



Illinois State-Operated Facility Closure: Serving Individuals with Dual Diagnoses of Mental Illness and Developmental Disabilities

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Illinois State-Operated Facility Closure: Serving Individuals with Dual Diagnoses of Mental Illness and Developmental Disabilities

Summary Recommendations

There are multiple challenges inherent in serving individuals with dual diagnoses of mental illness and developmental disabilities. To successfully transition large numbers of people from living in any state-operated facility, challenges must be identified and effectively addressed for each consumer to maximize their potential for success. Illinois currently does not have the infrastructure of agencies / providers ready to move massive numbers of people into community settings. There is, however, a solid core of expertise among some agencies and staffs that have an established track record of success in serving this population. Six such Illinois agency leadership and staff teams were interviewed for this report. We asked them questions about what works well when delivering services to persons with a dual diagnosis (for clients and staff alike), needed resources (training, funding, programs, etc.) for the service delivery system and potential barriers to successfully serving the population. We believe transitions to community –based settings can be successful, and can be done well, but not without significant and systematic work.

Throughout the course of this project, Illinois providers offered a wealth of information, insights and wisdom – all based on solid experience. The following recommendations are broad in scope, but they provide the framework for success; detailed recommendations begin on page 6 of this document.

1. Create bold and innovative models of community services that are strength-based.
2. Provide small settings or scattered units throughout a mixed-use building with access to a range of wraparound services and supports.
3. Develop and implement workforce development plans to engage and retain quality staff.
4. Establish an *ad hoc* Technical Assistance Center to be in operation for three to four years to provide ongoing technical assistance and support to providers as they transition individuals from state-operated facilities to the community.
5. Assess medications on a routine basis, especially during the transition phase.
6. Develop an ability to coordinate all potential funding streams and support services to enhance each individual's success.
7. Invest in capacity building and training service providers.
8. Break the barriers between and within state divisions, departments and bureaus.
9. Develop a system that can track individuals who have moved from state-operated facilities and measure their progress.

Context

The Supportive Housing Providers Association (SHPA) and NAMI Illinois (National Alliance on Mental Illness) were engaged by the Chicago Community Trust (CCT) in September 2011 to assist the state with planning for proposed closures of state operated facilities (SOF). Following discussions with Illinois' Transition Coordinator, Governor's Office, and staff from the Division of Developmental Disabilities (DDD), the Division of Mental Health (DMH) and The Chicago Community Trust (CCT), a work plan with timelines and deliverables was developed and approved. The first deliverable was determined to be a report identifying best practices and challenges in serving persons with dual diagnoses of developmental disability and mental illness. We met with six social service providers who have proven their ability to provide exemplary services and housing to this population. We interviewed agency leaders and pertinent staff using a standard questionnaire (see Appendix A) for the purpose of gleaning from statewide experts the challenges and recommendations for successfully serving this population (see Appendix B-G for agency response).

This document reflects our efforts to identify and summarize findings related to the readiness of Illinois social service organizations to provide the necessary level of care to individuals with dual diagnoses of mental illness and developmental disabilities. There are a number of issues to consider in competently serving this unique population. Many of the recommendations laid out in this document underline the need for careful identification of providers who currently have capacity, those who need to enhance their capacity, and the need for strategic planning for future capacity development.

Closure of any facility – or change of provider or service location raises anxieties on a number of levels for everyone involved in the process (parents, guardians, persons receiving service, staff of facilities, etc.). In order to allay these anxieties, the state must step off on the right foot and ensure successful placements and supports for early adopters who move into the community. Mark Doyle, Illinois' Transition Coordinator, indicated that Jacksonville Developmental Center will be the initial state-operated developmental center closed. Facility census materials indicate that more than half of the individuals living in that facility have a dual diagnosis of mental illness and developmental disability. The level of service needs of this population often necessitates complex community placements. For individuals who have been living in state-operated facilities for long periods of time, it is essential to provide the necessary supports and services to ensure a successful transition process to community-based settings.

For years, Illinois has failed to adequately fund community services, resulting in cuts to community support and mental health services. This lack of resources effectively pushed many people into nursing homes and institutional care which resulted in Illinois' overreliance on state-operated facilities, nursing homes and Institutions for Mental Diseases (IMDs). This has created liabilities for the state, via three class action lawsuits based on the 1999 U.S. Supreme Court Olmstead Decision that says persons with disabilities must have the right to live in the least restrictive setting possible. The Governor's Rebalancing Initiative seeks to remedy this

situation, saving money and providing persons with disabilities the opportunity to move to community-based settings.

Transition / Service Planning

With thoughtful and bold planning and implementation of systematic change, there is incredible potential to positively impact the lives of persons with disabilities. However, even the most careful planning won't be enough without adequate funding and an implementation plan and process supported by multiyear funding guarantees. It is vital that each entity – and each individual involved in this process collaborates and looks beyond short term interests to the larger systemic changes that need to be made.

The transition team should focus on each individual affected by the closure of state-operated facilities. There are numerous stakeholders and many community impacts related to loss of employment / union issues, large gaps in community resources and economic impact. These recommendations do not begin to address those issues, they simply muddy the waters. This report only considers client impact; the transition team and implementation plan should be prepared to address the wider range of issues.

A thorough assessment of each individual –medical, cognitive, behavioral and psychological, will lay the foundation for transition. The compiled information should be shared with potential service providers and used in the development of an individual, comprehensive service plan. All services should be aimed at achieving high-quality outcomes for individuals and preventing costly unnecessary hospitalization or re-institutionalization. Any program design or placement must be able to meet the needs of the individual, including an ability to promote independence in daily living, economic self-sufficiency and the ability to meet and interact with nondisabled persons to the fullest extent possible. In this paper, a community-based setting may include:

- Permanent Supportive Housing
- Housing with family or friends
- Four person or less group homes
- Supported or supervised residential programs that meet criteria and receive funding within Illinois' DMH service taxonomy

Community Resource Associates (CRA), an independent firm, has contracted with the State of Illinois to assist with the Active Community Care Transition (ACCT) plan and conduct assessments of each individual affected by the closure. CRA is a training and management consultation firm that was founded in 1982. CRA has provided training and consultation in all 50 states and is widely known for having incorporated person-centered planning into all of their service designs and delivery efforts for many years.

CRA has been extensively involved in transitioning individuals, including those with significant behavioral, psychiatric, intellectual / developmental and physical disabilities, to the community from institutions.

Every individual in each targeted state-operated facility will receive an independent, professionally appropriate and person-centered evaluation of strengths, challenges and service needs to determine the community-based supports required for him or her to live in community-based settings. Based on the results of the assessments, CRA will develop service plans for transition to community-based settings. The service plan at a minimum must describe the community-based services that the individual requires, along with transition services and develop individual goals with a projected timeline for completing the transition. Goal development – supported by measurable outcomes are critical factors for transition and successful long-term community-based living.

