

**Community Capacity to Provide Mental/Behavioral Health Services
to People with Developmental Disabilities**

BY

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DISSERTATION

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LIST OF ABBREVIATIONS

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ANOVA	Analysis of Variance
APTD	Aid to the Permanently and Totally Disabled
ARRA	American Recovery and Reinvestment Act
ASD	Autism Spectrum Disorder
BCBA	Board Certified Behavioral Analyst
CART	Clinical Administrative Review Team
CFC	Community First Choice
CMHC	Community Mental Health Center
CMS	Centers for Medicare and Medicaid Services
CILA	Community Integrated Living Arrangement
CRIPA	Civil Rights of Institutionalized Persons Act
DD	Developmental Disabilities
DDD	Division of Developmental Disabilities
DHHS	Department of Health & Human Services
DHS	Department of Human Services (Illinois)
DHS/DDD	Department of Human Services/Division of Developmental Disabilities
DI	Deinstitutionalization
DMH	Division of Mental Health
DOJ	Department of Justice
DSP	Direct Support Professional

LIST OF ABBREVIATIONS (continued)

EG	Environmental Gerontology
EMS	Emergency Medical Services
ER	Emergency Room
FMAP	Federal Medical Assistance Percentage
FQHC	Federally Qualified Health Center
FY	Fiscal Year
GIS	Geographic Information Systems
GPS	Global Positioning System
HCBS	Home and Community Based Services
HFS	Health and Family Services
HRST	Health Risk Screening Tool
HRSA	Health Resources and Services Administration
HSRI	Human Services Research Institute
ICAP	Inventory for Client and Agency Planning
ICF/ID	Intermediate Care Facility for Intellectual Disabilities
ICF/MR	Intermediate Care Facility for people with Mental Retardation
ID	Intellectual Disability
IDD	Intellectual and/or Developmental Disabilities
ISSA	Individual Service and Support Advocacy
LCPC	Licensed Clinical Professional Counselor
LCSW	Licensed Clinical Social Worker
LEND	Leadership Education in Neurodevelopmental and related Disabilities

LIST OF ABBREVIATIONS (continued)

LMFT	Licensed Marriage and Family Therapist
LTSS	Long Term Services and Supports
MFP	Money Follows the Person
MHP	Mental Health Professional
MSA	Metropolitan Statistical Area
NAMI	National Alliance on Mental Illness
OIG	Office of Inspector General
OMB	Office of Management and Budget
PCP	Primary Care Physician
QIDP	Qualified Intellectual Disability Professional
RDI	Relationship Development Intervention
RHC	Rural Health Center
SODC	State Operated Developmental Center
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SST	Support Services Team
TA	Technical Assistance
UCEDD	University Center for Excellence in Developmental Disabilities
UIC	Urban Influence Code

ABSTRACT

The United States' long history of providing services to people with intellectual and/or developmental disabilities (IDD) in large public congregate settings has been in reversal over the past four decades. Since peaking in 1967 (U.S. Department of Health, Education and Welfare, 1972), census reduction of such facilities has occurred at an average annual rate of 5% nation-wide (Braddock et al., 2013). Despite having closed four state operated developmental centers (SODCs) since 1982, Illinois continues to be among states with the highest rates of institutionalization of persons with IDD in the country, although efforts are being made to change this through the Governor's Rebalancing Initiative. A longitudinal analysis of institutional depopulation in Illinois revealed that the majority of individuals who transitioned out of an SODC and were readmitted returned due to behavioral issues. The aim of this study, therefore, was to explore the capacity of community-based providers of residential supports and services, as well as the surrounding community, to provide behavioral and mental health services to individuals who transition out of an SODC. Results indicate a need for strengthening of the mental/behavioral health system available to adults with IDD in four ways: strengthen technical assistance and crisis response to behavioral issues; enhance the availability of community-based mental/behavioral health professionals through training; improve collaboration between state developmental disability and mental health agencies; and increase Medicaid reimbursement rates. Additionally, the need for continued investigation of environmental factors and community capital contributing to post-deinstitutionalization outcomes for people with IDD is implicated. Finally, the need for continued exploration of programs addressing challenges to community living

experienced by persons with IDD and behavioral concerns is highlighted. As the U.S. continues to move toward a lessened reliance on publically funded state-operated congregate settings, monitoring of outcomes of individuals who have transitioned to other settings and examining factors contributing to these outcomes is imperative.

I. INTRODUCTION

A. Background

The United States has had a long tradition of providing services to people with intellectual and/or developmental disabilities (IDD) in large public congregate settings. This tradition, however, according to contemporary data, has been in reversal. Since peaking in 1967 (U.S. Department of Health, Education and Welfare, 1972) census reduction of such facilities has occurred at an average annual rate of 5% nation-wide, resulting in the initiation of closure processes or completed closures of 168 public institutions in 42 states and the District of Columbia (Braddock et al., 2013). Data indicates that in 2011 there were 85% fewer persons living in such facilities as compared to the peak in 1967. Between 2009 and 2011, there was a 12% reduction overall in institutional census. Downsizing has not been concentrated in a few states; all but two states reduced public institutional census between 2009 and 2011 (Braddock et al., 2013).

In addition to census reductions, many states have ceased operations of publicly-funded congregate institutions altogether. By 2011, 13 jurisdictions had done so: Alabama, Alaska, the District of Columbia, Hawaii, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia. Conversely, 10 states (California, Illinois, Mississippi, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Texas, and Virginia) had an average daily institutional census in excess of 1,000 persons in 2011. These ten states provided 63% of the state-operated institutional services in the United States (Braddock et al., 2013).

Despite having closed four publicly-funded state operated developmental centers (SODCs) since 1982, Illinois continues to be in the company of states with the highest rates of institutionalization of persons with IDD in the country. By the end of FY2011, Illinois had eight SODCs, providing residential services to an average of 2,034 individuals daily, ranking in the top 12 jurisdictions nationally in utilization of publically-funded institutions (Braddock et al., 2013).

Although Illinois appears to rely heavily on state-operated publically funded institutions, efforts are being made to rebalance the system. The William A. Howe Developmental Center, a publicly funded and state-run Intermediate Care Facility for people with Intellectual Disabilities (ICF/ID), was decertified by the Illinois Department of Public Health and its Medicaid contract was terminated by the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS) in April of 2007, resulting from the identification of serious deficiencies by CMS surveyors. In December of 2007, Howe underwent an investigation by the U.S. Department of Justice (DOJ) which resulted in findings of deficiencies related to transition planning, protection from harm, health care, psychiatric care, behavioral treatments and habilitation, and integrated treatment planning (U.S. Department of Justice, 2009). On August 29, 2009, prior to the release of the DOJ report, Illinois Governor Pat Quinn announced the closure of Howe by the end of April 2010. At the time of announcement, Howe had 251 residents and 694 staff. Despite opposition by local community leaders, parents, and members of the employee union, Howe closed on June 21, 2010. It was the first SODC in Illinois to cease operations since the closure of Lincoln Developmental Center in 2004.

In October of 2011, Governor Pat Quinn announced a rebalancing initiative, which included his intent to close at least two SODCs and provide for transition to community-based services for a majority of these residents. The last resident moved out of Jacksonville Developmental Center in November of 2012. Currently, Illinois is in the process of closing Murray Developmental Center. A total of 459 residents are involved in the announced closures of Jacksonville and Warren G. Murray Developmental Centers. Murray Developmental Center was scheduled to close October 31, 2013, however litigation has kept it in operation.

B. Statement of the Problem

As Illinois slowly moves toward a lessened reliance on publically funded state-operated settings for individuals with IDD, monitoring of outcomes of individuals who have made the transition to other settings and examining factors contributing to these outcomes is imperative. Lulinski-Norris, Rizzolo, and Heller (2012a) have been involved in such an analysis of outcomes of individuals who have left SODCs in Illinois. In their 2012 research brief, the authors reported that 10% of the 1,594 individuals who transitioned out of an Illinois SODC between October of 2001 and June 30, 2009 returned to an SODC; of that group, 72% returned due to behavioral issues. They stated, "Similar to past studies (e.g., Beadle-Brown, 2007), the majority (75%) of the individuals in the present study that returned to an SODC from any setting after transition, did so due to behavioral reasons despite [the receiving setting] having received technical assistance" (Lulinski-Norris, Rizzolo, & Heller, 2012a, p. 46). When considering only individuals ($n = 983$) who transitioned to a community setting (for 15 persons or fewer) during that same time period, 11.2% ($n = 88$) returned to an SODC.

Of this group, 89% returned due to behavioral issues. Fifty-seven percent of the individuals who returned to an SODC did so without receiving technical assistance (supports offered to individuals transitioning out of an SODC that fall outside of the parameters of routine follow-up) (Lulinski-Norris, Rizzolo, & Heller, 2012a).

A study by the National Alliance on Mental Illness (NAMI) Illinois and the Supportive Housing Providers Association (2012), included interviews with community-based provider agencies focused on access to mental health services for individuals with dual diagnoses (having both an intellectual/developmental disability and psychiatric diagnosis). Among their conclusions, they indicated the need for applied behavior analysis and psychiatric services for this population. Specifically, they concluded that there is a need to “cultivate and train counselors, psychiatrists and psychologists for working with persons with cognitive deficits” (National Alliance on Mental Illness Illinois and the Supportive Housing Providers Association, 2012, p. 11).

Given the efforts currently being made in Illinois to rebalance its service delivery system away from institutional settings to those which are community-based, exploration of factors contributing to individual outcomes is necessary. Data from Lulinski-Norris, Rizzolo, and Heller (2012a) has shown that for some individuals, existing community-based services and supports are insufficient. The NAMI Illinois and the Supportive Housing Providers Association Report (2012) have demonstrated a need for psychiatric and behavioral services for individuals who have dual diagnosis and live in the community. The aim of the proposed study, therefore, is to explore the capacity of community-based providers of residential supports and services, as well as the surrounding community, to provide behavioral and mental health services to individuals

who transition out of an SODC and have a dual diagnosis. The intent is to identify service gaps and inform public policy discourse at the state level as Illinois makes strides to decrease its reliance on institutionalized service systems.

II. A REVIEW OF LONG-TERM SERVICES AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES IN THE UNITED STATES

Provision of long-term services and supports (LTSS) for individuals with intellectual and/or developmental disabilities (IDD) have undergone a significant metamorphosis since the utilization of almshouses during the U.S. colonial era. The ‘training schools’ of the mid-19th century were the first formal residential service settings, however, the structure and purpose of these facilities has changed. This chapter will review the development of LTSS for individuals with IDD in the United States from the rise of institutions during the 19th century to the passage of the 2010 Affordable Care Act that impacts the lives of people with disabilities and their families. Additionally, the LTSS landscape in Illinois will be discussed with special attention to current efforts to rebalance Illinois’ system of residential supports.

A. The Rise of Institutions

During America’s colonial period, while there were no formalized systems of support for people with disabilities, the Protestant Church and Britain’s Elizabethan Poor Laws had considerable influence on the attitudes toward the poor, which included various groups such as widows, orphans, and the disabled. The Church viewed the circumstances of the poor as being due to Providence, or God’s will, which provided Christians the opportunity to do good acts. The colonists, however, did not provide relief without prejudice in terms of those individuals who were deemed ‘deserving’ and those deemed ‘undeserving’. Widows, the elderly, orphans, the disabled, and the sick were regarded as being in their particular situations as determined by God and through

no fault of their own, and were thus considered “deserving poor.” The “idle,” or those choosing not to work and that were seemingly of sound body and mind, were not provided the same type of relief, particularly those whom were ‘outsiders,’ or not of the community. Such ‘vagabonds’ were not welcome into such close-knit communities and it followed that settlement laws were established to preclude receipt of relief based upon residency. In fact, beggars were sent back from whence they came in an effort to avoid providing unwarranted assistance (Rothman, 1990).

In dense population centers, such as Boston and New York, poor relief around the turn of the 18th century became very expensive for the local economies. In an effort to lessen the economic impact of the care of the needy in these urban communities, almshouses were constructed. Initially almshouses were typically family-style homes in which the owner lived alongside their needy inhabitants, usually widows and their children, and had meals together. Over time, however, the purpose of these institutions turned to that of custodial care, providing only basics such as food and shelter, for the poor. By the end of the colonial era, almshouses had become crude hospitals where the sick, elderly, disabled, and those with mental illness were properly ‘managed’ by physicians, experimented upon to find cures, and used to educate medical professionals (Rothman, 1990).

Persons with disabilities were mainly cared for by family members until the 1800’s. Over time, however, almshouses came to fill the role of caregiver for those without families to rely on or those too sick and burdensome to be cared for by a neighbor. Those individuals considered to be ‘unmanageable,’ such as persons that would be considered in contemporary society as having acute mental illness, were

housed in the cellars of almshouses or in shacks within city limits (Rothman, 1990). Care for the ill was merely a consequence of such provisions, as inevitably a resident would become ill and require infirmary care (Shi & Singh, 2004). In fact, most of the inhabitants of the early almshouses were individuals with chronic illness or disabilities. By 1800, the urban almshouse was considered "... a home for hopeless causes," (Ferguson, 2004, p. 47), and by the mid-19th century, almshouses became a common treatment for the indigent.

Over time, newly constructed municipal hospitals became de facto almshouses. The Industrial Revolution and wartime economy during the early 19th century led to increased internal migration and subsequent urbanization as Americans were increasingly relocated away from such community provision of care. As a result, many had to seek medical treatment at local hospitals (Engel, 2006). In urban areas, few non-secular or municipal hospitals provided medical treatment for the poor. Barely more than almshouses, they offered little actual medical treatment as few remedies were available (Field, 2007). Hospitals with religious affiliations, initially funded by philanthropy and generally having cultural ties (which, at the time, were more important than a patient's ability to pay), provided free care to those within their religious, ethnic, cultural, and/or geographic communities, provided the patient was of the 'deserving poor.' Persons deemed to be 'undeserving poor,' such as "...the drunkard and the sloth..." (Engel, 2006, p. 9), were sent to the municipal hospitals for treatment. Municipal hospitals, funded by local and state taxes, were considered a mechanism by which to maintain public order by removing vagrants and other such 'undesirables' from the city streets (Engel, 2006).

As a result of urbanization, and to take advantage of employed patients with the money to pay for treatment, non-municipal hospitals created private and semi-private rooms as an alternative to the open wards for the poor in hopes of attracting the “moneyed sick” and thus offsetting operational costs (Engel, 2006). The charity care model of earlier hospitals began to dissolve and the idea of treatment for the worthy poor began to fade, as “...now there were simply those who could pay, and those who couldn’t” (Engel, 2006, p. 13).

Hospital stays of the able-bodied were temporary, as compared to the elderly and the disabled who became long-term residents. This arrangement continued until the rise of ‘special’ schools for ‘the feeble-minded,’ asylums for the ‘insane,’ and orphanages, leaving the ‘hospitals’ to the elderly. By the middle of the 19th century, based on success in Europe, experimental private pay schools for ‘idiots’ (*sic*) began to open on the East Coast of the United States. The aim of such schools was to prepare children with disabilities to live and work in society, thus freeing their families from the burden of their care (Trent, 1994). Other schools opened in Ohio, New York, Illinois, and Pennsylvania (Braddock & Parish, 2000) with the intent to demonstrate that “[i]diots were able to learn and most educated idiots were able to become productive citizens” (Trent, 1994, p. 23). The Post Civil War depression, however, made it difficult for graduating students to obtain employment as intended, and many found their way back into almshouses, asylums, or jails. In reaction, schools changed their focus from training students to supervising ‘inmates’ (Braddock & Parish, 2000).

Despite this departure from the original intent of the special schools, construction continued. Admission of private pay pupils decreased, while publicly supported charity

admissions soared. Additionally, more and more families chose to institutionalize their relatives with IDD during the Great Depression as unemployment and poverty made it increasingly difficult for families to provide care (Braddock & Parish, 2000).

B. **The Evolution of Community-Based Approaches to the Provision of Supports and Services**

1. **Social Security and Medicaid**

The Great Depression took its toll on many Americans, and in 1935 in reaction to insistence by unemployed workers for economic relief, the Roosevelt administration created the Social Security Act (SSA) in 1935 (Clarke & Fox-Piven, 2001). Initially SSA was intended to provide assistance to the unemployed and retired; however, it was extended to widows and their dependents as well as the sick and disabled in later amendments. Social Security benefits were accumulated by employment, but the original Act provided benefits to only about 40% of the workforce (Karger & Stoesz, 2006), leaving out domestic and agricultural workers who were mostly women, African-Americans (Clarke & Fox-Piven, 2001) and no doubt, people with disabilities.

In 1950, amendments to the Social Security Act added Aid to the Permanently and Totally Disabled (APTD) which provided benefits to those unable to work due to old age, blindness, or chronic disability. This was the first time that people with disabilities under the age of 65 were eligible for federal assistance. Until the addition of APTD as a benefit to Social Security, people with disabilities relied on state and local program benefits. In 1956, the Social Security Act was amended to add Social Security Disability Insurance (SSDI). SSDI allows disabled children of retired, disabled or a deceased

parent to collect Social Security benefits provided that parent was eligible for such benefits. This particular provision allowed for the transfer of earned Social Security benefits from parent to adult child (Braddock, 1987).

The Forand Bill, introduced in 1957 (Shi & Singh, 2004), took advantage of the popularity of the Social Security program, and offered an additional 60 days of hospitalization/nursing home care coverage for all Americans 65 and older (Engel, 2006; Grogan, 2006). Opposed by the American Medical Association due to fear of threat to the patient-physician relationship (Shi & Singh, 2004) as well as concerns over creating socialist style medicine in an era of anticommunist sentiment, the bill was defeated in both 1957 and 1959 (Engel, 2006). As an alternative to the defeated bill, Senator Robert Kerr (D-OK) and Representative Wilbur Mills (D-AR) proposed a bill addressing the medically indigent elderly (Engel, 2006; Grogan, 2006). To be considered medically indigent made one 'deserving poor' and therefore in need of assistance due to the high costs of medical care in proportion to one's income (Grogan, 2006).

The Kerr-Mills bill, passed in 1960, established matching federal grants to states (based on state wealth) and used means-testing as an eligibility guideline. The precursor to the Medicaid program, it covered hospital and physician costs with eligibility varying from state to state (Engel, 2006). Though the Kerr-Mills bill was not viewed as successful because it was not implemented in many states, it was a top priority for President Linden B. Johnson's Administration leading to the enactment of Medicaid in 1965 (Shi & Singh, 2004).

Amendments to the Social Security Act in 1965 created Medicaid through Title XIX. Medicaid is a voluntary, open-ended, federal-state entitlement program that "...provides a legal right to services for individuals who are eligible because of their age, income, disability, or medical need" (Hemp & Braddock, 2003, p. 2), providing a reimbursement match for state funding from the federal government (Braddock, 2002). Within the first year of its passage, 19 states had created Medicaid programs (Engel, 2006). The overall significance of The Social Security Amendments of 1965 is very succinctly summed up by Relman (2007):

This legislation resulted in sudden, major expansion of health insurance, covering in particular those citizens who had been least able to pay for their care and therefore were most dependent on the charity of physicians and private community hospitals. Overnight, the federal government became the largest single insurer of health care and relieved physicians and hospitals of the burden of treating many patients who previously could not pay their bills. (p. 24)

There are a myriad of programs offered under the umbrella of Medicaid which vary from state to state. Each state has the authority to determine the type, amount, duration, and scope of services through its Medicaid program (Centers for Medicare and Medicaid Services, 2007), however, Federal Medicaid law mandates that specific services are covered. Table I, reproduced from Lulinski Norris (2008), provides a summary of each of the required and optional categories.

Medicaid is the nation's largest program serving the needs of low-income Americans with disabilities (Crowley & Elias, 2003). Since its inception, Medicaid has grown into a three-pronged program, providing health care insurance for low-income Americans, a long-term care program for the elderly, as well as a specialized service and long-term care program for people with disabilities (Hemp & Braddock, 2003).

TABLE I
MANDATORY AND OPTIONAL MEDICAID SERVICES

<u>Health Care</u>	
<u>Mandatory Services</u>	<u>Optional Services</u>
Physician services	Medical or remedial care provided by state licensed practitioners
Laboratory and x-ray services	Prescription drugs
In/outpatient hospital services	Diagnostic, screening, preventative, and rehabilitative services
Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) for individuals <21	Primary care case management services
Family planning services and supplies	Dental services
Health center services	Physical therapy and related services
Rural health clinic services	Prosthetics and eyeglasses
Nurse midwife services	TB related services
Vaccinations for children	Transportation services
Certified pediatric and family nurse practitioner services	Targeted case management services
<u>Long Term Care</u>	
<u>Mandatory Services</u>	<u>Optional Services</u>
Skilled Nursing facility (SNF) services for people >21	Inpatient hospital and NF services for individuals 65+ in an Institute for Mental Disease (IMD)
Home health care services for those entitled to nursing facility services	ICF/ID services
	Inpatient psychiatric hospital services for individuals 21+
	Home health care
	Case management
	Respiratory Care services for ventilator-dependent
	Personal care services
	Private duty nursing
	Hospice
	Services under Program of All-Inclusive Care for the Elderly (PACE)
	HCBS Waiver

Sources: Braddock, Hemp, & Rizzolo, 2003; Centers for Medicare and Medicaid Services, 2007

Eligibility for Medicaid falls into two broad categories based on a mixture of financial and group membership standards (Illinois Department of Healthcare and Family Services, 2014). As a federal condition of participation in the Medicaid program, three basic groups of low-income Americans are covered: those 65 and older, those with disabilities, and children and some parents based on varying financial criteria (Crowley & Elias, 2003). Additional requirements for persons with disabilities include residence in a nursing home, or eligibility for nursing home services, as well as limited income and resources (Centers for Medicare and Medicaid Services, 2014a). Additional eligibility requirements may vary from state to state.

Two core Medicaid programs for persons with IDD are the Intermediate Care Facilities for persons with Mental Retardation¹ Program (ICF/MR) and the Home and Community Based Services (HCBS) Waiver. A critical feature of both is Title XIX's provision of federal matching funds as a reimbursement to states for costs incurred from payment to providers for the delivery of covered services to eligible persons. Prior to this matching provision, initiated in 1971, states predominantly used local funds to finance services for individuals with disabilities as the federal government did not have a long-term care program for people with IDD (Prouty, Smith, & Lakin, 2007; U.S. Department of Health and Human Services, 2000). The amount of federal match received by each state is based upon that state's Federal Medical Assistance Percentage (FMAP) which is derived from per capita personal income in that state (Braddock et al., 2005).

¹ The term "mental retardation" remains in use in the statute, however, in keeping with modern language the term "mental retardation" will be replaced with "intellectual disability" throughout this paper.

2. **Intermediate care facilities for people with intellectual disabilities program**

The Intermediate Care Facilities for persons with Intellectual Disabilities (ICF/ID) program option (called Intermediate Care Facilities for persons with Mental Retardation at the time) was added to the Medicaid program in 1971 by Section 1905(d) of the Social Security Act (Centers for Medicare and Medicaid Services, 2006). Under this option, receipt of federal funds is contingent upon adherence to eight conditions of participation: 1) facility regulations with regard to governing body and management, 2) client protections, 3) facility staffing, 4) active treatment, 5) client behavior and facility practices, 6) health care services, 7) physical environment, and 8) dietetic services (Requirements for States and Long Term Care Facilities, 1988). Within the eight conditions of participation, there are 49 standards outlining the specifics of the service delivery. These standards are pivotal in the history of 24-hour residential facilities in that for the first time, regulations with regard to rights, quality of life, and medical care were enacted. The need for this type of regulation was made abundantly clear the previous year in the 1972 *Wyatt v. Stickney* lawsuit.

ICF/ID spending peaked at \$17.1 billion in 1993; three-fourths of which went to settings for 16 or more individuals. Since 1994, ICF/ID spending has declined as utilization of the Home and Community Based Services Waiver increased; ICF/ID spending accounted for \$12.6 billion in 2011 (Braddock et al., 2013). Larson, Salmi, Smith, Anderson, and Hewitt (2013) reported that 87,754 individuals were living in an ICF/ID in 2011, a slight increase from 87,560 in 2010.

3. **Home and community based services waiver program**

Following the creation of the ICF/ID program, the rising cost of skilled nursing care and accusations of Medicaid bias toward institutions caused states to examine other service delivery methods (U.S. Department of Health and Human Services, 2000). In response, Congress authorized the Home and Community Based Services (HCBS) Waiver in 1981 as an alternative to the ICF/ID program (Braddock et al., 2005). Under the HCBS Waiver, three main provisions of the Social Security Act were 'waived,' thus allowing services to be delivered in community-based settings (DHHS, 2000). The three waived provisions are: 1) 'statewideness,' requiring the program to be offered state-wide and therefore allowing states to target waiver programs in particular areas; 2) comparability of services, which requires availability of services for all Medicaid eligible persons therefore allowing states to make waiver services available to those at risk of being institutionalized; and 3) income and resource rules allowing states to provide Medicaid services to those who would otherwise be eligible for an institutional setting (Centers for Medicare and Medicaid Services, 2008).

Services covered under the HCBS Waiver include: case management (i.e., service coordination), personal assistance (i.e., homemaker, home health aide, and personal care attendant), adult day health services, habilitation (both day and residential), and respite care. Additionally, states can propose "other" types of services that may assist in maintaining individuals in their community homes and rather than divert them to institutional settings (CMS, 2014). For inclusion in the HCBS waiver program, the state must assure the following: 1) waiver services cost less, on average, than institutional care; 2) protection of the health and welfare of individuals served;

3) standards meet the needs of the population served; and 4) services are provided in accordance with a plan of care (Centers for Medicare and Medicaid Services, 2008).

While the Centers for Medicare and Medicaid Services (CMS) is the federal agency responsible for Medicaid oversight, HCBS Waivers are administered by the state in which they are housed, and thus allow states flexibility in the management of them. The Secretary of the U.S. Department of Health and Human Services has the legal authority to waive these Medicaid requirements and approve state waiver program applications (Crowley & Elias, 2003).

Each state is required by federal law to designate a single state Medicaid agency to provide oversight of its Medicaid activities (Kaiser Commission on Medicaid and the Uninsured, 2013). That single state Medicaid agency has the option of overseeing Medicaid programs itself, and/or entering into agreements with other state agencies to administer specific services. Participating states must submit an application for approval of each waiver program to CMS and renew as required (CMS, 2008). In 2014, there were 459 waiver programs available for persons with HIV/AIDS, traumatic brain injury, cystic fibrosis, mental illness, Alzheimer's disease, physical disabilities, persons that are technologically dependent, as well as persons with intellectual and/or developmental disabilities among others (CMS, 2014b). There is no limit on the number of waiver programs or services provided by a state, and states have the choice of the number of individuals they intend to serve in their HCBS Waivers. As such, state Medicaid programs vary greatly from state to state.

The provision of the HCBS Waiver allows states to provide persons with disabilities the option of receiving community-integrated services rather than segregated

institutional care. The number of Waiver programs available as well as the scope of and spending on such programs indicate a trend toward provision of services in the community. In fact, since the early 1980's, amendments to federal laws and policies have been chipping away at Medicaid's institutional bias and making way for funding options for home and community based long-term care alternatives. The HCBS Waiver "...has been an essential part of community services expansion in the states..." (Braddock et al., 2005, p. 28). Incorporation of the federal match under the Medicaid program has allowed states to offer an array of Medicaid funded community-based services to individuals with IDD who would otherwise require institutional admission to skilled nursing, intermediate, or ICF/ID facilities.

C. **System Rebalancing**

Since peaking in 1967 (U.S. Department of Health, Education, and Welfare, 1972) census reduction of institutions has occurred at an average rate of 5% nationwide annually, resulting in the closure or in process closure of 168 public institutions in 42 states. There were still, however, 84,433 individuals living in institutional settings in the U.S. in 2011 (Braddock et al., 2013). Much of the rebalancing completed in the U.S. has been the result of advocacy, class action litigation, including *Olmstead* cases, waiting list cases, and access to Medicaid benefits cases (Braddock et al., 2013).

1. **Litigation**

The *Olmstead* Decision of 1999 was issued by the United States Supreme Court (*Olmstead v. L.C.*, 1999) in response to a lawsuit brought by Lois Curtis and Elaine Wilson in 1995 (Bazelon Center for Mental Health Law, 2009). Both women had a dual diagnosis (developmental disability and mental illness) and were voluntarily

admitted to Georgia Regional Hospital's psychiatric unit (*Olmstead*, 1999). After receiving clearance from treating professionals, neither woman was granted their desired community placement (Bazelon, 2009). The court rejected the state's claim of inadequate funding for community placement and ruled this was a violation of the women's rights under Title II of the Americans with Disabilities Act (ADA) of 1990 (*Olmstead*, 1999). Title II states, "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" [28 CFR § 35.130(d)]. *Olmstead* found states are to comply with Title II of the ADA in order to avoid discriminatory practices of institutionalization when community-based alternatives would be an appropriate setting (Ng, Wong, & Harrington, 2012).

Olmstead has had a significant impact on litigation related to institutionalization. As of May of 2013, Ng, Wong, and Harrington (2013) reported a total of 193 *Olmstead*-related cases in all but five states (Iowa, Idaho, North Dakota, South Dakota, and Vermont) and the District of Columbia. Despite the number of lawsuits, progress on moving people from segregated institutions into community based living situations has been slow. The Civil Rights Division of the U.S. Department of Justice (DOJ) has the authority to enforce Title II of the ADA (National Disability Rights Network, 2009). On June 22, 2010, then Assistant Attorney General Thomas E. Perez testified before the Senate Committee on Health, Education, Labor and Pensions on the role of the DOJ in relation to Title II of the ADA and the *Olmstead* decision. He stated that the Disability Rights Section of the Civil Rights Division of the DOJ had made the enforcement of *Olmstead* a "top priority." This reprioritization signaled what Assistant Attorney General

Perez called a “paradigm shift” from previous work done primarily under the authority of Civil Rights of Institutionalized Persons Act of 1997 (CRIPA). Under CRIPA authority, the DOJ primarily focuses on the safety of institutions and the protection of Constitutional rights of the persons living in them. Under the renewed focus of *Olmstead* enforcement, the DOJ will be questioning the appropriateness of institutional as compared to community-based settings (DOJ, 2010). In fact, Assistant Attorney General Perez stated that “... the *Olmstead* decision makes it clear that states have an obligation to provide services to individuals with disabilities in the most integrated setting appropriate to their needs” and that the DOJ is “...committed to aggressive enforcement of *Olmstead*” (DOJ, 2010).

2. **Policy**

Money Follows the Person (MFP) was first authorized by the Deficit Reduction Act of 2005 with the intent to provide states with assistance in balancing long term services and supports (LTSS) spending with HCBS waiver spending by assisting Medicaid recipients with the transition to communities from institutions (CMS, 2014). Federal MFP funds were not to exceed \$1.75 billion through fiscal year 2011, however were extended through the Patient Protection and Affordable Care Act of 2010. The extension included \$2.25 billion from fiscal year 2012 through 2016. As of December 2012, nearly 30,000 individuals (15% with IDD in 2012) were enrolled in MFP and had received assistance to transition to a community placement from an institutional setting (Mathematica Policy Research, 2013). MFP is significant in that it acknowledges the institutional bias of Medicaid and allows for money that was intended to be spent on institutional services to ‘follow’ the person into a community-based option. In addition, it

allows for assistance with the costs associated with an individual's transition to a community-based setting.

The American Recovery and Reinvestment Act of 2009 (ARRA), signed into law in February of 2009, provided an economic stimulus including a temporary increase in state FMAPs to provide relief from increased medical expenditures during the recessionary period (Association of University Centers on Disabilities, 2010a). The FMAP increase was retroactively effective October 1, 2008 and intended to last for nine quarters, ending December 31, 2010. In August of 2010, due to the continued economic recession, however, the FMAP increase was extended an additional six months through June of 2011 (AUCD, 2010a). The increased FMAP extension was critical to Medicaid service provision, particularly during the Great Recession, as Medicaid utilization has an inverse relationship with the economy. The Great Recession, which occurred in 2007-2009, saw an increase in unemployment and an increase in Medicaid beneficiaries coupled by a decrease in state revenues (Holahan & Chen, 2011) which created a gap between revenues and spending (Kaiser Commission on Medicaid and the Uninsured, 2011).

The Patient Protection and Affordable Care Act of 2010, which was signed into law on March 23, 2010 by President Obama, contains provisions which will provide individuals with disabilities opportunities for community-based living (AUCD, 2010b). One provision in particular, the Community First Choice Option (CFC), should have a significant impact on people with IDD. The CFC is available to states as a waiver option, however, participation in the program requires that home and community-based attendant services and supports are made available to all eligible individuals for

assistance with activities of daily living. In addition, states participating in this option are not allowed to cap the number of people served or maintain waiting lists for services. All eligible persons, those individuals that would otherwise require an institutional level of care and meet income requirements, must receive benefits under this option should they require them. States are not mandated to provide this option, however, an additional 6% will be added to the FMAP of states that have an approved plan (AUCD, 2010b; Caldwell, 2010). As of 2013, eight states were offering this option (Kaiser Family Foundation, 2014).

The CFC is significant for people with IDD in that it allows states greater flexibility in their Medicaid Waiver programs (Caldwell, 2010) and provides a more comprehensive home and community-based program (AUCD, 2010b). It is also expected that the CFC will support *Olmstead* implementation by offering services in the least restrictive setting appropriate to an individual's needs. Finally, due to the restriction on waiting lists and limits on the numbers of individuals served, it is hoped that more people with IDD will be removed from waiting lists and receive the services necessary to lead to a fulfilling and integrated life in the community.

D. **Illinois Intellectual/Developmental Disability Residential Service Landscape**

1. **Intermediate care facilities for people with intellectual disabilities**

Illinois relies heavily on large ICF/ID settings for the provision of residential services. In 2011, Illinois had 301 public and privately operated ICF/IDs in operation serving 8,460 individuals. Included in this number were the eight publicly funded state operated developmental centers (SODCs) which provided residential services to an average of 2,034 individuals daily in 2011 at an average annual cost of \$195,949

(Braddock et al., 2013). Thirty-nine percent of all users of IDD residential services in Illinois lived in an ICF/ID setting in 2011; of which 23% lived in settings for sixteen or more people (Larson et al., 2013).

Despite having closed five publically-funded state operated developmental centers (SODCs) since 1982, Illinois continues to be in the company of states with the highest rates of institutionalization of persons with IDD in the country. By the end of FY2012, Illinois had eight SODCs, providing residential services to 1,965 individuals (Illinois Department of Human Services, 2012), ranking in the top 12 jurisdictions nationally in utilization of publically-funded institutions (Braddock et al., 2013).

E. **Home and Community-Based Services Waiver Programs in Illinois**

In the state of Illinois, Medicaid services are primarily overseen by the Department of Healthcare and Family Services, or HFS (Illinois Department of Healthcare and Family Services, 2014). HFS has an agreement with three principal state agencies responsible for program administration – Department of Human Services, Department of Children and Family Services, and Department on Aging. These agencies accept program applications and make eligibility determinations for their respective programs (Illinois Legal Aid, 2006). Illinois currently offers nine HCBS Waivers (Illinois Department of Healthcare and Family Services, 2014). They are: 1) Children that are Technology Dependant/Medically Fragile, 2) Persons with Disabilities, 3) Persons with Brain Injury, 4) Adults with Developmental Disabilities, 5) Persons who are Elderly, 6) Persons with HIV or AIDS, 7) Supportive Living Facilities, 8) Children and Young Adults with Developmental Disabilities - Support Waiver, and 9) Children and Young Adults with Developmental Disabilities - Residential Waiver.

1. **Services and supports offered under the Illinois Adults with Developmental Disabilities Waiver**

Illinois offers the following program options under its HCBS Waiver for Adults with Developmental Disabilities: residential rehabilitation (24-hour or less than 24-hour), day habilitation, expanded rehabilitation services, supported employment, adult day care, personal support, home accessibility modifications, vehicle modifications, non-medical transportation, adaptive equipment, assistive technology, emergency home response services, training and counseling services for unpaid care givers, skilled nursing, physical therapy, occupational therapy and speech therapy, behavior intervention and treatment, behavioral services (psychotherapy and counseling), and crisis services (State of Illinois, 2012).

Behavior intervention and treatment, provided by behavioral consultants, are comprised of “a variety of individualized, behaviorally based treatment models consistent with best practice and research on effectiveness that are directly related to the participant’s therapeutic goals. Interventions include, but are not limited to: Applied Behavior Analysis, Relationship Development Intervention (RDI), and Floor Time. These services are designed to assist participants to develop or enhance skills with social value, lessen behavioral excesses and improve communication skills” (CMS, 2008, p. 19). A maximum of 66 hours of behavior intervention and treatment services are provided under the Waiver per person per fiscal year (State of Illinois, 20012). Behavioral services (e.g., psychotherapy and counseling) include psychotherapy and counseling. “Psychotherapy is a treatment approach that focuses on a goal of ameliorating or reducing the symptoms of emotional, cognitive or behavioral disorder

and promoting positive emotional, cognitive and behavioral development. Counseling is a treatment approach that uses relationship skills to promote the participant's abilities to deal with daily living issues associated with their cognitive or behavioral problems using a variety of supportive and re-educative techniques" (CMS, 2008, p. 21). Behavioral services are capped at 60 hours per person per state fiscal year (State of Illinois, 2012).

F. **System Rebalancing in Illinois**

For years, advocates in Illinois have been pressing for system rebalancing as both a safety and cost issue. The William A. Howe Developmental Center, a publically-funded and state-run ICF/ID, was decertified by the Illinois Department of Public Health and its Medicaid contract was terminated by the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS) in April of 2007, resulting from the identification of serious deficiencies by CMS surveyors. In December of 2007, Howe underwent an investigation by the U.S. Department of Justice (DOJ) which resulted in findings of deficiencies related to transition planning, protection from harm, health care, psychiatric care, behavioral treatments and habilitation, and integrated treatment planning (Department of Justice, 2009). On August 29, 2009, prior to the release of the DOJ report, Governor Pat Quinn announced the closure of Howe by the end of April 2010. At the time of announcement, Howe had 251 residents and 694 staff. Despite opposition by local community leaders, many parents, and members of the employee union, Howe closed on June 21, 2010. It was the first SODC in Illinois to cease operations since the closure of Lincoln Developmental Center in 2004.

In October of 2011, Governor Pat Quinn announced a rebalancing initiative, which included his intent to transition at least 600 individuals to community-based

settings and the proposed closure of at least two SODCs (Office of the Governor, 2011). A total of 181 residents were involved in the closure of Jacksonville Developmental Center and an additional 278 currently reside at Warren G. Murray Developmental Centers (Office of the Governor, 2012). Jacksonville Developmental Center relocated 181 individuals and closed in November of 2012 (State of Illinois, 2012). Murray Developmental Center had a closure date of November 30, 2013 (Office of the Governor, 2012), however, has not yet done so due to a pending court case (Lester, 2013).

In addition to concerns over human rights and safety concerns in Illinois SODCs, parallel arguments have been made urging rebalancing measures as a means to more equitable allocation of resources. On average, it costs the State of Illinois \$196,000 per person annually to provide services in an SODC (Braddock et al, 2013), while the average cost for 24-hour community-based waiver services (not including day habilitation) was \$40,343 in FY2009 (Nelis, Rizzolo, & Hemp, 2011). As a rough measure of (in)equity, consider this: the average costs associated with the provision of care to one individual in an SODC could provide supports to up to five individuals in the community. Given there were 21,807 unduplicated individuals on the waiting list for services in March of 2014, nearly one-third ($n = 7,030$) of whom are in need of 24-hour residential services (Illinois Department of Human Services, 2014b), this disparity demands attention.

