The DeKalb County Mental Health Needs Assessment 2009

Presented by:
The DeKalb County Community Mental Health Board
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INTRODUCTION AND METHODOLOGY

Purpose

This report summarizes information from the four components of the Comprehensive Community Mental Health Assessment sponsored by the DeKalb County Community Mental Health Board. These components include a community analysis of related secondary data about the county, a household survey regarding residents’ views of DeKalb County mental health services and needs, key informant interviews of individuals who are considered to be experts in their field based on professional experience, knowledge of the local mental health system, or who are in a position of influence in the community, and focus group interviews of service users.

The DeKalb County Community Mental Health Board is responsible for planning, evaluating, coordinating, and funding mental health services in DeKalb County. The purpose of the Comprehensive Community Mental Health Assessment is to assist the Community Mental Health Board in this responsibility by identifying and prioritizing the mental health, substance abuse, and developmental disability needs of the community in order to effectively address solutions and allocate resources.

Mental health problems, substance abuse, and developmental disabilities affect individuals and families in all walks of life, classes, ages, and races. Without treatment and services, the consequences can be staggering: unnecessary disability, unemployment, homelessness, inappropriate incarceration, suicide, lost productivity, and wasted lives. While many individuals utilize services available through the health sector, social service agencies, schools, churches, and self-help groups, gaps remain between those in need and those who receive services. This report seeks to help identify those gaps in ways that can be addressed by the Mental Health Board and DeKalb County as a whole.

Health Systems Research of the University of Illinois College of Medicine at Rockford, an applied research unit which specializes in community needs assessments for health and human service organizations, prepared this summary report as part of the comprehensive needs assessment.

Methodology

The summary report is a composite of findings from the four component studies described below. Further information on each study is found later in this report.

The Community Analysis presents a comprehensive overview of DeKalb County, characterizing its population through secondary information from a variety of sources that describe the need for and use of mental health, substance abuse, and developmental disability services. Topics covered include mortality and morbidity, incidence and prevalence of various conditions, alcohol and substance abuse disorders, disabilities, utilization of services and the need for services, special education, and health care use, cost, insurance, and medical access.
The Household Survey sought to assess:

- Perceptions of mental health, substance abuse, and developmental disability problems and needs which should be given priority attention by the community and health and human service system.
- Personal and household needs regarding mental health, substance abuse, and developmental disabilities.
- Household mental health problems.
- Use of mental health, substance abuse, and developmental disability services.
- Benefits of mental health, substance abuse, and developmental disability services.

The survey used a mailed questionnaire which was sent to a random sample of 4,000 DeKalb County households. The survey mailing included a flier with the theme “Help Us Help You,” an eight-page booklet including a cover letter from Board President Charles G. Rose urging participation and setting out the survey purpose, structured questions, and space for open-ended comments. No identification number or other identifying mark was used so respondents could be assured that their answers would be anonymous.

The survey was organized to provide a complete picture of the views of all residents in the county, by distribution proportional to the population residing in each zip code area within DeKalb County.

A follow-up postcard was sent ten days after the original mailing. At the “cut off” date, 417 surveys were completed and returned for a response rate of 10.4%.

Key Informant Interviews obtain information and perceptions from the people considered to be experts in their field based on professional expertise, knowledge of the local human services system, or a position of influence within the community.

Key informants were selected by the DeKalb County Community Mental Health Board. Fifty-two key informants received face-to-face interviews. Discussion topics were focused on a set of questions about mental health needs and services, which included major groups of people served, target populations needing greater attention, the mental health services system as a whole, changes and challenges for the county, important actions to be taken, and beneficial continuing education offerings. Interviews averaged approximately one hour.

Figure 1 provides the questions that were asked of key informants as part of the study. Figure 2 shows the names and organizational affiliations of those individuals interviewed as part of the key informant study.
Figure 1
DEKALB COUNTY COMPREHENSIVE MENTAL HEALTH ASSESSMENT
KEY INFORMANT INTERVIEW QUESTIONS

- What are the major groups of people that you or your organization serve in DeKalb County and what services are provided?
- Overall, in DeKalb County, which population groups requiring mental health, substance abuse, or developmental disabilities services (including both groups served by you and groups served by other organizations) would you say are in greatest need of increased community attention? For each group named:
  a) What are the major needs of this group?
  b) What are the major unmet needs for this group?
  c) What evidence do you see of their unmet needs?
  d) What are the barriers to services for this group?
  e) What services are currently provided for these groups and what services for these groups need expansion or improvement in the way they are delivered?
- How well do the delivery systems providing services to mental health, substance abuse, and developmental disabled populations work for those requiring services in DeKalb County?
  a) How would you rate the following aspects of the delivery systems for mental health, substance abuse, and developmentally disabled populations in DeKalb County?
     ✓ Availability of services ✓ Quality of services
     ✓ Accessibility of services ✓ Continuity of services
     ✓ Cost of services ✓ Acceptability and satisfaction with services
  b) What are the strengths, weaknesses, gaps in the systems of services for these populations that we might not have touched on? These systems of services could be outside of the mental health service system.
  c) What examples of duplication exist? In what ways might efficiency be improved?
  d) What would you say are the major barriers that keep people from using services already available?
- How have services to mental health, substance abuse, and developmentally disabled populations changed over the last five years?
- What changes or challenges do you feel will emerge for those populations in the next five or ten years?
- (If not discussed already) What are the most important actions that are needed to improve services to these populations? For example, these actions might include additional funding, revised eligibility, etc.
- Which partnerships or collaborations have you or your organization found most beneficial in providing services to mental health, substance abuse, or developmentally disabled populations? Are there partnerships or collaborations that do not exist which you feel would enhance services to these populations?
- What half day continuing education offerings not now available to you would you or your organization find valuable if those offerings could be provided?
- In closing, is there anything else that you would like to tell us?
### Figure 2
DEKALB COUNTY COMPREHENSIVE MENTAL HEALTH ASSESSMENT
KEY INFORMANTS INTERVIEWED

<table>
<thead>
<tr>
<th>Name</th>
<th>Position/Office</th>
</tr>
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<tbody>
<tr>
<td>Matthew Toohey</td>
<td>Executive Director Access Services of Northern Illinois</td>
</tr>
<tr>
<td>Michael Flor, President &amp; CEO</td>
<td></td>
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<tr>
<td>Jerry Strachan, CFO</td>
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<tr>
<td>Heather Mucha, Program Manager of the</td>
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<td>Community Support Program</td>
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<tr>
<td>Ben Gordon Mental Health Center</td>
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<tr>
<td>Richard Salazar</td>
<td>Consumer Advocacy Agency</td>
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<td>Chief Don Thomas, Sycamore Police Dept</td>
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<tr>
<td>Lt. Carl Leoni, Representing Chief Bill Freithen</td>
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<tr>
<td>DeKalb Police Dept</td>
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<tr>
<td>Ron Matekaitis, DeKalb Co State’s Attorney</td>
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<tr>
<td>Margi Gilmour, Administrator, DeKalb Co Court</td>
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<td>Services</td>
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<td>Lt. Joyce Klein, Jail Administrator, DeKalb Co</td>
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<td>Sheriff’s Office</td>
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<td>DeKalb Co Court Services and Sheriff’s Office</td>
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<tr>
<td>Bette Chilton, Dir of Personal Health Services</td>
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<td>Kay Chase, Coordinator of WIC and Family Case</td>
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<td>Management</td>
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<td>DeKalb County Health Department</td>
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<td>Thomas Dennison, MD, Psychiatrist</td>
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<tr>
<td>Thomas Kirts, MD, Psychiatrist</td>
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<td>DeKalb Co Psychiatrists in Private Practice</td>
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<td>Gil Morrison, Regional Office</td>
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<tr>
<td>Tasia Beckwith, Regional Office</td>
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<td>School Superintendents:</td>
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<td>James Biscoe, DeKalb</td>
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<tr>
<td>Scott Wakeley, Genoa-Kingston</td>
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<td>Christine Demory, Hiawatha</td>
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<tr>
<td>Jim Hammack, Hinckley-Big Rock</td>
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<td>Pam Rockwood, Indian Creek</td>
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<td>Rick Schmitt, Sandwich</td>
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<td>Susan Workman, Somonauk</td>
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<td>Wayne Riesen, Sycamore</td>
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<td>Carolyn Beard, DeKalb Co Special Education</td>
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<td>Kathy Watkins, KEC</td>
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<td>Lori Fanello, Kishwaukee Intermediate Delivery</td>
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<td>System DeKalb Co School Superintendents and</td>
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<tr>
<td>Administrators</td>
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<td>Carolyn Beard, Director</td>
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<tr>
<td>DeKalb Co Special Education Association</td>
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<tr>
<td>Lynette Spencer, Kim Volk, Lynette Swedberg,</td>
<td></td>
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<td>Steve Withrow, Emily Hummel</td>
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<td>DeKalb Co Therapists in Private Practice</td>
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<tr>
<td>Deanna Cada, Executive Director</td>
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<td>DeKalb Co Youth Service Bureau (YSB)</td>
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<td>Ziv Sabin, Executive Director</td>
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<td>Elder Care Services</td>
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<td>Cara Witkowski, Director of Client Services</td>
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<td>Epilepsy Foundation of North/Central Illinois,</td>
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<td>Iowa, and Nebraska</td>
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<td>Susan Plote, Executive Director</td>
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<td>Family Service Agency</td>
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<tr>
<td>Lesley Wicks</td>
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<td>Hope Haven</td>
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<tr>
<td>Dolly Scanlon, Mental Health Administrator</td>
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<td>Illinois Department of Human Services, Division of</td>
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<tr>
<td>Mental Health</td>
<td></td>
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<tr>
<td>Kevin Poorten, President &amp; CEO</td>
<td></td>
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<tr>
<td>Pamela Duffy, Vice President of Patient Care</td>
<td></td>
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<tr>
<td>Services and Medical Staff</td>
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<td>Kish Health System</td>
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<tr>
<td>Kathleen Dust, Volunteer</td>
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<td>National Alliance for the Mentally Ill (NAMI)</td>
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<td>Dr. Micky Sharma, Director</td>
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<tr>
<td>Northern Illinois University Counseling Center</td>
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<tr>
<td>Dave Baker, Executive Director</td>
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<td>Open Door Rehabilitation Center</td>
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<td>Bob Shipman, Executive Director</td>
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<td>Opportunity House</td>
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<td>Pam Wiseman, Executive Director</td>
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<td>Safe Passage</td>
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<td>Lillian Pickup, Dir of Planning &amp; Performance State</td>
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<tr>
<td>of IL Division of Alcohol &amp; Substance Abuse</td>
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<tr>
<td>Kevin Byrd, Northwest Region Coordinator State of</td>
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<tr>
<td>IL Division of Developmental Disabilities</td>
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<tr>
<td>Mary Gentile, Social Worker</td>
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<tr>
<td>Pam Pickins, Counselor; Katie Peska, Counselor;</td>
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<tr>
<td>Julie French, Counselor; Michelle Eklund, Counselor</td>
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<td>Sycamore and Genoa-Kingston School Districts</td>
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<td>Tom Zucker, Executive Director The Voluntary Action</td>
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<td>Center (VAC)</td>
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Focus Groups are small groups of individuals formed to discuss a topic of common interest. Focus groups were formed primarily from populations which tend to have similar problems and require similar services within the DeKalb County mental health, substance abuse, and developmental disability service system. The groups were brought together to discuss their experiences with and perceptions of mental health, substance abuse, and developmental disability needs in the county, particularly within the specific population group they represent. Focus groups afforded an opportunity for the views of certain target populations to be heard, especially at-risk individuals who might not otherwise be involved in the study.

The eleven focus groups were Hispanics/Latinos, homeless persons, two groups of mental health consumers, parents of individuals with developmental disabilities, a parent of a child with mental illness, a person with Asperger’s Syndrome, substance abusing persons, seniors, teenagers aged 16 and older, and veterans. The sessions were convened at a variety of sites with an effort to involve persons from all areas of DeKalb County. A total of seventy-three persons took part in the eleven focus groups. Most of the sessions lasted between one hour and one hour and fifteen minutes. A $15 stipend was given to participants as an expression of appreciation for taking part in the session.

For each focus group, questions may have been modified to reflect the experiences and views of the particular group (Figure 3). Participants in the Teenagers, Age 16 and Older focus group were asked similar, but not identical questions (Figure 4).