The assessment should provide preliminary information for service provider planning. During every site visit interview, staff discussed the importance of a comprehensive assessment and a strength-based, person-centered approach. Agency staff viewed intake as an opportunity to get to know the person, fully consider their range of needs and develop a service delivery package that will meet those needs. Most agencies indicated that dually diagnosed individuals often demonstrate higher risk factors that may include a wide range of challenging behaviors from elopement to aggression (against person and property) to inappropriate sexual behaviors. Specialized programming to meet the needs and behavioral challenges of each individual should be considered. This means that Illinois must invest in and support the development of community-based housing models that can meet a wide variety of needs.

To ensure successful transition, there will need to be ongoing communication with each client and family and the timeline must walk a delicate balance of not feeling rushed but also not unduly dragging the process out. The earlier an agency can engage with the person transitioning and begin to develop relationships, the smoother the process will be. As with any significant life change there will be complex feelings: enthusiasm, tempered by apprehension and fear. As many individuals have been in state-operated facilities for a number of years, encouragement, support and motivation will be critical factors in instilling confidence that will set the stage for transition success. Building stable relationships early in the process is an ideal way to begin. Peer to peer supports would be ideal.

Recommendations

- Launch a campaign to educate stakeholders (parents, guardians, service providers, general public and the individuals affected) about best practices, services and life in the community. (A peer to peer education model may be most effective.)
- Be realistic about options and steps that may need to be incorporated into the transition process as an unlimited range of consumer choice may not always be possible, especially during initial transitions.
- Coordinate services between the Division of Developmental Disabilities, the Division of Mental Health, the Department of Healthcare and Family Services and the Division of Rehabilitation Services. (For example, enroll persons transitioning in the DRS Personal Care Assistance program, allowing for initial concentration on developing skills of daily living with adequate supports.)

- Assess and analyze community capacity, capability and interest of in serving persons transitioning from state-operated facilities.
- Focus on people – not the diagnosis. Diagnoses are stigmatizing and polarizing.
- Ensure that a comprehensive assessment of needs is completed for each individual and the assessment is shared with the service provider.
- Set up a series of visits for individuals transitioning with potential service agencies when feasible. Day long or weekend visits help everyone assess the fit for the client, the agency and other residents.
- Develop specialized programming to better serve persons with high risk behaviors such as elopement, aggression and inappropriate sexual behaviors.
- Create bold and innovative models of community services that are strength-based. Reinforce the philosophies of evidence-based and best practices for living in the community.
- Assess medications on a routine basis, especially during the transition phase.

Housing

The idea of home is much larger than a place to live. It encompasses self-determination, integration, community involvement, safety, security, support, family and love. Unfortunately, thirteen years after the landmark Supreme Court decision in *Olmstead vs. L.C. and E.W.*, Illinois still trails far behind other states in funding services that make it possible for people with disabilities to live in the least restrictive setting of their choice.¹ People with disabilities who receive SSI payments continue to be the nation’s poorest citizens. In 2010, a person with a disability in Illinois receiving monthly Supplemental Security Income (SSI) payments needed to spend 115% of their monthly income –impossibility – in order to rent a modest one bedroom unit.² This effectively traps people with disabilities in institutional care or homelessness. It costs significantly more money for people to remain institutionalized and / or homeless than it does to provide affordable housing linked with supportive services in the community (supportive housing).³

Supportive housing is a Substance Abuse and Mental Health Services Administration (SAMHSA) Evidence-Based Practice. Virtually hundreds of studies have proven its cost-efficiency and efficacy. *Supportive Housing in Illinois: A Wise Investment*, a study released in 2009 by the Social

¹The Chicago Community Trust Persons with Disabilities Fund. 2010. *A Quest for Equality: Breaking the Barriers for People with Disabilities*.

² Technical Assistance Collaborative. 2010. *Priced Out in 2010: State by State Analysis*.

³ Kitchner, M, et al., “Institutional and Community-Based Long-Term Care: A Comparative Estimate of Public Costs.” *Journal of Health and Social Policy* 22, no.2 (2006):3150.

IMPACT Research Center in conjunction with the Supportive Housing Providers Association and the Corporation for Supportive Housing, showed supportive housing reduced the volume of publicly-funded services residents used, changed the type of services used, and resulted in significant cost savings over time. (See Appendix H)

During the interview process, common housing themes appeared: small settings with individual bedrooms or individual units and appropriate supports available onsite or within close proximity are optimal. By providing individual bedrooms, many problems automatically resolve or don't occur in the first place. Communal living is difficult in the best of situations, let alone when there are challenging behavioral issues. Group living is hard to manage and it doesn't lend itself to allowing people self-determination. In some cases if one person is not willing to engage in activities no one can participate. One team reminded us to "recognize the impact of having ten people in your house. It's always a volatile environment." Individual apartments are the preferred setting; and living alone is ideal when proper supports are in place. Several agencies readily admitted that they have discharged people who could have been served if private bedrooms were available.

Recommendations

- Provide small settings or scattered units throughout a mixed-use building with access to a range of wraparound services and supports.
- Consider independent housing models. If congregate living models are utilized, ensure a private bedroom for each resident.
- Ensure all housing units meet or exceed HUD Housing Quality Standards.
- Separate housing and service funding streams to allow for greater personal choice and more resources for services.
- Create a Rental Subsidy Program for persons with disabilities to meet the needs of persons in each class action lawsuit and involved with facility closures. Pursue HUD Section 811 Project Rental Assistance for extremely low-income (30% of Area Median Income) persons with at least one adult member with a disability and explore ways to enhance funding in the Rental Housing Support Program and DMH Bridge Subsidy Program.
- Explore "Smart Home" options like virtual case management available through video links. Utilize technology as a means of support for residents. Create a database of housing options currently available in the State of Illinois so that potential resources aren't overlooked as new resources are created. Develop a statewide Housing Plan that brings together all of the current State priorities (MFP, SODC and Mental Health Center closings, Consent Decree Implementations, Affordable / Accessible Housing for persons with disabilities and persons with very low-income, and homeless services) to facilitate the development of housing options, effectively use current housing resources and more efficiently use the limited resources of the State.
- Develop respite services; allow for movement within the system so that a person who isn't succeeding in one setting can try a different setting.

Workforce Development / Staffing

A common problem among most social service / nonprofit agencies is hiring qualified staff when wages are historically low and less than competitive within the job market. Social service levels of funding, state reimbursement rates, silos of services and funding, combined with Illinois' track record of late payments, conspire together to keep social service staff wages low and flat. Experience has taught agencies that hiring entry-level minimum wage staff brings its own set of challenges. In many instances, it's a staff member's first job; in other cases, it's the only job they were able to find. Challenging working conditions and consumers' frustrating behaviors can easily escalate into power struggles. Perceived power in lieu of good wages sometimes translates into less than quality care, ongoing staff / client tensions and staff burnout. Agencies that were interviewed were gravely concerned that this type of power can be abused and lead to high rates of staff turnover. Recently, due to the economy, many agencies report that they are able to recruit college-educated staff despite the wages they offer. Their main concern now lies in their ability to retain these staff members.

