

EVALUATION OF THE RESIDENTS OF ILLINOIS INSTITUTIONS FOR MENTAL DISEASE (IMDs)

Report Prepared For:

Plaintiff Class
Williams v. Blagojevich et al
Illinois

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INTRODUCTION

This report was prepared at the request of counsel representing the class of plaintiffs in the civil rights class action suit of Williams v. Blagojevich, et al. The law suit is pending in the United States District Court for the Northern District of Illinois.

The plaintiffs are residents of 26 intermediate care nursing homes for people with mental illness that in Illinois are known as Institutions for Mental Disease, or IMDs. In the Court's order dated November 11, 2006, the class of plaintiffs was defined as Illinois residents who: "(a) have a mental illness; (b) are institutionalized in a privately owned Institution for Mental Diseases; and, (c) with appropriate supports and services may be able to live in an integrated community setting."

This report describes a systematic professional evaluation of a representative sample of residents of IMDs that was conducted by a team of mental health professionals. The purpose of the evaluation, which was requested by plaintiff class, is to determine whether residential services and programs in the IMDs are being provided in the most integrated setting appropriate to each resident's disability, and whether with appropriate supports and services, residents who participated in the evaluation could live in more integrated community settings.

The Evaluation Team and Its Qualifications

The mental health professionals who conducted the evaluation are three faculty members from the Yale University School of Medicine: Jacob K. Tebes, Ph.D., a psychologist and the team leader; Paul T. Amble, M.D., a psychiatrist; and Madelon V. Baranoski, Ph.D., MSN, a psychologist and nurse. The team has considerable experience in public-sector mental health services and administration, including: clinical psychology and psychiatry; evaluation methodology; quality assurance; community program development; community service system development; clinical and service system consultation; forensic psychiatry; and clinical and outcome assessment.

Dr. Tebes is an Associate Professor of Psychology in Psychiatry, Child Study Center, and Epidemiology and Public Health, Yale University School of Medicine. He is also Deputy Director of The Consultation Center and Co-Director of the Division of Prevention & Community Research at Yale, and has served as President of the Medical and Professional Staff of the Connecticut Mental Health Center. In a professional career of more than 20 years as a licensed psychologist, Dr. Tebes has worked extensively with persons who have serious mental illness and the systems that serve them, including: conducting hundreds of clinical and research interviews; developing community-based evaluation and quality assurance programs; and consulting to municipal, state, and federal agencies. He has also published on the treatment and evaluation of persons with serious mental illness, and presented to scientific and professional audiences on issues pertaining to this population.

Dr. Paul T. Amble is an Assistant Clinical Professor of Psychiatry at the Yale University School of Medicine and the Chief Forensic Psychiatrist of the Division of Forensic Services, Connecticut Department of Mental Health and Addiction Services. He is a Diplomat of the

American Board of Psychiatry and Neurology and a Board Certified Forensic Psychiatrist. He has 18 years experience conducting over 1,000 forensic evaluations and clinical assessments, and providing treatment to persons with serious mental illness in a variety of hospital, residential, correctional, and community settings. In the course of this work Dr. Amble is routinely consulted to assist mental health treaters who are transitioning high risk persons with serious mental illness from institutional settings to the community. He has completed numerous professional presentations and conducted research in this area.

Dr. Madelon Baranoski is an Associate Professor of Psychology in the Department of Psychiatry, Yale University School of Medicine. She is also currently the Director of the New Haven Diversion Project and the Associate Director of the New Haven Court Clinic of the Connecticut Mental Health Center. As a licensed clinical psychologist, she has over 25 years of professional experience working with persons with serious mental illness. In the last 10 years, she has conducted over 2,000 competency-to-stand-trial evaluations of adults with serious mental illness, including hundreds of assessments to determine the appropriateness of discharge from institutional to community-based settings. She also has extensive published work and professional presentations involving community care for persons with serious mental illness.

In visits to eight IMDs during February 5 - 7, 2008 and March 5 - 7, 2008, Drs. Baranoski and Tebes interviewed a representative sample of IMD residents, and Dr. Amble reviewed their available medical records. In addition, on June 19, 2008 all members of the team visited two community residential sites, C4 and Thresholds, in Chicago, Illinois. As part of their work, team members also examined various relevant scholarly articles and measures, including those cited as references at the end of this report, and reviewed the following materials:

- Medical records of all residents interviewed in the IMDs as well as portions of individual medical records not available at the time of the visit.
- Combined Agreed Protective Order in Williams v. Blagojevich (Includes Agreed Order Supplementing Protective Order and Second Agreed Order Supplementing Protective Order)
- Governor's Housing Task Force Working Group's "Supportive Housing Report"
- Swartz, Luchins & Hanrahan report "Minimum Data Set Classification of PASR Clients in Nursing Homes"
- Deposition transcript of Lorrie Rickman Jones, February 27, 2008 & May 29, 2008
- 3/15/05 Report to the General Assembly
- Defendants' motion to exclude expert testimony and plaintiffs' response in New York Adult Home case
- Materials related to IMDs' motion to quash subpoenas
- Plaintiffs' response in opposition to motion to quash subpoenas & exhibits
- IMDs' replies to plaintiffs' response in opposition to motion to quash
- Judge Hart's January 2, 2008, Order and Opinion re: motion to quash subpoenas
- Elizabeth Jones' and Denny Jones' redacted reports in NY Adult Home case
- List of IMDs and DPH website (www.idph.state.il.us)
- Amended Complaint in Williams v. Blagojevich
- Website for random selection of IMDs (www.graphpad.com/quickcalcs/randomSelect1.cfm), website for random selection of

residents for interviews (www.randomizer.org/form.htm), and websites to calculate sample size (www.marketresearchworld.net and www.raosoft.com).

BACKGROUND

Two abiding objectives for the evaluation were to develop and implement an evaluation that adheres to principles of scientific rigor, and to ensure that the evaluation is consistent with current standard practice in mental health. Each of these objectives is discussed below as background to the report.

Develop and Implement an Evaluation that Adheres to Principles of Scientific Rigor

Scientific rigor refers to methods that are drawn from science that are systematic, reliable, valid, and replicable, and that are theoretically linked to concepts being examined empirically (Tebes, Kaufman, & Connell, 2003; Tebes, 2005). The evaluation of IMD residents developed and implemented by the team adhered to principles of scientific rigor by following these principles:

- 1) assemble a qualified team of experts to carry out the evaluation;
- 2) develop an explicit, systematic, and efficient methodology that is focused on issues and constructs relevant to the specific issues in the case;
- 3) collect data to address issues relevant to the case using multiple sources of data, such as reports from the residents of the IMD, reviews of medical records, and observations of experienced mental health professionals;
- 4) whenever possible, use measures that have been previously shown to be reliable and valid; and,
- 5) gather sufficient data to ensure that representative generalizations can be made to the population involved in the complaint.

Specific information regarding the measures and procedures employed that illustrate how the evaluation adhered to principles of scientific rigor is provided in the Methods section of this report.

Ensure that the Evaluation is Consistent with Current Standard Practice in Mental Health

Another central objective of this evaluation was that it be consistent with current standard practice for serving persons with serious mental illness. Over the past 50 years, treatment for serious mental illness has steadily advanced from the provision of total institutional care, including residential services, to the delivery of a range of community-based services for persons living independently in the community (Koyangi, 2007; Levine & Perkins, 2004). These developments occurred as the result of advances in psychological theories and related applications, medications, psychiatric diagnosis, and community-based services, as well as due

to dramatic changes in the law and to increased societal knowledge and understanding of mental illness (Lamb, 1984; Levine & Perkins, 2004; Mechanic & Rochefort, 1990; Mueser, Bond, Drake, & Resnick, 1998).

The Emergence of Family- and Consumer-Driven Services

An important component of the shift to community-based care was prompted by family members and patients themselves, exemplified by the emergence of the National Alliance on Mental Illness (NAMI), a national advocacy organization with affiliate chapters in every state. In the 1970s, family members, who often were blamed indirectly by mental health professionals as contributing to their child's mental illness, began to advocate for better treatments for their adult sons or daughters to address what was increasingly viewed as a neurobiological illness similar to other medical illnesses (Hatfield & Lefley, 1987). Patients themselves began to articulate poignant first person accounts of their illness that captured the public attention, referring to themselves as mental health "consumers" capable of assisting in the management of their care (Deegan, 1988). These developments prompted the mental health field to regard family and consumer involvement in mental health care as essential to the provision of quality services. Practically, this also meant that family members and consumers gradually became involved in treatment and discharge planning; medication management; and choice of housing, vocational, and socialization services. Mental health providers also needed to attend more closely to issues of consumer satisfaction with services. Currently, family-driven and consumer-driven services are integral to current standard practice in the mental health field, as noted in the President's New Freedom Commission Report (Hogan, 2003).

Institutionalism

The path toward family- and consumer-driven services has been gradual, and derives from many sources. One source was scholarly work in the late 1960s and early 1970s which identified the concept of institutionalism (Wing & Brown, 1970). Institutionalism refers to a condition among institutionalized persons with serious mental illness that is marked by apathy; loss of learning capacity, curiosity, and initiative; passivity and dependence; social withdrawal; restricted emotion or "flatness" of affect; and acquiescence and submissiveness to authority (Wing & Brown, 1970; Wirt, 1999). It is the by-product of long-term residential stays in institutional settings for persons with mental illness, and is often accompanied by the person's reluctance to leave the institutional setting (Wirt, 1999). Professional recognition of institutionalism prompted a redoubling of efforts to provide community-based services outside of institutional settings.

Deinstitutionalization

A parallel development to institutionalism was emerging public concern over abuses in psychiatric hospitals (Lamb & Bachrach, 2001). These concerns, coupled with the advances noted earlier -- in psychological theories and related applications, medications, diagnosis, community-based services, and the law -- furthered the growing movement toward "deinstitutionalization" of persons with serious mental illness from hospital and residential psychiatric settings to the community (Lamb, 1984; Levine & Perkins, 2004). Policies that

promoted deinstitutionalization, however, rarely provided sufficient resources for the development of appropriate community supports and services, including case management, vocational, socialization, and housing services (Lamb & Bachrach, 2001). This resulted in widespread homelessness among persons with mental illness beginning in the 1970s and inadequate service systems to provide comprehensive community-based mental health services.

Recovery-Oriented Care

Over the past several decades, federal and state agencies, family and consumer advocacy groups, and researchers have attempted to address these issues by instituting a variety of measures, such as: establishing comprehensive and coordinated community-based systems of care; involving consumers and family members in treatment choice and decision-making, and developing innovative approaches to treatment. The recent President's New Freedom Commission Report on Mental Health (2003) captures well the current standard practice in the mental health field when it refers to mental health care that is "consumer-centered" and "recovery-oriented" and whose emphasis is on a plan of care that includes "treatment, supports, and other assistance to enable consumers to better integrate into their communities" and allows them "to realize improved mental health and quality of life."

The inclusion within the President's New Freedom Commission Report of the principles of "recovery" and "community integration" reflects the most current thinking in the field. The Report defines recovery as "the process in which people are able to live, work, learn, and participate fully in their communities." Recovery-oriented models of care for persons with mental illness have been adopted by state mental health agencies across the United States, including the recent adoption of this philosophy by the Illinois Department of Human Services (DHS).

Quoting directly from DHS (2005), "a philosophy of recovery:

- Emphasizes the potential of all individuals to recover from the challenging impact of psychiatric illness,
- Is consumer directed, family/support-centered,
- Encourages independence, integration and a productive role in the community for all individuals.
- Identified and uses consumer strengths.
- Skillfully integrates 'natural supports' (friends, family, support groups, other community resources) with professional supports.
- Delivers professional services in the consumer's natural environment where healing and re-learning can be maximized."

These principles, among others, are consistent with those espoused in other states.

Community Integration

By defining community integration as integral to recovery, the President's New Freedom Commission Report also captures current thinking within the field about the centrality of community integration to recovery. Traditionally, community integration has been defined as the extent to which persons with psychiatric disabilities participate in community activities and use community resources (Segal & Aviram, 1978). However, in more recent years, community integration has been reconceptualized to refer more generally to whether an individual lives, participates, and socializes in the community (Gulcur, Tsemberis, Stefancic, & Greenwood, 2007; Wong & Solomon, 2002).

This more comprehensive understanding of community integration has redefined it as consisting of three interrelated components: physical integration, social integration, and psychological integration (Wong & Solomon, 2002).

- *Physical integration* refers to the actual behavior of engaging in activities outside of one's residence and in the community.
- *Social integration* refers to the extent of interaction and involvement with others in the community, including neighbors.
- And *psychological integration* refers to the feeling of connection and belonging to the community as well as experiences of emotional attachment to members of the community, such as neighbors.

This evaluation uses the tri-partite definition of community integration, which is consistent with a recovery-oriented philosophy.

Supportive Housing

Consistent with a recovery orientation, the broader definition of community integration focuses community care on enhancing independence for persons with mental illness. This focus requires greater attention to housing in the community. Currently, community-based mental health services include several types of housing for individuals with serious mental illness. One traditional housing approach is community-based residential treatment, such as group homes. Current practice has moved away from this model of care because it is expensive and is generally not oriented toward promoting independence and community integration (Carling, 1995; Gulcur et al., 2003; Nelson et al., 2007; President's New Freedom Commission, 2006; Wong & Solomon, 2002). More recent approaches have emphasized two other types of community living more consistent with a recovery-oriented philosophy -- supervised apartments in which staff is present on-site for all or part of a 24-hour period, or independent living apartments in which individuals live in their own apartments and supportive services are provided as needed (Gulcur et al., 2003; Nelson et al., 2007; Wright & Kloos, 2007). In combination, supervised or independent living apartments provide a continuum of residential services in the community that can be tailored to the individual's needs. Either type of apartment can be offered in scattered sites or in congregate settings, although scattered sites have recently gained favor and are more

integrated. As noted in the President's New Freedom Commission report, the availability of supportive housing options that are tailored to individual needs is essential if persons with mental illness are to reach their potential and maximize their independence and recovery.