### Figure 3
**DEKALB COUNTY COMPREHENSIVE MENTAL HEALTH ASSESSMENT**
**FOCUS GROUPS QUESTIONS**

- Do you agree with the following statements?
  - Treatment can help people with mental illness to lead normal lives.
  - Mental illness is a sign of personal weakness.
  - Mental health can be caused by biological imbalances.
  - Alcoholism is a disease which should be treated like other medical conditions.
- If you or someone you know needed help for an emotional, mental health, substance abuse problem, or a disability related issue, would you/they know where to go for help in DeKalb County?
- What services for mental health, substance abuse, or developmental disabilities do you believe need extra attention?
- What services for mental health, substance abuse, or developmental disabilities have you or someone that you know received in the past year? Did the service help them to deal better with the problem or issue? How?
- Are there any services for mental health, substance abuse, or developmental disabilities that you or someone you know needed but did not receive? Why didn’t you/they receive services - what were the barriers to receiving the needed service?
- How would you rate the following aspects of the delivery system of mental health, substance abuse, and developmentally disabilities populations in DeKalb County?
  - Availability of services
  - Quality of services
  - Accessible of services
  - Continuity of services
  - Cost of services
  - Satisfaction with services
- What is the most important action that is needed to improve services to the citizens of DeKalb County with mental health, substance abuse, or disability related issues?
- Is there anything else you would like to tell us?
DEKALB COUNTY COMPREHENSIVE MENTAL HEALTH ASSESSMENT
TEENAGERS, AGE 16 AND OLDER FOCUS GROUPS QUESTIONS

- Do you think that a teen’s mental health is important for health, academic success, and/or well-being?
- If you or someone you know needed help for an emotional, mental health, or drug problem, do you think they would know where to go for help? Would they know what places could help them?
- What kinds of mental health or emotional problems do you think kids your age have? What are the most important mental health services needed by DeKalb County youth? Most important substance abuse services?
- What kinds of services do teens with disabilities in DeKalb County need?
- What services for mental health, substance abuse, or developmental disabilities have you or someone you know received in this past year? Did the service help with the problem?
- Are there any services for mental health, substance abuse, or developmental disabilities that you or someone you know needed but did not receive? Why didn’t you/they receive services?
- What is the most important action that is needed to improve services to teenagers with mental health, substance abuse, or disability?
- Is there anything else you would like to tell us?

Figure 5 below, lists the focus groups that were held as part of the comprehensive community assessment.

DEKALB COUNTY COMPREHENSIVE MENTAL HEALTH ASSESSMENT
FOCUS GROUPS AND INDIVIDUALS
WITH NUMBER OF PARTICIPANTS AND MEETING SITES

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Participants</th>
<th>Meeting Site</th>
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<tbody>
<tr>
<td>Hispanics/Latinos</td>
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<td>Conexion Comunidad</td>
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<tr>
<td>Homeless Persons</td>
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<td>Hope Haven</td>
</tr>
<tr>
<td>Mental Health Consumers (Group One)</td>
<td>3</td>
<td>Reality House</td>
</tr>
<tr>
<td>Mental Health Consumers (Group Two)</td>
<td>3</td>
<td>Reality House</td>
</tr>
<tr>
<td>Parents of a Individuals with Developmental Disabilities</td>
<td>9</td>
<td>Opportunity House</td>
</tr>
<tr>
<td>Parent of a Child with Mental Illness</td>
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<td>Reality House</td>
</tr>
<tr>
<td>Person with Asperger’s Syndrome</td>
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<td>Ben Gordon Center</td>
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<td>Seniors</td>
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<td>Oak Crest Retirement Center</td>
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<tr>
<td>Substance Abusing Persons</td>
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<td>Reality House</td>
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<td>Teenagers, Age 16 and Older</td>
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<td>Youth Service Bureau</td>
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<td>Veterans</td>
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<td>DeKalb Government Center</td>
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<tr>
<td><strong>Total Participants</strong></td>
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EXECUTIVE SUMMARY OF PRIORITIES

Broad-Based System Priorities

Information from the four Comprehensive Community Assessment 2009 components, the Community Analysis, Household Survey, Key Informant Interviews, and Focus Groups, was analyzed to identify themes describing those mental health, substance abuse, and developmental disability target areas most in need of community action. The Broad-Based System Priorities address larger system issues while the Population Focused Priorities speak to the needs of specific populations within DeKalb County.

Selection of priorities was based on the magnitude of the problem according to its size and severity, the problem’s significance to the community, and whether current activities designed to address the problem are already in place and effectively addressing the needs. Selection was based purely on information derived from the four study components.

The three Broad-Based System Priorities are:

1. Achieve an Effective Information and Referral System
2. Educate the Community on Mental Health Conditions and Stigma
3. Organize a Community Services Networking Forum

On the following pages are summaries for each of the priorities. Detailed information from the studies for each priority follows later in this report with information derived from each study component verifying need for the priority.

Achieve an Effective Information and Referral System

Those in need must be connected with appropriate services to help them. However, though services may be present, people may still not be aware of them or may not be referred when a helper is not aware of sources of help.

“Not knowing where to go for services” was the second highest barrier to receiving services reported by respondents to the household survey. Focus group participants described struggling to learn about services in the midst of crisis and stress. They did not express confidence in knowing about services prior to actual involvement in the service system and emphasized the need for increasing the effectiveness of the information and referral services in DeKalb County.

Educate the Community on Mental Health Conditions and Stigma

Many people believe that mental disorders, substance abuse, and developmental disabilities are rare and “happen to someone else,” but these conditions are common and widespread. Just slightly less than half of households responding to the DeKalb County Household Survey reported being affected by a mental health problem or condition.
Community education about mental health, substance abuse, and developmental disabilities was one of the top three services survey respondents said they needed but did not receive.

The Community Analysis underscores the importance of educating the community on mental disorders as more than one-fourth (26.3%) or 20,597 DeKalb County residents 18 or older experience a mental or substance abuse disorder within a twelve-month period.

22.9% of respondents also reported that “others having a negative view of them for using mental health services” was a barrier for them in receiving services.

Stigma erodes confidence that mental disorders, substance abuse, and developmental disabilities are real, treatable conditions that can allow persons to function and participate in society.

Both key informants and focus groups indicated that stigma is still a major issue that needs to be addressed in DeKalb County to increase community acceptance and understanding of persons with mental health conditions, substance abuse, or developmental disabilities.

Organize a Community Services Networking Forum

Key informants reported a strong consensus that the service delivery system for mental health, substance abuse, and developmental disabilities lacks a regular forum for broad-based provider communication, coordination, and information sharing.

Suggested were both an annual summit for provider agencies to review system functioning, coordination, and problem solving as well as quarterly meetings for providers to receive program updates and engage in problem solving. Key informants observed a strong need for an organizer and catalyst to bring together organizations to facilitate communication and coordination.

Population Focused Priorities

Population Focused Priorities are issues which speak to the needs of specific populations in DeKalb County rather than larger system issues. Addressing these target group areas was viewed as having the same level of urgency as the Broad-Based System Priorities, and their selection was based on the same criteria used in selecting the system level priorities. Population Focused Priorities are issues for which significant evidence of need appeared in the process of doing the community assessment.

The four Population Focused Priorities are:

1. Provide Additional Support Groups and Services
2. Develop New Strategies to Meet the Needs of Adults with Acute Mental Illness and Other Mental Health Conditions
3. Overcome Cultural Barriers for Hispanics
4. Expand Housing Options and Supportive Services for Persons with Developmental Disabilities
Provide Additional Support Groups and Services

Individuals and families often require services which support them in strengthening and optimizing their capabilities. Caring for a child with a mental or physical disability can add extra work, activities, and expenses for a family. Individuals recovering from a mental illness or substance abuse addiction can require supports in addition to therapy or medication to further the recovery process.

Respondents to the community survey reported that support groups of all types are needed but not being received. Examples include groups for coping with daily living as well as groups for families coping with a mentally ill family member. Key informants also identified support groups for families as needing much greater attention. Focus groups strongly indicated that parents and caregivers need additional resources at every stage of development or recovery. The focus group for Parents of Children with Disabilities firmly underscored this need.

Develop New Strategies to Meet the Needs of Adults with Acute Mental Illness and Other Conditions

To address the needs of adults with acute mental illness, both key informants and focus group participants strongly supported the continued availability of a local inpatient psychiatric unit as a primary need in DeKalb County. They emphasized the importance of not removing a person from their local support system in order to receive inpatient treatment as well as the transportation difficulties inherent in getting a person to an out-of-county treatment facility. The anticipated closing of Kishwaukee Hospital’s inpatient psychiatry unit, although not supported by the majority of key informants and focus groups, prompted them to focus on the need for the county to develop a new, coordinated community response to meet the crisis needs of acute mentally ill adults.

The household survey, key informants, and focus groups also stressed the importance of addressing the outpatient treatment needs of adults with acute mental illness as well as adults with severe symptoms. Counseling for adults with emotional problems led the list of supportive or treatment services that survey respondents indicated they or household members require but are not receiving. Family Service Agency’s refocusing on the needs of children and seniors highlights the need for additional community dialogue and strategizing to meet the mental health outpatient treatment needs of adults.

Survey respondents, key informants, and focus groups cited the need for additional psychiatrists and advanced practice psychiatric nurses as a major element influencing the provision of mental health services in DeKalb County. These manpower needs affect the staffing of both inpatient and outpatient treatment programs and consequently extend the waiting times for an appointment.

Two needs that received significant attention in the study were the need for eating disorder treatment specialists and need for additional specialists and training for treating Post Traumatic Stress Disorder.
**Overcome Cultural Barriers for Hispanics**

Hispanics or Latinos are one of the fastest growing racial/ethnic groups in the country as well as DeKalb County. However, they are likely to experience a number of barriers to accessing mental health, substance abuse, or developmental disability services. Particularly pressing, according to key informants and focus group participants, are the availability of Spanish-speaking professionals, the promotion and provision of services in Spanish, and education to improve their use of services.

Even when translation is available, cultural elements make communication, understanding, or willingness to take action even more difficult. Hispanic culture may impede seeking help outside the family or seeking help at all. Key informants mentioned the need to have mental health personnel conversant in elements of Hispanic culture as well as relocation issues as Hispanics move to the county from other areas.

**Expand Housing Options for Persons with Developmental Disabilities and Other Populations**

Many key informants commented on the increasing life span of persons with disabilities as a major development requiring increased planning and resources. Due to better care and medical advances, persons with disabilities are now living into mid-life and longer, a time in which parents may no longer be able to assist them.

Personal care attendants and stable, independent housing for persons with disabilities were the two needs that survey respondents, key informants, and focus groups strongly agreed should get much greater attention. Support for housing included an increase in the number of units available as well as the number of options. Parents are left to find personal care attendants on their own. Payment has been available, but the number of available personal care attendants is very limited.
BROAD-BASED SYSTEM PRIORITIES
ACHIEVE AN EFFECTIVE INFORMATION AND REFERRAL SYSTEM

INTRODUCTION

Although an adequate supply of mental health, substance abuse, and developmental disability services may exist in a community, people may not be aware of all services available to them. Services must be publicized in order for consumers to be able to successfully navigate the processes needed to enroll in and utilize the services. In some cases, they must be referred by a professional through case management.

Lack of awareness can occur on two major levels: individual and provider. When individuals are unaware of a service in advance of a need, they may be left with nowhere to turn when they experience need. When providers are not aware of a service, they are unable to refer their clients to an appropriate program in the community. Mental health, substance abuse, and developmental disability services must be publicized so that citizens know where to turn when a need for those services arises and providers must have guides to services or personal knowledge of referral contacts.

Optimally, this information should be available through a variety of modalities, i.e., brochures, crisis lines, or web sites. Since programs and services change, an ongoing mechanism to update this information should be in place.

COMMUNITY ASSESSMENT FINDINGS

HOUSEHOLD SURVEY

“Not knowing where to go for services,” was the second highest barrier to receiving services as reported by 52.9% of the respondents to the household survey.

The importance of this barrier is underscored by the fact that nearly 40% of the survey respondents had thought about seeking professional help for a personal or emotional problem last year with over half of those respondents actually seeking help.
KEY INFORMANT STUDY

Key informants consistently mentioned the lack of up-to-date, readily available crisis and service information as a significant barrier for persons with mental health conditions, substance abuse, and developmental disabilities as well as for their families. Constant efforts to improve education are essential to inform the public about what is offered, service locations and hours, and the eligibility criteria procedures to access services.

Physicians and hospitals may not be aware of supportive services available, so sometimes do not make referrals. The Ben Gordon Center Crisis Line serves as a central point of access to services, but some people may not know that number and would not view the crisis line as a source of information and referral. Constant education about the service providers and community resources available are required through many different avenues such as networking meetings, media coverage, and continuing staff training.

In light of funding challenges, information sharing and collaboration among organizations will become even more important to maximize resources and focus on areas of strength. Communication among agencies and with the public about available services must continue constantly.

Key informants regularly cited as a system weakness, the lack of updates on how consumers and referring agencies can best access psychiatric and counseling services. Key informants noted that agency programs may make changes in the populations they serve, services offered, hours of service, and staff. Providers hesitate to make referrals due to the time needed to gather the information to make appropriate referrals as well as to update information.

Regular updates of information and referral information could be achieved through the periodic meetings of the community service networking forum suggested by a wide range of key informants.