This chapter has reviewed the history of LTSS for individuals with IDD in the United States, highlighting the impact of Social Security and Medicaid policies. The ICF/ID and Home and Community Based Services Waiver programs were explored,

stressing the importance of these policies on deinstitutionalization; that is transitioning people from large institutional settings into smaller community-based home-like ones amongst their neighbors. The next chapter will summarize research on individual outcomes after such moves as well as survey the literature related to how environmental variables impact an individual's relocation outcomes.

III. REVIEW OF DEINSTITUTIONALIZATION RESEARCH

Numerous studies have been completed over the past three decades examining deinstitutionalization (DI) outcomes for individuals with IDD. Through this body of research, it has been well-established that moving from institutional settings and into smaller community-based ones lead to better outcomes for people with IDD (Kim, Larson, & Lakin, 1999; Larson & Lakin, 1989, 2012). The following chapter will highlight findings of studies examining post-deinstitutionalization outcomes, focusing first on individual factors and outcomes including mortality and placement breakdown and then on environmental factors impacting post-deinstitutionalization outcomes.

A. **Individual Outcomes as a Result of Deinstitutionalization**

For decades, research teams have explored changes in individual behaviors as a result of deinstitutionalization in an effort to quantify the impact of DI. Such variables have included academic skills, challenging behaviors, community living skills, domestic skills, language and communication skills, leisure/recreational skills, maladaptive behaviors, mobility, mortality, motor/ physical skills, receipt of mental health services, self-care, sensorimotor ability, social skills, toileting ability, visual processing, and vocational skills. This section will explore the use of individual characteristics as variables in DI research.

To determine categorical changes in adaptive behaviors of persons with IDD associated with moves from institutions to community-based settings, Larson and Lakin (1989) performed a review of literature from 1976 – 1988 examining changes in adaptive behavior associated with moves from institutions to communities between. Comparison studies between individuals moving into the community and those

remaining in the institution indicated significant increases in adaptive behaviors for community individuals as compared to their counterparts, although significant changes in challenging behaviors were not found. Longitudinal studies also indicated increased adaptive behaviors; however, results regarding challenging behaviors varied. The authors concluded that there is overwhelming evidence that individuals moving from institutions to community based settings display an increase in adaptive behavior as compared to their institutionalized counterparts. Larson and Lakin also offer explanations for the variance in challenging behaviors: 1) environmental variations across community settings may be influential; 2) expectation regarding and interpretation of challenging behaviors may vary from institutional to community based setting; 3) the act of moving may stimulate challenging behavior; or 4) assessment tools may not be sensitive to all variables and behaviors. The authors conclude that size is a reliable proxy for environmental characteristics, all the more important because of its policy influence.

In a follow-up study, Kim, Larson, and Lakin (1999) again conducted a literature review of deinstitutionalization studies published between 1980 and 1999. Outcomes were categorized into either changes in adaptive or challenging behaviors. Adaptive behaviors included: overall, academic skills, community living skills, language and communication skills, motor/ physical skills, leisure/recreational skills, self care/domestic skills, social skills, and vocational skills. Challenging behaviors were categorized as overall, frequency, severity, external (e.g., property destruction, physical aggression toward others), internal (e.g., self-injurious behaviors), and social.

The studies reviewed included both cross-sectional comparison group studies and longitudinal ones that examined changes over time. The 14 comparison group studies in this review compared data of those who moved out of the institution (“movers”) versus those who did not (“stayers”). Only one of the studies failed to show an improvement in adaptive behaviors. Of those that did indicate an improvement, seven were statistically significant. Only one study reported a significant difference between movers and stayers and in this case showed a significant decline in challenging behaviors amongst stayers. With regard to specific domains of adaptive behavior, self-care/domestic skills were consistently determined to have a significant difference between stayers and movers. Other domains in which there was a significant difference were: academic skills, community living skills, language/communication skills, social skills, and vocational skills. With respect to challenging behaviors, findings are inconsistent between movers and stayers. In two studies, however, externalized behaviors significantly declined for movers.

Of the 19 longitudinal studies included, 13 reported significant improvements in adaptive behaviors for movers. Social skills, community living skills, and motor/physical skills also showed consistent significant improvement for movers. Findings for challenging behaviors, however, were inconsistent as five demonstrated a significant decline in these behaviors while two indicated an increase.

Overall, the authors concluded that studies continue to show that people benefit from moving to the community from an institution. In addition, the authors observed that the studies published in the 1990s consistently indicated a decrease in challenging behaviors in community settings as compared to studies published in the 1980s. They

surmise that this is due to an increased availability of behavioral supports in the 1990s compared to the 1980s.

1. **Mortality**

An outcome of deinstitutionalization which has received considerable attention, as well as has stirred controversy, is post-transition death. Conroy and Adler (1998) conducted an historical mortality analysis concerning the 1,154 individuals who moved from Pennhurst Center to smaller community based settings after Pennhurst Center received a court-ordered closure on March 17, 1978. Mortality data was collected on the 130 persons who lived at Pennhurst on the closure date but had died between that date and 1989, which was two years after its official closure. The authors hypothesized that the mortality rate for movers would be higher than that expected had they remained at Pennhurst; however, they found the opposite. Estimates of mortality rate, had Pennhurst remained open, were actually higher than that of actual former resident deaths. The authors concluded that movement from Pennhurst appeared to be life-prolonging, which was in contrast with previous studies of mortality.

Strauss, Kastner, and Shavelle (1998) used the California Client Development Evaluation Report to study the relationship between mortality and type of residence (institutions and community-based settings). The authors reported that the risk factor-adjusted mortality was 72% higher for those living in the community as opposed to those living in California institutions.

In their commentary on the California mortality studies, Strauss and Shavelle (1998) point out that a key finding, aside from mortality, has been the shortcoming present in community healthcare and supervision in California's community-based living

arrangements. The authors suggested that such factors are critical to policy and program development and evaluation and therefore merit attention. They pointed out that at the time of their publication, such dimensions were not adequately studied, in part due to lack of state level record keeping on such information.

Borthwick-Duffy, Widaman, and Grossman (1998) assert in their commentary on the California mortality studies, that the data from the studies have been widely misinterpreted by the media. Specifically, reporters have inferred a causal link between leaving an institution to move into a community setting and death. The authors suggest that among other explanations, the trauma of moving as opposed to the transition setting has been shown to increase risk of death. Because such error is inherent in research and interpretations of findings, the authors encourage public policy decisions be based on bodies of work from multiple researchers rather than on one study or studies completed by a single research team.

In his commentary on Strauss, Kastner, and Shavelle (1998) and O'Brien and Zaharia (1998), Fujiura (1998) reminds researchers that the community is neither a research variable nor a cause of death. Several other factors, he cautions, contribute to health and impact mortality and submits that the study of such impacts is what should be on the research agenda. He argues that general comparison between institutions and community placements are "crude" and not meaningful in facility level implementation (Fujiura, 1998, p. 401). Fujiura reminds the research community that the *meaning* that is attached to data is what is important, not the mere numbers themselves.

Blacher proposed in her 1998 commentary regarding the California mortality studies that mortality has been studied as though “longevity is a, even *the* primary measure of community success” (p. 412). She argued that all people experience risk in community living situations and so it should not be the only variable taken into consideration when evaluating success of residential placement. She suggested research be done in the areas of family involvement and program placements, both structurally and programmatically, as well as areas involving autonomy, relationships, spirituality, and vocational programs as a way of better evaluating the qualities of community placements as opposed to the common practice of comparison between institutional and community living, whose time, she states, “is past” (Blacher, 1998, p. 413).

In 2003, Lerman, Hall Apgar, and Jordan published findings from a controlled research design to determine differences between mortality with regard to residential status between those moving out of institutional settings (“movers”) and those remaining in them (“stayers”). They did not find a significant difference in the mortality rates between movers and stayers.

B. Individual Characteristics as a Predictor of Transition Placement

In addition to studying changes in individual characteristics after transitioning out of an institution, researchers have studied variables such as age, diagnosis, IQ, communication to determine if there is a predictive element which would determine which settings would lead to successful transition outcomes. Borthwick-Duffy, Eyman, and White (1987) examined the placement patterns of individuals receiving services for an intellectual disability in California among four settings: institutions, health care

facilities, community care facilities, and parent/relative homes. Findings indicated that individual characteristics were a significant factor in the residential placement of individuals with intellectual disabilities, which was consistent with previous studies.

Hayden, Lakin, Hill, Bruininks, and Chen (1992) also examined whether residents' individual characteristics predict deinstitutionalization placement. To attempt to answer this question, they conducted a comparison of small group homes (six or fewer residents) and foster homes with regard to resident characteristics, residential services, placement histories, and experiences of a nationally representative sample of residential facilities licensed, contracted or operated by states that provided around the clock room, board, and supervision of persons with ID and related conditions in June of 1982. Fifty percent of the sample ($n = 15,679$) lived in foster homes, 13,172 (42%) lived in 3,065 group homes and 2,529 (8%) lived in 490 ICF/MRs. Nearly half (45.3%) of all study participants lived in a state institution prior to placement at the time of the study. Reasons for moving out of the institutional settings were readiness for less restrictive homelike setting, facility closure, changes in size/characteristics of populations served, and program/services.

The study reported a significant correlation between age at the time the individual left home and type of placement to which they moved. Nearly half of persons in foster care were placed there before the age of 10; 33% entered a residential facility prior to age 10; and 44% entered a residential facility after the age of 40. Differences in age between settings was also statistically significant – foster homes with 5-6 residents had the highest proportion of children 9 and under. Older people typically relocated to 5-6

person foster homes or 1-4 person ICF/MRs. Placements in foster homes were longer (average of 9 years) as compared to group homes and ICF/IDs (average of 4-5 years). Additionally, the authors reported differences in level of intellectual disability (ID) between settings revealing that foster homes typically served persons with moderate to severe levels of intellectual disability. Approximately 25% of individuals residing in group homes had mild ID, 50% had moderate ID and <25% had severe ID. They did not find statistically significant differences with regard to gender and race.

Other characteristics measured in that study included presence of seizure disorder, toileting ability, mobility, challenging behavior, and primary means of communication. The authors determined that certain resident characteristics (especially communication, personal care ability, age, and mobility) are “associated with differential use” of foster care or small group homes. Persons with better communication skills and toileting skills who were older and more mobile were more likely to live in group homes than foster homes.

1. **Placement breakdown**

In addition to examining variables predictive of successful transitions, researchers have also examined those contributing to unsuccessful community placements. The majority have concluded that the primary reason for return to an institution after community placement is residents' maladaptive behaviors (Causby & York, 1991; Intagliata & Willer, 1982; Lakin, Hill, Hauber, & Bruininks, 1983; Lulinski-Norris, Rizzolo, & Heller, 2012a; Schalock, Harper, & Genung, 1981; Windle, Stewart, & Brown, 1961), although successful community placement for people that exhibit such behavior is possible with appropriate supports (Allen, 1999).

In an early study, Windle, Stewart, and Brown (1961) investigated reasons for placement failures for individuals transitioning out of institutional and into community-based settings. They conducted the study in two phases; phase 1 was an empirical study examining the relationship of individual characteristics to placement failure and phase 2 was a literature review. Phase 1 compared three groups of individuals who had transitioned out of an institutional setting and into a community-based residence; vocational, home/family leave. Findings indicated that those placed in community-based residential settings (including the family home) were more likely to return to the institution due to challenging behaviors, while those on home leave returned most often due to antisocial behavior. In addition, those reinstitutionalized from their family home had poor health and lack of environmental support. The literature review in phase 2 corroborated these findings. While the authors fail to operationally define settings and participants (referred to in the article as “subnormals”) in terms of diagnosis (all were former residents of Pacific State Hospital) it should be noted that the authors concluded that, “[p]atients on family care were most likely to fail because of environmental lack of support, poor health, or intolerable behavior... These differences in reasons for failure give further evidence that different processes operate in the different leave programs produce failure” (Windle, Stewart, & Brown, 1961, p. 215). This conclusion demonstrates an early understanding of the impact of environmental characteristics on deinstitutionalization outcomes.

Jacobson and Schwartz (1983) studied three groups with regard to impact of individual characteristics on placement success: 1) individuals living in group homes (n = 2,742); 2) individuals living in group homes who were in jeopardy of placement failure

(n = 491); and 3) individuals living in state operated institutions who were thought by staff to be appropriate for group home placement (n = 3,092). Findings suggested that those in jeopardy of placement failure were less likely to have severe or profound intellectual disabilities and less likely to be receiving needed services, such as counseling, mental health services, or psychological/behavioral intervention, though they were more likely to display cognitive or affective behaviors.

Causby and York (1991) sought to identify predictors of successful community placement of individuals transitioning out of institutions. Using the Balthazar Scales of Adaptive Behavior, the authors collected adaptive and maladaptive behavior data as well as demographics upon discharge. Of the 91 individuals participating in the study, 62 successfully remained in their community placement for a year (referred to by the authors as 'stayers'), while 29 individuals returned to an institutional setting (referred to as 'returners').

Results of the Causby and York (1991) study indicated there was no significant difference between stayers and returners with respect to IQ, age, or gender and the authors concluded that the client demographics measured were not related to successful placement. There was, however, a significant difference between the stayers and returners with respect to certain maladaptive behaviors: inappropriate contact with others, verbal aggression, physical aggression, and non-compliance. The authors concluded that the presence of aggressive behaviors, both physical and verbal, were strong predictors of unsuccessful community placements. They suggested that this data reflected a need for support planning as part of transition services.

Other studies have been conducted to determine organizational factors contributing to placement breakdown. Broadhurst and Mansell (2007) conducted a non-experimental group comparison study to determine if there was any difference between settings in which individuals have successful community placements and those in which placement 'broke down'. They hypothesized that individual characteristics would not differ between groups and 'breakdown' placements would have received less specialized support, less management support, and have less written guidelines with regard to skills and behavior management as compared to 'maintained' placements. Questionnaires were completed by home managers with regard to resident characteristics and setting support capacity in both placements that 'broke down' ($n = 19$) and those that maintained ($n = 20$). They found no significant difference between groups with regard to individual characteristics; however, there was a significant behavioral difference with respect to duration of sexually inappropriate behavior. As hypothesized, the 'maintained' group had better written guidelines, management and extended support as compared to the 'breakdown' group. The authors concluded that technical competence of placement staff and staff support are important factors to consider when choosing a placement and suggested that future researchers should pursue information related to professional external support required to maintain community placements.

Phillips and Rose (2010) conducted a study using a non-experimental between-subjects design to validate a proposed framework for placement breakdown as well as to identify the roles of other predictive factors. The framework considers individual

characteristics and staff perceptions of the individual's ability to control their challenging behavior coupled with environmental factors as being related to placement failure.

Residential staff served as the research participants and were divided into two groups; the breakdown group ($n = 20$), whom had experienced a placement breakdown in 2006, and the maintained group ($n = 23$), whom had maintained community-based placement for three or more years. Data collected from staff included demographic information about the individual receiving services and external services received. The Disability Assessment Scale was used to measure challenging behavior, the Adaptive Behavior Scale was employed to measure individual competence across three domains (personal self-sufficiency, community self-sufficiency, and personal-social responsibility), the Controllability Beliefs Scale measured how in control the respondent believed the individual is over their behaviors, and the Service System Assessment was used to assess the organizational functioning of the service provision agency.

Findings indicated that there was no significant difference between individuals with regard to individual or service characteristics, although individuals in the breakdown group were more likely to have higher personal and community skills, a psychiatric diagnosis, and one or more acute admissions to a psychiatric or behavioral service. There did not appear to be a significant difference between groups with respect to frequency and severity of challenging behavior; however, the breakdown group displayed more frequent and severe anti-social behavior, 'temper tantrums' (*sic*), verbal abuse and sexual 'delinquency' (*sic*), indicating a difference in the types of behaviors displayed. In addition to these findings, the authors reported that the

individuals in the breakdown group were rated by staff as being more in control of their behaviors as compared to those in the maintain group.

The authors concluded that the services in the breakdown group were of poorer quality as compared to the maintained group in terms of staff resources, motivation, physical environment, social environment and overall effectiveness of administrative systems. They stated, "...placement breakdown is best predicted by an individual who is more able in terms of community self-sufficiency, is judged...as being more in control of their challenging behavior, and is living in a poorer social environment in terms of staff assistance and interactions" (Phillips & Rose, 2010, p. 208).

2. **Post-deinstitutionalization transition breakdown in Illinois** **community-based settings**

Lulinski-Norris, Rizzolo, and Heller (2012a) conducted an analysis of outcomes of individuals who have transitioned out of SODCs in Illinois between October 1, 2001 and June 30, 2009. The authors reported that 1,594 individuals transitioned out of an Illinois SODC during the study period. Of the 1,594, 51% moved into a community-based setting while 49% moved into a congregate living arrangement. Ten percent eventually returned to an SODC; 72% did so due to behavioral issues. Individuals who returned to an SODC were significantly younger, had significantly higher adaptive behavior scores, had a higher health risk, and had a significantly longer length of previous stay at an SODC. Presence of a psychiatric diagnosis, however, was not statistically significant between groups; 46% of those who remained in their community placement and 54% of those who returned to an SODC had a psychiatric

diagnosis. Nearly one-third of returners received a type of technical assistance² (TA) from the state; of the TA provided, 97% was in response to behavioral issues.

This section has explored the use of individual characteristics as predictors of placement setting and success. Variables measured have included academic skills, age, challenging behavior, community living skills, diagnosis, domestic skills, IQ, language and communication skills, leisure/recreational skills, maladaptive behavior, mobility, mortality, motor/ physical skills, receipt of mental health services, self-care, sensorimotor ability; social skills, toileting ability, visual processing, and vocational skills. Neither people nor services, however, exist unaffected by their surroundings. The following section will explore how environmental characteristics have been used as a variable in the exploration of transition to the community.

C. **Impact of Behavioral Interventions on Individual Outcomes**

Personal characteristics alone, although associated with DI outcomes, do not predict placement success (Jacobson & Schwartz, 1983). Studies examining the effect of community placements on challenging behaviors of individuals with IDD, however, are equivocal. Several studies have suggested that community placements are less successful than institutions in terms of the management of challenging behaviors

² Technical assistance (TA) is defined as “supports offered to individuals transitioning out of an SODC that fall outside of the parameters of routine follow-up. Such routine follow-up is called Direct Linkage and Aftercare (DLA) and is outlined in Illinois Administrative Code, Title 59, Chapter 1, Part 25 entitled *Recipient Discharge/Linkage/Aftercare*. Technical assistance is support provided in addition to DLA, and is offered for individuals experiencing behavioral and/or medical concerns for which the service provider requires input from a specific discipline. Technical assistance may include: face-to-face visits by a staff member familiar with the individual; observation, evaluation, and provision of recommendations by discipline-specific professionals to address identified issues; a focused review of past records, information gathering, information dissemination, training, consultation, and related activities; or a conference call with an interdisciplinary team from the SODC and community provider, as well as Division of Developmental Disability staff” (Lulinski-Norris, Rizzolo & Heller, 2012a, p. 36).

(Kozma, Mansell, & Beadle-Brown, 2009). Others, however, have reported success when using specialist interventions.

Lowe, Felce, and Blackman (1996) evaluated the effectiveness of two specialist interventions in Wales by comparing the outcomes of a group receiving specialist intervention (n = 30) with a group not receiving that intervention (n = 21) across institutional and community based settings. The groups that received the intervention received it from two different organizations. Groups were compared based on changes in skills, behaviors, mental health and quality of life. Data was collected through interviews with staff and direct observation. The authors reported no significant difference between the intervention and non-intervention groups with regard to outcomes at post-intervention; however, there were significant differences within the intervention groups related to which agency provided the intervention. The individuals differed with respect to frequency of challenging behaviors as well as increased mental health and quality of life. The authors concluded that service factors, not merely the provision of services, impacts individual improvement. The group having successful outcomes had less staff turnover, a more structured organization, more budgetary resources, and staff with more professional training and experience as compared to the group that had less successful outcomes. Based on this finding, the authors recommended continued research to identify methods that lead to success of specialist intervention teams.

Another study examining the use of specialist interventions on challenging behaviors of those transitioning out of institutions was conducted by Allen (1998). Allen studied institutional admission to a Welsh hospital for individuals with intellectual

disabilities over a period of 20 years (1975-1995) to analyze the change in admission patterns. The baseline period, which served as phase one, was from 1975 to 1983. In 1983 community support teams were implemented and in 1990 specialist intervention services were added to the community support teams creating phases two and three. Phase two was from 1983 -1990 and phase three from 1990-1995. Admissions were categorized as either short-term admissions (a stay less than six months) or long-term (a stay greater than six months). Allen reported that short-term admissions significantly decreased in phase three after the addition of specialist intervention services to the community support teams. With respect to long-term stay admissions, however, there was a significant decrease after the initiation of community support teams in 1983 and again in 1990 when specialist intervention services were added. Allen concluded that although improvements were still necessary, the increase in available community support resource combination reduced reliance on the hospital as evidenced by the decrease in admissions after initiation of those services.

Allen (1999) examined the individual and environmental characteristics of two groups using a non-experimental natural comparison design over six years. Group 1 consisted of individuals ($n = 14$) that had been permanently excluded from community placement and had since received services in an institutional setting for at least 12 months (referred to as the 'breakdown' group). Group two consisted of individuals ($n = 33$) that had successfully maintained community placement (called the 'maintained' group). The maintained group had received specialized services for behavioral challenges which included clinical services from a support team. The author considered

them a comparison group as they had behavioral challenges and were at high risk of placement breakdown.

With respect to individual characteristics, Allen reported no significant differences between groups on the Psychopathology Instrument for Mentally Retarded Adults total scale scores. He noted, however, a higher rate of stereotypy among the maintained group, and a higher frequency and severity of anti-social behavior in the breakdown group. The breakdown group also received a lower Service System Adjustment score, indicating poor organizational status with respect to the availability of appropriate resources, organizational structure and leadership quality, as well as a higher frequency of acute admissions. Of those in the breakdown group, 92.8% received specialized services at some point, however, only 50% were receiving them at the time of placement breakdown, while 100% of the maintained group received these services by definition. An additionally significant difference between groups was in terms of the receipt of emergency training by the staff: 81.8% of the staff in the maintained group received this training as compared to 35.7% of the breakdown group. Allen concluded that people with challenging behavior can be supported in the community with the proper supports.

In general, there is a lack of community-based services for people with a dual diagnosis of IDD and mental illness. Hemmings (2008) suggested that “[r]esearch should utilize the opinions of service users and their carers as well as professionals...” (p. 460) to determine how services should be modeled.

D. **Impact of Environmental Factors on Individual Outcomes**

As presented above, a significant amount of exploration has consistently concluded that individuals have better outcomes in community-based settings as compared to institutional facilities. Another major focus of deinstitutionalization research has been the impact of environmental factors on individual outcomes. Until the early 2000's, studies investigating the influence of environmental characteristics on the successful placement of individuals with intellectual disability (ID) in community settings as a result of deinstitutionalization were sparse (Heller, Miller, & Hsieh, 2002), particularly in comparison to the studies of individual characteristics. Factors have included agency size, setting size, physical attractiveness of setting, setting location, social networks, community supports, staffing patterns, staff-resident interactions, and hours of programming. Several of these factors are discussed below in an effort to understand major findings related to research on the effects of environmental factors on placement success. This section will review the array of environmental variables that have been studied and examine to what extent they impact individual outcomes.

Types of setting have received considerable attention as a variable contributing to transition outcomes. An early study by Bjaanes and Butler (1974) investigated behavior patterns in two different settings: two board and care homes (n = 30 and 24) and two home care facilities (n = 4 and 6). They found substantial differences between facilities with respect to behavior in both the way time was spent and the amount of time spent on activities. Board and care homes were more normalizing and were more focused on social competence, were less socially and geographically isolated, provided more opportunities for community integration, and had a higher frequency of

independent behavior as compared to home care facilities. Additionally, individual and social competency appeared to be related to geographic location and caretaker involvement. This led Bjaanes and Butler to conclude that differences in environments produce different outcomes.

Seltzer (1981) studied the relationship between residential characteristics and client adjustment, where skill adjustment was measured on two levels: skill performance (performance of mastered skills) and satisfaction (Community Adjustment Scale by proxy). Demographic and social history was collected for 153 study participants that had previously lived in an institution and were currently residing in a foster home, family home, group home, boarding home, independent apartment or had returned to an institutional setting. He reported that semi-independent and independent settings provided individuals with more autonomy, increased access to resources and responsibilities, while institutions and foster homes scored low in these areas. He also reported that client adjustment correlated with residential characteristics and that there was a positive relationship between client satisfaction and residential environment. Additionally, he stated that the more normalized the environment, the more likely residents are to perform mastered skills and be satisfied with the setting.

In addition to setting type, setting size has been extensively studied, where size indicates number of facility residents. In an early study, Balla (1976) conducted a literature review to investigate the relation of institutional size to quality of care along four dimensions: resident care practices, behaviors, release rates, and parental/community involvement. With regard to resident care practices, Balla stated that they have typically been defined as either 'resident-oriented' or 'institution-oriented'.

He concluded that resident care practices in smaller community based settings are more resident-oriented as compared to large institutions. Further, quality of life was better on average in smaller community based settings.

Balla did not report significant differences related to behavioral functioning with respect to facility. As only one study explored discharge rates no conclusion was drawn on that factor. With respect to parental and community involvement, he found "...little evidence that if parents lived closer to an institution they would visit their children (*sic*) more often" (p. 122). He noted that there are not enough empirical studies to promote a social policy promoting smaller community based settings, although he stated that care is "more adequate" (p. 122) in smaller community based settings, particularly those with a census of under 100.

Baroff (1980) reported that facility size does not have a significant impact on residents' outcomes. However there were differences between types of settings but not within settings. He concluded that smaller settings are more resident-oriented and individualized. In addition, he noted that they are typically located in residential neighborhoods and therefore allow for increased access to community services.

Landesman-Dwyer, Sackett, and Stein Kleinman (1980) completed a study to explore whether or not size of community-based group homes was related to staff or resident behavior patterns. They posed three questions: 1) Is size correlated with daily activity patterns of residents or staff?; 2) If so, is size as important as other variables regarding behavioral differences?; and 3) Do staff patterns relate to resident patterns? The authors observed 419 staff and residents of 20 group homes and coded observed behaviors in 15 categories. Only four of the 15 categories were associated with number

of residents. The larger the site, the less eating and organized activities occurred. General social behavior and unobservable behaviors (behind closed doors) increased with home size. They concluded that size may be correlated with resident activities but not staff activities. They also found that geographical location, heterogeneity of residents' backgrounds, and age were better predictors of activity as compared to size. In answer to their third line of inquiry, they reported that staff behavioral patterns did not relate to those of the residents. Staff tended to interact with other staff in larger group homes but the opposite was not true in smaller group homes meaning that smaller homes did not increase staff interaction with residents. Resident interaction, however, was significantly related to home size. The greatest amount of interaction was observed in medium sized settings of 9 -17 individuals, while the least amount of interaction occurred in smaller settings of 6 - 8. In larger homes, 18 - 20 residents, more social behaviors and peer interactions were observed. In addition, individuals were more likely to have a 'best friend' in larger homes. Despite these findings, the authors reported no statistically significant differences between community group homes with respect to size.

Tossebro (1995) studied residential setting size on two quality dimensions: self-determination and deprivatization. Self-determination was assessed by asking staff to rate on a scale of 1 to 5, "What degree of freedom to make important decisions him/herself, to influence the every-day life do you think the person has?" Deprivatization was assessed on six categories including home-likeness, participation in relocation, influence about with whom the home is shared, and presence of locked doors to which the residents have access. Data was gathered from staff interviews

regarding 591 individuals across 36 facilities in three Norwegian counties. Tossebro reported that facility size had no significant impact on self-determination or deinstitutionalization; however, the size of the residential unit, as opposed to size of the overall facility, was significant.

In a review of 68 studies published between 1997 and 2007, Kozma, Mansell, and Beadle-Brown (2009) identified 49 studies that explored the impact of deinstitutionalization by comparing institutions to community-based settings, while 19 examined post-deinstitutionalization outcomes between varying types of community-based residential settings. The authors reported that smaller settings offer more community involvement, larger social networks and more friends, more opportunities for choice and self-determination, a higher quality of life, and greater satisfaction of residents and their families as compared to larger settings. Interestingly, the type and frequency of family contact was not determined by type or size of setting but by distance of setting from family home as well as personal characteristics (e.g., resident ability and parental age). Reviews of studies of adaptive behaviors revealed mixed findings. Some studies found no improvements in adaptive behaviors while others reported improvements. Research suggested that individuals that remained in congregate settings, however, were more likely to experience a decline in adaptive behaviors.

The authors did note three areas in which smaller settings do not appear to provide better outcomes as compared to larger settings: presence of challenging behaviors, use of psychotropic medications, and mortality. According to the reviewed studies, the majority reported no significant changes in challenging behaviors upon relocation from an institutional setting to one that is community-based; other studies

however, reported changes in the nature of the challenging behaviors but not an overall decrease.

Another area in which reviewed studies suggested that community settings were less effective than congregate settings was in the use of psychotropic medications.

Some studies reported a decrease in use in community settings while others reported that there was no significant change, about which the authors concluded,

“[i]nvestigators have suggested that community service providers are not well equipped to deal with individuals who have challenging behaviors that then leads to the overuse of medication” (Kozma, Mansell, & Beadle-Brown, 2009, p. 216). Mortality was a third area in which community settings were not better performers than institutional settings, as reviewed studies reflected a higher rate of death in community settings as opposed to larger settings. These studies, however, are not necessarily generalizable as they were mainly conducted in one state (CA) over a relatively short period of time (1993 - 1999). Studies in other geographical areas did not support those findings as discussed earlier.

A second smaller category of studies identified by Beadle-Brown, Mansell, and Kozma (2007) focused on the impact of facility/setting characteristics and healthcare access and quality on deinstitutionalization outcomes. The studies examining facility/setting characteristics revealed that people had a better quality of life in the community as compared to in the institution as well as experienced greater choice-making and increased adaptive behavior. Additionally with regard to healthcare access, they reported that studies typically focused on the training of healthcare professionals

which, while it increased knowledge of healthcare providers, there was no research on the effect that training has on individual experience.

The third category of studies focused on challenging behaviors of individuals and consistently reported that persons with such behaviors were more likely to remain in an institutional setting, or if transitioned to a community setting, were more likely to be reinstitutionalized as well as have a psychiatric diagnosis, use psychotropic medications, and have a lesser quality of life as compared to their peers who do not exhibit challenging behaviors.

Kozma, Mansell, and Beadle-Brown (2007) concluded that the literature reviewed had similar outcomes to earlier studies. Most notable is that data does seem to suggest generally positive outcomes (in regards to community involvement, friends and size of social networks, opportunities for choice and self-determination, quality of life, and greater satisfaction of residents and their families) as compared to larger settings versus institutional settings. As the process of deinstitutionalization is likely to continue, sustainability of good outcomes within varied settings is required.

Heller, Miller, and Hsieh (2002) conducted a study to determine the impact of environmental characteristics on the well-being of individuals with developmental disabilities that transitioned from nursing home placements to community-based living arrangements. Using interviews, record reviews and observations, they collected resident and environmental measures. Resident measures included: adaptive behavior, level of intellectual disability, community integration and physical health. Environmental measures included: choice making, family involvement, type of setting, size of setting (measured by number of residents in a site), and the home's physical attractiveness.

Results indicated that environmental features of residential settings, such as opportunity for choice, the attractiveness of a setting and family involvement, do have an influence on the well-being of individuals with IDD.

The importance of environment was highlighted by Heller 's (2002) review of studies on residential settings along four dimensions: the impact of type and size of setting on individual outcomes; the impact of organizational features on individual outcomes; and the interaction of personal and environmental characteristics that promote quality of life. She indicated that early research explored the effect of environmental characteristics of pre-institutional settings (e.g., family home) and institutional settings on individual behavioral and developmental progress. The next phase of research involved the study of deinstitutionalization outcomes, such as the effect of size and type of settings on individual adaptive and maladaptive behaviors. At the time of the review, Heller characterized the current trends as involving the impact of the residential environment on individual function, health, community integration, and quality of life issues (e.g., autonomy, satisfaction, etc.).

Heller's 2002 review concluded that research indicates that individuals experience better outcomes related to adaptive behavior, increased self-determination, community participation and friendships with non-disabled peers in community-based settings as compared to institutional settings. Little research, however, has been conducted on the impact of organizational and programmatic interventions on individual outcomes. As environmental features effect people in different ways, it is critical to consider person-environment fit, or the match between an individual's needs and supports provided, when evaluating setting quality.

E. **Summary and Statement of the Problem**

The studies presented here all seem to share the sentiment expressed by Jacobson and Schwartz 30 years ago when they concluded that "...while personal characteristics alone are not powerful predictors of successful community placement, they are associated with placement success to some degree" (1983, p. 5). In addition, as discussed earlier, research has implied that the nature of the environment in which a person lives (which includes agency and service characteristics) contributes to successful placement.

Given the efforts currently being made in Illinois to rebalance its service delivery system away from institutional settings to those which are community-based, exploration of community capacity to address behavioral/mental health issues and how it contributes to individual outcomes is necessary. Data from Lulinski-Norris, Rizzolo, and Heller (2012a) has shown that for some individuals, existing community-based services and supports are insufficient. Additionally, a study by the Illinois chapter of the National Alliance on Mental Illness (NAMI) and the Supportive Housing Providers Association (2012), demonstrated a need for psychiatric and behavioral services for individuals who have dual diagnosis and live in the community. The Illinois NAMI and the Supportive Housing Providers Association Report (2012) included targeted interviews with six community-based provider agencies focused on access to mental health services for individuals with dual diagnoses. Among their conclusions, they indicated a need for applied behavior analysis and psychiatric services for this population. More specifically, they concluded that there is a need to "cultivate and train

counselors, psychiatrists and psychologists for working with persons with cognitive deficits” (p. 11).

In 2008, Human Service Research Institute (HSRI) released “A Blueprint for System Redesign in Illinois.” The Blueprint identified a seven-year action plan that would act as a means to reducing Illinois’ reliance on congregate facilities and strengthen community capacity to provide services and supports. One of the weaknesses identified by the Blueprint, was a lack of community capacity to provide for the needs of individuals with challenging behaviors. They stated, “As a consequence, *de facto* the SODCs play the role of serving individuals whose needs cannot be met in the community due to their challenging conditions. Indeed, this is one of the rationales for maintaining the operation of the SODCs. So long as the capacity is not present in the community to address the needs of people with challenging conditions, Illinois will face ongoing pressures to admit people to the SODCs” (HSRI, 2008, p. 25).

In a 2012 follow-up, HSRI released “Illinois at the Tipping Point: Blueprint for System Redesign Update,” a report which reviewed and assessed Illinois’ progress on the Blueprint since 2008. The authors noted that Illinois “[i]mproved its response to people with behavioral challenges by increasing service reimbursement rates associated with behavior therapy and expanded statewide capacity by altering qualification requirements for individuals delivering this service” (HSRI, 2012, p. 43). Despite its efforts, however, HSRI recommends that “...Illinois build capacity to address behavioral challenges among service recipients” (HSRI, 2012, p. 74). They suggested: specialized residences, staff and family training, and improvement of community crisis support.

Heller, Hsieh, Owen, and Badetti (2012) released findings from an evaluation of one such program, the Illinois Support Services Team (SST). The SST Program, initiated in August of 2010, is an interdisciplinary team which provides TA and training in response to situations in which a person with an IDD is in medical or behavioral crisis which challenges their ability to live and thrive in community-based settings. SSTs observe, assess, evaluate, consult with and provide training to family and provider staff to support individuals living in community-based settings who are experiencing urgent medical and/or behavioral concerns that have not been responsive to intervention. The six SSTs included: Qualified Intellectual Disability Professionals (QIDPs), nurses, Board Certified Behavior Analysts (BCBAs), psychologists and psychiatrists (Illinois Department of Human Services, 2010).

Heller, Hsieh, Owen, and Badetti (2012) reported the most common reason for referral of an individual to the SSTs was due to physical aggression (78%), followed by verbal aggression (46%) and property destruction (44%). Services delivered by the SSTs included service planning, observation and evaluation, TA and individual support. These services were delivered via phone or in-person consultation. More than 4/5 of cases for whom SST support was received resulted in a reduction in the severity and/or frequency of the behaviors which led to the SST referral. In addition, staff and families reported improvement in the behaviors of individuals for whom referrals were sought. During the study period, short-term admissions to an SODC increased as that was also an option in the SST program. The average length of stay prior to the referral was 91.1 days, while stays after referral averaged 84.2 days, both considerably shorter lengths of

time as compared to typical SODC stays averaging 20 years (Lulinski-Norris, Rizzolo, & Heller, 2012b).

While stakeholders expressed concerns about the short time frame of the SSTs and perceived lack of follow-up, SST services did improve medical and behavioral outcomes for referred persons. In some cases, stakeholders learned how to more effectively navigate community services as well as became aware of others. There are, however, still few alternatives to SODC admissions for people in need of short-term placement due to behavioral and/or medical issues. The research team recommended further exploration of short-term placement alternatives to keep SODCs from remaining the default option (Heller, Hsieh, Owen, & Badetti, 2012).

As noted previously, however, Heller (2002) concluded that little research has been conducted on the impact of organizational and programmatic interventions on individual outcomes. It can also be said that the majority of the DI research conducted has focused on the individual and their immediate environment. As indicated by the Illinois NAMI Report, Illinois must address systemic issues in order to strengthen its community support system. The HSRI reports from 2008 and 2012 both indicate a need to improve community capacity to treat individuals with challenging behaviors. Heller, Hsieh, Owen, and Badetti (2012) conclude that reliance on SODCs in Illinois must be reduced in favor of alternatives. Therefore, consideration of person-environment fit, or the match between an individual's needs and supports provided, is critical when exploring outcomes of deinstitutionalization.

The aim of this study is to respond to those needs by exploring the capacity of community-based providers of residential supports and services as well as the

surrounding community to provide adequate behavioral and mental health services to individuals who transition out of an SODC and have behavioral/mental health challenges. The intent is to identify service gaps contributing to placement breakdown and inform public policy discourse at the state level as Illinois makes strides to decrease its reliance on institutionalized service systems. The following chapter will discuss conceptual approaches to the exploration of environmental factors beyond immediate residential settings which can be applied to DI outcome research.

IV. CONCEPTUAL FRAMEWORK AND RELATED LITERATURE

A. The Role of the Ecology of Human Development

As concluded in the previous chapter, the vast majority of DI research has been centered on individual characteristics and those of the immediate residential setting. Examination of human behavior cannot be accomplished in isolation from one's environment. As such, research that fails to consider environmental factors in the study of human behavior is insufficient. This section will review the concept of Bronfenbrenner's ecology of human development and explore geographic information systems as a means to explore its application to DI research.