Summary and Conclusions

Advances in the mental health field over the past 50 years as well as the emphasis on recovery over the past decade, have created a consensus among mental health professionals that individuals with mental illness will move toward ever-increasing independence and community integration. As a result, institutions that require more restrictive and congregate care are generally viewed as temporary and transitional settings whose purpose is to promote recovery from acute psychiatric illness, address serious risk that arises from severe psychiatric symptoms, enhance life skills, and provide a basis for developing discharge plans that support a person's trajectory to independence and increased integration into the community. Although some persons—because of substantial risk to the person or to public safety, complicating medical conditions requiring higher levels of care, or severe cognitive deficits—may require higher levels of care for sustained periods, these instances are expected to be relatively few. Even for individuals in these circumstances who may require more restrictive care, ongoing reassessment of their potential for increased independence and community integration is the current standard of practice within the mental health field.

METHOD

Overview

The evaluation involved completion of interviews with a representative sample of residents and reviews of resident medical records. Interviews, which included the collection of structured and scientifically-supported measures of relevance to the issues in the case, were completed by Drs. Baranoski and Tebes, and medical records were reviewed by Dr. Amble. Interview and record review data were entered into a statistical database and analyzed using standard scientific data analytic techniques.

Procedures

Selecting an Appropriate Evaluation Design

The evaluation design sought to determine whether IMD residents were capable of living in more integrated community settings with appropriate services and supports, and to identify possible barriers to independent living and community integration. The design emphasized the integration of quantitative and qualitative data about common domains, such as resident functioning, that was drawn from multiple data sources, such as resident self-reports, medical records completed by professional staff, and clinical observations by experienced interviewers. Such a "triangulation" strategy for data collection enhanced the scientific rigor of the evaluation because it sought to obtain related or similar information from multiple data sources so as to strengthen the validity of conclusions made (Tashakkori & Teddie, 2003; Tebes, 2005).

Selecting a Random Sample of Residents for Interviews and Record Reviews

To ensure that data collected could be generalized to residents of all 26 IMDs, a stratified random sample of residents was invited to participate in the evaluation. Stratified random sampling divides a population into separate “strata” or groups of relevance to the evaluation, and then selects randomly from each stratified group in proportion to its distribution in the population (Levy & Lemeshow, 2003; Thompson, 2002). Two relevant strata for this evaluation are IMD geographic region and census.

The stratified random sampling procedure divided IMDs into the following five Illinois geographic regions (with the number of IMDs located in each region listed in parenthesis): Downstate (2 sites), Chicago-South Side (4 sites), South Suburban Chicago (4 sites), North Suburban Chicago (6 sites), and Chicago-North Side (10 sites). In addition, IMDs also were divided into categories by their total census: facilities with over 400 residents (3 sites), those with less than 100 residents (4 sites), those with 200 - 299 residents (6 sites), and those with 100 - 199 residents (13 sites). (No IMDs had 300 - 400 residents.)

A total of 30% of all IMDs, or eight sites, were selected to be included in the evaluation. In addition, a decision rule was applied such that all strata -- defined by region or census -- with four or fewer sites would contribute one site for random inclusion into the evaluation until a total of eight sites were selected. Thus, for example, strata with six or eight sites would contribute two sites for random selection, and so on. Each site was then assigned a number in alphabetical order from 1 to the total number of IMDs in a given strata, and then matched with a list of randomly generated numbers. Beginning with the geographic region with the fewest number of sites (e.g., Downstate) and ending with the region with the largest number of sites (Chicago-North Side), IMDs were selected randomly.

Table A (in Appendix A) shows the strata for each of the five geographic regions (e.g., columns) and four census groups (e.g., rows), and notes in bold the IMDs that were randomly selected into the evaluation. These were: **Sharon Health Care Woods** (Downstate, census 100-199), **Columbus Manor** (Chicago-South Side, census 100-199), **Thornton Heights Terrace** (South Suburban Chicago, census 200-299), **Bayside Terrace** (North Suburban Chicago, census 200-299), **Greenwood Care** (North Suburban Chicago, census 200-299), **Margaret Manor North** (Chicago-North Side, census <100), **Somerset Place** (Chicago-North Side, census >400), and **Clayton Residential Home** (Chicago-North Side, census 200-299).

A target number of residents to be interviewed across all eight IMDs was then obtained by determining the sample size that best balanced the precision needed to estimate population means for IMD residents on various measures with an acceptable margin of error. A sample size of 120 residents provided reasonable balance between these two competing constraints while also affording scientific rigor.

Finally, a second randomization procedure was used to obtain a target number of residents from among the 120 to interview within each IMD so that the sample would be representative of all IMD residents. To obtain this number, the proportion of the total number of possible residents for the eight sites chosen was computed. Thus, for example, across all eight

sites selected the total possible census was 1,672 residents. Each site's total census was then divided into this number and multiplied by 120 to determine the total number of residents to be interviewed from that IMD. Once the evaluation team arrived at each site, the IMD manager was asked to provide a list of residents. Each resident was assigned a number consecutively, and then selected for an invitation to participate in the evaluation based on whether their number came up on a list of randomly generated numbers for each site. A copy of the IMD site visit schedule that contains the targeted sample within each IMD and a Resident Code Sheet that displays the random number list used for each site can be found in Appendix B and C, respectively.

Ensuring Consent, Confidentiality, and the Protection of Data

Each of the interviews was conducted in private by Drs. Baranoski or Tebes after residents were given an opportunity to be informed about the purpose, details, and risks of participating in the evaluation by the interviewers. The procedures used to obtain consent were common in forensic and clinical evaluations, and residents who did not wish to participate were excused. A total of 22 residents declined after being invited to participate, and two residents were unable to complete the interview (one because of a language barrier and another because the interviewer was uncertain that informed consent was obtained). A copy of the consent procedure, including the interviewer script, in which residents were invited to participate in the evaluation is included in Appendix D, the first page of the interview protocol. After residents provided verbal assent to participate, Drs. Baranoski or Tebes began the interview. Once assent was obtained, Dr. Amble began reviewing the medical record.

To ensure confidentiality, all interviews and record review protocols contained only code numbers that were assigned immediately after assent was provided. Code numbers matched to names were stored in a locked file cabinet to which only Dr. Tebes had access. In addition, data entered into the statistical database for analyses was stored only by code numbers and followed usual procedures for the protection of data.

Minimizing Disruption to the Setting and for the Residents and Staff

The evaluation team and the plaintiffs' attorneys were committed to minimizing any disruption to the IMD and to residents and staff. Each IMD was informed at least one week prior to the visit the approximate date and time of arrival for the evaluation team, and every effort was made by the team to keep to their planned schedule. In addition, once on site, the team attempt to conduct interviews or review records in mutually convenient locations for the staff, residents, and the team, and to make minimal demands on site. For the most part, IMD leadership and staff were gracious and welcoming hosts who made every effort to assist the team to ensure that they could complete their work as efficiently as possible.

Measures

Two types of measures were used: a resident interview protocol and a record review protocol. These are included in this report as Appendix D and E, respectively. These two protocols collected data about:

- residents' level of community integration (physical, social, and psychological),
- residents' housing preferences, satisfaction, and housing choice;
- possible barriers to independent living and community integration, such as:
 - residents' capacity for independent living;
 - residents' activities of daily living skills (e.g., dressing, bathing, feeding, etc.);
 - residents' mental status/cognitive functioning;
 - residents' level of psychiatric symptomatology;
 - the presence of medical conditions among residents that could limit independence;
 - residents' risk to self or others; and
 - the extent of transition planning for independent living and community integration.

In addition to these measures, basic demographic and background information was obtained for each resident in the interview and the medical record. Each interview began with a series of 13 open-ended questions designed by the evaluation team for the purpose of the evaluation. The questions requested descriptive information about the participants' length of stay, prior living history, participation in current treatment, psychiatric history and risk to self or others, and residents' marital status, level of education, and most recent employment. In addition, the record review recorded each person's gender, age, race/ethnicity.

Each of these types of data is described briefly below.

Residents' Level of Community Integration

Data about distinct types of community integration were collected in the interview. ***Physical integration*** was assessed using an instrument adapted from Kruzich (1985). For this evaluation, residents were asked to rate the frequency of their involvement, from 0 (Never) to 4 (Very much), in 10 typical community activities outside of their IMD, such as going to a shopping area; going to restaurants, bars, or taverns; attending church or another place of worship, or taking a walk outside. Ratings were then summed to produce an overall score of physical integration. In addition, for each activity, residents were asked to indicate whether they usually did this activity alone, with others from the IMD, or with others outside of the IMD, such as family members, neighbors, or friends living in the community.

Social integration was assessed using the Social Integration Scale (Aubry & Myner; 1996), a widely adapted 13-item instrument of the frequency of social interaction activities. Sample items include: "How often have you said hello or waved to a neighbor (or someone outside of the IMD)?" "How often have you gone on a social outing with a neighbor (or someone

outside of the IMD)?” and “How often have you had a conversation in the street with a neighbor (or someone outside of the IMD)?” Responses to each item are answered from 0 (Never) to 4 (Frequently). Residents were asked each question in relation to the IMD and to the community/neighborhood outside of the IMD.

Psychological integration was assessed with an adapted version of the Neighborhood Cohesion Index (Buckner; 1988), an established 18-item instrument that assesses individuals’ sense of connection or belonging to the community and their experiences of emotional attachment to members of the community, such as neighbors. Sample items include: “Overall, I am very attracted to living here”; “I feel like I belong here”; and “Living (here) gives me a sense of community.” Responses to each item are answered from 1 (Strongly Disagree) to 5 (Strongly Agree). Residents were asked each question in relation to the IMD and to the community/neighborhood.

Residents’ Housing Preferences, Satisfaction, and Housing Choice

Residents’ housing preference was assessed by examining two items: residents’ responses to an item from the psychological integration measure described above in which they were asked the following: “Given the opportunity, I would like to move out of this place,” and indications of residents’ stated preference for independent living noted on the Minimum Data Set (MDS) form in the medical record.

Residents’ satisfaction with their current living situation was obtained through the use of two items selected from the Housing Environment Survey by Kloos, Shah, Frisman, & Rodis (2005). One item asked respondents about their neighborhood and another asked about their current housing, the IMD. Each item is answered on a five-point scale, ranging from 1 (Very Dissatisfied) to 5 (Very Satisfied). An additional item was included that asked residents how satisfied they would be if they could live independently in an apartment with all the supports that they need.

In recent years, **housing choice** has been shown to be an important factor influencing housing preference and satisfaction, and was included to provide context for understanding each. Housing choice was assessed using 20 items from the Housing Environment Survey by Kloos et al (200) which was adapted from a similar instrument developed by Srebnik et al. (1995). Sample items include: “how much choice did you have over the neighborhood you moved into” and “how much choice did you have over decorating and furnishing.” Each item is answered on a five-point scale, ranging from 1 (No Choice at All) to 5 (A Great Deal of Choice). Items were summed to create a total score, with higher scores indicating greater choice over housing matters.

Possible Barriers to Independent Living and Community Integration

Residents’ capacity for independent living was assessed by each interviewer by means of an adapted version of the Role Functioning Scale (Goodman, Swell, Cooley, & Leavitt; 1993). Two domains from the original scale were retained for rating: independent living/self care and social relationships. Each domain was modified so that it was rated on a five-point scale from 1 (minimal level of functioning) to 5 (optimal level of functioning). These domains were then

combined into a composite score that provided an overall assessment of each resident's capacity for independent living in the community. It is important to note that the ratings by Drs. Baranoski and Tebes on this instrument took into account all previous information obtained in the interview, including other direct assessments of functioning, symptoms, and risk status as well as the interviewer's clinical observations of each resident.

A related measure of adaptive functioning was also assessed using the Independent Functioning Scale (Rappaport et al., 1985). This scale asked residents' their capacity for independent functioning in seven areas, including: money management, housekeeping, and meal preparation by scoring their responses on a three-point scale with a score of (1) indicating others' responsibility, (2) shared responsibility, and (3) their own responsibility. Items were summed, with higher scores indicating greater independent functioning. One concern with this data, however, was that IMDs appeared to assume so much responsibility for many of these hallmarks of independent functioning that accurate assessment of this capacity may not be possible.

Residents' activities of daily living were assessed using the Katz Index of Independence in Activities of Daily Living (ADL) (Shelkey & Wallace, 1999). This instrument assesses each resident's ability to perform 6 basis activities of daily living: bathing, dressing, toileting, feeding, transferring, and continence. Each ADL is scored 1 if the person is able to complete the task independently and 0 if the person requires assistance. Scores are totaled across the 6 areas, with 6 indicating full function, 4 moderate impairment, and 2 or less severe functional impairment.

Residents' mental status/cognitive functioning was assessed using the Mini Mental Status Exam (Folstein, Folstein, & McHugh, 1975). The MMS assesses cognitive functions in five domains: orientation, registration, attention and calculation, recall, and language. Each item is scored 0 for incorrect responses and 1 for correct responses. Scores are then summed to create a total score, with a range from 0 to 30.

Residents' level of psychiatric symptomatology was assessed using the 18-item version of the Brief Psychiatric Rating Scale (Overall & Gorham, 1962; Faustman & Overall, 1994), a clinician-rated instrument. Each item is rated on a seven-point scale ranging from 0 (Not Present) to 6 (Extremely Severe). Higher scores indicate greater psychiatric difficulty.

The presence of medical conditions that could limit independence was assessed with careful reviews of the medical record. Each medical condition specified in the record was noted and recorded, and supporting documentation was sought to determine whether a particular medication condition could limit living independently in the community.

Residents' risk to self or others was assessed using a combination of medical record review and direct questioning of residents. Medical records were reviewed to determine whether the treatment or discharge plan, or any part of the medical record specified whether the resident posed a risk to self or others. In addition, the record was examined for evidence that the resident's deficits in current functioning required them to live in the level of care provided in the IMD. Finally, residents' risk to self or others was assessed in the interview with the question: "Over the past year, have you tried to physically harm yourself or someone else?"

