: The research done to find out if something is “do-able.”

**Federal Financial Participation (FFP)**: Money provided by the federal government to pay for mental health services.

**Fiscal Year (FY)**: The special way organizations have of organizing their time to plan programs and budgets. There is a federal fiscal year that runs from October 1 to September 30. The State fiscal year goes from July 1 to June 30. Some organizations have a fiscal year that is the same as the calendar year - January 1 to December 31. This can all become very confusing! For example, in July of 2005, we will be in the State fiscal year of 2006.

**Focus Group**: A group who meets to discuss a specific issue.

**Forensic**: Having to do with legal matters. Forensic issues will most likely refer to programs and services available or needed for persons with mental illnesses who have also become involved with the legal system.

**Forum**: An opportunity to listen to a speaker or speakers and then voice your own opinion.

**Funds**: Money available for a specific purpose. See also **allocation**.

**GAAP**: The acronym for generally accepted accounting practices.

**GAC**: The acronym for the Guardianship and Advocacy Commission.

**GAF**: The acronym for Global Assessment of Functioning.

**GIA**: The acronym for grant-in-aid.

**GRF**: The acronym for General Revenue Fund.

**Gap**: This refers to a service that is not available in your area.

**Gatekeeper**: An agency or person within an agency who decides who may use certain services.
Generally Accepted Accounting Practices (GAAP): The standard way of keeping track of money used in business.

General Revenue Funds (GRF): Tax money the state collects to use for the wide variety of programs it funds, including mental health services.

Geocode: A special number assigned to each community in Illinois by the DMH to help keep track of how many persons are using mental health services there. This helps in the process of planning where more services might be needed.

Geropsychiatric: Special services for elderly persons with mental illnesses.

Grant: Money given by one organization to another for a specific purpose. The federal government gives State government grants to provide mental health services. The states then give grants to mental health agencies to operate their programs. Grants may also be given for specific projects and programs. There are rules to follow about who may receive a grant and how the money is to be spent.

Grant-in-Aid (GIA): Money given to community agencies to provide mental health services in that community.

Group Counseling: A mental health service in which one or more mental health staff meets with two or more persons with mental illness in ongoing periodic formal sessions to deal with daily living issues associated with their emotional, cognitive or behavioral problems using a variety of supportive and re-educative techniques.

Group therapy: A mental health service in which one or more professionals deliberately establish a relationship with two or more persons with mental illness seen simultaneously in periodic formal sessions with the goal of reducing the symptoms of emotional, cognitive or behavioral disorder and promoting positive emotional, cognitive, and behavioral development.

GROW: A self help organization for persons with mental illnesses that offers specific steps for recovery. GROW receives some funding from the DMH and is, in some areas, considered to also be a service provider. GROW is not an acronym.

Guardian: The court-appointed guardian or conservator of the person under the Probate Act of 1975 [744 ILCS 5] or a temporary custodian or guardian of the person of a child appointed by an Illinois juvenile court or a legally-appointed guardian or custodian or other party granted legal care, custody and control over a minor child by a juvenile court of competent jurisdiction located in another state whose jurisdiction has been extended into Illinois via the child’s legally authorized placement in accordance with the applicable interstate compact. (The Juvenile Court Act of 1987; Interstate Compact on the Placement of Children [45 ILCS 15]).

Guardianship and Advocacy Commission (GAC): The State agency that makes sure the rights of a persons with mental illnesses and other disabilities are protected. The central intake Number is 708-338-7500.

Hope!: The acronym for House Bill.

HIPAA: The acronym for Health Insurance Portability and Accountability Act.

HMO: The acronym for Health Maintenance Organization.

HUD: The acronym for Housing and Urban Development.

Hx: The medical abbreviation for history.
Health Maintenance Organization (HMO): An organization which hires health care professionals to provide services to its members. This is a form of health insurance, but you are limited to the services and providers selected by the HMO. This arrangement is also a form of Managed Care.

House Bill (HB): A proposed law that is being considered by the “house” branch of the Illinois Legislature.

Housing and Urban Development (HUD): The federal agency that provides funds for a variety of housing programs such as low income housing.

**Invest In Your Future!**

ICF: The acronym for Intermediate Care Facility.

ICF/MI: The acronym for Intermediate Care Facility/Mentally Ill.

ICG: The acronym for Individual Care Grant.

IFF: The acronym for Illinois Federation of Families.

IMHPAC: The acronym for the Illinois Mental Health Planning & Advisory Council.

ITP: The acronym for Individual Treatment Plan.