1. Bronfenbrenner's 1977 Ecology of Human Development framework

Bronfenbrenner (1977) discussed the inadequacies of experimental research design in a laboratory environment for studying human behavior and development. He stated, "...the understanding of human development demands going beyond the direct observation of behavior...it requires examination of a multiperson *system of interaction* not limited to a single setting and must take into account aspects of the environment beyond the immediate situation containing the subject" (Bronfenbrenner, 1977, p. 514, italics added). As a result, Bronfenbrenner proposed an "expansion" and "convergence" of naturalistic and experimental approaches with which to study human development. He called this framework the "ecology of human development" and defines it as the study of "...progressive, mutual accommodation, throughout the lifespan" between a person and their changing "immediate environment" (Bronfenbrenner, 1977, p. 514). The environment, in this model, is not static, but represented by a "nested arrangement of structures, each contained within the next" (p.

514). Mutual accommodation, or person-environment fit, varies within each of these nested structures. Studying the impact and relationships within and between persons and their environments throughout the lifespan, illuminates a “larger social context” within which settings are “embedded” allowing adequate study of human development.

Bronfenbrenner (1977) classifies the “nested structures” within a person’s environment as being in one of four categories: microsystem, mesosystem, exosystem, and macrosystem (see Figure 1). The microsystem represents the relationship between the individual and their immediate setting. Immediate settings are particular places in which particular roles are played for specific periods of time such as school and the workplace. The mesosystem, which is a structure of microsystems, is composed of the interactions of *settings* at a particular point in a person’s life. The exosystem includes social structures that don’t necessary contain the person, but affect the immediate settings in which the person is (e.g., major societal institutions such as neighborhoods, government, etc.). Finally, the macrosystem refers to the “overarching institutional patterns of the culture or subculture” (p. 515) which informs cultural norms and ideologies. Examples can be found within economic, social, educational, and political systems which shape the patterns and structures of custom and practice of day to day living.

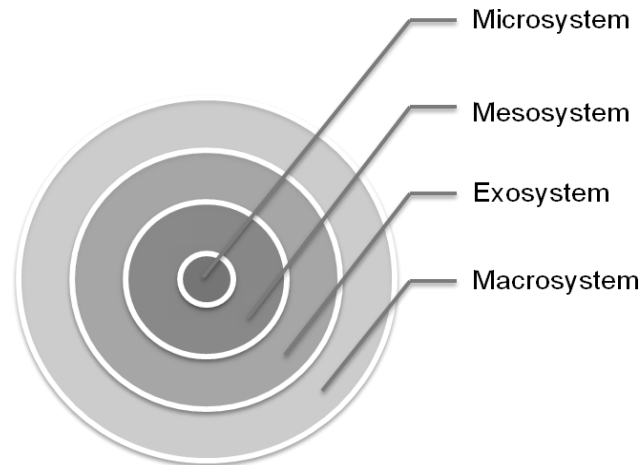


Figure 1. Bronfenbrenner's model of the environment.

Based on this ecology of human development model, Bronfenbrenner proposed a research model with which to study it referred to as an “ecological experiment.” This model relies on four major premises of the ecology of human development: 1) detection and analysis of system properties; 2) discovery-based exploration of systems’ properties and processes that impact and are impacted by human development and behavior; 3) consideration of all environmental factors; and 4) acceptance of the interdependency of environmental structures.

Based on these assumptions nine cumulative requirements at each of the four systems levels were presented (Bronfenbrenner, 1977). At the microsystem level, reciprocity, or the mutual engagement between two individuals, must be allowed as opposed to the traditional unidirectional model of research in which the experimenter affects the subject and not vice versa. Second, there must be recognition of the social system and its effect on the research setting. Third, human interactions must go

beyond dyads and allow for group interactions. Fourth, physical environment and its influence on social processes must be taken into consideration.

At the mesosystem level, consideration must be given to the joint impact of the setting, the subsystems and subsequent higher order effects across settings, and lifespan transitions affecting not only the individual but their subsystems (e.g., family, friends) as well. Consideration of the larger context, “ecological circumstances and events that determine with whom and how people spend their time” (Bronfenbrenner, 1977, p. 526), must be given at the exosystem level. Finally, at the macrosystem level, the research design must include a restructuring of the ecological system that “fundamentally alter(s) the character of society” (Bronfenbrenner, 1977, p. 527). Based on Dearborn’s statement that to understand something you must change it (as cited in Bronfenbrenner, 1977), transformation or intervention is necessary to the understanding of the system.

2. **Bronfenbrenner’s revised 1999 Ecological Model**

Twenty years later, Bronfenbrenner (1999) discussed a theoretical development in his ecology of human development framework which is the addition of *proximal process*. The revised model, referred to as bioecological, takes into account processes of interactions which were excluded in the original ecological model. He referred to these multiple interactions as a proximal process, defined as “...progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects and symbols in its immediate external environment” which occurs on a “regular basis over extended periods of time” (Bronfenbrenner, 1999, p. 5). The proximal process itself has five

properties: 1) engagement of the person; 2) regular occurrence over an extended period of time; 3) increased complexity; 4) reciprocity; and 5) limitless interaction. In short, the bioecological model takes one's engagement with their surroundings into account in addition to the interaction between said individual and that environment acknowledging that a person is both a producer and a product of development.

B. **Ecological Models in Gerontology Research**

In their chapter in the *Handbook of the Psychology of Aging*, Scheidt and Windley (2006) provided an update on classic environmental gerontology theory, methods and application. In their review of the current status of theory, they summarized Lawton and Nahemow's (1973 as cited in Scheidt & Windley, 2006) competence-press model (also referred to as the general ecological model), which was based on a modification of Lewin's ecological equation of $B = f(P, E)$ which illustrates that behaviors are a function of the person and their environment (where B = behavior, f = function, P = person and E = environment). Lawton revised the model to express the effects an environment has on an individual: $B = f(P \times E)$ and to reflect the concept of environmental press, which is, as summarized by Scheidt and Windley, "...environmental demands or contexts that normally would elicit some response" (2006, p. 107). The equation expresses that, "...behavioral outcomes occur and vary as a function of personal competence and environmental press". An individual's competency level, which is his/her maximum performance, acts as a mediator on the impact environmental press has on the individual. Scheidt and Windley explained that the equation illustrates that individuals with lower levels of competence are more likely to experience a demanding environment as "aversive" as compared to individuals with

higher levels of competency. The response to environmental demands, whether perceived as aversive or not, are presented through the individual's behavior either externally, through observable behaviors, or internally, manifested through psychological well-being.

Scheidt and Windley (2006) reported that the competence-press model was applied by Geboy and Diaz-Moore in 2005 to the organizational level. Their Occupational Competence-Press Model allowed analysis of outcomes at both the microlevel of the individual and the macrolevel of the organization using five domains: structure, function, knowledge, resource use, and interrelationships. Geboy and Diaz-Moore suggested application of OCPM in long-term care settings in order to allow for exploration of interactions between the organization, staff, settings, and the needs of the consumer.

The concept of environmental press has been applied to dementia research as well (Gitlin et al., 2003 as cited in Scheidt & Windley, 2006). The authors suggested that alteration of environmental support may result in behavioral change as opposed to attempting to modify the elder. Scheidt and Windley (2006) suggested that the environmental gerontology literature could benefit from studies that focus on the setting, as opposed to the individual as the unit of analysis.

Environmental gerontology (EG) focuses on the "description, explanation and modification and optimization of the relation between elderly persons and their socio-spatial surroundings" (Wahl & Weisman, 2003, p. 616) from the microlevel to the macrolevels. Notably, Lawton and Nahemow's 1973 press-competence model has had a profound impact on EG theory, specifically in the study of planned environments. The

model includes the following environmental functions: maintenance, stimulation and support, and contends that these functions provide “a meta-level perspective for person-environment relations in old age” (Wahl & Weisman, 2003, p. 620). Lawton’s maintenance function concerns environmental consistency and predictability, stimulation is indicated by novel stimuli and subsequent behavioral effects, and support refers to environmental compensation for decreased ability.

C. **Research Applications of Bronfenbrenner’s Human Ecology Framework**

Though the theories of environmental press are foundational in gerontology research, they can be applicable to any study of human behavior because they focus on the interactions of a human and their environment. Berry (1995) employed Bronfenbrenner’s model to examine family adjustment to the deinstitutionalization of their relative with a developmental disability. She suggested that the model was an informative framework to utilize as it considered the individual within the family unit as being the microsystem, the immediate community (e.g., neighbors and extended family) as the mesosystem, the service systems (e.g., the schools and institutions) as the exosystem, and finally society as the macrosystem. Berry emphasized the role of understanding the impact of each of the systems on a family’s decision to place their relative in an institution in order to better understand the effects of deinstitutionalization. This framework, she posited, would assist counselors in supporting the family through the deinstitutionalization process, not only as a means to understand the family situations at the time the decision to institutionalize was made, but also to understand the situations that families were in at the time of deinstitutionalization. Knowledge of

family history and present family situations, she suggested, would assist counselors in linking families with appropriate resources for each of the systems in which they exist.

The concept of the person-environment fit has also been applied to occupational therapy (Law et al., 1996). The Person-Environment-Occupation Model contextualizes the individual, environmental, and occupational domains throughout the lifespan illustrating that the “fit” between the three is impacted temporally. Optimal performance is determined by the fit of the three domains at any point in time, so that there are situations in which people are able to optimally perform and others in which they are not. Law and colleagues (1996) suggest that this model could be helpful to clinicians in determining which aspect of one’s life requires attention throughout varying time periods and situations.

Several researchers have determined that there is a relationship between individual outcomes and environmental variables in terms of deinstitutionalization (Bjaanes & Butler, 1974; Gillett & Stenfert-Kroese, 2003; Heller, 2002; Heller, Miller, & Hsieh, 2002; Intagliata & Willer, 1982; Seltzer, 1981; Tossebro, 1995). Heller, Miller, and Hsieh (2002), however, noted that investigations related to environmental influence on successful transition to community-based settings from institutionalized settings are sparse. Given the rate of deinstitutionalization of state operated institutions accelerated to 12% between 2009 and 2011 (Braddock et al., 2013) there exists a need to more closely examine outcomes of individuals who transition to different settings. One method used to analyze/compare data about a given environment and its attributes, which has received little attention in studies of deinstitutionalization, is geographical

information systems (GIS). GIS is a promising approach to examine the relationship between environmental characteristics and human attributes.

D. **Geographic Information Systems**

Study of the environment is not a new concept, although technological capability to deconstruct location into environmental variables is evolving. Shellito (2012) described geospatial technology as “the use of a number of different high-tech systems and tools that acquire, analyze, manage, store, or visualize various types of location-based data” (p. 2). Examples of geospatial technology include geographic information systems (GIS) and remote sensing and global positioning systems (GPS); both are used in a variety of fields ranging from archeology to law enforcement. At the core of these technologies are geospatial, or location-based, data. More complex than just a point on a map (e.g., an address), the overlaying of geospatial data can allow us to explore spatial relationships associated with that address, such as its relation to schools, libraries, and public transportation, allowing comparisons of various locations to one another based on specific attributes to be made. One method used to analyze and compare data about a given environment or location is geographic information systems (GIS) which allow visualization of data as well as an analysis of spatial relationships (Renger, Cimetta, Pettygrove, & Rogan, 2002).

GIS is “... a computer-based set of hardware and software used to capture, analyze, manipulate, and visualize spatial information” (Shellito, 2012, p. 99). Created by Roger Tomlinson in Canada during the early 1960s, GIS has various applications which assign actual data to a visual computer-based model allowing for analysis and manipulation. In the GIS vector data model, three basic units of measurement, or

vector objects, are used: points, lines, and polygons. A *point* is a specific location using a set of coordinates (e.g., a street address). A *line* is a one-dimensional object connecting one point to another (e.g., the path from one address to another). A *polygon*, is a two-dimensional object made up of a set of lines (e.g., city borders). Each of these objects represents a data layer. Topography establishes relationships between two objects (e.g., adjacent, connected by a line, or contained by another). While a map has rich information about the point's spatial properties, the non-spatial attributes of each layer illustrate a more complete context. Nominal, ordinal, interval, and ratio data are used to create an attribute table for each layer so that each piece of non-spatial data is associated with a spatial location. The information can then be mapped by superimposing the information onto a pictorial representation of the space under examination. Resulting maps can be either reference maps, such as an atlas, or thematic maps, such as those used to display weather patterns. Ricketts (2003) stated that "GIS is, at its heart, a simple extension of statistical analyses that join epidemiological, sociological, clinical, and economic data with references to space... (and) relates data using a system of references that describe spatial relationships" (p. 3).

E. **Variables Used in Geographic Information Systems Research**

"GIS is being used to map and explore geographical variation in need for health services and to develop innovative indicators of health care need" (McLafferty, 2003, p. 26). Despite these promising uses, "...evaluators have failed to realize the potential of using GIS by adding the results of primary data collection to an existing secondary database" (Renger, Cimetta, Pettygrove, & Rogan, 2002, p. 471). Secondary

databases used in GIS research have included Census data, results of the American Community Survey, National Health Interview Survey of Disability, and the Department of Health and the National Vital Statistics System (Pantaleoni, 2012). These databases include information on demographics (e.g., age, race, employment, educational level, poverty level, disability status, births, deaths, marriages, and divorces) to provide an overall sketch of the population in the defined area being studied and as a means of comparison to other defined areas. This study proposes to use GIS variables to determine if there are differences between population characteristics in communities in which people successfully transition out of an SODC and those from which individuals return to an SODC.

1. **Research applications of geographic information systems**

Broad examples of use of GIS include examination of: disaster management, security, employment trends, school enrollment, environmental contamination, disease and violent crime (Renger, Cimetta, Pettygrove, & Rogan, 2002). Gerard Rushton (2003) remarked, "...[p]ublic health is now presented with the opportunity to examine key relationships between health characteristics of populations and both human and physical environmental characteristics" (p. 43). Indeed, the fields of public health and health care have used GIS to study disease (Cromley, 2003), health care need (McLafferty, 2003), healthcare access (Graves, 2008; Higgs, 2004; McLafferty, 2003), healthcare utilization (McLafferty, 2003), and healthcare outcomes (Graves, 2008).

2. **Geographic information systems in health use and access research**

Telfair, Haque, Etienne, Tang, and Strasser (2003) conducted a study to explore relationships between geographic distribution and socioeconomic variables of 662 individuals with sickle cell disease in Alabama during 1999-2001. Specifically, they examined the relationship between urban and rural disparities with respect to socioeconomic/community distress, health status and access to and use of health services. Using ZIP codes and U.S. Census data, the research team analyzed data maintained by the Alabama Sickle Cell Disease Registry Project. The database contained demographic, medical history, and services information obtained from active clients through a face to face or telephone interview. GIS software was used to map and categorize urban/rural ZIP codes of both clients and sickle cell disease center locations. Additionally, they used three indices: Community Distress (measuring employment, poverty, and education), physical functioning and medical problems (self-reported), and utilization of sickle cell disease treatment centers. They reported a significant disparity in socioeconomic conditions between urban and rural client cases; those living in urban areas lived in neighborhoods with a higher median family income, higher educational attainment, higher rates of employment, and lower poverty rates. Additionally, they found that individuals living in rural areas reported more physical limitations and were less likely to use health care services as compared to their urban counterparts.

GIS was also used to explore access to health care services in central Missouri's Boone County (Phillips, Kinman, Schnitzer, Lindbloom, & Ewigman, 2000). Specifically, they used GIS as a platform through which to visually combine data from 3,314

community health center patient records, data from the 1998 Boone County Health and Human Services Needs Assessment, and geographic information (including polygons of ZIP codes, census tracts, and district boundaries of the Missouri House of Representatives) in an effort to determine to what extent the target population used the community health center. The researchers determined that the community health center's intended service area in 1998 was different from the actual service area established in 1994; the areas with the "highest proportion of adults with poor health care access [were] generally outside the actual [community health center] service area" (Phillips, Kinman, Schnitzer, Lindbloom, & Ewigman, 2000, p. 975). Such information can assist policymakers and other stakeholders in service design, outreach plans, and funding prioritization in order to best serve the intended constituency.

GIS was used to analyze availability and accessibility of dentists in three Ohio databases: the Ohio State Dental Board which listed all of the licensed dentists in Ohio in 1998, information on dentists who billed Medicaid for services in 1998 from the Ohio Medicaid Program, and a list of clinics providing free or low-cost dental services maintained by the Ohio Department of Health (Susi & Mascarenhas, 2002). Regional inequalities, such as those between rural-urban areas, metropolitan and non-metropolitan areas and Appalachian and non-Appalachian counties were also examined. Based on this information, Susi and Mascarenhas (2002) were able to produce a map of Ohio illustrating the distribution of dentists at the county and ZIP code level as well as a dentist-to population ratio. They reported that dentist-to population ratio in Appalachian counties was half of that found in metropolitan areas, although Appalachian counties had a higher percentage of dentists who billed Medicaid as

compared to metropolitan areas. The authors also report ZIP codes in which there were no dentists; this included metropolitan areas. Most striking, however, was the finding that the nine most-populated Ohio counties composed 52% of the state population and 65% of its dentists. This means that 35% of Ohio dentists are responsible for 48% of the population. The authors surmised that dentists are choosing to locate their practices in areas of high population density and not necessarily where services are needed. Based on this inequity of dental services, the authors suggest the State of Ohio embark upon an incentive program to attract dentists to areas that need them. Studies such as these can be used to determine service gaps based on specific needs of a population and the availability of services in a given environment.

Though use of GIS to analyze health-related issues has been increasing over the past two decades, little has been published on individuals with developmental disabilities (Pantaleoni, 2012). Research, Pantaleoni found, has mostly been limited to children's access (including physical proximity, accessibility, safety) to services (e.g., health care, recreation and food stores) and the role of pollution and environmental toxins on the health of children with disabilities and their mother at gestational age.

One study of adults with developmental disabilities was located. A research team from the United Kingdom (Kiani, Tyrer, Hodgson, Berkin, & Bhaumik, 2013) was the first to explore prevalence of mental illness, autism spectrum disorders, and behavioral disorders in people with IDD living in urban and rural areas. Subjects were assigned a local authority district based upon their postcode (equivalent to U.S. ZIP code) and this district was then assigned as either urban or rural. The team reported

that there was no significant difference in the percentage of mental illness by rural/urban classification, however, diagnoses on the autism spectrum were higher in rural areas.

F. **Summary and Statement of the Problem**

Research has consistently shown that residents with developmental disabilities have better outcomes in community-based settings as compared to institutional facilities (Heller, 2002; Kim, Larson, & Lakin, 1989; Larson & Lakin, 1999, 2012). The majority of studies, however, have primarily focused on individual or organizational characteristics as indicators or predictors of success. Applying units of analysis from Bronfenbrenner's ecological model, deinstitutionalization research has mainly been investigated at the micro- and mesosystem levels. Some studies, however, have suggested that the exosystem can impact deinstitutionalization outcomes. Kim, Larson, and Lakin (1999), for example, observed that studies published in the 1990s consistently indicated a decrease in challenging behaviors in community settings as compared to studies published in the 1980s. They surmise that this is due to an increased availability of behavioral supports in the 1990s as compared to the 1980s. This represents differences within the temporal context which may prove to impact placement success.

Maladaptive behaviors are a common reason for failure of community-based residential placements after transition from institutional settings (Causby & York, 1991; Intagliata & Willer, 1982; Lakin, Hill, Hauber, & Bruininks, 1983; Schalock, Harper, & Genung, 1981; Windle, Stewart, & Brown, 1961). The majority of the research, however, has focused on the individual and organizational characteristics in failed placement attempts instead of examining the service system within which they occurred. As discussed earlier, there are some exceptions (see Allen, 1998, 1999;

Broadhurst & Mansell, 2007; Lowe, Felce, & Blackman, 1996; Philips & Rose, 2010).

Research has implied that the nature of the environment in which a person lives (which includes agency and service characteristics) contributes to successful placement. In fact, many authors have indicated shared sentiments with Jacobson and Schwartz (1983) who concluded that "...while personal characteristics alone are not powerful predictors of successful community placement, they are associated with placement success to some degree" (p. 5).

By and large, investigation of the resources available to persons with IDD who have behavioral support needs and the agencies that support them has not been done at a systemic level, or what Bronfenbrenner would refer to as the macrolevel. Therefore, consideration of person-environment fit, or the match between an individual's needs and supports provided, is critical when exploring outcomes of deinstitutionalization. Figure 2 illustrates the application of Bronfenbrenner's environmental model to the nested structures composing a residential setting for individuals with IDD in which the microsystem is the residential setting, the mesosystem is the agency which manages the setting, the exosystem is the community within which the agency is located and the macrosystem is the state in which the agency is located.

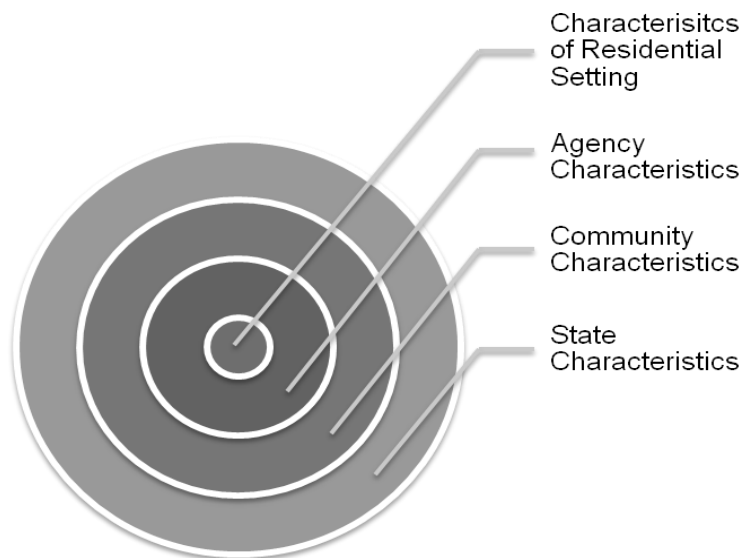


Figure 2. Application of Bronfenbrenner's environmental model to deinstitutionalization research.

In 2012, Lulinski-Norris, Rizzolo, and Heller released data concerning transitions out of Illinois SODCs between October 2001 and June 2009. Data revealed that 10.2% ($n = 163$) of the 1,594 individuals who transitioned out of an SODC were readmitted to one. Of those who returned, 72% ($n = 118$) did so due to behavioral issues; yet in only 32% of cases was technical assistance (TA) received from the Illinois Department of Human Services related to the behavioral concern. The percentage of people returning due to behavioral reasons is concerning. Of more concern, however, is the number of persons returning to an SODC after having received no TA. These findings indicate a gap in either the availability or effectiveness of behavioral health supports and services for people with IDD in the Illinois community service delivery system.

This was the case three decades ago. Findings from Jacobson and Schwartz (1983) suggested that individuals in jeopardy of placement failure were less likely to be receiving needed services, such as counseling, mental health services, or psychological/behavioral intervention, though they were more likely to display cognitive or affective behaviors. More recently, Beadle-Brown, Mansell, and Kozma noted, “[t]here is also the challenge of stopping reinstitutionalization and promoting effective support and treatment for those with more complex needs, such as challenging behavior” (2007, p. 441).

Additionally, the need to explore geographical gaps in community mental health services has not gone unnoticed by researchers. Noonan et al. (2010) noted an absence of geographical variation including neighborhood and community characteristics stating, “[r]esearchers should include more information about the qualities and descriptions of the environments that they are studying” (p. 140). Among their conclusions was that more attention should be paid to determinants of quality of life including geographical factors, such as rurality, in an effort to examine “regional variations in outcomes” (Noonan et al., 2010, p. 142).

As environmental characteristics have been shown to impact an individual’s outcomes, GIS appears to be a natural method of exploring differences between regions, counties and cities and how these differences impact individual outcomes. The overall aim of this study, therefore, is to analyze the meso- and exosystem level environmental characteristics and the availability of behavioral supports with respect to microsystem outcomes in an effort to determine the support gaps that are contributing to placement failure of deinstitutionalized persons. The specific research questions are:

1) What types of behavioral supports are available to individuals with IDD residing in Illinois community-based residences?; 2) Does the availability of behavioral supports differ between agencies with respect to geographic characteristics?; and 3) How do geographic characteristics and the availability of behavioral supports impact an individual's transition from a state operated developmental center (SODC) to a community-based setting? The conceptual framework presented in Figure 3 illustrates the variables which will be explored to determine whether or not they impact transition outcome. It includes individual characteristics such as age, gender, IQ, psychiatric diagnosis, years the individual lived in an SODC, and adaptive behavior skills. The agency, or the mesosystem, will be represented by variables including number of individuals served, number of people living in a home, number of in-house therapists and therapies offered and satisfaction with community mental/behavioral health services. Finally, the community, or the exosystem, variables will include urban/rural designation and availability of mental/behavioral supports.

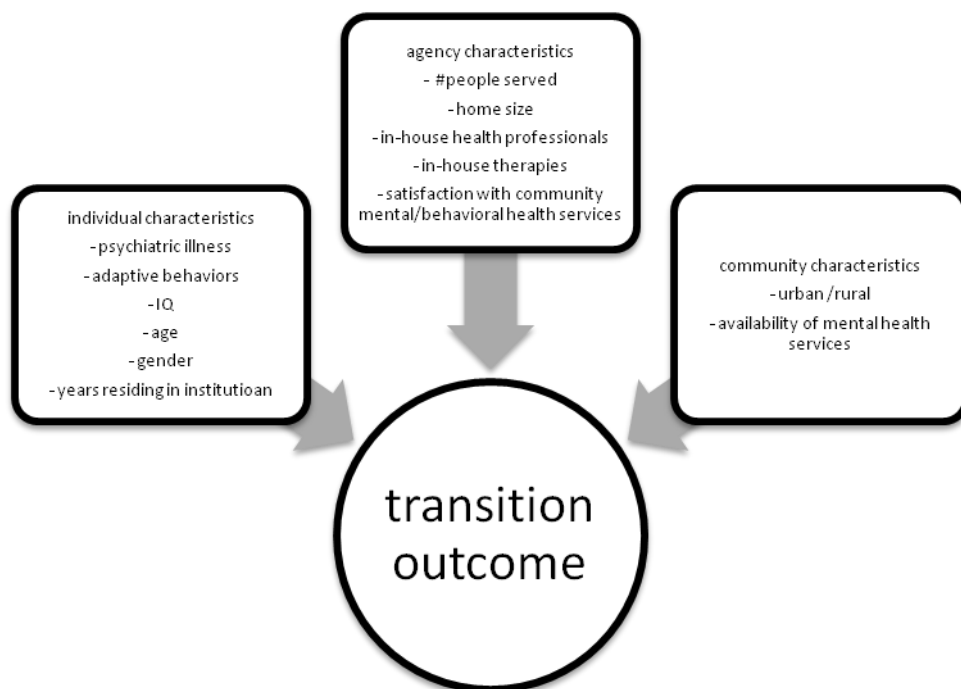


Figure 3. Conceptual Framework.

V. METHODS

A. Aim and Objectives

A significant amount of research concluded that individuals have better outcomes in community-based settings as compared to institutional facilities (Heller, 2002; Kim, Larson, & Lakin, 1999; Larson & Lakin, 1989, 2012). The majority of studies, however, have primarily focused on individual or organizational characteristics as indicators or predictors of success. Applying units of analysis from Bronfenbrenner's ecological model, deinstitutionalization research has mainly been investigated at the micro- and mesosystem levels. Some studies, however, have suggested that the exosystem can impact deinstitutionalization outcomes. Kim, Larson, and Lakin (1999), for example, observed that studies published in the 1990s consistently indicated a decrease in challenging behaviors in community settings as compared to studies published in the 1980s. They surmise that this is due to an increased availability of behavioral supports in the 1990s than compared to the 1980s, representing differences within the temporal context which may prove to impact placement success.

Maladaptive behaviors are a common reason for failure of community-based residential settings after transition from an institutional setting (Causby & York, 1991; Intagliata & Willer, 1982; Lakin, Hill, Hauber, & Bruininks, 1983; Lulinski-Norris, Rizzolo, & Heller, 2012a; Schalock, Harper, & Genung, 1981; Windle, Stewart, & Brown, 1961). Lulinski-Norris, Rizzolo, and Heller (2012a) released a report which analyzed data concerning transitions of individuals out of Illinois SODCs between October of 2001 and June of 2009. Data revealed that 10.2% ($n = 163$) of the individuals that transitioned from an SODC into a setting for 15 or fewer individuals returned to an SODC.

Individuals who returned to an SODC were on average younger, had higher ICAP Adaptive Behavior scores and higher Inventory for Client and Agency Planning (ICAP) Service Level scores, had a lower health risk, and had a shorter length of previous stay at an SODC as compared to their counterparts who remained in the community-based setting to which they transitioned. While the presence of a psychiatric diagnosis did not differ significantly between the two groups (46% of those remaining in their community placement and 54% of those returning to an SODC had a psychiatric diagnosis), 72.4% of returners did so due to behavioral issues, of whom 32% received technical assistance (TA) from the Illinois Department of Human Services related to the behavioral concern. Nearly all (97%) of the TA provided to those returning was to address behavioral concerns (Lulinski-Norris, Rizzolo, & Heller, 2012b). These findings illustrate a gap in either the availability or accessibility of behavioral supports in the Illinois community service delivery system.

To date, the majority of DI research has focused on individual and organizational characteristics in failed placement attempts instead of examining the service systems within which they exist. Investigation of the resources available to persons with IDD who have behavioral support needs and the agencies that support them has not been done at a systemic level, or what Bronfenbrenner would refer to as the exosystem level.

The overall aim of this study, therefore, was to analyze the meso- and exosystem levels in terms of the need for and availability of behavioral supports with respect to microsystem outcomes in an effort to determine support gaps that contribute to placement failure of deinstitutionalized persons. The specific research questions are:

- 1) What types of mental/behavioral health supports are available to individuals with IDD

residing in Illinois community-based settings?; 2) Does the availability of behavioral supports differ with respect to geographic characteristics?; and 3) How does the availability of behavioral supports impact an individual's transition from a state operated developmental center (SODC) to a community-based setting? Given the Governor's Rebalancing Initiative in Illinois, this exploration is timely and stands to inform policies and practices in Illinois that will improve the likelihood of successful community-based residential placement.

The research design employed the use of a retrospective quasi-experimental mixed methods design. Two datasets were used. Dataset 1 is a non-experimental retrospective design which includes an analysis of SODC discharge information between October 1, 2001 and December 31, 2012. Dataset 2 is the survey of community-based agencies into which persons transitioning out of SODCs moved.

B. Individual Variables

1. Participants

Research participants were any individual who transitioned out of an Illinois SODC between October 1, 2001 and December 31, 2012. Individual participants were identified only by their Department of Human Services' identification number to which the researcher did not have access to the key which would identify to whom the identification numbers belonged. A database similar to the one used in the Lulinski-Norris, Rizzolo, and Heller (2012b) study was used. The database contains information gathered about individuals who transitioned out of the ten Illinois SODCs and into a community-based residence during the period of time between October 1, 2001 and

December 31, 2012. Data was gathered by staff at each of the SODCs, de-identified, and submitted to the researcher (Appendix A for form used in data collection).

2. **Settings**

The ten SODCs which were in operation during this study period were: Choate, Fox, Howe³, Jacksonville⁴, Kiley, Lincoln, Ludeman, Mabley, Murray, and Shapiro. For the purposes of this study, community-based residences are defined as: Community Integrated Living Arrangements (CILA) which are group homes for eight or less individuals typically under the management of an agency in which 24-hours/7-days a week supports and services are provided; Intermittent CILAs, which are residences typically not under agency management but rather owned or rented by the individual receiving services, and provide less than 24-hours/7-days a week supports and services; or family homes in which the individuals reside in a family member's home which is privately owned or rented in which agency support may or may not be provided. Federal statute refers to home and community-based service waivers as an alternative to ICF/IDs. Statute further categorizes ICF/IDs in terms of size; 16 or more residents and less than 16 (for example, see 42 CFR 483.430). Additionally, two federally funded projects of national significance (The State of the States in Developmental Disabilities Project and the National Residential Information Systems Project) use the number 15 as a determining factor in the category of size (the categories are 1-6; 7-15; or 16+; see <http://rtc.umn.edu/RISP/main/index.asp>). State of the States in Developmental Disabilities (www.stateofthestates.org) categorizes a

³ Howe Developmental Center closed in June of 2010.

⁴ Jacksonville Developmental Center closed in November of 2012.

setting as community-based if it houses 15 or less residents. In keeping with Federal statute and two major Federal Projects of National Significance, for the purposes of this study, community-based was defined as a setting for 15 or fewer persons.

3. **Measures**

Data was gathered on the following measures as of December 31, 2012: gender; age; length of stay at SODC; SODC individual transitioned to/from; Health Risk Screening Tool level; ICAP Adaptive Behavior Score; ICAP Service Level Score; IQ at time of transition; presence and level of intellectual disability; presence of autism spectrum disorder and diagnosis; presence and type of psychiatric diagnosis; name of residential provider to which the individual transitioned; name of residential provider to which the individual transitioned; type of residential setting transitioned to; number of residents residing in transition setting; guardianship status; current type of residence; current residential status; and provision and type of technical assistance post-transition received. The collection tool can be found in Appendix A.

a. **Health Risk Screening Tool scores**

The Health Risk Screening Tool (HRST) was designed to screen for health risks associated with disabilities and is determined by rating an individual's risk and care levels across five domains: functional status, behaviors, physiological, safety, and frequency of services. The final HRST score indicates health care levels and degrees of health risk for the individual as indicated in Table II.

TABLE II
HEALTH RISK LEVELS

Level 1	Low Risk
Level 2	Low Risk
Level 3	Moderate Risk
Level 4	High Moderate Risk
Level 5	High Risk
Level 6	Highest Risk

b. **Inventory for Client and Agency Planning Scores**

i. **Service level scores**

The Inventory for Client and Agency Planning (ICAP)

Service Level Score is a combination of adaptive behavior scores and maladaptive behavior scores. ICAP Service Scores range from 0 to 100, and indicate the need for various levels of support (higher scores indicate a lower level of assistance needed) listed in Table III.

TABLE III
ICAP SERVICE LEVEL SCORES

Level	Description
Level 1	Total personal care and intense supervision
Level 2	Total personal care and intense supervision
Level 3	Extensive personal care and/or constant supervision
Level 4	Extensive personal care and/or constant supervision
Level 5	Regular personal care and/or close supervision
Level 6	Regular personal care and/or close supervision
Level 7	Limited personal care and/or regular supervision
Level 8	Limited personal care and/or regular supervision
Level 9	Infrequent or no assistance for daily living

4. **Procedure**

Individual-level data regarding transitions out of any Illinois SODC was gathered by Department of Human Services/Division of Developmental Disabilities (DHS/DDD) staff employed at one of the State Operated Developmental Centers, transcribed onto the data collection tool (Appendix A) and then transmitted electronically to the author via email. Once received, data were reviewed for missing variables or inconsistencies, coded, and entered into SPSS 22.0 for analysis.

C. **Agency Variables**

1. **Survey of community capacity for serving individuals with mental/behavioral healthcare needs**

The survey, included in Appendix B, was designed to collect information related to: agency size (in terms of individuals served); staff training on behavioral supports; number of behavioral health professionals on staff; mental/behavioral supports offered (either in-house or contracted); attempts to obtain community-based mental/behavioral health services and satisfaction with service; and overall assessment of available community-based mental/behavioral health services. Categories of mental/behavioral health professionals used in the multiple choice selections included those listed in the Illinois Adults with DD Waiver: Associate Behavior Analyst, Board Certified Behavioral Analyst, Clinical Psychologist, Licensed Clinical Professional Counselor, Licensed Clinical Social Worker, Licensed Marriage and Family Therapist, Psychiatrist, Social Worker (State of Illinois, 2012). Additionally, the category of “other” was included for respondents to list any mental/behavioral health professionals they had access to in-house but were not listed. Categories of mental/behavioral health

therapies were also taken from the Illinois Adults with DD Waiver, and included: Applied Behavioral Analysis (ABA), group counseling/therapy, individual counseling/therapy, and Relationship Development Intervention (State of Illinois, 2012). Additionally, the category of “other” was again included for respondents to list any mental/behavioral health therapies provided in-house but were not listed. The category of Telehealth, while not listed in the Waiver, was included to determine its use in rural areas of the state.

Open-ended questions asked for participant feedback on positive aspects of the service system, barriers to obtaining services and resulting impact on agency’s ability to provide supports/services to individuals transitioning out of SODCs, and suggestions for improvement of the mental/behavioral health system as it relates to people with IDD. The addition of open-ended questions allowed participants the opportunity to share their perspective and allow for triangulation with quantitative results (Patton, 2002).

The survey was piloted with a small group of professionals who have many years experience in the leadership of Illinois organizations which provide residential services to adults with IDD. Pilot testing allows an opportunity for an intended group to provide comments and suggestions as well as note any ambiguities (Mertens, 2005). Based on participant feedback, the survey was revised prior to distribution.

The survey was conducted on-line using Qualtrics (www.qualtrics.com). In July of 2013, an email inviting participation in the voluntary on-line survey (Appendix C) was sent to the Executive Director at each of the 117 community agencies to which an individual had transitioned to from an SODC during the study period. Follow-up emails were sent to non-responsive Executive Directors at approximately 4, 8, and 12 weeks

post initial contact. In some cases, follow-up phone calls were made to the individual to determine if s/he had any questions or concerns, or if they would prefer a paper copy be sent to him/her via U.S. Mail. A final call for participation was sent out in October of 2013 and the survey was closed later that same month.

Quantitative survey data was downloaded directly from Qualtrics into an Excel worksheet for cleaning and then entered into SPSS 22.0 for statistical analysis. Qualitative data, answers to the open-ended questions, were entered into an Excel spreadsheet by individual question. Analysis of the answers to the open-ended survey questions employed a grounded theory approach. Grounded theory, established by Glaser and Strauss (1967), has been described as "...a general methodology for developing theory that is grounded in data systematically gathered and analyzed" (Strauss & Corbin, 1994, p. 273). Mertens (2005) explains that the "...defining characteristic of grounded theory is that the theoretical propositions are not stated at the outset of the study. Rather, generalizations (theory) emerge out of the data themselves and not prior to data collection" (p. 242). Grounded theory allows the researcher to consider the data objectively as the researcher is not constrained by a predetermined hypothesis. Instead, grounded theory allows the data to produce theory through data collection and analysis instead of conform to it by focusing "...on the process of generating theory rather than [on] a particular theoretical content" (Patton, 2002, p. 125). This approach allows data to inform a theoretical framework that will structure future explorations of the impact of deinstitutionalization on community providers.

Inductive analysis was utilized in an effort to discover themes, patterns and categories from the data after which the researcher looked to the literature to sensitize

the concepts and refine the themes (Patton, 2002). When necessary, clarification from the participant was sought via email in the event that an answer was unclear to the researcher. Initial themes and subthemes are listed in Appendix D. Member checking, a vehicle used to establish credibility of findings by verifying them with the respondents (Mertens, 2005) was conducted by emailing a synopsis of the key themes to all survey participants in an effort to provide the opportunity for comment. No objections were received. Various sources of previously collected qualitative and quantitative data afforded the opportunity for triangulation.

D. **Community-Level Variables**

1. **Metropolitan and non-metropolitan**

This study employed the use of a first-level GIS analysis using counties in which agencies were located. The U.S. Office of Management and Budget (OMB) delineates geographic entities of metropolitan and micropolitan statistical areas, based on U.S. Census Data. Metropolitan (metro) areas contain a core urban area of $\geq 50,000$ residents while a micropolitan (micro) area has a core urban area between 10,000 and 49,999 residents. Each metro and micro area includes at least one county containing the core urban area as well as any adjacent counties contributing to social and economic integration of the urban core. All other areas are designated as non-metropolitan (U.S. Census Bureau, 2013). The county of the organization's headquarters into which an individual moved was categorized as either metropolitan or non-metropolitan.