The elderly and their families are one group needing greater education, so that help is not sought only in a crisis. A barrier to the Hispanics in the county accessing services is the lack of knowledge of existing services or how to access them.

Many people are embarrassed to seek counseling due to the stigma or weakness or “being crazy.” Individuals do not want others to know they need outside help to deal with their problems or they may not admit they need help and are thus reluctant to seek help. Information and referral mechanisms need to ease the access to mental health, substance abuse, and developmental disability services.
FOCUS GROUP STUDY

One of the most common barriers to receiving services, according to focus group participants, appears to be lack of awareness of basic services. Many of the focus groups stated that a significant number of people are not aware of services or agencies until the time comes when services are needed.

Many focus group participants described struggling to learn about services in the midst of crisis and stress. They did not express confidence in knowing about services prior to actual involvement in the service system and emphasized the need for increasing the effectiveness of information and referral services in DeKalb County.

While focus group members now know where people in DeKalb County can go for mental health, substance abuse, and developmental disability services, the vast majority of respondents emphasized the need for greater public awareness of resources in the early stages of seeking service.

Specific groups and participants highlighted what they considered important knowledge about community services. Mental health consumers emphasized the importance of people receiving information and close guidance in learning about and securing services following an acute episode. The substance abuse group suggested that many consumers and their families might not know about the recent opening of the halfway house in Cortland. The veterans noted that veterans, especially younger veterans, might not know about the support group run by the chairman of the Veterans Assistance Commission or the counseling services provided by Dr. Peter Coe.

The focus group of senior citizens discussed the need for “the public” to be better educated about mental health and local resources. The group suggested public service announcements and other promotional vehicles. Their discussion reaffirmed the need for a more accessible and effective information and referral system in DeKalb County, with one participants commenting that she had not fully considered just how difficult initiating a search for resources is in the county.
INTRODUCTION

Many people believe that mental disorders, substance abuse, and developmental disabilities are rare and “happen to someone else,” but these conditions are common and widespread. The national lifetime prevalence for mental health and substance abuse disorders is 46.4%, meaning that almost half of the population in a community is expected to have at least one mental health or substance abuse disorder at some time in their lives.

Given the high prevalence of mental illness, substance abuse, and developmental disabilities, the availability of information about the range of illnesses, types of conditions, causes, and treatment alternatives is of great value in assisting individuals and families in making informed choices and handling the anxiety and other feelings that often accompany these conditions. Information about the increasing effectiveness of treatments and supportive services also provides the hope of achieving a measure of control of what often appear to be an unmanageable set of circumstances.

Additionally, education on mental health, substance abuse, and developmental disabilities also benefits both the individual and community by addressing misconceptions and prejudices related to having one of these conditions. Community education increases self, family, and community acceptance and enhances an understanding of persons with these conditions or disabilities. This includes an understanding of both their strengths and needs.

These misconceptions and prejudices form the basis for the phenomena generally referred to as “stigma.” Stigma leads to isolation and the negative stereotyping which undercuts the provision of treatment and support services for mental illness, substance abuse, and developmental disabilities. Giving positive consideration to education, employment, housing, and treatment needs is very difficult when the general populace operates out of fear of mental illness. For example, over 60% of American still think that people with schizophrenia are likely to be dangerous to others. However, in reality these individuals are rarely violent.

Stigma erodes confidence that mental disorders, substance abuse, and developmental disabilities are real, treatable conditions that can allow persons to function and participate in society. Individuals or families may be reluctant to seek care because of stigma.

Community education is a major strategy for increasing knowledge about mental health, substance abuse, and developmental disabilities as well as addressing the effects of stigma.
COMMUNITY ASSESSMENT FINDINGS

COMMUNITY ANALYSIS

Based on estimates from the National Comorbidity Survey Replication (NCS-R), more than one-fourth (26.3%) or 20,597 DeKalb County residents 18 or older experience a mental or substance abuse disorder within a twelve month period. 22.3% are classified as serious, leading to a severity estimate for DeKalb County of 4,593 residents with “serious” disorder effects.

Anxiety disorders are more prevalent but mood disorders are more severe led by major depressive disorder with an estimate of 5,627 DeKalb County residents and Bipolar Disorder with an estimate of 2,044 residents of DeKalb County.

Lifetime prevalence is the proportion of persons who have a disorder at some time in their life. Lifetime prevalence for having any disorder is 46.4%, meaning that almost fifty percent or one-half of DeKalb County residents are expected to have at least one mental or substance disorder at some time in their lives, with the most likely type being an anxiety disorder, estimated to affect 22,641 residents.

HOUSEHOLD SURVEY

Community education about mental health, substance abuse, and developmental disabilities was one of the top three services survey respondents said they needed but did not receive.

22.9% of respondents also reported that “others having a negative view of them for using mental health services” was a barrier for them in receiving services.

Results of the household survey indicated that just slightly less than half (49.4%) of the households responding are affected by a mental health problem or condition.

One in five respondents (20.1%) indicated that an emotional problem or disability interfered with doing work or other usual daily activities for at least one day in the last 30 days.
KEY INFORMANT STUDY

In commenting on the service delivery system, key informants identified community education opportunities for mental health, substance abuse, and developmental disabilities as a significant gap in services. They observed that a major opportunity exists for community education about these conditions to be integrated into the educational offerings of the major health system. They were highly complementary of the educational offerings regarding physical health conditions offered by the health system and saw educational sessions for mental health conditions as an important addition to the health system’s educational curriculum.

Key informants also expressed the view that adding community education about mental health, substance abuse, and developmental disabilities into health system educational offerings would promote the integration of physical and mental health care, a goal many key informants reported as highly desirable in providing holistic care and improving services. Many organizations and agencies already have educational sessions that they provide. Broadening their inclusion in a wide set of offerings was seen as a significant addition to services as participation and exposure to information increases.

In responding to questions about major actions and initiatives that would improve mental health, substance abuse, and developmental disability services, key informants stressed continued work on stigma as well as the provision of information about conditions, resources, and treatment options. Key informants commented positively on Ben Gordon Center’s efforts to reduce stigma related to mental health and substance abuse.

DeKalb Family Service and the Ben Gordon Center reported working on the development of what they are calling a “Family University” that would bring individuals and families together four times a year for relevant educational offerings. The National Alliance for the Mentally Ill (NAMI) has a wide range of curriculums to provide educational workshops on a variety of topics.

FOCUS GROUP STUDY

Focus group participants joined key informants in indicating that more attention needs to be given to educating the public about mental health, substance abuse, and developmental disabilities. Many focus group participants responded that a community education program about these areas was an important action needed to increase community acceptance and understanding of persons with these conditions or disabilities.
Participants of focus groups of mental health consumers, substance abusing persons, and parents of children with disabilities joined with other participants to emphasize that persons with mental illness, substance abuse, or developmental disabilities are often made to feel of lesser value with nothing to offer because of their condition or disability. Accordingly, key informants expressed the belief that strategies and initiatives to combat “stigma” need much greater attention.
ORGANIZE A COMMUNITY SERVICES NETWORKING FORUM

INTRODUCTION

An efficient and effective system of providing mental health, substance abuse, and developmental disability services relies on a high degree of communication and collaboration to improve the capacity of those services to meet increasingly complex needs. Such communication and collaboration function best when working with other elements of the human service system such as public and private health systems in order to achieve optimal services and use of resources.

Well operating service systems have a forum to bring together providers and other responsible organizations on a regular basis to update program information, identify problems and solutions to service delivery, and support collaborations. Networking forums provide the opportunity to be proactive and responsive to emerging issues by building a base on which to organize and meet identified needs.

Geographical areas such as counties often have the elements that can form the foundation for a networking forum but lack an entity with the vision and commitment to convene and sustain such a forum. At the core, such a forum increases the capacity of organizations to improve services to those in need.

COMMUNITY ASSESSMENT FINDINGS

KEY INFORMANT STUDY

Key informants reported a strong consensus that at least once a year, and perhaps semi-annually or quarterly, a broad-based group of mental health, substance abuse, and developmental disability providers be convened to provide for consistent communication, coordination, information, and problem solving.
Several informants observed that the DeKalb Community Mental Health Board had convened such a networking forum in previous years. Many informants indicated that they had participated in those meetings and found the experience extremely valuable. They also commented that having such a forum in the current environment when organizations and their programs are experiencing rapid, major change would lead to more effective referrals and program utilization and ultimately better services for those DeKalb County residents in need of mental health, substance abuse, and developmental disability services.

Beyond the updating of organizational and program information, key informants saw great value in having occasions when they could explore and clarify issues as well as resolve any problems that might occur with changes in programs and services. Several key informants also saw significant value in having such occasions to do periodic reviews of the service delivery system.

Key informants commented that the lack of a networking forum leads to less integration in service delivery and provides limited opportunities for resolving the differing philosophical approaches of key service providers and lowering the barriers between agencies that historically compete for funding.

The key informants who are therapists in outpatient mental health settings voiced a strong need to stay up-to-date on the various programs and services in the county. They stressed the need for regular periodic updates on program eligibility, hours of service, referral procedures, and fees. While they view written materials with updates as a main communication vehicle, they also stressed the need for in-person opportunities to ask questions and clarify information in the written materials.

Interviews with key informants surfaced a number of important issues that could benefit from communication and mutual problem solving. Such issues included manpower shortages in a variety of areas, waiting times, the need to expedite referrals in emergency situations, and the importance of avoiding duplication in services and ensuring coordinated case management.

As might be expected, the other parts of the Comprehensive Community Mental Health Assessment – the community analysis, household survey, and focus group interviews – did not speak directly to the importance of organizing a community networking forum. Their focus was on different aspects of the needs assessment.

The DeKalb County Community Mental Health Board was mentioned consistently by key informants as one of the logical conveners of regular, periodic networking forums.
POPULATION FOCUSED PRIORITIES
Individuals and families often require services that support them in strengthening and optimizing their capabilities. Caring for a child with a mental or physical disability can add extra work, activities, and expenses for a family. Individuals recovering from a mental illness or substance abuse addiction can require supports in addition to therapy or medication to further the recovery process.

Support groups assist individuals and families in developing strategies to meet their needs, finding information, learning how to access resources, and sharing experiences and receiving support from others who have similar needs or experiences.

These groups are as varied as the challenges faced by those who join them and can include individuals with depression or anxiety, substance abuse, members of their families, teenagers, victims of abuse or crime, veterans, or persons caring for an elderly parent or a child with special needs. Groups can also be self-help groups organized and run by the members or groups led by a professional facilitator.

Support services also include personal assistants, transportation, technical and financial support, resource rooms, respite, and other services. They serve a vital function in meeting the basic needs of individuals as well as optimizing their levels of functioning. These services are also pivotal in meeting the needs of the family members and caregivers.
COMMUNITY ASSESSMENT FINDINGS

HOUSEHOLD SURVEY

Survey respondents indicated that “support groups for coping with daily living” are the second highest need for supportive or treatment services that they or someone in their household have but are not receiving at this time.

High on the list of supportive or treatment services that survey respondents or household members need but are not receiving are support groups for families coping with a mentally ill family member.

KEY INFORMANT STUDY

Key informants noted the lack of local support groups for many areas of need, ranging from Al-Anon and Alateen to specialized parent groups to mental health support groups. Offering and publicizing existing groups, key informants observed, are areas needing greater attention.

Key informants indicated that not only individuals need up-to-date information on services, but also their family members who are often instrumental in getting individuals the assistance that they need. Hence, greater attention, according to key informants, needs to be given to ensuring that family members have both online and hard copy information on the services available in the county and how to access them. One representative respondent said, “Families having the information they need at the time they need it, can make all the difference.”

Families with seniors who are increasingly physically and emotionally vulnerable and are having difficulty in handling the tasks of everyday living require support services that can assist with coping.

Many key informants noted that families with a developmentally disabled family member are in need of greater attention to assist them in moving into entirely different service system as their family member ages. One key informant summarized by saying, “Families need assistance as they move from services provided in the education system to waiting lists in the adult system.”
FOCUS GROUP STUDY

In reflecting on services that they had not received, but may have needed, many focus group participants observed that families and caregivers do not receive the amount of support needed for their role in caring for individuals with mental illness, substance abuse, or developmental disabilities.

In carrying out what they called a part-time bordering on full-time job, parents of individuals with disabilities expressed the need for support in the initial stages of caring for their child or family member. They also stressed that ongoing support is needed. The support consists of learning about resources, connecting with those resources as well as other parents, and obtaining respite services to give them a chance to build their energy and address their own needs. Parents said they had great difficulty in finding personal attendants as state reimbursement is very low and persons willing and capable of doing the work are in short supply.

Several focus groups cited the need for parenting groups for specialized populations as well as groups of teens and preteens and anger management groups. Participants also signaled the need for a variety of other groups, including court-related services related to behavioral management, anger management, and coping skills.