Illinois Federation of Families (IFF): A family advocacy and support group. Phone 1-630-858-1649 for information.

Implement: To put an idea or program into practice or operation.

Illinois Mental Health Planning & Advisory Council: The State council, mandated by federal law, which is comprised of consumers, family members, stakeholders and advocates, which serves to review the State’s application for Block Grant funding, advocates for services for adults with serious mental illnesses and children with serious emotional disturbances, and serves to monitor and evaluate the State’s mental health planning systems.

Implementation Planning: The process of deciding how to put an idea or program into practice or operation.

Individual Care Grant (ICG): A program to assist parents who are seeking funding for services for a child who has a serious emotional disturbance or mental illness. Call 1-773-794-4884 for information.

Individual Counseling: A mental health service in which one mental health staff person meets with one person with a mental illness in ongoing periodic formal sessions, and uses relationship skills to promote their ability to deal with daily living issues associated with his or her emotional, cognitive or behavioral problems.

Individual Therapy: A mental health service in which a professional deliberately establishes a relationship with a person with a mental illness in ongoing periodic formal sessions with the goal of ameliorating or reducing the symptoms of emotional, cognitive or behavioral disorder and promoting positive emotional, cognitive and behavioral development.

Individual Treatment Plan (ITP) or Treatment Plan: A written document developed by the appropriate service provider staff with the participation of the person with a mental illness and, if applicable, their guardian, which specifies the
Listen!
Learn! Lead!

person's choice of services to address their needs.

Initiative: A proposal for new idea, program or law.

Input: Sharing your ideas, suggestions or opinions with others, especially when planning mental health services.

Inspector General: The department and/or person within DMH who investigates complaints about mental health services.

Integration of Services: The process of coordinating services from different programs or agencies to meet the needs of persons with mental illnesses.

Intermediate Care Facility (ICF): A place that provides long term 24 hour care and supervision for its residents.

Intermediate Care Facility/Mentally Ill (ICF/MI): A residential facility that provides long term 24 hour care and supervision for persons who have mental illnesses.

Join!

JCAHO: The acronym for the Joint Commission on Accreditation of Health Care Organizations.

JCAR: The acronym for the Joint Committee on Administrative Rules.

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Joint Commission on Accreditation of Health Care Organizations (JCAHO): An organization that sets standards of quality for hospitals and other health care providers (including mental health services) and regularly inspects to make sure quality care is being given.

Joint Committee on Administrative Rules (JCAR): A committee made up of members of the State legislature who make sure a proposed rule is appropriate.

Knowledge is Power!
**LAN:** The acronym for Local Area Network.

**LCPC:** The acronym for a Licensed Clinical Professional Counselor.

**LCSW:** The acronym for Licensed Clinical Social Worker.

**LOS:** The acronym for Length of Stay.

**LPHA:** The acronym for Licensed Practitioner of the Health Arts.

**LTC:** The acronym for Long Term Care.

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**Licensed Clinical Professional Counselor (LCPC):** Someone with a master's degree in psychology, counseling or a related field who has been licensed as an LCPC according to the State guidelines.

**Legislator:** A member of the legislature.

**Legislature:** The part of the government that creates and passes laws.

**Length of Stay (LOS):** The average length of time an individual receives services.

**Level of role functioning:** For adults, refers to the person's level of functioning in everyday life in three critical areas including vocational/educational productivity, independent living and self-care, and social network relationships. For adults, rating scales such as the GAF, Global Assessment of Functioning or the (SLOF) Specific Level of Functioning Assessment, shall be used to assess the severity of the impairment in role functioning for the purpose of initiating services but shall not be used as the criteria for termination or discontinuation of services. For children and adolescents, these areas include family/home, school and community. Scales approved for use with children and adolescents include, but are not limited to the (CGAS) Children's Global Assessment Scale and the CFAS the Children’s Functional Ability Scale.

**Liaison:** A person or organization who helps two or more groups work together better - especially to coordinate services.

**Licensed Clinical Social Worker (LCSW):** A person who has a master’s degree in Social Work and has also been licensed by the State. Not all social workers are licensed.

**Licensed Practitioner of the Health Arts (LPHA):** Provides services in the community. A clinical psychologist licensed under the Clinical Psychologist Licensing Act [225 ILCS 15], a licensed clinical social worker (LCSW) licensed under the Clinical Social Work and Social Work Practice Act [225 ILCS 20] or a clinical professional counselor holding a permanent license pursuant to the Professional Counselor and Clinical Professional Counselor Licensing Act [225 ILCS 107].