2. **Urban influence codes**

In 1993, Ghelfi and Parker developed county-level measures of urban influence categories called Urban Influence Codes (1997). Urban influence codes (UIC) categorize counties based on population, size of the metropolitan area, as well as non-metropolitan counties by the population of their largest cities in addition to proximity to metro- and micropolitan areas (U.S. Department of Agriculture, 2013). Currently used by the U.S. Department of Agriculture's Economic Research Service and last updated in 2013, these categories divide counties into two major groups based on population; metro and non-metro. Metro counties are further divided into two groups – large metro areas with one million residents, and small metro areas with fewer than one million residents. Non-metro areas are further divided into 10 categories according to their adjacency to small or large metro areas and then further grouped based on city size. This results in a 12-part county classification system which allows researchers to further divide county-level data into smaller residential categories beyond the dichotomous metropolitan and non-metropolitan classifications. Table IV displays each of the 12 urban influence codes and corresponding definitions.

TABLE IV
2013 URBAN INFLUENCE CODES AND DESCRIPTIONS

Code	Description
<u>Metropolitan Counties</u>	
1	In a large metro area of >1M residents
2	In a small metro area of 49,999 – 999,999 residents
<u>Non-metropolitan Counties</u>	
3	In a micro ^a area adjacent to large metro ^b area
4	In a non-core ^c area adjacent to a large metro area
5	In a micro area adjacent to small metro area
6	In a noncore area adjacent to small metro area containing a city/town of $\geq 2,500$ residents
7	In a noncore area adjacent to small metro area and not containing a city/town of $\geq 2,500$ residents
8	In a micro area not adjacent to a metro area
9	In a noncore adjacent to micro area containing a city/town of $\geq 2,500$ residents
10	In a noncore adjacent to micro area and does not contain a city/town of $\geq 2,500$ residents
11	In a noncore area non-adjacent to a metro or micro area containing a city/town of $\geq 2,500$ residents
12	In a noncore area non-adjacent to a metro or micro area and does not contain a city/town of $\geq 2,500$ residents

Source: U.S. Department of Agriculture, Economic Research Service (2013)

^a micro areas have between 10,000 and 49,999 residents

^b metro areas have $\geq 50,000$ residents

^c Non-core refers to counties that do not contain a city or town of at least 10,000 residents.

3. **Urban categories**

Bennett, Olatosi, and Probst (2008) re-organized the urban influence codes consolidating them into four groups: urban, micropolitan rural, small adjacent rural and remote rural. Given the size and population diversity in the state of Illinois, however, Bennett, Olatosi, and Probst's categories were not used as this categorization was not sensitive enough to detect differences between large and small metropolitan areas. Instead, the researcher collapsed the categories as such: large metropolitan, small metropolitan and micropolitan/rural. Table V displays the urban categorization which was used in the present study. The resulting re-categorization of the urban influence codes allowed for a more evenly dispersed delineation between population categories and thus allowed for more reliable analysis.

TABLE V
URBAN CATEGORIES USED IN STUDY

Category	Code	Description
Large Metro	1	In a large metro area of >1M residents
Small Metro	2	In a small metro area of 49,999 – 999,999 residents
Micropolitan/Rural	3	In a micro area adjacent to large metro area
	5	In a micro area adjacent to small metro area
	8	In a micro area not adjacent to a metro area
	4	In a non-core area adjacent to a large metro area
	6	In a noncore area adjacent to small metro area containing a city/town of $\geq 2,500$ residents
	7	In a noncore area adjacent to small metro area and not containing a city/town of $\geq 2,500$ residents
	9	In a noncore adjacent to micro area containing a city/town of $\geq 2,500$ residents
	10	In a noncore adjacent to micro area and does not contain a city/town of $\geq 2,500$ residents
	11	In a noncore area non-adjacent to a metro or micro area containing a city/town of $\geq 2,500$ residents
	12	In a noncore area non-adjacent to a metro or micro area and does not contain a city/town of $\geq 2,500$ residents

E. Data Analysis

Individual-level and survey data were cleaned, coded and entered into SPSS

22.0. Community characteristics, including designation as metropolitan or non-

metropolitan, urban influence codes and categories, were used as variables in order to detect relationships between individual placement success or failure, and resources available to the community agencies to which they moved. Independent *t* tests, chi-square tests of independence and analysis of variance were conducted to determine if there were significant differences between returners (individuals who return to an SODC due to behavioral issues) and stayers (individuals who remain in transition placement) with respect to demographics, HRST and ICAP scores. Pearson correlations were conducted to determine how variables corresponded with one another. A binary logistic regression analysis was completed to detect impacts of the following on an individual's residential status: individual demographics, agency capacity to provide behavioral services, and the county's urban influence categories. Finally, a hierarchical regression was conducted based on three models to explore variables' predictive properties.

F. **Institutional Review Board**

All Institutional Review Board policies of the Office of the Protection of Research Subjects at the University of Illinois at Chicago were followed in seeking and obtaining approval prior to initiating any research procedures (Appendix E).

VI. RESULTS

A. Subjects

1. Responding agency characteristics

Initially, 68 of the 117 organizational representatives who were contacted participated in the on-line survey, yielding a 58.1% response rate. Responses from three organizations, however, had to be disqualified. In two instances, responses were disqualified due to the agency not providing residential services. In one instance, an organization did not accept an individual into its program within the time period under study. The final response rate was 65 out of 117 organizations, yielding a 55.6% response rate.

a. Geography

i. Regions and counties represented

Figure 4 indicates Illinois counties in which a recruited agency provider was located as well as those agencies that did and did not respond to survey recruitment.

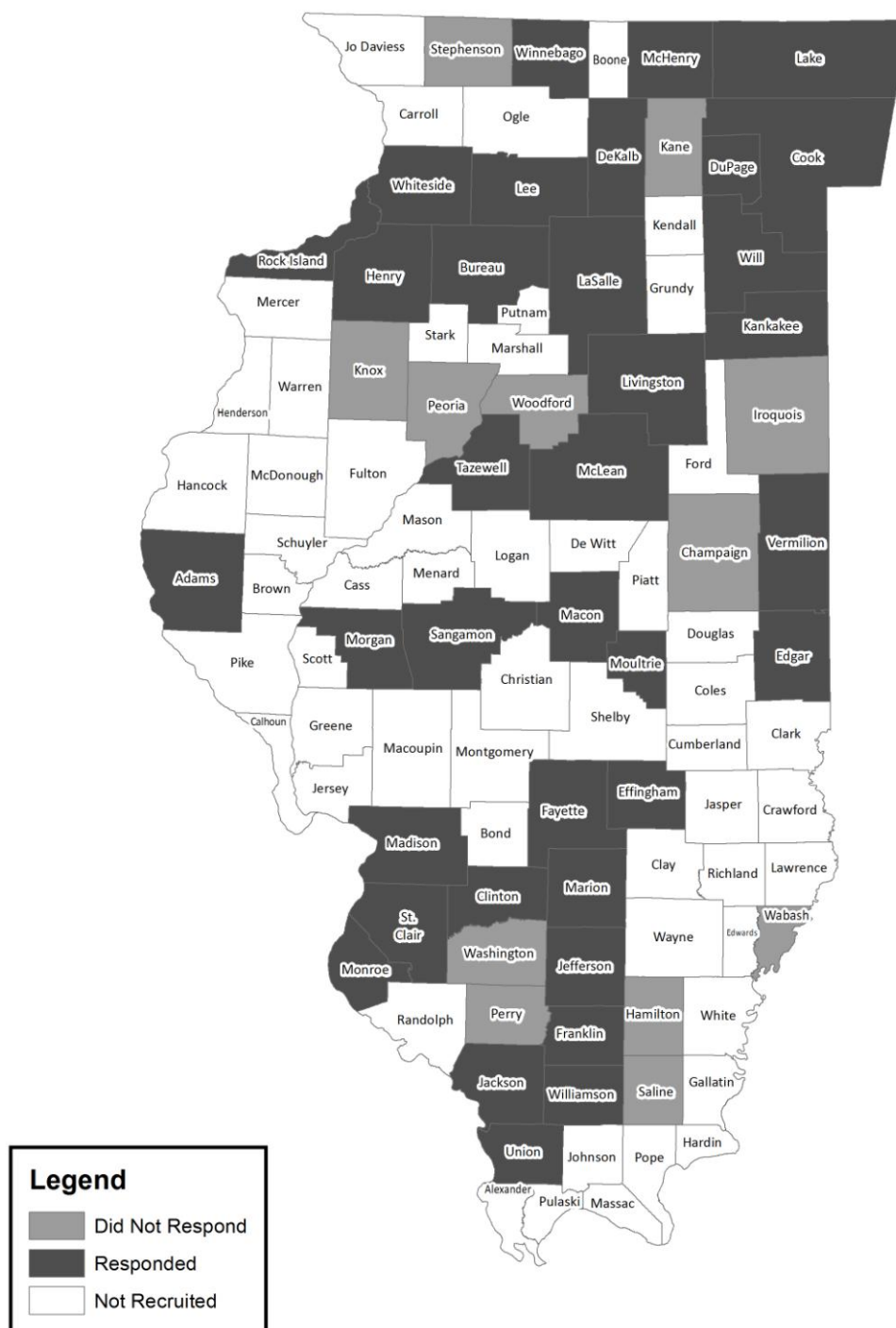


Figure 4. Counties containing responding and non-responding agencies.

Table VI displays the percentage of counties represented, the individual counties represented by respondents in each of the five Illinois DHS Regions, and the number of organizations participating in each Region. Participating organizations offered residential services in 67 of 102 total Illinois counties (65.7%). Region 2 had the highest representation of counties; 15 of its 17 counties (88%) were represented in the survey. Region 2 also had the largest number of organizations respond; 21 organizations (32%) were represented in the survey. Region 1 was represented by 31% ($n = 20$) of all participating organizations provided services in Region 1, which is comprised of Cook County encompassing the city of Chicago and several of its neighboring suburbs. Eighteen organizations (28%) from Region 5 participated which represented 58% of counties in that region. Region 3 also had a high percentage of counties represented; 87% of all counties in Region 3 were represented by eleven participating organizations (17%). Region 4 had the lowest level of participation in the survey; nine organizations (14%) representing 12 of the 28 counties (43%) completed the survey.

TABLE VI
GEOGRAPHIC REPRESENTATION OF PARTICIPATING ORGANIZATIONS BY
DHS REGION AND COUNTY

DHS Region	% of Total Counties Represented	Illinois Counties Represented in Region	Number of Responding Organizations	% of Total Organizations
1	1/1 = 100%	Cook	20	30.8%
2	15/17 = 88%	Boone, DeKalb, DuPage, Grundy, JoDaviess, Kane, Kankakee, Kendall, Lake, Lee, McHenry, Ogle, Whiteside, Will, Winnebago	21	32.3%
3	20/23 = 87%	Bureau, Ford, Fulton, Henderson, Henry, Iroquois, Knox, LaSalle, Livingston, Marshall, McDonough, McLean, Mercer, Peoria, Putnam, Rock Island, Tazewell, Vermillion, Warren, Woodford	11	16.9%
4	12/28 = 43%	Adams, Christian, Clark, Edgar, Effingham, Greene, Jersey, Macon, Montgomery, Morgan, Moultrie, Sangamon	9	13.8%
5	19/33 = 58%	Bond, Clinton, Fayette, Franklin, Jackson, Jasper, Jefferson, Madison, Marion, Massac, Monroe, Pulaski, Randolph, Richland, St. Clair, Union, Wayne, Williamson, Washington	18	27.7%

ii. **Metropolitan and micropolitan statistical areas represented**

Table VII shows the metropolitan or micropolitan statistical areas in which the headquarters of participating agencies were located. The largest metropolitan statistical area (MSA) represented was Chicago-Naperville-Joliet. Twenty-eight (41%) of organizations were located in that MSA. The second largest MSA represented was Illinois Non-Metropolitan Areas, which are considered to be rural. Twenty-two (32%) of responding organizations are located in rural areas of Illinois. Other micro- and metropolitan statistical areas represented included (from highest to lowest): St. Louis, MO-IL (n = 7; 10%); Bloomington-Normal, Kankakee – Bradley, and Springfield (each with n = 2; 3%); Danville, Davenport-Moline-Rock Island, Decatur, Peoria, and Rockford (each with n = 1; 1.5%).

TABLE VII
METROPOLITAN AND MICROPOLITAN STATISTICAL AREAS (MSA)
REPRESENTED (N = 65)

MSA	Number of Organizations Responding	% of Responding Organizations
<u>Metropolitan Areas</u>		
Chicago – Naperville – Joliet, IL – IN – WI	25	38.5%
St. Louis, MO – IL	7	10.8%
Bloomington – Normal, IL	2	3.1%
Kankakee – Bradley, IL	2	3.1%
Springfield, IL	2	3.1%
Danville, IL	1	1.5%
Davenport-Moline-Rock Island, IA – IL	1	1.5%
Decatur, IL	1	1.5%
Peoria, IL	1	1.5%
Rockford, IL	1	1.5%
IL Non-metropolitan Area	22	33.8

iii. **Urban influence codes and categories**

Table VIII shows the urban influence codes in which responding agencies' administrative offices are located. Nearly half (49.2%) of responding agencies were located in urban influence code 1 which represents large metropolitan areas containing more than one million residents. Slightly over one-fifth (21.5%) of responding agencies were located in urban influence code 2 representing small metropolitan areas having between 49,999 and one million residents.

TABLE VIII
RESPONDING PROVIDERS' URBAN INFLUENCE CODES

Urban Influence		
Code	# Respondents	% of Respondents
1	32	49.2%
2	14	21.5%
3	3	4.6%
4	1	1.5%
5	4	6.2%
6	5	7.7%
7	0	0%
8	5	7.7%
9	1	1.5%
10	0	0%
11	0	0%
12	0	0%
Total	65	*

*does not equal 100% due to rounding

Table IX displays the urban influence categories within which responding agencies were located. Urban influence code 1 is the same as the urban influence code category of 'large urban' and thus had the same percentage of respondents, 49.2%. Similarly, urban influence code 2 is the same as urban influence code category 'small urban' and also has the same respondents (21.5%). Urban influence codes 3 - 12 are grouped together in urban influence code category 'micropolitan/rural' and have the same amounts – each had 29.2% of responding agencies located in these areas.

TABLE IX
RESPONDING PROVIDERS' URBAN CATEGORIES

Urban Category	# of Respondents	% Respondents
Large Urban	32	49.2%
Small Urban	14	21.5%
Micropolitan/Rural	19	29.2%
Total	65	100%

B. Survey Participants

Participation was open to the Executive Director of an organization or his/her designee. As can be seen in Figure 6, the majority of respondents (57.8%, n = 37) listed their position as one of executive leadership within the organization.

Respondent title categories included: Chief Executive Officer/President/Executive Director (35.4%, n = 23), Vice President/Associate or Assistant Executive Director (21.5%, n = 14), Program Director (24.6%, n = 16), and Manager/Coordinator/Administrator (16.9%, n = 11). One individual did not provide a title.

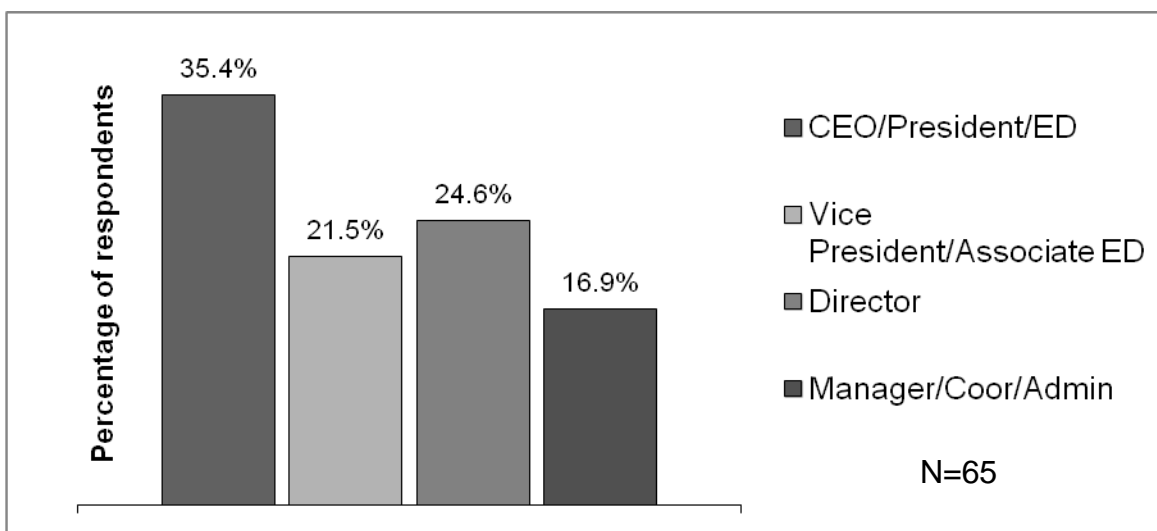


Figure 6. Survey respondents' titles.

C. Organizational Characteristics

1. Size

Participating organizations ranged in size (defined here as the number of individuals served) from two to 1,300 individuals participating in all programs (including residential and day services). The average size of a participating organization was 120 ($sd = 185$). Table X shows the distribution of agency size grouped by categories of individuals served. The majority (38.5%, $n = 25$) of the participating organizations served up to 50 individuals across all programs. The next largest category of responders were organizations serving 51-100 individuals across all programs (29.2%, $n = 19$). Combined, agencies serving 100 or less individuals across all programs made up over two-thirds (67.7%) of the respondent pool. The third largest category of organizations responding are those serving 200 individuals

or more across all programs (15.4%, n = 10). Seven organizations (10.8%) serving 101-150 individuals responded. The smallest group represented was that of organizations serving 151-200 individuals across all programs, composing 6.2% of all respondents.

TABLE X
RESPONDING AGENCIES BY NUMBER OF INDIVIDUALS
SERVED ACROSS ALL PROGRAMS (N = 65)

Individuals served	# Agencies	%	Cumulative %
0-50	25	38.5%	38.5%
51-100	19	29.2%	67.7%
101-150	7	10.8%	78.5%
151-200	4	6.2%	84.6%
200+	10	15.4%	100%
Total	65	100%	

2. **Provision of residential services to former residents of state operated developmental centers**

In order to be eligible for participation in this study, agencies were required to have accepted at least one individual from an SODC between October 1, 2001 and December 31, 2012. During that period of time, the 65 surveyed organizations together claimed to have accepted individuals from all ten SODCs which were in operation during that study period. Table XI indicates the number of respondents indicating that they accepted individuals from each SODC listed. Forty percent of responding agencies accepted an individual transitioning out of

Jacksonville, nearly 37% of respondents indicated that their organization had accepted an individual from Shapiro, 31% from Murray, 28% from Ludeman, 25% from Howe, 22% each from Kiley and Choate, 20% from Lincoln, 14% from Mabley, and 8% from Fox.

TABLE XI
NUMBER AND PERCENTAGE OF RESPONDING AGENCIES
ACCEPTING INDIVIDUALS FROM EACH SODC (N = 65)

SODC	# of agencies	% of respondents
Jacksonville	26	40.0%
Shapiro	24	36.9%
Murray	20	30.8%
Ludeman	18	27.7%
Howe	16	24.6%
Choate	14	21.5%
Kiley	14	21.5%
Lincoln	13	20.0%
Mabley	9	13.8%
Fox	5	7.7%

D. Research Questions

1. **What types of behavioral supports are available to individuals with intellectual/developmental disabilities residing in Illinois community-based settings?**
 - a. **Crisis intervention training**

The vast majority (86.2%, $n = 56$) of organizations surveyed indicated that they offer crisis intervention training to staff; 52.3% ($n = 34$) offer training from the Crisis Prevention Institute, 9.2% ($n = 6$) offer Mandt Training, while 24.6% ($n = 16$) indicated that they offer another type of crisis intervention training. These “other” types of curricula included: agency developed training ($n = 10$), Safety Care ($n = 2$), Crisis Prevention Management ($n = 1$), Aggression Management ($n = 1$), ABA model crisis intervention ($n = 1$), Effective Behavioral Supports ($n = 1$), External Control Training ($n = 1$), Mental Health First Aid ($n = 2$), Quality Behavioral Solutions ($n = 1$) and training through the SSTs.

b. **In-house access to mental/behavioral health professionals**

Participating agencies were asked about their access to different categories of mental/behavioral health specialists in-house (e.g., the specialist is either a staff member of the agency or has a contract with the agency to provide services). These categories of professionals were chosen as they are included as approved service providers in the Illinois Adults with Developmental Disabilities HCBS Waiver Application which was effective during the study period (State of Illinois, 2012). Agencies were asked if they had access to the following: clinical psychologist, psychiatrist, Licensed Marriage and Family Therapist (LMFT), Licensed Clinical Social Worker (LCSW), Licensed Clinical Professional Counselor (LCPC), social worker, Board Certified Behavior Analyst (BCBA), Associate Behavior Analyst, or a professional in another category. Those “other” categories included: medical doctor ($n = 2$); certified educators, rehabilitation counselors, certified case managers, doctoral psychology intern, peer recovery support

specialist, occupational therapist, physical therapist, pet, art and music therapist, massage therapist, acupuncturist, psychiatric nurse practitioner, and a registered nurse (for each, n = 1). Table XII contains information on the percentage of represented organizations that have access to each type of mental/behavioral health specialist included in the HCBS Waiver. The most common type of professional responding agencies had access to was a psychiatrist (46.2%) while the least common was an LMFT.

TABLE XII
SURVEY RESPONDENT ACCESS TO MENTAL/BEHAVIORAL HEALTH
PROFESSIONALS (N = 65)

Professional	# of Respondents that have access	%
Psychiatrist	30	46.2%
Board Certified Behavior Analyst	28	43.1%
Clinical Psychologist	26	40.0%
Licensed Clinical Social Worker	24	36.9%
Social Worker	20	30.8%
Licensed Clinical Professional Counselor	18	27.7%
Associate Behavior Analyst	15	23.1%
Other professional	9	13.8%
Licensed Marriage & Family Therapist	2	3.1%

c. **In-house mental/behavioral health service provision**

Participating agencies were also surveyed about different categories of mental/behavioral health treatments provided in-house (by professionals either in their employ or who have a contract to provide on-site

services). Again, predetermined categories indicated in the IL Adults DD Waiver were used, with the exception of telehealth. Telehealth was included to determine 1) if participating organizations are utilizing information technology as an approach to care and 2) if that use varies between organizations with respect to urban influence code category. As shown in Table XIII, the most popular type of treatment offered in-house was individual counseling/psychotherapy while the least common was RDI. Treatment strategies that were indicated in the category of “other” included: music, dance, drama, art, pet therapy, treatment for substance abuse, behavior plan review, psychotropic medication monitoring, and dialectical behavioral therapy. Only one organization (1.5%) indicated using relationship development intervention (RDI).

TABLE XIII
MENTAL/BEHAVIORAL HEALTH THERAPIES USED
BY SURVEY RESPONDENTS (N = 65)

Therapy	#	%
Individual counseling/ psychotherapy	31	47.7%
Applied behavior analysis (ABA)	27	41.5%
Group counseling/therapy	21	32.3%
Telehealth	6	9.2%
Other	5	7.7%
Relationship Development Intervention (RDI)	1	1.5%

d. **Use of community-based services**

Participating agencies were also surveyed about the different types of community-based mental/behavioral health services used. As shown in Table XIV, options provided included: Community Mental Health Centers (CMHC), inpatient psychiatric treatment/crisis services, DHS/DDD funded SSTs and Clinical Administrative Review Teams (CART), private sector mental health services, Federally Qualified Health Centers (FQHC), Rural Health Centers (RHC), university-based clinics, emergency rooms (ER), and police/911/emergency medical services (EMS). Space was provided to indicate “other” categories of community services used and included: private ambulance services and an SODC. Table XIV provides information on what community-based resources agencies reported using for mental/behavioral health services.

TABLE XIV
AGENCY UTILIZATION OF COMMUNITY-BASED
MENTAL/BEHAVIORAL HEALTH SERVICES (N = 65)

Community-based service	#	%
Police/911/Emergency Medical Services	59	90.8%
DHS/DDD supports	58	89.2%
Emergency Room	54	83.1%
Inpatient psychiatric treatment/crisis services	53	81.5%
Community Mental Health Centers	43	72.6%
Private sector mental health services	29	44.6%
University based clinics	16	24.6%
Federally Qualified Health Centers	10	15.4%
Rural Health Centers	9	13.8%
Other	3	4.6%

Over 80% of all respondents reported using police/911/EMS (90.8%, n = 59), DHS/DDD supports (89.2%, n = 58), emergency rooms (83.1%, n = 54), and inpatient psychiatric treatment or crisis services (81.5%, n = 53). Community Mental Health Centers were used by 72.6% (n = 43) of respondents. Less than half of respondents reported using private sector mental health services (44.6%, n = 29) while less than one quarter reporting using university based clinics (24.6%, n = 16). FQHCs were used by 15.4% (n = 10) of respondents, while 13.8% (n = 9) reported using Rural Health Centers. Three organizations (4.6%) reported using “other” categories of community-based services, which included: behavior analyst, private ambulance, and an SODC.

e. **Reasons for seeking services**

In addition to being asked from which community-based entities services were sought, survey participants were asked for what reason(s) treatment was sought. Categories of behaviors for which treatment might be sought was taken from the ICAP maladaptive behavior listing and included: harmful to self, harmful to others, property destruction, sexually inappropriate behavior, illegal behavior, unusual behaviors (e.g., pacing, rocking, grinding teeth, or eating non-food items) as well as an open-ended category for “other”. The remainder of this section will discuss survey participants’ responses by community service and include reasons for which services were sought and satisfaction with service(s). If a respondent indicated that they had used a service category, they were then asked to rate their satisfaction with that particular service on a scale of 1-5 where 1 = very dissatisfied, 2 = dissatisfied, 3 = neutral, 4 = satisfied, and 5 = very satisfied.

f. **Use of specific services**

i. **Police/911/emergency medical services**

Nearly 91% (n = 59) of survey respondents sought assistance for mental/behavioral issues from local police, 911, and/or EMS. As illustrated in Table XV, the most frequent behavior for which these services were sought was due to an individual being a harm to others (75.4%, n = 49), followed by harmful to self (69.2%, n = 45), and property destruction (52.3%, n = 34). Thirteen agencies (20%) have sought assistance from police/911/EMS due to unusual behaviors. Illegal behaviors caused 11 agencies (17%) to seek assistance. Five percent of agencies sought services due to sexually inappropriate behaviors (4.6%,

n = 3) and two agencies sought assistance with behaviors categorized as “other” (3.1%). Overall, of the 59 respondents who indicated that their agency had used police/911/EMS services, 58% indicated that they were satisfied or very satisfied with services received, while 16.7% indicated being dissatisfied or very dissatisfied. Twelve agencies (20%) reporting feeling neutral. Table XVI illustrates satisfaction from the interactions.

TABLE XV
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM POLICE/911/EMS

Reason	# of agencies	% of agencies (n = 59)
Harmful to self	45	69.2%
Harmful to others	49	75.4%
Property destruction	34	52.3%
Sexually inappropriate behavior	3	4.6%
Illegal behavior	11	16.9%
Unusual behavior	13	20.0%
Other	2	3.1%

TABLE XVI
SURVEY RESPONDENT SATISFACTION WITH POLICE/911/EMS ASSISTANCE

Level of Satisfaction	# of agencies responding	% of agencies (n = 57)
Very satisfied	3	5.3%
Satisfied	32	56.1%
Neutral	12	21.1%
Dissatisfied	8	14.0%
Very dissatisfied	2	3.5%

ii. **Department of Human Services/Division of**
Developmental Disabilities community supports

Nearly 90% (n = 58) of survey respondents sought assistance for mental/behavioral issues from DHS/DDD community supports. As can be seen in Table XVII, the most frequent behavior for which these services were sought was due to an individual being harmful to self (61.5%, n = 40), followed by harmful to others (56.9%, n = 37) and property destruction (46.2%, n = 30). Nineteen agencies (29.2%) have sought assistance from community supports due to unusual behaviors. Thirteen agencies sought services due to sexually inappropriate behaviors (20.0%). Illegal behaviors caused 8 (12.3%) agencies to seek assistance.

Table XVIII indicates satisfaction with interactions with DHS/DDD community supports. One-third (33.4%) were satisfied/very satisfied with services, while nearly one-quarter (24.6%) felt neutral, and 42.1% felt dissatisfied/very dissatisfied with services received.

TABLE XVII
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM DHS/DDD COMMUNITY SUPPORTS

Reason	# of agencies	% of agencies (n = 58)
Harmful to self	40	61.5%
Harmful to others	37	56.9%
Property destruction	30	46.2%
Sexually inappropriate behavior	13	20.0%
Illegal behavior	8	12.3%
Unusual behavior	19	29.2%
Other	3	4.6%

TABLE XVIII
SURVEY RESPONDENT SATISFACTION WITH
DHS/DDD COMMUNITY SUPPORTS

Level of Satisfaction	# of agencies responding	% of agencies (n = 57)
Very satisfied	3	5.3%
Satisfied	16	28.1%
Neutral	14	24.6%
Dissatisfied	13	22.8%
Very dissatisfied	11	19.3%

iii. **Emergency room**

Eighty-three percent (n = 54) of survey respondents sought assistance for mental/behavioral issues from local emergency rooms. As show in Table XIX, the most frequent behavior for which these services were sought was due to an individual being a harm to self (70.8%, n = 46), followed by harmful to others (64.6%, n = 42) and property destruction (40.0%, n = 26). Eleven agencies (16.9%) sought assistance from an emergency room due to unusual behaviors. Five agencies sought services due to sexually inappropriate behaviors (7.7%). Illegal behaviors caused three (4.6%) agencies to seek assistance. In terms of satisfaction with services, as shown in Table XX, nearly one-third (32.1%) of respondents indicated that they were satisfied/very satisfied with services received from emergency rooms, nearly 36% felt neutral and another third (32.1%) felt dissatisfied/very dissatisfied with ER services.

TABLE XIX
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES FROM
EMERGENCY ROOM

Reason	# of agencies	% of agencies (n = 54)
Harmful to self	46	70.8%
Harmful to others	42	64.6%
Property destruction	26	40.0%
Sexually inappropriate behavior	5	7.7%
Illegal behavior	3	4.6%
Unusual behavior	11	16.9%
Other	0	0.0%

TABLE XX
SURVEY RESPONDENT SATISFACTION WITH
EMERGENCY ROOM

Level of Satisfaction	# of agencies responding	% of agencies (n = 53)
Very satisfied	0	0.0%
Satisfied	17	32.1%
Neutral	19	35.8%
Dissatisfied	10	18.9%
Very dissatisfied	7	13.2%

iv. **In-patient psychiatric hospitals/crisis services**

Nearly 82% (n = 53) of survey respondents sought assistance for mental/behavioral issues from in-patient psychiatric hospitals or other crisis services. As shown in Table XXI, the most frequent behavior for which these

services were sought was due to an individual being a harm to self (76.9%, n = 50), followed by harmful to others (72.3%, n = 47) and property destruction (38.5%, n = 25). Thirteen agencies (20%) sought assistance from an in-patient psychiatric hospital/crisis services due to unusual behaviors. Illegal behaviors caused seven (10.8%) agencies to seek assistance. Two agencies sought services due to sexually inappropriate behaviors (3.1%), while three sought assistance for behaviors categorized as “other” (4.6%). Table XXII illustrates that nearly half (47.5%) of respondents felt satisfied/very satisfied with services received from in-patient psychiatric hospitals/crisis services, while nearly a third (30.2%) felt neutral and another third (30.2%) felt dissatisfied/very dissatisfied.

TABLE XXI
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM IN-PATIENT PSYCHIATRIC HOSPITALS/CRISIS SERVICES

Reason	# of agencies	% of agencies (n = 53)
Harmful to self	50	76.9%
Harmful to others	47	72.3%
Property destruction	25	38.5%
Sexually inappropriate behavior	2	3.1%
Illegal behavior	7	10.8%
Unusual behavior	13	20.0%
Other	3	4.6%

TABLE XXII
SURVEY RESPONDENT SATISFACTION WITH
IN-PATIENT PSYCHIATRIC HOSPITALS/CRISIS SERVICES

Level of Satisfaction	# of agencies responding	% of agencies (n = 53)
Very satisfied	4	7.5%
Satisfied	18	40.0%
Neutral	16	30.2%
Dissatisfied	9	17.0%
Very dissatisfied	7	13.2%

v. **Community mental health centers**

Nearly 66.2% (n = 43) of survey respondents sought assistance for mental/behavioral issues from Community Mental Health Centers (CMHCs). As seen in Table XXIII, the most frequent behavior for which these services were sought was due to an individual being a harm to others (43.1%, n = 28), followed by harmful to self (40%, n = 26) and property destruction (36.9%, n = 24). Seventeen agencies (26.2%) have sought assistance from CMHCs due to unusual behaviors. Twelve agencies sought services due to sexually inappropriate behaviors (18.5%). Illegal behaviors caused nine (13.8%) agencies to seek assistance, while behaviors categorized as “other” (15.4%, n = 10) preceded contact. The “other” category included seeking counseling due to grief (n = 2) and/or depression (n = 3), routine counseling (n = 2) as well as medication management (n = 2) and verbal aggression (n = 1). Table XXIV displays satisfaction with services obtained from a CMHC. Nearly one-third (34.9%) of respondents indicated feeling

satisfied/very satisfied with services received, over one-third (37.2%) felt neutral and a fifth (20.9%) indicated feeling dissatisfied/very dissatisfied.

TABLE XXIII
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM COMMUNITY MENTAL HEALTH CENTERS

Reason	# of agencies	% of agencies (n = 43)
Harmful to self	26	60.4%
Harmful to others	28	65.1%
Property destruction	24	55.8%
Sexually inappropriate behavior	12	27.9%
Illegal behavior	9	20.9%
Unusual behavior	17	39.5%
Other	10	23.3%

TABLE XXIV
SURVEY RESPONDENT SATISFACTION WITH
COMMUNITY MENTAL HEALTH CENTERS

Level of Satisfaction	# of agencies responding	% of agencies (n = 43)
Very satisfied	5	11.6%
Satisfied	10	23.3%
Neutral	16	37.2%
Dissatisfied	5	11.6%
Very dissatisfied	4	9.3%

vi. **Private-sector mental health services**

Just under half (45%, n = 29) of survey respondents sought assistance for mental/behavioral issues from private sector mental health services. As seen in Table XXV, the most frequent behavior for which these services were sought was due to an individual being a harm to self (26.2%, n = 17), followed by harmful to others (24.6%, n = 16) and unusual behavior (20%, n = 13). Twelve agencies (18.5%) sought assistance from private sector mental health services due to property destruction. Sexually inappropriate behaviors caused eight (12.3%) agencies to seek assistance. Seven agencies sought services due to illegal behaviors (10.8%) and six organizations sought services for behaviors categorized as “other” (9.2%). The “other” category included counseling and medication management. Table XXVI displays respondent satisfaction scores with private sector mental health services. Nearly 70% indicated feeling satisfied/very satisfied, nearly one-quarter (24.1%) indicated neutral feelings and 3.4% indicated feeling dissatisfied/very dissatisfied.

TABLE XXV
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM PRIVATE SECTOR MENTAL HEALTH SERVICES

Reason	# of agencies	% of agencies
Harmful to self	17	26.2%
Harmful to others	16	24.6%
Property destruction	12	18.5%
Sexually inappropriate behavior	8	12.3%
Illegal behavior	7	10.8%
Unusual behavior	13	20.0%
Other	6	9.2%

TABLE XXVI
SURVEY RESPONDENT SATISFACTION WITH
PRIVATE-SECTOR MENTAL HEALTH SERVICES

Level of Satisfaction	# of agencies responding	% of agencies (n = 28)
Very satisfied	4	13.8%
Satisfied	16	55.2%
Neutral	7	24.1%
Dissatisfied	1	3.4%
Very dissatisfied	0	0.0%

vii. **University-based clinics**

Nearly 25% (n = 16) of survey respondents sought assistance for mental/behavioral issues from university-based clinics. The most frequent behaviors for which these services were sought, as shown in Table XXVII, was due to an individual being a harm to self (n = 9, 56%) and others (n = 9, 56%),

followed by property destruction (n = 4, 25%). Five agencies (31%) have sought assistance from university-based clinics due to unusual behaviors. Three organizations sought assistance for behaviors categorized as “other” (19%) which included regular monitoring and psychotic episode. Two agencies sought services due to sexually inappropriate behaviors (13%). Illegal behaviors caused one (6%) agency to seek assistance. As can be seen in Table XXVIII, over half (57.2%) of respondents indicated feeling satisfied/very satisfied with services obtained from a university-based clinic, while 38.1% felt neutral; just under 5% reported feeling dissatisfied/very dissatisfied.

TABLE XXVII
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM UNIVERSITY-BASED CLINICS

Reason	# of agencies	% of agencies (n = 16)
Harmful to self	9	56.3%
Harmful to others	9	56.3%
Property destruction	4	25.0%
Sexually inappropriate behavior	2	12.5%
Illegal behavior	1	6.3%
Unusual behavior	5	31.3%
Other	3	18.8%

TABLE XXVIII
SURVEY RESPONDENT SATISFACTION WITH
UNIVERSITY-BASED CLINICS

Level of Satisfaction	# of agencies responding	% of agencies (n = 21)
Very satisfied	1	4.8%
Satisfied	11	52.4%
Neutral	8	38.1%
Dissatisfied	1	4.8%
Very dissatisfied	0	0.0%

viii. **Federally qualified health centers**

Fifteen percent (n = 10) of survey respondents sought assistance for mental/behavioral issues from Federally Qualified Health Centers (FQHCs). As seen in Table XXIX, the most frequent behavior for which these services were sought was due to an individual being a harm to self (n = 4, 40%), harmful to others (n = 4, 40%), followed by property destruction (n = 3, 30%). Illegal behaviors caused one agency to seek assistance, while another sought services due unusual behaviors. Two agencies sought services for behaviors categorized as “other” which included assistance with psychotropic medication. Service satisfaction is illustrated in Table XXX, 50% of respondents indicated feeling satisfied with services received from FQHCs, while 40% felt neutral. One-tenth felt very dissatisfied.

TABLE XXIX
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM FEDERALLY QUALIFIED HEALTH CENTERS

Reason	# of agencies	% of agencies (n = 10)
Harmful to self	4	40.0%
Harmful to others	4	40.0%
Property destruction	3	30.0%
Sexually inappropriate behavior	1	10.0%
Illegal behavior	1	10.0%
Unusual behavior	1	10.0%
Other	2	20.0%

TABLE XXX
SURVEY RESPONDENT SATISFACTION WITH
FEDERALLY QUALIFIED HEALTH CENTERS

Level of Satisfaction	# of agencies responding	% of agencies (n = 10)
Very satisfied	0	0%
Satisfied	5	50%
Neutral	4	40%
Dissatisfied	0	0%
Very dissatisfied	1	10%

ix. **Rural health centers**

Nearly 14% (n = 9) of survey respondents sought assistance for mental/behavioral issues from Rural Health Centers. As seen in Table XXXI, the most frequent behavior for which these services were sought was

due to an individual being a harm to self (n = 6, 67%), harmful to others (n = 6, 67%), followed by property destruction (n = 5, 56%). One agency sought assistance from a rural health center due to unusual behaviors. One agency sought services due to sexually inappropriate behaviors while another and behaviors categorized as “other.” Table XXXII illustrates satisfaction scores with services obtained from rural health centers. Half indicated that they felt satisfied while half indicated feeling neutral.