Selecting the right staff is critical; it's important to match staff skills and clients' needs. Serving a dually-diagnosed population requires a certain expertise and a wide range of skills, from being able to provide basic companionship and one-on-one attention to engagement in group activities and complex behavioral interventions. Staffing that meets the needs of the client must be maintained to keep each client well.

There are several models of community-based care and housing and many agencies felt that a home manager model of care works better than traditional shift work. They felt that in working with individuals with dual diagnoses, you cannot have different people coming in to staff the residence all the time and expect positive behaviors or results. One organization has adopted a "fireman's shift schedule" with staff members working three days on / three days off. Staff can also go home during group activities. This agency has found that due to the intensity of the work, having three days off supports the employees' recuperative process. Within this scheduling model, they supplement the staffing pattern with shift staff to build quality outcomes for clients and staff alike.

Furthermore, staff should have direct input into the running of the organization which creates pride in their work, buy-in and positively impacts quality. Frontline staff must have access to clinical support and supervision. This greatly reduces instances of inappropriate care and alleviates staff stress levels. The best supervisors help identify problems and solve them. Agency staff must be able to call for supervisory support at any time and get help to alleviate emerging issues and problems before the situation escalates. Supervisors are often able to recognize potential problems and redirect behaviors before crises occur.

Recommendations

- Create a statewide approach to social service workforce development that reinforces and supports recovery and life in the community.

- Develop and implement workforce development plans to engage and retain quality staff, assist them to build skills and recognize career path opportunities within community-based care programs.
- Create training programs for current staff of state-operated Developmental Centers who might become employed by community-based service providers.
- Allow for adequate staff training time, currently an employer can't bill for hours of staff training or weekly staff meetings to facilitate information exchange, feedback and peer support.
- Fund an adequate staff to client ratio (one staff for each four to five clients seems to work for most agencies).

Applied Behavior Analysis / Psychiatric Services

It's often difficult to line up appropriate counseling services for individuals with developmental disabilities (many psychiatrists, psychologists and counselors haven't been properly trained on serving persons with cognitive deficits), but most agencies serving a dually-diagnosed population recognize counseling as a valuable service. Counseling outcomes sometime progress at a slower pace (taking into account limited verbal ability), but experienced, properly trained counselors achieve significant results.

Most counselors who work with individuals with a dual diagnosis engage in activity-based groups versus typical group counseling. Art, dance and sensory activities are useful and they ensure individualized attention which leads to improvement in social skills. Many persons with a dual diagnosis are nonverbal or have a limited ability to communicate. If people are nonverbal, much of group work focuses on teaching them to express themselves so staff and housemates alike can better communicate.

Applied behavioral analysis involves using modern behavioral learning theory to modify behaviors. Specially trained behavioral analysts focus on observing relationships between an individual's behavior and their environment and then developing specific plans to change targeted behaviors.

Behavioral analysis is recognized as an effective service when working with a dually diagnosed population, but it is not a commonly available staff skill within traditional providers who serve individuals with mental illness. Among the agencies interviewed, behavior analysis was initially delivered by contracting for services outside of the agency. The services have proven so successful many of the agencies have subsequently hired Behavior Analysts into staff positions. Behavioral Analysts give guidance and support to clients with different diagnoses and staff members who work with them. This service – supported by an effective agency staffing pattern, ensures consistent communication, messaging and techniques that positively guide client behaviors and progress toward meeting goals.

Some agencies indicated that initial attempts to integrate behavioral analysis into an agency culture created stress among staff who didn't necessarily understand the efficacy of the

behavioral support plan. Eventually staff recognized and appreciated the ability to achieve better outcomes through teamwork and consistency. Behavioral analysis has widespread appreciation among quality agencies that are motivated to meet client needs and it's a skill set that could ease transitions for individuals who are exiting institutional care.

Recommendations

- Encourage, support and fund behavioral analysts and behavioral training for all staff working with a dually diagnosed population.
- Cultivate and train counselors, psychiatrists and psychologists for working with persons with cognitive deficits.

Funding

Rates and rules, challenges and barriers were the mantra of all of the providers we interviewed but there was a strong feeling that anyone can be supported in the community with the proper funding. Funding buys the necessary services. A cap on hours of service each year – especially for those who are dually diagnosed – is not reasonable. Creative solutions might include: banking each client's hourly cap for the year for every person in the community-based setting to increase staff flexibility to meet emerging needs, or changing the current thinking about how services are funded by separating the housing and services funding streams. Providers have worked hard to piece together applicable services from the Department of Rehabilitation Services (DRS), Individual Placement and Support (Supported Employment), Division of Alcoholism & Substance Abuse (DASA) and others, achieving astounding success with this population. They encourage the State and other providers to replicate their success. Developmental Disabilities / Mental Health and all ancillary transition services must work together.

Providing a specific dollar amount per person for their service array will not work if you don't have the services available in the community for purchase. For example, if a person needs day programming and the local service provider's funding has been cut which caused them to close their day program, they can't provide access to day programming even though there might be funding available to pay for the service. Non-Medicaid billable services are critical to enable individuals to make successful transitions into the community.

Recommendations

- Create flexibility within rates and funding streams.
 - Review and enhance rates for Rule 132 funded services.
 - To ensure the success of this transition to the community consider modifying the state plan and to structure all services into a single day of service rate.
 - Rewrite waivers and explore model programs (like supportive housing) that address new trends in client needs, and develop innovative financial strategies to support them or institute the following combination of billing models: A

wraparound of non-Medicaid billable services via grant plus Medicaid eligible Rule 132 fee-for-service billing.

- Rewrite waivers to increase flexibility to deliver services when needed so staff can intervene before crises escalate; crisis supports will be needed.
- Develop an ability to coordinate all potential funding streams and support services to enhance each individual's optimal success, e.g. Personal Care Assistance through DRS; peer-to-peer support; employment services and supports; all tasks involved in obtaining, preparing, and getting established in an apartment.
- Develop a community-based service plan – supported by realistic funding for individuals with a dual diagnosis of mental illness and developmental disability.
- Recognize the value of nontraditional services and fund them.
- Recognize and resolve that in this environment of late payments, real cash will be needed to get people into services.
- Create less intense and cost effective alternative options for adults who could live at home with family or friends.
- Prescriptive service requirements stymie the ability to meet an individual's needs, especially a person with a dual-diagnosis that requires more service than is currently allowed. There is little to no flexibility for agencies to deliver additional services when needed.

Capacity Building for Division of Mental Health / Division of Developmental Disabilities / Office of the Inspector General

Illinois' proposed closure of state-operated facilities is a complex undertaking, driven by short timelines and dramatic budget reductions. The state's focus on quality care, safe transitions and long-term benefits has been compromised because of the politics involved and exacerbated by often inadequate information exchange. Transparency must be improved with evidence of communication and collaboration imbuing every step of the process. Every Rebalancing Initiative must begin with an explanation of quality of care issues and how this will benefit individuals who are transitioning to their home community. Messages and plans must be realistic and consistent.

The Transition Team, as well as DDD / DMH staffs need to be supported – and mutually supportive as they undertake this effort so that clinical, administrative, and fiscal responsibilities are coordinated. Additional divisional staff with appropriate expertise and concentration of authority will be required. It will not work to have this endeavor “silo-ed” or spread over several state divisions and departments. Assistance from CRA may be helpful in developing and defining this initiative.