**Line Item:** The part of a budget that tells how much is to be spent for a specific purpose.

**Lobby:** To try to convince a group or organization to listen and respond to your point of view or needs. This is most often used when talking about efforts to get the State legislature to fund mental health services.

**Local Area Network (LAN):** This is a planning group made up of providers and consumers who plan for mental health services in pre-determined geographic areas.
Mental Illness Is Not The End of The World!

MCAS: The acronym for Multnomah Community Ability Scale.

MHA: The acronym for Mental Health Association.

MHP: The acronym for Mental Health Professional.

MHSIP: The acronym for Mental Health Statistics Improvement Project.

MHT: The acronym for Mental Health Technician.

MI: The acronym for mental illness or mentally ill.

MI/DD: The acronym for the dual diagnosis of Mental Illness/Developmental Disability.

MIS: The acronym for Management Information System.

MI/SA: The acronym for Mental Illness/Substance Abuse.

MRO: The acronym for Medicaid Rehabilitation Option.

MSW: The acronym for Master of Social Work.

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Managed Care: The general term for a variety of systems or programs to keep down the cost of mental health services. In these plans, a person's need for services is reviewed and approved or rejected by someone other than the service provider.

Management Information Services (MIS): The branch of DHS which provides timely, reliable, user-friendly computer services for all staff within the Department.

Mandatory: Something that must be done.

Master of Social Work (MSW): The educational degree given to a person who has completed social work training at the graduate level (beyond four years) of college.

Matrix: An outline that explains how something should be done or organized.

Maximizing Resources: Making the best possible use of the money, services, programs and people available. See also cost effective.

Medicaid: The public system of paying for health services for persons who have little or no income. This includes some mental health services.
Medicaid Community Mental Health Services Program: Mental health services which are provided by an agency which has a contract with DMH and has been approved by the Department of Public Aid for Medicaid certification. These services are described in Rule 132.

Medicaid Rehabilitation Option (MRO): Mental health services provided in a mental health clinic which may be paid by Medicaid if certain requirements are met. One of the biggest requirements is that the agency providing the services have Medicaid Certification. These requirements are described in Rule 132 which is the Medicaid Community Mental Health Services Program.

Medicaid Rehabilitative Services Option: Mental health services which are provided in a community setting by an agency that has Medicaid Certification. These services are paid for by Medicaid.

Medicare: The national system to pay for health care expenses of persons who are elderly or disabled through Social Security funds.

Mental Health Assessment: The formal process of gathering into a written report(s) demographic data, presenting problems, history or cause of illness, history of treatment, psychosocial history and current functioning in emotional, cognitive, social and behavioral domains through a face-to-face or personal contact with the client and collaterals. This helps determine mental health service needs and in making recommendations for services appropriate for the individual.

Mental Health Association (MHA): An organization formed to educate and advocate about mental health issues. The organization is active on national, State and local levels. For more information, you may call (312) 368-9070.

Mental Health Authority: An organization which may be formed by a 708 Board to oversee mental health services in a community. Not all communities have a Mental Health Authority and each of those who do, organize them differently.

Mental Health Code: The set of rules that describes how the DMH and the mental health system in Illinois is supposed to operate.

Mental Health Professional (MHP): A person who provides mental health services under the supervision of a QMHP. This person must have a bachelor’s degree, a practical nurse license or five years supervised experience in mental health or human services. These qualifications are necessary to meet Medicaid Certification.

Mental Health Technician (MHT): A person who provides mental health services, usually under supervision of a nurse, at one of the DMH State Operated Facilities. The person must be 18 years of age and completed established standardized training.

Mental Illness (MI): A mental or emotional disorder verified by a diagnosis contained in the DSM-IV or ICD-9-CM which substantially impairs a person's cognitive, emotional and/or behavioral functioning. This includes individuals with a dual diagnosis of mental retardation or psychoactive substance abuse disorders as long as a mental illness is the principal diagnosis.

Mental Illness/Developmental Disabilities (MI/DD): Used to refer to these two conditions combined (dual diagnosis), or to a person who has these two conditions ("MI/DD client," for example).

Mental Illness/Substance Abuse (MISA): Used to refer to these two conditions combined (dual diagnosis), or to a person who has these two conditions ("MISA Client," for example).

Minutes: The written record kept of what happens at a meeting.

Motion: The formal way of making a suggestion at a meeting so that it may be voted on. A person might say, “I make a motion that we have a meeting next Tuesday.” See also Parliamentary Procedure.