TABLE XXXI
REASONS FOR SEEKING MENTAL/BEHAVIORAL HEALTH SERVICES
FROM RURAL HEALTH CENTERS

Reason	# of agencies	% of agencies (n = 9)
Harmful to self	6	66.7%
Harmful to others	6	66.7%
Property destruction	5	55.6%
Sexually inappropriate behavior	1	11.1%
Illegal behavior	0	0.0%
Unusual behavior	1	11.1%
Other	1	11.1%

TABLE XXXII
SURVEY RESPONDENT SATISFACTION WITH
RURAL HEALTH CENTERS

Level of Satisfaction	# of agencies responding	% of agencies (n = 8)
Very satisfied	0	0.0%
Satisfied	4	50.0%
Neutral	4	50.0%
Dissatisfied	0	0.0%
Very dissatisfied	0	0.0%

TABLE XXXIII
USAGE AND SATISFACTION WITH COMMUNITY SERVICES

	Police/ 911/ EMS (n=59)	DHS/ DDD supports (n=58)	ER (n=54)	Inpatient psychiatric services (n=53)	CMHC (n=43)	Private sector (n=29)	University- based (n=16)	FQHC (n=10)	Rural Health Centers (n=9)
Overall use* (n=65)	90.8%	89.2%	83.1%	81.5%	66.2%	44.6%	24.6%	15.4%	13.8%
Behavior									
Harm to self	69.2%	61.5%	70.8%	76.9%	60.5%	26.2%	56.3%	40.0%	66.7%
Harm to Others	75.4%	56.9%	64.6%	72.3%	65.1%	24.6%	56.3%	40.0%	66.7%
Property destruction	52.3%	46.2%	40.0%	38.5%	55.8%	18.5%	25.0%	30.0%	55.6%
Sexually inappropriate	4.6%	20.0%	7.7%	3.1%	27.9%	12.3%	12.5%	10.0%	11.1%
Illegal	16.9%	12.3%	4.6%	10.8%	20.9%	10.8%	6.3%	10.0%	0.0%
Unusual	20.0%	29.2%	16.9%	20.0%	39.5%	20.0%	31.3%	10.0%	11.1%
Other	3.1%	4.6%	0.0%	4.6%	23.3%	9.2%	18.8%	20.0%	11.1%
Mean satisfaction score	3.5 (n=57)	2.8 (n=53)	2.9 (n=53)	3.1 (n=53)	3.2 (n=40)	3.8 (n=28)	3.8 (n=16)	3.6 (n=10)	3.5 (n=8)

*Percentage of respondents that reported using service.

The data presented has been consolidated and is displayed in Table XXXIII for comparative purposes. As can be seen, the most frequently used community-based service was police/911/EMS while the least used were rural health centers.

Respondents indicated highest satisfaction scores were from private sector services (3.8/5.0) and university based services (3.8/5.0). The lowest satisfaction scores were given to DHS/DDD services (2.8/5.0), of which 89.2% of respondents indicated using.

g. **Satisfaction with community-based supports**

i. **Availability of community mental/behavioral health services and/or supports**

Survey respondents were asked to rate their overall assessment of the current availability of community mental health services and/or behavioral supports for individuals with IDD in their primary service area. As illustrated in Figure 7, over two-thirds (67.7%) of respondents assessed the current availability of community mental health and/or behavioral supports for people with IDD as being “poor” (26.2%, n = 17) or “very poor” (41.5%, n = 27), while 10.7% assessed the current system as “good” (9.2%, n = 6) or “very good” (1.5%, n = 1). Nearly 19% (n = 12) assessed availability as “fair”.

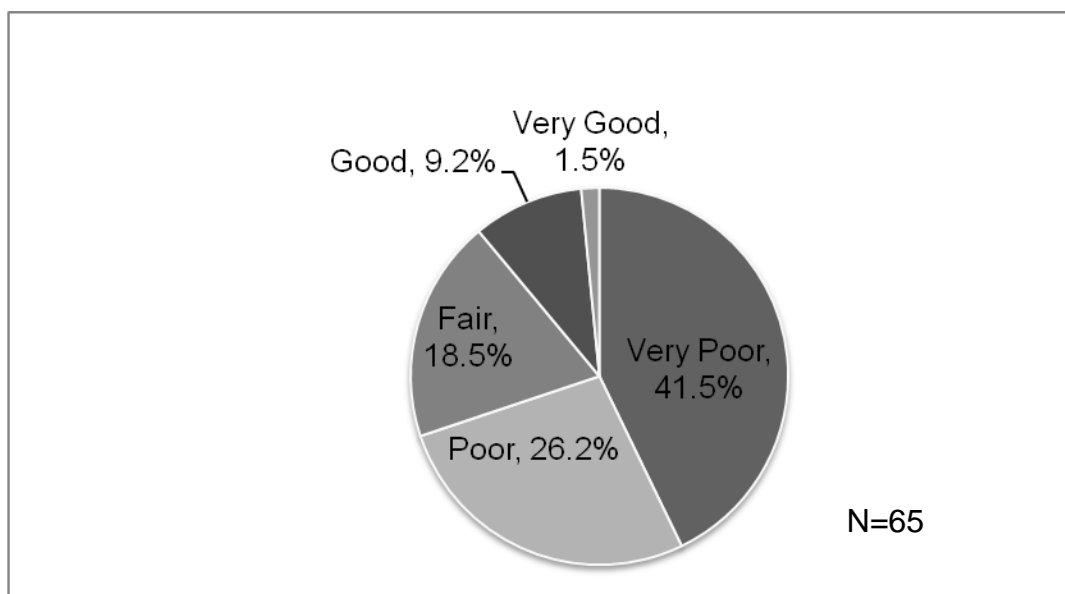


Figure 7. Assessment of availability of community mental and/or behavioral health services.

h. **Capacity of community mental/behavioral health services and/or supports**

Survey respondents were also asked to rate their overall assessment of the current capacity of community mental health services and/or behavioral supports for individuals with IDD in their primary service area. As illustrated in Figure 8, two-thirds (66.2%) of respondents assessed the current capacity of community mental health and/or behavioral supports for people with IDD as being “poor” (20%, n = 13) or “very poor” (46.2%, n = 30), while 4.6% assessed the current system capacity as “good” (3.1%, n = 2) or “very good” (1.5%, n = 1). Over one-quarter (26.2%, n = 17) assessed capacity as “fair”.

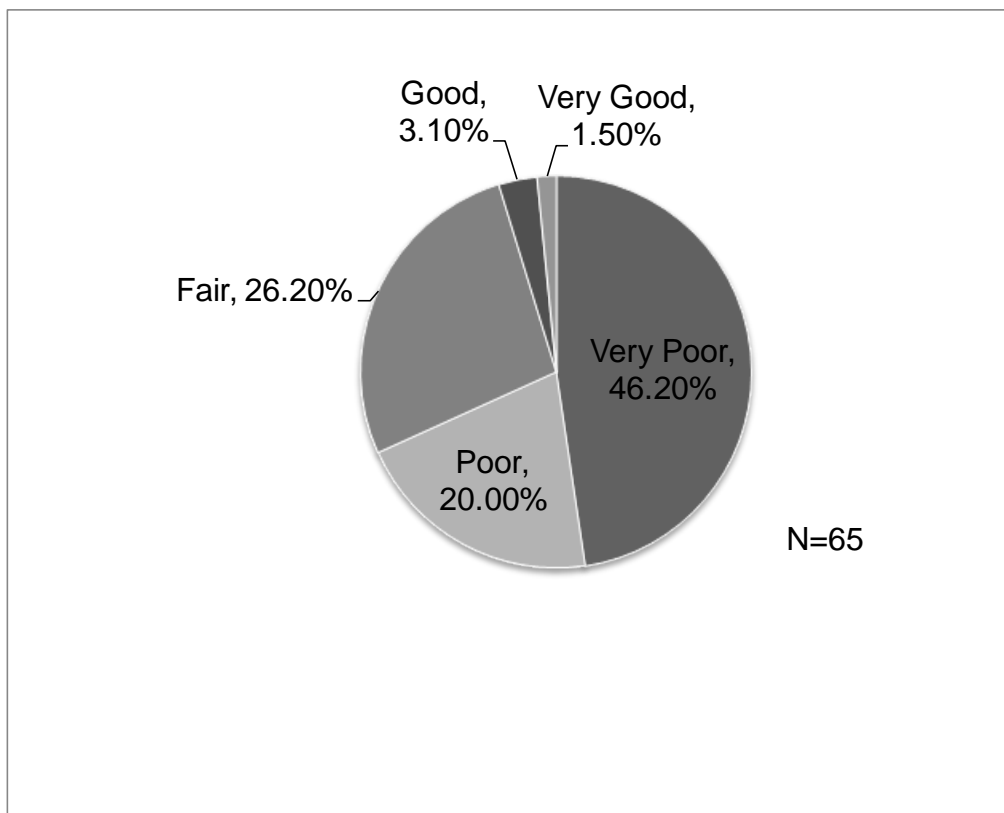


Figure 8. Assessment of capacity of community mental and/or behavioral health services.

i. **Change in overall assessment**

Survey respondents were asked to what extent had their overall assessment of community mental health services and/or behavioral supports for individuals with IDD in their primary service area changed over the past 3-5 years. As can be seen in Figure 9, 40% indicated that there had been a decrease; 26.2% (n = 16) indicated that it had worsened slightly while 15.9% (n = 10) indicated it had worsened greatly. Thirty-seven percent (n = 23) indicated it had remained the same, while 22.2%

(n = 14) indicated it had improved slightly. No respondents indicated that supports and services had improved greatly.

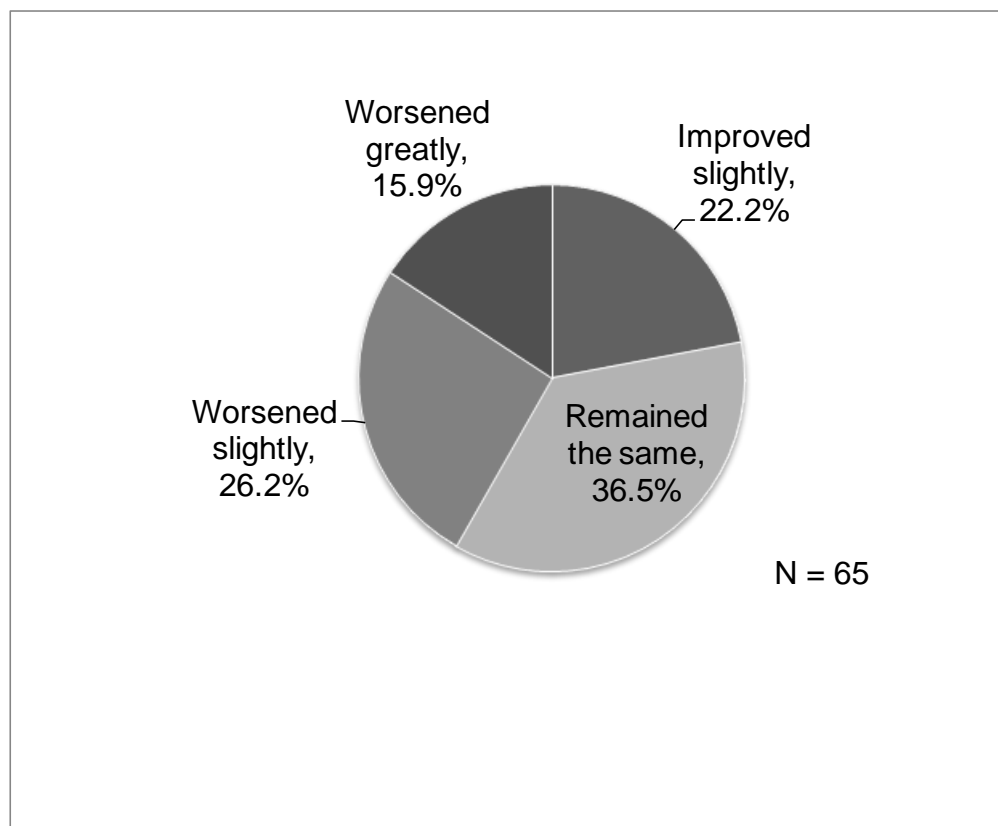


Figure 9. Change in overall assessment of community mental and/or behavioral health services.

j. **Positive aspects of the community mental/behavioral health system available to people with intellectual/developmental disabilities**

Survey respondents were asked to respond to the following statement: "Please describe positive aspects of the community mental/behavioral health system available to persons with IDD". Forty-eight (74%) participants responded. Responses included: access, availability, competence, funding, responsive community, relationships, self-sufficiency, SSTs, and specific programs.

A key theme which was uncovered from the responses which did indicate the presence of positive aspects of the current service system was related to competence. Several participants indicated specific skills which lend to competent professionals, including: familiarity with persons with IDD; awareness and attentiveness to individual needs; a willingness to work with individuals with IDD and the organizations that serve them; communication; consistency, and a desire to provide quality services and teamwork. One respondent stated, "Most staff interact more directly with my consumers and attempt to use words they are able to understand." Additionally, respondents indicated specific categories of professionals that display competence including medical professionals, BCBAs and organization staff members. One participant wrote: "There aren't territorial issues; everyone works well as a team to provide the best services. We have an excellent contractual psychiatrist who is part of our team and listens to team concerns and recommendations. We have an excellent Clinical Psychologist who is available when needed." A few respondents mentioned specific community service providers. One stated, [the] "UIC Family Clinic has been supportive of service needs".

Another positive theme that emerged from responses was the existence of SSTs. One respondent noted, "The addition of the SST has offered true technical support that was not available in the past. They can also help access other services." Another stated,

There have been some instances where SST and CART have intervened with DHS to assist us in alternative placement for a harmful individual. For example, SST along with the PAS agent has been of assistance when an individual was a harm to himself and others and after many incidents of battery and assault he was admitted into an SODC. Without the assistance of SST I do not think that could have occurred. CART has also assisted in providing 1:1 funding to some of our individuals with high needs.

Additionally, one respondent noted, "SST has been generally quick to respond."

There were a few respondents who indicated that their organization is self-sufficient in terms of behavioral services. One person said,

Our agency has an integrated service system that includes outpatient mental health and substance, residential services and an adult day program and vocational program. Because these services are integrated within one agency we can access needed help quickly and the treatment team can be easily organized around the client's needs. Also, we do get good support and access from area medical personnel. They will accept our clients and they make referrals to our agency. The EMT/Police resources are also very helpful.

Not all feedback was positive. A few respondents expressed frustration specifically with CART and SST, stating,

Services such as CART/SST have occasionally helped us help an individual. But typically (maybe 80-90% of the time), they do not provide the supports we need to help an individual. No one seems to understand that when we are in crisis with an individual, we need help that day. Not in two weeks to have a meeting to set-up a meeting. FRUSTRATING.

Another stated, “There are no positive aspects. They are virtually non-existent,” while another said, “At this point, the positive aspects of the community mental/behavioral system are not very evident.” In fact, nearly 31% (n = 16) of those participants who responded to this question indicated that there are no positive attributes in the Illinois mental/behavioral health service system for adults with IDD.

k. **Barriers to the provision of services to persons with intellectual/developmental disabilities**

Fifty-nine (90.7%) survey participants responded to the following:

“Describe any barriers to the provision of services to persons with IDD who have behavioral challenges experienced by your organization.” Several barriers were identified in the following key areas: access to psychiatric treatment, lack of timely crisis services, lack of skilled professionals, and Medicaid rates.

The theme of lack of access to psychiatric treatment had several sub-themes including: availability of psychiatric hospitals willing to serve the IDD population, lack of availability of psychiatric beds, difficulty in admitting an individual to a psychiatric hospital due to the consulting psychiatrist not having admitting privileges, and long distances to psychiatric hospital from provider agency. One respondent simply stated, “[There is a] [l]ack of psychiatric in-patient programs for persons with IDD,” while another said, “Many times it is impossible to get psychiatric hospitalizations for DD when needed.” Another respondent wrote,

Too few psych units will accept clients and those that do are often full or too far away. Also, while currently have a good psychiatrist, most of them either do not want to serve this population, are not available or are only available limited hours, or do not have admitting privileges.

Another respondent stated,

Psychiatry is difficult for individuals who are dually diagnosed MI/ID. Most psychiatrists do not have hospital privileges. Individuals are sent to [metropolitan area] to receive treatment for a maximum of 7 days. We have seen less than 5 [days] on a couple of occasions. Medication changes are difficult in that short of time. Usually, the psychiatrist in the hospital does [not] take away medications just adds to current medications which result in poly-pharmacy. Individual comes home with more medication unsure whether it works due to shortness of [hospital] stay and when individual goes to psychiatrist in community not sure which medication is working and [the psychiatrist is] reluctant to discontinue any medication.

Another theme that emerged from participant responses was the lack of skilled mental/behavioral health professionals who are willing or able to serve this population. Respondents stated, “[There is a] [l]ack of access to community mental health providers willing/capable of working with persons with IDD,” while another noted “[a] lack of willingness by almost everyone to actually work with and treat the individuals.” Statements were also made that indicated an unwillingness of providers to treat individuals who have a severe or profound intellectual disability. One respondent stated, “[There is an] [u]nwillingness of most agencies to provide assistance and services to the dual diagnosed and or those whose fall in the severe to profound range of IDD.” Another respondent specified, “[There is a] lack of physicians/therapists who want to provide service to people with IDD especially the severe and profound population.”

Another key area that respondents indicated serves as a barrier to the provision of mental/behavioral health services are Medicaid reimbursement rates, specifically providers who are unwilling to accept said rates and therefore don’t accept patients who rely on Medicaid for their health insurance. One participant stated simply, “Not enough

doctors take Medicaid,” while another noted, “[a] lack of therapists who will take state funding.” One provider wrote, “Providing the appropriate care at our agency often requires an increase in staffing and this becomes expensive without proper reimbursement,” thus indicating reimbursement rates are a barrier to support within residential services as well as in-patient services.

A final major key theme that emerged was the lack of timely response to behavioral/mental health crisis in Illinois. One person wrote, “the DD system lacks a crisis response” while another noted a lack of preventive measures to avoid crisis. Some respondents indicated frustration with the existing system of crisis supports, writing, “our agency is small and we lack the depth of professionals to deal with difficult or changing behaviors (negative) [and] no efficient way to deal with a crisis. ISSA, PAS, DHS do not engage to create safe solutions in a timely manner.” Another individual wrote, “[There is] [n]o clear system of referral. Who do we turn to first? SST, CART. CART makes recommendations that we may not have the resources to follow up on...” noting the cost of extra staff as a burden. Another wrote,

The State's system of CART and now the [SST] Team is poor. Our experience... was that the support teams began making suggestions for use of very basic interventions, without studying the material adequately and recognizing what had already been tried by the agency, Valuable time wasted, extremely hard on individual and housemates. Support teams are too far away and the whole process is too long.

A sub-theme that emerged as a barrier is the difficulty providers have discharging an individual they feel they can no longer serve due to behaviors. One provider said, “The system makes it difficult for a provider to serve and if necessary discharge a client that is continually violent towards his peers.” Another stated, “Issues have centered on

consumers whom we could no longer safely serve and DDD being very slow to allow discharge...”

One respondent succinctly summed up the key themes stating, “There are very few providers who will both, take Medicaid and support individuals with a developmental disability. Typically those that do have a very limited number of appointments available each month, which requires ER visits during "emergency" psychiatric episodes. The ERs/hospitals are typically overloaded, and when an individual presents with any psychiatric issue it is labeled as behavioral and they are sent home with instructions to follow-up with their PCP or psychiatrist.” Another respondent offered, “Our greatest success has been when a person can be stabilized within their homes, and taught the skills to manage their behavior and or their illness where those skills will be practiced.”

I. **Impact of barriers on organizational ability to provide services to individuals who are transitioning out of state operated developmental centers**

Fifty-seven survey respondents answered the following question:

“How do these barriers impact your organization’s ability to provide services/supports to individuals who are transitioning out of SODCs?” A large number of respondents indicated that barriers they had mentioned serve as a deterrent to the provision of services to people with behavioral challenges. In fact, many providers indicated that they would be hesitant or not willing to consider admitting a person with behavioral issues into their programs due to safety concerns for other residents and staff (including risk to the agency and potential for increase in workers’ compensation claims) or inability to serve the individual due to lack of resources (e.g., therapists, system

supports, and cost). One person noted, “Due to the lack of support for individuals in our community and state [who] are dually diagnosed we will not provide service.” Another respondent stated, “[These barriers] impact us greatly as we do not want to serve someone who will not be successful in the community if those supports are not available.” Several additional respondents indicated a hesitancy to accept people with both IDD and behavioral challenges into their program. To illustrate, additional responses are presented here:

We are hesitant to take individual[s] from state operated facilities due to the lack of close psychiatric care. The state SST team does not provide an added benefit--it takes too long for them to respond and we have found that their ideas are not any different than what we as an organization have tried on our own.

We are cautious because of the lack of resources for individuals with dual diagnosis especially individuals with diagnosis of personality disorder or bi-polar disorder. We have had issues stabilizing these individuals. The supports they need are different than individuals who are not dually-diagnosed so it becomes problematic to have them living together. There are also financial barriers as the State is not supporting the community programs at a level that allows us provide the quality of care we would like to provide. Our Board of Directors has directed us not to start any new living arrangements or programs until the rates are increased to a level that allows us to provide the needed supports.

We might simply decline them. With a certain type of difficult client, an agency can count not only on behavioral challenges, but on the DHS system not being supportive and then it being next to impossible to discharge the client. The system forget/does not care about the impact challenging people have on the other clients in the home, as well as the staff. It can be extremely difficult. Even if one wants to give such persons a chance, it takes careful consideration to determine which ones are likely to work out. It is no fun to have no real help, no real money to work with difficult people, and then to know if there is a problem, the agency will be held accountable. It is a no win situation.

We take a very close look at the current supports offered in the SODC and make sure we have supports in place before we begin to provide services to the person. Once the person moves, we try to set them up with behavior consultants before any behavior may begin so the person has a

relationship and if behavioral services are needed, the foundation has already been laid. If the person has a strong need for clinical psychiatric or psychological supports, we might not be the best agency for them.

The lack of mental health centers or psych units that individuals could go to on a temporary basis, during crisis, prevents us from admitting individuals with extensive maladaptive behaviors.

Due to limited resources to cover the added costs of supporting individuals with behavioral needs, [our] agency has been less willing to consider those persons who may have significant behavioral issues.

We walk a very fine line in committing our agency to accept individuals from SODC and the need to fill vacancies in order to be financially stable. We totally understand that once we accept an individual, we are on our own. There will be no help from outside agencies.

Without supports being available... we are reluctant to take on an individual that we know have little or no chance of being successful. The negative impact on individuals currently being served in the program is always a primary concern. It does not make sense to upset individuals who are already being served, if the prognosis for success is poor.”
 “I also believe the SODC's serve a role and it needs to be easier for someone to get readmitted. If so, more people might be willing to say yes to some of the more difficult clients from such facilities.

Other respondents indicated that the barriers that they experience do not have an impact on whether or not they admit a person into their program who has transitioned out of an SODC and has behavioral challenges. One person stated, “It doesn't, the community providers can serve the SODC individuals,” while another said, “We struggle, but we continue to offer the services.”

More participant responses are included to further illustrate that viewpoint:

Individuals with minor mental health concerns can be served adequately.

If we choose to accept someone from the State Operated Center, we will make it work, in spite of all obstacles.

With the appropriate funding and supports we feel we can serve most individuals.

We can accept and serve some but those with serious behaviors present issues for community providers who have homes in neighborhoods with children and others at risk. Those with sexual issues are particularly challenging.

Minimally, as we have access to a variety of resources within the organization (especially therapists, behavior analysts, consulting psychiatrist, etc).

m. **Suggestions to strengthen the availability and capacity of the Illinois system for people with intellectual/developmental disabilities**

Fifty-six (86%) survey participants responded to the following, “Please list your suggestions to strengthen the availability and capacity of the Illinois mental/behavioral health service system for people with IDD.” Five major themes emerged from participant responses. They were to increase: access to services, reimbursement rates, training, collaboration, and policy change.

The call for an increase in access to services was the most common suggestion by survey respondents. Specifically, a large number of respondents suggested an increase in crisis services, including the availability of psychiatric hospital services, immediate crisis services, and short-term crisis respite. The following responses are illustrative of that suggestion.

[We need] more psychiatrists...psychiatric services for those with IDD in the local hospital, crisis support that is quicker to respond, reimbursement rates that accommodate additional staff needed for 1:1 support or housing in a smaller setting.

In patient treatment options for short term respite or medication adjustments would be beneficial.

Short term crisis units that allow for drug holidays and 24 hour professional medical oversight for medication changes.

[We are] desperately in need of a crisis respite service. When one of our individuals is in crisis, we are left reacting and not being proactive to insure safety. There should be a place for people to go on a short-term respite stay to receive the help he/she needs. We perform thorough pre-screen assessments on potential individuals. But there are still times when the pre-screening/observation/pre-visits do not reveal the true problems that put people at risk. There needs to be a place to provide emergency crisis respite to help individuals as well as keeping the peers/staff safe.

The most critical ... need [is] a place for people to go who are having severe behavior issues to become stabilized through behavior programming or medication. Hospitals don't do it and we can't.

Additional suggestions to increase access to services included: incentivizing psychiatrists and psychologists to both accept Medicaid and serve the IDD population; investing in preventative measures; building partnerships between the IDD and mental health system; increasing availability of therapies which benefit individuals who have a severe/profound intellectual disability (e.g., alternatives to “talk therapy”); creating alternative housing options (e.g., transition settings); and increasing the number of hours one can receive behavioral therapies (as outlined in the Adults with DD Waiver). One participant wrote, “Increase the annual number of hours per year that behavior analysts can bill DHS for those persons needing extraordinary services.” Another elaborated further, saying,

There needs to be relaxed limits on the amount of BCBA hours of supports an individual is allowed per year. No one says that you can cure or eliminate a behavior in 66 hours but that is all we are allowed so the problem continues long after the hours are exhausted.

Another suggestion to strengthen the capacity of the Illinois mental/behavioral health system available to people with IDD was to increase reimbursement rates. One participant wrote, “Current billing for services is well below market value.” Others indicated that an increase in rates would allow them to increase Direct Support

Professional wages, allow more flexibility in individual budgets, as well as incentivize mental/behavioral health professionals to serve this population. One respondent wrote,

Interestingly, I would evaluate the most pressing need to be increased funding, especially for DSPs. These staff members are vital to serving individuals with challenging behaviors. If you don't have good DSPs, you will not be able to support individuals with challenging behaviors no matter what access you have to other professionals (e.g. psychiatrists, behavior analysts). These days, most community providers lament the difficulty recruiting staff members to work as DSPs.

Another commented, "We need access to counselors, psychiatrists, and doctors that understand IDD and the impact of IDD on the co-occurring mental illnesses they may have." Another added, "There should be additional funding for on staff BCBAs, psychiatrists, RN, and counselors. Funding for another RN would be extremely useful."

Another offered that the system should be:

Providing additional compensation or incentives to psychiatrists and psychologist/LCSWs who are willing to work with agencies to provide supports to individuals with DD [and] providing agencies with appropriate levels of compensation to hire in-house supports, and provide the agencies with the financial support to hire enough staff, and provide on-going support and training to the staff.

In addition to the need for an increase in reimbursement rates, respondents overwhelmingly called for an increase in training of mental/behavioral health professionals to be competent in working with individuals who have IDD and behavioral issues. Additionally, some respondents called for training of current hospital staff on issues specific to individuals with IDD. One wrote, "They need to work with the medical and nursing schools and hospitals to start to make it a part of the medical training (understanding disabilities and mental illness). Rotations working with individuals should be a standard part of the requirements." Another suggested that Illinois should, "develop university curriculum, degrees and/or specialization in the field of dual

diagnosis” to prepare future clinicians to meet the mental health needs of this population. In addition to current and future clinicians, it was suggested by a few respondents that intensive training on behavioral/mental health be provided to direct support professionals (DSPs). One person suggested the development of “[a] training program for DSPs that prepare them to provide the intensive behavioral programming prescribed by programs written by BCBAs.” Another respondent stated, “I believe that providing additional behavioral and mental health support would make transition from SODCs easier on the community agency and the individual.”

Collaboration was another theme that emerged. Participants indicated a desire for more collaboration between the Division of Developmental Disabilities and the Division of Mental Health, both of which are under the umbrella of the Illinois Department of Human Services. One respondent suggested that “...DDD and DMH [should] seriously talk with each other.” Respondents also suggested building relationships between community providers and to “[w]ork with local hospital[s] to develop a relationship with psychiatrist[s] with access to hospital[s] [and increase their] knowledge of individuals with cognitive disability.”

Specific suggestions for policy change that would contribute to strengthening the capacity of the Illinois mental/behavioral health service system were offered. One participant expressed frustration with the current waiver system, stating,

We definitely need more flexibility in the way we can provide services in the State. Every time there is a discussion about looking at ways to provide more innovative services or ways to improve services the comment that is always made is-"it's not in the waiver" or "we cannot do that because of the waiver"...We need to look at how we can improve services and assist individuals ...We need the ability to look at alternative options that could work for individuals and actually try to implement verses continuing with a system that doesn't really work all that well.

One suggestion was to allow for the conditional placement of an individual transitioning from an SODC into a community-based setting:

In the 90s, there was a program whereby providers could admit individuals from a[n] SODC on a conditional basis for six months. If severe problems arise within the six-month period and the individual is unmanageable by the providers, he or she can be transported back to the SODC.....without any barriers to the admission. We utilized this program for about 10 individuals and all placements were successful. We may not have given the individuals a chance without the assurance of what to do if the placements were unsuccessful.

Another participant suggested that DHS Redirect funding from the SST and CART to community agencies:

Pump the money that is going into the CART and SST programs directly into the service providers [be]cause most of what they offer had already been tried or suggested and not working. This is just one added step to get the ear of the Department and a big time consuming process. SST is so backed up that by the time they are involved the crisis is over with and we are on to something new.

Another suggested loosening the regulations requiring psychological evaluations every five years:

Psychological evaluations are very expensive and should be covered by Medicaid/DHS since this is mandatory for all consumers every five years. Perhaps this should not be mandatory except for during entry into the system if no psychological issues/diagnosis are found. The general population doesn't get regular psych [evaluations] which are costly for no reason.

Additional areas in which a loosening of regulations was suggested were medications and Office of Inspector General (OIG) reporting. Regarding medications, the following was submitted:

We have experienced a nursing audit of our [IDD] residential program and found it to be very intense. The expectation on residential providers for medications and physician's orders is incredible, particularly in terms of labeling meds, documenting meds and so forth. For instance, the expectation is that if a physician states that staff should apply lotion if the

resident has dry skin, the auditors interpret this as a physician's order and expect us to label the product and treat it in all ways as if it is a prescription drug. The effort and cost to document and handle safe products like skin lotion is impractical compared to the low potential for harm. We had an audit two years ago where four state auditors reviewed 15 CILA cases. The audit went for 2 1/2 days. That's ten man-days for 15 records. We are a good provider and never before experienced an audit like this. I have spoken with other residential providers in the region and they have experienced the same. The intense focus on minor issues seems unwarranted. We are not nursing homes, we are residential providers without the benefit of 24-hour on premises nursing.

Another participant commented on state Medicaid restrictions on medications:

There are problems with medication. Example: Abilify which is a fabulous assist for mental illness isn't the Illinois Medicaid preferred drug list. We have very few options. So, people are placed on medication that doesn't work and we have a lot of difficulty meeting their needs until we can finally get a better medication. We have to have a prior approval. Then there is another problem. Decreasing medication to fulfill the rule to decrease psychotropic medication. This creates another problem. I agree with evaluating but decreasing a medication when the person is stable is just wrong.

With regard to reporting to the Office of Inspector General (OIG), Rule 50 requires mandated reporters (which include all employees of a DHS-funded agency) to call the Abuse and Neglect hotline to report any allegation of abuse and or neglect. This includes allegations by service recipients, whether or not the mandated reporter believes it to be true. One respondent stated, "The system ... needs to tone down the OIG system. For instance, why take someone who is behaviorally challenging, but who also makes threats and accusations. Wh[o] wants constant OIG investigations?"

An additional suggestion was to make changes to Medicaid billing for crisis services: "Work with the Mental Health community on [how] we can eliminate rule 132 or a proper fix so we can utilize our local Mental Health community." Other suggestions included updating and maintaining Community Mental Health Centers in operation (specifically in

Chicago), alternative housing options (e.g., transition houses), allowing clinical psychologist to prescribe psychotropic medications, and creation of an alternative to 911 for behavioral emergencies.

n. **Additional information**

Thirty-six survey (55%) participants responded to the following question, “What additional information, experience, or insight would you be willing to share regarding mental/behavioral health services or related issues impacting individuals with IDD in Illinois community-based settings?” This allowed respondents an opportunity to comment on a topic not already addressed through the survey.

Responses included suggestions around general themes such as policy changes and streamlining bureaucracy, as well as increasing: rates, the range of services offered, the mental/behavioral health workforce, and collaboration between the Division of Developmental Disabilities and the Division of Mental Health. The majority of responses addressed topics that have already been covered and have been interjected into previous appropriate topic sections. There were, however, some issues that respondents took the opportunity to expand upon and about which to express frustration. Those few topics will be briefly addressed here.

One issue brought up by a respondent was the notion of connecting individuals transitioning out of SODCs into provider agencies that have expertise in working with the types of challenging behaviors that a specific individual may have:

The ‘DD system’ should do a better job of matching client needs (especially those who exhibit challenging behaviors) with community provider skill sets; Too many individuals with complex challenging behaviors (e.g. individuals with a dual diagnosis) are moving into small community providers who lack the internal resources to meet the persons' needs. These small providers do so because they can't survive having

vacancies. There is also tremendous need for the development of crisis beds as an alternative to inpatient hospitalization. For individuals who exhibit the most challenging behavior, alternative residential models need to be developed and funded.

One respondent voiced his/her opinion on the size of residential settings considered appropriate:

Current value of small residential agencies should be questioned. Should agencies be rated as being able to effectively manage crises? Agencies should be developed that can quickly take over cases when another agency is unable to assure the safety of the client in crisis, his/her peers, agency staff, and the community. Agencies that abuse this proposed system, or historically fail to provide care should be taxed to support these crisis agencies.

Another respondent, however, wrote in favor of smaller settings:

Our experience is smaller is better for individuals with severe behavioral needs. Once they are able to establish their own routine and establish good relationships with fewer people they begin to manage their own behavior. We have had good success in 1 & 2 person CILA arrangements.

A small number of participants indicated a need for the provision of training to community-based support providers. One stated, "Education to community providers as a needed service," and another wrote, "Illinois should have trainings for providers through state on how to maximize funding for each individual." A third suggested a need to "Improve the provider's ability to obtain permanent enhanced funding to support people that need to live in a small capacity home."

E. **How Do Mental/Behavioral Health Resources Differ Between Agencies With Respect To Geographic and Population Characteristics?**

In addition to exploring the types of mental/behavioral health services available to adults with IDD living in community-based settings in Illinois, a second research

question asked whether or not the availability of such services varies with respect to location and census.

1. **Differences based on urbanicity**

An analysis of variance (ANOVA) was conducted to determine the presence of significant differences between the means of key mental/behavioral health variable groupings with respect to urban categories. As illustrated in Table XXXIV, the only significant difference between urban categories was with respect to the number of in-house mental/behavioral health professionals and the number of in-house therapeutic interventions provided. Providers in the large metro group have a significantly higher number of mental/behavioral health providers as compared to those in micropolitan/rural areas, $F(2, 62) = 4.142, p = .021$. Additionally, providers in large metro areas offer more in-house therapies as compared to those in small metro and micropolitan/urban areas, $F(2,62) = 5.937, p = .004$.

TABLE XXXIV
MEANS OF KEY VARIABLES BY URBAN CATEGORY

	Large Metro (n = 32)		Small Metro (n = 14)		Micro/Rural (n = 19)	
	M	SD	M	SD	M	SD
# Ind. Served	150.4	244.2	130.1	133.1	64.3	49.8
#MHP	3.44*	2.37	2.36	1.39	1.79*	1.84
# in-house therapies	2.06**	1.46	0.71**	0.91	1.05*	1.51
# services used	5.22	1.50	5.43	1.91	4.95	2.07
Satisfaction						
Availability	2.03	1.00	2.08	1.26	1.89	1.13
Capacity	2.00	1.02	1.92	1.04	1.72	1.02
Mean satisfaction	3.05	0.76	3.19	0.89	3.27	0.68
Change 3-5 years	3.25	1.02	3.23	0.83	3.61	1.09

* $p > .05$; ** $p > .01$

Chi square tests of independence were conducted to determine differences between urban influence categories with respect to in-house professionals and therapies as well as community-based supports. As illustrated in Table XXXV, the 'urban' category had a significantly larger proportion of Associate Behavior Analysts, $\chi^2(2, N = 65) = 8.239, p = .016$, as compared to the other urban categories. There also significant differences between urban categories with respect to provision of in-house therapy. Agencies located in large metro areas were provided a higher percentage of

TABLE XXXV
NUMBER OF IN-HOUSE RESOURCES BY URBAN CATEGORY

	Large metro (n = 32)	Small metro (n = 14)	Micro/ Rural (n = 19)	χ^2
Professional				
Psychiatrist	46.9%	57.1%	36.8%	1.350
BCBA	53.1%	50.0%	21.1%	5.350
Clinical Psychologist	50.0%	35.7%	26.3%	1.923
LCSW	50.0%	14.3%	31.6%	5.663
Social Worker	34.4%	28.6%	26.3%	0.404
LCPC	35.5%	14.3%	26.3%	2.188
Associate Behavior Analyst	34.4%	28.6%	0.0%	8.239*
Other	21.9%	7.1%	5.3%	3.430
LMFT	3.1%	0.0%	5.3%	0.749
Therapy				
Individual counseling/ psychotherapy	68.8%	21.4%	31.6%	11.536**
ABA	56.3%	35.7%	21.1%	6.331*
Group counseling/therapy	53.1%	7.1%	15.8%	12.765**
Telehealth	3.1%	7.1%	21.1%	4.666
RDI	3.1%	0.0%	0.0%	1.047
Other	12.5%	0.0%	5.3%	2.366

* $p < .05$; ** $p < .01$

individual counseling, $\chi^2(2, N = 65) = 11.536, p = .003$ and group counseling, $\chi^2(2, N = 65) = 12.765, p = .002$, as compared to agencies located in small metro and micro/rural areas. Agencies located in large metro areas also offered ABA therapy more often than agencies in micro/rural areas, $\chi^2(2, N = 65) = 6.331, p = .042$.

To discover differences between urban categories with respect to community resource utilization, a chi square test of independence was conducted. As shown in Table XXXVI, use of Community Mental Health Centers significantly differed between micro/rural and large metro, $\chi^2(2, N = 65) = 6.524, p = .038$, with agencies in micro/rural

using CMHCs more than those located in large metro areas. Agencies located in micro/rural areas also reported a greater use of rural health centers as compared to large or small metro areas, $\chi^2(2, N = 65) = 6.455, p = .040$. Agencies located in large metro areas, however, used in-patient treatment/crisis services at a higher rate than those located in small metro or micro/rural areas, $\chi^2(2, N = 65) = 10.215, p = .006$.