Most agencies interviewed have dealt with complaints, accusations and investigations that have been lodged with the Office of the Inspector General. Developing relationships, protocols

and procedures that facilitate communication and mutual understanding and expectations would be beneficial.

Recommendations

- Create a vision that incorporates all community-based program initiatives; break silos that create or sustain classes or separation of programs.
- Centralize management of this initiative to maximize division and departmental expertise and authority.
- Co-train agencies and OIG personnel on roles / responsibilities and implementation of a system designed to protect individuals.

Capacity Building for Providers

Providers for this project should be selected based on a Request for Information (RFI) / Request for Proposal (RFP) process with providers competing on the basis of quality and added value rather than cost. Agencies that already have significant experience, capacity and expertise in supporting individuals with dual diagnoses should be considered for initial placements. Management teams and staff of experienced providers can facilitate easier transitions into community-based services initially.

At the same time, an ongoing training and capacity building program must be implemented to increase the pool of qualified service providers prepared to meet the increasing need. Geographic coverage and cultural competency must be considered, and once again skill-building opportunities and creative ways to provide on the job training for provider staff must be developed in a number of areas.

Agency Identified Training Needs:

Theory:

- Motivational interviewing and interventions
- “Transtheoretical Model” Stages of Change
- Cognitive Behavioral Therapy (CBT)
- Trauma informed services
- Harm reduction
- Integrated dual disorders treatment
- Wellness management and recovery services
- Peer support and education
- Anger management
- Engagement vs. compliance: positive behavior supports

Practice:

- Flexible Assertive Community Treatment team models and services

- Higher intensity community support team services with focus on recovery and community integration
- How to develop collaborative relationships with local primary care providers, hospitals, and other health care entities
- Individual placement and support (Supported Employment)
- Representative payee services
- Medical case management & supportive services (education, monitoring, etc.)
- Housing development and resources including community housing options and models
- Transition planning and support
- Specialized training for support of corrections involved people
- Trainings for counselors, psychiatrists, psychologists for working with persons with developmental disabilities
- Service planning for high risk behaviors
 - i. Management team techniques and responsibilities
 - ii. Staff planning, techniques and perspectives
- Guardianship issues and techniques for working with guardians
- Cross-trainings across the developmental disability / mental illness systems
- Collaborating with parents /guardians
- Medication management
- Consumer as a person (actually your employer) not an illness
- Recognizing the impact of staff behavior and environment on clients
- Crisis Management and Intervention
- Holistic approach to the consumer
- Frontline staff role in observing changes in behavior and affect in order to address emerging psychiatric needs
- Provider education for all agency staff – from a client / family perspective
- Increase staff training to become more customer-oriented, customer service oriented
- Strong recovery orientation as measured by a standardized assessment
- Strong program outcomes evaluation and quality management processes
- Robust information management capacity

Delivery / Implementation:

- Motivational interviewing and interventions
- Engagement vs. compliance: positive behavior supports
- How to work within an individualized behavior support plan
- Assessment of high risk consumers
- Cross-trainings across the DD / MI systems
- Mental Health 101

- Responding to potential situations (practicing how to react before you have to react using real life examples)

The key issue here is that all staff needs exposure to new, effective theories. Following exposure to theory, staff needs training on putting the theory into practice and delivery / implementation in order to understand and demonstrate new skills.

Technical Assistance and Training

Technical assistance and training needs are great. The State should establish an *ad hoc* Technical Assistance Center to be in operation for three to four years to provide ongoing technical assistance and support to providers as they transition individuals from state-operated facilities to the community. As part of this center, provision should be made for provider's frontline and clinical staff to learn from one another and to share challenges and best practices.

Another suggestion is that management staff at each agency should be trained in risk assessment and risk mitigation planning aimed at finding better ways to effectively bring people into integrated community settings. There is a definitive need and there will be a steep learning curve for many agencies, especially during the development and readiness stages of building agency capacity.

Recommendations

- Establish an *ad hoc (three – four year)* Technical Assistance Center to develop and provide technical support and oversee development of a comprehensive curriculum for supporting providers as individuals transition from state-operated facilities into the community.
- Train management staff and agency boards of directors in risk assessment and mitigation planning.

Organizational Culture

The agencies involved in this study all stressed the importance of organizational culture. The perception that from the Executive Director down, the organization and its staff are committed to creating solutions for everyone, that there is no one that can't be served, that we need to do what needs to be done to serve people. One organization's mission statement sums up their organizational philosophy by simply stating "Creating Solutions for Everyone" and they work to live up to that mission. Strong communication skills, teams that work together, supportive management, a high level of responsiveness to clients and families are all highly valued skills that lay a solid foundation and create a culture for serving this population well. The interviewed agency leaders are passionate people who have worked in the field for some time. They are overextended, overworked and underpaid but open to developing and modifying services to better meet consumer needs. State leadership must respond by encouraging and supporting innovation.

Recommendations

- Foster innovation, communication and creative models of service delivery that maximize community-living.

Community Supports

Provision of high quality, medical services and other medical partnership planning will be necessary. Individuals with developmental disabilities sometimes need to be hospitalized, but there is a severe lack of hospitals with the capacity to serve the population, especially when there is a dual-diagnosis. Depending on the community and the resources available, options to explore may include: nurses as part of the service team; partnerships with community-based primary care providers including Federally Qualified Healthcare Centers, hospitals or integrated care programs; and strong collaborations with local dentists.

Several agencies that are participating in the Integrated Care Pilot Program, serving six collar counties of metropolitan Chicago, expressed dismay that no hospitals in their area have signed on to either of the two contracted managed care programs. To alleviate these problems, agencies are beginning work to see if physicians will come to them or exploring mobile medical unit options. Others are hoping to develop 72 hour emergency room/support service team resources that have an ability to connect with other medical resources. Following some transitions, providers have found that consumers are simply overmedicated. Health and behaviors often improve as medications are monitored and adjusted accordingly.

The community support system must allow movement between and within community-based settings, including access to respite services. When things get out of control, staff and agencies alike must have respite time to figure out next steps.

Recommendations

- Explore innovations and be open to revamping all aspects of the system.
- Define new ways to provide short term respite or develop specialized units for caring for individuals with a dual diagnosis.
- Explore all community resources (including the use of peer supports) to create new models that meet the needs of clients and providers.
- Monitor medications on a routine basis, especially during periods of transition.

Tracking and Evaluating

While client outcomes are vital to measuring success of the overall initiative, evaluation of system performance should also be a high priority. Process measures (assessment of recovery orientation, quality process, fidelity measures, etc.) in addition to outcome measures are critical so agencies avoid pitfalls of only working to serve those who are easiest to serve.

Recommendations

- Develop a system that can track individuals who have moved from state-operated facilities into community-based settings.
- Measured system outcomes should include: housing stability, ability to perform daily living tasks, employment, integration into the community, connection with family, increased independence, and progress on individual goals.