One of the suggested actions supported by a majority of focus group participants was increasing support services to family members and other caregivers.
DEVELOP NEW STRATEGIES TO MEET THE NEEDS OF
ADULTS WITH ACUTE MENTAL ILLNESS AND OTHER CONDITIONS

INTRODUCTION

In recent years, mental health services have received more attention from the general public. The efforts of advocates, scientists, and consumers have increased acceptance of mental health as part of "mainstream" health. While continuing educational and advocacy efforts need to be made, the public has shown increasing acceptance of the fact that mental disorders are real, common, and treatable.

Most people with serious mental disorders require medication to help control symptoms, but they also rely on a system that provides a range of services from hospitalization, emergency, and intensive outpatient services to supportive counseling, self-help groups, assistance with housing, vocational services, and other services to achieve the highest level of functioning.

Significant gaps continue to challenge the ability of adults to obtain the mental health services they require. With the ability to profoundly disrupt a person’s thinking, feeling, moods, ability to relate to others, and capacity for coping with the demands of life, mental disorders require the ongoing development of new strategies to assist persons afflicted with these disorders.

The need for new strategies to meet the needs of adults with acute mental illness and other conditions is prompted not only by individual and family needs and the innovative treatments that are continuously evolving, but also by changes in funding, programs, and the overall service delivery system.
COMMUNITY ANALYSIS

Based on estimates from the National Comorbidity Survey Replication (NCS-R), more than one-fourth (26.3%) or 20,597 DeKalb County residents 18 or older experience a mental or substance abuse disorder within a twelve month period. 22.3% are classified as serious, leading to a severity estimate for DeKalb County of 4,593 residents with “serious” disorder effects.

Lifetime prevalence is the proportion of persons who have a disorder at some time in their life. Lifetime prevalence for having any disorder is 46.4%, meaning that almost fifty percent or one-half of DeKalb County residents are expected to have at least one mental or substance disorder at some time in their lives, with the most likely type being an anxiety disorder, estimated to affect 22,641 residents.

The most prevalent lifetime mental health disorders are major depressive disorder (16.6%) affecting an estimated 13,050 DeKalb County residents and social phobia (12.1%) affecting an estimated 9,512 residents. For a twelve month period, anxiety disorders are more prevalent but mood disorders are more severe led by major depressive disorder with an estimate of 5,627 DeKalb County residents and bipolar disorder with an estimate of 2,044 residents of DeKalb County.

The hospitalization rate for behavioral hospitalizations for DeKalb County residents was 68.3 discharges per 10,000 population, considerable lower than the rate of 100.0 for all Illinois residents.

Psychoses (DRG 430) with 470 discharges accounted for two-thirds of all inpatient psychiatric hospitalizations for DeKalb County residents.

Provena Mercy was the leading destination for behavioral hospitalizations for DeKalb County residents at 28.1%, followed by Kishwaukee Community Hospital at 25.4%, Linden Oaks at 10.3%, and Alexian Brothers, Streamwood, and Provena St. Joseph's at approximately 5.0% each.

In 2008, DeKalb County residents made 1,050 hospital emergency department visits for mental health reasons, not including patients who were admitted to the hospital. Of these 70.4% took place at Kishwaukee Community Hospital and 11.6% took place at Valley West Hospital in Sandwich.

According to the American Medical Society, six psychiatrists practice or live in DeKalb County, a rate of 5.8 per 100,000 population. The national average is 9.1 per 100,000 population.
HOUSEHOLD SURVEY

Leading the list of supportive or treatment services that survey respondents or someone in their household needs but are not receiving at this time was counseling for adults with emotional problems.

KEY INFORMANT STUDY

Key informants cited the provision of a coordinated system for responding to the crisis needs of the acute mentally ill as a major challenge for the service delivery system.

When asked which groups are in the greatest need of community attention, key informants named adults with acute mental illness as a primary group, especially their need for a local inpatient psychiatric unit and for local, coordinated psychiatric services. During their interviews, many key informants reported that they were aware that Kishwaukee Health System was considering closing the inpatient psychiatric unit, noting that the community would view closure of the psychiatric unit as a major loss.

If Kishwaukee Health System chooses to close the inpatient psychiatric unit, key informants said the community would need to develop a coordinated response to the closing to ensure that adults with acute mental illness and their families would continue to receive high quality care. Students at Northern Illinois University are one of the adult populations requiring access to inpatient services.

Adults with acute mental illness who are dependent on Medicaid currently leave the county for inpatient psychiatric services, primarily through Singer Mental Health Center in Rockford, located fifty miles to the north.

Concerns voiced by key informants included issues regarding transportation to facilities outside of the county, involvement of family members in the inpatient treatment process, and the lack of familiarity that the staff of facilities outside of the county would have with local resources for treatment following an inpatient stay. For both public and private sectors, key informants signaled the importance of developing a coordinated system for responding to the needs of acute mentally ill adults.
If retention of the impatient psychiatric unit at Kishwaukee Community Hospital is not possible, then key informants suggested that community providers work together to determine the arrangements for facilitating the crisis needs of the acute mentally ill when an out-of-county placement is required, including facilitating travel, family involvement, and aftercare components.

Key informants also raised issues regarding the outpatient needs of persons with mental disorders. One issue cited was the long wait for initial psychiatric appointments in less acute but still severe cases. Caps on Medicaid reimbursement for the Ben Gordon Center, according to number of key informants, continue to contribute to long waiting lists at Ben Gordon Center for initial appointments with psychiatrists and ongoing appointments with counselors.

Another issue regards the change in programing at DeKalb Family Service in which adults who do not have linkages to a child or senior will assume decreased priority in DeKalb Family Service’s counseling program. DeKalb Family Service indicated that the agency’s role with these adults is to assist the community in defining the adults in need of counseling, asking what their needs are and exploring who might provide counseling services to those adults.

Key informants overwhelmingly cite the inability of health system and public sector facilities to recruit and retain psychiatrists and advanced practice psychiatric nurses as a major challenge for the delivery of services. Other unmet needs in the system referenced by a significant number of key informants include the availability of therapists specifically trained to treat eating disorders and post traumatic stress disorder.

The majority of the focus groups mentioned maintaining a local inpatient psychiatric inpatient psychiatric unit as a primary need in the community. Participants strongly emphasized the importance of not removing a person from their local support system in order to receive inpatient psychiatric treatment. They constantly reaffirmed the importance of family and friends, much less, the connections with local therapeutic resource as significant elements in recovery from acute episodes of mental health disorders.

Participants highlighted the transportation difficulties in getting the person to an out-of-county treatment facility as well as family and friends traveling back and forth to the treatment facility during a person’s inpatient stay. One participant summed up comments of several groups in saying that a town with tens of thousands of college students should certainly have a local inpatient psychiatric unit.
Focus groups also emphasized the need to reduce the waiting time to see psychiatrists in non-emergency but high stress situations. As a corollary, they also referenced the importance of having counselors or therapists available to see patients or clients regularly beyond initial appointments.

As major actions or initiatives, participants proposed developing a community action plan to address staff shortages at the Ben Gordon Center and other agencies and decrease the waiting time for psychiatric appointments.
COMMUNITY ASSESSMENT FINDINGS

INTRODUCTION

Hispanics/Latinos are one of the fastest growing ethnic groups in the country as well as DeKalb County. However, they are likely to experience a number of barriers in accessing needed care or services. Particularly pressing needs can include provisions of services in Spanish and education to improve services. Those with lower incomes or less proficiency in English are at particular risk and current immigrants may not use services because they fear being deported.

Even when translation is available cultural elements make communication, understanding, or willingness to take action even more difficult. Hispanic culture may impede seeking help outside the family or seeking help at all. A sensitivity to relocation issues is an important consideration in providing services to Hispanics.

COMMUNITY ANALYSIS

In DeKalb County, the number of Hispanics rose by 67% from 2000-2007, increasing from 5,830 to 9,738, now accounting for 9% of the population. In 1990, Hispanics accounted for 3% of the population of DeKalb County.

Four in five (84.4%) of Hispanics in DeKalb County say they are of Mexican origin.
KEY INFORMANT STUDY

DeKalb County’s rapidly growing Hispanic population is one of the key themes mentioned by a majority of the key informants. Language is seen as a considerable barrier for the increasing number of Hispanics in the county, due to an inadequate number of Spanish-speaking staff members at human service agencies. Not all agencies have Spanish-speaking staff or those that do, typically lack enough to meet demand.

Furthermore, Hispanic or Latino residents may not understand how to apply for various services unless information is readily available in Spanish. Organizations report that they are working at translating their brochures and other informational materials translated into Spanish. Undocumented residents may be hesitant to seek services because of the fear of being discovered or deported.

Language is a considerable barrier preventing Hispanics from receiving some services. Spanish-speaking staff members are in great demand at virtually all organizations due to the increase in Hispanics in the general population of the county. Key informants report that many agencies have made an effort to recruit and retain Spanish-speaking staff. Significant premiums are offered to Spanish-speaking employees by several agencies to assist in recruitment and retention.

Key informants commented specifically on the lack of Spanish-speaking psychiatrists as well as the lack of Spanish-speaking mental health and substance abuse providers. Younger family members often become the translators for their parents or grandparents. Such arrangements make constructive therapy difficult when needing to talk about adult or parent-child issues. Adult translators also need to be used when a person in an abusive situation needs to communicate both facts and feelings. Several key informants also noted the lack of Spanish-speaking professionals who are trauma trained and educated as a barrier in dealing with emergency situations.

Recruiting and retaining these bilingual staff is a constant challenge with stiff competition for qualified employees. Several key informants expressed frustration with investing in training these staff members only to have them lured away for higher paying jobs in other areas. When Spanish-speaking staff are available in agencies, a longer waiting period is sometimes required to meet with them.

As a major action or initiative, key informants encouraged the community to develop and implement a plan to increase the number of bilingual, Spanish-speaking professionals and staff at community agencies, especially psychiatrists, advanced practice nurses, and counselors. The plan should include, say key informants, actions to develop culturally competent staff familiar with Hispanic culture and relocation issues as well as the mental health, substance abuse, and developmental disability fields.
FOCUS GROUP STUDY

Focus groups reinforced many of the observations shared by key informants, especially in regard to a lack of Spanish-speaking staff at community agencies and the challenges Hispanics face in learning about community resources.

The DeKalb County Health Department, Ben Gordon Center, and Safe Passage are organizations which, according to focus group participants, periodically had Spanish-speaking staff and counselors, although their availability fluctuated based on what they perceived as a high turnover rate for Spanish-speaking staff.

Focus groups reported that there is currently a PhD candidate at Northern Illinois University who is bilingual and providing academic counseling in Spanish. This person is a mental health educator who is also providing counseling through the University for four hours on Fridays. The first appointment to see this person is in early September. Child care is provided during the counseling sessions.

Conexion Comunidad has translators that can be arranged on an “as needed” basis. A Spanish-speaking Alcoholics Anonymous group also meets at Conexion Comunidad. Focus group members knew of Spanish-speaking therapists in Rockford and Aurora but felt that distance and transportation as well as cost put these resources out of reach for most DeKalb County residents.

The Hispanic/Latino focus group cited past community workshops given by Spanish-speaking professionals about a variety of topics. Participants in the focus group felt that workshops can be a major vehicle in raising awareness and sharing information with DeKalb County’s Hispanic community.

Members of the Hispanic/Latino focus group also indicated that Hispanic citizens might not recognize what is normal and what is unhealthy in regard to mental health, substance abuse, and developmental disabilities, and stressed the importance of those citizens having the opportunity to receive information to help them with their issues and feelings. Feelings about relocation were one example mentioned. The Family University being explored by Ben Gordon Center and DeKalb Family Service might provide a vehicle for offering these workshops.
INTRODUCTION

For the first time in history, due to medical advances and better treatment, people with developmental disabilities such as Down’s syndrome are living normal life spans. The average life span of an individual with Down’s syndrome has increased from nine years in the 1920’s to 65 years or greater. And the rapid increase in the number of children with autism foreshadows a time when these children will grow into adulthood and require adult oriented services.

With these phenomena, however, has come unchartered territory for service providers, caregivers, and the wider community to understand and address the unique issues the developmentally disabled face as they age. In addition to medical care and employment, persons with developmental disabilities have unique needs for housing and residential options as well as for supportive services such as personal assistants. Housing with the required supports and assistance forms the basis of stability for the lives of these persons.

As persons with developmental disabilities grow into adulthood, they seek opportunities to be as independent as possible. While many of these persons continue to live with their families, an increasing number are seeking more independent living arrangements. As they age, persons with developmental disabilities who have continued to live with their parents are often outliving their parents who have historically functioned as their primary caregivers.

Both of these developments have led to a need for residential and other options geared to persons with developmental disabilities as they move from young adulthood through their middle and senior years.

Just as communities are providing ongoing services to developmentally disabled children and developmentally disabled adults through in-school programing, day programing, workshops, and the like, the need for residential and other supports will grow more acute with the graying of the disabled population.
COMMUNITY ASSESSMENT FINDINGS

COMMUNITY ANALYSIS

About 2% of the children under the age of 18 have a serious developmental disability such as cerebral palsy or mental retardation. Of the 25,116 children under eighteen in DeKalb County, 502 children would be affected.