The extent of transition planning for independent living and community integration was assessed through reviews of medical records. First, evidence of a current treatment plan and discharge plan was assessed, and then evidence was sought in either plan of a process of transition planning leading to independent living and enhanced community integration.

RESULTS

Characteristics of Residents Interviewed

Table 1 summarizes various characteristics of residents interviewed.

Table 1: Characteristics of Residents Interviewed		
Resident Characteristics	Number	Percent
Gender		
Female	38	31
Male	83	69
Race/Ethnicity		
African American	49	41
Asian American	7	6
Caucasian	56	46
Hispanic	8	7
Other/Unknown	1	1
Education Completed		
Less than High School	38	31
High School Graduate	45	37
Greater than High School	38	31
Age (<i>Mean: 49.3, st. deviation=10.7, range=21 to 82</i>)		
21 - 30 years	5	4
31 - 40 years	20	17
41 - 50 years	45	37
51 - 60 years	33	27
Older than 60 years	18	15
Number of Residents Interviewed from Each IMD		
Bayside Terrace	12	10
Clayton Residential Home	18	15
Columbus Manor	14	12
Greenwood Care	10	8
Margaret Manor North	7	6
Sharon Health Care Woods	11	9
Somerset Place	32	26
Thornton Heights Terrace*	17	14
Length of Time in the Current IMD		
Less than 2 Years	26	21
3 to 10 Years	55	46
More than 10 Years	50	41

* One additional interview was conducted at Thornton Heights Terrace because one resident returned to complete a partially-completed interview just as the final interviews were being completed. Rather than omit this interview, it was included in the sample.

Community Integration

To What Extent are Residents Physically Integrated into the Community?

Residents' average involvement in activities outside of the IMD yielded a score of 5.07 (out of a possible 40) which is comparable to that found for residents with mental illness living in intermediate care facilities, and lower than individuals living in community settings. Table 2 shows the percent of residents who answered "Never" to their involvement in 10 community activities in the past month. As the table shows, the majority of residents did not leave the IMD in the past month to attend a movie, a sports event (as spectator or participant), a community center, or a church, or to visit a park or museum, or to go to a job/volunteer activity. In addition, for more common activities, within the previous month at least one-third of residents reported that they had never left the IMD to go shopping (38%), to a restaurant (42%), or to take a walk outside (33%).

Physical Community Integration Activities (within the past month)	Percent Who Answered "Never"
Going to a shopping area	38
Going to movies or concerts	70
Going to restaurants, bars, or taverns	42
Go to sports events	89
Playing or participating in sports events outside of IMD	94
Going to a community center	96
Going to church or another place of worship (outside of the IMD)	68
Going to a park or museum	68
Taking a walk outside	33
Going to your job or volunteer activity	81

Table 3 (next page) depicts whether residents participated in community activities *usually alone, usually with others in the IMD, or usually with others outside of the IMD* (such as family or friends). The table includes in the far right column the percent, based on **all** residents, of those who engaged in community activities usually with others outside of the IMD. Residents' engagement with persons outside of their IMD provides some estimate of their involvement with persons in the community outside of their residence which can include non-psychiatrically-disabled individuals as well as former IMD residents who no longer lived in their facility.

As is shown in the table, across all activities, IMD residents who participated in community activities did so alone or with others in the IMD the majority of the time. When activities did take place with others outside of the IMD, residents told Drs. Baranoski and Tebes that these usually involved family members, such as parents or siblings.

The column on the far right in the table combines data from Tables 2 and 3 to compute a percent of residents (based on the total number interviewed) who engaged in community

activities usually with others outside of the IMD. As is shown, that percent ranged from 1 to 21 percent, indicating that the majority of residents had reported no engagement in community activities on a regular basis with individuals outside of the IMD. The most frequent activities done with others included going to a restaurant/bar/tavern (21%), going to a shopping area (16%), and going to a movie/concert (10%) during the past month. In the vast majority of cases, the residents identified family members as those with whom they did these activities.

Physical Integration Activities (within the past month)	Usually Alone (%)	Usually with Others at IMD (%)	Usually with Others Outside of IMD (%)	Percentage of ALL Residents Who Engaged in Community Activities Usually with Others Outside of IMD
Going to a shopping area	49	26	26	16
Going to movies or concerts	19	49	32	10
Going to restaurants, bars, or taverns	33	30	38	21
Go to sports events	33	33	33	2
Playing or participating in sports events outside of IMD	14	57	29	2
Going to a community center	50	33	17	1
Going to church or another place of worship (outside of the IMD)	47	31	22	6
Going to a park or museum	60	30	11	3
Taking a walk outside	69	22	9	6
Going to your job or volunteer activity	48	22	30	6

Conclusion:

- **IMD residents do not show evidence of physical integration into the community.**
- **Those residents who do engage in community activities mostly do so alone or with others from the IMD.**
- **A small proportion of residents engage with others outside of the IMD.**
- **Those who do so usually go to a restaurant, shopping area, or a movie with a family member.**
- **Overall, community integration by actual physical involvement in community activities with individuals who do not have psychiatric disabilities is extremely low.**

To What Extent are Residents Socially Integrated into the Community and the IMD?

Table 4 shows residents' average social integration score with individuals in the community or neighborhood (e.g., labeled "in the community") and with other residents of the IMD (e.g., labeled "in the IMD"). Social integration scores provide an assessment of social interactions with others, and for the purposes of this evaluation, interactions "in the IMD" are more likely to involve other individuals with disabilities while those "in the community" may involve more individuals without disabilities. Examples of the social interactions assessed include: *saying hello or waving to others, going on social outings with others, talking to someone about personal issues, having a conversation with someone in the hall or the street, and so on.*

Table 4: Comparison of Social Community Integration Scores "In the Community" and "In the IMD"		
Social Community Integration Score	In the Community	In the IMD
Mean average score	16.85	26.50
Possible range of scores	13 - 65	13 - 65

Note. For the social integration measure, the standard deviation *In the Community* was 5.79, and *In the IMD* was 9.01.

As is shown, the social integration score for interactions with others in the community is 16.85, and the score for interactions with others in the IMD is 26.50. Both of these scores are out of a possible range of scores from 13 - 65. The results indicate that residents' social interactions with individuals in the community/neighborhood are infrequent and significantly lower than what is generally found for community residents with psychiatric disabilities living in community-based housing. As shown, social interactions with others in the IMD are higher, and are comparable to those reported for social interactions in the community for persons with psychiatric disabilities.

The difference between the average social integration score for "in the community" vs. "in the IMD" is statistically significant ($t=12.76$, $df = 120$, $p < .0001$). The p level in the analysis shows that the difference between the low score for interactions "in the community" and higher score for the interactions "in the IMD" is a reliable difference and not due to chance.

The social community integration scores also reflect the residents' capacity for an interest in social interactions. The moderate level of interactions reported by residents in the IMD with others there indicates that, as a group, residents demonstrate both a capacity for and interest in social engagement but that their interactions are limited almost exclusively to other individuals with psychiatric disabilities who live in the same IMD.

Table 5 below shows residents' percents for a few types of social interactions that illustrate the differences in social integration "in the community" and "in the IMD."

Table 5: Comparisons “In the Community” and “In the IMD” for Various Social Community Integration Items Answered as “Never”		
Social Integration Activities	In the Community (% - Never)	In the IMD (% - Never)
Said hello or waved to someone	45	11
Gone on a social outing with someone	86	49
Been invited to someone’s <i>apartment/home</i>	85	38
Talked to someone about personal issues	87	47
Had a conversation <i>in the hall/on the street</i> with someone	63	32

Conclusion:

- **IMD residents are not socially integrated into the community and report few social interactions with persons outside of the IMD.**
- **Residents show significantly greater social interactions with other residents in the IMD.**
- **The moderate social interaction with residents in the IMD demonstrates the residents’ capacity for and interest in social interactions.**
- **Thus, the lack of community social integration probably reflects limited access by residents to opportunities to engage in common social interactions with others who do not have psychiatric disabilities.**

To What Extent are Residents Psychologically Integrated into the Community and the IMD?

Table 6 summarizes the average psychological integration score “in the community” and “in the IMD” for residents. Psychological integration reflects residents’ sense of connection or belonging either to the community/neighborhood outside of the IMD or within the IMD. Examples of residents’ connectedness or cohesion to the neighborhood or the IMD include: feeling like they belong there, reporting that friendships made mean a lot to them, being able to go to others for advice, feeling others could help them in an emergency, and feeling a “sense of community” with others. Residents’ average psychological integration score “in the community” is 2.46, and the average score “in the IMD” is 3.13. Both scores are out of a possible range of scores from 1 - 5. Although less data are available on psychological integration within various

Table 6: Comparison of Psychological Community Integration Scores “In the Community” and “In the IMD”		
Psychological Integration Measure	In the Community	In the IMD
Mean Average Score	2.46	3.13
Possible Range of Scores	1 - 5	1 - 5

Note. For the psychological integration measure, the standard deviation *In the Community* was .64 and *In the IMD* was .59.

settings for individuals with psychiatric disabilities, average scores under 2.75 are generally considered indicative of lower psychological integration and those above 3.50 are indicative of

higher integration. Thus, residents' average score of 2.46 in the community fall in the low range, while their average score of 3.13 indicates moderate psychological integration to the IMD.

The difference between residents' average psychological integration score in the community vs. their average score reported for the IMD is statistically significant ($t=11.18$, $df=120$, $p < .0001$). This indicates that it is very unlikely that the difference in psychological integration is due to chance. The IMD score which reached a level of moderate psychological integration indicates that, as a group, residents have the capacity for and interest in psychological connection to a community; currently that community is comprised mostly of residents in the IMD.

Conclusion:

- **IMD residents have low psychological integration into the surrounding community comprised of individuals without psychiatric disabilities.**
- **Residents show a moderate psychological integration to the IMD and its residents.**
- **The moderate level of psychological integration to the IMD indicates that residents have the capacity for and interest in psychological connections to others.**
- **Therefore, the low score on psychological integration to the outside community probably reflects a lack of access to and involvement in that community, rather than a lack of capacity on the part of residents.**

Housing Preferences, Satisfaction, and Housing Choice

Where Would Residents Prefer to Live?

Several sources of data were obtained about residents' preference for living in the IMD vs. other settings. One source was an item from the psychological integration instrument discussed in the previous section. Table 7 shows residents' agreement with the statement "Given the opportunity, I would like to move out of *this place/this neighborhood*." As shown, almost 70% of residents reported that they agreed with the statement that they would like to move out of the IMD, with 54% indicating that they "strongly agree." Furthermore, 54% agreed that they wanted to move out of their neighborhood, with 32% providing strong agreement with that statement.

Table 7: Comparison of Preferences for Moving Out of the IMD vs. Out of the Neighborhood/Community	
Housing Preference	Agree or Strongly Agree (%)
Given the opportunity, I would like to move out of this place	69.4
Given the opportunity, I would like to move out of this neighborhood	53.7

Responses to this question provided an opportunity for Drs. Baranoski and Tebes to solicit additional information about residents' housing preferences. For those residents who wanted to move out, most wanted to live independently in their own apartment. After responding to the above question, many residents made unsolicited comments such as: "I want to get an apartment of my own" or "I want my own apartment" or "I want a place of my own."

Another source of data about residents' housing preferences was residents' ratings of satisfaction with their current housing. Responses to satisfaction questions are displayed in Table 8. Consistent with the housing preference summarized in Table 7, two-thirds of residents said they would be "very satisfied" if they could live independently in the community with all the supports that they needed, and 76% indicated that they would be satisfied to some degree with this option.

Satisfaction with Housing	Fairly Satisfied (%)	Very Satisfied (%)
Satisfaction with neighborhood as a place to live	36	35
Satisfaction with IMD as a place to live	29	39
Satisfaction with living independently in an apartment with all the supports you need	9	67

When considered in combination with the responses shown previously in Table 7, however, Table 8 also reveals what, at first glance, is an apparent contradiction -- that 39% of residents reported feeling "very satisfied" with living in the IMD and another 29% indicated that they were "fairly satisfied." Drs. Baranoski and Tebes probed this apparent contradiction by gently asking residents to explain their strong preference for wanting to live independently in the community while also being generally satisfied with living in the IMD. Residents' responses were immediate. Most voiced concern about the practical realities of living independently, such as: whether they would find an apartment, whether they had the money to afford and keep it, whether they could prepare their meals, whether they could get around the city safely, whether they could manage their money, and how they could continue with treatment. Some also raised concerns about living in a safe neighborhood and having people around for friendship. In contrast to the interviewers' experience with individuals living in community settings, to a striking degree, residents did not seem to have been prepared in fundamental ways for community living. These responses indicated that there was little contradiction in wanting to live independently while at the same time recognizing that to do so seemed daunting, given the lack of information about what services and supports would be available in community-based settings. However, a few residents did voice concern that they would be "stuck" at the IMD their entire life. As one resident put it: "I kind of like it here, but I don't want to live here my whole life." With more 40% of residents living in the IMDs 10 years or longer as shown in Table 1, and several residents reporting lengths of stay -- off and on -- of more than 40 years in the same IMD, such sentiments were understandable.

A final source of data about housing preference was obtained from the Minimum Data Set (MDS) that was located in each residents' record and reviewed by Dr. Amble. Overall, the

most recent MDS indicated that only 26% of residents indicated a preference to live in the community. This finding is discrepant from the three other data sources cited, and may indicate that residents either do not feel comfortable telling staff that they want to live elsewhere or that when asked this question it is framed in so that residents answer it mostly in the negative.

Conclusion:

- **Using multiple sources of data, the vast majority of IMD residents expressed a preference for living independently in the community.**
- **A majority of residents report being fairly to very satisfied living in the IMD.**
- **A greater majority would prefer to move out and live independently in the community.**
- **The apparent contradiction between residents’ being generally satisfied with living at the IMD but even more strongly wanting to move out and live independently is understandable given the lack of information that residents have about the services and supports that would be available to them in community-based settings, such as supportive housing.**

What Choices about Their Housing Do Residents Have in Daily Living?