Conclusion

Few Illinois agencies currently have the ability to provide quality services to individuals who have a dual diagnosis of developmental disability and mental illness; they have not historically been encouraged or funded to do so. Because of this disconnect, the dually diagnosed population have fallen between the cracks, often landing in state-operated facilities. A few nonprofit agencies in Illinois are ready to take clients who are ready to move out of state-operated facilities, but the majority of Illinois providers are not at the appropriate level of readiness or capacity. All agencies that demonstrate current capacity should be utilized and all agencies that are interested in increasing their capacity should be able to participate in capacity building opportunities. This type of enhanced service provision is the wave of the future.

If proper transitional steps are taken and adequate funding is allocated to develop a solid foundation, the state will realize its goal of successfully transitioning people from state-operated facilities into community-based settings.

The Supportive Housing Providers Association and NAMI Illinois thanks:

The Chicago Community Trust

Mark Doyle, Illinois Transition of Care Project Manager, Office of the Governor

Director Kevin Casey and Staff of the Division of Developmental Disabilities

Director Lorrie Rickman-Jones and Staff of the Division of Mental Health

Staff Leadership and Teams from:

- AID, Aurora
- Bridgeway, Galesburg
- Cornerstone Services, Joliet
- Search, Inc., Mt. Prospect
- Southside Office of Concern, Peoria
- Trinity Services, Joliet

Appendix A: Introductory Letter and Survey Questions

This letter was sent to six selected agencies / Appointments were scheduled via telephone follow-up.

Dear (name...)

NAMI Illinois and the Supportive Housing Providers Association have an opportunity to identify promising practices in delivering services to individuals with a dual diagnosis of developmental disabilities and mental illness.

We have chosen a small number of organizations who are recognized as providing quality services to this population. You are among them, and we would like your assistance in working with us to further this initiative.

We envision that your success involves a team of people who work together to meet specialized needs. We'd like to meet with you and your team for approximately two hours to attempt to determine what sets your organization apart in the delivery of quality services.

To make this process as easy as possible, we'll come to you. Please choose from the following list of dates and times.

Monday, December 19 th	afternoon
Tuesday, December 20 th	morning or afternoon
Wednesday, December 21 st	morning
Thursday, December 22 nd	morning or afternoon
Friday, December 23 rd	morning or afternoon

We look forward to partnering with you in the effort to enhance services for persons with developmental disabilities and mental illness in Illinois.

Sincerely,

Lore Baker
Supportive Housing Providers Association

Lora Thomas
NAMI Illinois

Survey questions to interview agency teams:

We are interested in the presentation of a person with a dual diagnosis = Walk us through entry / intake for that person.

(Inclusive of: Intake, assessment, treatment plan, housing placement / how you determine & deliver services)

How often do you see the dual diagnosis of developmental disability and mental illness?

Identify unique needs of someone with a dual diagnosis versus someone with one diagnosis (or the other).

What are the barriers to serving this special population?

Are there any limitations to what you can do or the services you can provide?

Have you refused referrals in the past? (Why)

Have there been failed placements where the person could not succeed within your organization? (Again why)

What special trainings are needed for your agency staff to (more) effectively serve this population?

What resources are needed to serve this population?

What are the services you need to deliver to individuals with a dual diagnosis?

Where do you receive referrals from?

Is there anyone in the community that provides these same types of services?

What is your organizational culture regarding service to dually diagnosed individuals?

How do you cultivate / find the right people to be a part of the team – or – create the team's orientation?

Appendix B: Response from AID – Aurora, IL

Unique Needs:

- AID routinely uses Behavioral Analysts to complete comprehensive functional analysis, utilizing testing, observation and staff input. They then develop protocols and teach staff how to effectively use them.
- AID recommends a Home Manager Model versus shift staff when working with dually diagnosed individuals with developmental disabilities and mental illness. They feel they cannot have different people coming in all the time and expect same results. They utilize a traditional fireman shift – 3 days on – 3 days off – and supplement with shift staff. House Manager Model – main model but must supplement with shift staff. Three days off provides staff with recuperative time.
- DD / MI come through intake coordinator on Day 1 through a PAS agency – all have an IQ of 69 or less; the PAS Agent tells you what services are approved; that’s where referrals stop.
- The agency carries a strong philosophy that if clients are local, they do their best to serve them.
- Dually diagnosed care requires more energy and additional training to ensure appropriate and effective client service and support.

Challenges:

- Helping Psychiatric staff understand there are differing intellectual capabilities found among DD population
- Psychiatrists / counselors have different experience and expertise
- No one will be approved for years of counseling – considering short time issues only
- DD model of service versus MI model of services, e.g. DD are waiver services that are capped. There is no flexibility to deliver additional services when needed. After 200 hours of services they have to reapply. For Behavioral Intervention, clients are eligible for 86 hours per year. That can be used in less than one month.
- Many of the services that clients need are not reimbursable, or they are not funded at the level of support that individuals need.

Staffing / Organizational Culture:

- AID management teams work hard to match staff and clients well and then they train and support the staff to the max. They look for laid back personalities that don’t control and work to avoid anyone who may abuse the power of their position.
- Staff must rely on their own personal skills. Some of the best staff is currently coming out of college with text book knowledge; the agency’s overall problem will be retention. Good employee benefit packages are critical.
- They work to staff the agency, not the individual group home or placement assignment. Typical services have changed over the past 10 years; the agency now sees only crisis cases, and they recognize that crises are stressful. Management staff rotates staff on a routine basis.
- Stakeholder involvement in planning and program implementation is paramount from the beginning. They feel that having clients participate in both interview and evaluation processes helps sets the right mindset for the staff: “I’m working to help this person succeed.”

- Management and leadership staff know that attitude and philosophy infiltrates front line staff.
 - All must be responsive to families and concerns that are brought to attention (front line and administrative). All must know clients and families.
 - Philosophy – not here to take care of this person, but to work with them to achieve realistic concrete plans and goals.

Training Needs:

- Quality counseling models and techniques that are effective with individuals with a DD diagnosis.
- Anger management training & effectively managing behaviors
- Positive behavior supports – engagement versus compliance
- OIG referrals and expectations
 - Note: They have found that everything must be reported
 - AID staff recommends that OIG staff participate in ongoing conversations; joint meetings of OIG and agency staff (Support Services Team) have been useful.

Agency Suggestions:

- Resources must be allocated differently.
- Environment is one of the most crucial issues; when people can't be served well everyone suffers. Small residential settings are better than larger settings.
- Crisis funds must be available for clients, regardless of payer; it's a good stop gap measure to identify how (and what) services can be accessed.
- There is a severe lack of hospitals with specialties – and access can often be quite far away; develop short-term, specialized DD/MI units – or respite services so hospitals or the current placements are not the only options. When things are out of control they have to leave group setting; that is the best time to figure out what to do and how to do it.
- Apartment living: 1 or 2 people per apartment; not more than two. Living alone is ideal if you can put supports in place. Under no circumstances should anyone share bedrooms unless they can pick their roommates; AID has experience where one bedroom units changed behaviors.
- Staffing ratio: 1 staff to 5 clients; they feel that a minimal amount of personality testing may assist in identifying staff who can work well with this special population.
- There is a certain level of service that everyone may be able to get to, but at some point it cannot be able to be less / and remain successful.
- Develop residential settings with this population in mind. From AID's experience, an apartment design (four units for four people) with two entry ways on each side ensures a private entry, supervisory ease and a normal life, with each individual having their own home. Group living doesn't lend itself to having people make choices. In a group home if one person is not willing to go, no one goes, as many individuals can only be alone for up to four hours. Explore electronic monitoring / smart home concepts of security, although words, concepts and implementation must be carefully considered.
- Well defined supports are needed for clients and families.