TABLE XXXVI
COMMUNITY RESOURCES BY URBAN CATEGORY

Resource	Large metro (n = 32)	Small metro (n = 14)	Micro/ Rural (n = 19)	χ^2
DHS/DD supports	90.6%	100.0%	78.9%	3.845
CMHC	56.3%	57.1%	89.5%	6.524*
FQHC	15.6%	14.3%	15.8%	.017
Rural Health Center	3.1%	28.6%	21.1%	6.455*
University-based	28.1%	35.7%	10.5%	3.174
ER	87.5%	78.6%	78.9%	.878
Police/911/EMS	93.8%	92.9%	84.2%	1.388
In-patient supports	96.9%	71.4%	63.2%	10.215**
Private sector	37.5%	57.1%	47.4%	1.603
Other	3.1%	7.1%	5.3%	.383

* $p < .05$; ** $p > .01$

a. **Pearson correlations between key variables**

Pearson correlations were performed between key variable means and results are displayed in Table XXXII. As illustrated, there is a moderate statistically significant negative correlation between the number of in-house mental/behavioral health professionals (MHPs) and urban influence code category, $r(64) = -.299$; $p = .015$, suggesting that the more rural the service region, the less in-house MHPs are available to the organization. Additionally, there is a moderate statistically significant negative correlation between the urban category and the number of in-house therapies provided, $r(65) = -.286$; $p = .021$. This suggests that the more rural an area, the less the number of in-house therapies offered.

The number of in-house MHPs has a medium and statistically significant positive correlation with number of services used, $r(63) = .301$; $p = .015$, while there is a strong and statistically significant positive correlation between the number of MHPs and the number of in-house therapies provided. The number of in-house MHPs has a weak yet statistically significant positive correlation with the number of individuals served by responding agencies $r(62) = .285$; $p = .023$. Finally, the number of in-house MHPs has a weak but statistically significant positive correlation with respondent's satisfaction scores on the capacity of community mental/behavioral health supports $r(61) = .274$; $p = .030$. The number of in-house treatments provided by an agency has a moderate statistically significant positive correlation with satisfaction scores rating the availability, $r(61) = .361$; $p = .004$, and capacity, $r(61) = .320$; $p = .01$, of community mental/behavioral health services.

TABLE XXXII
PEARSON CORRELATIONS BETWEEN KEY VARIABLES

	Urban category	# served	#MHP	# in-house treatments	# services used	Satisfaction		Mean satisfaction
						Availability	Capacity	
# served	-.162							
# MHP	-.299*	.285*						
# in-house therapies	-.286*	.235	.706**					
# services used	-.081	.029	.301*	.243				
Satisfaction with availability	-.051	-.152	.247	.361**	.100			
Satisfaction with capacity	-.112	-.060	.274*	.320*	.182	.843**		
Mean satisfaction	.023	.005	.103	.244	.012	.427**	.343**	
Change 3-5 yrs	.132	-.111	.089	.171	-.115	.478**	.507**	.123

* $p < 0.05$; ** $p < 0.01$

With regard to satisfaction scores, there was a strong statistically significant positive correlation between satisfaction scores related to availability and capacity of services, $r(61) = .843$; $p = .000$. Mean satisfaction scores also had a moderate statistically significant positive correlation with satisfaction with availability scores $r(60) = .427$; $p = .001$. Mean satisfaction scores also had a moderate statistically significant positive correlation with capacity satisfaction scores $r(60) = .343$; $p = .006$. Satisfaction with availability, $r(61) = .478$; $p = .000$, and capacity, $r(61) = .507$; $p = .000$, of community services also had moderate statistically significant positive correlations with assessment of change over the past 3-5 years.

F. **How Do Mental/Behavioral Health Resources Impact Individual Post-Transition Outcomes?**

1. **Sample characteristics**

a. **Individual characteristics**

For inclusion in this study, subjects needed to transition out of one of Illinois' SODCs between October 2001 and December 31, 2012 into a setting for ≤ 15 individuals within one of the 65 responding organizations. Additionally, as of July 1, 2013, the individual's residential status needed to have been either "continuing to receive services from the receiving agency" (termed "stayers") or having "returned to an SODC" (termed "returners"). Figure 10 illustrates counties in which a responding agency meeting study criteria are located.

During the study period, a total of 2,499 individuals transitioned out of an SODC and into another setting. This number does not include the 213 (7.9%) deaths that occurred while the individuals were still residing in an SODC. Four hundred and fifty-

four subjects (18.2%) met the study criteria for inclusion in the study, having transitioned into 47 (72%) of the responding agencies. Of the 454 study participants, there were 411 “stayers” and 43 “returners” as of July 1, 2013. Of the 43 returners, 39 (90.7%) returned due to behavioral issues, two (4.7%) returned for reasons not documented, while one (2.3%) returned for a medical reason and another returned for both a medical and a behavioral issue.

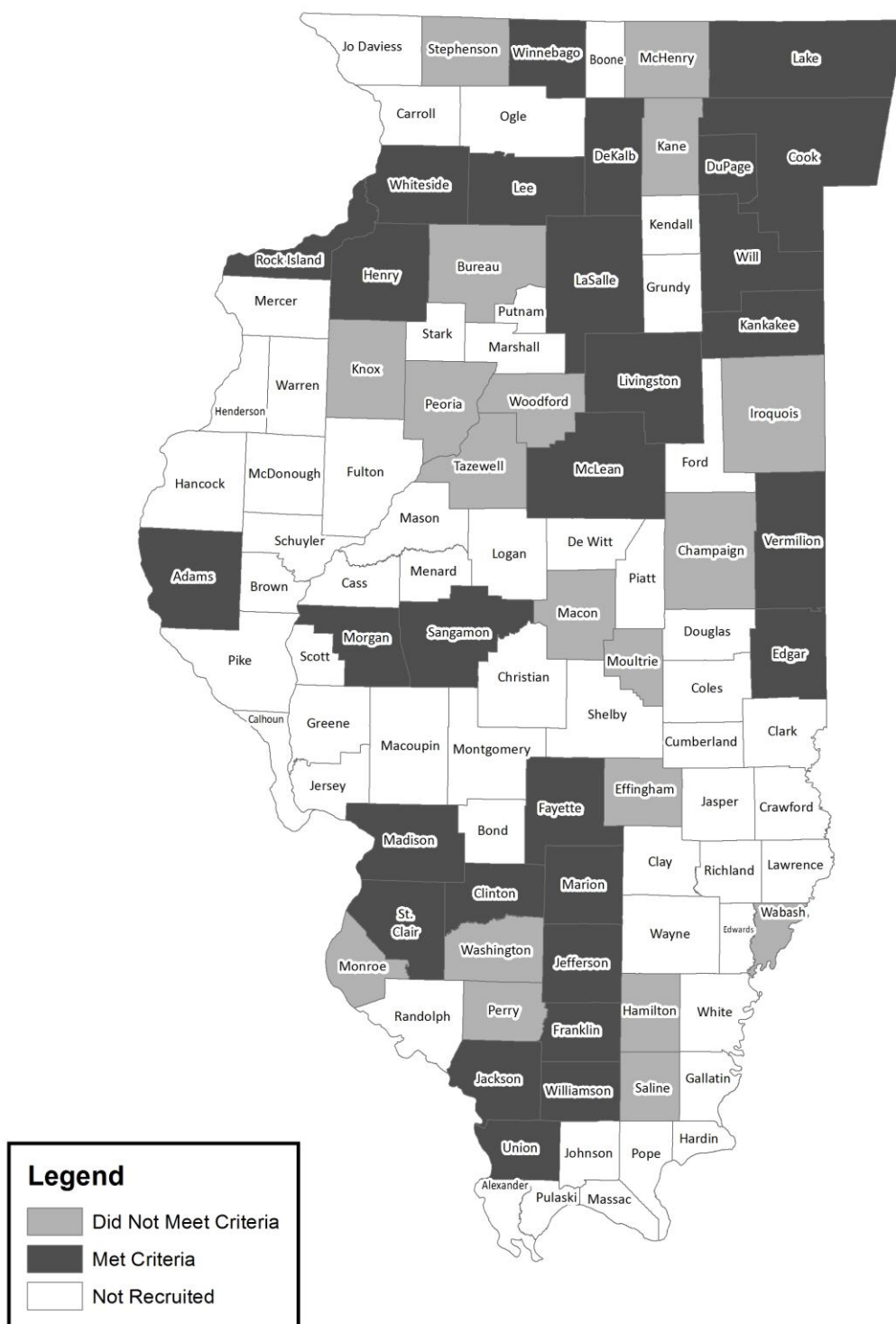


Figure 10. Counties of participating agencies.

Table XXXVIII displays demographic information for the individual participants in each of the two status categories. *T*-tests were conducted to determine differences in age, length of previous stay at an SODC, HRST, IQ and ICAP scores with respect to transition status (stayers and returners). Individuals who returned to an SODC were significantly younger, $t(452) = 3.604$, $p = .000$, had a shorter length of stay in the SODC $t(452) = 4.60$, $p = .000$, and a higher IQ score, $t(416) = -2.242$, $p = .025$, than those who remained in their transition settings. There was no significant difference in HRST scores or ICAP service level with respect to transition status.

Chi squares were conducted to determine differences between stayers and returners with respect to gender and presence of psychiatric diagnosis or ASD, and receipt of TA. There was no statistically significant difference between stayers and returners with respect to gender or ASD diagnosis. There were, however, proportionately more returners who had a psychiatric diagnosis, $\chi^2(2, N = 454) = 7.033$, $p = .008$. Additionally, returners were more likely to have received TA than stayers, $\chi^2(2, N = 454) = 27.247$, $p = .000$.

TABLE XXXVIII
INDIVIDUAL CHARACTERISTICS (N = 454)

	Stayers		Returners	
	(n = 411)		(n = 43)	
Demographic	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age	47.97***	13.25	40.47	10.12
Length of stay	15.53***	12.82	6.37	7.181
HRST	2.29	1.15	2.21	1.059
IQ	32.47*	21.36	40.49	20.37
ICAP Service Level	45.17	19.39	48.33	22.64
	%		%	χ^2
Gender				
Male	68.6%		79%	1.953
Female	31.1%		20.9%	
Psychiatric diagnosis				
Yes	53.3%		74.4%	7.033**
ASD				
Yes	10.9%		9.3%	.113
Receipt of TA				
Yes	23.1%		61.0%	27.247***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

A Pearson Correlation was conducted between the following individual variables: age, IQ, length of stay at SODC, HRST, gender, presence of psychiatric diagnosis, diagnosis on the autism spectrum, and current status. As displayed in Table XL, an individual's age had a medium positive correlation with HRST, $r(450) = .217$; $p = .000$, while there was a high positive correlation with length of stay, $r(454) = .521$; $p = .000$. Age had a weak negative correlation with ICAP service level, $r(450) = -.265$; $p = .000$,

psychiatric diagnosis, $r(454) = -.236$; $p = .000$, and current status, $r(454) = -.167$; $p = .000$. Age had a medium negative correlation with IQ, $r(418) = -.381$; $p = .000$.

TABLE XXXIX
PEARSON CORRELATIONS BETWEEN INDIVIDUAL CHARACTERISTICS

	Age	IQ	Length of Stay	ICAP Service Level	HRST	Gender	Psych. Diagnosis	ASD
IQ	-.381***							
Length of Stay	.521***	-.536***						
Service Level	-.265***	.721***	-.379***					
HRST	.217***	-.216***	.156**	-.262***				
Gender	-.001	-.107*	.007	-.146**	.013			
Psych. Diagnosis	-.236***	.259***	-.293***	.164***	.003	-.025		
ASD	-.089	-.109*	.015	-.107*	-.061	-.040	-.058	
Current Status	-.167***	.109*	-.212***	.047	-.020	-.066	.124**	-.016

*p< 0.05; **p<0.01; ***p<.001

IQ had a strong positive correlation with ICAP service level, $r(414) = .721$; $p = .000$, and a strong negative correlation with length of stay, $r(418) = -.536$; $p = .000$.

Additionally, IQ weak negative correlations with HRST, $r(416) = -.216$; $p = .000$, gender, $r(417) = -.107$; $p = .028$, and ASD, $r(417) = -.109$; $p = .027$. IQ had a weak positive correlation with psychiatric diagnosis, $r(418) = .259$; $p = .000$, and current status, $r(418) = .109$; $p = .025$.

Length of stay had a statistically significant, but weak, positive correlation with HRST, $r(450) = .156$; $p = .001$. Length of stay had a medium negative correlation with ICAP service level, $r(450) = -.379$; $p = .000$, and weak negative correlations with psychiatric diagnosis, $r(454) = -.293$; $p = .000$, and current status, $r(454) = -.212$; $p = .000$.

ICAP service level scores had a weak positive correlation with psychiatric diagnosis, $r(450) = .164$; $p = .000$, and weak negative correlations with HRST, $r(446) = -.262$; $p = .000$, gender, $r(449) = -.146$; $p = .002$, and diagnosis on the autism spectrum, $r(449) = -.107$; $p = .023$. Psychiatric diagnosis had a weak but statistically significant positive correlation with current status, $r(454) = -.124$; $p = .008$.

2. **Organizational characteristics**

As mentioned previously, 47 responding agencies were eligible for this phase of the study. The 47 responding agencies accepted an average of 9.66 individuals from an SODC ($sd = 13.23$) during the study period. The smallest number of individuals accepted from an SODC by a responding organization was one, the largest was 65. A chi square test of independence revealed that there was no significant difference between the original 65 responding agencies and the 47 sample agencies

used in this phase with respect to urban influence category, $\chi^2(2, N = 47) = 3.444$, $p = .179$. As shown in Table XL, the majority (63.8%) of the responding agencies fell into the two smallest size categories, size equating number of persons served across all programs. Eight agencies (17.0%) served in excess of 200 individuals across all programs.

TABLE XL
RESPONDING AGENCIES BY SIZE (N = 47)

Individuals served	n	%
0-50	16	34.0%
51-100	14	29.8%
101-150	5	10.6%
151-200	3	6.4%
200+	8	17.0%
Missing	1	2.1%
Total	47	100.0%

A frequency distribution was also completed to determine proportion of responding agencies that fell into the following population-based categories: large metropolitan, small metropolitan, and micropolitan/rural. As seen in Table XLI, the majority of the responding agencies were operating within large metropolitan areas ($n = 22$, 46.8%), while 32% of responding agencies ($n = 15$) were located in micropolitan/rural areas and 21% ($n = 10$) were located in small metropolitan areas. Figure 11 illustrates to which urban influence code category counties in which eligible

responding agencies are located. As can be seen, the large metropolitan cities represented were Chicago, St. Louis, and DeKalb. Small metro areas represented were Rock Island, Rockford, Kankakee, Bloomington, Springfield, and Decatur.

TABLE XLI
GEOGRAPHIC AND POPULATION-BASED CHARACTERISTICS OF
SAMPLE AGENCIES (N = 47)

	N	%
Urban Category		
Large metro	22	46.8%
Small metro	10	21.3%
Micropolitan/rural	15	31.9%

A frequency distribution was conducted on the in-house mental/behavioral health resources an organization provided; results are presented in Table XLII. The most common type of crisis prevention training provided to agency staff is from the Crisis Prevention Institute (n = 26, 55.3%). Examples of crisis prevention training that were categorized as “other” included: agency developed training, Safety Care, Crisis Prevention Management, ABA model crisis intervention (n = 1), Effective Behavioral Supports, and External Control Training.

With respect to in-house professionals, over half (n = 24, 51.5%) of responding agencies had access to a Board Certified Behavior Analyst (BCBA). The second and third most popular in-house professionals indicated were psychiatrists (n = 22, 46.8%) and psychologists (n = 20, 42.6%). Licensed Marriage and Family Therapists (LMFT)

were the least represented professional ($n = 2$, 4.3%). Examples of professionals in the “other” category include: rehabilitation counselor, psychology intern, medical doctor, occupational and physical therapists, acupuncturist, massage therapist, pet, art and music therapists, and a Peer Support Recovery Specialist.

TABLE XLII
ACCESS TO IN-HOUSE MENTAL/BEHAVIORAL HEALTH RESOURCES (N = 47)

	N	%
<u>Crisis prevention training</u>		
CPI	26	55.3%
Mandt	4	8.5%
Other	11	23.4%
None	6	12.8%
<u>Professionals</u>		
Psychiatrist	22	46.8%
Psychologist	20	42.6%
LCPC	14	29.8%
LMFT	2	4.3%
LCSW	17	36.2%
SW	14	29.8%
BCBA	24	51.1%
Associate Behavior Analyst	11	23.4%
Other	7	14.9%
<u>Therapies</u>		
Individual counseling/ psychotherapy	23	48.9%
Group counseling	16	34.0%
RDI	1	2.1%
ABA	23	48.9%
Telehealth	5	10.6%
Other	3	6.4%

The two most popular therapies provided in-house are individual counseling/psychotherapy (n = 23, 48.9%) and Applied Behavior Analysis (ABA) Therapy (n = 23, 48.9%). The least utilized therapy by responding organizations was Relationship Development Intervention (RDI), used by only one agency (2.1%). Other therapeutic interventions reported by responding organizations included: music, art, drama, dance, pet therapies, and dialectical behavior therapy.

3. **Differences in mental/behavioral health resources based on geography and population characteristics**

As a key question in this study was related to potential differences in mental/behavioral supports between geographic and population areas in Illinois, it was necessary to explore differences on multiple levels. Data was compared with respect to three levels of urbanicity: large metropolitan, small metropolitan, and micropolitan/rural areas.

Chi square tests of independence were conducted and results are displayed in Table XLIII. With respect to access to in-house professionals, agencies in large metro areas had a higher percentage of LCSWs as compared to smaller metro areas, $\chi^2(2, N = 47) = 8.936, p = .011$. Additionally, agencies in large metro areas had more access to in-house associate behavior analysts compared to their micro/rural neighbors, $\chi^2(2, N = 47) = 6.887, p = .032$. With respect to provision of in-house therapeutic interventions, organizations in large metro areas more often provided individual counseling/psychotherapy as compared to both their small metro and micro/rural peers, $\chi^2(2, N = 47) = 18.563, p = .000$. Applied Behavior Analysis was provided most often in agencies located in large and small metro areas as compared to agencies located in micro/rural areas, $\chi^2(2, N = 47) = 6.557, p = .038$. Finally, group counseling was provided more often in large metro areas than in small metro areas, $\chi^2(2, N = 47) = 12.262, p = .002$.

Chi square tests of independence were also conducted to determine differences between use of community resources based on urban category; results are displayed in Table XLIV. Agencies located in micropolitan/rural areas used Community Mental Health Centers with a higher frequency than those located in either large or

TABLE XLIII
PERCENTAGE OF IN-HOUSE RESOURCES BY URBAN CATEGORY

	Large Metro (n = 22)	Small Metro (n = 10)	Mircro/ Rural (n = 15)	χ^2
<u>Professional</u>				
Psychiatrist	50.0%	50.0%	40.0%	.410
BCBA	63.6%	60.0%	26.7%	5.284
Clinical Psychologist	54.5%	40.0%	26.7%	2.870
LCSW	54.5%	0.0%	33.3%	8.936*
Social Worker	27.3%	30.0%	33.3%	.157
LCPC	42.9%	10.0%	26.7%	3.604
Associate Behavior Analyst	36.4%	30.0%	0.0%	6.887*
LMFT	4.5%	0.0%	6.7%	.663
Other	22.7%	10.0%	6.7%	2.055
<u>Therapy</u>				
Individual counseling/ psychotherapy	81.8%	10.0%	26.7%	18.563***
ABA	68.2%	40.0%	26.7%	6.557*
Group counseling/therapy	59.1%	0.0%	20.0%	12.626**
Telehealth	4.5%	10.0%	20.0%	2.246
RDI	4.5%	0.0%	0.0%	1.161
Other	9.1%	0.0%	6.7%	.954

* $p < .05$; ** $p < .01$; *** $p < .001$

small metro areas, $\chi^2(2, N = 47) = 7.417, p = .025$. Organizations located in small metro areas used rural health centers more often than those in large metro areas, $\chi^2(2, N = 47) = 6.386, p = .041$. Use of in-patient/crisis supports by agencies located in large

metro areas was significantly higher than that of those in small or micro/rural areas, $\chi^2(2, N = 47) = 8.531, p = .014$.

TABLE XLIV
COMMUNITY RESOURCES BY URBAN CATEGORY

Resource	Large Metro (n = 22)	Small Metro (n = 10)	Micro/ Rural (n = 15)	χ^2
DHS/DD supports	90.9%	100.0%	80.0%	2.629
CMHC	54.5%	50.0%	93.3%	7.417*
FQHC	18.2%	20.0%	20.0%	0.025
Rural Health Center	4.5%	40.0%	26.7%	6.386*
University-based	31.8%	30.0%	13.3%	1.736
ER	90.9%	90.0%	80.0%	1.099
Police/911/EMS	90.9%	90.0%	86.7%	0.174
In-patient supports	100.0%	70.0%	66.7%	8.531*
Private sector	31.8%	50.0%	46.7%	0.522
Other	4.5%	0.0%	6.7%	0.663
Receipt of TA	29.9%	16.3%	24.8%	3.858

* $p < .05$

An ANOVA was conducted to compare means of key agency variables with respect to urbanicity; results are shown in Table XLV. The number of in-house mental health professionals and in-house therapeutic interventions offered was significantly statistically different between urban categories. A post hoc LSD test revealed that agencies located in large metro areas have more in-house mental health professionals

as compared to those in micro/rural areas, $F(2,44) = 2.555$, $p = .021$. Additionally, post hoc testing revealed that agencies located in large metro areas provided a higher number of in-house therapies as compared to both small metro, $F(2,44) = 6.164$, $p = .004$, and micro/rural areas, $F(2,44) = 6.164$, $p = .024$.

TABLE XLV
MEANS OF KEY AGENCY VARIABLES BY
URBAN CATEGORY (N=47)

	Large Metro (n = 22)		Small Metro (n = 10)		Micropolitan/rural (n = 15)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
# individuals served	177.86	285.29	123.90	131.54	70.93	54.17
#MHP	3.77*	2.60	2.30	1.49	2.00	1.93
# in-house therapies	2.41*	1.44	0.60	0.70	1.13	1.64
# services used	5.32	1.64	5.30	2.21	5.20	1.897
Satisfaction w/ all services used	3.05	0.80	3.22	0.95	3.30	0.68
Satisfaction w/ availability	2.05	0.90	1.78	1.09	1.80	1.15
Satisfaction w/ capacity	1.95	0.90	1.67	1.12	1.67	1.05
Change 3-5 yrs	3.18	0.96	3.22	0.83	3.60	1.056

* $p < .05$

Individual characteristics were analyzed to detect differences in variable means with respect to which urban influence code category an individual moved to. Table XLVI displays results from an ANOVA conducted on continuous variables: age, length of stay in SODC, HRST, IQ, and ICAP Service Level score. Results indicated that there was a

significant difference between IQ scores and ICAP Service Level Scores with respect to urban category. IQ scores of individuals who moved into large metropolitan areas were significantly lower as compared to scores of those moving into smaller metropolitan areas, $F(2, 415) = 4.411, p = .013$. There was no significant difference in IQ scores of people who moved into large metropolitan and micropolitan/rural areas; nor was there a difference between small metropolitan and micropolitan/rural areas. ICAP scores of individuals who moved into small metropolitan areas were significantly higher than average scores of their peers who moved into large metropolitan, or micropolitan/rural areas, $F(2, 447) = 5.972, p = .003$. In addition, chi square tests of independence were performed for gender and presence of psychiatric diagnosis and an ASD. There were no statistically significant differences between these variables with respect to urbanicity.

TABLE XLVI
INDIVIDUAL CHARACTERISTICS BY URBAN CATEGORY

	Urban Category					
	Large Metro (n = 237)		Small Metro (n = 53)		Micro/rural (n = 164)	
Demographics	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Age	47.20	13.43	48.80	12.78	46.80	12.94
Length of stay	15.20	12.08	11.20	9.73	15.10	14.18
HRST	2.34	1.03	2.33	1.40	2.17	1.20
IQ	30.83	19.71	40.47*	22.53	34.24	22.74
ICAP ^a	44.06	18.87	54.13**	18.70	44.69	20.62
	%		%		%	
Gender						
Male	67.8%		83.0%		68.3%	
Female	32.2%		17.0%		31.7%	
Psych. Diagnosis						
Yes	55.3%		56.6%		54.9%	
ASD						
Yes	12.7%		5.7%		9.8%	

* $p < 0.05$; ** $p < 0.01$; ^aICAP Service Level Score

4. **Impact of mental/behavioral health resources on transition success**

The third area of inquiry for this study sought to explore how regional variations in resources impact individual transition outcomes. A chi square test of independence was performed to determine if expected returns were proportionate to actual returns with respect to geographic region. Results, presented in Table XLII, indicate that there are no statistically significant differences between urban influence code categories with respect to the percentage of individuals returning to an SODC.

TABLE XLVII
PERCENTAGE OF STAYERS AND RETURNERS BY GEOGRAPHIC AREA

	Stayers (n = 411)	Returners (n = 43)	χ^2
<u>Urban Category</u>			
Large metro	52.1%	53.3%	2.857
Small metro	10.9%	18.6%	
Micropolitan/rural	37.0%	27.9%	

To determine differences in agency resources and satisfaction with respect to individual status, a *t*-test of independence was conducted on the mean key variables. As illustrated in Table XLVIII, there were no statistically significant differences between stayers and returners with regard to the failed agency placement's number of mental

health professionals, number of in-house therapy offerings, number of community-based services used, satisfaction scores, or perceived change in past 3-5 years in mental health system. There was, however, a statistically significant difference between the stayers and returners with respect to how many people lived in the setting, $t(426) = 2.111$, $p = .035$. Individuals who returned to an SODC lived in larger community settings; in other words the fewer people in a home the more likely they were to stay in their placement.

TABLE XLVIII
MEANS OF IN-HOUSE RESOURCES BY INDIVIDUAL STATUS (N = 454)

	Stayers (n = 411)		Returners (n = 43)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
# Ind. served	187.9	212.60	212.35	296.60
# in setting	6.04*	1.89	6.74	1.79
#MHP	3.72	2.54	3.05	2.54
# in-house treatments	2.19	1.57	1.74	1.53
# services used	5.17	1.30	5.21	1.23
Satisfaction with availability	1.79	0.82	1.76	0.82
Satisfaction with capacity	1.90	0.95	1.81	0.89
Satisfaction with all services	3.22	0.73	3.11	0.84
Change 3-5 yrs	2.94	1.07	3.26	1.04

* $p < .05$

A chi square test of independence was performed to determine differences between agencies with respect to in-house access to mental/behavioral health professionals and treatment interventions offered with respect to individual status. As displayed in Table XLIX, stayers remained in agencies which offered a higher percentage of ABA therapy as compared to agencies from which individuals returned to an SODC, $\chi^2(1, N = 454) = 5.527, p = .019$.

TABLE XLIX
PERCENTAGE OF AGENCIES WITH IN-HOUSE ACCESS TO
RESOURCES BY INDIVIDUAL STATUS

<u>Professional</u>		Stayers (n = 411)	Returners (n = 43)	χ^2
	Psychiatrist	61.8%	51.2%	1.848
	BCBA	62.3%	53.5%	1.272
	Clinical Psychologist	52.8%	46.5%	0.617
	LCSW	44.8%	37.2%	0.903
	Social Worker	37.7%	30.2%	0.934
	LCPC	36.5%	30.2%	0.456
	Associate Behavior Analyst	31.4%	34.9%	0.220
	LMFT	14.8%	14.0%	0.024
	Other	16.5%	7.0%	2.701
<u>Therapy</u>				
	Individual counseling/ psychotherapy	60.3%	53.5%	0.760
	ABA	68.9%	51.2%	5.527*
	Group counseling/therapy	49.1%	46.5%	0.108
	Telehealth	13.6%	9.3%	0.634
	RDI	6.3%	0.0%	2.885

* $p < .05$

Chi square tests of independence were also conducted to explore differences between community resource use and successful transitions. As displayed in Table L, the only variables that differed with respect to transition success was use of in-patient psychiatric/crisis treatment and provision of technical assistance. Agencies in which stayers resided used in-patient services more than agencies from which individuals returned to an SODC, $\chi^2(1, N = 454) = 6.082, p = .014$. Similarly agencies from which returners came received TA more than agencies from which individual remained, $\chi^2(1, N = 454) = 27.247, p = .000$.

TABLE L
NUMBER OF COMMUNITY RESOURCES USED BY
INDIVIDUAL STATUS (N = 454)

<u>Resource</u>	Stayers (n = 411)	Returners (n = 43)	χ^2
DHS/DDD supports	92.5%	95.3%	0.483
CMHC	41.8%	46.5%	0.347
FQHC	25.8%	20.9%	0.486
Rural Health Center	10.7%	18.6%	2.395
University-based	35.5%	27.9%	0.995
ER	87.8%	90.7%	0.305
Police/911/EMS	92.5%	93.0%	0.018
In-patient psychiatric/crisis supports	90.1%	79.0%	6.082*
Private sector	35.8%	32.6%	0.175
Other	1.2%	2.3%	0.367
Receipt of TA	23.1%	61.0%	27.247***

* $p < .05$; *** $p < .001$

Independent *t*-tests were conducted to determine if any significant differences with respect to individual demographics varied based on status of ‘stayer’ and ‘returner’. As displayed in Table LI, as compared to stayers, returners were, on average, younger, $t(454) = 3.604$, $p = .000$, had a shorter length of stay at an SODC, $t(454) = 4.604$, $p = .000$, higher IQ score, $t(454) = -2.242$, $p = .025$, and came from a setting with a larger number of residents, $t(454) = -2.111$, $p = .035$. A chi square test of independence was conducted for the categorical variables of gender, psychiatric diagnosis, and diagnosis on the autism spectrum. The only significant difference was with respect to psychiatric diagnosis; returners had a higher percentage of psychiatric diagnosis as compared to stayers, $\chi^2(1, N = 435) = 27.247$, $p = .000$.

TABLE LI
INDIVIDUAL CHARACTERISTICS BY STATUS

	Status			
	Stayers (n = 411)		Returners (n = 43)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Demographics				
Age	47.97*	13.25	40.47	10.117
Length of stay	15.53*	12.823	6.37	7.181
HRST	2.29	1.150	2.21	1.059
IQ	32.47*	21.361	40.49	20.374
ICAP ^a	45.17	19.391	48.33	22.644
Number of residents	6.04*	1.893	6.74	1.788
	%		%	
Gender				χ^2
Male	68.8%		79.1%	1.953
Female	31.2%		20.9%	
Psych. Diagnosis				
Yes	53.3%		74.4%	7.033**
ASD				
Yes	11.0%		9.3%	.113

* $p < 0.05$; ** $p < 0.01$; ^aICAP Service Level Score

In order to determine the predictive ability of each variable, a univariate analysis was conducted by entering variables into a binary logistic regression one at a time. The following individual variables were used: age, length of stay in the SODC, IQ, and presence of a psychiatric diagnosis. These variables were chosen for the regression as they significantly differed with respect to stayers and returners (Table LI). Additionally, when examined for inter-correlation, none of these variables had a strong statistically significant Pearson's r value (Table LII). The following agency factors were used in the binary logistic regression: provision of ABA therapy, use of in-patient services, size of home, and receipt of technical assistance. Again, these variables showed statistically

TABLE LII
PEARSON CORRELATIONS BETWEEN MODEL FACTORS

	Age	IQ	Length of Stay	Psych. Diagnosis	ABA therapy	Use of in-patient services	Home size	Receipt of TA
Age	-							
IQ	-.381***	-						
Length of Stay	.521***	-.536***	-					
Psych. Diagnosis	-.236***	.259***	-.293***	-				
ABA therapy	.090	-.189***	.226***	-.100*	-			
Use of in-patient services	-.057	-.125*	.080	-.038	.325***	-		
Home size	-.041	.066	-.030	-.023	-.134**	-.184***	-	
Receipt of TA	.139**	-.063	.071	-.065	.022	.014	.025	-
Urban category	-.012	.081	-.010	-.003	-.329***	-.271***	.254***	.057

* $p < 0.05$; ** $p < 0.01$; *** $p < .001$

significant differences with respect to stayers and returners while having weak correlations with each other. Finally, urban categories were entered to determine predictive value. Although urban category did not show statistically significant differences with respect to stayers and returners, the value was used for inclusion in the regression models.

As displayed in Table LIII, results from the binary logistic regression indicate that individual characteristics (age, $\text{Exp}(B) = .956$, 95% CI = .932 - .981, $p = .001$, length of stay, $\text{Exp}(B) = .921$, 95% CI = .886 - .958, $p = .000$, IQ, $\text{Exp}(B) = 1.017$, 95% CI = 1.002 – 1.033, $p = .028$, and psychiatric diagnosis, $\text{Exp}(B) = 2.550$, 95% CI = 1.252 – 5.197, $p = .010$, are predictive factors in transition success. Youth is a significant predictor of the likelihood of placement failure as is shorter length of stay in an SODC. Higher IQ scores and presence of a psychiatric diagnosis are also significant predictors of placement failure. The odds ratio indicates that those with a psychiatric diagnosis are 2.55 times more likely to return to an SODC after transition to a community setting as compared to their peers who do not have a psychiatric diagnosis.

In terms of agency factors, results indicate that the lesser the number of individuals living in a home, the lower the likelihood of return to an SODC. Finally, despite agency receipt of TA, an individual living at an agency which has received TA is 5.2 times more likely to return to an SODC relative to those who have not. Urban category was not a significant predictor of transition success, $\text{Exp}(B) = .883$, 95% CI = .63 – 1.25, $p = .48$.

TABLE LIII
BINARY LOGISTIC REGRESSION FOR OVERALL MODEL

	B	SE	Wald	Odds Ratio	95% CI
Individual Factors					
Age	-.045	.013	12.093	0.956**	.93 - .98
Length of SODC stay	-.082	.020	17.126	0.921***	.89 - .96
IQ	.017	.008	4.858	1.017*	1.00 – 1.03
Psychiatric diagnosis	.936	.363	6.644	2.550**	1.25 – 5.20
Agency Factors					
ABA therapy	-.747	.323	5.342	0.474*	.25 - .89
Use of in-patient services	-.984	.413	5.690	0.374*	.17 - .84
Home size	.217	.105	4.316	1.243*	1.01 – 1.53
Receipt of TA	1.649	.342	23.287	5.203***	2.66 – 10.17
Urban Category	-.125	.177	.499	0.883	.63 – 1.25

Note: CI = confidence interval; ABA = Applied Behavior Analysis; TA = technical assistance;

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Three hierarchical models were used and are presented in Table LIV. Individual factors in Model 1 include age, previous length of SODC stay, IQ, and presence of psychiatric diagnosis. In Model 2, these variables were again used with the inclusion of agency factors: use of ABA therapy, use of in-patient/crisis services, number of residents in a home, and receipt of TA. Model 3 added the previous variables from Models 1 and 2 as well as urban influence code category, using large metropolitan areas as a reference variable.

a. **Impact of individual factors**

Model 1 was used to examine associations between individual characteristics and transition outcome. Age, length of stay at SODC, IQ, and presence of a psychiatric diagnosis were used as variables. Wald chi-square tests revealed that when all other factors were controlled, unsuccessful transition was significantly associated with a shorter length of stay in an SODC, $\text{Exp}(B) = .932$, 95% CI = .890 - .976, $p = .003$.

b. **Impact of agency factors**

Model 2 was used to examine agency factors, controlling for individual factors, on transition outcome. Agency factors included in Model 2 were offering of ABA therapy, use of in-patient/crisis services, home size and receipt of TA. Controlling for all other variables, length of stay in an SODC remained a significant predictor of return to an SODC, $\text{Exp}(B) = .929$, 95% CI = .881 – .980, $p = .007$. Use of in-patient psychiatric/crisis services was a significant predictor of transition success, $\text{Exp}(B) = .215$, 95% CI = .068 – .677, $p = .009$. Those living in agencies that utilize in-patient services are more likely to remain in their transition setting. Those living in agencies

TABLE LIV
MODELS OF INDIVIDUAL CHARACTERISTICS, AGENCY RESOURCES, AND URBANICITY

	Model 1 Individual Factors		Model 2 Agency Factors		Model 3 Urban Category	
	OR	95% CI	OR	95% CI	OR	95% CI
Age	.987	.959 – 1.017	.995	.961 – 1.030	.993	.959 – 1.029
Length of stay	.932**	.890 – .976	.929**	.881 – .980	.931**	.883 – .982
IQ	.997	.979 – 1.015	.999	.978 – 1.021	.999	.978 – 1.022
Psych. diagnosis	1.540	.725 – 3.270	1.256	.516 – 3.058	1.266	.519 – 3.089
ABA therapy			1.338	.518 – 3.455	1.133	.390 – 3.295
Use of in-patient services			.215**	.068 – .677	.191*	.054 – .677
Home size			1.241	.976 – 1.578	1.291*	1.000 – 1.666
Receipt of TA			10.542***	4.322 – 25.711	10.586***	4.286 – 26.147
Urban Category						
Large Urban						
Small Urban					.831	.170 – 4.076
Micropolitan/rural					.531	.172 – 1.641

Note: OR = odds ratio; CI = confidence interval; TA = technical assistance; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

who receive technical assistance, however, are ten times more likely to experience transition failure; $\text{Exp}(B) = 10.542$, 95% CI = 4.322 – 25.711, $p = .000$.

c. **Impact of urbanicity**

Model 3 was used to examine how the urban influence categories impacted individuals' transition success controlling for individual and agency factors. Controlling for all other individual and agency factors, length of previous stay in an SODC remained a significant predictor of transition failure, $\text{Exp}(B) = .931$, 95% CI = .883 - .982, $p = .009$. Use of in-patient psychiatric/crisis services also remained a protective factor; $\text{Exp}(B) = .191$, 95% CI = .054 - .677, $p = .010$; individuals living in homes managed by an agency that uses in-patient services are less likely to return to an SODC. Receipt of technical assistance remained a significant predictive factor; people living in agencies who received technical assistance were 10.6 times more likely to return to an SODC, $\text{Exp}(B) = 10.586$, 95% CI = 4.286 – 26.147, $p = .000$. Urban influence code categories, do not appear to have a statistically significant impact on an individuals' transition success. Individuals living in small urban, $\text{Exp}(B) = .831$, 95% CI = .170 – 4.076, $p = .820$, or micropolitan/rural areas, $\text{Exp}(B) = .531$, 95% CI = .172 – 1.641, $p = .272$, were no more likely than those living in large metropolitan areas to return to an SODC based on geographic location, controlling for all other individual and agency factors.

VII. DISCUSSION

This study explored three questions related to the types of mental/behavioral health services that are available to organizations which provide residential services to adults with IDD; differences in the availability and capacity of these services based on geographic location; and the impact service availability had on transition outcomes of people moving from institutions into community-based settings. Community capacity to provide such services appears to influence the degree to which individuals transitioning from state operated institutions successfully adapt to community-based settings. As the United States continues to transition people out of large publicly operated institutions in favor of smaller community-based settings, it is critical that we continue to explore effective methods of mental/behavioral health treatment for people with IDD and a psychiatric diagnosis to ensure a successful transition and an ongoing high quality of life.