Table 9 lists several responses by residents to questions about the amount of choice they had/have in their IMD housing. Previous research has shown that being able to have choices in one’s living situation is a key factor in individuals’ overall satisfaction with their housing. Thus, these responses provide some context for residents’ housing preferences and satisfaction noted above. As is shown in the table, a large majority of residents say that they have no choice at all in having overnight guests (99%), a pet (96%), cooking meals (88%), and living in a building without other people who have psychiatric disabilities (79%). About one-half to three-fifths of residents report not having any choice in locking their room door (50%), being able to come and go as they please (59%), and selecting a roommate (62%). Finally, many fewer residents said they had no choice at all when it comes to “decorating and furnishing” their rooms (21%) and in “having visitors over” (23%).

How much choice did/do you have...	Percent Who Answered “No Choice at All”
...over decorating and furnishing?	21
...over who you live with?	62
...over whether visitors can come over?	23
...over having overnight guests?	99
...over having a pet?	96
...over whether you can lock your room?	50
...over being able to come and go at any time without having to notify people?	59
...over when to cook meals and what you can eat?	88
...over whether you lived in a building where other consumers (people with psychiatric difficulties) live?	79

Conclusion:

- **The amount of choice residents had in daily living in the IMD varied by the nature of the activity.**
- **The majority reported having some choice about decorating and furnishing their rooms or having visitors during the day or evening.**
- **Nearly all residents reported no choice in whether they could have overnight guests, have a pet, or whether they could cook meals.**
- **Residents' lack of choices in key areas of daily living (e.g., cooking, having pets, locking doors, having overnight guests, being able to come and go as one pleases) are common to institutional living, and explains residents' strong preference identified earlier for wanting to live independently in the community.**

Assessment of Possible Barriers to Increased Independence and Community Integration

The evaluation also assessed several possible barriers that could impede residents' increased independence and community integration. These included:

- residents' capacity for independent living;
- residents' ability to take care of their basic activities of daily living, such as dressing, bathing, feeding, and so on;
- residents' mental status/cognitive functioning;
- residents' level of psychiatric symptomatology;
- the presence of medical conditions that could limit residents' independence and community integration;
- residents' risk to self or others; and
- the extent of transition planning for independent living and community integration.

Residents' Capacity for Independent Living

At the conclusion of each interview, Drs. Baranoski and Tebes also completed a global rating of each residents' independent living/self care skills and social relationship skills, and then combined these ratings into a composite assessment of residents' capacity for independent living. Since these ratings were completed after obtaining all the other information in the interview, including other direct assessments of resident functioning, symptoms, and risk status as well as any clinical observations made regarding each resident, this composite rating provided a global assessment of each person's capacity for independent living. In fact, correlations between this composite rating and all other functioning and community integration scores were positive and statistically significant, indicating that this score provided a useful indicator of each resident's potential for successful community integration and independent living.

Table 10 depicts five categories of composite scores for residents' capacity for independent living. These provide a general estimate of the approximate percentage of IMD residents who could live independently in the community with the appropriate services and supports. As noted earlier, all ratings of self-care and social role functioning were supplemented by all other resident responses to the interview and clinical observations made by the interviewers. About 11% of residents showed considerable independent living capacity (scores of 9 or 10), and would be likely to require only minimal ongoing community supports to live independently. In contrast, about 13% of residents exhibited a limited capacity for independent living (scores of 2 or 3), making independent community living difficult. About 47% of residents showed a moderately high or moderate capacity for independent living (scores of 6, 7, or 8), and should be able to live independently with minimal to moderate supports. Finally, about 29% of residents exhibited a reduced capacity for independent living (scores of 4 or 5), and thus would require moderately higher levels of services and supports for independent community living, but at a level that is common for community-based housing programs found in other states.

Table 10: Residents' Composite Scores of Capacity for Independent Living	
Composite Scores of the Capacity for Independent Living	Percent (%)
High (Scores of 9 or 10)	10.7
Moderate - High (Scores of 7 or 8)	29.2
Moderate (Scores of 6)	17.4
Moderate - Low (Scores of 4 or 5)	28.9
Low (Scores of 2 or 3)	13.2

It is important to note that one's capacity for independent living is dramatically influenced by exposure to socially and cognitively stimulating environments as well as targeted skills training and transition planning. Institutional living is likely to diminish such capacities over time because of residents' limited opportunities to exercise self-care, social functioning, and other related skills for independent living. Thus, it is probable that the overall scores above underestimate individual capacity.

Drs. Baranoski and Tebes attempted to obtain additional information about independent living skills by asking residents about their capacity for independent functioning in the following areas: handling money, cleaning one's room, preparing meals, scheduling medical appointments, planning community activities, organizing recreational activities, and managing medications. However, because residents live in institutions that routinely managed these activities for them independent of their capacity to do so, their responses were not a meaningful indicator of independent functioning, and thus were not used.

Conclusion:

- **About 85-90% of residents' demonstrated a capacity for independent functioning that would enable them to live in the community given an appropriate level of services and supports.**
- **About 10-15% of residents demonstrated a limited capacity for independent functioning, thus making independent community living difficult and likely to require considerable services and supports.**

Residents' Activities of Daily Living

As noted earlier, six activities of daily living (ADLs) were assessed in consultation with each resident and supplemented by observations made by Drs. Baranoski and Tebes during the interview. The six activities assessed were: transferring from one surface to another (e.g., a bed to a chair), feeding, dressing, bathing, toileting, and continence. Residents who could perform each of these activities unassisted scored a six.

A total of 92% of residents (112 out of 121) obtained a score of six which indicated that they were able to complete all ADLs without assistance, 4% (5 residents) scored a five, 3% (3 residents) scored a four, and 1% (1 resident) scored a three. The proportion of residents able to complete all ADLs is markedly higher than is typical for persons with mental illness residing in nursing homes or skilled nursing facilities. Only the four residents who needed assistance with 2 or more ADLs (those who scored a 3 or 4) would have limitations for independent living.

Conclusion:

- **With only a few exceptions, residents' potential for increased independence and community integration is not limited by an inability to complete basic activities of daily living.**

Residents' Mental Status/Cognitive Functioning

The Mini-Mental Status Exam (MMSE) was administered to each resident by Drs. Baranoski and Tebes. Scores for this instrument can range from a low of 0 to a high of 30. The mean average score for residents was 24.3, with a standard deviation of 4.4 and a range of 12 to 30. A total of 19% of residents scored below 20, a score generally considered indicative of markedly diminished cognitive status.

Cognitive functioning has been shown to improve with targeted skills training, and increased social and cognitive stimulation. National norms, adjusted by age and level of education, indicate that, overall, the scores of IMD residents are generally comparable to individuals receiving outpatient treatment for serious mental illness. Such scores consistently show that individuals with serious mental illness score about two standard deviations below those observed in the general population.

Conclusion:

- **Residents' mental status/cognitive functioning scores are generally comparable to other persons with serious mental illness living in the community.**

- **Almost 20% of residents showed evidence of markedly diminished cognitive status; however, as has been shown in previous research, such functioning is diminished when cognitive demands are low as is commonly found in institutional living.**
- **With targeted skills training and exposure to more enriched and demanding cognitive environments typical of community settings, cognitive functioning among this lower cognitive functioning group of residents would almost certainly increase, and thus, not serve as a significant barrier to independent living.**

Residents' Level of Psychiatric Symptomatology

Reviews of each residents' medical record by Dr. Amble revealed a range of psychiatric diagnoses for serious mental illness, including schizophrenia, bipolar disorder, and schizoaffective disorder.

In addition, Drs. Baranoski and Tebes completed symptom ratings of each resident after the completion of the interview. These ratings were based on the responses made during the interview and their clinical observations. Symptom ratings were based on a standardized measure -- the 18-item Brief Psychiatric Rating Scale (BPRS) in which symptoms were rated from 0 (Not present) to 6 (Extremely Severe), with the total possible range of scores being 0 to 108. The mean average score for the BPRS was 18.93, with a standard deviation of 11.01 and an actual range of 3 - 61. The average score of 18.93 indicates "very mild" psychiatric symptoms. The standard deviation indicates that about two-thirds of clients had scores between 7 and 30, which falls in the "mild" range or lower. This level is comparable to that found in research of persons with mental illness who are receiving outpatient treatment and living in the community.

Finally, Dr. Amble sought to find global symptom ratings and any assessments of residents' level of psychiatric functioning in the medical record in order to provide additional information about the symptomatology of residents. However, only one record out of 121 contained a widely-used symptom functioning score, the Global Assessment of Functioning (GAF) scale, which is a standard part of completing the psychiatric diagnosis when updating the treatment plan. In addition, only 12% of treatment plans specified the resident's level of functioning or the present level of care required using another proxy measure of psychiatric symptomatology.

Conclusion:

- **Residents' psychiatric symptomatology is predominantly "very mild" to "mild", with extremely few residents exhibiting symptoms that present unusual difficulties for living independently in the community.**
- **Residents' psychiatric symptomatology is not a significant barrier to independent living and community integration.**

Medical Conditions that Could Limit Residents' Independence and Community Integration

Dr. Amble reviewed each resident's medical record to determine whether any medical conditions could function as a barrier to independence and community integration. For all but one resident, or 99% of the sample, the treatment or discharge plan did not specify a medical reason that would prevent the resident from being able to live independently in the community with services and supports. This low rate of medical problems impeding a resident's ability to live independently is expected since staff at the IMD's said they were not licensed to provide care to the medically disabled.

Conclusion:

- **With one exception, residents' medical conditions are not a barrier to independent living and community integration.**

Residents' Risk to Self or Others

Each medical record was reviewed by Dr. Amble to determine whether the treatment or discharge plan, or any part of the medical record specified whether the resident posed a risk to self or others. Whenever possible, all relevant information in the record was reviewed to determine risk status. Using this criterion, 12% of records specified some risk to self or others, but not necessarily a risk so severe that it required hospitalization. Indeed, a person who poses an imminent risk of danger to self or others would require hospitalization and would not be able to be served by the level of care provided in an IMD. Thus, the level of risk indicated in the record was broad and not necessarily one that would preclude community living.

The medical record was also reviewed to assess whether it contained any evidence that a resident's deficits in their current functioning required an IMD level of care. Data in the record indicated that 17% of residents might be considered to require the services provided in the present placement.

A third source of data regarding residents' risk to self or others was obtained directly in the interviews conducted by Drs. Baranoski and Tebes. Each resident was asked whether: "Over the past year, have you tried to physically harm yourself or someone else?" A total of 7% of residents reported that they had tried to harm themselves or someone else during the past year, but were no longer at risk to themselves or others.

Conclusion:

- **A small percentage of residents, ranging from about 7% to 17% pose a risk to self or others at some time during the time they reside in the IMD, but may not reflect current risk.**
- **For the vast majority of residents, however, dangerousness to self or others does not serve as a barrier to community integration at any time.**
- **Furthermore, even for those residents judged to be at risk to self or others, this status is almost certainly temporary because clinical treatment is expected to mitigate risk, thus making it possible for the resident to be available for transition to greater independence and community integration at some future time.**

The Extent of Transition Planning for Independent Living and Community Integration

Dr. Amble's review of the medical records found that 96% of residents had a current treatment plan, although for only 46% of these records was there documentation that the resident was involved in its formulation. A total of 55% of residents had documentation that assessed their potential for discharge. Treatment and discharge plans as well as other information in the record were used to determine whether there was evidence of transition planning that would lead to independent living and enhanced community integration. In order to assure that the proper materials in the medical record were reviewed, Dr. Amble asked the staff member assisting with the site visit to identify where in the record such documentation could be found.

Transition planning is essential if residents are to shift their orientation from the institution to the community. Typically included in such a plan are organized contacts with community-based service providers, including: housing services, psychosocial and vocational programs, and other community agencies and resources that will be part of the individual's future outside of the institution to support independent community living. Residents' ability to make the transition to community living is greatly enhanced by training and practice in the community of the basic skills needed for community living, such as: use of transportation, managing medication, meal preparation, shopping, and so on. However, when such skills are taught without any opportunity to practice their application in the community, they generally are not retained. Critical in transition planning is the identification of specific housing that is appropriate for the resident so that skills training and transition planning can be tailored to the specific needs of the individual.

After a careful review of the records, 98% did not show evidence of a process taking place that would realistically lead to independent living and community integration. In many instances, records regularly repeated goals/objectives from previous treatment plans from one update to another, and showed virtually no documented evidence that staff were attempting to identify appropriate housing or community living options that would allow residents to move out of the facility to independent living with services and supports. Interviews with residents were consistent with this observation; no real evidence of training and supervised practice for independent community living was reported.

Further evidence of a lack of transition planning was obtained directly from the medical record. The MDS form in the record provides an opportunity to note each residents' anticipated date of discharge. Options on the form have changed over the years and not all IMDs use the same version of the form. However, Dr. Amble recorded data from the record review concerning the anticipated date to discharge for each resident. Checklist options on this form provide opportunities for staff to specify a time interval to discharge, such as 31 - 90 days, 181 days to 1 year, > 90 days, and so on. In some records, staff were provided space for write-in responses. In reviewing these records, Dr. Amble noticed the frequency with which staff selected the maximum possible date to discharge among the options given. This date ordinarily provided an anticipated date of indeterminate length, such as "> 90 days" or indicated "not at present." He also noticed that such dates of indeterminate length were frequently checked from one updated MDS to the next. Dr. Amble noted one facility wrote the anticipated date to discharge as "not at

present” for many years with no actual anticipated date to discharge. Table 11 (next page) summarizes this data.

As is shown in the table, 92% of responses indicated no specific anticipated date to discharge, with comments often included on the form, such as “discharge uncertain” or the maximum option checked on that particular form, such as “> 90 days.” Fixed anticipated time intervals to discharge were provided for only 6% of residents. These results make clear that comprehensive transition planning for independent community living is not actively taking place at the IMDs.