Scenarios:

- John is a resident who has been diagnosed, with a high functioning developmental disability and a diagnosis of bipolar and schizoaffective disorder. He has fallen through the cracks a number

of times and has been through a number of homes. He is an eloper who has fairly frequent outbursts. With a Behavioral Analyst's intervention, group counseling and carved out DD services, they have defined specific outings, activities and staff finding the right "recipe" to serve him.

Appendix C: Response from Bridgeway – Galesburg, IL

Unique Needs:

- Behavior Analysis.
- Higher risk factors such as elopement, aggression, sexualized behavior.
- Difficult to get counseling for a person with cognitive deficits, aren't trained personnel available.
- Working with the standard two staff person on site, if one person is taking a group to an activity, the second staff person may have a very difficult time maintaining the required line of sight, etc.

Challenges:

- A person who is developmentally disabled and approved / receiving special education services in school you can't get approved for adult services once they age out of educational system.
- How long it takes to be approved by Medicaid. Who helps people apply for Medicaid?
- Qualified counseling is very difficult to find. There aren't very many counselors, psychologists or psychiatrists who are trained to work with clients with cognitive deficits.
- Relatively low rates paid for counseling from DDD and very difficult to get counseling services approved.
- Persons with high risk factors: elopement, aggression, sexualized behaviors – danger to others.
- OIG calls.
- Since you can't discharge if someone doesn't work out in a particular setting, agencies are cautious about accepting referrals.
- Very difficult (lots of hoops to jump through) to get mental health services approved for a person with DD. Rate for MI Community Support is \$65 for DD it is \$23.
- Crisis is the only way to enter the system which starts a consumer at a disadvantage.
- In some areas, the PAS agencies are very political, don't refer to all agencies.

Staffing/Organizational Culture:

- Currently more than 50% of clientele is receiving both mental health services (seeing the doc) and DD services.
- Finding qualified staff is difficult. Better pay is needed for direct service staff so that the best service can be provided. Challenging to find someone who can break each activity down into small steps, look at where the person is at today and not be frustrated if you need to provide the same level of assistance (breaking down each task into simple steps) every time the consumer does something.
- Communication is key. Provide clear, understandable answers to staff.
- Assist staff in positively dealing with stress, especially when serving persons with high risk behaviors.
- Must believe in creating solutions for everyone.
- Believe in the mission of your organization, what you are doing.
- Organizational culture starts from the top and flows down to front line staff.

- Management staff are over extended which means that frontline staff doesn't always have the access for clinical support and supervision.

Training Needs:

- Provide trainings to counselors, psychiatrists, psychologists on serving persons with cognitive deficits. Counseling works but you must alter your style: slower, repetitive, not talk therapy, more behavioral therapy.
- DD / MI cross trainings between and within both systems.
- Substance abuse trainings. Harm Reduction / Housing First models.
- Mental Health 101 or Mental Health First Aid.
- Trauma Informed Services (being able to understand how a person's past influences their current behavior, ways service should be delivered and where a person can be placed).
- How to work with the consumer plus their parent or guardian.
- How to see the person as a customer not an illness so that service is delivered in a positive manner.
- There are excellent trainings provided: OJT, Health & Safety, MH Medication, DO, Human Interactions, Basic Communication, etc.

Agency Suggestions:

- It is vital when working with challenging clientele that you have a Behavior Analyst on staff to create a positive behavior modification plan and work with the staff to implement the plan. Follow through is vital to the success of the plan but isn't always easy to implement due to staffing.
- Make it easier for a person with both a DD and MI diagnosis to be approved for and receive mental health services.
- Perhaps a specialized group home or living arrangement for persons with high risks such as elopement, aggression, sexualized behaviors?
- Higher rates to serve persons with high risk factors so that you can adequately staff.
- DDD Services Support Teams need to be staffed by people with direct service experience; they must be able to spend more time with consumers to observe behaviors before they make service recommendations.
- Services must be individualized.
- Provide better wages for direct service staff to attract and reward excellence.
- Provide respite settings, allow for movement within the system so that a person who isn't succeeding in one setting can try a different setting.
- The Division of Mental Health and the Division of Developmental Disabilities needs to coordinate services for persons with a dual diagnosis of DD / MI.
- Also coordinate with the Division of Rehabilitation Services since personal care assistance can be very useful.

Appendix D: Response from Cornerstone Services - Joliet, IL

Unique Needs:

- Don't focus on the diagnoses but the person.
- Need behavior analysis services – they are critical for the consumer's success.
- Allow for time to transition. Don't move straight out of current situation into a new setting. Allow for dinner visit, weekend stay, time to settle in, exploratory behavior, be patient. Remember that those who have been living at a SODC have had no control of their situation so choices are going to be anxiety provoking and overwhelming. Be prepared for this.
- Allow exploratory behavior as the person acclimates to new home.
- Look at history and staff appropriately.
- Complex medical issues.
- Complexity of assessment: behavioral, psychiatric, and cognitive.
- Antipsychotics affect a person with a developmental disability differently. You must be able to assess and track a person's functioning in relation to type of medication prescribed.
- Psychotherapists must modify their therapy. Talk therapy isn't effective with this population.
- Difficult for this population to explain what they are feeling, experiencing (voices, hallucinations) so you must be able to sift through exhibited behaviors to determine the cause.
- More significant highs and lows lead to more intense needs and calls for appropriate interventions before the situations worsens not months later when the service is approved.

Challenges:

- Currently training is polarizing, must assess all of the person needs.
- DD service delivery is less a medical model than MH services. This affects how you deliver the services.
- Behavioral Analysis is capped at 66 hours per year / person. It needs to be individualized to the person's need.
- From application for a 53DNR it can take months for an approval. Their needs to be more service flexibility.
- Difficulty accessing appropriate psychiatric care, especially in inpatient hospitalizations. Most dually diagnosed persons end up over medicated due to the complexity of their diagnoses.
- It is difficult to "think outside" of the rigid funding box.
- Serving people boils down to a resource issue, who you are able to serve; who are you willing to serve?
- There are not many that can't be served. Violence and staffing capacity are the big issues.
- No hospitals are signed on to the Integrated Care Program in the area.
- Difficult for staff to spend time debriefing, not enough time but it is necessary to maintain quality service delivery and mental health of staff.

Staffing / Organizational Culture:

- Behavior Analyst on staff is a must.