Multnomah Community Ability Scale (MCAS): A scale which is a part of aftercare planning. It rates readiness for the transition from the hospital to the community.
NAMI: The acronym for National Alliance of the Mentally Ill.

NASMHPD: The acronym for the National Association of State Mental Health Program Directors.

NGRI: The acronym for Not Guilty by Reason of Insanity.

NIMH: The acronym for National Institutes of Mental Health.

National Alliance for the Mentally Ill (NAMI): An organization of people who have family members with a mental illness, persons with mental illness and anyone interested in mental illness, that offers emotional support, information and advocacy. You can call 1-800-346-4572 for the location of the group nearest you.

National Association of State Mental Health Program Directors (NASMHPD): A non-profit organization dedicated to serving the needs of the nation’s public mental health system through policy development, information dissemination, and technical assistance.

National Institutes of Mental Health (NIMH): The federal agency for research on mental and behavioral disorders.

Negotiate: To discuss an issue and reach an agreement that is acceptable to everyone concerned. Usually this involves some “give and take.”

Network: To work together with other service providers or to form such working relationships. This requires cooperation!

Network Meetings: Meetings held within Networks. Everyone in the community who is concerned or would like to voice an opinion about mental health and State Operated Hospital services are encouraged to participate.

Networks: A Division of Mental Health structure for organizing services for persons with mental illnesses.


Omnibus Reconciliation Act of 1987: A federal law which requires that persons with mental illnesses who do not have physical health needs requiring skilled nursing care cannot be housed in a nursing home. Since this had happened to many people, communities had to develop more community support services, especially housing, for persons with mental illness.
mental illnesses.

**Open meetings**: Meetings which anyone can attend.

**Operating Budget**: The part of the budget that includes costs for things such as salaries, supplies, travel, rent of office space and other things needed to do agency business.

**Outcome-Based Services**: Programs and services which must show they get positive results in order to continue to receive funding.

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**Participate!**

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**PAS**: The acronym for **Pre-Admission Screening**.

**PI**: The acronym for **Performance Indicators**.

**PIT**: The acronym for **Performance Improvement Team**.

**PL**: The acronym for **Public Law**.

**POC**: The acronym for **Point of Contact**.

**PPO**: The acronym for **Preferred Provider Organization**.

**PRN**: An abbreviation for the Latin term *take as needed*.

**PSR**: The acronym for **Psychosocial Rehabilitation**.

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**Paradigm**: A model or plan for doing something.

**Parity**: Equality.

**Parliamentary Procedure**: A formal way of conducting a meeting that involves following an agenda, making and seconding motions and voting.

**PAS Agent**: The person or agency responsible for **Pre-Admission Screening**.

**Peer Support and Socialization**: Structured and unstructured social activities that encourage social interaction and provide opportunities for relationship building.

**Performance Indicators (PI)**: Ways to measure how well a program or person is doing in meeting their responsibilities.

**Plenary**: A meeting which anyone may attend.

**Point of Contact (POC)**: The person within an organization you would need to talk to, to get information.

**Point of Entry**: The person within an agency who you would need to talk to, to get involved with that agency's services. See also *gatekeeper*.

**Policies**: The written rules or guidelines an agency follows to do its business.
Pre-Admission Screening (PAS): The process of evaluating a person to decide if it is appropriate to admit him/her to certain mental health programs such as an SOF or ICF-MI.

Preferred Provider Organization (PPO): An agency that has a contract or agreement with an HMO, managed care system, insurance company or other organization to provide services in their area.

Primary Consumer: A person with a mental illness who uses or has used mental health services.

Priority: The most important thing to do. To “prioritize” or “set priorities” is to make a list of all the things to be done in order of their importance.

Priority Population: The State mental health system must first serve persons with the greatest need for mental health services who can’t afford private care. See also Target Population.

Procedure: A plan or method for doing something.

Program Book: Lists all community services funded by the Division of Mental Health.

Projection: A plan based on “guesses” about what might happen in the future.

Protocol: A written plan for doing something.

Psychiatric Evaluation: An in-depth evaluation of the client conducted by a psychiatrist, or a physician with training in mental health services or one year of clinical experience, under supervision, in treating problems related to mental illness. The psychiatric evaluation covers all aspects of assessment generally accepted as reasonable clinical practice in the field of psychiatry including a statement of assets and deficits and results in a formulation of problems, diagnosis, and treatment recommendations.