HOUSEHOLD SURVEY

Almost five percent (4.6%) of survey respondents checked that they or a member of their household needs but are not receiving disabled person’s housing and independent living.

KEY INFORMANT STUDY

Many key informants commented on the increasing life span for persons with developmental disabilities due to better care and medical advances. One of the key informants specified that DeKalb County is already experiencing an increase in the Down syndrome population over sixty years old. A group with totally different needs from seniors without disabilities.

These key informants expressed the belief that this increasing life span is requiring increased planning for persons with developmental disabilities in mid-life and later as well as geriatric services for those persons reaching their senior years, especially when parents can no longer assist. A primary need, according to one key informant, is to begin developing a life plan at younger ages that includes the senior years, with alternative plans for caregivers in their senior years.
FOCUS GROUP STUDY

Participants in the focus groups commented that stable housing provides a key component in optimizing the functioning of persons with developmental disabilities.

The person with Asperger’s syndrome was the most specific about housing options, although her comments echoed the comments of many other participants with housing needs that were not met. She suggested that housing options similar to senior assisted living would be beneficial for persons with Autism Spectrum Disorders (ASD). These living arrangements would assure lower levels of noise and activity. The assisted living component of senior living would be beneficial for persons with ASD as they often have need for personal assistance in order to function optimally.

Other focus group participants indicated that suitable housing and housing choices were not available to them. The lack of housing and housing choices were needs voiced by several different groups, including mental health consumers, persons with substance abuse, homeless persons, and persons with disabilities as well as the parents of individuals with developmental disabilities. Participants in recovery for both mental illness and substance abuse said that a variety of housing options was needed at different stages in the life cycle.

Stable independent housing was a need that survey respondents, key informants, and focus groups strongly agreed needed much greater attention. Support for housing included an increase in the number of units available as well as the range of options.
STUDY COMPONENT
SUMMARIES
COMMUNITY ANALYSIS

Population Characteristics

- The DeKalb County population on July 1, 2008 was estimated by the Census Bureau at 106,321, up 19.5% since 2000.

- Two communities which grew very rapidly 2000-2007 were Maple Park (93.8%) and Cortland (90.1%). Also growing rapidly were Kirkland (45.8%) and Sycamore (43.0%).

- DeKalb (43,714), Sycamore (17,188), and Sandwich (7,170) continue as the largest communities according to 2007 Census estimates.

- Updated information on characteristics of residents is available from the 2005-2007 American Community Survey. Men and women reside in almost equal numbers with similar median ages of females (28.4) and males (27.8).

- Only 22.0% of residents are under 18, while 9.3% are seniors 65 or older. The county has a very young population profile due to the presence of NIU which enrolls about 25,000 students, three-quarters undergrad and one-quarter graduate.

- In the 2005-2007 ACS, 87.3% of DeKalb County residents were white, 5.7% black, 2.8% Asian/Pacific Islander, and 0.3% American Indian. “Other race” accounted for 3.9% of the population, while 1.9% identified themselves as being two or more races. The City of DeKalb is somewhat more diverse.

- 9% classify themselves as Hispanic or Latino with 7.6% saying that they are Mexican. The Census considers Hispanic to be an ethnicity, not a race.

- Most persons (72,148) live in a family household (two or more related persons living together), though 21,169 are not in families and 7,958 live in group quarters like dorms. Single female parents constitute 6.7% of households, 9.0% in the City of DeKalb.

- Nine of ten residents 25+ hold a high school diploma and 28.4% have a Bachelor's or higher, 36.6% in the City of DeKalb.

- 7.5% are foreign born and 12.0% speak a language other than English at home, 7.5% of those speaking Spanish. Ancestry otherwise is primarily German and Irish.

- The median county income is $53,758, though 13.9% of persons are “in poverty.” Poverty is highest (32.1%) for female parents.

- 40.1% of workers are employed outside the county. Mean travel time to work is 24.4.

- Major occupations are management and professional (33.4%) and sales/office (25.1%). Education, health and social assistance employ 25.7%. During 2005-2007, 7.8% were unemployed.
Housing includes both owner-occupied (64.6%) and renter occupied (35.4%). Median home value is $189,700, while the median rental is $749.

Mortality and Morbidity

- **Cause of Death**
  - Men are far more apt to commit suicide. From 1999 through 2005, suicide accounted for 43 deaths, with 30.2% occurring in the 35-44 age group. The rate of suicide per 100,000 for men was 10.6 compared to 2.8 for women.
  - The suicide death rate of 6.7 per 100,000 was the lowest of northwest Illinois Counties and well below Illinois (8.4) and the United States (10.8).
  - Suicide was the highest in recent years when 14 suicides took place in 2006.
  - Alzheimer’s disease accounted for 3.2% of all deaths in 2006, suicide, 2.2%, and chronic liver disease and cirrhosis of the liver 1.6%.

- **Crime and Violence**
  - Crime victimization is common among persons with mental disorders living in the community. A 2005 study of crime victimization in adults with serious mental illness by Northwestern showed that more than one in four of persons with a serious mental illness (SMI) had been victims of a violent crime in the past year, a rate more than 11 times higher than the general population even after controlling for demographic differences between the two groups. In addition, crime victimization for anyone can cause psychological wounds that last long after the physical wounds have healed. The Victims of Crime Act of 1984 provides grant funding to state victim assistance and compensation programs.
  - In DeKalb County, the overall crime index has dropped from 3,393 offenses per 100,000 population in 1998 to 2,878 offenses in 2007, decreasing in most years.
  - The highest crime rate for crimes against persons in the county is for aggravated assaults, with 2007 reporting 173 offenses, 172.8 per 100,000.
  - Domestic crimes in the county totaled 252 in 2007 or 251.7 per 100,000. The 2007 rate is lower than three of the five preceding years.
  - As reported by DCFS, the number of indicated cases of child abuse has exhibited a downward trend in DeKalb County between 1990 and 2006, with 6.9 indicated abuse cases per 1,000 children 0-17 in 2006 compared to 19.3 cases per 1,000 in 1990.
  - In just nine months in FY-2009, the Northwestern Illinois Area Agency on Aging received 87 reports of elder abuse for DeKalb County, up from 78 for the entire prior fiscal year.
○ The BRFS for 2004 estimated that about one in eleven adults in DeKalb County experienced physical violence in the prior 12 months.

● Drug Offense Arrests

○ Drug offense arrests totaled 563 in 2007 including cannabis (295), controlled substances (46), and drug paraphernalia (217).

○ Drug offense arrests increased from 2006 to 2007 in the county from 539.2 arrests per 100,000 to 562.2 per 100,000, but the 2007 rate is lower than in years 1999-2001. The local drug arrest rate is well below the state at 857.6.

Incidence and Prevalence of Conditions

● Prevalence of Mental Disabilities by Demographic Group

○ According to the 2005-2007 American Community Survey, 3.4% of the DeKalb County population has a mental disability, 4.1% of those 5-15 years, 2.8% of those 16-64 years, and 7.7% of those 65 and older living in DeKalb County were reported to have a mental disability, defined as “difficulty with learning, remembering, or concentrating.”

○ The 2004 IDPH Behavioral Risk Factor Survey (BRFS) for DeKalb County reported 10.2% of county residents with mental health “not good” for eight or more days of the past 30 days, with the highest levels among respondents who are divorced/separated (22.7%) or with incomes between $15,000-$35,000 (14.7%). Only adults 18+ completed the survey and data for some groups is suppressed because of small numbers.

○ In the BRFS survey, “feeling sad, blue or depressed” for more than two of the past 30 days was reported by 21.4%, although 30.3% of divorced/separated respondents and 29.0% of respondents living alone felt sad, blue or depressed for more than two days.

○ Overall, according to the BRFS, one of seven respondents (14.2%) were limited in activities by physical, mental, or emotional problems, with the highest percentages reported by “one adult, no children” households (31.0%), adults 65 or older (30.2%), and divorced/separated respondents (28.3%).

● Twelve-Month Prevalence of Mental and Substance Abuse Disorders

○ Based on estimates from the National Comorbidity Survey Replication (NCS-R) applied to the age structure of DeKalb County, more than one-fourth (26.3%) or 20,597 DeKalb County residents 18 or older experience a mental or substance abuse disorder within a 12-month period. The following estimates for DeKalb County residents 18 and older are also based on the National Comorbidity Survey.

○ The disorders exhibiting the highest prevalence are estimated to be: specific phobia (6,839 adults), social phobia (5,346), major depressive disorder (5,267), attention deficit hyperactivity disorder (3,223), and post-traumatic stress disorder (2,751).
Among disorder classes or groups, anxiety disorders are the most common, with an estimated 14,229 county residents expected to experience an anxiety disorder over a twelve-month period, 7,468 residents a mood disorder, 6,997 residents impulse control disorders, and 2,987 residents a substance disorder.

For all reported disorders, 22.3% are classified as “serious,” 37.3% as “moderate,” and 40.4% as “mild,” leading to severity estimates for the county of 4,593 residents with “serious” disorder effects, 7,683 with “moderate” effects, and 8,321 with “mild” effects from the disorders.

“Serious” effects include serious role impairment, violence, 30 or more days unable to perform their usual “role” in the year, suicide attempts with lethal intent. “Moderate” effects include moderate work limitation or role impairment in things like work, household maintenance, social life, and intimate relationships. Specific behavioral effects depend on the disorder.

Certain disorders exhibit a higher percentage of cases with “serious” severity levels especially bipolar disorder (82.9%), drug dependence (56.5%), and dysthymia (49.7%). For DeKalb County residents, an estimated 1,694 of the 2,044 residents with bipolar disorder, 178 of the 314 residents with drug dependence, and 586 of the 1,179 residents with dysthymia are estimated to have “serious” severity levels.

Among anxiety disorders, specific phobias are most common with an estimated 8.7% or 6,839 estimated DeKalb County residents experiencing the disorder during a year followed by social phobia at 6.8% or 5,346 residents. “Specific” phobia is an anxiety disorder connected to specific objects or situations, such as “arachnophobia” (spiders), or “claustrophobia” (small spaces).

While specific phobia and social phobia are the most frequently reported anxiety disorders, they have the lowest percentages of “serious” severity levels within the anxiety disorders group at 21.9% and 29.9% respectively, compared to 50.6% for obsessive-compulsive disorder, 44.8% for panic disorder, 43.3% for separation anxiety disorder, 40.6% for agoraphobia without panic, 36.6% for post-traumatic stress disorder, and 32.3% for generalized anxiety disorder. In DeKalb County, an estimated 3,244 cases of anxiety disorders are at the “serious” severity level.

DeKalb County estimates for 12-month prevalence for bulimia nervosa and binge eating disorder for females are: bulimia nervosa (197), binge eating disorder (631). For males bulimia nervosa (39) and binge eating disorder (313).

Mood disorders tend to be more severe than anxiety disorders. Although the estimated number of DeKalb County residents with mood disorders (7,468) is almost 50% less than for residents with anxiety disorders, the percent estimated to have “serious” severity levels (45.5%, 3,361 persons) is double that of residents with anxiety disorders.
Major depressive disorder is the most prevalent mood disorder, experienced by an estimated 5,627 DeKalb County residents (6.7%), with Bipolar I and II second most prevalent (2,044 residents, 2.6%), and dysthymia least prevalent (1,179 residents, 1.5%). Dysthymia is also referred to as chronic depression with symptoms less severe than major depression, but sometimes lasting two years more.

Mood disorders yield the highest estimated number of DeKalb County residents with a “serious” severity level, and Bipolar disorder I and II has both the highest estimated number and percent for any specific disorder, 1,694 DeKalb County residents.

• Impulse Control Disorders

• Three of the four impulse control disorders surveyed in the national study are considered to be childhood disorders: oppositional defiant disorder, conduct disorder, and attention-deficit/hyperactivity disorder (ADHD).

• An estimated 6,997 DeKalb County residents are estimated to have an impulse control disorder. Highest in estimated prevalence is attention-deficit/hyperactivity disorder (ADHD) with 5,267 county residents (4.1%) followed by intermittent explosive disorder, estimated at 2,044 residents, (2.6%).

• Lifetime Prevalence of Mental Disorders

• Lifetime prevalence is the proportion of persons who have a disorder at some time in their life. Lifetime prevalence data for the DeKalb County population is also based on the National Comorbidity Study.

• The most prevalent lifetime disorders are: major depressive disorder, 16.6%, affecting an estimated 13,050 DeKalb County residents and social phobia, 12.1%, affecting an estimated 9,512 residents. These two disorders also have the highest 12-month prevalence, though the order is reversed.

• Lifetime prevalence for any disorder is 46.4%, meaning almost half of all DeKalb County residents are expected to have at least one mental or substance disorder at some point in their lives, with the most likely type being an anxiety disorder, estimated to affect 22,641 county residents.