- Nurses on staff can greatly assist with persons with complex medical issues and with medication monitoring. This allows for Integrated Care Plan implementation also.
- Need to attract good staff people stymied by low salaries.
- People are people; we need to do what needs to be done to serve people.
- Staff has direct input into the running of the organization, creates pride, buy in and quality.
- Days of creaming are over!

Training Needs:

- Training enhancement must be a priority.
- Need more appropriately trained therapists, psychologists and psychiatrists. Assist these professionals to overcome their trepidations about serving people with dual diagnoses.
- DSP, specificity, teaching staff to be behaviorists. Recognizing the impact of staff behavior on clients, environment on the clients, etc.
- Teach staff to not react emotionally, to separate from behaviors exhibited by consumers.
- Cross training of DD / MI issues. Here is what it looks like, here is how you respond, don't go with your gut.
- Specific trainings of what a situation might look like and the proper response to the situation. Teaching alternative strategies before a situation happens.
- Crisis Management – how to think on your feet, strategically. Crisis Intervention.
- How to work within an individualized behavior support plan.
- Trauma informed services.
- Holistic approach to the person.
- The importance of reporting changes in behavior, affect, etc. in order to address emerging psychiatric needs.
- Support and train the parents / guardians who fear failure for their loved one, primarily because the services have failed their loved one in the community in the past.

Agency Suggestions:

- Reimbursement rates should be individualized.
- Crisis intervention must be flexible.
- Behavior support plans are a vitally important tool.
- There should be a backup plan in place for when the mental illness cycles through a difficult time.
- Need an alternate Day Program option since current programs are geared towards serving persons with a mental illness and are often not as concrete as a person with cognitive deficits might need. Need a Day Program to address both MI and DD diagnosed persons.
- Amend the waiver to allow for a bank of hours that you could pull from rather than a set amount of hours per person. Instead of saying 66 hours per person per year, bank the 66 hours per person and these hours could be pulled from for any person who needs behavioral health services. That way those that need more than 66 hours could get the services. This way you could respond in a proactive manner to a situation rather than waiting months for approval for a service.
- Institutional behavior must be acknowledged, not punished.

- The industry must be professionalized in order to attract good people to entry level positions; it boils down to how people are paid.
- Need to address issues as they arise.
- Must attract doctors to provide services to consumers.
- Matrix funding for homes, develop a model staffing plan and fund it.
- Smaller residential placements are ideal.
- In communal living, a person must have their own bedroom. It is vital to be able to have some place to go to separate from the situation.
- If a person has been institutionalized for a long time, there might need to be steps built into services and supports. Start out more intense and then step down when the person acclimates.
- There needs to be time for the staff to debrief with each other, weekly staffing to share info and provide feedback and suggestions to peers and from supervisors.
- As you explain closures to parents/guardians use these arguments:
 - Consumer Choice
 - Education of Parents/Guardians
 - Education of Community
 - Balancing resources
 - Comfort
 - Regular meetings with parents / families
 - Acknowledge fears
 - Provides lots of information
 - Trauma Informed Services

Scenarios:

- Consumer with Intermittent Explosive Disorder received services in a group home, meds were gradually decreased and now consumer is off all medication. One of the primary issues was over medication.

Appendix E: Response from SEARCH, Inc. – Mt. Prospect, IL

Unique Needs:

- The Agency is cautious in their assessment of who they can serve on a residential basis. Their transition process takes anywhere from 90 days to six months, often including temporary stays in communal living situations to explore patterns of behavior.
- They have accepted people in crisis, but only those known to them, i.e. individuals with developmental disabilities they have served through day care programs.

Challenges:

- Rates, rates, rates.... Search feels they can support anyone with the right rates, for rates buy necessary service.
- Behavior and medical issues are the primary reason for turning down referrals. They often feel they have staff skills to support people, but they know that some clients need more services than rates will support.

Staffing/Organizational Culture:

- Counselors don't run typical groups, they use activity based groups to engage clients, i.e. art, dance, sensory activities. They ensure individualized attention to develop social skills.
- When the staff starts to see physical aggression, they view it as an indication of new needs, exploring what needs to change to better meet the client's needs. Follow-up services / supports are built into their plan.
- There is no agency hierarchy; the expectation is that when someone sees a need they do it. And, supervisors do more than identify problems, they help solve them.

Training Needs:

- They often see communication barriers and people who are nonverbal, so much of their service focuses on teaching people to express themselves.
- A mutual training for Agency Staff and OIG staff would be helpful to both parties.
- Medication management / Medication Monitoring – the agency's experience has been that they are more likely to reduce medications than increasing or adding to them.

Agency Suggestions:

- Search Inc. Staff recommends that the state rewrite waivers that include other models, new trends and needs.

Appendix F: Response from Southside Office of Concern - Peoria, IL

Unique Needs:

- A good professional guardian is essential to effectively serving the person. Guardian must understand corrective behavior plans.
- Violence Tendency Assessment.
- Representative payee must understand that money can be a therapeutic tool.
- Consumer can be easily preyed upon, even by phone solicitations. Staff must be vigilant to mitigate this risk by enrolling (sometimes continuously) in no call lists.

Challenges:

- Prescribed service delivery requirements for persons with a developmental disability rather than individualized to the person needs.
- Difficulty in delivering the prescribed service, such as dental review yearly.
- Intermittent CILAs don't have a rental subsidy attached which means that the operations of the housing must be covered by service funding, this takes away from the services a person can and should receive.
- Prescriptive training (DSP, Clinical, ADL, Med Management) but you can't bill for hours that the staff is being trained and you can't get the clients served while the staff is in training. You are stuck in the rate plan with no flexibility to meet individual circumstances.
- Determining what residential situation is best for each consumer takes a clinician with a lot of experience and skill.
- Complexity of using multiple funding streams to serve one person.
- Fiscally, 5 clients are matched with one DSP so if clients don't come in batches of 5, we can't hire a person to provide the services.
- Individual rate sheets are very prescriptive and don't allow for individualized service.
- DMH doesn't recognize the continuum of models of supportive housing throughout the state.
- State doesn't recognize the number of potential units / resources in the community if they don't pay for them. Organizations have been resourceful and put together funding to meet the need from local, state, federal and foundation resources.
- Serving persons required to be on the sex offender list because of the 500 feet rule.

Staffing/Organizational Culture:

- Must attend all appointments with the consumer. Doesn't work in the current rate plan/staffing plan.
- A good professional guardian is essential, brings a different skill set and understanding than parent or family member.
- Representative payee should be someone outside of organization, professional.
- Staff must be compassionate, be able to document and bill, set professional boundaries, have patience, be consistent, willing to do anything, humble, be able to model successful behaviors, lack arrogance, be a problem solver, not controlling, accepting, tolerant.

- Organization and its staff must create real relationships with building manager, residents 'council, community members, consumers. The relationship must be more than clinical.
- Weekly staffing between property management and clinical staff.
- Be open to creative ways to deal with situations rather than let something small create a large issue.
- Must be willing to do anything needed to assist the person in succeeding, administratively and clinically.
- It's a special person that you're trying to get to be the DSP, far more than clinical relationship.
- Inclusive rather than exclusive.
- Don't want people to exit for the same reasons that they came into the program.
- Harm reduction, incremental change.

