

Community Capacity to Provide Mental/behavioral Health Services for Individuals with  
IDD Transitioning from State Operated Developmental Centers

Running title: IDD mental/behavioral health services

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## **Abstract**

The study's aim was to explore the capacity of community-based providers of residential supports and services to support individuals with intellectual and developmental disabilities who had transitioned out of state operated institutions into community-based settings. Receiving agency survey results from 65 agencies and individual-level variables of 2,499 people who had transitioned from an institution to a community-based setting indicated that individuals who returned to an institution post-transition tended to be younger, have a higher IQ score, were more likely to have a psychiatric diagnosis, tended to have shorter previous lengths of stay at an institution, transitioned to larger settings, and received services from an agency receiving behavioral health technical assistance as compared to those who remained in their transition settings.

**Key words:** Medicaid home and community-based services, intellectual and developmental disabilities, dual diagnosis, mental/behavioral health treatment

## **Introduction**

Over the past three decades, numerous studies have explored deinstitutionalization (DI) outcomes for individuals with intellectual and developmental disabilities (IDD).

Research teams have studied changes in individual-level variables including academic skills, challenging behaviors, community living skills, domestic skills, language and communication skills, leisure/recreational skills, maladaptive behaviors, mobility, mortality, motor/ physical skills, self-care, sensorimotor ability, social skills, toileting ability, visual processing, and vocational skills in an effort to quantify the impact of DI. Through this body of research, it has been well-established that moving from institutional settings and into smaller community-based ones leads to better outcomes for people with IDD (Kim, Larson, & Lakin, 1999; Larson & Lakin, 1989, 2012).

Researchers have also examined those variables contributing to unsuccessful community placements. 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 characteristics in failed placement attempts instead of examining the service system within which they occurred. 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.

The present study examines the capacity of the Illinois community-based system to support adults with IDD who need mental health and behavioral services. The federal

Home and Community Based Services (HCBS) Waiver program, authorized in 1981 as an alternative to the ICF/ID program (Braddock et al., 2005), included in its menu of services during the study period behavioral intervention, treatment, and crisis services (State of Illinois, 2012).

Several reports have examined the provision and availability of these services in the state. 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 (a psychiatric diagnosis and IDD) and live in the community. 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 a 2008 evaluation, the Human Service Research Institute (HSRI) identified Illinois’s lack of community capacity to provide for the needs of individuals with challenging behaviors as a weakness stating, “As a consequence, *de facto* the state operated developmental centers (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 review, authors noted that while Illinois had “[i]mproved its response to people with behavioral challenges by increasing

service reimbursement rates associated with behavior therapy and expanded statewide capacity ...” (HSRI, 2012, p. 43), authors recommended that “...Illinois build capacity to address behavioral challenges among service recipients” (HSRI, 2012, p. 74).

Heller, Hsieh, Owen & Bedetti (2012) reported findings from an evaluation of the Illinois Support Services Team (SST), an interdisciplinary team which provides technical assistance (TA) and training in response to situations in which a person with an IDD is in medical or behavioral crisis that challenges their ability to live and thrive in community-based settings. Findings indicated that 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%). 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. 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 SST study concluded that reliance on SODCs in Illinois must be reduced in favor of alternatives (Heller, Hsieh, Owen & Bedetti, 2012).

Lulinski-Norris, Rizzolo, & Heller (2012a) conducted an analysis of outcomes of individuals who transitioned out of SODCs in Illinois between October 1, 2001 and June 30, 2009. Of the 1,594 individuals who transitioned out of an Illinois SODC during the study period, 163 (10.2%) eventually returned to an SODC; 118 (72%) did so due to behavioral issues.

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. Furthermore, a need exists for systematic research examining the community capacity to support individuals with IDD in need of mental health and behavioral services.

The aim of this study was to explore the capacity of community-based providers of residential supports and services to people with IDD, 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. This was done by asking two main research questions: 1) What type of behavioral and mental health services are available for individuals receiving supports from community-based provider agencies; and 2) How do these services impact individual post-transition outcomes? The intent of this study is to identify service gaps contributing to placement breakdown and inform public policy discourse at the state level as a state makes strides to decrease its reliance on institutionalized service systems.

## **Methods**

In an effort to address the two research questions, two datasets were used: Dataset 1 is from a survey of community-based agencies into which persons transitioning out of SODCs moved; Dataset 2 is from an analysis of SODC discharge information between October 1, 2001 and December 31, 2012.