• Prevalence for a disorder usually increases between the ages of 18-29 and 30-44 and then declines in the older age groups and is lowest for the oldest age group (60+), regardless of disorder.

• Eating Disorders

• Little research-based information exists on the prevalence of eating disorders.

• Eating disorders though relatively uncommon, are frequently associated with other disorders. In most cases studied in the National Comorbidity Study, few individuals with eating disorders sought treatment over a 12-month period.
○ Lifetime prevalence estimates for anorexia nervosa, bulimia nervosa, and binge eating disorder are: 0.9%, 1.5%, and 3.5% among women, and 0.3%, 0.5%, and 2.0% among men.

○ Applying these estimates to the DeKalb County population, for women an estimated 355 will have anorexia nervosa, 592 bulimia nervosa, and 1,380 a binge eating disorder over a lifetime. For men, 118 will have anorexia nervosa, 196 bulimia nervosa, and 784 a binge eating disorder.

Alcohol and Substance Abuse Disorders

● Alcohol Abuse and Dependence

○ From the National Comorbidity Study an estimated 2,437 (3.1%) DeKalb residents 18 and older abuse alcohol, with an estimated 1,022 residents (1.4%) affected by an alcohol dependence disorder.

○ Estimates of alcohol abuse in DeKalb County from other studies range from 14.1% for residents 16 or older in an Illinois Alcohol, Tobacco, and Drug Use 2003 study (UIC Survey Research Lab for DASA) to 25.5% for binge alcohol use in the past month for residents 12 or older in the federal National Study on Drug Use and Health: 2002-2004 (NSDUH) and 32.2% for binge alcohol use among DeKalb County residents 18+ in the BRFS 2004 County survey, with 40.2% of males at risk for binge drinking versus 24.5% of females.

○ In the NSDUH surveys, binge alcohol use in the past month for the 12-20 age group is estimated at 19.8% or 3,373 DeKalb youth. Binge drinking is five or more drinks on one occasion.

○ Estimates for alcohol dependence range from of 1.3% or 1,022 DeKalb County residents 18+ in the study to 3.3% or 2,873 residents 12+ (NSDUH), with the 2003 Illinois DASA study at 2.4% or 1,985 residents 16 and older.

● Illinois Youth Survey Results for Alcohol and Substance Abuse

○ The Illinois Youth Survey program is a voluntary program for schools that measures rates of youth substance abuse and violence anonymously and provides school districts with confidential results by district while reporting summary results for geographic areas. Summary data for DeKalb County are not available as only one school in the county participated in the 2006 study. As a result, these estimates for DeKalb County use non-Cook County urban counties results which include the Collar Counties and communities statewide with populations 40,000 or greater. The Survey is conducted by Chestnut Health Systems for the Illinois Department of Human Services (DHS).

○ The 2006 Illinois Youth Survey reported binge drinking by 35.1% of 12th graders, 23.7% of 10 graders, and 10.9% of 8th graders, rates higher than the national average for 10th and 12th grades.
○ An estimated 27.2% of DeKalb County eighth graders, 40.7% of 10th graders, and 53.7% of 12th graders used alcohol in the past month.

○ Lower use exists for marijuana use: 9.3% of county eighth graders, 18.3% of 10th graders, and 26.2% of 12th graders are estimated to have used marijuana in the past month.

○ Use of inhalants decreases with age, with estimated highest levels reported for eighth graders: 8.2%, followed by 4.2% of 10th graders, and 3.5% of 12th graders.

○ Using Illinois statewide results for estimates, 35.1% of 12th graders engaged in binge drinking over the past month.

○ According to 2006 results, estimates for DeKalb County students reveal that 1,858 students (13.4%) in 8th through 12th grade have been drunk or high at school in the past year, with 499 students (3.6%) drunk or high six or more times, 4,257 (30.7%) have ridden in a car driven by a drunk or high driver, 5,394 (38.9%) gambled for money, and 4,922 (35.5%) have been in a physical fight.

○ Substance abuse reports for sixth graders show an estimated 259 boys (13.9%) and 194 girls (10.9%) using alcohol in the past month, and about seven percent in each group using inhalants over the same period.

● Alcohol Related Vehicle Incidents

○ Fatal crashes involving alcohol have remained fairly constant in DeKalb County with the number fatalities ranging from five and seven yearly between 2003 and 2007 with the exception of 2006, when there were two alcohol related deaths.

○ DUI arrests rose between 2003 with 860.0 arrests per 100,000 population to 997.0 in 2006, then dropping in 2007 to 827.0 per 100,000. The DeKalb County rates each year are substantially higher than the state.

● Substance Abuse and Dependence

○ Based on results from the National Comorbidity Study, an estimated 1,101 DeKalb County residents 18 or older (1.4%) abuse drugs over a 12-month period, and 314 have a drug dependence disorder (0.4%).

○ Using data from the National Study on Drug Use and Health (NSDUH) an estimated 1,476 county residents 12 or older have an illicit drug dependence while 2.5% or 2,183 residents are affected by illicit drug dependence or abuse.

○ The 2003 Alcohol, Tobacco and Other Drug Use in Illinois study by Chestnut Health Systems for DHS reported 1.7% of residents in northwestern Illinois counties have a drug dependence, equating to an estimated 496 DeKalb County residents, with 414 abusing drugs (0.5%).
Disabilities

- Prevalence of Developmental Disabilities
  
  - About two percent of children under the age of 18 have a serious developmental disability such as mental retardation or cerebral palsy. Of the 25,116 children under 18 in DeKalb County, 502 children would be affected.
  
  - About 17% of children have some type of developmental disability, including more mild conditions such as speech and language disorders, learning disabilities, and ADHD. For DeKalb County, an estimated 4,270 children would be affected.
  
  - Down syndrome occurs in 1 out of 800 births. DeKalb County women had 1,334 births in 2006.

- Autism Spectrum Disorders
  
  - Based on results from the CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network, the average estimated prevalence of Autism Spectrum Disorder (ASD) across all study sites was 6.7 per 1,000 8-year-old children or approximately one in 150.
  
  - Because the ADDM sites are not a nationally representative sample, the rates should not be generalized to every community, but can help to estimate how many children may have an ASD.
  
  - In seven sites for the 2002 study, the median age range of earliest reported ASD diagnosis was four years - one month (UT) to five years - six months (AL).
  
  - Between 51% and 91% of children with an ASD had documented developmental concerns before the age of three.
  
  - If children with ASDs were identified only on the basis of receiving special education services or having a documented diagnosis for an ASD, the prevalence of ASD would have been underestimated by as much as 30%.

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Utilization of Services, Need for Services

- Community Hospitals
  - In calendar year 2007, 708 hospital discharges took place involving DeKalb County residents in community or private hospitals for diagnoses related to mental illness, substance abuse, or developmental disabilities.
  - The hospitalization rate was 68.3 discharges per 10,000 population, considerably lower than the rate of 100.0 for all Illinois residents.
  - This DeKalb County rate is about seven-tenths of one percent of the population, although the same person could have been an inpatient more than once in a year.
  - Viewed by demographic characteristics, female discharges (374) were slightly higher than male discharges (334). Persons in the 25-44 year old age group experienced the most discharges with 270 followed by 15-24 (197), 45-64 (118), 0-14 (70), and 65+ (53).
  - Only for the 0-14 age group is the DeKalb County rate (36.9) higher than the state (31.0) although the DeKalb 65+ rate is relatively similar to the state. However, hospitalization in the 45-64 age group is less than half of the state rate, 58.4 for DeKalb County residents versus 130.9 for the state.
  - By diagnosis related group (DRG), of the 708 discharges, 555 (78.4%) involved mental illness, 133 (18.8%) were related to substance abuse, and 20 (2.8%) involved developmental disabilities.
  - Psychoses (DRG 430) with 470 discharges accounted for two-thirds of all behavioral hospitalizations. However, the psychoses hospitalization rate of 45.3 per 10,000 is well below the state rate at 62.0.
  - During 2007, for all age groups, Provena Mercy in Aurora was the leading destination for behavioral hospitalizations with 199 discharges or 28.1% of all DeKalb County resident discharges.
  - Kishwaukee Hospital was second for DeKalb County resident discharges with 180 (25.4%) followed by Linden Oaks at Edward Hospital in Naperville (10.3%). About five percent of patients each went to Alexian Brothers, Streamwood, and Provena St. Joseph.
  - Younger persons are more apt to leave DeKalb for inpatient care. Kishwaukee was the leading inpatient site for individuals aged 25 or older.

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\(^2\)Data for inpatient and emergency department use from Illinois Hospital Association COMPdata provided by Kishwaukee Hospital.
Hospitalization - State Hospitals

- The Illinois Department of Human Services (DHS) publishes reports which describe the use of state facilities (such as at Elgin, Singer at Rockford) which are operated by the Office of Mental Health and Developmental Disabilities (OMH/DD).

- In fiscal year 2008 (July 1, 2007-June 30, 2008), 62 DeKalb County residents were admitted to Illinois OMH/DD hospitals. Diagnoses were mental illness (48), drug abuse (6), developmental disabilities (5), and alcoholism (3). Of the 62 admissions, 30 were readmissions. Average stay was 312 days or about ten months.

- Demographically, DeKalb residents admitted were white (45), black (11), Hispanic (3), Asian (2), and other (1). Average age at discharge was 39.5. Gender was not available, but for the entire state, males received three of four days of care in state facilities.

- Diagnoses were not available, but leading statewide diagnoses are major affective disorders, substance use disorders other than alcohol, schizoaffective disorders, and dysthymic disorders.

- According to OMH/DD, the FY 2008 facility admission rate per 100,000 from DeKalb County was 69.6, somewhat less than the entire state at 86.2.

Emergency Department Use

- During calendar 2008, DeKalb County residents made 1,050 hospital emergency department visits for mental health reasons not including patients who were admitted to the hospital.

- Of these visits, the great majority, 739 or 70.4% took place at Kishwaukee Hospital. An additional 122 or 11.6% took place at Valley West. Out of county ED visits totaled 189 or 18.0% of DeKalb resident ED mental health visits. Of these 78 (7.4%) went to Aurora, 25 (2.4%) to Elgin, and 22 (2.1%) to Rockford.

- By age group, ED visits were as follows: 15-24 (34.0%), 25-44 (37.9%), 45-64 (16.5%), 0-14 (6.1%), and 65+ (5.5%). Females made 544 or 51.8% of the visits compared to 506 or 48.2% for males.

- Three diagnoses dominate the ED visit reasons when categorized by three digit ICD-9 code. These are neurotic disorders such as anxiety, panic, phobia, and OCD with 255 (24.3%) visits, nondependent use of drugs including alcohol abuse - 225 or 21.4%, and depressive disorder - 200 (19.0%). One of nine ED visits (10.9%) are for affective disorders such as bipolar, manic-depressive.

- For men, nondependent abuse of drugs is the leading diagnosis with 25.3% of visits. For women, neurotic disorders (31.1%) place first.

- The major disorders also account for most visits in the same order for ages 15-24 and 25-44. The other age groups are similar except that conduct disturbance tops 0-14,
nondependent drug abuse 45-64. Neurotic disorders again tops visits in the 65+ age group.

- Long-Term Care
  - Of the 681 residents of DeKalb County long-term care facilities on December 31, 2007, 35 (5.1%) had mental illness as their primary diagnoses, 18 (2.6%) had developmental disability, and 95 (14.0%) had Alzheimer’s disease.

**Health Care Use, Cost, Insurance, Medical Access**

- Use of Mental Health and Substance Services
  - From the National Comorbidity Study, of those who reported having any mental or substance abuse disorder in the prior 12 months, fewer than half (41.1%) received some treatment in that time period, 12.3% from a psychiatrist, 16.0% from a non-psychiatrist mental health specialty, 22.8% from a general medical provider, 8.1% from a human services provider, and 6.8% from a complementary and alternative medical provider.
  - In the same study, about half of those who had either alcohol or drug dependence used some service provider for treatment, with almost all of those receiving treatment for drug dependence using a health care provider as opposed to a non-health care provider, such as human services or complementary alternative medicine.
  - The most likely group to receive any treatment were respondents with mood disorders (56.4%), compared with 42.2% with anxiety disorders, 38.1% with substance abuse disorders, and 29.6% with intermittent explosive disorder.
  - Using psychiatrists most were persons with mood disorders (21.0%), with substance disorders at 13.2% and anxiety disorders at 13.0%.
  - Cases treated in the mental health services sector received more visits in the prior twelve months (median = 7.4 visits) compared to either the general medical sector (median = 1.7 visits) or non-health care providers (median = 3.9 visits).
  - DeKalb County estimates based on the NSDUH are that 215 residents need, but not receive treatment for alcohol dependence in the past year with 32 residents estimated to need, but not receive treatment for illicit drug dependence in the past year.
  - Based on the Alcohol, Tobacco, and Other Drug Use in Illinois, using Illinois statewide estimates, 12,902 DeKalb County residents 16 and older (15.6%) need treatment for alcohol and drug abuse.
  - Persons having a mental disorder or reporting domestic violence are more likely to need treatment services for alcohol or drug abuse, with an estimated 26.8% of those having a mental disorder and 23.6% of those reporting domestic violence needing treatment.
○ In 2004, 180 youth were served in the Illinois Department of Human Services, Division of Alcohol and Substance Abuse (DASA) Network, with 133 (73.9%) served through “Intervention,” and 41 (22.8%) served in outpatient facilities.