Psychological Assessment: An assessment of the client's functioning in emotional, cognitive, intellectual and/or behavioral domains by a licensed clinical psychologist consistent with the Clinical Psychologist Licensing Act using nationally standardized psychological assessment instruments. The assessment results in a formulation of problems, tentative diagnosis and recommendation for treatment or service(s).

Psychologist: A person who provides mental health services including, counseling, therapy, psychological evaluation and testing and case coordination. In the community, a psychologist may function as a Licensed Practitioner of the Health Arts (LPHA) if he/she meets the following criteria: A clinical psychologist licensed under the Clinical Psychologist Licensing Act [225 ILCS 15], counselor holding a permanent license pursuant to the Professional Counselor and Clinical Professional Counselor Licensing Act [225 ILCS 107].

Psychosocial Rehabilitation: Psychiatric rehabilitation services that help adults recover basic living skills (socializing, working, meal preparation, shopping, managing finances, etc.).

Psychosocial Rehabilitation (PSR) Day Program: A formal program of daily services directed towards assisting clients with mental illnesses to function at their highest level in the community. Clients participate, based on individual needs as determined in their treatment plan, in a variety of integrated individual and group services during the regularly scheduled formal program.

Psychotropic Medication Monitoring and Training: Ongoing observation of the client's response to his or her medication and information provided to a client with mental illness regarding the appropriate use of the psychotropic medication prescribed for his or her mental illness.
Qualified Mental Health Professional (QMHP): One of the following: a physician, a psychiatrist, a licensed psychologist, an LCSW, an LCPC, licensed clinical professional counselor, a registered nurse with at least one year’s experience in a mental health setting or a master’s degree in psychiatric nursing, a registered occupational therapist with at least one year’s experience in a mental health setting or a person with a master’s or doctoral degree in guidance and counseling, rehabilitation counseling, social work, vocational counseling, pastoral counseling or family therapy, or related field, who has successfully completed a practicum or internship with a minimum of 1000 hours, or who has at least one year of clinical experience under the supervision of a QMHP.

Quality Assurance (QA): The process of making sure that good and appropriate services are being provided.

Quality Care Line: Call 1-800-843-6154 to report complaints and concerns about your care. (Hearing impaired call 217-524-2504 TT).

Reasonable Accommodation: A policy of making sure a person’s mental illness is not used to keep him/her from participating in things everyone else can. Any special considerations that persons with mental illnesses might need to make participation possible should be made if at all possible.
Recipient Identification Number: A unique number assigned to each person who uses DMH services. This number is necessary for providers to link individuals to services.

Recovery: Refers to the process in which persons are able to live, work, learn and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual’s recovery.

Recovery Vision: To help persons with mental illness reach their individual potential and maximize productive community living. Recovery is about self-determination and empowerment to control one’s own life – not just to receive treatment.

Registered Nurse (RN) Working in a Psychiatric Setting: A person who is licensed by the State of Illinois. They can provide the following mental health services: nursing assessment, medication administration, education and training, counseling, and groups. Nurses work in the State Operated Hospital and in some community programs.

Rehabilitative Services Associate (RSA): A rehabilitative services associate assists in the provision of mental health services in a community program, most likely a residential setting. A rehabilitative services associate must be at least 21 years old, have demonstrated skills in the field of services to adults or children, have demonstrated the ability to work within agency structure and accept supervision, and have demonstrated the ability to work constructively with persons with mental illnesses, other providers and the community.

Residential Services: These housing options provide a setting for professional and paraprofessional services to assist consumers in living in a community setting (i.e., group home), apartment or individual home. Residential options are: Supported, Supervised, CILA, ACT and Client Transition Subsidy.

Resilience: Resilience means the personal and community qualities that enable us to rebound from adversity, trauma, tragedy, threats, or other stresses - and to go on with life with a sense of mastery, competence, and hope. We now understand from research that resilience is fostered by a positive childhood and includes positive individual traits, such as optimism, good problem-solving skills, and treatments. Closely knit communities and neighborhoods are also resilient, providing support for their members.

Resources: This usually refers to the money available to do something, but remember that people and their experiences are important resources in the planning of mental health services!

Respite: Services which provide care to persons with mental illnesses in a crisis situation in order to prevent a hospitalization and give that person a safe place to “get it together.”

Revenue: The money an agency or organization makes - income.

Rule: The official guidelines that describe how a law is going to be implemented.

Rule 132: The rule that describes the Medicaid Community Mental Health Services Program.

Success!

SASS: Screening, Assessment and Support Services.

SED: The acronym for Serious Emotional Disturbance.

SH: The acronym for State Hospital.