### Dataset 1: Agency Variables

To address the first research question regarding the type(s) of in-house (including contractual employees) behavioral and mental health services available for individuals receiving supports from community-based provider agencies, a survey was

used to collect information related to organizational characteristics and experiences with mental/behavioral health services.

### *Participants*

In order to be eligible for participation in the survey, agencies were required to have accepted at least one individual from an SODC between October 1, 2001 and December 31, 2012. In July of 2013, an email inviting participation in the voluntary on-line survey 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 recipients at approximately 4, 8, and 12 weeks post initial contact. In some cases, follow-up phone calls were made. A final call for participation was sent out in October of 2013 and the survey was closed later that same month.

Sixty-five out of 117 organizations responded, yielding a 55.6% response rate. 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.

### *Measures*

The survey requested information on agency size (in terms of the number of individuals served); staff training on behavioral supports (e.g., CPI's Nonviolent Crisis Intervention Training<sup>®</sup> which focuses on diffusing behaviors ([www.crisisprevention.com](http://www.crisisprevention.com)))

and/or The Mandt System<sup>®</sup> which is an approach to preventing, de-escalating, and intervening when a person's behavior threatens themselves or others ([www.mandtssystem.com](http://www.mandtssystem.com)); 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 (including technical assistance from the state DD agency) 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 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 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.

Participating agencies were also surveyed about the different types of community-based mental/behavioral health services used. Options provided included: Community Mental Health Centers (CMHC), inpatient psychiatric treatment/crisis services, technical assistance through 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. The category of telehealth, while not listed in the Waiver, was included.

The on-line survey was piloted and revised prior to being conducted via Qualtrics ([www.qualtrics.com](http://www.qualtrics.com)). Quantitative survey data was downloaded directly from Qualtrics into an Excel worksheet for cleaning and then entered into SPSS 22.0 for statistical analysis.

#### Dataset 2: Individual Variables

To gather information related to individuals who had transitioned out of an SODC and into community-based settings, individual-level data on those who transitioned out of an SODC and into a community-based setting was collected.

#### *Participants*

For inclusion in this study, subjects needed to transition out of one of Illinois’s SODCs between October 2001 and December 31, 2012 into a setting for  $\leq 15$  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”).

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 people (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” (remained in transition setting) and 43 “returners” (returned to an SOCD) 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.

### *Measures*

Individual-level data was gathered on the following measures as of December 31, 2012: sex; 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 an autism spectrum disorder diagnosis; presence and type of psychiatric diagnosis; 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; and current residential status (i.e., remains in setting, transitioned to another setting, or returned to SODC).

### Procedure

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

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.

## **Findings**

### Organizational Characteristics

#### *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 ( $sd = 185$ ). The majority (38.5%,  $n = 25$ ) of the participating organizations served up to 50 individuals across all programs. Nineteen responding organizations served 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. Ten organizations reported serving 200 individuals or more across all programs (15.4%,  $n = 10$ ).

### Availability of in-house behavioral supports

#### *Crisis intervention training*

The vast majority (86.2%,  $n = 56$ ) of responding organizations offered crisis intervention training to staff; 52.3% ( $n = 34$ ) offered 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 Illinois Support Services Team (SST).

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

Participating agencies were asked about their access to different categories of in-house mental/behavioral health specialists (e.g., either a staff member of the agency or has a contract with the agency to provide services). Table 1 contains information on the percentage of represented organizations that have access to each type of mental/behavioral health specialist included in the HCBS Waiver. 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).

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Insert Table 1 about here

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*In-house mental/behavioral health service provision*

Participating agencies were also surveyed about different categories of mental/behavioral health treatments provided in-house. As shown in Table 1, 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%). ‘Other’ therapeutic interventions reported by responding organizations included: music, art, drama, dance, pet therapies, and dialectical behavior therapy.

**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 2, options provided included: police/911/emergency medical services (EMS), technical assistance provided by DHS/DDD funded SSTs and Clinical Administrative Review Teams (CART), emergency rooms (ER), inpatient psychiatric treatment/crisis services, Community Mental Health Centers (CMHC), private sector mental health services, university-based clinics Federally Qualified Health Centers (FQHC), and Rural Health Centers (RHC). Space was provided to indicate “other” categories of community services used and included private ambulance services and an SODC.

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Insert Table 2 about here  
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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.

### **Reasons for seeking and satisfaction with services**

Survey participants were asked for what reason(s) treatment was sought. Categories of behaviors for which treatment might be sought were 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”. 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. Reasons for use of and satisfaction with each service category are presented in Table 2 and detailed below.