A. Research Questions

1. **What types of behavioral supports are available to individuals with intellectual/developmental disabilities residing in Illinois community-based residences?**

The first research inquiry explored the types of services available to community agencies in Illinois. Less than one-half of respondents reported having access to at least one in-house mental/behavioral health professional category. The number of in-house mental/behavioral therapies offered by responding agencies was similar; less than half of agencies reported providing at least one category of therapies included in the current adult HCBS waiver.

The vast majority of respondents (91%) reported using police/911/emergency medical services (EMS) in response to an individual who was harmful to his/herself or someone else, or was engaged in property destruction. Over 60% of respondents reported feeling satisfied/very satisfied with the interaction with the police/EMS, while 17.5% reported feeling dissatisfied/very dissatisfied. Use of the ER for the same behaviors was reported by 83% of respondents; however, reported mean satisfaction (2.9/5.0) was lower than interactions with police/911/EMS (3.5/5.0).

Use of the emergency room (ER) for individuals with IDD experiencing a behavioral episode is not uncommon. Lunsky and Elserafi (2011) reported that individuals with intellectual disabilities who had experienced a life event (move out of house or residence; serious problem with family, friend or caregiver; problems with police or other authority figure(s); unemployment in excess of one month; recent trauma/abuse; or a problem with drugs or alcohol) within the prior year were more likely (88%) to seek services from an ER as compared to individuals who had not had a life event. Changes in roommate/housemate and changes in direct support professionals (DSPs) were included as life events, however, did not differ significantly between groups with respect to ER use. Given the criteria for inclusion in this study of having moved out of an institution and into a community setting, it is not surprising that ERs are being used for behavioral episodes during the transition period.

Nearly 82% of survey respondents reported using inpatient psychiatric services, mainly in response to an individual being harmful to his/herself or others. In general, respondents scored satisfaction with inpatient services in the neutral range (3.1/5.0), which was a higher mean satisfaction score than either ER or supports provided by the

Illinois Department of Human Services/Division of Developmental Disabilities (DHS/DDD) which includes the Clinical Administrative Review Team (CART), the Support Services Team (SST), or other technical assistance provided by the Department.

Use of generic community services (ER, 911/police/EMS) was similar to that of specialized services specifically for people with IDD (DHS/DDD community supports; CART and SST). While nearly 90% of respondents indicated use of DHS/DDD supports in response to an individual who was harmful to his/herself, harmful to someone else, or engaged in property destruction, overall satisfaction with these supports was lower than that with the ER (2.9) or police/911/EMS (3.5). In general, the majority (over 65%) of respondents indicated that the availability and capacity of community services for persons with IDD were poor/very poor. Survey respondents were asked to score their assessment of change in community mental/behavioral health supports over the previous three to five years; 36.5% indicated it had remained stable while 40.3% indicated it had worsened. Only 22.2% indicated that it had improved.

The three most common behavior categories for which community services were sought in the current study were similar to those reported in Heller, Hsieh, Owen, and Badetti's (2012) evaluation of the Illinois Support Services Team (SST). The most common reasons for referral of an individual to the SSTs was due to physical aggression (78%), followed by verbal aggression (46%) and property destruction (44%).

2. **Does the availability of mental/behavioral supports differ between agencies with respect to geographic and population characteristics?**

“If you are not in a metropolitan area, move to another state or seek out-of-state services.” This was the sentiment shared by one survey respondent. In fact, survey results indicated that agencies located in large metropolitan areas have a significantly larger mean number of in-house mental/behavioral health professionals as compared to micropolitan/rural areas. Agencies located in large metropolitan areas had a significantly larger proportion of associate behavior analysts as compared to agencies located in smaller areas. Additionally, agencies located in large metropolitan areas provided a greater number of in-house therapies as compared to agencies located in both small metropolitan areas and micropolitan/rural areas. Moreover, agencies located in large metropolitan areas offered a higher proportion of individual counseling/psychotherapy and group counseling as compared to small metro and micropolitan/rural areas. They also offered more ABA therapy as compared to micropolitan/rural areas. Despite differences in the number of professionals and therapies provided, there was no significant difference between urban influence categories with respect to satisfaction scores with community capacity to provide mental/behavioral health services or availability of these services. This suggests that the mental/behavioral health resources available state-wide are not meeting the needs of people with IDD and mental/behavioral challenges and the agencies that support them.

With respect to use of community mental/behavioral health resources, large metropolitan areas reported using a higher proportion of in-patient psychiatric supports as compared to small metropolitan and micropolitan/rural areas, while agencies located

in micropolitan/rural areas used community mental health centers and rural health centers at a higher percentage as compared to large metropolitan areas. This may be due, in part, to the location and/or proximity of such services as well as an overall lack of specialist services in rural areas (Sawyer, Gale, & Lambert, 2006). It has been well established in the literature that residents of rural areas have less access to mental health services as compared to urban areas (Gustafson, Preston, & Hudson, 2009). Use of ERs for mental health issues decreased in rural areas between 1991-2001 (Larkin, Claassen, Emond, Pelletier, & Camargo, 2005), while community mental health centers are a major source of mental health treatment in rural communities (Gamm, Stone, & Pittman, 2003). Data from the present study is consistent with established literature.

3. **How do geographic and population characteristics and the availability of mental/behavioral supports impact an individual's transition from a state operated developmental center to a community-based setting?**

While data demonstrate the disparity in the availability of mental/behavioral health practitioners between rural and urban areas, results from the present study, however, indicate that these disparities did not impact post-deinstitutionalization outcomes. Individuals were not significantly more likely to succeed in a post-transition placement located in a rural area than an urban one.

Unlike previously published studies (Broadhurst & Mansell, 2007; Causby & York, 1991; Philips & Rose, 2010), individual characteristics in the present study (age, IQ, and presence of a psychiatric diagnosis) differed between stayers and returners.

Returners tended to be younger (consistent with Intagliata & Willer, 1982; Lulinski-Norris, Rizzolo, & Heller, 2012b), have a higher IQ score, and were more likely to have a psychiatric diagnosis as compared to those who remained in their transition placement, which is consistent with previous Illinois studies (Lulinski Norris, Rizzolo, & Heller, 2010; Lulinski-Norris, Rizzolo, & Heller, 2012b). In addition, length of stay at an SODC prior to transition was significantly different between groups: returners tended to have shorter previous lengths of stay as compared to stayers. This is also consistent with previous findings specific to Illinois in which returners had a significantly shorter previous length of stay as compared to those who remained in transition placement (Lulinski-Norris, Rizzolo, & Heller, 2012a).

Transition placement setting size also differed between stayers and returners; the number of individuals living in the home of those who returned to an SODC was significantly larger as compared to stayers. This differs from early findings from Baroff (1980) and Landesman-Dwyer, Sackett, and Stein Kleinman (1980) which concluded that facility size did not have a significant impact on resident outcomes. Baroff did suggest, however, that settings for 10 or fewer could be more responsive to individual needs. More recent studies of size of setting as a contributing factor to post-deinstitutionalization placement breakdown were not located, pointing to the need for more research into this component of community living. As Larson and Lakin (1989) noted, "...the fact that changes in adaptive behavior systematically vary according to whether people with mental retardation (*sic*) living in large or small residential environments is significant. It is significant because size is obviously an important proxy for environmental conditions that enhance a person's development" (p. 14).

Results of the present study indicated that individuals who returned to an SODC after an attempted community placement were younger, had a shorter previous length of stay in an SODC, a higher IQ score, and were more likely to have a psychiatric diagnosis as compared to those individuals who successfully remained in their placement setting. These individual factors did not significantly differ with respect to urban influence category.

There were no significant differences between stayers and returners with respect to their provider agency's overall access to in-house mental health professionals. With respect to the provision of specific in-house therapies, however, the only significant difference between stayers and returners was whether or not their agency provided ABA therapy⁵; those at agencies which did provide ABA therapy were more likely to remain in their transition placement as compared to those who were at agencies that did not provide ABA therapy. This is similar to Broadhurst and Mansell's (2007) finding that settings in which placement breakdown occurred had significantly fewer professional staff. Additionally, qualitative data indicated that access to mental/behavioral health professionals posed a barrier to the provision of services to individuals with IDD and behavioral challenges. When individual and agency factors (home size and use of in-patient services) were controlled for in the regression model, however, the provision of

⁵ ABA therapy is an approach used to increase the likelihood of 'desirable' behaviors and decrease the likelihood of 'undesirable' behaviors through the application of behavioral science in real-world environments such as school, home, and work (Baer, Wolf, & Risley, 1968; Hagopian & Hardesty, 2012). ABA-based approaches include: "1) the objective measurement of behavior, 2) use of procedures based on scientifically established principles of behavior, and 3) precise control of the environment to allow for the objective evaluation of outcomes. Any clinical procedure or research investigation adhering to these basic criteria can be considered to be an ABA-based procedure. This includes 'functional behavioral assessment,' approaches such as 'Positive Behavioral Support,' and forms of 'Behavior Therapy' that rely on direct observation of behavior, procedures based on behavioral principles, and analysis of behavior-environment relations" (Hagopian & Hardesty, 2012, p. 2).

ABA therapy no longer was a significant predictor of transition outcome. Since the provision of ABA therapy and use of in-patient psychiatric/crisis services have a medium correlation this suggests that these two variables are closely related and may cancel one another out in the regression model.

The provision of technical assistance (TA) did differ significantly with respect to stayers and returners. Individuals who lived at agencies that received TA were more likely to return to an SODC as compared to individuals who lived at agencies that did not. Provision of TA remained a significant predictor when controlling for all other agency factors, individual factors and urban setting. This may be related to timing; qualitative data from the current study suggested that TA was not delivered in a timely manner. Additionally, survey respondents indicated that there is a need for crisis services. It is possible that the provision of TA was “too little, too late” and was not provided quickly enough to prevent readmission to an SODC due to the behavioral challenges for which TA was being sought. Another possible explanation is that one method of TA, the Support Services Team (SST), used SODCs as a crisis respite placement which did result in short-term returns to SODCs (Heller, Hsieh, Owen, & Badetti, 2012). A third possibility is the finding that not all agency staff chose to “follow, implement, or follow-up on [SST] recommendations” (Heller, Hsieh, Owen, & Bedetti, 2012, p. 24). The evaluation team recommended that future SST response include community-based crisis respite placements as opposed to reliance SODCs for short-term crisis placement.

Another area which differed between stayers and returners was responding agencies’ use of in-patient psychiatric hospitalization/crisis services. Individuals who

lived in agencies which used in-patient services were more likely to remain in their transition setting. Despite qualitative data suggesting a need for increased psychiatric hospital access, existing hospital bed availability resources appear to be benefitting some organizations. More research should be conducted to determine what characteristics make these in-patient psychiatric services a viable option for some organizations as well as why it appears to be a deterrent to SODC readmission.

Finally with respect to use of community resources, large metropolitan areas reported using a higher proportion of in-patient psychiatric supports as compared to small metro and micro/rural areas while agencies located in micro/rural areas used community mental health centers and rural health centers at a higher percentage. While it is not surprising that rural areas use rural health centers more, it warrants further investigation into the types of mental/behavioral health services offered by such entities and staff preparation to work with individuals with IDD. Additionally, it becomes apparent that accessibility of mental/behavioral treatments in ERs located in more urban areas warrants exploration to further understand why services are sought at particular facilities and not others. It may be, as stated earlier, that residents of rural areas have less access to mental health services as compared to urban areas (Gustafson, Preston, & Hudson, 2009). Additionally, as indicated earlier, ERs are used at a higher rate in urban areas for mental health situations as compared to rural areas (Larkin, Claassen, Emond, Pelletier, & Camargo, 2005), while community mental health centers serve as a major source of mental health treatment in rural communities (Gamm, Stone, & Pittman, 2010). Further investigation of rural/urban differences in treatment utilization will assist in decisions related to appropriations of funding for such facilities and their related

programs. Further, it will provide data to guide the creation of additional service sites and/or therapeutic interventions which are proven effective in specific service areas.

B. **Research Implications**

Results from this study indicate the need for continued investigation of macrosystem factors and community capital contributing to post-deinstitutionalization outcomes for people with IDD. Additionally, they highlight the need for continued exploration of programs addressing challenges to community living experienced by persons with ID and behavioral concerns which threaten their ability to remain in the community.

1. **Application of Bronfenbrenner's Environmental Model to deinstitutionalization research**

As community-based agencies rely on both government funding and the availability of services and supports within their geographic location which exist within the macrosystem (e.g., state programs, legislation, social constructions of disability, political ideology), it becomes clear that it is necessary to look beyond the individual and his/her microsystem (setting) when analyzing reasons for successful and unsuccessful outcomes related to deinstitutionalization. This study examined the impact of environment, operationally defined as the macrosystem (agency) and its exosystem (community), to determine potential reasons for transition failure.

Research has consistently shown that individual-level factors impact transition success. As deinstitutionalization continues across the nation due to the continued implementation of *Olmstead*, exploration of environmental factors contributing to transition success is imperative. This research should reach beyond individual

characteristics and focus on the relationship of individuals to their environments to determine which is not only the least restrictive, but is the best fit for the individual.

2. **Application of geographic information systems to
deinstitutionalization research**

It is critical to approach the study of deinstitutionalization from the lens of human ecology, specifically taking geography into account as a potential factor contributing to outcomes. Though urban categories were not statistically significant predictors of post-transition outcomes in the current study, they did contribute to the differences between agencies with respect to the number of in-house mental/behavioral health providers an agency had access to, and the number of therapies offered by that agency and the types of community resources utilized by agencies. Additionally, data indicated that people who moved to agencies located in small metropolitan areas had significantly higher IQ scores and ICAP service scores as compared to those who moved into large metro or micro/rural areas. This appears to indicate that agencies located in small urban areas with populations ranging from 50,000 – 1M residents admit individuals with less service needs as compared to large urban and micropolitan/rural areas. It is not clear whether this is due to risk aversion on the part of provider agencies, to individual choice, or other factors. It does, however, point to the need for continued research into how community capital impacts post-deinstitutionalization transition success.

3. **Additional research is needed in the United States**

Research on type and impact of mental/behavioral health intervention is lacking in the United States, though it has been estimated that about one third of

individuals in the IDD service system have a co-occurring psychiatric diagnosis (NASDDDS & HSRI, 2012). The vast majority of research conducted exploring issues of dual diagnosis has occurred in the United Kingdom and to a lesser extent, in Canada. The UK and Canada differ from the U.S. largely in that both of these countries have a national health care insurance program. Federalism, or states' rights, in the U.S. creates an additional layer of potential inquiry due to the numerous combinations of Medicaid programs possible. Researchers should capitalize upon these differences as a means of collecting research and evaluation data on dozens of different program combinations across the states in order to create a comprehensive database of evidence-based interventions from which states can glean information that may meet the needs of their residents. Work toward this end has been initiated by Rizzolo, Friedman, Lulinski-Norris, and Braddock (2013) through a nationwide study of spending on Medicaid Home and Community Based Waiver programs, in which it was reported that \$451.8 million (1.92%) of total proposed spending was dedicated to health and professional services, which included spending on behavioral/therapeutic services. Friedman, Lulinski, and Rizzolo (in preparation) offer further exploration of spending on mental health services for people with IDD. In FY2011, 36 states analyzed offered a total of 73 waivers providing behavioral/therapeutic services. For FY2011, they report a projected \$219.5 million (0.69%) in spending on behavioral/therapeutic services, which include behavioral intervention, psychological therapy, and counseling and therapeutic services. In terms of crisis services, defined as those having a goal of prevention of placement in a more restrictive institutionalized setting, FY2011 figures projected \$18.02 million in total spending for 16 of the waivers analyzed from 11 states, of which

only 0.7% (\$126,140) went toward crisis services. The authors highlighted some unique services being provided through such waivers such as the mobile crisis intervention team and a crisis respite facility employed in California's DD waiver. Further inquiry into the variety and successes of behavioral and crisis services offered through other state waivers would provide valuable models for states grappling with similar issues. A national review of crisis intervention and technical assistance programs would allow creation of a database containing evidence-based, effective and budget-neutral program models.

There exists a need for a comprehensive and coordinated approach to issues affecting individuals with a dual diagnosis in the United States. The present study on the impact of geographically available behavioral/mental health services to individuals with IDD on their longitudinal post-deinstitutionalization outcomes is the first of its kind located in the literature. As the remaining 38 states move toward the abolition of publically operated institutions, this will become an increasingly pressing issue. There is a need for continued exploration of variations in the provision of mental/behavioral health services for individuals with IDD from state to state due to flexibility in Medicaid programs which allow states to determine components and mechanisms of service delivery.

Continued research of effective treatment for mental/behavior issues and evaluation of model programs is necessary to continue the deinstitutionalization trend in a systematically responsible manner. As we continue to depopulate institutions, the nation would benefit from such a resource to assist states in the development of an

interdisciplinary and holistic crisis response system that is consistent, effective, person-centered, and timely.

C. **Policy Implications**

Data from the present study demonstrate the need for strengthening of the mental/behavioral health system available to adults with IDD in four ways: build up the availability of technical assistance and crisis response to behavioral issues, enhance the availability of community-based mental/behavioral health services through training, improve collaboration between state DD and mental health agencies, and increase Medicaid reimbursement rates to providers of mental/behavioral health services.

1. **Technical assistance and crisis response**

The availability and capacity of crisis supports in Illinois is lacking which will continue to be a challenge to efforts to rebalance the system. The Human Services Research Institute concluded in its analysis of the Illinois service system that "...it is imperative that Illinois build capacity to address behavioral challenges among service recipients" (2012, p. 74). They recommended that the Illinois IDD system "[s]trengthen community-based supports for people with extraordinary behavioral challenges." While a large percentage of survey respondents indicated using supports provided by the Illinois Department of Human Services/Division of Developmental Disabilities, overall satisfaction with service outcomes was low as compared to that with ER and 911/police/EMS. The main concern expressed with DHS/DDD supports was the lack of immediate crisis response available; ER and police intervention, however, offer near instant intervention.

As mentioned previously, the majority of states experience issues resulting from a lack of behavioral crisis services available in the community. Present study results are similar to a national survey of 44 states and the District of Columbia conducted by the National Association of State Directors of Developmental Disability Services (NASDDDS) and the National Association of State Mental Health Program Directors (NASMHPD), in which 56% of respondents indicated that the lack of crisis services was a “frequent or consistent impediment to the provision of supports to individuals with co-existing conditions” (Moseley, 2004, p. 6).

Given the significant relationship between receipt of technical assistance (TA, which includes CART and SST) and SODC readmission in the current study, there exists an urgent need to further investigate the provision of TA in Illinois. Specifically, future studies should explore the type of TA delivered as opposed to solely for what type of behavior the TA is addressing. Additional evaluation of CART and other TA options should be examined to add to the evaluative data presented by Heller, Hsieh, Owen, and Badetti (2012) in an effort to provide a deeper understanding of supports offered through DHS/DDD. As discussed previously, this team evaluated the Illinois Support Services Team (SST). More than 80% of cases for whom SST support was received resulted in a reduction in the severity and/or frequency of the behaviors resulting in the SST referral. In addition, staff and families reported improvement in the behaviors of individuals for whom referrals were sought. During the study period, short-term admissions to an SODC increased as short-term respite was an option through the SST program.

While stakeholders expressed concerns about the short time frame of the SSTs and perceived lack of follow-up, SST services did improve medical and behavioral outcomes for referred persons. In some cases, stakeholders learned how to more effectively navigate community services and discovered others. There are, however, still few alternatives to SODC admissions for people in need of short-term placement due to behavioral and/or medical issues. The research team recommended further exploration of short-term placement alternatives to keep SODCs from remaining the default option (Heller, Hsieh, Owen, & Badetti, 2012). This sentiment was echoed in responses from survey participants from the current study who also indicated the need for short-term placement alternatives including psychiatric hospital beds and crisis respite.

Three additional examples of state response to such needs not previously discussed warrant discussion, though have not been evaluated such as the SST in Illinois was. In 1992, the Minnesota legislature authorized a 2-year budget-neutral pilot project to maintain residential placement during behavioral crises. The project, called the Special Services Program, provided community outreach and short-term crisis service units. Outreach, conducted at home, school or work, included: functional analysis, technical assistance, training and temporary additional direct support professional staff at the residential site. The crisis unit served a maximum of four individuals at a given time and was staffed 24-hours by a ratio of one staff to two individuals during waking hours. The Special Service Program staff provided follow-up for one-year after initial service contact; initially occurring every one to two weeks after the initial intervention period until the individual stabilized and then quarterly or as

requested up to one year. Results indicated that individuals who received Program services remained in their residential placement (58%). Twenty-five percent of individuals who received crisis unit services remained in their residential placement (which included family homes) while others moved into more structured environments. Caregivers indicated high (44%) and very high (56%) satisfaction with the program. In addition, the program cost nearly \$300,000 less overall as compared to the cost of other service usage. In 1995, the Minnesota legislature authorized additional programs (Rudolph, Lakin, Oslund, & Larson, 1998).

A more recent report from Maine outlines their crisis prevention and intervention service teams. Coordinated through three regional teams staffed 24 hours with state employees, there are six major components: phone contact, outreach contact, consult/education contact, in home support, crisis unit, and a support line. In addition to the Crisis Teams, funding was committed to provide on-line training to police officers throughout the state on supporting people with IDD in a behavioral crisis. Based on demand the program was extended for an additional two years which included additional training opportunities and the development of a two person crisis home (Department of Behavioral and Developmental Services, State of Maine, 2004).

The state of New Jersey's Trinitas Regional Medical Center developed a three-pronged approach to address behavioral challenges which were threatening individuals' ability to remain in community placement. The Integrated Service Delivery Team provides clinical case management to eligible persons as well as psychological and behavioral assessments, behavioral skills training, family support, linkage to psychiatric services, and 24-hour on call crisis support (Calefati & Livingston, 2012).

A second intervention is through the Statewide Clinical Consultation and Training (SCCAT) team, who provide face to face consultation and treatment recommendations to screening and crisis centers across New Jersey. In addition, SCCAT clinicians act as consultants to families and service providers through the provision of on-site clinical outreach including the assessment and creation of stabilization plans for individuals in jeopardy of losing community services due to behavioral issues. On-site training and coaching as well as linkage to local resources are also provided in an interdisciplinary manner involving all impacted parties. Free and open regional trainings are offered regularly on topics of concern to those supporting individuals with a dual diagnosis in addition to agency-based in-services. SCCAT is funded through a state contract from the Division of Developmental Disabilities and the Division of Mental Health and Addiction Services, both housed in the New Jersey Department of Human Services (Patwardhan, Rechtman, Life, & Esralew, 2012). .

Thirdly, since 2003 Trinitas Regional Medical Center's Department of Behavioral Health and Psychiatry has operated a 10-bed inpatient mental health program called the 2D Unit. The unit provides a medical and psychiatric evaluation, behavior assessment, crisis intervention, treatment planning, individualized therapies, family consultation, advocacy, referral to local community services, and post-discharge recommendations. Post-discharge instruction may include follow-up with the Integrated Service Delivery Team or the Statewide Clinical Consultation and Training team, discussed above to assist with community reintegration (Guglielmino, Melici, & Shah, 2012).

These are just some examples of states' responses to behaviors which threaten an individual's ability to remain in a community-based residential program.

Unfortunately, evaluation data for the three latter examples is not available but is needed. Despite the lack of an evaluative component, there are some facets of the programs that might prove beneficial in Illinois based on data presented here. For example, a training program for police and emergency responders, such as used in Maine, may prove useful in Illinois as 91% of participating agencies indicate the use of emergency responders in behavioral situations. New Jersey offers 24-hour-on-call crisis support; survey participants from the present study indicated a need for such immediate response to behavioral crises. To avoid confusion about whom to call as indicated by one survey respondent from the current study, a toll-free number should be implemented which would reach the on-call personnel. New Jersey also offers face to face consultation at screening and crisis centers as a non-immediate option. Illinois could explore adding a behavioral support unit in some of its 18 Pre-Admission Screening/Individual Service Coordination agencies located throughout the state for similar purposes.

2. **Increased training of mental health professionals**

While an estimated 34% of individuals with IDD in the service system also have a psychiatric diagnosis (NASDDDS & HSRI, 2012), definitive evidence of the efficacy of specialized versus generalist psychiatric treatment is lacking, mainly due to the absence of randomized control studies for obvious ethical reasons. Studies suggest, however, that the addition of training and supplementary specialist staff to generalist psychiatric treatment facilities could improve access (Chaplin, 2009). While 80% of people with IDD in state psychiatric hospitals also have a psychiatric diagnosis,

only 7% receive services from a unit specializing in dual diagnosis (National Association of State Mental Health Program Directors, 2004).

A lack of providers and an unwillingness of providers were identified as barriers to service provision in the current study. Previous research has explored attitudes of general mental health practitioners toward providing treatment to persons with IDD. Rose, Kent, and Rose (2012) conducted a study to measure the attitudes and emotions of health professionals toward working with individuals with ID and mental health needs. They found that 100% of professionals with an ID specialty had weekly contact with persons with ID; 83% of the specialists had received 4+ weeks of ID training; and 83% of the specialists had worked with 30+ individuals with ID. ID specialists had significantly more contact with this population, significantly more positive attitudes and emotional feelings about people with ID as compared to general mental health professionals. They reported that numbers of clients with ID and contact frequency appeared to impact attitude scores, suggesting that all health care staff should receive training on adults with ID as they are "...increasingly being encouraged to access mainstream services" (Rose, Kent, & Rose, 2012, p. 862).

As mentioned previously, a study by the Illinois chapter of the National Alliance on Mental Illness (NAMI) and the Supportive Housing Providers Association (2012), implicated a need to "cultivate and train counselors, psychiatrists and psychologists for working with persons with cognitive deficits" (p. 11). Training was also implicated by Barksdale (2011) as having a positive impact on health professionals' willingness to treat persons with dual diagnosis. He reported findings from a survey of Pennsylvania behavioral health clinicians. Nearly 68% (n = 168) of respondents indicated that they

had received no specialized training to work with people who have IDD. Despite not having received training, 57% reported providing services to individuals with IDD over the previous two years. Forty percent of clinicians who were not currently treating this population, indicated that they would be willing to while 34% indicated that they were not willing to provide treatment. Sixty-eight percent indicated they had an interest in receiving training and 64% indicated that with the proper training they would be willing to add the IDD population to their practice.

In a 2001 report, the U.S. Surgeon General made a number of recommendations that would minimize health disparities between people with IDD and their non-disabled peers. Goal number 4 was related to the integration of training on health care issues impacting people with IDD through both didactic and clinical training into the basic and specialized training curricula for health care providers (U.S. Public Health Service, 2001). Potential curriculum topics included: dual diagnosis, counseling, and alternative behavior management techniques and would be delivered in an interdisciplinary and culturally competent manner. Continuing education opportunities for providers at all levels was also included as part of the action steps.

The nation currently has access to a federal pre-service training program that, since the 1950s, has sought to increase the competence of clinicians who work with people with IDD; the Leadership Education in Neurodevelopmental and related Disabilities (LEND) program. Funded by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau, the purpose of the LEND network is to improve the health of infants, children and adolescents with disabilities through an interdisciplinary pre-service training program. Illinois obtained funding to

create a LEND program in 2008. Since its inception, 129 trainees from 14 disciplines (Applied Behavior Analysis, Disability Studies, Developmental Behavioral Pediatrics, Family, Nursing, Nutrition, Occupational Therapy, Physical Therapy, Psychology, Public Health, Self-Advocacy, Social Work, Special Education, and Speech Language Pathology) have received training on disability history, policy, culture and systems as well as in-depth hands-on clinical training from clinicians with decades of experience working with disabled populations. Annually, this program produces a team of practitioners competent not only in their chosen fields of study but who have an additional set of skills related to working with people with disabilities and their families. This resource could be very beneficial to states which are rebalancing systems of support, particularly as it directly addresses the lack of clinicians who have the necessary competency to adequately address the needs of people with IDD and their families. In fact, this vast network of 43 LENDs and their affiliated University Centers for Excellence in Developmental Disabilities (UCEDDs) have a significant research and clinical practice base from which contributions to these issues moving forward should be sought. State agencies should seek out this expertise when creating new programs.

3. **Training of first responders and emergency room staff**

As previously stated, the vast majority of respondents (91%) reported using police/911/emergency medical services (EMS) in response to an individual who was harmful to his/herself or someone else, or was engaged in property destruction. Use of the ER for the same behaviors was reported by 83% of respondents. Given the common use of emergency responders and ER for individuals with IDD experiencing a behavioral episode, it becomes clear that training of individuals likely to come into

contact with an individual who has IDD and is experiencing a behavioral crisis is necessary. One way in which this could be accomplished is through training to all health care professionals on the provision of treatment to people with IDD. For those already practicing this could be completed through continuing education training; addition of such information to curriculum would better prepare future health care practitioners to provide competent care. Additionally, training on de-escalation techniques and other evidence-based interventions should be provided to health care providers working in ERs. This would ensure that all health professionals working in emergency departments, as well as other health care settings, would have the ability to recognize and appropriately intervene in situations in which an individual's behavior is causing danger to him/herself and/or others. In addition to health care practitioners working in ERs, first responders (e.g., law enforcement, EMS workers, and 911 dispatchers) would benefit from similar training.

The Center for Development and Disability at the University of New Mexico (UCEDD for the State of New Mexico) developed a tip sheet for emergency responders which covers considerations to take into account when working with people with a variety of disabilities (e.g., mobility impairments, visual impairments, autism, or cognitive disabilities). The tip sheet can be accessed at: <http://cdd.unm.edu/dhpd/pdfs/FifthEditionTipsSheet.pdf> and is available in both English and Spanish. The sharing and use of these types of materials may prove beneficial for professionals who come into contact with people with IDD who are in an emergency situation.

4. **Smaller settings**

Study data indicated that stayers receive services from agencies which have a smaller average number of people living in a CILA as compared to returners; returners, on average, came from larger settings. This data is consistent with previous studies. For example, Balla (1976) indicated that smaller settings have more resident-oriented practices (Balla, 1976; Baroff, 1980) and thus offer a better quality of life as compared to larger settings (Balla, 1976). Additionally, Baroff (1980) reported smaller settings are more individualized as compared to larger settings. Further, a literature review completed by Kozma, Mansell, and Beadle-Brown (2009) indicated that smaller settings offer more community involvement, larger social networks and more friends, more opportunities for choice and self-determination, a higher quality of life and greater satisfaction of residents and their families as compared to larger settings. Based on the data from the current study and data from previous decades, it appears that smaller settings not only increase quality of life but individual transition outcomes as well.

5. **Improved collaboration between state developmental disability and mental health agencies**

Survey response data from the current study indicated that participants wish to see better collaboration between the Division of Developmental Disabilities and the Division of Mental Health, both of which fall under the umbrella of the Illinois Department of Human Services. Similarly, results from a 2003 nationwide survey conducted by NASDDDS and NASMHPD revealed that the working relationship between IDD and mental health agencies was described by 56% of IDD agency directors as being “not or not very effective” (Moseley, 2004). Moseley outlined

philosophical differences between state IDD agencies and those focused on mental health of the general population which might be contributing factors to the relative lack of mental health professionals who serve the IDD population. He observed that IDD agencies are based on a foundation of long-term supports and services often including residential supports, while mental health agencies focus on providing episodic, short-term, out-patient treatment. The needs of persons with mental illness, he remarked, can often be met by a generalist and rely on communication and cognition abilities; people with IDD may not have command of these attributes to the same extent. These subtle differences in foundational approach may impact the ability for integration between the IDD and mental health service sectors and thus are important to keep in mind when collaborating. Regardless, due to the large number of individuals who have a dual diagnosis, it is important that state DD and mental health agencies consider collaborative efforts including a joint research and data agenda and the sharing of effective models of collaboration such as interagency agreements, joint task forces and cross-system training and technical assistance (National Association of State Mental Health Program Directors, 2004).

6. **Increased Medicaid rates**

Another area participants in the present study noted a need for improvement is Medicaid rates. Survey respondents indicated that an increase in Medicaid reimbursement rates would increase the number of mental health care providers willing to serve individuals who rely on Medicaid for health care insurance. In fact, it has been established that physicians accept Medicaid patients at a lower rate as compared to patients who are self pay or have private insurance (Decker, 2012).

Further, increased Medicaid rates lead to an increase in the number of private physicians who will accept Medicaid patients (Decker, 2007).

Similar data for mental/behavioral health practitioners was not located, however, it is likely to be comparable. Friedman, Lulinski, and Rizzolo (in preparation) reported an hourly national average of \$63.77 per hour for projected spending on behavioral/therapeutic services in FY2011 in an analysis of national spending on behavioral/therapeutic services offered through HCBS waiver programs. The budgeted amount for such services as part of Illinois' HCBS waiver was slightly higher than the national average at \$65.00 per hour for behavior intervention and treatment (State of Illinois, 2012). Rates for individual and group psychotherapy were \$37.00/hour and \$12.00/hour respectively, while rates for individual and group counseling were \$30.00/hour and \$10.00/hour respectively. While Medicaid rates for behavioral/therapeutic services may be comparable between national and state levels in Illinois, funding for crisis services is well below the national average. The national projected hourly rates for crisis services for FY2011 were \$55.27 per hour (Friedman, Lulinski, & Rizzolo, in preparation) while the Illinois rate was \$11.00/hour (State of Illinois, 2012).

Not only are Medicaid reimbursement rates capped in the state of Illinois, but the number of therapy hours an individual may receive is capped as well. For example, the maximum number of combined hours of behavioral intervention and treatment an individual can receive is 66 hours per year (State of Illinois, 2012). Based on these figures and survey participant statements, further investigation of the relationship between Medicaid reimbursement rates and the number of mental health professionals

treating Medicaid recipients is warranted. In addition, a comparison of state Medicaid rates for behavioral/therapeutic services is necessary to determine facets of state Medicaid plans that may need adjustment to maintain accessibility of services to recipients.

D. Limitations

Potential study limitations should be taken into consideration when interpreting results of this study. The main limitation is the use of a retrospective survey design which asked participants to reflect on events that occurred in the past involving multiple individuals and multiple community resources. Additionally, participants were asked to assign a single satisfaction score to a service category that may have been used multiple times for multiple issues and people. Finally, response bias is a limitation as it is plausible that survey respondents only participated due to a strong feeling (in either direction) about the survey topic.

Another study limitation is human error in the data collection phase. DHS staff collected retrospective data from medical records and transcribed data onto hard copy before transmitting to the researcher, which can introduce error into the data whether through omission or transcription error. At the present time, DHS/DDD does not have its recipient files digitized and therefore the only method of collection is by hand and paper-based. Future research would be enhanced by the ability to share digitized data files for a more swift and precise analysis.

A third study limitation is related to the collection of information about technical assistance provided. Data was only collected on whether or not TA was provided to an individual and for what type of issue (medical, behavioral, other). Future studies would

benefit from a deeper exploration of the provision of TA including the type of TA provided (SODC-based, CART, SST, etc.), specific services provided (face to face consultation, phone contact), programmatic changes (revised individual service plan, medication change, addition of therapy, etc.), and results of TA (admission to psychiatric facility or SODC, improved function in current placement). As results from this study suggest that the provision of TA has a significant impact on individual outcomes, additional investigation is warranted.

A final study limitation is the inconsistent availability of ICAP Maladaptive Behavior Scores. Prior to the July 1, 2009 – December 31, 2012 data collection, maladaptive behavior scores were not regularly collected by the researcher and therefore rendered that variable unusable as less than 50% of the sample had these scores. Future research concerning behavioral challenges should include an analysis of maladaptive behavior scores to determine if they are a predictor of transition failure.

E. **Conclusion**

Indeed, the ability to support people with developmental disabilities who demonstrate substantial behavioral disorders is widely perceived to be a critical measure of a local service system's capacity to act as a holistic alternative to institutional care. (Moseley, 2004, p. 2)

This study highlights the necessity to look beyond the individual and his/her immediate surroundings to the systems within which services occur. It brings the nation a step closer to understanding the community's capacity to support people transitioning out of institutions and highlights areas in which community support system improvement is necessary. States must prepare the community to support its citizens who have behavioral challenges in addition to IDD. As the public institutional census continues to

decline, we will find ourselves needing to develop treatment options for people with behavioral challenges, as they are often the last to be discharged (Wing, 1989).

This study underscores the need to continue evaluating individual post-deinstitutionalization outcomes to determine how to best support individuals with challenging behaviors in community-based settings and avoid institutional readmission, which occurs as a "...result of the lack of appropriate services to adequately support people with challenging needs" (Broadhurst & Mansell, 2007, p. 294). In order for continued success, the community must be adequately prepared to serve all of its citizens, specifically those who have behavioral challenges which threaten their ability to remain in the communities where they belong.

Resources must, therefore, be invested into the reinforcement of our mental/behavioral health system including training of mental health professionals to properly treat individuals with IDD and the availability and accessibility of such services to those who need them. Without shoring up community mental health resources, system rebalancing will pose a serious challenge for those individuals who have acute behavioral needs. We must continue to strengthen community-based supports to enable successful transitions of persons with challenging behaviors from institutionalized settings to community living as well as maintain people who have behavioral challenges in their home and communities. Future research should focus on the impact of systems and policies on the ability of people with IDD to assume their place as full and equal citizens. This includes the capacity and accessibility of the general mental/behavioral health system as well as the ability of mental health practitioners to treat people with a dual diagnosis.

APPENDICES

APPENDIX A

SODC Name _____ Time Period of this Report _____ to _____ Page ____ of ____

DHS ID	Month/year of birth	Race of Individual	Ethnicity of Individual	Admit Date	Short Term Admission?	Discharge Date	HRST	ICAP Adaptive Behavior Score	ICAP Service Level Score	ICAP Maladaptive Behavior	IQ	Diagnosis of Intellectual	Level of Intellectual Disability	Psychiatric Diagnoses	ASD Diagnosis? (specify)	D/C to name of provider & ZIP code	Type of residence # of residents	Guardian status	Current Status	Reason for return to SODC (if	Technical Assist	Type TA

APPENDIX B

Survey of Community Capacity for Serving Individuals with Mental/Behavioral Healthcare Needs

Q1 Agency name:

Q2 Address of administrative offices:

Q3 County or counties served:

Q4 Person completing this survey (name and title):

Q5 Contact information of person completing this survey (phone number and e-mail address):

Q6 From which of the following state operated developmental centers (SODCs) has your organization accepted transitioning individuals? (check all that apply)

- ☐ Choate Developmental Center
- ☐ Fox Developmental Center
- ☐ Howe Developmental Center
- ☐ Jacksonville Developmental Center
- ☐ Kiley Developmental Center
- ☐ Lincoln Developmental Center
- ☐ Ludeman Developmental Center
- ☐ Mabley Developmental Center
- ☐ Murray Developmental Center
- ☐ Shapiro Developmental Center

Q7 How many people did your agency serve across all of its residential programs as of December 31, 2012?

APPENDIX B (continued)

Q8 Aside from the DHS/DDD mandated training (for DSPs and QIDPs), list any additional formal/informal trainings your staff receive on providing mental health or behavioral supports to people with IDD. Please indicate name and source of curriculum, number of hours of additional training and what staff positions are required to complete training (if none, type N/A):

Q9 Which crisis intervention program does your agency employ?