SIS: The acronym for Statistical Inquiry System.
SMHA: The acronym for State Mental Health Authorities.

SMI: The acronym for Serious Mental Illness.

SOF: The acronym for State Operated Facility.

SOH: The acronym for State Operated Hospital.

SRI: The acronym for System Restructuring Initiative.

SSDI: The acronym for Social Security Disability Insurance.

SSI: The acronym for Supplemental Security Income.

SSW: The acronym for Support Service Worker.

STA: The acronym for Security Therapy Aid.

Screening: Evaluating a person to decide what kind of mental health services he/she may need before services are provided. See also PAS.

Screening, Assessment and Support Services (SASS): Intensive community-based mental health services for children and adolescents who are at risk of hospitalization due to psychiatric reasons.

Second: After a motion is made, it must be "seconded" before it can be voted upon. If a person agreed with a motion, he/she would say, "I second that motion." See also Parliamentary Procedure.

Secondary Consumer: A family member, friend or significant other of a person who has a mental illness and uses or has used mental health services.

Security Therapy Aid (STA): A person who provides mental health services usually under the supervision of a nurse at one of the Division of Mental Health State Operated Facilities which provides services for persons with mental illnesses who, because of their illness, have been arrested or jailed. The person must be 18 years of age and completed established standardized training.

Serious Emotional Disturbance (SED): A mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the DSM-III-R that results in functional impairment that substantially limits one or more major life activities in an individual up to 18 years of age. Examples of functional impairment that adversely affect educational performance include an inability to learn that cannot be explained by intellectual, sensory, or health factors; and inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal or school problems.

Serious Mental Illness (SMI): A diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R that has resulted in functional impairment which substantially interferes with or limits one or more major life activities, including basic daily living skills (i.e., eating, bathing, dressing); instrumental living skills (i.e., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts.

Social Worker: A person who provides mental health services including case coordination, counseling and therapy, treatment and discharge planning and can include:

Master of Social Work (MSW): The educational degree given to a person who has completed social work training at the graduate level (beyond four years) of college.
Licensed Clinical Social Worker (LCSW): A person who has a master’s degree in Social Work and has also been licensed by the State. Not all social workers are licensed. A licensed clinical social worker (LCSW) licensed under the Clinical Social Work and Social Work Practice Act [225 ILCS 20] can function in the community as a Licensed Practitioner of the Health Arts (LPHA).

Stakeholders: People, groups or agencies who play important parts in planning mental health services. YOU are a very important stakeholder since decisions are decisions about Your life!

State Hospital (SH): See State Operated Hospital definition.

State Operated Facility (SOF): See State Operated Hospital definition.

State Operated Hospital (SOH): A place run by the State mental health system to provide intensive psychiatric treatment for persons with mental illnesses whose symptoms are so severe they cannot live in their own community. Also referred to as SOF or SH.

Steering Committee: The decision making committee.

Strategic Planning: Setting goals for the future of an organization.

Subcommittee: A group formed from a committee to take care of a specific issue or job of the main committee. A “Housing” committee may form a subcommittee to look at residential housing issues.

Supplemental Security Income (SSI):

Support Service Worker (SSW): A person who works in the State hospital and provides support services such as dietary or housekeeping.

Technical Assistance: Information or training to help a person or organization do something.

Tx: The medical abbreviation for “treatment.”

Understanding takes Time!

UR: The acronym for Utilization Review.

USPRS: The acronym for the United States Psychiatric Rehabilitation Association (formerly IAPSRS).

UST: The acronym for Unfit to Stand Trial.

Unduplicated Clients: The number of clients receiving mental health services in all of an agency’s programs. This
count makes sure that a person isn’t counted more than once even though he/she may be using more than one of that agency’s programs.

**United State Psychiatric Rehabilitation Association (formerly IAPSRA):** An organization of people and agencies who provide services to persons with mental illnesses. This organization is dedicated to providing its members with the latest education and research about effective kinds of treatments. It is also interested in the participation of persons who have mental illnesses and family members.

**Utilization Review (UR):** A formal process of evaluating how services are used to see if they are being used in the right way - meeting people’s needs and being cost effective.

**Voice your opinion!**

**V**

consumers get and keep employment.

**We’re all Winners!**

**W**

**Waiver:** Official permission to not follow requirements.

**EXPECT great things!**

**X**

**You can do it!**

**Y**

**Zap those negative thoughts!**

**Z**
Be A Word Watcher:
We need you to be our eyes and ears. Mail, e-mail or phone any corrections, additions to:

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