○ In 2007, 946 adults were served in the DASA Network, 391 (41.3%) in “Outpatient” facilities, 310 (32.8%) through “Intervention,” 99 (10.5%) with “Intensive Outpatient,” 62 (6.7%) with “Residential Rehabilitation,” 35 (3.7%) in “Case Management,” 33 (3.5%) in “Detox,” and 16 (1.7%) in “Home Recovery.”

○ In the 2007-2008 Fiscal Year, 18 adults and 13 adolescents received inpatient care at a Rosecrance facility in Rockford.

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<th>Health Care Utilization and Access</th>
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| ○ In the 2004 BRFS, an estimated 13.8% of DeKalb County residents had no health care coverage with the number increasing to 28.7% for residents with incomes between $15,000 and $35,000, 26.7% for those never married and 26.4% for those divorced or separated. Data for some groups is suppressed due to small numbers.
| ○ More than one in five (21.8%) county residents had no usual health care provider, with higher percentages for residents never married (35.6%), divorced/separated (32.5%), males (29.3%), and with incomes between $15,000 and $35,000 (26.7%).
| ○ One of seven residents 18 or older couldn’t fill a prescription due to cost.
| ○ One in nine residents couldn’t see a doctor due to cost, with 28.3% with incomes between $15,000 and $35,000 unable to do so.

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| ○ According to the AMA, six psychiatrists practice or live in DeKalb County, a rate of 5.8 per 100,000 population; the national average is 9.1 per 100,000.
| ○ Forty-two primary care physicians, including family medicine, general practice, internal medicine, and pediatrics, either practice or live in the county. The rates for each of these specialties is lower in DeKalb County than the national rate.

**Special Education**

<table>
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<th>Developmental Disabilities</th>
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| ○ The Special Education Profile for DeKalb County School Districts in total for December 31, 2007 reports seven categories with more than 50 students: specific learning disability (756), other health impairment (377), speech/language impairment (501), other health impairment (377), emotional disability (172), developmental delay (109), autism (108), and cognitive disabilities (83) students.
The age distribution shows similar numbers of students in special education with between six and seven percent (133-172 students) in each year from 6 through 17, with fewer students in the pre-school and post-17 year age groups. Just seven students are 20-21 years.
Chapter 1: Introduction and Methodology

- The DeKalb County Community Mental Health Board (DCMHB) engaged Health Systems Research of the University of Illinois College of Medicine to conduct a comprehensive mental health survey of area households. The survey sought to determine the prevalence of conditions, whether help was sought or whether certain barriers prevented access to services.

- The survey mailing included a flyer with the theme “Help Us Help You,” an eight-page booklet including the cover letter from Board President Charles G. Rose urging participation and setting out the survey purpose, structured questions, and space for open-ended comments. No identification of the respondent appeared on the survey or return envelope so that responses were anonymous.

- Of the 4,000 surveys mailed, 417 were completed and returned for a response rate of 10.4%. For the entire sample (417) chances are 95 out of 100 that the margin of error can be no greater than plus or minus 4.5%.

Chapter 2: Respondent Characteristics

- Survey respondents tended to be female, with 64.3% of returns coming from female respondents.

- Median age of respondents stood at 53.9, somewhat older than the Census indicates. However, predominately student areas were excluded from the survey sample, so that survey respondents should be expected to be somewhat older than the Census reports.

- Educational levels of those responding were considerably higher than the Census would predict. Nearly half (47.7%) hold a bachelor’s degree or higher while Census data for the county pegs the proportion at 28.5%.

- Like the county as a whole, the respondents were dominantly white, non-Hispanic. Minority responses were sparse – Hispanic (2.2%) and black (1.4%).

- Median years living in the county for respondents was 21 years with 42.4% of respondents having lived in DeKalb County for 25 years or more.

Chapter 3: Respondent Views of Mental Illness

- Nearly two-thirds (64.5%) of respondents strongly agree that children’s mental health is essential to health, academic success, and well-being.

- Almost half (48.2%) of those surveyed marked strongly agree for the statement that treatment can help people with mental illness to lead normal lives.
Strongly agreeing that mental illness can be caused by biological imbalances are 38.8% of participants.

More than one-third (37.2%) voiced strong agreement that alcoholism is a disease which should be treated like other medical conditions.

Only one person (0.2%) strongly agrees that mental illness is a sign of personal weakness.

Women are more agreeable than men that treatment can help people with mental illness, mental illness can be caused by biological imbalances, children’s mental health is essential to health, and alcoholism is a disease to be treated like other medical conditions. For the fifth statement that mental illness is a sign of personal weakness, men were more likely to agree than women.

Respondents under age 65 were more likely to agree than their older counterparts that treatment can help people with mental illness to lead normal lives, that mental illness can be caused by biological imbalances, and that children’s mental health is essential to health, academic success, and well-being.

The youngest respondents aged 18-29 and the oldest aged 65+ voiced stronger agreement than middle-aged respondents aged 30-64 that mental illness is a sign of personal weakness. Respondents aged 65 and older agreed most strongly that alcoholism is a disease which should be treated like other medical conditions.

Individuals with a graduate degree were more likely to agree than those with less education that treatment can help people with mental illness, mental illness can be caused by biological imbalances, children’s mental health is essential to health, and alcoholism is a disease to be treated like other medical conditions. Those with a graduate degree were also least likely of all the educational groups to feel that mental illness is a sign of personal weakness.

Chapter 4: Personal and Household Needs

One in eleven (8.9%) respondents checked participation by a household member in Alcoholics Anonymous, while 6.7% had someone in the household involved with Al-Anon. Somewhat fewer had a household member involved with a depression and bipolar support group such as Group Hope (5.3%) or an Alzheimer’s support group (4.3%). Much smaller numbers checked participation in Narcotics Anonymous (2.4%) or NAMI (2.2%).

Leading the list of supportive or treatment services that they or someone in their household needs, but are not receiving at this time was counseling for adults with emotional problems at 9.8%, followed by support groups for coping with daily living (9.1%), community education about mental health (7.9%), support groups for families coping with a mentally ill family member (7.2%), and alcohol abuse treatment (7.0%).

Somewhat fewer checked that they are not receiving mental health services for children with emotional problems (6.0%), bereavement services or help coping with death (4.6%), disabled person’s housing and independent living (4.6%), eating disorders treatment (4.6%), mental health emergency/crisis assistance (4.6%), counseling and support services for senior citizens
(4.3%), counseling for families and children in crisis (4.3%), and disabled person’s employment and training (4.3%).

- Fewer noted that they or a family member are in need of community education about substance abuse (3.4%), mental health services for veterans and military families (2.9%), autism related services (2.6%), drug abuse treatment (2.4%), youth, adolescent substance abuse, prevention services (2.2%), sexual assault victim support (1.7%), or domestic violence services (1.4%).

- The mean number of needed services for the overall sample was 2.67 services per household. Respondent groups leading in mean number of services needed are residents of the communities in the South (3.59) portion of DeKalb County, respondents with a high school education or less (3.33), residents of the area 5-14 years (3.32), male respondents (3.11), and residents of the communities in the North (3.09).

- Asked whether anything has kept them or a household member from receiving the mental health, substance abuse, or disability related services needed, about one in six respondents (16.8%) said yes.

- Respondent groups most likely to report that they or another household member have been kept from receiving needed services included those with some college/Associate degree (27.2%), aged 30-44 (26.1%), aged 18-29 (25.8%), females (23.1%), and living in the area 5-14 years (22.9%).

- Barriers encountered by those unable to receive needed services include the following: cost of treatment (78.6%), didn’t know where to go for services (52.9%), lack of insurance to help with the cost of treatment (50.0%), others having a negative view of them for using mental health services (22.9%), the wait for help is too long (17.1%), transportation to get to services (14.3%), no agency has the services I need (12.9%), and I owe money to the agency (7.1%).

Chapter 5: Household Mental Health Problems

- The leading problem across the entire sample of household members is sadness or blue mood lasting more than two weeks, or depression, seriously affecting one in ten persons (9.9%) in the past year. Problems rounding out the top five include difficulty focusing or easily distracted (attention deficit disorder) at 9.1%, trouble controlling anger at 7.6%, frequently anxious and fearful (general anxiety disorder) at 6.4%, and mood swings from high to low (bipolar disorder or manic depressive) affecting 4.9% of household members.

- Half of households are affected by a mental health problem or condition. Just over half (51.6%) of respondents did not note any problems or conditions checking that no one in their household has any of the listed problems. Only 33.3% of respondents aged 18-29 and 38.1% of respondents aged 30-44 said that none of the problems applied to household members in the past year.

- In the 0-17 age group, the leading problems are difficulty focusing or easily distracted (15.9%), trouble controlling anger (11.6%), and sadness or blue mood lasting more than two weeks (5.6%).
Among those aged 18-44, sadness or blue mood lasting more than two weeks leads at 15.0%, followed by trouble controlling anger (10.7%), difficulty focusing or easily distracted (10.7%), frequently anxious and fearful (10.5%), mood swings from high to low (9.0%), and abuse of alcohol (8.8%).

For household members aged 45-64, sadness or blue mood lasting more than two weeks led at 11.8%, but other top problems were well behind at 6.8% for frequently anxious and fearful, 6.5% for serious conflict in marriage, and 6.2% for trouble controlling anger.

Percentages for seniors aged 65 and older are quite low compared with the younger age groups except for loss of ability to think or remember which affects 5.0% of senior household members and is the leading problem for the age group.

The problems or conditions that peak in the 0-17 age group are difficulty focusing or easily distracted, Autism or Asperger's Syndrome, seizures, trouble controlling anger, violent behavior, intense need to repeat thoughts and actions, and uncontrollable tics and outbursts.

Peaking in the 18-44 age group are abuse of alcohol, sadness or blue mood lasting more than two weeks, sadness or blue mood lasting more than two weeks after the birth of a child, frequently anxious and fearful, anxiety following a terrifying event, afraid to be around people, intense fear of objects or situations, and mood swings from high to low.

Those in the 45-64 age group are most likely to experience serious conflict in marriage and afraid to leave the house in crowds.

The only problem experienced by seniors aged 65 and older at a rate higher than the younger age groups is loss of ability to think or remember.

One in five respondents (20.1%) indicated that at least one day in the past 30 days an emotional problem or disability interfered with their doing work or other usual daily activities.

Across the entire sample, the mean number of days of emotional problems or disabilities interfering with daily activities was 2.1, but among those who indicated at least one day, the mean was 10.4 days or approximately one-third of the time. Respondent groups with the highest mean days of disability included the following: North (3.71), age 30-44 (3.65), some college/Associate degree (3.33), and age 18-29 (2.94).

Chapter 6: Use of Services

Nearly four in ten (39.3%) respondents said that they had thought about seeking professional help for a personal or emotional problem in the past year.

Respondent groups with half or more saying they thought about seeking help include age 30-44 (55.8%), some college/Associate degree (52.0%), and 15-24 year residents (50.0%). Least likely to think about seeking professional help are seniors aged 65 and older at 14.4%.

Just over half (51.2%) of those who contemplated seeking help actually sought help. Least likely to access services were participants aged 18-29 (14.3%) and persons living in the area 15-24 years (28.0%).
Family doctor for counseling at 6.5% of persons in survey households, social worker at 6.4%, and psychiatrist at 6.0% constituted the top three professionals seen by household members for a counseling, mental health, or emotional problem.

Among the 0-17 age group, 11.6% had seen a social worker in the past year, while fewer sought help from a psychiatrist (6.8%), psychologist (6.0%), family doctor for counseling (4.4%), or clergy member (1.6%).

Among persons aged 18-44, the largest percentage had seen a family doctor for counseling (9.3%), followed by a psychiatrist (7.9%), social worker (6.5%), psychologist (6.2%), or clergy member (3.4%).

Family doctor led for respondents aged 45-64 (6.5%), followed closely by psychiatrist (5.6%) and social worker (5.4%), and less closely by psychologist (4.2%) and clergy member (3.9%).

Seniors aged 65 and older also saw a family doctor (4.6%) more often than the other listed professionals. Psychiatrist (2.7%), psychologist (2.3%), social worker (2.3%), and clergy member (1.4%) were listed less often among seniors.

Private counseling office led at 8.1% as the location at which professionals were seen.

Coping with life events at 8.4% with the leading reason that mental health treatment was needed.