- ☐ N/A this organization does not offer crisis intervention training
- ☐ Mandt Training
- ☐ Crisis Prevention Institute (CPI) Training
- ☐ Other: _____
- ☐ Other: _____

Q10 Which of the following mental/behavioral health specialists does your agency have access to in-house*? (check all that apply) *in-house refers to a specialist who is a permanent full or part time employee or one who has a contractual relationship with the agency

- ☐ Clinical psychologist
- ☐ Psychiatrist
- ☐ Licensed Marriage and Family Therapist (LMFT)
- ☐ LCSW (Licensed Clinical Social Worker)
- ☐ LCPC (Licensed Clinical Professional Counselor)
- ☐ Social Worker
- ☐ Board Certified Behavior Analyst (BCBA)
- ☐ Associate Behavior Analyst
- ☐ Other _____
- ☐ Other _____
- ☐ Other _____
- ☐ Other _____

APPENDIX B (continued)

Q11 Which of the following types of mental/behavioral health services does your agency provide in-house by a licensed professional? (check all that apply)

- ☐ Individual counseling/psychotherapy
- ☐ Group counseling/therapy
- ☐ Applied Behavior Analysis
- ☐ Relationship Development Intervention (RDI)
- ☐ Telehealth
- ☐ Other _____
- ☐ Other _____
- ☐ Other _____
- ☐ Other _____
- ☐ Other _____

APPENDIX B (continued)

Q12 Does your agency use any of the following mental/behavioral health services on behalf of individuals served by your agency? (check all that apply):

	Yes	No
Community Mental Health Centers	<input type="radio"/>	<input type="radio"/>
Inpatient psychiatric treatment/crisis services	<input type="radio"/>	<input type="radio"/>
Community supports (e.g., SST, CART)	<input type="radio"/>	<input type="radio"/>
Private-sector mental health services	<input type="radio"/>	<input type="radio"/>
Federally Qualified Health Centers	<input type="radio"/>	<input type="radio"/>
Rural Health Centers	<input type="radio"/>	<input type="radio"/>
University-based (e.g., UIC Family Clinics)	<input type="radio"/>	<input type="radio"/>
Emergency room	<input type="radio"/>	<input type="radio"/>
Police/911/Emergency Medical Services	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>

APPENDIX B (continued)

Answer If Did your agency seek any mental/behavioral health service... Community Mental Health Centers - Yes Is Selected

Q12a For what type(s) of behaviors was support sought from a Community Mental Health Center? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

Answer If Did your agency seek any mental/behavioral health service... Inpatient psychiatric treatment/crisis services - Yes Is Selected

Q12b For what type(s) of behaviors was support sought from an inpatient psychiatric treatment facility? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

APPENDIX B (continued)

Answer If Did your agency seek any mental/behavioral health service... Community supports (e.g., SST, CART) - Yes Is Selected

Q12c For what type(s) of behaviors was support sought from a community support provider? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

Answer If Did your agency seek any mental/behavioral health service... Private-sector mental health services - Yes Is Selected

Q12d For what type(s) of behaviors was support sought from a private-sector mental health service provider? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

APPENDIX B (continued)

Answer If Did your agency seek any mental/behavioral health service... Federally Qualified Health Centers - Yes Is Selected

Q12e For what type(s) of behaviors was support sought from a Federally Qualified Health Center? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

Answer If Did your agency seek any mental/behavioral health service... Rural Health Centers - Yes Is Selected

Q12f For what type(s) of behaviors was support sought from a Rural Health Center? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

APPENDIX B (continued)

Answer If Did your agency seek any mental/behavioral health service... University-based (e.g., UIC Family Clinics) - Yes Is Selected

Q12g For what type(s) of behaviors was support sought from a University-based center? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

Answer If Did your agency seek any mental/behavioral health service... Emergency room - Yes Is Selected

Q12h For what type(s) of behaviors was support sought from an emergency room? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

APPENDIX B (continued)

Answer If Did your agency seek any mental/behavioral health service... Police/911/Emergency Medical Services - Yes Is Selected

Q12i For what type(s) of behaviors was support sought from police/911/emergency medical services? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

Answer If Did your agency seek any mental/behavioral health service... Other - Yes Is Selected

Q12j For what type(s) of behaviors was support sought from "other"? (check all that apply)

- ☐ an individual was harmful to his/herself
- ☐ an individual was harmful to others
- ☐ an individual engaged in property destruction
- ☐ an individual engaged in sexually inappropriate behavior
- ☐ an individual engaged in illegal behavior
- ☐ an individual displayed unusual behavior
- ☐ Other _____

APPENDIX B (continued)

Q14 What is your overall assessment of the current availability of community mental health services and/or behavioral supports for individuals with intellectual and/or developmental disabilities (IDD) in your primary service area(s)?

- ☐ Very Poor
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very Good

Q15 What is your overall assessment of the current capacity of community mental health services and/or behavioral supports for individuals with IDD in your primary service area(s)?

- ☐ Very Poor
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very Good

Q16 Over the past 3-5 years, has your overall assessment of community mental health services and/or behavioral supports for individuals with IDD in your primary service area:

- ☐ Improved greatly
- ☐ Improved slightly
- ☐ Remained the same
- ☐ Worsened slightly
- ☐ Worsened greatly

Q17 Please describe positive aspects of the community mental/behavioral health system available to persons with IDD (please be specific):

Q18 Describe any barriers to the provision of services to persons with IDD who have behavioral challenges experienced by your organization (e.g., cost, lack of therapists, distance, etc.)? Please be specific.

APPENDIX B (continued)

Q19 How do these barriers impact your organization's ability to provide services/supports to individuals who are transitioning out of state operated developmental centers (e.g., inability to serve these individuals, etc)?

Q20 Please list your suggestions to strengthen the availability and capacity of the Illinois mental/behavioral health service system for people with IDD (e.g., what services are needed or should be increased?).

Q21 What additional information, experience or insight would you like to share regarding mental/behavioral health services or related issues (e.g., billing, waiver flexibility, etc.) impacting individuals with I/DD in Illinois community-based settings?

APPENDIX C

Recruitment Letter

Hello,

My name is Amie Lulinski and I am a PhD Candidate in Disability Studies in the Department of Disability and Human Development at the University of Illinois at Chicago. You are being asked to participate in a research study I am conducting concerning the availability of community-based mental/behavioral supports and services to organizations and the individuals with intellectual/developmental disabilities they serve. You have been asked to participate in this study because your organization accepted at least one individual into your residential programs from a State Operated Developmental Center between October 1, 2002 and December 31, 2012. Either you, or a designee, are invited to participate. Ideally, the individual who completes the survey would have knowledge of the number of individuals served, use of crisis intervention programs; types of mental/behavioral health professionals on staff and the types of services provided; use of mental/behavioral health entities and satisfaction with encounters; as well as be able to answer some open-ended questions about community mental/behavioral health services to individuals with intellectual and/or developmental disabilities. There is no limit on how many staff from your agency participate. If you feel they survey should be distributed to other staff members, please share this email with them or send me their contact information and I will send them a link to the survey. The survey will take 15-20 minutes to complete. To proceed to the on-line survey, please click on this link: https://qtrial.qualtrics.com/SE/?SID=SV_86A3HHEY1ZRwrnD and enter in the password "2014" when prompted.

If you prefer a hard copy of the survey, please email me at Lulinski@uic.edu and I will either email you an MS Word version, or place one in U.S. Mail to the address you request.

If you have any questions, please do not hesitate to contact me by phone 312-996-1792 or by email Lulinski@uic.edu.

Thank you for your consideration.

Amie Lulinski, MS
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APPENDIX D

Themes and Subthemes of Responses to Open-Ended Survey Questions

Q.28 Please describe positive aspects of the community mental/behavioral health system available to persons with IDD (please be specific):

Initial Themes	Refined Themes	Final Themes
able to get appointments	access	Access
Access to community resources	access	
access to psychiatrist	access	
access to psychologist	access	
occasional access	access	
availability of behavior specialists (2)	availability	Availability
availability of counseling	availability	
availability of support groups	availability	
competence of medical professionals	competence	Competence
competency of BCBA	competence	
competency of staff	competence	
familiarity with IDD	competence	
attentive to individual needs	competence	
awareness of need	competence	
psychiatrists who specialize in IDD	competence	
willingness to work with individuals	competence	
willingness to work with organizations	competence	
communicative	competence	
consistency	competence	
good communication	competence	
professionals' desire to do good work	competence	
teamwork	competence	
CART allowed for 1:1 funding	funding	Funding
funding of services	funding	
location	location	Location

APPENDIX D (continued)

n/a	negative	
negative - don't accept staff input	negative	
negative - inconsistent	negative	
negative - lack of bilingual services	negative	
negative - lack of competence	negative	
negative - lack of crisis services	negative	
negative - lack of cultural competence	negative	Negative
negative - lack of MH availability	negative	
negative - lack of supports	negative	
negative - no access	negative	
none (6)	negative	
relationship with psychiatrist's nurse	relationship	
good relationship with community resource: Safe Passage	relationship	Relationships
development of in-hospital unit	responsive community	
hospital-offered training	responsive community	
quick psych hospital admission	responsive community	Responsive community
receive good psychiatric services through local MHC	responsive community	
support from area medical personnel	responsive community	
self-sufficient	self-sufficient	Self-sufficient
Pilsen MH Services	site specific	
UIC clinic	site specific	Site specific
SST	SST	SST

Q29. Describe any barriers to the provision of services to persons with IDD who have behavioral challenges experienced by your organization (e.g., cost, lack of therapists, distance, etc.)? Please be specific.

Initial Themes	Refined Themes	Final Themes
cost (15)	cost	
cost of private care	cost	
cost of property destruction	cost	cost
costs of addition staffing	cost	
difficult to access funding	cost	
difficult to discharge (3)	discharge difficulty	discharge difficulty

APPENDIX D (continued)

in-house availability	lack of access	
lack of alternate short-term services	lack of access	
lack of bilingual therapists	lack of access	
lack of choices for non-verbal individuals	lack of access	
location (6)	lack of access	
psychiatric hospitalizations are too brief	lack of access	lack of access
timely assistance	lack of access	
transportation (3)	lack of access	
wait lists	lack of access	
wait time (2)	lack of access	
lack of language skills	lack of bilingual skills	
communication between hospital and community psychiatrist	lack of communication	lack of communication
lack of communication	lack of communication	
crisis services (3)	lack of crisis services	lack of crisis services
lack of crisis response (6)	lack of crisis services	
lack of crisis services (4)	lack of crisis services	
lack of effective strategies	lack of intervention	lack of intervention
Lack of novelty in SST plans (2)	lack of intervention	
lack of proactive interventions	lack of intervention	
lack of competent therapists (2)	lack of providers	
lack of experienced therapists	lack of providers	
lack of knowledgeable providers (2)	lack of providers	
lack of professionals	lack of providers	
lack of providers who accept Medicaid (7)	lack of providers	lack of providers
lack of psychiatry	lack of providers	
lack of therapists (13)	lack of providers	
lack of trained therapist	lack of providers	
lack of understanding of DD population	lack of providers	
lack of willing providers (12)	lack of providers	
lack of resources	lack of resources	
lack of services (5)	lack of resources	
lack of staff training	lack of resources	
lack of system knowledge	lack of resources	lack of resources
size of agency	Lack of resources	
the system	Lack of resources	
lack of understanding of community provider (limits)	lack of resources	
denial of services	lack of services	lack of services

APPENDIX D (continued)

lack of DHS support	lack of support	lack of support
changes in Medicaid coverage	Medicaid	
lack of face time with client	Medicaid	
quick appointments	Medicaid	Medicaid
rates	Medicaid	
service caps (2)	Medicaid	
admission to psych hosp	lack of access to psychiatric treatment	
admitting privileges (2)	lack of access to psychiatric treatment	
availability of psychiatric beds	lack of access to psychiatric treatment	
difficulty getting psychiatric hospitalization	lack of access to psychiatric treatment	lack of access to psychiatric treatment
lack of psychiatric beds (2)	lack of access to psychiatric treatment	
lack of psychiatric hospital	lack of access to psychiatric treatment	
lack of psychiatric hospitals willing to accept IDD (3)	lack of access to psychiatric treatment	
distance to psychiatric hospital	lack of access to psychiatric treatment	
psychiatry monopoly	lack of access to psychiatric treatment	lack of access to psychiatric treatment

Q30. How do these barriers impact your organization's ability to provide services/supports to individuals who are transitioning out of state operated developmental centers (e.g., inability to serve these individuals, etc)?

Initial Themes	Refined Themes	Final Themes
hesitant to accept (8)	Hesitant/unwilling to accept	
hesitant to accept - cost	Hesitant/unwilling to accept	
hesitant to accept - lack of ability to provide supports	Hesitant/unwilling to accept	
hesitant to accept - lack of resources (2)	Hesitant/unwilling to accept	Hesitant/unwilling to accept
hesitant to accept ppl with high MH needs	Hesitant/unwilling to accept	
will not accept (7)	Hesitant/unwilling to accept	
will not accept - lack of resources (4)	Hesitant/unwilling to accept	

APPENDIX D (continued)

cost-prohibitive (7)	lack of resources	
access to resources	lack of resources	
access to services due to location	lack of resources	
difficulty in finding services	lack of resources	
difficulty in service provision	lack of resources	
immediate crisis services	lack of resources	
inability to provide services		
- lack of resources	lack of resources	
lack of effective crisis response	lack of resources	
lack of experienced therapists	lack of resources	
lack of providers willing to take Medicaid	lack of resources	lack of resources
lack of supports	lack of resources	
lack of system support	lack of resources	
lack of therapists	lack of resources	
lack of therapeutic progress	lack of resources	
lack of treatment	lack of resources	
long distances to travel	lack of resources	
long waiting periods for services	lack of resources	
overutilization of ER and 911/police	lack of resources	
inability to meet state regulations	lack of resources	
no plan B	lack of resources	
it doesn't (4)	none	
minimally	none	
no barrier to providing services to people with minor MH concerns	none	none
places agency at risk (2)	safety concerns	
workers comp claims/cost	safety concerns	
safety concerns - staff (2)	safety concerns	safety concerns
safety concerns - other residents (4)	safety concerns	

APPENDIX D (continued)

unable to serve (2)	unable to serve	
unable to serve - lack of resources	unable to serve	
return to SODC	unable to serve	unable to serve
difficulty in serving people with moderate to severe MH concerns	unable to serve	

Q31. Please list your suggestions to strengthen the availability and capacity of the Illinois mental/behavioral health service system for people with IDD (e.g., what services are needed or should be increased?).

Initial Themes	Refined Themes	Final Themes
seek provider input when making changes	collaboration	
build relationships with psychiatrist at local hospitals	collaboration	collaboration
communication between DDD and DMH	collaboration	
ability to use discretion in contacting OIG	policy change	
decrease frequency of psychological evaluations		
to cut costs	policy change	
eliminate rule 132	policy change	
make regulations more flexible	policy change	policy change
support legislation to allow clinical psychologists to prescribe	policy change	
funnel SST/CART appropriations directly to agencies	policy change	
allow trial placement	policy change	

APPENDIX D (continued)

increase rates (2)	reimbursement	
increase rates - MH professionals (3)	reimbursement	
increase rates to cover staffing needs	reimbursement	
increase rates-staff	reimbursement	
increased rates - DSP salary (2)	reimbursement	Reimbursement
increased rates - individualized budgets	reimbursement	
increased rates - MH providers (2)	reimbursement	
increased rates to pay DSPs more	reimbursement	
timely reimbursement	reimbursement	
alternate payment in addition to Medicaid	reimbursement	
clarify ability to bill Medicaid for MH services	reimbursement	

APPENDIX D (continued)

incentivize psychiatrists to accept Medicaid	service access	
incentivize psychologists and psychiatrists to serve IDD pop	service access	
access to sensory therapy	service access	
accessible crisis system	service access	
additional housing options	service access	
alternative to 911 for emergency behavioral response	service access	
alternatives to "talk" therapy	service access	
crisis services	service access	
immediate crisis services (6)	service access	
increase availability of effective treatments	service access	
increase availability of MH services	service access	
increase availability of psychiatric hospital services (5)		service access
increased treatment hours caps	service access	
increased use of AAC	service access	
invest in preventative services	service access	
keep MHC open	service access	
partner with hospitals	service access	
partner with MHCs	service access	
responsive crisis services	service access	
short-term crisis respite (8)	service access	
temporary respite homes for crisis	service access	
transition settings	service access	
increase access to private pay providers	service access	
increase availability bilingual/bicultural services	service access	
increase number of psychiatrists willing to serve pop.	service access	
increase resources for ppl with severe/profound IDD	service access	

increase treatment caps	service access	
increased behavioral supports	service access	
increased supports for age-related issues such as dementia	service access	
mobile crisis units	service access	
respite	service access	
smaller settings	service access	
customize supports	service access	
flexibility to allow agencies to provide additional supports when needed (extra staff)	service access	
MFP allowing for purchase of private services	service access	
<hr/>		
create certificate/curriculum at university level for specialization in dual diagnosis	training	
educate local hospitals and their psychiatrists about people with IDD	training	
educate MH providers about people with IDD (2)	training	
incorporate training re: IDD into medical/nursing school curriculum	training	
increase availability of competent MH professionals (17)	training	training
increase staff education requirements	training	
increased DSP training	training	
increased DSP training on behavioral programming	training	
increased training opportunities	training	
sponsor BCBA certification training	training	
<hr/>		

APPENDIX D (continued)

Q32. What additional information, experience or insight would you like to share regarding mental/behavioral health services or related issues (e.g., billing, waiver flexibility, etc.) impacting individuals with I/DD in Illinois community-based settings?

Initial Themes	Refined Themes	Final Themes
quicker turn-around time when errors occur	bureaucracy	
work to decrease bureaucratic errors	bureaucracy	bureaucracy
bureaucracy inhibits support	bureaucracy	
decrease bureaucracy	bureaucracy	
DDD and DMH need to work together on system improvement	collaboration	collaboration
MH supports would make transition easier	collaboration	
inadequate funding	funding	
inadequate staffing rates	funding	
increase rate to incentivize smaller settings	funding	funding
increase rates (2)	funding	
increase rates - DSP	funding	
increase rates - MH professionals	funding	
fee for service for some community-based services without award letter	incentives	
rate agency ability to effectively manage crisis situations and then tax agencies that consistently fail to support other agencies that are successful	incentives	incentives

APPENDIX D (continued)

jail is de facto MH treatment police and emergency responders are de facto crisis system	lack of system supports	
need for DHS support	lack of system supports	lack of system supports
over-reliance on ER and police are byproduct of poor rates, training and system support	lack of system supports	
change survey process to one based on quality, not checking boxes	policy	
Drug holidays are problematic.	policy	
excessive regulatory burden	policy	
flexibility within the waiver fund necessary supports (dental)	policy	
Medicaid preferred drug list is limiting	policy	
Private insurance companies need to cover counseling and behavior therapy	policy	policy
simplify readmission process to SODCs as plan B	policy	
streamline behavioral add- on process to be more time sensitive	policy	
need for "reality check" on criminal offenders	policy	
increase max therapy hours	policy - waiver	

APPENDIX D (continued)

match resident needs with agency strengths	process	Process
update billing system	process	
community has inadequate MH support	professional workforce	
increase availability of competent MH professionals	professional workforce	professional workforce
development of alternative residential models	services	
difficult for staff to provide crisis support and protect other residents	services	
do away with service coordination system	services	
explore alternative options	services	
lack of services in rural areas	services	
lack of support from DHS during crisis	services	
options for individuals in crisis	services	services
short-term crisis respite	services	
smaller settings are more effective	services	
SSTs are over used but not effective	services	
there is a need for alternative day programs	services	
use evidence based practices to determine direction of the system	services	
without proper supports in place, SODCs are necessary	services	
provider training on how to maximize available funds	training	Training
in over two decades, never seen things so bad	Commentary	Commentary

APPENDIX E

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Amendment to Research Protocol and/or Consent Document – Expedited Review UIC Amendment # 6

July 2, 2013

Mary Kay Rizzolo, Ph.D.
Disability and Human Development
1640 W Roosevelt Rd, Rm 245
Chicago, IL 60612
Phone: (312) 413-8879 / Fax: (312) 413-1620

RE: Protocol # 2008-0874
"An Analysis of Movement from State Operated Developmental Centers in Illinois"

Dear Dr. Rizzolo:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: July 1, 2013

Amendment:

Summary: UIC Amendment #6 (response to modifications), dated 26 June 2013 and submitted to OPRS 27 June 2013, is an investigator-initiated amendment regarding the following:
(1) adding recruitment/enrollment of approximately 300 executive directors, or their designee, from 300 agencies which received an individual who transitioned out of a state-operated developmental center; subjects will participate in an online survey; subject contact information will be obtained through the website of their organizations, through telephone enquiry, or through the Department of Human Services/Division of Developmental Disabilities; a link to the online survey will be included in the body of an email recruitment text and a follow-up phone call will be made within one month to enquire whether or not the subject has completed the survey, has any questions or concerns, or wishes a paper copy of the survey to be sent; subject phone numbers will also be publicly available through agency websites; surveys may be sent via a link with Qualtrics, as a Word document via email, or via USPS; neither individuals nor organizations will be identified in publications and presentations; results will be presented in a dissertation scheduled for 2014; extension of data collection period to 31

Appendix E (continued)

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July 2, 2013

December 2012 to capture data about individual who transitioned from Jacksonville Developmental Center until its closure in late November 2012 (Initial Review application, v4, 6/10/2013; Protocol, v4, 6/10/2013; instrument, no footer);
 (2) removing Dora Fisher as key research personnel (Appendix P); and
 (3) submission of recruitment and consent documents reflecting the above (Survey Recruitment Email Text, v1, 6/10/2013; Survey Consent, v2, 6/26/2013).

Research Protocol(s):

- a) An Analysis of Movement from State Operated Developmental Centers in Illinois, Version 4, June 10, 2013

Recruiting Material(s):

- a) Survey Recruitment Email Text; Version 1; 06/10/2013
- b) Qualtrics Survey Software (Welcome; Page 1 of 15); 6/10/2013

Informed Consent(s):

- a) Waiver of Signed Consent Document granted under 45 CFR 46.117 for On-line Survey
- b) Alteration of Informed Consent granted under 45 CFR 46.116(d)(1) for On-line Survey
- c) Survey Consent, Version 2; 6/26/2013

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
06/14/2013	Amendment	Expedited	06/17/2013	Modifications Required
06/27/2013	Response To Modifications	Expedited	07/01/2013	Approved

Please be sure to:

→ Use only the IRB-approved and stamped consent document(s) and/or HIPAA Authorization form(s) enclosed with this letter when enrolling subjects.

→ Use your research protocol number (2008-0874) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,

"UIC Investigator Responsibilities, Protection of Human Research Subjects"

(<http://tiger.uic.edu/depts/over/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 355-2939. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

APPENDIX E (continued)

2008-0874

Page 3 of 3

July 2, 2013

Sincerely,



Jewell Hamilton, MSW
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s):

1. Informed Consent Document(s):

a) Survey Consent, Version 2; 6/26/2013

2. Recruiting Material(s):

a) Survey Recruitment Email Text; Version 1; 06/10/2013

b) Qualtrics Survey Software (Welcome; Page 1 of 15); 6/10/2013

cc: Tamar Heller, Disability and Human Development, M/C 626
Privacy Office, Health Information Management Department, M/C 772

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VITA

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Research and Teaching Interests: Disability history and policy, Medicaid policy, long-term supports and services, and dual diagnosis (IDD and MI)

EDUCATION

Ph.D. Candidate, Disability Studies (ABD; defense date: April 16, 2014)
University of Illinois at Chicago, Chicago, IL
Dissertation: Factors Impacting Transition from Illinois' Developmental Centers into Community-based Settings

M.S. in Disability and Human Development (August 2008),
University of Illinois at Chicago, Chicago, IL
Thesis: The Impact of Medicaid Drug Policies on People with Intellectual and Developmental Disabilities

B.A. in Psychology (May 1995), Illinois Wesleyan University, Bloomington, IL. Major courses and research focused on behavior analysis and neuroscience.

ACADEMIC POSITIONS

Senior Research Specialist in Developmental Disabilities: Institute on Disability and Human Development, University of Illinois at Chicago, January 2011 – present.

Responsibilities: Co-PI and lead staff for study of institutional census reduction in the state of Illinois; Co-PI and lead staff in evaluation of Jacksonville and Murray Developmental Centers Closure Evaluations; administer social media (Facebook and Twitter); respond to requests for technical assistance; and Policy and Advocacy Director for the Illinois Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program.

Research and Policy Analyst: State of the States in Developmental Disabilities Project, Department of Psychiatry, School of Medicine, University of Colorado Health Sciences Center and University of Illinois at Chicago, June 2012- January 2014.

Responsibilities: Report writing, presentations, and technical assistance; coordinated information dissemination using social networks (Facebook and Twitter); and lead relationship building efforts with the U.S. Territory UCEDD Directors in an effort to include Territory data on Medicaid spending.

Disability Policy Leadership Fellow: Association of University Centers on Disabilities (AUCD), Silver Spring, MD, January 2011 – December 2011.

Responsibilities: Monitored federal level policy related to developmental disabilities; provided policy summaries for *InBrief*, weekly newsletter; regularly updated on-line Health Reform Hub; served on Consortium for Citizens with Disabilities (CCD) Task Forces on Developmental Disabilities, Long Term Services and Supports and Health; co-chaired task force on Medicaid; served as AUCD representative on Medicaid Coalition; served as AUCD representative on Friday Morning Collaborative; assisted with overall coordination and facilitation of Allies in Self-Advocacy Summits funded by the Administration on Developmental Disabilities; provided technical assistance to network.

Project Coordinator: Institute on Disability and Human Development, University of Illinois at Chicago, May 2007 – December 2010.

Responsibilities: Coordinate all research aspects of grant funded by Illinois Department of Human Services' Division of Developmental Disabilities which explored longitudinal trends in institutional census reduction in Illinois, including data collection, analysis and writing of final report; worked in the Developmental Disabilities Family Clinics to assist with medical records and intake paperwork; assisted in the coordination of the final report from the interdisciplinary team evaluations; acted as Research Assistant to Director of the Family Clinics; and trained all incoming interns on Illinois abuse and neglect reporting requirements.

Academic Coordinator: Illinois LEND, University of Illinois at Chicago, May 2009 – December 2010.

Responsibilities: Assisted with all aspects of the LEND training program including: recruitment and coordination of interview process review of potential trainees; management of class syllabus; coordination of didactic schedule including recruiting of speakers, collection of materials and handouts; tracking completion of trainees' required hours and assignments; maintenance of Blackboard for all course materials and assignments; and assistance with all required federal reports.

Teaching Assistant: DHD 564: Community Integration in Developmental Disabilities, Department of Disability and Human Development, University of Illinois at

Chicago, Fall 2009.

Responsibilities: Co-taught course with Mary Kay Rizzolo, PhD

Project Coordinator: Association for University Centers on Disability and Social Security Administration Pediatric Medical Unit project, University of Illinois at Chicago, May 2007 – December 2007.

Responsibilities: Coordinated all aspects of the PMU Grant under the direction of the director including receipt of requests for team consultation from Social Security Determination offices.

Graduate Assistant: Institute on Disability and Human Development, University of Illinois at Chicago, August 2006 – May 2007.

NON-ACADEMIC EXPERIENCE

Director of Quality Enhancement & Training Services: Oak-Leyden Developmental Services, Oak Park, IL, January 2004 – May 2007.

Responsibilities: Evaluated compliance of adult programs to applicable DHS and/or IDPH standards including file reviews, environmental survey, and ISP review; coordinated agency process for policy and procedure review; functioned as Liaison to the Office of Inspector General & OIG approved Agency Investigator; HIPAA Privacy Officer; co-chaired Behavior Management Committee & Human Rights Committee, as well as chaired Safety Committee; Created and maintained injury/incident/illness data base; analyzed and co-authored responses to Employee Satisfaction Survey; coordinated and delivered DSP and QMRP Training; maintained CARF standards and coordinated Outcome Management System.

Program Coordinator: New Hope Center, Inc., Dolton, IL, November 2000 – January 2004.

Responsibilities: provided administrative leadership, supervised DSPs, and managed operation of 16-bed Intermediate Care Facility for persons with IDD; assured adherence to all local, state, and federal regulations; served as QMRP and case manager to 16 program participants; served as chairperson of agency Human Rights Committee.

Individual Service Coordinator: Suburban Access, Inc., Homewood, IL, November 1999 – October 2000.

Responsibilities: Provided Individual Service Coordination to individuals with

IDD in nursing homes, state-operated facilities, Intermediate Care Facilities for adults with Developmental Disabilities (ICF/DD), and community placements; coordinated specialized services and Individual Service Plans; conducted Pre-Admission Screenings to persons interested in receiving Department of Human Services funded services and provided initial service coordination.

State Quality Assurance/Training Coordinator: Community Alternatives Missouri, St. Louis, MO, June 1997 – July 1999.

Responsibilities: Developed, standardized, coordinated, and oversaw state-wide New Employee Orientation Training Program; revised New Employee Training Manual, Program Manager Reference Guide, and Guide to Conducting Internal Investigations; provided internal consulting and cooperatively developed Action Plans; assured consistency across four state operations according to Company and State of Missouri regulations by serving as liaison between agency and State Quality Improvement personnel; completed employee/consumer satisfaction surveys twice yearly; coordinated hiring and training of DSPs; co-founded and chaired inter-agency Human Rights Committee, served as member of Program Management Team and Missouri State Certification Survey Team.

Assistant Program Coordinator: I.T.E., Inc., St. Louis, MO, June 1996 – June 1997.

Responsibilities: Trained, supervised, and acted as liaison between work and home for 85 adults with developmental disabilities working in a sheltered workshop setting; created and implemented individual behavior and/or training programs.

Psychiatric Aid: Hawthorne Children's Psychiatric Hospital, St. Louis, MO, October 1995 – June 1996.

Responsibilities: Emotional, physical, behavioral, and environmental care of adolescents receiving in-patient psychiatric services.

Teacher's Aide: Childgarden, St. Louis Arc, St. Louis, MO July 1995 – October 1995.

Responsibilities: Assisted with all aspects of operating a classroom for 4-year-olds at an integrated day care.

Direct Support Professional, McLean County Arc, Bloomington, IL, Summer 1995.

Responsibilities: Supported individuals with IDD in activities of daily living in a residential setting.

PUBLICATIONS

Braddock, D., Hemp, R., Rizzolo, M.C., Haffer, L., Tanis, E.S., **Lulinski, A.** & Wu, J. (2013). State of the States in Developmental Disabilities 2013: The Great Recession and its Aftermath. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities, Department of Psychiatry, and Department of Disability and Human Development, UIC.

Rizzolo, M. C., Friedman, C., **Lulinski-Norris, A.**, & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1), pp. 1-21.

Lulinski-Norris, A., Rizzolo, M.C. & Heller, T. (October, 2012). An Analysis of Movement from State Operated Developmental Centers in Illinois. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

Lulinski-Norris, A., Rizzolo, M. C., & Heller, T. (October, 2012). Post-transition returns to IL SODCs: An analysis. Disability Research Brief, Chicago, IL: The University of Illinois at Chicago.

Sorensen, A., Rizzolo, M. C., **Lulinski-Norris, A.**, & Heller, T. (May 2012). An Evaluation of Howe Developmental Center Closure: Results from a Survey of Family Members and Guardians and Interviews with Individuals who Lived at Howe. Final Report to the Illinois Department of Public Health. Chicago: The University of Illinois at Chicago, Department of Disability and Human Development.

Lulinski-Norris, A., Rizzolo, M.C. & Heller, T. (April 2012). The Closure of Lincoln Developmental Center: An Analysis of Outcomes. Disability Research Brief. Chicago: The University of Illinois at Chicago, Department of Disability and Human Development.

Lulinski-Norris, A., Rizzolo, M. C., & Heller, T. (October, 2012). Jacksonville Developmental Center: An analysis of transition outcomes. Disability Research Brief, Chicago, IL: The University of Illinois at Chicago.

Lulinski-Norris, A., Rizzolo, M. C., & Heller, T. (October, 2012). Murray Developmental Center: An analysis of transition outcomes. Disability Research Brief, Chicago, IL: The University of Illinois at Chicago.

Rizzolo, M.C., **Lulinski-Norris, A.**, Collins, S., & Heller, T. (2010). An analysis of the Somerset Place nursing facility closure: Insights from key stakeholders. Chicago, IL: The University of Illinois at Chicago.

Lulinski-Norris, A., Rizzolo, M.C. & Heller, T. (2010). *An Analysis of Movement from State Operated Developmental Centers in Illinois*. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

Lulinski-Norris, A. (2009). Chassin, Mark R. In Mullner, Ross, Tricia J. Johnson, and Robert F. Rich (Eds.), *Encyclopedia of Health Services Research*. Volume 1, pp. 157-58, Los Angeles, CA: Sage.

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Lulinski-Norris, A. (2009). Drummond, Michael. In Mullner, Ross, Tricia J. Johnson, and Robert F. Rich (Eds.), *Encyclopedia of Health Services Research*. Volume 1, pp. 321-22, Los Angeles, CA: Sage.

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Lulinski-Norris, A. (2009). Lee, Philip R. In Mullner, Ross, Tricia J. Johnson, and Robert F. Rich (Eds.), *Encyclopedia of Health Services Research*. Volume 2, pp. 681-82, Los Angeles, CA: Sage.

Lulinski-Norris, A. (2009). Maynard, Alan. In Mullner, Ross, Tricia J. Johnson, and Robert F. Rich (Eds.), *Encyclopedia of Health Services Research*. Volume 2, pp. 717-18, Los Angeles, CA: Sage.

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PRESENTATIONS

“Mental Health, Intellectual Disability, and Services Across the Lifespan: A Call to Action for Systems Improvement”, Accepted, AAIDD, Orlando, FL, June 25, 2014.

“Community Capacity to Provide Behavioral/Mental Health Services to Adults with IDD in Illinois”, Arc of Illinois Annual Conference, Lisle, IL, April, 23, 2014.

“*Olmstead*”, Guest Lecture, LEND, Department of Disability and Human Development, University of Illinois at Chicago, February 27, 2014.

“The Policy Cycle in Five Acts: A Case Study of the Combating Autism Reauthorization Act of 2011”, Guest Lecture, LEND, Department of Disability and Human Development, University of Illinois at Chicago, December 5, 2013.

“Neuroscience + Learning Psychology + Education Technology = Education 3.0”. Invited panelist, Association of University Centers on Disabilities, Training Symposium, November 18, 2013, Washington, D.C.

“Trainee Networking Session”, Invited Panelist, Association of University Centers on Disabilities, Training Symposium, November 17, 2013, Washington, D.C.

“The Politics of Disability Policy”, Guest Lecture, DHD 501, Chicago, IL, October 30, 2013.

“Community Supports for Persons with Disabilities in the U.S. ”, Guest Lecture, LEND, Chicago, IL, October 31, 2013.

“Long Term Services and Supports for People with IDD in Virginia”, Guest Lecture, doctoral seminar on disability policy, Virginia Commonwealth University, October 9, 2013.

“The Role of UCEDD Research in Illinois’ Rebalancing Initiative”, Guest Speaker, Advocates United, Homewood, IL, September 10, 2013.

“Using State of the States in Developmental Disabilities Data in Advocacy and Planning”. Guest Speaker, Arizona DD Council, Phoenix, AZ, August 2, 2013.

“Services and Supports for People with Intellectual and/or Developmental Disabilities in Illinois: An Introduction”. Invited speaker, Illinois Health Care Association, Chicago, IL, June 12, 2013.

“Projects of National Significance and the U.S. Territories: What Does It Mean?” Workshop, Pacific Rim International Conference on Disability & Diversity, Honolulu, HI, April 29, 2013.

“Making Data Work for You: Using Data in your Advocacy Efforts”, Presenter, Arc of Illinois Annual Conference, Lisle, IL, April 24, 2013.

“Deinstitutionalization: The Role of UCEDD Research in the Rebalancing Initiative”, Invited Speaker, Japanese delegation, Chicago, IL, April 22, 2013.

“Making Data Work for You: Using State of the States in Developmental Disabilities Data in Advocacy and Federal Reporting”. Keynote Address, National Association of Developmental Disabilities Council Executive Director's Retreat, Rosemont IL, November 28, 2012.

- “Advocacy Matters! Achieving the Combating Autism Reauthorization Act”, Presenter, Arc of Illinois and The Autism Program Annual Convention, Lisle, IL, April 2012.
- “Medicaid 101”, Guest Lecture, IL LEND, Department of Disability and Human Development, University of Illinois at Chicago, February 2012.
- “Celebrating Ten Years of Leadership in Disability Policy”, Panelist, Association of University Centers on Disabilities’ Annual Conference, Washington, DC, November 2011.
- “Policy Behind the Scenes: A Case Study of the Combating Autism Reauthorization Act”, Guest Lecture, IL LEND, Department of Disability and Human Development, University of Illinois at Chicago, November 2011.
- “Deinstitutionalization in Illinois”, Guest Lecture, Department of Disability and Human Development, University of Illinois at Chicago, January 2010.
- “Medicaid & Developmental Disabilities”, Guest Lecture, LEND, Department of Disability and Human Development, University of Illinois at Chicago, April 2009.
- “Medicaid in Illinois”, Invited Speaker at Keshet Day School, March 2009.
- “Obama/Biden Disability Policy Agenda”, Guest Lecture via video conference, MSc Programme in Rehabilitation and Disability Studies, University of Dublin, January 2009.
- “Healthcare Policy in the United States”, Guest Lecture, Department of Disability and Human Development, University of Illinois at Chicago, November 2008.
- “The Impact of Medicaid Drug Policies on People with Intellectual and Developmental Disabilities”, Poster presentation, Association of University Centers on Disability, Washington, D.C., November 2008.
- “Strengthening Our Supports: Building Opportunities for Education, Growth, and Development”, Panelist, Arc of Illinois Annual Convention, Lisle, IL April 2006.
- “Direct Support Professional Workforce Initiative” – Panelist, AAMR of Illinois Annual Convention, Naperville, IL, March 2006.
- “The Role of Stimulant Dependent Component Duration on Within-Session Responding”, Poster, Association for Behavioral Analysis, Georgia, May 1994
- “The Role of Stimulant Dependent Component Duration on Within-Session Responding”, Poster, Student Research Conference, Illinois Wesleyan University in Bloomington, IL, April 1994.

AWARDS

Ann and Edward Page-El Scholarship, March 2014

LEADERSHIP AND COMMUNITY SERVICE

Chair, Combating Autism Act Workgroup, Legislative Affairs Committee, Association of University Centers on Disabilities, July 2013 – present.

Member, Legislative Affairs Committee, Association of University Centers on Disabilities, January 2010 – present.

Secretary, Board of Directors, Arc of Illinois, July 2013-present.

Chair, Managed Care Task Force, Arc of Illinois, November 2012 - present

Member, Arc of Illinois, July 2012-present.

Member, Public Policy Committee, Arc of Illinois, December 2011-present

Member, NADD U.S. Public Policy Committee, June 2013 – present.

Member, Human and Social Services Committee, Legislative Advisory Council to Rep. Chris Nybo (R, IL, 41st), 2012.

Member, Allies in Self-Advocacy Summit Planning Committee, January 2011-April 2012

Member, Howe Closure Advisory Committee, October 2009 – September 2010.

Member, Illinois DSP Comprehensive Workforce Initiative, 2004 – 2006.

Member, Steering Committee and co-chair of subgroup for Education and Training, Illinois DSP Comprehensive Workforce Initiative, 2004-2006.

PROFESSIONAL MEMBERSHIPS:

American Association on Intellectual and Developmental Disabilities

Arc of the United States

NADD (formerly National Association for the Dually Diagnosed)