Table 11: Residents’ Anticipated Date to Discharge Using the Most Recent Minimum Data Set (MDS) Form		
Anticipated Date to Discharge Categories	Frequency	Percent
No Anticipated Date to Discharge Provided (Responses included: “discharge uncertain”, “not at present”, “not at this time”, “unknown”, “uncertain”, “none”, “discharge status uncertain”, “> 1 year (maximum allowed on form)”, “> 90 days (maximum allowed on form)”, “not within the next 6 months”)	111	92
Fixed Anticipated Time to Discharge Provided (Responses included: “1-2 years”, “181 days - 1 year”, “31 - 90 days”)	7	6%
None given (response left blank)	2	2%
No MDS completed	1	1%

Finally, the lack of transition planning and the pervasive indeterminate estimates of time to discharge were corroborated by residents in their interviews with Drs. Baranoski and Tebes. A resident’s spontaneous statement that “I want my own apartment” or “I want a place of my own” was routinely followed by some account of waiting years for an apartment, not knowing what was needed to initiate the transition process, a lack of clarity about the skills needed in order to leave, or confusion over whether such a move would take place.

Conclusion:

- **Evidence from multiple sources indicates that comprehensive transition planning for independent living and community integration rarely takes place in the IMDs.**
- **The lack of transition planning is a significant barrier to independent living and community integration.**

A Final Note on the Availability of Community-Based Services and Supports that Foster Independence and Community Integration

It is widely known among mental health professionals and policymakers that one of the factors essential to enhanced independent living and community integration is the availability of community-based mental health services and supports. Without such resources, independence and community integration is simply not possible. As stated in the President's New Freedom Commission report: "The lack of decent, safe, affordable, and integrated housing is one of the most significant barriers to full participation in community life for people with serious mental illnesses."

This evaluation was not charged with examining the availability of community-based services and supports that foster independence and community integration. However, interviews with residents, reviews of court materials, and site visits to two community-based residential programs in Chicago indicated that several such programs currently exist that offer integrated housing options that would be appropriate for the vast majority of IMD residents.

SUMMARY AND CONCLUSIONS

This report describes a systematic professional evaluation of a representative sample of 121 residents of IMDs that was conducted by a team of mental health professionals from the Yale University School of Medicine. The team has considerable experience directly relevant to the evaluation.

The purpose of the evaluation was to determine whether residential services and programs in the IMDs are being provided in the most integrated setting appropriate to each resident's disability, and whether with appropriate supports and services, residents who participated in the evaluation could live in more integrated community settings.

Over the past 50 years, the mental health field has increasingly emphasized a recovery-oriented perspective involving mental illness in which individuals move toward ever-increasing independence and community integration. As a result, institutional and more restrictive care settings are widely viewed among professionals as temporary and transitional for individuals with mental illness. During acute episodes when such settings may be necessary or, on occasion, when they are required for more extended periods, restrictive care settings also provide a basis for transition planning to support a person's trajectory to independence and increased integration into the community. Current standards of mental health practice hold that individuals receiving care in such settings are entitled to ongoing reassessment of their potential for increased independence and community integration.


The primary results of this evaluation are as follows: 1) residents of IMDs are not currently integrated into their community on any measure of community integration -- physical, social, or psychological, 2) overall, approximately 85-90% of residents demonstrate a capacity for independent living that would enable them to live in the community given a level of services and supports typically available; 3) approximately 10-15% of all residents demonstrate a more limited capacity for independent functioning, thus making independent community living

difficult and likely to require considerable services and supports; 4) no significant sustained barriers exist to community integration related to residents' housing preferences, ability to complete activities of daily living, mental status/cognitive functioning, severity of psychiatric symptoms, medical conditions, or risk to self or others; and, 5) a major barrier to independent living and community integration is the lack of comprehensive transition planning for community living within the IMDs.

Finally, evidence from multiple sources, including interviews with residents, reviews of court materials, and site visits to two community-based residential programs in Chicago, indicated that community-based programs currently exist that offer integrated housing options that would be appropriate for the vast majority of IMD residents

DATED: August 1, 2008

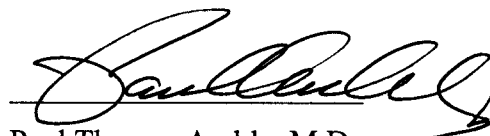
Respectfully submitted,



Jacob Kraemer Tebes, Ph.D.

DATED: August 1, 2008

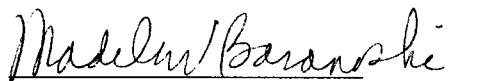
Respectfully submitted,



Paul Thomas Amble, M.D.

DATED: August 1, 2008

Respectfully submitted,



Madelon Visitainer Baranoski, Ph.D.

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Appendix A

Stratification by Geographic Region and Total Census

Table A: IMDs Stratified by Geographic Region and Total Census*					
Total Census**	Geographic Region				
	Chicago - North	Chicago - South	North Suburban Chicago	South Suburban Chicago	Downstate
< 100	Belmont N H <i>Margaret Manor North</i> Wincrest Nursing C			Bourbonnais Terrace	
100 - 199	Bryn Mawr Care Margaret Manor Wilson Care	<i>Columbus Manor</i> Monroe Pavilion Home Care Sacred Heart Home	Abbott House <i>Bayside Terrace</i> <i>Greenwood Care</i> Skokie Meadows	Kankakee Terrace	Pershing Estates <i>Sharon Health Care Woods</i>
200 - 299	Central Plaza <i>Clayton Residential Home</i> Grasmere Place	Rainbow Beach Nursing Care	Lake Park Center	<i>Thornton Heights Terrace</i>	
>400	<i>Somerset Place</i>		Albany Care	Lydia Healthcare Center	

* IMDs in bold italics are those included in the evaluation by random selection.

** No facilities had a census of 300 - 400 residents.

Appendix B**Illinois IMD Visit Schedule and Plan**

IMD	Visit Dates: February 5, 6, 7 (T-Th)			Geographic Location
	Schedule	Census	Sample	
Sharon Health Care Woods 3223 W. Richwoods Blvd. Peoria, IL 61604 309-685-5241	Feb. 5 Tues: 1-5 (Travel 10-1)	152	11	Downstate
Bayside Terrace 1100 South Lewis Waukegan, IL 60085 847-244-9099	Feb. 6 Wed: 9-2 (Travel 2-3)	168	12	North Suburban Chicago
Greenwood Care 1406 N. Chicago Avenue Evanston, IL 60201 847-328-6503	Feb. 6 Wed: 3:30-7:30	145	10	North Suburban Chicago
Clayton Residential Home 2026 North Clark Street Chicago, IL 60614 773-549-1840	Feb. 7 Thurs:9-4	247	18	Chicago-North
Totals		712	51	

IMD	Site Visit Dates: March 5, 6, 7 (W-F)			Geographic Location
	Schedule	Census	Sample	
Columbus Manor Res Center 5107-21 West Jackson Blvd. Chicago, IL 60644 773-378-5490	Mar. 5 Wed: 10-4 (Travel 4-5:30)	189	14	Chicago-South
Margaret Manor North 940 West Cullom Avenue Chicago, IL 60613 773-525-9000	Mar. 5 Wed: 5:30-8:30	99	7	Chicago-North
Somerset Place 5009 N. Sheridan Road Chicago, IL 60640 773-561-0700	Mar. 6 Thurs: 9-9	450	32	Chicago-North
Thornton Heights Terrace 160 West 10 th Street Chicago Heights, IL 60411 708-754-2220	Mar. 7 Fri: 9-3	222	16	South Suburban Chicago
Totals		960	69	

RESIDENT CODE SHEET

Clayton Residential Home, 2026 North Clark Street, Chicago, IL 60614

Census: 247 (+10% = 272) Residents to be interviewed: 18

Complete Random List of Numbers up to 272

183, 161, 89, 201, 136, 16, 110, 167, 156, 49, 214, 177, 150, 264, 10, 38, 85, 116, 193, 227, 99, 115, 64, 235, 237, 252, 149, 67, 78, 88, 251, 95, 56, 230, 130, 1, 131, 192, 139, 259, 121, 263, 271, 92, 4, 137, 169, 159, 266, 83, 232, 25, 48, 184, 114, 206, 223, 182, 179, 256, 142, 234, 199, 244, 254, 60, 104, 218, 93, 220, 74, 12, 269, 155, 231, 158, 123, 224, 8, 216, 203, 53, 189, 98, 152, 111, 52, 133, 166, 97, 268, 90, 250, 157, 243, 103, 144, 35, 61, 160, 129, 221, 163, 22, 17, 73, 96, 81, 205, 122, 32, 11, 57, 77, 153, 76, 86, 191, 44, 258, 247, 162, 43, 208, 239, 174, 219, 151, 33, 173, 55, 3, 257, 14, 119, 79, 9, 228, 68, 233, 70, 249, 106, 69, 59, 5, 188, 225, 7, 212, 140, 19, 178, 134, 202, 107, 261, 255, 187, 34, 229, 248, 196, 222, 42, 170, 186, 211, 50, 135, 146, 141, 242, 108, 253, 172, 171, 21, 209, 127, 112, 125, 2, 71, 210, 262, 51, 94, 47, 54, 113, 6, 62, 165, 37, 30, 40, 20, 41, 267, 147, 260, 87, 195, 101, 241, 213, 181, 198, 31, 226, 118, 168, 75, 215, 84, 236, 124, 65, 100, 23, 148, 66, 26, 29, 126, 143, 36, 200, 15, 154, 207, 204, 270, 13, 138, 128, 175, 132, 18, 39, 180, 117, 28, 105, 63, 238, 24, 176, 272, 185, 145, 240, 265, 80, 164, 102, 58, 109, 217, 197, 46, 45, 91, 82, 245, 120, 246, 72, 190, 194, 27

Baranoski

183, 161, 89, 201, 136, 16, 110, 167, 156, 49, 214, 177, 150, 264, 10, 38, 85, 116, 193, 227, 99, 115, 64, 235, 237, 252, 149, 67, 78, 88, 251, 95, 56, 230, 130, 1, 131, 192, 139, 259, 121, 263, 271, 92, 4, 137, 169, 159, 266, 83, 232, 25, 48, 184, 114, 206, 223, 182, 179, 256, 142, 234, 199, 244, 254, 60, 104, 218, 93, 220, 74, 12, 269, 155, 231, 158, 123, 224, 8, 216, 203, 53, 189, 98, 152, 111, 52, 133, 166, 97, 268, 90, 250, 157, 243, 103, 144, 35, 61, 160, 129, 221, 163, 22, 17, 73, 96, 81, 205, 122, 32, 11, 57, 77, 153, 76, 86, 191, 44, 258, 247, 162, 43, 208, 239, 174, 219, 151, 33, 173, 55, 3, 257, 14, 119, 79, 9, 228, 68, 233, 70, 249, 106, 69, 59, 5, 188, 225, 7, 212, 140, 19, 178, 134, 202, 107, 261, 255, 187, 34, 229, 248, 196, 222, 42, 170, 186, 211, 50, 135, 146, 141, 242, 108, 253, 172, 171, 21, 209, 127, 112, 125, 2, 71, 210, 262, 51, 94, 47, 54, 113, 6, 62, 165, 37, 30, 40, 20, 41, 267, 147, 260, 87, 195, 101, 241, 213, 181, 198, 31, 226, 118, 168, 75, 215, 84, 236, 124, 65, 100, 23, 148, 66, 26, 29, 126, 143, 36, 200, 15, 154, 207, 204, 270, 13, 138, 128, 175, 132, 18, 39, 180, 117, 28, 105, 63, 238, 24, 176, 272, 185, 145, 240, 265, 80, 164, 102, 58, 109, 217, 197, 46, 45, 91, 82, 245, 120, 246, 72, 190, 194, 27

Resident Code

Name

Tebes

183, 161, 89, 201, 136, 16, 110, 167, 156, 49, 214, 177, 150, 264, 10, 38, 85, 116, 193, 227, 99, 115, 64, 235, 237, 252, 149, 67, 78, 88, 251, 95, 56, 230, 130, 1, 131, 192, 139, 259, 121, 263, 271, 92, 4, 137, 169, 159, 266, 83, 232, 25, 48, 184, 114, 206, 223, 182, 179, 256, 142, 234, 199, 244, 254, 60, 104, 218, 93, 220, 74, 12, 269, 155, 231, 158, 123, 224, 8, 216, 203, 53, 189, 98, 152, 111, 52, 133, 166, 97, 268, 90, 250, 157, 243, 103, 144, 35, 61, 160, 129, 221, 163, 22, 17, 73, 96, 81, 205, 122, 32, 11, 57, 77, 153, 76, 86, 191, 44, 258, 247, 162, 43, 208, 239, 174, 219, 151, 33, 173, 55, 3, 257, 14, 119, 79, 9, 228, 68, 233, 70, 249, 106, 69, 59, 5, 188, 225, 7, 212, 140, 19, 178, 134, 202, 107, 261, 255, 187, 34, 229, 248,

196, 222, 42, 170, 186, 211, 50, 135, 146, 141, 242, 108, 253, 172, 171, 21, 209, 127, 112, 125, 2, 71, 210, 262, 51, 94, 47, 54, 113, 6, 62, 165, 37, 30, 40, 20, 41, 267, 147, 260, 87, 195, 101, 241, 213, 181, 198, 31, 226, 118, 168, 75, 215, 84, 236, 124, 65, 100, 23, 148, 66, 26, 29, 126, 143, 36, 200, 15, 154, 207, 204, 270, 13, 138, 128, 175, 132, 18, 39, 180, 117, 28, 105, 63, 238, 24, 176, 272, 185, 145, 240, 265, 80, 164, 102, 58, 109, 217, 197, 46, 45, 91, 82, 245, 120, 246, 72, 190, 194, 27

Resident Code	Name
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RESIDENT CODE SHEET
Columbus Manor, 5107-21 West Jackson Blvd., Chicago, IL 60644
Census: 189 (+10% = 208) Residents to be interviewed: 14