Across all survey household members, 11.0% or about one in nine persons, had received medication for an emotional problem in the past year. More than one in seven (15.8%) household members aged 18-44 received medication for an emotional condition in the past year, followed by 10.7% of those aged 45-64, 8.4% of children aged 0-17, and 6.8% of seniors age 65 and older.

Hospitalization in a psychiatric unit in the past year affected just 1.1% of the overall sample.

For the 54 household members receiving services who were covered for their mental health condition, the reimbursement came from partial insurance (62.9%), full insurance (7.4%), Medicare (16.7%), Medicaid (7.4%), and self-pay (5.6%).

Chapter 7: Benefits From Services

Of those who received services or were involved sufficiently with a family member who did, 74.3% agree that they are now getting along better within their family, 73.7% agree that they are doing better in social situations/dealing with others, and 72.9% agree that they now deal more effectively with daily problems.

Feeling better about the problem and/or situation are 69.8% of respondents who received services, 69.9% are now better able to deal with crisis/stress, 65.5% agree they are better able to control their lives, and 62.4% agree that they are doing better in school or work.
● Females voiced stronger agreement than males that they or a family member experienced a favorable outcome after receiving mental health services.
KEY INFORMANT INTERVIEWS

Chapter 1: Introduction and Methodology

- This report on key informant interviews is one component of the 2008-2009 Comprehensive Community Mental Health Assessment sponsored by the DeKalb County Community Mental Health Board. Other components include a household survey, focus groups, and a community analysis. The study was conducted by Health Systems Research, an applied community research unit at the University of Illinois College of Medicine, Rockford.

- The report summarizes information from 27 in-person interviews with 52 key informants regarding mental health services in DeKalb County. Key informants were chosen by the DeKalb County Mental Health Board.

- Topics of discussion were focused on a set of questions about mental health needs and services, which included major groups of people served, target populations needing greater attention, the mental health services system as a whole, changes and challenges for the county, important actions to be taken, and beneficial continuing education offerings.

Chapter 2: Mental Health, Substance Abuse, and Developmental Disabilities Delivery System

- When asked about various aspects of DeKalb County’s mental health delivery system, key informants often framed their comments in light of broader societal conditions. They also commented on pivotal roles played by federal and state government in the delivery of mental health, substance abuse, and developmental disabilities services.

- Strengths
  - DeKalb County has competent agencies and organizations that offer reputable quality programs.
  - DeKalb County has a good system of outpatient mental health and substance abuse services.
  - Transportation services through the Voluntary Action Center provide a good, reliable, and basic system of transportation and mobility services that assists in preventing duplication of transportation services on the part of various agencies.
  - DeKalb County has excellent developmental disabilities resources through the county’s provider agencies and schools.

- Weaknesses
  - The system lacks a regular forum for broad-based provider communication, coordination, and information sharing.
Shortcomings in government funding, including reimbursement rates, funding cuts, caps on funding, and delayed state payments. Increasing numbers of residents cannot afford the cost of care even with sliding fee scales.

Shortages of specific personnel, including psychiatrists, advanced practice nurses, and counselors as well as Spanish-speaking bilingual professionals and certain certified staff sought by the school districts.

Boundary issues between agencies and services create problems for service delivery, including a lack of clear protocols, policies, communication, and collaboration.

DeKalb County does not have a comprehensive, integrated system of mental health, substance abuse, and developmental disabilities services that ensures continuity of care.

- Barriers to Service
  - Language and cultural barriers, especially for Spanish-speaking residents.
  - Shortages of specific personnel, including psychiatrists, advanced practice nurses, and counselors as well as Spanish-speaking bilingual professionals and certain certified staff sought by the school districts.
  - Shortfalls in government funding which increase costs, lengthen waiting lists, and eliminate programs.
  - The lack of specific programs and expertise, including an inpatient psychiatry program and therapists with a specialty in treating eating disorders.
  - Administrative practices, policies, and protocols, including health plans with high deductibles and no pharmacy benefit, less flexible access to emergency psychiatric services, and need for protocols for coordinating services among the therapeutic agencies.
  - Information and referral services that are not working effectively.

- Service Gaps
  - Services for traumatic brain injury, particularly for veterans.
  - Therapists with a specialty in treating eating disorders.
  - Emergency services to get prescriptions to seriously mentally ill homeless individuals.
  - Support groups for families.
  - Community education forums for mental health, substance abuse, and developmental disabilities, especially as integrated into health system education offerings.
• Duplication
  ○ Service or program duplication is said to be minimal in DeKalb County although a lack of clarity and “fuzzy boundaries” exist between services.
  ○ Administrative cost share could reduce administrative duplication among agencies.

• Collaboration
  ○ Many collaborations already exist between agencies in DeKalb County, including interagency agreements and a variety of current and potential partnerships.
  ○ Key informants reported a strong consensus that at least once a year the Mental Health Board convene a mental health, substance abuse, and developmental disabilities summit for the Board and the provider agencies to review system functioning, coordination, and problem solving. Provider agencies should come together several times a year for informational updates, communication, and problem solving.
  ○ Collaboration within and among school districts was also viewed as having strong potential for enhancing services.
  ○ Ben Gordon Center could be the centerpiece of coordinating the mental health and substance abuse systems if other agencies experienced greater collaboration in working with BGC.

Chapter 3: Changes, Challenges, and Opportunities in Providing Mental Health, Substance Abuse, and Developmental Disabilities Services

• Changes
  ○ In addition to the increasingly unstable and challenging economy, key informants commented on changes in the State of Illinois Medicaid program and the decrease in available affordable housing in the county.
  ○ DeKalb County has an increasingly diverse and low-income population with significant growth in the Hispanic population.
  ○ Local health systems and public sector facilities are unable to recruit and retain psychiatrists.
  ○ Changes in federal and state government funding has become inadequate to meet the needs of DeKalb County residents.
  ○ With the passage of the 2008 federal Mental Health Parity Act, health plans providing mental health coverage must ensure that coverage for physical and mental health are identical, a possible improvement for consumers.
  ○ Eating disorders are more extensive in DeKalb County than in the past.
The life span for persons with developmental disabilities is increasing due to better care and medical advances.

- **Challenges**
  - Growth in the population of the county and population subgroups, especially Hispanics, will increase the need for mental health services serving these populations.
  - Continued broad-based problems in the economy and basic service system such as medical care and housing.
  - Retrenchment in funding for the human services safety net.
  - Continued shortages of psychiatrists, advanced practice nurses, and counselors as well as bilingual mental health professionals.
  - Provision of community support services for the homeless and elderly as well as mental health, substance abuse, and developmentally disabled populations as the state funds less services through nursing homes and congregate care.
  - Provision of a coordinated system for responding to the crisis needs of the acute mentally ill.
  - Need for more outreach and intervention services to address the increase in gang activity in DeKalb County.

- **Opportunities**
  - The Mental Health Board has the opportunity to provide regularly scheduled, broad-based provider forums to enhance coordination, collaboration, and information sharing.
  - Community leaders and the medical, mental health, substance abuse, and developmental disabilities networks have the opportunity to work together to develop and implement a Federally Qualified Health Clinic for DeKalb County.
  - Ben Gordon Center could play a vital leadership role in coordinating the mental health service system if other agencies experienced greater collaboration in working with BGC.

**Chapter 4: Target Groups Needing Greater Attention**

- Adults with Acute Mental Illness.
- Low-income Persons in Need of Mental Health and Substance Abuse Services.
- Hispanics in Need of Bilingual Mental Health Professionals.
- Persons with Eating Disorders.
Chapter 5: Actions and Initiatives

- Convene a broad-based group of mental health, substance abuse, and developmental disabilities providers at least once a year, and possibly semi-annually or quarterly, to provide for consistent communication, coordination, information sharing, and problem solving.

- Retain the inpatient psychiatric unit at Kishwaukee Health System, or if not possible, then community providers work together to determine arrangements for meeting the crisis needs of the acute mentally ill.

- Develop and implement a plan to increase the number of bilingual, Spanish-speaking professionals and staff at community agencies, especially psychiatrists, advanced practice nurses, and counselors.

- Collaborate with legislators and state departments to increase funding for mental health, substance abuse, and developmental disabilities services.

- Develop a community action plan to work with the Ben Gordon Center to decrease the waiting time for psychiatric evaluations and for counseling appointments beyond the first appointment.

- Convene a broad-based coalition of community leaders and providers to establish a Federally Qualified Health Clinic with both physical and mental health services to increase access to physical and mental health care in DeKalb County.

- Continue to work on reducing stigma related to mental health, substance abuse, and developmental disabilities as well as the integration of physical and mental health.

- Develop an action plan to increase the number of therapists with a specialty in treating eating disorders.

- Increase the effectiveness of information and referral services in DeKalb County.

Chapter 6: Educational Workshops Desired

- Topics Suggested for Provider Workshops
  - Post Traumatic Stress Disorder (PTSD).
  - Substance abuse training for non substance abuse providers.
  - Substance abuse training for overlapping diagnoses.
  - Sensitivity training on cultural and social issues.
  - Skills for service providers in building relationships with persons with mental illness.
  - Crisis intervention services.
• **Topics Suggested for Consumer Workshops**
  o Stress reduction.
  o Financial and credit workshops for the public.
  o Education for family members on accessing services.

• **Workshop Format Suggestions**
  o Quarterly forums for consistent agency communication and problem solving paired with an educational component.
  o For some agencies, schedule workshops on nights and weekends.
  o Work with the training consortium at Kishwaukee Community College.
  o Some workshops might be one and a half hours, preferably at breakfast.
  o Local sites are preferred for workshops rather than out-of-town.
FOCUS GROUP STUDY

Chapter 1: Introduction and Methodology

- This report on focus group interviews is one component of the 2008-2009 Comprehensive Community Mental Health Assessment sponsored by the DeKalb County Community Mental Health Board. Other parts include a community analysis, a household survey, and key informant interviews. The study was conducted by Health Systems Research, an applied community research unit at the University of Illinois College of Medicine, Rockford.

- The report summarizes information from seven focus group and two individual interviews with a total of 73 participants interviewed regarding their views, knowledge, and experiences with mental health services in DeKalb County. Target group populations for the focus groups were chosen by the DeKalb County Mental Health Board in conjunction with Health Systems Research.

Chapter 2: Views of Mental Health and Substance Abuse

- In responding to four statements about mental health and substance abuse, the majority of focus group participants agreed that:
  - Treatment can help people with mental illness lead normal lives.
  - Mental illness can be caused by biological imbalances.
  - Alcoholism is a disease which should be treated like other medical conditions.
  - Respondents strongly disagreed that:
    - Mental illness is a sign of personal weakness.

- The teen focus group responded to the single question: Do you think a teen’s mental health is important for health, academic success, and well-being? The overwhelming majority of teens agree that mental health is very important for all three of these areas.

Chapter 3: Services for Mental Health, Substance Abuse, and Developmental Disabilities

- Knowledge of Services:
  - While the majority of respondents currently know where to go for services, they did not express confidence in knowing about the services prior to actual involvement in the service system.
  - Participants emphasized the need for increasing the effectiveness of information and referral services in DeKalb County.

- Experiences with Services, Including Services Needing Greater Attention:
  - Participants received services from a wide range of organizations and professionals and offered many insightful comments about their experiences.
When asked to rate aspects of the service system based on their knowledge and experiences, participants rated the cost and continuity of services as major concerns with low to very low ratings. Accessibility and availability were rated as significant concerns with medium to low ratings. Quality and satisfaction with services received very mixed ratings ranging from low to very high.

Medications were prescribed to the majority of participants. Both adult and teen participants stressed that too much focus was placed on medications without considering and monitoring both the physical and behavioral side effects of medications. When medications were necessary, participants reported the cost of medications was problematic.

Participants indicated that they experienced significant waiting periods to see psychiatrists for non-emergency but highly stressful situations.

Adult focus groups identified five main services needing greater attention:
- Counseling, medication management, and other therapeutic services.
- Educational and support services, including groups.
- Continued availability of a local inpatient psychiatric unit.
- Housing and housing options.
- More effective information and referral services, including public awareness and education.

The teen focus group identified two main services needing greater attention:
- Teen counseling services, including groups.
- Local drug and alcohol rehabilitation services for teens.

Chapter 4: Actions and Initiatives

- Recommendations by the focus groups were to:
  - Increase support services to family members and other caregivers.
  - Support the development of additional housing units and housing options for populations with mental illness, substance abuse, and developmental disabilities.
  - Retain the inpatient psychiatric unit at Kishwaukee Community Hospital.
  - Increase the effectiveness of information and referral services in DeKalb County.
  - Continue to educate the community about mental illness, substance abuse, and developmental disabilities to increase community acceptance and understanding of persons with these conditions or disabilities.
  - Develop community action plans to address staff shortages at the Ben Gordon Center and other agencies and decrease the waiting time for psychiatric appointments and counseling appointments beyond the first visit.