### **Use of specific services**

#### *Police/911/emergency medical services*

Nearly 91% (n = 59) of survey respondents sought assistance for mental/behavioral issues from local police, 911, and/or emergency medical services (EMS). 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). Overall, of the 59 respondents reported a mean satisfaction score of 3.5/5.

#### *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. 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). Mean satisfaction score was 2.8/5.

#### *Emergency room*

Eighty-three percent (n = 54) of survey respondents sought assistance for mental/behavioral issues from local emergency rooms (ER). 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). Mean satisfaction score was 2.9/5.

#### *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. 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). Mean satisfaction score was 3.1/5.

#### *Community mental health centers*

Nearly 66.2% (n = 43) of survey respondents sought assistance for mental/behavioral issues from Community Mental Health Centers (CMHCs). 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). Mean satisfaction score was 3.2/5.

#### *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, most frequently 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). The “other” category included counseling and medication management. Mean satisfaction score was 3.8/5.

#### *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 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%). Three organizations sought assistance for behaviors categorized as “other” (19%) which included regular monitoring and psychotic episode. Mean satisfaction score was 3.8/5.

#### *Federally qualified health centers*

Fifteen percent (n = 10) of survey respondents sought assistance for mental/behavioral issues from Federally Qualified Health Centers (FQHCs). 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%). Two agencies sought services for behaviors categorized as “other” which included assistance with psychotropic medication. Mean satisfaction score was 3.6/5.

#### *Rural health centers*

Nearly 14% (n = 9) of survey respondents sought assistance for mental/behavioral issues from Rural Health Centers most frequently due to an individual

being a harm to self ( $n = 6, 67\%$ ), harmful to others ( $n = 6, 67\%$ ), followed by property destruction ( $n = 5, 56\%$ ). Mean satisfaction score was 3.5/5.

In summary, 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.

To determine how an agency's mental/behavioral health resources impacted individuals' post-transition outcomes,  $t$ -tests were conducted to determine differences in agency-level variables with respect to transition status (stayers and returners). As illustrated in Table 3, there were no statistically significant differences between stayers and returners with regard to the total of individuals served across all programs, the number of agency mental health professionals, or the number of in-house treatment offerings. There was, however, a statistically significant difference between 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.

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Insert Table 3 about here

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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 4, stayers remained in agencies which offered a higher percentage of

ABA therapy as compared to agencies from which individuals returned to an SODC,  $\chi^2(1, N = 454) = 5.527, p = .019$ .

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Insert Table 4 about here

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Chi square tests of independence were conducted to explore differences between community resource use and successful transitions. 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,  $\chi^2(1, N = 454) = 6.082, p = .014$ .

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 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,  $t(454) = -2.111, p = .035$  (Table 5). 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,  $\chi^2(1, N = 435) = 27.247, p = .000$ .

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Insert Table 5 about here

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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. Additionally, when examined for inter-correlation, none of these variables had a strong statistically significant Pearson's  $r$  value. As displayed in Table 6, 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.

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Insert Table 6 about here

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Two hierarchical models are presented in Table 7. 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 technical assistance. Again, these variables showed statistically significant differences with respect to stayers and returners while having weak correlations with each other.

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Insert Table 7 about here

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#### *Model 1. Impact of individual factors*

Results indicate that youth, shorter length of stay in an SODC, higher IQ scores, and presence of a psychiatric diagnosis are significant predictors of placement failure.

#### *Model 2. Impact of agency factors*

Results indicated that smaller transition settings and 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 which received TA, however, were ten times more likely to experience transition failure and return to an SODC;  $\text{Exp}(B) = 10.542$ , 95% CI = 4.322 – 25.711,  $p = .000$ .

### **Discussion**

The first research inquiry explored the types of services available to waiver-funded 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. Use of the ER for the same behaviors was reported by 83% of respondents. Use of the emergency room (ER) for individuals with IDD experiencing a behavioral episode is not uncommon. Lunskey 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. 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. 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). 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.

The three most common behavior categories for which community services were sought in the current study were similar to those reported in the Heller, Hsieh, Owen, and Badetti (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%).

Research question two addressed how community-based services provided impacted individual post-transition outcomes. 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 the agency provided ABA therapy; 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. When individual and agency factors (home size and use of in-patient services) were controlled for in the regression model, however, the provision of 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.