Complete Random List of Numbers up to 208

57, 4, 22, 70, 60, 141, 80, 35, 129, 7, 192, 158, 45, 97, 132, 156, 203, 153, 208, 101, 110, 21, 96, 89, 102, 185, 43, 42, 207, 82, 103, 25, 32, 150, 196, 19, 165, 84, 91, 105, 12, 145, 154, 174, 168, 83, 204, 138, 190, 18, 151, 205, 180, 53, 191, 127, 139, 48, 69, 124, 77, 133, 76, 130, 147, 142, 46, 188, 90, 179, 85, 92, 86, 54, 134, 31, 27, 17, 73, 117, 87, 2, 182, 50, 8, 137, 167, 206, 159, 94, 23, 197, 198, 148, 74, 177, 152, 176, 199, 1, 14, 143, 186, 36, 99, 175, 13, 40, 170, 58, 183, 122, 59, 194, 81, 157, 20, 161, 66, 3, 52, 173, 62, 79, 15, 71, 88, 160, 163, 131, 38, 164, 140, 24, 78, 6, 166, 72, 136, 100, 30, 149, 126, 169, 108, 178, 109, 112, 5, 95, 106, 162, 9, 63, 68, 98, 26, 195, 200, 146, 111, 181, 16, 93, 104, 34, 193, 67, 41, 201, 144, 135, 172, 119, 114, 115, 28, 64, 51, 155, 123, 39, 29, 187, 75, 61, 125, 37, 128, 202, 44, 56, 120, 121, 65, 33, 171, 55, 47, 49, 107, 113, 184, 189, 11, 118, 116, 10

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57, 22, 60, 80, 129, 192, 45, 132, 203, 208, 110, 96, 102, 43, 207, 103, 32, 196, 165, 91, 12, 154, 168, 204, 190, 151, 180, 191, 139, 69, 77, 76, 147, 46, 90, 85, 86, 134, 27, 73, 87, 182, 8, 167, 159, 23, 198, 74, 152, 199, 14, 186, 99, 13, 170, 183, 59, 81, 20, 66, 52, 62, 15, 88, 163, 38, 140, 78, 166, 136, 30, 126, 108, 109, 5, 106, 9, 68, 26, 200, 111, 16, 104, 193, 41, 144, 172, 114, 28, 51, 123, 29, 75, 125, 128, 44, 120, 65, 171, 47, 107, 184, 11, 116

Resident Code	Name
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Tebes

4, 70, 141, 35, 7, 158, 97, 156, 153, 101, 21, 89, 185, 42, 82, 25, 150, 19, 84, 105, 145, 174, 83, 138, 18, 205, 53, 127, 48, 124, 133, 130, 142, 188, 179, 92, 54, 31, 17, 117, 2, 50, 137, 206, 94, 197, 148, 177, 176, 1, 143, 36, 175, 40, 58, 122, 194, 157, 161, 3, 173, 79, 71, 160, 131, 164, 24, 6, 72, 100, 149, 169, 178, 112, 95, 162, 63, 98, 195, 146, 181, 93, 34, 67, 201, 135, 119, 115, 64, 155, 39, 187, 61, 37, 202, 56, 121, 33, 55, 49, 113, 189, 118, 10

Resident Code	Name
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RESIDENT CODE SHEET
Greenwood Care, 1406 N. Chicago Avenue, Evanston, IL 60201
Census: 145 (+10% = 160) Residents to be interviewed: 10

Complete Random List of Numbers up to 160

70, 152, 55, 29, 121, 4, 135, 124, 61, 92, 13, 42, 30, 97, 143, 73, 22, 31, 123, 110, 60, 95, 101, 94, 24, 38, 75, 117, 99, 34, 18, 69, 59, 11, 50, 85, 19, 12, 158, 5, 106, 67, 91, 104, 111, 98, 116, 52, 21, 64, 71, 17, 108, 25, 72, 46, 136, 32, 140, 26, 44, 81, 87, 78, 2, 126, 93, 90, 77, 139, 138, 86, 53, 125, 9, 154, 8, 151, 132, 48, 159, 157, 33, 128, 37, 58, 127, 28, 10, 89, 148, 133, 114, 23, 49, 119, 7, 145, 88, 51, 105, 79, 129, 47, 120, 131, 137, 36, 118, 63, 147, 54, 144, 115, 41, 43, 122, 15, 3, 134, 68, 150, 160, 146, 112, 1, 102, 83, 57, 141, 149, 153, 20, 14, 109, 84, 74, 82, 96, 39, 56, 76, 35, 65, 27, 66, 130, 6, 113, 45, 62, 16, 156, 142, 155, 107, 103, 80, 40, 100

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70, 55, 121, 135, 61, 13, 30, 143, 22, 123, 60, 101, 24, 75, 99, 18, 59, 50, 19, 158, 106, 91, 111, 116, 21, 71, 108, 72, 136, 140, 44, 87, 2, 93, 77, 138, 53, 9, 8, 132, 159, 33, 37, 127, 10, 148, 114, 49, 7, 88, 105, 129, 120, 137, 118, 147, 144, 41, 122, 3, 68, 160, 112, 102, 57, 149, 20, 109, 74, 96, 56, 35, 27, 130, 113, 62, 156, 155, 103, 40

Resident Code	Name
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Tebes

152, 29, 4, 124, 92, 42, 97, 73, 31, 110, 95, 94, 38, 117, 34, 69, 11, 85, 12, 5, 67, 104, 98, 52, 64, 17, 25, 46, 32, 26, 81, 78, 126, 90, 139, 86, 125, 154, 151, 48, 157, 128, 58, 28, 89, 133, 23, 119, 145, 51, 79, 47, 131, 36, 63, 54, 115, 43, 15, 134, 150, 146, 1, 83, 141, 153, 14, 84, 82, 39, 76, 65, 66, 6, 45, 16, 142, 107, 80, 100

Resident Code	Name
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RESIDENT CODE SHEET
Margaret Manor North, 940 West Cullom Avenue, Chicago, IL 60613
Census: 99 (+10% = 109) Residents to be interviewed: 7

Complete Random List of Numbers up to 109

45, 106, 7, 1, 68, 99, 52, 102, 96, 94, 48, 63, 79, 73, 39, 23, 74, 103, 104, 64, 98, 35, 88, 61, 38, 62, 108, 78, 8, 76, 97, 4, 59, 107, 83, 92, 81, 13, 36, 89, 6, 3, 100, 105, 25, 31, 15, 30, 51, 17, 10, 26, 53, 93, 19, 34, 11, 5, 90, 101, 37, 58, 55, 50, 14, 22, 46, 84, 9, 86, 75, 12, 60, 28, 49, 32, 16, 69, 71, 40, 27, 85, 29, 41, 80, 57, 21, 20, 18, 42, 24, 43, 47, 2, 44, 91, 65, 109, 33, 56, 67, 72, 70, 54, 82, 66, 95, 87, 77

Baranoski

45, 7, 68, 52, 96, 48, 79, 39, 74, 104, 98, 88, 38, 108, 8, 97, 59, 83, 81, 36, 6, 100, 25, 15, 51, 10, 53, 19, 11, 90, 37, 55, 14, 46, 9, 75, 60, 49, 16, 71, 27, 29, 80, 21, 18, 24, 47, 44, 65, 33, 67, 70, 82, 95, 77

Resident Code	Name
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Tebes

106, 1, 99, 102, 94, 63, 73, 23, 103, 64, 35, 61, 62, 78, 76, 4, 107, 92, 13, 89, 3, 105, 31, 30, 17, 26, 93, 34, 5, 101, 58, 50, 22, 84, 86, 12, 28, 32, 69, 40, 85, 41, 57, 20, 42, 43, 2, 91, 109, 56, 72, 54, 66, 87

Resident Code	Name
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RESIDENT CODE SHEET
Sharon Health Care Woods, 3223 W. Richwoods Boulevard, Peoria, IL 61604
Census: 152 (+10% = 167) Residents to be interviewed: 11

Complete Random List of Numbers up to 167

30, 91, 106, 120, 135, 67, 88, 49, 136, 129, 79, 48, 141, 131, 18, 6, 39, 94, 47, 73, 86, 21, 37, 13,
 119, 150, 160, 84, 64, 100, 25, 52, 118, 82, 157, 99, 19, 71, 53, 110, 32, 63, 112, 122, 17, 72,
 162, 90, 78, 83, 146, 51, 38, 111, 28, 142, 24, 20, 124, 95, 10, 149, 87, 42, 57, 74, 134, 132, 117, 126,
 155, 12, 65, 145, 68, 61, 54, 33, 4, 139, 40, 60, 23, 148, 101, 7, 55, 161, 125, 41, 109, 22,
 114, 96, 144, 35, 147, 36, 107, 46, 137, 153, 154, 77, 45, 123, 159, 5, 108, 165, 62, 1, 130, 143, 164, 103,
 76, 58, 156, 34, 26, 9, 11, 8, 15, 2, 116, 158, 152, 75, 102, 98, 138, 14, 56, 104, 85, 29, 80, 3, 93, 113, 27,
 115, 44, 133, 89, 121, 43, 140, 59, 92, 16, 163, 97, 31, 69, 128, 127, 166, 66, 151, 105, 167, 50, 70, 81

Baranoski

30, 106, 135, 88, 136, 79, 141, 18, 39, 47, 86, 37, 119, 160, 64, 25, 118, 157, 19, 53, 32, 112, 17, 162, 78,
 146, 38, 28, 24, 124, 10, 87, 57, 134, 117, 155, 65, 68, 54, 4, 40, 23, 101, 55, 125, 109, 114, 144, 147,
 107, 137, 154, 45, 159, 108, 62, 130, 164, 76, 156, 26, 11, 15, 116, 152, 102, 138, 56, 85, 80, 93, 27, 44,
 89, 43, 59, 16, 97, 69, 127, 66, 105, 50, 81

Resident Code	Name
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Tebes

91, 120, 67, 49, 129, 48, 131, 6, 94, 73, 21, 13, 150, 84, 100, 52, 82, 99, 71, 110, 63, 122, 72, 90, 83, 51,
 111, 142, 20, 95, 149, 42, 74, 132, 126, 12, 145, 61, 33, 139, 60, 148, 7, 161, 41, 22, 96, 35, 36, 46, 153,
 77, 123, 5, 165, 1, 143, 103, 58, 34, 9, 8, 2, 158, 75, 98, 14, 104, 29, 3, 113, 115, 133, 121, 140, 92, 163,
 31, 128, 166, 151, 167, 70

Resident Code	Name
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RESIDENT CODE SHEET

Somerset Place, 5009 N. Sheridan Road, Chicago, IL 60640
Census: 450 (+10% = 495) Residents to be interviewed: 32

Complete Random List of Numbers up to 495

178, 348, 396, 347, 91, 337, 237, 452, 10, 489, 110, 428, 368, 409, 269, 420, 158, 96, 254, 81, 458, 19, 173, 434, 249, 13, 379, 85, 416, 58, 293, 230, 105, 447, 464, 225, 354, 200, 175, 453, 274, 63, 118, 438, 92, 317, 208, 2, 330, 315, 288, 264, 154, 378, 203, 37, 170, 34, 380, 89, 207, 297, 401, 14, **454**, 461, 72, 29, 93, 16, 406, 68, 362, 90, 485, 8, 11, 479, **137**, 167, 450, 418, 285, 182, 286, 79, 316, 281, 387, 433, 20, 266, 148, 9, 460, 55, 123, 480, 41, 169, 22, 15, 375, 229, 481, 463, 403, 300, 443, 222, 46, 45, 284, 30, 455, 283, 23, 181, 163, 94, **36**, 442, 161, 52, 98, 130, 44, 350, 240, 119, 168, 18, 253, 425, 132, 492, 271, 397, 302, 59, 7, 80, 494, 256, 252, 339, 53, 466, 322, 457, 437, 493, 35, 371, 150, 67, 251, 431, 421, 196, 21, 278, **221**, 204, 226, 66, 436, 319, 287, 176, 331, 334, 115, 194, 262, 351, 305, 292, 338, 413, 213, 336, 370, 57, 17, 415, 131, 50, 4, 325, 273, 268, 31, 159, 320, 33, 180, 234, 247, 291, 99, 258, 424, 244, **95**, 32, 117, 394, 76, 125, 238, 459, 369, 382, 157, 147, 358, 120, 265, 87, 248, 114, 304, 228, 239, 491, 495, 469, 65, 440, 449, 429, 56, 100, 101, 257, 465, 179, 467, 116, 366, 279, 321, 444, 276, 162, 145, 97, 104, 160, 359, 307, 142, 333, 210, 183, 477, 172, 191, 303, 209, 177, 405, 146, 462, 439, 216, 412, 275, 352, 435, 474, 487, 156, 470, 134, 82, 407, 270, 488, 472, 310, 312, 192, 361, 102, 24, 410, 202, 296, 402, 231, 218, 373, 61, 242, 71, 309, 70, 306, 27, 77, 332, 219, 478, 404, 486, 111, 376, 374, 324, 215, 42, 282, 25, 484, 372, 129, 26, 364, 217, 411, 290, 390, 277, 298, 223, 112, 73, 108, 471, 128, 383, 346, 327, 255, 360, 224, 301, 363, 263, 385, 153, 289, 113, 430, 451, 39, 232, 197, 38, 272, 64, 482, 28, 386, 136, 422, 122, 241, 186, 250, 69, 74, 441, 205, 6, 341, 149, 448, 314, 227, 393, 121, 187, 243, 445, 220, 84, 133, 294, 212, 367, 490, 384, 135, 188, 400, 109, 389, 206, 199, 195, 144, 342, 245, 344, 426, 483, 1, 326, 236, 308, 166, 345, 12, 51, 456, 355, 349, 198, 164, 295, 47, 185, 83, 318, 40, 3, 75, 54, 395, 417, 88, 138, 381, 377, 5, 174, 60, 329, 126, 78, 323, 473, 340, 214, 343, 388, 139, 165, 151, 235, 233, 171, 399, 86, 103, 391, 190, 365, 267, 43, 476, 49, 419, 280, 398, 140, 201, 475, 328, 260, 414, 155, 468, 423, 48, 143, 152, 357, 62, 211, 392, 311, 259, 408, 246, 446, 189, 356, 124, 193, 107, 261, 427, 127, 353, 313, 432, 141, 106, 299, 184, 335