Training Needs:

- Property Management staff should be trained about mental health, developmental disabilities, substance abuse, etc.
- Train doctors, nurses, dentists to serve persons with cognitive deficits.
- Train therapists, psychologists, psychiatrists to better serve the population.
- Judicial training to close the front door to the Department of Corrections.
- More training around clinical issues, medication management, ADL.
- Fix how training affects your ability to bill, which in turn affects your ability to pay your staff.
- Harm reduction, incremental change, nonlinear.

Agency Suggestions:

- State needs to cultivate doctors, nurse, dentists in communities that will be trained to work with specific populations.
- Should pool hours that people need to or can be served so that you can still meet payroll when you are sending staff to required/necessary trainings and still meet the needs of the consumers.
- Wrapping services: Rule 132 billable, Community Support Counselors, providing truly integrated MI / DD services.
- Supportive housing must have a resident council that self-governs, creates own bylaws and makes house rules. Residents' should receive leadership training and be responsible for self-policing.
- Sense of community is essential for the success of supportive housing.
- Property Management of building must combine administration/operations/maintenance with a clinical understanding of the persons living in the housing. Be prepared to deal with "frivolous" complaints that might be associated with symptoms of person's illness.
- Simplify billing: perhaps nights of care billing?
- Expedited presumptive eligibility for Medicaid.
- Coordinate care between DMH, DDD and DRS (personal assistants can be a great tool, especially for someone exiting an institution).
- Funding flexibility to meet the individual needs of each person.
- Community Support Model – permanent supportive housing, building manager, community support counselor, mental health counselor, wrapped services with DRS (personal assistant, employment assistance).

Scenarios:

- Supportive Housing tenant who had been in a nursing home for ten years was peeing into a bottle during the night rather than getting up to go to the restroom. Property management wanted to evict for health/safety reasons. Clinical staff recognized it as an institutional behavior (in a nursing home you use a bedpan at night, you don't get up). Rather than "punishing" the tenant for their learned behavior, a creative plan was put into place. Secure glass bottles were provided for the tenant and then front line staff worked with the tenant to dispose of the waste properly in the morning.
- Recent fire in single site supportive housing building with 79 units. Safety captains on each floor assured that not one person was injured. Tenants were so tied to their community that those with apartments that weren't damaged hosted those whose apartments were damaged during the day. In the evening, the tenants with damaged units that were being repaired chose to stay in the gymnasium of the building rather than be in a hotel because they wanted to be in their "home".
- "Terrence" was found in his deceased brother's attic. Hears voices, shakes, screams and threatens to kill his voices. He is a big guy so other tenants were scared but once they realized (because "Terrence" shared with his neighbors) that he was responding to external stimuli and wasn't threatening them, a rapport was built. Tenants learned that it is okay to complain and that there are reasons for behaviors.
- Gentleman released from Jacksonville developmental center because his IQ was 1point above the requirement. DD/SMI diagnosis and he was released into homelessness. Southside housed him; he had two episodes of property destruction in his apartment (institutional attention seeking behavior). Southside didn't evict him but recognized the behavior for what it was. Still difficult to pay for apartment repairs, etc.

Appendix G: Response from Trinity – Joliet, IL

Unique Needs:

- Most contacts come from case coordination referrals, regarding individuals who are aging out of placements, parents or hospitals where clients have been dumped.

Challenges:

- Individuals with a dual diagnosis who receive services at Trinity tend to be people who have not made it in the community because of challenging behaviors and/or families who want them in state operated facilities.
- Staff must intervene before the staff and / or housemates decide they don't like the person, otherwise staff and housemates alike undermine individuals to get them out of the home versus working to accommodate them.
- They feel group homes are not ready for all issues, i.e. elopement, sex offenders, fire starters, etc.
 - During transitions an agency must work with individuals to create a new history; as that happens, new behavior problems sometimes occur. The state has no idea how many people with a dual diagnosis need to be served; many are moving from one provider to another because of behavioral issues.
 - Options don't exist for community providers. Illinois says you cannot kick people out of services or discharge them, without recognizing that some are dangerous to themselves and others. Trinity is the rare exception that can move people from unit to unit, but it clearly becomes a resource issue.

Staffing/Organizational Culture:

- Keeping clients engaged in enjoyable activities is nice, but it does not replace competent staffs that help individuals meet goals.
- There must be a commitment of upper management within any organization to serving dually diagnosed folks, along with a belief system that the agency and each person must succeed.
- Leadership staff must adopt that same commitment and must create staffing patterns that support staff and individuals alike, i.e. shift sabbaticals, immediate relief with no questions asked, celebrate success.
- They work hard to maintain a highly educated staff on the 3:00pm – 11:00pm shift as someone who can be aware of (and available) as issues arise within the house. They serve as role models to staff and also review data / trends / client files.
- Traditional skills are not effective on their own. There must be a very strong commitment to working with challenging behaviors.

Training Needs:

- Staffs need a basic understanding of mental illness, behavioral health, and the difference between the two. Trinity has modules for training staff; they serve as a foundation for ongoing services.

- Community living is not all about choice; it's about person centered level of need.
- Client Culture and Engagement become huge issues, i.e. the first time they've been accepted, first time they find peers, diagnosis, ages, etc. Rituals are important because the agency is their family and many are in their first real connection; the agency and all agency staff have to work to create a tight community.

Agency Suggestions:

- Take Rebalancing slow; decrease institutional care by 10% over the next four years.
- Because it's hard to get people into a hospital, crisis beds must be maintained for respite. A high level of expertise is necessary.
- Rates must support people who are carrying a lot of medical problems.
- NOTE: Concerns about Inner Cities – there's a strong feeling that inner cities will prove to have too many challenges that there will be no chance of success. Elopement and gangs were two examples cited.
- Primary funding for people with developmental disabilities is an ICAP grant focusing on independent skill levels in independent living. Right now funding is a capped rate, and all too often workers comp & liability issues arise.
- Create a comprehensive management information system to track people in the community, including 911 calls.
- Start with four person alternative housing situations; they key is having an individual bedroom and an ability to have privacy, staff intervention and support to effectively manage behaviors.
- Trinity staff cited opposition to massive rebalancing initiative based on their experience, i.e.
 - a. Forensic / Sexual Population
 - b. Extreme behaviors
 - c. Medically fragile individuals
 - d. Re. Workers Comp Claims / funding for increased risk
 - e. Property destruction – no reimbursement for personal or agency property.
 - f. Tensions between community and campus based programs, i.e. pull an alarm on a campus and there is immediate response versus that in the community.

Scenarios:

Ryan killed a cat; staff feels he needs to be at Shapiro, but in lieu of that option, he needs specialized staffing. There is a feeling that approximately 20% of the client population may need specialized staffing services.

Clients have also keyed staff cars.

Appendix H: Supportive Housing In Illinois: *A Wise Investment*

Please see PDF attachment included in this message