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 in community

living and returners to SODCs. 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 studies (Lulinski Norris, Rizzolo, & Heller, 2010; Lulinski-Norris, Rizzolo, & Heller, 2012b). In addition, and also consistent with previous findings (Lulinski-Norris, Rizzolo, & Heller, 2012a), 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.

Study data indicate that stayers received services from agencies with a smaller average number of people living in a residential setting as compared to returners; returners, on average, came from larger settings and is consistent with previous studies (Balla, 1976; Baroff, 1980; Kozma, Mansell, and Beadle-Brown, 2009). 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.

Research on type and impact of mental/behavioral health intervention is lacking in the United States, though it has been estimated that approximately 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 was initiated by Friedman, Lulinski, and Rizzolo (2015). 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. 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. Additional efforts should be made to capture the satisfaction of individuals both receiving and providing support services in an effort to triangulate findings. This will be particularly important as states prepare for implementation of the CMS Final Settings Rule planned for March 2022.

While many states have behavioral intervention systems in place, a gap still exists. 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). Continued research and evaluation 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 and implement the HCBS Final Settings Rule, 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.

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 (including training in and utilization of positive behavior supports), improve collaboration between state DD and mental health agencies, and increase Medicaid reimbursement rates to providers of mental/behavioral health services.

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 key community-based service administrators to reflect on events that occurred in the past involving multiple individuals and multiple community resources. As previously stated, additional efforts to include exploration of the experiences of individuals receiving and providing support services should be considered in future studies. Additionally, 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 potential 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. DHS/DDD did not have its recipient files digitized and therefore the only method of collection available was paper-based transcription. Finally, services provided (particularly positive behavior supports) rather than those merely available should be considered in future inquiries.

This study highlights the necessity to look beyond the individual and his/her immediate surroundings to the systems within which services occur, bringing us closer to understanding community 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. In FY2017, censuses of public IDD institutions was 18,431, a 91% decrease (Tanis, Lulinski, Wu, Braddock, & Hemp, in preparation) since peaking at 194,650 in 1967 (U.S. Department of Health, Education, and Welfare, 1972). As the public institutional census continues to decline, communities will need to refine the training and provision of positive behavioral support 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 communities where they belong.

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Table 1

*Access to In-house Mental/Behavioral Health Resources (N = 47)*

<u>Variable</u>	<u>N</u>	<u>%</u>
Crisis prevention training		
CPI	26	55.3%
Mandt	4	8.5%
Other	11	23.4%
None	6	12.8%
Professionals		
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%
Therapies		
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%

Table 2

*Usage of 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%	8+1.5%	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.

Table 3

*Means of In-house Resources by Individual Status (N = 454)*

	Stayers ( <i>n</i> = 411)		Returners ( <i>n</i> = 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
# mental health professionals	3.72	2.54	3.05	2.54
# in-house treatments	2.19	1.57	1.74	1.53

\**p* < .05

Table 4  
*Percentage of Agencies with In-house Access to Resources by Individual Status*

	Stayers (n = 411)	Returners (n = 43)	$\chi^2$
<u>Professional</u>			
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

\* $p < .05$

**Table 5**

*Individual Characteristics by Status*

	<b>Status</b>			
	Stayers (n = 411)		Returners (n = 43)	
Demographics	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
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 <sup>a</sup>	45.17	19.391	48.33	22.644
Number of residents	6.04*	1.893	6.74	1.788
	<b>%</b>		<b>%</b>	<b><math>\chi^2</math></b>
Gender				
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

\* $p < 0.05$ ; \*\* $p < 0.01$ ; <sup>a</sup>ICAP Service Level Score

Table 6  
*Binary Logistic Regression for Overall Model*

	B	SE	Wald	Odds Ratio	95% CI
<b>Individual Factors</b>					
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
<b>Agency Factors</b>					
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

Note: CI = confidence interval; ABA = Applied Behavior Analysis; TA = technical assistance;  
 \* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$

Table 7  
*Models of Individual Characteristics and Agency Resources*

	Model 1 Individual Factors		Model 2 Agency Factors	
	OR	95% CI	OR	95% CI
Age	.987	.959 – 1.017	.995	.961 – 1.030
Length of stay	.932**	.890 – .976	.929**	.881 – .980
IQ	.997	.979 – 1.015	.999	.978 – 1.021
Psych. diagnosis	1.540	.725 – 3.270	1.256	.516 – 3.058
ABA therapy			1.338	.518 – 3.455
Use of in-patient services			.215**	.068 – .677
Home size			1.241	.976 – 1.578
Receipt of TA			10.542	4.322 –
			***	25.711

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