Baranoski

178, 396, 91, 237, 10, 110, 368, 269, 158, 254, 458, 173, 249, 379, 416, 293, 105, 464, 354, 175, 274, 118, 92, 208, 330, 288, 154, 203, 170, 380, 207, 401, 454, 72, 93, 406, 362, 485, 11, 137, 450, 285, 286, 316, 387, 20, 148, 460, 123, 41, 22, 375, 481, 403, 443, 46, 284, 455, 23, 163, 36, 161, 98, 44, 240, 168, 253, 132, 271, 302, 7, 494, 252, 53, 322, 437, 35, 150, 251, 421, 21, 221, 226, 436, 287, 331, 115, 262, 305, 338, 213, 370, 17, 131, 4, 273, 31, 320, 180, 247, 99, 424, 95, 117, 76, 238, 369, 157, 358, 265, 248, 304, 239, 495, 65, 449, 56, 101, 465, 467, 366, 321, 276, 145, 104, 359, 142, 210, 477, 191, 209, 405, 462, 216, 275, 435, 487, 470, 82, 270, 472, 312, 361, 24, 202, 402, 218, 61, 71, 70, 27, 332, 478, 486, 376, 324, 42, 25, 372, 26, 217, 290, 277, 223, 73, 471, 383, 327, 360, 301, 263, 153, 113, 451, 232, 38, 64, 28, 136, 122, 186, 69, 441, 6, 149, 314, 393, 187, 445, 84, 294, 367, 384, 188, 109, 206, 195, 342, 344, 483, 326, 308, 345, 51, 355, 198, 295, 185, 318, 3, 54, 417, 138, 377, 174, 329, 78, 473, 214, 388, 165, 235, 171, 86, 391, 365, 43, 49, 280, 140, 475, 260, 155, 423, 143, 357, 211, 311, 408, 446, 356, 193, 261, 127, 313, 141, 299, 335

32, 30, 39, 111, 96, 237, 117, 121, 148, 36, 220, 90, 181, 129, 110, 9, 37, 41, 87, 108, 243, 95, 176, 79, 46, 125, 226, 55, 47, 19, 86, 132, 223, 177, 106, 180, 44, 61, 168, 64, 204, 5, 214, 211, 13, 20, 215, 66, 23, 139, 150, 2, 199, 15, 62, 75, 65, 18, 221, 122, 24, 59, 159, 163, 21, 188, 27, 234, 76, 78, 3, 43, 175, 7, 1, 152, 126, 219, 83, 229, 147, 91, 107, 10, 174, 22, 40, 238, 51, 141, 112, 105, 151, 225, 213, 230, 6, 187, 11, 179, 102, 155, 114, 80, 109, 88, 89, 127, 178, 100, 233, 123, 85, 26, 119, 31, 195, 170, 227, 149, 104, 16

Resident Code	Name
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Appendix D

IMD Resident Professional Evaluation Interview

IMD: _____ Date: _____ Time: _____ Resident Code: _____

Hello, my name is Dr. _____. I am a psychologist from the Yale University School of Medicine and I am here to ask whether you would be willing to talk to me for a few minutes about how you are doing and your experiences here at _____ and in the surrounding neighborhood. We will be interviewing over 100 residents from all over the state who live in places like _____. I would need about half hour or so of your time.

I've been asked to talk to you today by a group of people, including the ACLU of Illinois, who are advocating in court for people who live here and in other places like this. The case focuses on whether Illinois provides services, including housing and other opportunities, to help integrate into the community people who live here and in places like this.

Now, there are a few things you should know about our talking together. If you agree to talk to me, we will also be reviewing your records. I will not share what you tell me or what we learn about you with anyone who works here or with the general public, and will not include your name on this survey interview. I will only give the information to the lawyers in the case and to the court and then summarize it, along with information from other people we are interviewing, in a report that does not include your name. I am really interested in your opinions, and until we get to the very end, there are no right or wrong answers to the questions I will be asking you. It is your opinion that I am most interested in. Finally, you should know that you can stop the interview at any time.

Now, I want to go over what I said to make sure you understand. I will be asking you questions about how you are doing and your experiences here and in the surrounding neighborhood. This will include information about opportunities you may have had to be involved in the community. I will share your information only with the lawyers in the case and the court, but not with anyone here, unless, I have concerns about your safety or the safety of others. Any information you give me will not be stored with your name on it, and what we learn from you and other people we interview will be summarized in a report that will be given to the lawyers in the case and the court. And, finally, your decision to speak with me is voluntary, and you can stop at any time.

Now, would you be willing to talk with me? ___ (Check if "yes.") Do you have any questions?

Background

1. How long have you lived here at _____?
2. Where did you live just before coming here? _____
3. What type of place was that (home, apartment, hospital, residential setting, shelter, or a place similar to this one)? _____

4. Who did you live with? _____
5. Have you ever lived independently in the community? Y N _____
6. Are you currently in any kind of mental health or psychiatric treatment? _____
7. If so, where do you go for treatment? _____
8. What was the last time you stayed overnight in a psychiatric hospital, even for just a day?

9. In the past 10 years, about how many separate times have you stayed in a psychiatric hospital overnight? _____
10. Over the past year, have you tried to physically harm yourself or someone else? Y N _____

Here's a few more questions about your background.

11. What is your current marital status? _____
12. What is the highest level of education that you have had the opportunity to complete? _____
13. In the past, what was your most recent employment? _____

PhI/BI

*Now I'm going to ask you some questions and I'd like you to use the scale on Card 1 and tell me which number or word (like 0 for Never, 2 for Sometimes, and so on) that best describes how often you did various activities in the past month. Next, I will ask you whether you usually do the activity alone, or with someone else from _____ or with persons who live outside of _____. Do you have any questions? OK, let's start. During **the past month**, please tell me how often you have been involved in any of the following activities.*

	0 = Never	1 = Rarely	2 = Sometimes	3 = Often	4 = Very Often	A = Usually Alone	B = Usually With Others Here	C = Usually With Others Outside of Here
1. Going to a shopping area.	0	1	2	3	4	A	B	C
2. Going to movies or concerts.	0	1	2	3	4	A	B	C
3. Going to restaurants, bars, or taverns.	0	1	2	3	4	A	B	C
4. Going to sports events.	0	1	2	3	4	A	B	C
5. Playing or participating in sports outside of this building.	0	1	2	3	4	A	B	C
6. Going to a community center. <i>(Do not code</i>	0	1	2	3	4	A	B	C

treatment programs or therapist/doctor visits.)

7. Attending church or another place of worship.	0	1	2	3	4	A	B	C
8. Going to a park or museum.	0	1	2	3	4	A	B	C
9. Taking a walk outside.	0	1	2	3	4	A	B	C
10. Going to your job or volunteer activity.	0	1	2	3	4	A	B	C

PsI

IMD

Now I am going to ask you a few questions about the place you are currently living, _____. Please answer each question on a 5 point scale as shown on Card 2 in front of you. So, for example, if I read to you this question "I like living at _____", I'd like you to think of the question from your point of view -- YOU like living at _____. Then you would give an answer that ranges from 1 (Strongly Disagree) to 5 (Strongly Agree) or somewhere in between. OK, let's start.

1 = Strongly Disagree	2 = Disagree	3 = Neither Disagree/ Nor Agree	4 = Agree	5 = Strongly Agree
------------------------------	---------------------	--	------------------	---------------------------

1. Overall, I am very attracted to living here at _____.	1	2	3	4	5
2. I feel like I belong here at _____.	1	2	3	4	5
3. I visit with other people who live here in their apartments.	1	2	3	4	5
4. The friendships and associations I have with other people here at _____ mean a lot to me.	1	2	3	4	5
5. Given the opportunity, I would like to move out of this place.	1	2	3	4	5
6. If the people here at _____ were planning something, I'd think of it as something "we" were doing rather than what "they" were doing.	1	2	3	4	5
7. If I needed advice about something, I could go to someone living here at _____.	1	2	3	4	5
8. I think I agree with most people here at _____ about what is important in life.	1	2	3	4	5
9. I believe other people living here at _____ would help me in an emergency.	1	2	3	4	5
10. I feel loyal to the people here at _____.	1	2	3	4	5
11. I borrow things and exchange favors with other people who live here.	1	2	3	4	5
12. I would be willing to work together with others who live here on something to improve this place.	1	2	3	4	5
13. I plan to remain a resident of this place for a number of years.	1	2	3	4	5
14. I like to think of myself as similar to the people who live here at _____.	1	2	3	4	5
15. I rarely have other people who live here at _____ over to my apartment to visit.	1	2	3	4	5
16. A feeling of fellowship runs deep between me and other people who live in this place.	1	2	3	4	5
17. I regularly stop and talk with people who live here at _____.	1	2	3	4	5
18. Living in _____ gives me a sense of community.	1	2	3	4	5

Neighborhood

Now I will be asking you about the neighborhood outside of _____. Again, please answer each question as shown on Card 2 in front of you and think of the question from YOUR point of view.

1 = Strongly Disagree	2 = Disagree	3 = Neither Disagree/ Nor Agree	4 = Agree	5 = Strongly Agree
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- | | | | | | |
|--|---|---|---|---|---|
| 1. Overall, I am very attracted to living in the neighborhood outside of _____. | 1 | 2 | 3 | 4 | 5 |
| 2. I feel like I belong to this neighborhood. | 1 | 2 | 3 | 4 | 5 |
| 3. I visit with neighbors who live outside of here in their homes. | 1 | 2 | 3 | 4 | 5 |
| 4. The friendships and associations I have with other people in this neighborhood mean a lot to me. | 1 | 2 | 3 | 4 | 5 |
| 5. Given the opportunity, I would like to move out of this neighborhood. | 1 | 2 | 3 | 4 | 5 |
| 6. If the people in my neighborhood were planning something, I'd think of it as something "we" were doing rather than "they" were doing. | 1 | 2 | 3 | 4 | 5 |
| 7. If I needed advice about something, I could go to someone in the neighborhood outside of _____. | 1 | 2 | 3 | 4 | 5 |
| 8. I think I agree with most people in this neighborhood about what is important in life. | 1 | 2 | 3 | 4 | 5 |
| 9. I believe my neighbors who live outside of here would help me in an emergency. | 1 | 2 | 3 | 4 | 5 |
| 10. I feel loyal to the people in this neighborhood. | 1 | 2 | 3 | 4 | 5 |
| 11. I borrow things and exchange favors with the neighbors outside of here. | 1 | 2 | 3 | 4 | 5 |
| 12. I would be willing to work together with others on something to improve my neighborhood. | 1 | 2 | 3 | 4 | 5 |
| 13. I plan to remain a resident of this neighborhood for a number of years. | 1 | 2 | 3 | 4 | 5 |
| 14. I like to think of myself as similar to the people who live in this neighborhood, the area that surrounds _____. | 1 | 2 | 3 | 4 | 5 |
| 15. I rarely have neighbors who live outside of _____ over to my apartment to visit. | 1 | 2 | 3 | 4 | 5 |
| 16. A feeling of fellowship runs deep between me and other people in this neighborhood, the area outside of _____. | 1 | 2 | 3 | 4 | 5 |
| 17. I regularly stop and talk with people in my neighborhood, the area outside of _____. | 1 | 2 | 3 | 4 | 5 |
| 18. Living in this neighborhood gives me a sense of community. | 1 | 2 | 3 | 4 | 5 |

SI

IMD

Now here are a few more questions about the place you are living, _____. This time, please answer how often a certain situation happens. Turn to Card 3 and use the scale that ranges from 0 to 4 as shown on the card in front of you.

0 = Never	1 = Rarely	2 = Occasionally	3 = Fairly Often	4 = Frequently		
1.	How often have you said hello or waved to someone who lives here at ____.	0	1	2	3	4
2.	How often have you received a ride from someone who lives here?	0	1	2	3	4
3.	How often have you gone on a social outing with someone who lives here?	0	1	2	3	4
4.	How often have you discussed this place, _____, with someone who lives here?	0	1	2	3	4
5.	How often have you taken care of a someone's apartment who lives here at ____?	0	1	2	3	4
6.	How often have you been told of an event by someone who lives here at ____?	0	1	2	3	4
7.	How often have you been invited into someone apartment who lives here at ____?	0	1	2	3	4
8.	How often have you assisted someone who lives here with a household task?	0	1	2	3	4
9.	How often have you talked with someone who lives here about personal issues?	0	1	2	3	4
10.	How often have you borrowed things from someone who lives here?	0	1	2	3	4
11.	How often have you discussed home maintenance with someone who lives here?	0	1	2	3	4
12.	How often have you told someone who lives here about professional services used?	0	1	2	3	4
13.	How often have you had a conversation in the hall with someone who lives here?	0	1	2	3	4

Neighborhood

Now just like the last time, I'm going to ask you some similar questions about the neighborhood that is outside of here. Please continue using the same Card 3 to answer these questions, too.

0 = Never	1 = Rarely	2 = Occasionally	3 = Fairly Often	4 = Frequently		
1.	How often have you said hello or waved to a neighbor who lives outside of here?	0	1	2	3	4
2.	How often have you received a ride from a neighbor who lives outside of here?	0	1	2	3	4
3.	How often have you gone on a social outing with a neighbor from outside of ____?	0	1	2	3	4
4.	How often have you discussed the neighborhood outside of here with a neighbor?	0	1	2	3	4
5.	How often have you taken care of the house of a neighbor who lives outside of here?	0	1	2	3	4

- | | | | | | |
|--|---|---|---|---|---|
| 6. How often have you been told of an event by a neighbor? | 0 | 1 | 2 | 3 | 4 |
| 7. How often have you been invited into the home of a neighbor who lives outside of here? | 0 | 1 | 2 | 3 | 4 |
| 8. How often have you assisted a neighbor with a household task? | 0 | 1 | 2 | 3 | 4 |
| 9. How often have you talked with a neighbor who lives outside of here about personal issues? | 0 | 1 | 2 | 3 | 4 |
| 10. How often have you borrowed things from a neighbor who lives outside of here? | 0 | 1 | 2 | 3 | 4 |
| 11. How often have you discussed home maintenance with a neighbor? | 0 | 1 | 2 | 3 | 4 |
| 12. How often have you told a neighbor who lives outside of here about professional services used? | 0 | 1 | 2 | 3 | 4 |
| 13. How often have you had a conversation on the street with a neighbor? | 0 | 1 | 2 | 3 | 4 |

HC

Now I have a few questions to ask you about the choice you had in this housing. Please turn to Card 4 and answer on a scale from 0 to 4.

0 = No Choice At All	1 = Almost No Choice	2 = Some Choice	3 = A Fair Amount of Choice	4 = A Great Deal of Choice
-----------------------------	-----------------------------	------------------------	------------------------------------	-----------------------------------

- | | | | | | |
|---|---|---|---|---|---|
| 1. How much choice did you have over the neighborhood you moved into? | 0 | 1 | 2 | 3 | 4 |
| 2. How much choice did you have over the specific place you moved into? | 0 | 1 | 2 | 3 | 4 |
| 3. How much choice did you have over who you live with (living alone)? | 0 | 1 | 2 | 3 | 4 |

OK, now here are a few more.

- | | | | | | |
|---|---|---|---|---|---|
| 1. How much choice did you have over decorating and furnishing? | 0 | 1 | 2 | 3 | 4 |
| 2. How much choice did you have over when visitors can come over? | 0 | 1 | 2 | 3 | 4 |
| 3. How much choice did you have over having overnight guests? | 0 | 1 | 2 | 3 | 4 |
| 4. How much choice do you have over whether you can use alcohol? | 0 | 1 | 2 | 3 | 4 |
| 5. How much choice do you have over having a pet? | 0 | 1 | 2 | 3 | 4 |
| 6. How much choice do you have over who has a key to your place other than your landlord and housemate? | 0 | 1 | 2 | 3 | 4 |
| 7. How much choice do you have over whether you or someone else takes care of the maintenance? | 0 | 1 | 2 | 3 | 4 |
| 8. How much choice do you have over having a yard or a garden? | 0 | 1 | 2 | 3 | 4 |
| 9. How much choice do you have over when case workers can come over? | 0 | 1 | 2 | 3 | 4 |
| 10. How much choice do you have over having children around the place you live? | 0 | 1 | 2 | 3 | 4 |
| 11. How much choice do you have over whether you can lock your room | 0 | 1 | 2 | 3 | 4 |

doors?

- | | | | | | |
|---|---|---|---|---|---|
| 12. How much choice do you have over whether or not you must participate in mental health services to stay in the place you live? | 0 | 1 | 2 | 3 | 4 |
| 13. How much choice do you have over purchasing food you want? | 0 | 1 | 2 | 3 | 4 |
| 14. How much choice do you have over being able to come and go at any time without having to notify people? | 0 | 1 | 2 | 3 | 4 |
| 15. How much choice do you have over when to cook meals and what you can eat? | 0 | 1 | 2 | 3 | 4 |
| 16. How much choice do you have over whether you lived in a building where other consumers live? | 0 | 1 | 2 | 3 | 4 |
| 17. How much choice do you have over what floor your place is on? | 0 | 1 | 2 | 3 | 4 |

RS

Now I'd like to ask you a few general questions about how satisfied you are with _____ and the surrounding neighborhood. Please turn to Card 5 and respond from 1 to 5 using the scale.

1 = Very Dissatisfied	2 = Slightly Dissatisfied	3 = Neither	4 = Fairly Satisfied	5 = Very Satisfied
------------------------------	----------------------------------	--------------------	-----------------------------	---------------------------

- | | | | | | |
|---|---|---|---|---|---|
| 1. How satisfied are you with this neighborhood as a place to live? | 1 | 2 | 3 | 4 | 5 |
| 2. How satisfied are you with _____ as a place to live? | 1 | 2 | 3 | 4 | 5 |
| 3. How satisfied do you think you would be if you could live independently in an apartment with all the supports that you need? | 1 | 2 | 3 | 4 | 5 |

(Take response cards back.)

AF

OK. Now I have a few questions about who has responsibility for taking care of certain things.

- Who handles and organizes your money? That is, who does things like write out checks, decide whether or not you can afford something?
 - _____ Manages own (own responsibility) (3)
 - _____ Gets some help in managing money (shared responsibility) (2)
 - _____ Someone else manages money (other's responsibility) (1)

- Who keeps the residence neat and clean? Does someone else help with the cleaning?
 - _____ Does own cleaning (own responsibility) (3)
 - _____ Gets some help in cleaning (shared responsibility) (2)
 - _____ Someone else does most of the cleaning (other's responsibility) (1)

- Who plans and prepares your meals?
 - _____ Does own (own responsibility) (3)
 - _____ Gets some help in meal planning and preparation (shared responsibility) (2)
 - _____ Someone else does most of the meal planning and

preparation (other’s responsibility) (1)

4. Who makes arrangements for appointments for your medical, dental, or psychological needs (i.e., visits to doctor, dentist, social worker, etc.)?

- _____ Does own (own responsibility) (3)
- _____ Gets some help with health care (shared responsibility) (2)
- _____ Someone else is responsible for most of the person’s health care (other’s responsibility) (1)

5. Who organizes your daily schedule for your involvement in community activities (i.e., education, work, social or day treatment programs, etc.)?

- _____ Organizes own schedule (own responsibility) (3)
- _____ Gets some help organizing schedule (shared responsibility) (2)
- _____ Someone else organizes schedule most of the time (other’s responsibility) (1)

6. Who plans and organizes the social and recreational activities in which you are involved?

- _____ Plans and organizes own (own responsibility) (3)
- _____ Gets help with planning and organizing social-recreational activities (shared responsibility) (2)
- _____ Someone else plans and organizes social and recreational activities most of the time (other’s responsibility) (1)

Now, here are a few questions about any medications you are taking.

7. Who is responsible for your medication?

- _____ Is completely responsible for obtaining prescription and taking own meds (own responsibility) (3)
- _____ Do you have help with someone getting your medication, getting your prescription refilled, and taking your medication (shared responsibility) (2)
- _____ Someone else gets the medication, takes the prescription to be refilled, and gives out the medication (other’s responsibility) (1)

8. What would you do if you ran out of medication? _____

ADLs

Now I have a couple of more questions. Some of these things I’m going to ask you about will probably seem pretty easy to do, but I need to ask everyone these questions.

ACTIVITIES
POINTS (1 OR 0)

INDEPENDENCE
(1 POINT)

DEPENDENCE
(0 POINTS)

NO supervision, direction, or personal **WITH** supervision, direction,

	assistance	personal assistance, or total care
TRANSFERRING POINTS: _____	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transferring aids are acceptable.	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
FEEDING POINTS: _____	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.
DRESSING POINTS: _____	(1 POINT) Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self to be completely dressed.
BATHING POINTS: _____	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area, or disabled extremity.	(0 POINTS) Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
TOILETING POINTS: _____	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
CONTINENCE POINTS: _____	(1 POINT) Exercises complete self control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder.

MMS

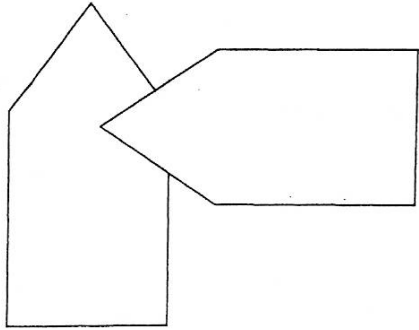
Now I am going to ask a few different kinds of questions. Some are easy and some harder. Just do your best.

Patient Score	Maximum Score	
_____	5	Orientation
_____	5	What is the – (year) (season) (date) (day) (month)?
_____	5	Where are we – (country) (state) (county) (city) (clinic)?
_____	3	Registration
_____	3	Name three objects, allotting one second to say each one. Then ask the patient to name all three objects after you have said them. Give one point for each correct answer. Repeat them until he hears all three. Count trials and record number.
		APPLE BOOK COAT Number of Trials
_____		_____
_____	5	Attention and Calculation
_____	5	Begin with 100 and count backward by 7 (stop after five answers) 93, 86, 79, 72, 65. Score one point for each correct answer. If the patient will not perform this task, ask the patient to spell “WORLD” backward (DLROW). Record the patient’s spelling: _____. Score one point for each correctly place letter.
_____	3	Recall
_____	3	Ask the patient to repeat the objects below. Give one point for each correct answer.
		APPLE BOOK COAT
_____	2	Language
_____	2	Naming: Show a pencil and a watch and ask the patient to name them.
_____	1	Repetition: Repeat the following: “No ifs, ands, or buts.”
_____	3	Three-Stage Command: Follow the three-stage command. “Take a paper on your right hand, fold it in half, and put it on the table.”
_____	1	Reading: Read and obey the following: “Close your eyes” (show the patient the item written on reverse side).
_____	1	Writing: Write a sentence (on reverse side). It must contain a subject and verb and make sense. Correct grammar and punctuation are not necessary.
_____	1	Copying: Copy the design of the intersecting pentagons (on reverse side). All 10 angles must be present and two must intersect to score 1 point. Tremor and rotation are ignored.
_____	30	Total Score Possible

CLOSE YOUR EYES

WRITE A SENTENCE

COPY DESIGN



BPRS

Directions: Circle the appropriate number to represent the level of severity of each symptom. Use the attached scoring guidelines.

	0 = Not Present	1 = Very Mild	2 = Mild	3 = Moderate	4 = Moderately Severe	5 = Severe	6 = Extremely Severe
1. Somatic concern – preoccupation with physical health, fear of physical illness, hypochondriases.	0	1	2	3	4	5	6
2. Anxiety – worry, fear, over-concern for present or future.	0	1	2	3	4	5	6
3. Emotional withdrawal – lack of spontaneous interaction, isolation, deficiency in relating to others.	0	1	2	3	4	5	6
4. Conceptual disorganization – thought process confused, disconnected, disorganized, disrupted.	0	1	2	3	4	5	6
5. Guilt feelings – self-blame, shame, remorse for past behavior.	0	1	2	3	4	5	6
6. Tension – physical and motor manifestations or nervousness, over activation, tension.	0	1	2	3	4	5	6
7. Mannerisms and posturing – peculiar, bizarre unnatural motor behavior (not including tic).	0	1	2	3	4	5	6
8. Grandiosity – exaggerated self-opinion, arrogance, conviction of unusual power or abilities.	0	1	2	3	4	5	6
9. Depressive mood – sorrow, sadness, despondency, pessimism.	0	1	2	3	4	5	6
10. Hostility – animosity, contempt, belligerence, disdain for others.	0	1	2	3	4	5	6
11. Suspiciousness – mistrust, belief that others harbor malicious or discriminatory intent.	0	1	2	3	4	5	6
12. Hallucinatory behavior – perceptions without normal external stimulus correspondence.	0	1	2	3	4	5	6
13. Motor retardation – slowed weakened movements or speech, reduced body tone.	0	1	2	3	4	5	6
14. Uncooperativeness – resistance, guardedness, rejection of authority.	0	1	2	3	4	5	6
15. Unusual thought content – unusual, odd, strange, bizarre thought content.	0	1	2	3	4	5	6
16. Blunted affect – reduced emotional tone, reduction in normal intensity of feeling, flatness.	0	1	2	3	4	5	6
17. Excitement – heightened emotional tone, agitation, increased reactivity.	0	1	2	3	4	5	6
18. Disorientation – confusion or lack of proper association for person.	0	1	2	3	4	5	6

RFS (Adapted as Skills for Independent Living Scale)

Self-Care Functioning <i>(management of household tasks, self care, safety)</i>	SC Score	Social Functioning <i>(relatedness, capacity to engage others, friendships, family, social networks)</i>	SF Score
Lacking independent living/self-care skills that threaten health and safety; 24- hour support needed	1	Severely isolated or withdrawn from others; extremely diminished capacity to engage others because of deviant or unusual behavior; extreme difficulty in establishing effective social relationships	1
Marked limitations in independent living/self-care skills; frequent and ongoing support needed	2	Marked isolation and withdrawal from others; diminished capacity to engage others because of deviant or unusual behavior; difficulty in establishing effective social relationships	2
Some independent living/self-care skills; some regular support needed	3	Limited interpersonally; limited range of successful and appropriate interactions with others; often no significant social relationships in the care setting or the community	3
Moderately self-sufficient with adequate independent living and self-care skills; minimal ongoing support needed	4	Adequate interpersonal relationships; moderate ability to engage others; moderately effective in establishing social relationships in the care setting or the community	4
Generally self-sufficient with good independent living and self-care skills; no ongoing support needed	5	Generally positive interpersonal relationships; generally effective in establishing social relationships in the care setting and the community	5

Appendix E

IMD Resident Medical Record Review Protocol

IMD: _____ Date: _____ Resident Code: _____

Gender: _____ Age: _____ Race/Ethnicity: _____ Current GAF: _____

Medications: _____

1. Is there a current treatment plan? Y N Date of Plan: _____

Frequency of treatment plan update? _____

Is this a single discipline care plan (ie. a nursing care plan) or a multi-disciplinary plan?

Note: _____

Documentation in the treatment plan that the patient was involved in its formulation? Y N

2. Does it specify a psychiatric diagnosis? Y N

Axis I: _____

Axis II: _____

Axis III: (below)

Axis IV: _____

Axis V: _____

Note: _____

3. Does it specify evidence of any current medical conditions? Y N

Note: _____

4. According to the treatment plan or medical documentation in the present chart, do the treatment requirements for the patient's medical condition(s) prevent the patient from being able to live independently with support? Y N

Condition	Treatment	Requires present placement Y N
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5. Does the treatment plan specify any concerns about risk to self or other?

Note: _____

6. Does the treatment plan specify the person's current functioning and why the person requires the present level of care? Y N

Note: _____

7. Is there a discharge plan? Y N What date is on the discharge plan? _____
Date discharge is anticipated? _____

8. Does the current treatment plan or the discharge plan specify a process leading to independent living with support? Y N

Note: _____

9. Does the current treatment plan or the discharge plan indicate the person's current preference for community living? Y N

Note: _____

10. Is there information in the treatment plan, discharge plan, or available medical record that provides the date of the person's last hospitalization? Y N

Date of most recent discharge? _____

Notes: