

PAVING THE WAY:

Meeting transition needs of young people with developmental disabilities and serious mental health conditions



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EXECUTIVE SUMMARY



Youth and young adults aged 16 to 24 who have dual diagnoses of a serious mental health condition and a developmental disability experience significant challenges as they transition to adulthood. Services to support these young people are inadequate and they are commonly served inappropriately either because they have been misdiagnosed or because the services they receive target only the developmental disability or only the mental health condition. Young people with both disabilities are considered particularly vulnerable because they are also transitioning from receiving services in the child and adolescent mental health system and the education system into adult serving systems. For many young people, the inadequate service system results in inappropriate hospitalizations, restricted living situations, homelessness, interrupted education, and incarceration.

Responding to the identified lack of information about effective interventions with young people with dual diagnoses, the research team developed an exploratory qualitative study. The purpose of the study was to identify and describe best practices for transition to adulthood services for young people aged 16 to 24 who are dually eligible for mental health and developmental disability services. In a two phase process, the

team first conducted telephone interviews with 12 policy-level experts, researchers, and program directors to identify the challenges serving youth with dual diagnoses, the services provided, and respondents' recommendations for improving services. Review of the literature and analysis of interview notes guided the development of plans for phase 2 in which the team used the "ideal" program characteristics identified by a workgroup of the National Association of State Mental Health Program Directors (2004) as criteria for examining programs identified through an expert nomination process. Fourteen semi-structured telephone interviews were conducted with program directors, providers, and experts who serve youth and young adults with dual diagnoses.

The report that follows includes eight case studies of programs providing innovative services and six short descriptions of specific best practices. The programs featured in the report include a school-based transition program; outpatient mental health services; an employment preparation program; programs supporting youth transitions from restrictive environments to community settings; system-level crisis prevention and intervention planning; and system level planning and consultation.

Programs featured in this report are:

- Project SEARCH, Cincinnati, Ohio
- Intercept Program, Aurora Mental Health Center, Aurora, Colorado
- Transition to Independence Program, Serendipity Center, Portland, Oregon
- Mosaic Program, ChristieCare, Lake Oswego, Oregon
- The Francis Foundation, Middlesex, Vermont
- Young Adult Program, Trillium Family Services, Albany, Oregon
- Vermont Crisis Intervention Network, Moretown, Vermont
- Systemic, Therapeutic, Assessment, Respite and Treatment Services (START), Concord, New Hampshire.

Discussion of the key features of these programs and of the related literature leads to a number of conclusions:

- There is some literature on the needs and challenges of young people with dual diagnoses.
- There are few programs designed specifically for this population. Programs serving young people with dual diagnoses fall into two groups (a) those designed for individuals with dual diagnoses, some of them in the young adult age range, and (b) those serving young people in transition with mental

health challenges a few of whom also have a developmental disability.

- Young people with dual diagnoses are characterized by a high rate of traumatization.
- There is a beginning understanding that individuals with developmental disabilities can benefit from mental health therapies that have been modified to accommodate a developmental disability.
- There is a growing recognition of the need for staff working with young people with dual diagnoses to be cross-trained in the fields of both mental health and developmental disabilities.
- While there are major differences in the philosophies and treatment approaches of the mental health and developmental disabilities service systems, there are communities where effective collaborations have been developed.

This study identified several innovative programs that are being delivered on a small scale in local areas or across a single state. Few programs focus specifically on transition into independent adulthood. In general the picture for young people with dual diagnoses is bleak and there is a need to focus planning and resources on meeting their needs effectively. Documentation of innovative programs and evaluation of their effectiveness will help to develop a research base for best practices with this population.

BACKGROUND



Youth aged 16 to 24 with serious mental health conditions often experience challenges as they assume adult roles and transition into adulthood (Armstrong, Dedrick, & Greenbaum, 2003; Clark & Unruh, 2009; Vander Stoep, Davis, & Collins, 2000). The long term outcomes for these youth have been poor and include higher rates of interrupted education, unemployment, homelessness, involvement in criminal activities and ultimately in the justice system, unplanned pregnancies, and the likelihood of suicide compared with their non-disabled peers (Blackorby & Wagner, 1996; Clark & Unruh, 2009; Collins, 2001; Levin-Epstein & Greenberg, 2003; McMillan, 2009; Vander Stoep, Davis, & Collins, 2000). In the last decade, service providers and policy makers have been working to improve services and increase positive outcomes. Strategies used include the implementation of system of care approaches (Duchnowski, Kutash, & Friedman, 2002); comprehensive individualized transition support services based on the Transition to Independence Project (Clark, & Unruh, 2009; Clark, Deschenes, & Jones, 2000); and supported employment (Bond, Becker, Drake, Rapp, Meisler, & Lehman, 2003) and supported education models (Mowbray, Collins, & Bybee, 1999).

The difficulties facing transitioning youth with serious mental health conditions are compounded when they also have a developmental disability. The oppression and exclusion imposed on this population create more barriers and fewer opportunities for employment and independent living and increase the need for continued support in their adult years. While evaluating a local alternative school's transition supports and services for youth who have both a serious mental health condition and a developmental disability we became interested in exploring the experiences, outcomes, and best practices for this particular sub-set of youth in transition, [those with an added developmental disability]. What we learned from our work with this local program and from the literature is that people who are dually eligible for both mental health and developmental disability services (see below for a detailed definition) experience more challenges than people with only a serious mental health condition or a developmental disability because their needs are not well understood and/or services are inadequate (Jacobstein, Stark, Laygo, 2007; USDHHS, 2009). The inadequate service system results in inappropriate hospitalizations, out of home and out of state placements, child welfare custody, homelessness, interrupted educa-

tion, and incarcerations (Jacobstein et al., 2007; USDHHS, 2009).

The goal of this study was to identify effective practices that support young people aged 16 to 24 who are dually eligible for services as they transition into adulthood.

Definitions

The terms used throughout this report are described in detail below.

- **Youth** means a person between the ages of 16 and 24.
- **Dually eligible** and **dually diagnosed** are used interchangeably to mean persons who are eligible for both mental health and developmental disability services.
- **Developmental disability** is defined as a “severe, chronic disability of an individual 5 years of age or older that:
 1. Is attributable to a mental or physical impairment or combination of mental and physical impairments,
 2. Is manifested before the individual attains age 22,
 3. Is likely to continue indefinitely, and
 4. Results in substantial functional limitations in three or more of the following areas of major life activity:
 - i. Self-care,
 - ii. Receptive and expressive language,
 - iii. Learning,
 - iv. Mobility,
 - v. Self-direction,
 - vi. Capacity for independent living, and
 - vii. Economic self-sufficiency”

(Developmental Disabilities Assistance and Bill of Rights Act, 2000).

The federal definition for developmental disability seems to be used commonly by programs, although some define developmental disabili-

ty categorically by listing certain disorders. State definitions of developmental disability vary, with some states including autism spectrum disorders in the definition while others do not. The National Association of Councils on Developmental Disabilities (NACDD) notes that “developmental disabilities may be cognitive, physical, or a combination of both. While not always visible, these disabilities can result in serious limitations in everyday activities of life, including self-care, communication, learning, mobility, or being able to work or live independently. Such disabilities are almost sure to result in a lifetime of dependence on publicly funded services, unless families receive sufficient support, children receive appropriate education, and adults receive appropriate services that enable them to live and work in their local communities” (NACDD, 2009).

- The term **serious mental health condition** was not predefined for this study but most programs define this to mean any Axis I disorder according to the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (American Psychiatric Association, 2000). Axis I identifies major mental disorders, developmental and learning disorders and includes depression, anxiety disorders, bipolar disorder, attention deficit hyperactivity disorder, autism, phobias, and schizophrenia.
- Most definitions of **transition** focus on the gradual developmental processes that occur for young people between the ages of 14-24, with associated physical, psychological, and emotional development and activities related to the assumption of adult roles, such as completion of education, engagement in full-time employment, long-term interpersonal relationships, and independent living (Armstrong, Dedrick, & Greenbaum, 2003; Arnett, 2001; 2003; VanderStoep, Davis, & Collins, 2000). The literature also draws attention to the concept of institutional transition which refers to the abrupt changes in legal or bureaucratic status that occur when young people are determined to be no longer eligible for services they were previously

entitled to, usually because of a birthday (Malloy, 1995; VanderStoep, Davis, & Collins, 2000). In this study, we defined transition as occurring between the ages of 16 and 24 because of our specific interest in the institutional supports and services available to young people as they proceed through institutional transitions.

Prevalence of Dual Disabilities

The separate occurrences of mental health disorders and developmental disabilities are well documented and generally accepted estimates exist. The U.S. Surgeon General estimates that 26.3% of American adults aged 18 and older have a diagnosed mental health disability and 6% of adults have a serious mental illness (Kessler, Chiu, Demler, & Walters, 2005; National Institute of Mental Health, 2008, para 1). The U.S. Surgeon General's Report of 2000 estimated that 21% of children in the general population have an emotional disorder and that around 11% might be classified as having a serious emotional disorder (U.S. Public Health Service, 2000). Other studies place the estimates of serious emotional disorders in children ages 9-17 at 5-9% (VanderStoep, Davis & Collins, 2000).

The Centers for Disease Control report that developmental disabilities affect approximately 17% of children younger than 18 years of age in the United States. In its Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) 2000 Surveillance Year, approximately 2% of 8-year-old children had at least one of the five developmental disabilities monitored. Estimates of the prevalence of mental retardation (one aspect of developmental disabilities) are most frequently reported. Bergman & Harris (2000) estimate the prevalence of mental retardation at just under 1% of the population. Despite the estimates available for the occurrence of developmental disability and mental health conditions when they occur separately, there is currently no widely accepted estimate of their joint occurrence in the population in general or in youth and young adults between the ages of 16 and 24.

There are some estimates of the occurrence

of mental health disorders in the population of individuals with developmental disabilities, particularly those with mental retardation. A study of the population of 9-11 year old children with mental retardation on the Isle of Wight, U.K. found that 30-40% had a psychiatric disorder (Bergman & Harris, 2000). A study of a Swedish birth cohort of adolescents with mental retardation reported that 57% of those with mild retardation and 64% of those with severe retardation had a psychiatric disorder (Bergman & Harris, 2000). Information on the National Association of Dual Diagnosis (NADD) website states that "many professionals have adopted the estimate that 30-35% of all persons with mental retardation or developmental disabilities have a psychiatric disorder" (Fletcher, 2009). The profile (types and percents) of each individual diagnosis in the general population seem to mirror that found in the population of individuals with a developmental disability (Fletcher, 2009; Bergman & Harris, 2000).

Another perspective on the incidence of dual diagnosis is found in studies of groups who are receiving services. The most common of these are studies that assess the level of psychiatric disability in groups of individuals receiving services for intellectual disabilities. Dykens (2000) describes estimates that range from a low of 10% to as high as 70% for individuals with intellectual disability. Reiss (2009) and Mosley (2004) both cite estimated rates of 10-40% for individuals served by community MR/DD programs. Reiss (2009) also notes that rates of mental health disorders are higher for adults than for children and demands for mental health services are greatest among dually diagnosed youth and young adults aged 15 to 30. This is different from the demand for mental health services in the general population, where service utilization drops dramatically after the age of 18 years (Davis & Koroloff, 2006; Pottick, Bilder, Stoep, Warner, & Alvarez, 2008).

Fewer studies exist that assess the incidence of developmental disabilities in populations receiving mental health services. In a study of 146 children and adolescents with severe emotional disorders and receiving services at a psychiatric day treatment center, 20% were assessed as hav-

ing pervasive developmental disorders (Sverd, Dubey, Schweitzer, & Ninan, 2003). Jacobstein et al. (2007) describes a large national study of children receiving services in system of care funded sites that reported 10.9% identified with co-occurring developmental disorders.

No matter which perspective is taken on the question of how frequently dual disorders occur, the high variability and wide range of estimates is important to discuss. Several limitations present challenges to studies that try to assess the incidence or prevalence of dual disabilities. First, the way in which the mental health disability is assessed is known to affect the validity of the estimate. Mental health assessments that are done face-to-face with a qualified assessor are thought to be the most accurate and are also the most expensive. Other approaches, such as case record reviews, are known to give lower estimates. Whatever method is used, the technology for assessing mental health disorders in people with developmental disabilities is not well developed with few well-tested measurement tools available and even fewer professionals who are trained to use them.

A second issue that challenges the field's ability to accurately estimate the incidence of dual disorders is the problem of **diagnostic overshadowing** (Reiss, Levitan, & Szyszko, 1982). Diagnostic overshadowing occurs when symptoms of a mental health condition are "overshadowed in importance" by the presence of a diagnosed developmental disability or the behavior is seen only as a result of the developmental disability, while in a person without a developmental disability, the behavior or symptom would be considered indicative of a mental health condition (Reiss et al., 1982).

A third reason for the difficulty in obtaining reliable estimates of dual disorders is the variability in the way that developmental disability and mental illness are defined. For example, the National Association of Dual Diagnosis, using estimates from providers, suggests that 30-% to 35% of people with intellectual or developmental disabilities also have a mental illness (Fletcher, 2009). However, if the more stringent federal definition of mental illness is used, this estimate would probably be low-

er (Fletcher, 2009). In another example, Jacobstein et al. (2007) estimate that as many as 30% of individuals with intellectual disabilities may have an autism spectrum disorder. As noted earlier, some states consider autism a developmental disorder while others do not, thus suggesting a potentially major source of undercounting.

Challenges in Serving Young People with Dual Eligibility for Mental Health and Developmental Disabilities Services

People with dual disabilities are likely to receive inadequate services because they have been misdiagnosed or because the services they receive target only the developmental disability or only the mental health condition. Young people in the 16 to 24 age range with both disabilities are considered particularly vulnerable because they are also transitioning from receiving services in the child and adolescent mental health system and the education system into adult serving systems, with the potential for "falling through the cracks" (Vander Stoep, Davis, & Collins, 2000). Many no longer meet eligibility requirements for having a developmental disability based on new adult criteria and therefore no longer qualify for developmental disability services. Because services are frequently unavailable or not appropriate, this population is at greater risk for involvement in the criminal justice system, out of state placements, child welfare custody, and institutionalization (USDHHS, 2009). There has been little research into the needs of this population or what types of services and supports are most helpful and most of what is known is based on research with either children or adults and not with youth in the transition years.

In April 2003 the National Association of State Mental Health Program Directors (NASMHPD) hosted a meeting of mental health and developmental disabilities administrators, providers, consumers and advocates to discuss the challenges of serving people who are dually eligible for services. Some of the challenges noted by this group and throughout the literature include differences in philosophies between the mental health and developmental disability systems, involvement

of multiple systems, deciding who is responsible for providing services, determining eligibility, conducting accurate assessments, securing funding, availability of adequately trained staff, and identifying and implementing effective interventions (NASMHPD, 2004). Each of the challenges is discussed below.

System differences. The most thorough analysis of the philosophical differences between the mental health and developmental disabilities is offered in a report by the National Association of State Mental Health Program Directors (NASMHPD, 2004). One of the key differences is in the way that each system views the individual's potential for a successful adulthood and independent life and the level of services needed to achieve these goals. Mental health systems, in response to consumer input, are increasingly adopting a philosophy consistent with the recovery movement that emphasizes individuals' abilities to manage their symptoms and create successful adult lives in the community with minimal or no services (Anthony, 1993). Developmental disabilities staff anticipates individuals may need some services and supports continued throughout their lives. These differences in philosophy have direct effects on the ways services are planned and delivered for young adults transitioning into adulthood.

The NASMHPD report (2004) notes that mental health systems assume that individuals have adequate cognitive and communication skills to participate in and benefit from their own treatment; mental health interventions are built on this premise. Developmental disabilities systems assume that many of their consumers will have difficulty with cognition, communication, or both, and that interventions must be created to accommodate these limitations. The differences in basic assumptions about the capacities of consumers make collaboration around the use of available services more difficult. For example, many mental health providers exclude individuals with low IQs from their services on the basis that "they won't be able to take advantage of the interventions." In fact, the general belief by the mental health community that "people with developmental disabili-

ties don't benefit from mental health therapies" is one of the major barriers to obtaining appropriate mental health services for young adults with both diagnoses. Developmental disabilities providers complain that it is difficult to find mental health services that are appropriately modified to meet the needs of their consumers who are dually eligible.

Another difference between mental health and developmental disabilities services is the differing evolution of the associated advocacy movements. Within the mental health arena, advocacy groups are increasingly run by consumers of services with fewer advocacy groups run by providers or family members. The focus of consumer advocacy efforts is on increasing resources and policies that will support self-determination, consumer-led recovery, and community integration (NASMHPD, 2004). The advocacy movement within developmental disabilities has historically been led by professionals and family members, although "self advocate" groups are now gaining a voice. The earlier advocacy efforts were successful in establishing entitlements for long term services and supports for individuals with developmental disabilities and some groups continue to expand this agenda. The difference between advocating for individual rights vs. specific services provides another difference between the two systems.

Multiple system involvement. Although the developmental disability system and the mental health system are receiving the most attention in this report, other services systems should also be included in the discussion. The special education system has the responsibility of serving dually eligible youth until they are 18 (or 21 in some situations). Further, Jacobstein et al. (2007) suggest that these young adults are increasingly involved in the juvenile and adult criminal justice systems. Casey and Keilitz (1990) found that youth with a learning disability and mental retardation were overrepresented in juvenile corrections and Quinn, Rutherford, Leone, Osher and Poirier (2005) in a national survey found that 33.4% of youth who were incarcerated were served under the Individuals with Disabilities Education Act (IDEA) compared

to 8.8% of youth (6 to 21) who are served under IDEA in the general population. Of the 33.4% in juvenile corrections with a disability, 47.7% had an emotional disability, 38.6% had a specific learning disability, 9.7% had mental retardation, 2.9% had other health impairments, and 0.8% had multiple disabilities (Quinn et al., 2005).

A particular challenge for youth who are dually eligible is the transition between the different service systems. Youth must transition from the child mental health system to the adult mental health system, from the educational system to the adult developmental disability services system and some must move from an institutional setting to a community based placement. Partly because of the differences in philosophy, language and procedures, these transitions often result in poor outcomes (Vander Stoep, Davis, & Collins, 2000). As Beasley and duPree (2003) point out, a goal of a coordinated system is to “avoid having individuals go from one system to the next with neither system having the resources or responsibility to meet the individuals’ needs” (p. 3).

Eligibility and funding of services. It is unusual for both mental health and developmental disabilities systems to accept the responsibility for contributing to the funding of services for dually eligible youth. Services are usually funded by one or the other system. Jacobstein et al. (2007) describes families being “ping ponged” between systems. The silos in funding are particularly exacerbated by the Medicaid Waiver system that gives states the ability to reduce their use of residential and group home facilities and divert the federal dollars into community-based services for the same individuals. Medicaid waivers are available to individual service systems and not issued for cross-system work.

Funding silos often dictate eligibility criteria to receive services. Each of the systems that serve youth including the mental health, developmental disability and the education systems, have their own distinct categorical definitions for eligibility, and an eligibility requirement for one system may exclude a youth from services in another system. For example, a youth may not be eligible for de-

velopmental disability services if she/he has behavioral symptoms or substance abuse or may be denied mental health services if s/he has a low IQ (Jacobstein et al., 2007). These categorical criteria for eligibility are not only barriers between the mental health, developmental disability and education systems but can also be a barrier to continuity of care between child and adult services. For example, the childhood diagnosis of conduct disorder does not qualify an adult for services in some states (Davis & Koroloff, 2006).

Modified mental health services. Another major challenge is the need for effective mental health services for dually eligible youth and young adults. There are two significant gaps in services: first, mental health conditions in youth with developmental disabilities are often misdiagnosed because there are few assessment instruments available that have been modified or created that are appropriate for this population (Bergman & Harris, 2000; Singh, Evans, Sireling, & Stuart, 2005), and secondly, there are few effective mental health interventions for people with a developmental disability (especially interventions that address trauma) (Mosley, 2004). If a mental health condition is diagnosed, treatment may be inadequate because few interventions have been modified and/or tested for effectiveness with people who have developmental disabilities (Charlton, Kliethermes, Tallant, Taverne, & Tishelman, 2004).

Youth with disabilities experience physical, sexual, and emotional abuse more often than youth without disabilities (Sullivan & Knutson, 2000). Charlton et al. (2004) point out that youth with developmental disabilities are more likely to experience trauma, and prolonged trauma can increase developmental delays. Though there is a high incidence of trauma in youth with disabilities, appropriate trauma interventions are lacking, and few professionals are trained to address abuse and trauma (Charlton et al., 2004).

Lack of trained providers. The lack of providers trained to work with youth who are dually eligible is a challenge to providing effective services (NASMHPD, 2004). For example, Schwartz, Ruedrich, and Dunn (2002) note that the need for train-

ing about developmental disabilities in psychiatric residency programs was identified in 1927 but since that time only a few programs have included this content. The lack of training across disciplines is often linked to the misconception that people with developmental disabilities will not benefit from mental health interventions (Charlton & Tallant, 2003; Mansell, Sobsey, & Moskal, 1998). Cross training is becoming more readily available from the National Association of Dual Diagnosis and through initiatives such as Ohio's Coordinating Center of Excellence in Dual Diagnosis ([www.ohiomidd.com/Ohio_Coordinating_Center_of_Excellence_\(CCOE\)/Home.html](http://www.ohiomidd.com/Ohio_Coordinating_Center_of_Excellence_(CCOE)/Home.html)) which develops best practices, trains professionals, and provides consultation about dual diagnosis.

Recommended Approaches to Serving Dually Eligible Young Adults

In addition to the above challenges, the meeting of experts hosted by the NASMHPD in 2003 concluded by identifying the following best practices or "ideal" characteristics of a service system for persons who are dually eligible (NASMHPD, 2004).

- Screening and assessments are completed by trained professionals with appropriate instruments.
- Programs adopt a "no reject" stance allowing access to mental health and developmental disability services for all youth who are dually eligible.
- Programs provide individualized or person-centered services that exceed diagnostic needs to incorporate comprehensive services to meet an individual's needs and goals.
- Funding for programs and services is flexible

enough to allow for cross-system collaboration and person-centered planning.

- Services are provided by professionals trained in both mental health and developmental disabilities interventions.
- Services provided to people who are dually eligible are based on the most current information and research specific to the needs of this population.
- Service providers are knowledgeable about the effects of trauma and interventions to address past trauma and to reduce retraumatization.
- Programs provide services to directly support caregivers.
- Programs provide services in the least restrictive setting appropriate for the individual and provide services to support individuals as they transition to less restrictive settings.
- The mental health and developmental disability systems work collaboratively to provide services to individuals and to change policy and system practices to support cross-system collaborations. Collaborations also include the criminal justice, primary care, and public health, and educational systems. (NASMHPD, 2004).

The research reported in this monograph was structured to examine how these ideal characteristics are being implemented in the field for young people who are dually eligible. This research project was conducted in two phases and the methods and findings are described in the next sections.



RESEARCH APPROACH

PHASE I

Methods

During the first phase of the project, we recruited experts, researchers, and administrators in mental health and developmental disabilities services throughout the country to participate in exploratory telephone interviews about the challenges in their work and to describe best practices and recommendations for serving this population. Participants for Phase I were recruited by an email invitation sent through national organizations focused on mental health, developmental disabilities, and dual diagnoses and through a process of snowball or chain sampling (Cresswell, 2007) by which we invited interviewees to recommend other experts. During Phase I, we conducted 14 interviews with researchers, service providers, administrators, and policy makers.

Data Collection and Analysis

In Phase I, interviews followed a semi-structured interview protocol that asked respondents to describe the characteristics of the population, the challenges facing young people with dual diagnoses, programs for this population, desired outcomes, and recommendations. We also invited participants

to nominate exemplary programs for further study. Interviews were taped and then reviewed by members of the research team to identify categories of information about serving dually eligible youth.

Findings

Interviews in Phase I were done with a variety of key informants who provided the research team with a broad foundation of knowledge about the challenges in serving youth and young adults who are dually eligible for mental health and developmental disabilities services. Although only one person interviewed in Phase I was involved with a program developed specifically for young people with dual eligibility, most service providers reported they served a broadly defined population with a percentage of their clients who were dually eligible. Throughout our interviews, providers expressed their interest in learning about best practices for serving this population and desire for further training.

Participants shared information about several challenges in providing services to youth and young adults with dual diagnoses. The majority of these challenges were related to the lack of coordination and communication between the mental

health and developmental disabilities systems. Respondents reported that coordination between the two systems is challenging because of the different funding streams and different philosophies.

Participants reported that the lack of system coordination resulted in youth being served by either the mental health or the developmental disabilities system based on what is considered their primary diagnosis, which system they had come into con-

tact with first or funding considerations. In general, youth who are dually eligible and only served by one system were thought to be underserved or inadequately served. A challenge mentioned throughout our interviews was the absence of providers trained to work with dually eligible youth and the lack of research supported interventions modified for this population.

PHASE II

Methods

To address the gap in knowledge and challenges participants reported in Phase I, we developed our Phase II methodology to examine programs that were identified as providing innovative or best practices specifically for youth 16 to 24 with dual disorders. The programs we identified were suggested by national experts in the field of dual diagnosis and by the program contacts themselves. In addition to the Phase I interviews we interviewed directors or other representatives of 11 programs of which eight, highlighted below, were developed specifically for this population and/or serve a large percentage of clients with dual diagnoses.

Program leaders were contacted by the research team and invited to participate in a telephone interview about their program. To address the gap in knowledge about best practices the interview questions addressed each of the “ideal” characteristic categories identified by NASMHPD (2004) and described above. Program staff were also asked if they had recommendations for implementing high quality services for this population. All of the programs highlighted served young people aged 16 to 24 years who were dually eligible but they differed in location and the focus of their services.

Data Collection and Analysis

Interviews in Phase II followed a semi structured protocol (see Appendix A). Respondents were asked to describe their services for dually diagnosed youth and to address specific ideal characteristics of programming identified in the NASMHPD (2004) report that were featured in their programs. Inter-

views were taped and transcribed and transcripts were reviewed by members of the research team to identify specific best practices. Team members prepared a draft description of each program, including a brief summary of key aspects of programming and where appropriate, illustrated by short quotes. Next, the program summaries were reviewed by other team members and revisions and clarifications incorporated. Then each summary was e-mailed to the interviewee with an invitation to verify the information, correct any errors and clarify points as a form of member checking (Lincoln & Guba, 1985), a strategy to increase the trustworthiness of qualitative research findings. Some interview participants responded with edits and corrections to the summaries and these were incorporated in the summaries that are presented here.

Findings

This first section includes detailed descriptions of the program characteristics and intervention strategies used by eight programs, some of which serve only dually diagnosed youth while others include these youth along with a wider population. Following these detailed descriptions, we provide short program reports on a number of innovative practices that were offered to dually diagnosed transition aged youth, but were not designed specifically for them. The programs were developed to meet a range of needs including employment preparation, crisis interventions, supportive residences, transition services from institutional care, education and preparation for independent living, and day and outpatient therapy (see Summarized Information, Table 1).

Table 1. Brief descriptions of the eight programs summarized in this report

PROGRAM	POPULATION SERVED	PRIMARY FUNDING SOURCE	SETTING	PRIMARY SERVICES	RECOMMENDATIONS
Project SEARCH Cincinnati, OH	Young adults 18-22 years; intellectual disability & some have a mental health condition	Braided funding from education, vocational rehabilitation, & business partners	Community/business	Employment	Offer competitive job opportunities for young adults with disabilities within a business model
Intercept Center Aurora Mental Health Center Aurora, CO	Children and youth 5-21 years; developmental disability & mental health condition	Medicaid	Community mental health	Mental health	Modify mental health interventions for persons with developmental disabilities (DBT & TF-CBT)
Transition to Independence Program Serendipity Center Portland, OR	Young adults 17-22 years; developmental disability & mental health condition	Local school districts	School	Life skills, education, & mental health	Combine education and mental health
Mosaic Program ChristieCare Marylhurst, OR	Young adults 17-24; mental health condition & some with developmental disability; transitioning from restricted residential setting	Medicaid	Community residence	Short term residential, life skills, & mental health	Train staff about typical developmental stages of adolescents and be flexible
The Francis Foundation Middlesex, VT	Young adults 16-24 years; developmental disability & mental health condition; transitioning out of residential facilities	Developmental disability Medicaid waiver	Therapeutic foster care	Mental health & therapeutic foster care	Train staff about attachment, learned helplessness, emotional & cognitive development, & trauma
Young Adult Program Trillium Family Services Albany, OR	Young adults 17-24; mental health condition & some with developmental disability; transitioning from restricted environment	Medicaid	Community residence	Short term residential & life skills	Residential programs are most effective when they serve not more than 4-5 participants at a time
Vermont Crisis Intervention Network Moretown, VT	Human service agencies in Vermont; caregivers	Developmental disability Medicaid waiver	Community developmental disability programs	Training, consultation, & crisis respite	Provide services in the community where the young person & family reside
Systemic, Therapeutic, Assessment, Respite & Treatment Services (START) Concord, NH	State developmental disability & mental health agencies	Fees from training and consultation	State agencies	System level crisis prevention & intervention planning	Enhance system collaboration to prevent crisis and help people stay in their natural environments

PROGRAM SUMMARIES



The program summaries presented below are intended to highlight best practices and provide recommendations and considerations to providers working with this population. These summaries are by no means a complete description of the programs or agencies and we have provided contact information for readers who desire more information.

PROJECT SEARCH, CINCINNATI CHILDREN'S HOSPITAL

"I think we go out of our way to really focus on jobs that people want... When we bring them into the program and do an orientation, we say 'What do you want to be when you grow up?' We show them what some options are."

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Overview—Program Description

Project SEARCH, originally based at Cincinnati Children's Hospital, is a one-year employment preparation and training program for young people with cognitive disabilities that continues to support eligible participants for as long as they remain employed. The program has been in existence for 13 years and has been replicated in many different types of businesses in 125 U.S. cities (31 states), in the UK and Australia. There are currently five programs in Cincinnati, all coordinated by public school districts and the host business. Most

participants have an intellectual disability, with about 20% having dual diagnoses. Participants receive an hour of employability skills curriculum each morning and then spend the rest of the day, Monday through Friday, five hours a day, working in a hospital department or in a business. The student interns participate in three 10-week internships learning competitive, transferable skills with the goal of employment. The first two internships are at a host business and the third may occur in the community.

Project SEARCH is based on partnerships that are led by the host business. As the program director commented,

It is the business saying, I want a hand in selecting the eight students. I am going to get involved with them. I am going to tell you where they can go. I want to be involved daily.

Project SEARCH is based on collaboration among many partners, including education, Vocational Rehabilitation, community rehabilitation providers, long term support, employers, and families. The program works with a variety of employers, including hospitals, banks, universities, insurance companies, nursing homes, manufacturers, and a zoo. Host businesses should be accessible through public transportation, have a cafeteria and high status in the community. The students are learning independent living skills as well as employment competencies. Businesses with an exercise facility are a bonus, giving young adults with disabilities access to exercise, because many young people with disabilities find it difficult to negotiate public transportation and once they get home from work, it is unlikely that they will go back out to the gym.

Typically each business in the program hires about 20 to 25 percent of each class each year. The Project SEARCH staff helps other student interns locate jobs, using their skills in related businesses. The placement rate from the Cincinnati programs is currently about 80 percent, and staff are working to increase it.

Twelve participants with significant disabilities

receive training for employment at each program site every school year. Several participants aged 18 to 32 who have both a developmental and a mental health disability have successfully completed the program and have been hired at Children's Hospital and other employment sites. The program focuses on young people with significant developmental and other disabilities based on the assumption that they are the least served. The program director noted that "Sometimes if you have a disability you may be likely to have a mental health issue, but it gets written off just as your disability. Some of the behaviors may, in fact, be mental health issues." Examples of disabilities addressed in the program include autism, cerebral palsy, spina bifida, traumatic brain injury, down syndrome, schizophrenia, and depression, all of which affect work performance.

Screening and Assessment

To determine eligibility, staff use assessment checklists developed for the program with students, parents, and teachers. Potential participants apply and are asked to visit the program so that staff can observe them and make a determination about how they might respond to program activities. Finally, there are interviews that focus on work preparation "as if they were applying to do this like a job or a college experience." The checklists may be used to guide activities in junior high and high school to prepare students to enter the program. The team also reviews individualized education plans and evaluations. Typically there are more applicants than are available slots. A selection committee with representation from education, business and Vocational Rehabilitation choose the student candidates based on an eligibility rubric and the results on the site visits and interviews. The student candidates participate in a drug screening and background check and must have their immunizations up to date.

Access to Services

There is information about Project SEARCH on the Worldwide web and program leaders make

public presentations to a wide variety of audiences including schools, hospitals, rehabilitation groups, business leaders, etc. There are over 140 Project SEARCH programs in cities across the United States and its reputation is spreading primarily by word of mouth. The program is designed to be accessible, but is limited by class size.

Project SEARCH participants must have finished the education credits and requirements necessary for graduation and be between the ages of 18 to 22 (prior to aging out of school services). The program seeks participants who are ready for community employment, specifically young people who “can have good attendance and punctuality” and have appropriate “work behaviors.” For example, as a program leader noted,

You can't wear jeans and a ... sweatshirt. You have to dress like the work people. You have to act like them. You have to have attendance like they do.

Participants must be able to take basic direction and modify their performance when appropriate, have a method of communication, and be independent in daily living skills, (assistance can be provided by a personal assistant). Parents are required to sign a contract saying that they will support the student intern toward competitive employment.

Participants must maintain 95 percent attendance. Staff teach professional behaviors and communication skills such as elevator etiquette and holding a door for others. These critical skills are taught and practiced through an employability skills curriculum and through the internship experiences. The most common reason for termination from the program or from a job has been hired has been inappropriate behaviors. The Project SEARCH graduates often develop friendships even though they work in different departments.

Program Services

The focus of the program is on education and employment. It is different from traditional high school special education experiences that may in-

volve functional academic and a short school or community work experience. In Project SEARCH, students are immersed in the host businesses for an entire school year. The curriculum occurs on site in a training room and focuses on employability skills such as problem solving, communication, use of technology, budgeting, nutrition, hygiene, all related to the specific business environments. The students spend five hours each day including a lunch break with their peers and co-workers on their individual internships. The internships focus on acquiring clinical and technical “core skills” that are competitive and transferable to other similar work environments.

At the Cincinnati Children's Hospital Medical Center (CCHMC) Project SEARCH program, every young adult, 16 to 21, with a mental health disorder or dual diagnosis can be referred to the transition clinic at the hospital staffed by a transition physician and two licensed social workers. This transition clinic has access to a psychiatric nurse as needed. These staff work with participants to develop a long-term educational and employment plan and now many of the participants are receiving therapy to help them stay employed. Of the more than 70 people with significant disabilities working at Cincinnati Children's Hospital as a result of Project SEARCH, the program director estimated at least a third are currently in ongoing therapy for mental health issues. For life skills, participants are typically referred to outside agencies. Substance use has not been an issue.

In each Project SEARCH program, internships are developed that have complex functions and lead to jobs. A career plan is developed for each student based on interests and aptitudes. Departments have the support of job coaches and the instructor for training and support purposes. Core skills are identified and taught in a systematic approach during the internships in order for the students to acquire competitive transferable competencies. Project SEARCH is not a sheltered workshop or enclave. When hired, the new employees make minimum or the prevailing wage for that position.

The Project SEARCH follows staff working with

the department managers to help them have high work expectations and provide them with individualized supervision strategies. They also work with human resources departments if necessary to help them to revise and adapt policies when appropriate. Staff intervene when necessary, and assist the employee with the disability through changes whether related to work or life! This assistance facilitates longevity and career advancement and is supportive to both the employee and employer. At the Cincinnati Children's Hospital's program the average work week is 32 hours and average salary is \$10.83 for Project SEARCH graduates. The length of stay is high and the program director reported that many participants have worked at the hospital for 10 to 13 years. Program staff attribute their success to high expectations and emphasis on what young people with disabilities can do and their interaction with typical employers to create opportunities. As an example, a program leader described a young woman who has been employed for two years in a hospital:

She said, 'Everybody here expects me to do my job and they really don't expect me to have a disability, so I don't... so I just do my job the best that I can and everybody takes me seriously.'

Program staff provide employer education related to disability awareness and sensitivity skills for supervising young people with disabilities. Project SEARCH also utilizes department mentors as an additional support for employees and managers to share skills with each other.

Person Centered Practices

Person centered planning is central to Project SEARCH's approach. During the first few weeks of the program, the students participate in an orientation period that includes a chance to take on-site tours, get hands on experience, and complete an interest inventory to assist in matching the person with their desired internship. Staff encourage them to consider all the options. The "Individual Career Plans" are revised and the students choose

their internships and then interview with the department managers. The interviews include questions like: What kind of work do you want to do? What interests you about working?

Community Integration/Independence

Cincinnati Children's Hospital has many departments and managers. There are rarely two program participants working in the same department, for an internship or competitive job, unless they work in different capacities. Program staff reported that four or five years into being employed, many participants move out of their family home to live independently or in a shared apartment.

Staff Roles and Training

The program maintains a staff-participant ratio of one to three, with one teacher-coordinator and three job coaches for each 12 student cohort. The teachers are hired by the school district. The job coaches are paid by a combination of funds through Vocational Rehabilitation, community rehabilitation providers and the school district. The teacher provides instruction and some job coaching, as well as identifying internships and acting in a case management role.

Requirements vary among the states. In Ohio, Project SEARCH teachers are required to have a special education degree or license and a Transition to Work endorsement, which is based on the completion of post graduate work and internships. Each Project SEARCH site has a business liaison that coordinates the program from the business side as a part of other typical job duties. At Cincinnati Children's Hospital there are three follow-along staff from the county board of Developmental Disabilities; one full-time and two part-time staff. They support the 70 Project SEARCH graduates that work throughout the hospital. Typically a follow-along specialist has about 25 people on her caseload. The team works collaboratively and shares duties to insure that both employees and employers receive the support needed. Marketing and education about Project SEARCH is a shared responsibility of all team members to recruit ap-

appropriate students, create program awareness, and increase job opportunities.

Staff receive specialized training in systematic instruction, disabilities, and mental health issues. Other training may be specific to the needs of the current students. Staff have not had substance abuse training or trauma training. Staff, job coaches, and teachers know each other's jobs and can fill in for each other. The program director expressed her view that the most important training is "to break the old stereotypes of what people with disabilities can do... the training needs to be about capabilities."

At Cincinnati Children's Hospital, staff consult with or refer participants to the psychiatric nurse who has specific training in dual diagnosis and trauma. They can consult a specialist related to the student's disability or condition. Students may be eligible for other specialized training and therapy dependent upon their disability

Family and Caregiver Involvement

Project SEARCH staff reported that all student interns live with their family members or a caregiver. Staff believe it is important to involve families to assure they are invested in the transition process and to increase the employment opportunities. The program has open houses at the beginning of the year for parents, school staff, and other community agencies to learn about the program and the internships. There is a picnic before the year begins for students and families to meet each other. At this event staff reinforces the dress code and other program rules.

For a young person to be in Project SEARCH, their parent or guardian must be willing to attend monthly meetings. Parents are required to sign a contract outlining their involvement. Families have input regarding each internship and participate in updating the career plan as the year progresses and the young person moves towards employment. Families who attend meetings have a joint understanding of the goals and are more likely to support their young person to be successful in the job search process. Project SEARCH is strengthening family involvement by creating a se-

ries of trainings around transition, Social Security benefits, creating community linkages, and the job search process.

Funding

Project SEARCH uses "braided funding" to create a program that taps into existing fiscal resources for staffing and support services. Except for the start-up year, the program is sustainable. The host business contributes the classroom or a meeting space, the internships and a business liaison. The business also provides desks or cubicles with computers, phone, and internet for teachers and staff. The business liaison (usually a department manager or human resource associate) assists the teacher to identify internships and helps navigate the business and its culture. The local school district typically provides the teacher and employability skills curriculum including supplies and equipment, such as a digital camera, laminator, several student computers, and any needed assistive technology. Job coaches are provided through combined funding from Vocational Rehabilitation, community agencies, and the school. Coaching staff provide systematic training at the internship site. This provides support to both the student intern and the co-workers. State or local Developmental Disabilities services or Mental Health funds pay for follow-along services for eligible graduates once they are employed. Ticket to Work funds could also be utilized for retention supports.

If a student needs speech or other supplemental services, the school provides this in a consultative environment directly at the internship site. Project SEARCH programs partner with other local community services such as the Workforce Investment Board, One Stop Center, or to supply needed supports.

System Collaboration

Cincinnati Children's Hospital Medical Center partnered with Great Oaks Career Campuses, a career and technical education district, to create the original Project SEARCH program. Great Oaks has

sponsored three other Project SEARCH programs in the Greater Cincinnati area and supports 36 local public school districts for career and technical education. These school districts are committed to this unique business-led option for their students with significant disabilities. They provide the teacher who acts as a coordinator, administrative support by the Special Education director and dean, and job development specialist. In other Project SEARCH programs across the country, schools provide similar support. The program brings together the student, families, a teacher, the business liaison, a department head in which the internship is taking place, a vocational rehabilitation counselor, and a developmental disabilities case manager to do initial planning so that goals and roles are well-understood. This also results in shared responsibility and accountability. The goal of the program is employment for each student intern. Everyone on the team is responsible to insure that the goal is met. Marketing is an ongoing activity to recruit appropriate participants and businesses to hire the graduates.

The national Project SEARCH leadership is a shared collaboration between Children's Hospital and Great Oaks. The overall sponsorship is housed at Cincinnati Children's Hospital Medical Center. Any community who wished to begin a program needs to initiate a licensing agreement in order to replicate the Project SEARCH model. Once the licensing agreement is signed the new site has access to all Project SEARCH materials, curriculum, application packet, forms, assessments, marketing tools, DVD, and grant application templates at no cost. Organizations that want to create a Project SEARCH program must agree to implement the model components including collaborating with

local partners, creating an inclusive work environment and paying a prevailing wage. If communities are interested in establishing a program, they invite one of the program leaders to provide training and share information about the model. Program leaders assist with the planning process which includes an implementation plans, curriculum, sample internships, and memoranda of understanding. The process typically takes six to ten months.

Best Practices and Recommendations

- Employment programs need to prepare young people with disabilities for competitive employment that incorporates the employment interests of the young adult.
- Internships provide young adults opportunities to experience a variety of different employment options.
- Braided funding is highly recommended because it encourages community partnerships to create a seamless system of supports and services that lead to positive employment outcomes.
- A successful employment program focuses on what young adults with disabilities can do and works with employers to increase job opportunities through work based learning.
- It is important that programs provide services to employers to change work culture and increase receptivity by providing employers education related to disability awareness and sensitivity as well as skills for supervising persons with disabilities.

THE INTERCEPT CENTER

“Intercept is a program that focuses solely on treating kids with developmental disabilities and major mental illnesses. We do a lot of skills groups, combined with individual and family therapy and lots of case management—coordinating treatment with other agencies.”

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Overview—Program Description

The Intercept Center (Intercept) is a program provided by the Aurora Mental Health Center, a private non-profit community mental health organization in Aurora, Colorado. Intercept provides services to children age 5 to 21 that have been diagnosed with a developmental disability and a mental illness. The Intercept Center offers a day treatment program serving ten children and youth and an intensive outpatient program serving more than 100 children, youth, and their families. The day treatment program is open from 9:30 am to 3:30 pm each week day and provides mental health treatment to the child or youth and family. The day treatment program also provides educational services to participants. Services available in the outpatient program include individual case management, skill building groups, and individual and family therapy. The outpatient program is open from 8:00 am to 6 pm, weekdays. The average length of receiving services for youth in the day treatment program is 18 months and outpa-

tient services are often provided until the youth is 21 years old. The number of services decreases as the youth transitions from the day treatment to the outpatient program. Youth in the day treatment program may also be receiving individual and family therapy and medication management, and in the outpatient program, they only need medication management.

To be eligible for services, a person must be diagnosed with a developmental disability and a mental illness, and be eligible for Medicaid. The most common diagnosed developmental disability is an intellectual disability. Typical mental illnesses diagnosed in the population served by Intercept include schizophrenia, bipolar disorder, and major depression. Autism is an “excluded diagnosis under Medicaid in Colorado” therefore if a child has only a diagnosis of autism, they are not eligible to receive services from Intercept. Most children receive services until they transition to the adult system though they may move from receiving services in the day treatment program to the outpatient program. Approximately half of the population served by Intercept is between the ages of 16-21.

Screening and Assessment

Developmental disability assessments are typically completed before the person is referred to Intercept by the local Community Center Board (CCB). CCBs are private non-profit organizations that are responsible for providing long term services to persons with developmental disabilities. Colorado contracts with twenty CCBs to provide services throughout the state. Intercept’s area of specialty is working with children and youth with co-occurring mental health and developmental disabilities. Since most children and youth have

already been diagnosed with a developmental disability when they are referred to Intercept, the assessment process is focused on identifying mental health concerns. When a person begins services at Intercept the primary clinician completes a structured diagnostic interview to assess for mental illness and to guide treatment planning. The structured diagnostic interview is used to “really look for what are the mental illness components that we are going to be treating.” Every six months there is a re-evaluation completed but it can be “pretty informal” depending on the individual’s needs. For children in the day treatment program, full testing is completed every three years.

Intercept has implemented assessment strategies that are appropriate and most accurate for persons who are dually eligible. For example, they modified their state mental health evaluation questions to “accommodate that concreteness in response pattern to try to get more accurate estimates of who really is psychotic or who is just telling you about their own internal dialogue.” The Intercept psychologist recommends not using projective assessment instruments with people with developmental disabilities because “they are not properly normed and because the concreteness of their typical response patterns are likely to give you a lot of false positives, where they will look psychotic when they are not.” Intercept uses the Behavior Assessment System for Children (BASC). The BASC is an assessment instrument that measures aggression, hyperactivity, conduct problems and social skills in children and adolescents (Reynolds & Kamphaus, 1992). The BASC includes data from the individual, parent teachers, developmental history and classroom observations. Intercept’s psychologist stated that they often complete the self-report section orally because some of the questions are “a lot higher than the reading level of some of our clients.” The psychologist also suggested that when using the BASC if “you get a response that seems a little out of line, to ask for an example of when that happened.”

Intercept’s psychologist recommends providers collect information about a participant’s trauma history. Intercept staff report a high prevalence

of “traumatic stress or full blown traumatic stress disorder” in the children served at Intercept.

Ordinarily the medical history and the psychiatric history is so complex that we were finding that we were well into treatment and then we find out that there was a head trauma that everybody forgot to tell us about.

Intercept uses and recommends the National Child Traumatic Stress Center (NCTSC) Baseline Trauma assessment (see resources below) and recommends this “as a way of sitting down with the kid and the parent and getting a comprehensive history of what’s going on.” The NCTSC Baseline Trauma assessment is recommended because it is done in a non-threatening way and does not re-traumatize the child and family. Other assessment instruments used at the Intercept Center include the Woodcock Johnson Tests of Achievement (Woodcock, McGrew, & Mather, 2001).

Access to Services

The primary referral source for the Intercept Center is word of mouth.

We have a pretty big reputation in the Denver metro areas, so when the schools are having problems with behaviors in the classroom, they will often tell the parents to contact us.

Referrals are also received from Children’s Hospital, the Department of Human Services, the ARC, and schools. Intercept does not have a wait-list because they serve youth with Medicaid in their catchments areas and are mandated to provide services when needed.

Program Services

Intercept provides educational services, individual, group and family therapy and case management services to children and youth who are dually eligible between the ages of 5 and 21. Services are provided in the home, at school or at the

center. Intercept also provides medication management to the children and staff served. Intercept delivers intensive services because services are needed multiple times per week. The psychologist at Intercept recommends that new programs “allow for more intensive services and be aware that many of the things that result in impulsivity and stress and frustration are misunderstanding of social rules.” Intercept’s psychologist suggests that programs working with this population be prepared to “do a lot of psycho-education, because it is just like physical education. If it isn’t done, then you end up developing much more significant expression of the mental illness.” She continues to advise that you need to be “aware that a lot of the things that other kids just absorb naturally, you are going to have to teach, like how to make a conversation, how to build a relationship, appropriate sexual boundaries. We do extensive education around human sexuality and understanding your value systems and setting limits.” In the past eleven years of providing education about human sexuality there have been no unplanned pregnancies and no Intercept participant has been charged with sexual harassment. Intercept offers Dialectical Behavioral Therapy and Trauma Informed Cognitive Behavioral Therapy which they have modified for people who are dually eligible. Intercept also uses Parent-Child Interaction Therapy (PCIT) and play therapy (Bagner & Eyberg, 2007).

- Dialectical Behavioral Therapy (DBT) was developed by Marsha Linehan and colleagues to treat people with borderline personality disorders (Linehan, 1997). Since the development of DBT it has become a widely used evidenced based practice for the treatment of self harm, addiction, eating disorders and borderline personality disorders. DBT uses individual and group methods to address emotional modulation, distress tolerance, interpersonal effectiveness, and mindfulness (Dykstra & Charlton, 2003). The Intercept psychologist and staff have modified DBT to be effective with adolescents who are dually eligible by modifying the language used, simplifying the concepts, re-writing and refor-

matting handouts and incorporating client feedback, repetition and rehearsal (Dykstra & Charlton, 2003).

- Trauma Focused Cognitive Behavioral Therapy (TF-CBT) was developed to address post traumatic stress disorder and other trauma related distress in children between the ages of 3 and 18 (Cohen, Mannarino, Berliner, & Deblinger, 2000). TF-CBT is a type of psychotherapy that uses cognitive behavioral therapy with children and their caregivers to enhance knowledge and skills for trauma processing, managing distress, assessing safety, positive parenting and family communication (<http://www.childwelfare.gov/>). Intercept has applied similar adaptations to TF-CBT as mentioned above with DBT to make the approach effective with persons dually eligible.

Person Centered Practices

The Intercept Center provides individualized planning services by asking clients about what they want to get from therapy and including the client’s exact words on the treatment plan.

Community Integration/Independence

When a child is close to moving into the adult system, Intercept staff members attend monthly meetings that include the adult service providers that will be joining the team. These meetings continue through the youth’s 20th year and into their 21st year so that Intercept is the last to end services as the transition to the adult system is happening.

Staff Training and Qualifications

The Intercept Center is staffed by a program director, psychologists, master level clinicians, case managers, psychiatrists, educators and paraprofessionals. It is preferred the clinical and education staff have previous experience with the population served. Intercept is also a training center and “will

train four to six students a year,” and sometimes these students can fill employment slots.

We just look for flexibility and an understanding that we are going to do treatment and we are going to do psychotherapy with this population so we don't get any of those old biases that therapy doesn't work with people with developmental disabilities.

Employees come to Intercept with basic mental health knowledge and skills and then receive additional training and supervision. All employees are required to complete the web-based Trauma Focused Cognitive Behavioral Therapy training (see reference list). During the first year of employment staff receive an hour per week of face-to-face supervision. When the staff and their supervisor decide they are ready, they move to weekly group supervision. Intercept's psychologist recommends that staff have knowledge about other agencies and services since most of the program participants are involved with multiple agencies.

Most of our clients are going to be involved with multiple agencies. So part of the reason that people practice under supervision when they first come to us is to learn to work with the ARC and Developmental Pathways, our community centered board and our school systems.

Caregiver and Family Involvement

The primary treatment modality provided at Intercept is family therapy. Approximately 50% of those served are living with family members and the other half are in foster care. To engage and retain families Intercept does a “whole lot of outreach.” Therapy can be provided in the home or at the child's school to best meet the child and families needs and “if the parent stops bringing them, we call and call and call and write letters to try to get them re-engaged.” The Intercept Center follows “kids through placements with corrections, back to different foster homes through departments of human services.” In regards to engaging families the Intercept Center believes:

Building a reputation in the community has been really important with that, for the last 11 years, we have worked on treating the whole family. Now people coming to us mostly are expecting that kind of service.

Funding

The Intercept Center is funded primarily by Medicaid. Having the primary Medicaid contract under a capitated system provides the Intercept Center with the flexibility to provide the type and amount of services they feel are most effective. “We get a lot of flexibility” as the primary contractor. Services have to be “medically necessary” but we don't have “to do a treatment plan every ten sessions or something like that.” Intercept has also received funding from a charitable organization used to provide a summer mental health program for the youth receiving services in the day treatment program.

System Collaboration

Intercept is able to serve dually eligible youth collaboratively because of “capitated Medicaid and a pretty enlightened management.” Intercept is not “locked into fee-for-service and our management is very aware of how expensive it can be if you let the problems develop to the point that the client is hospitalized.”

Best Practice and Recommendations

- It is important to specifically assess a person's trauma history since often it will not surface unless it is directly asked about.
- Be prepared to provide intensive services to this population to result in effective outcomes.
- Supervision for clinicians is an important program component.
- Implement techniques that have been adapted for this population such as DBT-SP and TF-CBT and learn how to adapt interventions to meet the needs of this population.

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SERENDIPITY'S TRANSITION TO INDEPENDENCE PROGRAM

"...We have a lot of kids with a lot of mental health needs and with emotional needs – they get to a certain age and graduate and are not ready to go out in the real world."

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Overview—Program Description

The Serendipity Center Inc., a private non-profit therapeutic school in Portland, Oregon, started the Transition to Independence Program (TTIP) in the 2006-2007 school year. The TTIP program combines special education and clinical case management services to support youth age 17 to 22 transitioning from high school to the adult world.

TTIP participants meet in a classroom several days a week working on vocational skills, educational credits, and life skills. Participants also spend at least one day a week in the community practicing the skills they have learned. Students who have not completed their modified diploma are able to work on educational credits for graduation and after graduation participants can continue in the TTIP program to work on vocational and independent living goals.

Participants are referred from school districts and also from Serendipity Center Inc.'s therapeutic K-12 school located close to the TTIP program. In the first two years of the program TTIP served sixteen youth and eight graduated, four exited before graduating, and the remaining four were still participating in the program.

I think that some of our kids are not ready to move on at 18 without some of the supports they have in place here—but they are

ready for more independent learning and living.”

Screening and Assessment

I think that what sets these kids apart is their complex mental health issues.

Prior to starting the TTIP program participants received special education services as a result of a serious emotional disorder, health concern, intellectual disability, and/or a communication disorder. Three primary assessments tools are used by the TTIP program to assist in developing individual transition plans and include the:

The Adult Needs and Strengths Assessment — Transition (ANSA-T) is an assessment instrument that provides agencies, families, care coordinators, and other helping-professionals essential information for the development and construction of individual plans of care and case service decisions. ANSA-T is comprised of eight major categories that are divided into several sub-categories. The categories include functioning, mental health, acculturation, education/vocation, risk behaviors, substance abuse, strengths, and caregiver needs and strengths. The rating per item are on a scale 0-3 with 0 = no need for action, 1 = a need for watchful waiting to see whether action is needed, 2 = need for action, and 3 = need for either immediate or intensive action; or 0 = a significant strength, 1 = a moderate level of strength is present, 2 = a mild level of the strength, and 3 = the strength is not present (Lyons & Bell, 2003).

The Woodcock Johnson is a test of academic achievement. The Woodcock Johnson is widely used to diagnose learning disabilities, assist with educational planning, and to measure growth. The test produces a Grade Equivalent (GE) for reading, oral language, mathematics, written language, and knowledge. A GE of 3.5 means that participant’s score is an average score for someone in the fifth month of the third grade (Woodcock, McGrew, & Mather, 2001).

The Life Centered Career Education (LCCE) is an instructional curriculum utilized to equip people with the skills needed to work and live in the home

and community. Specifically, the Life Centered Career Education (LCCE) curriculum is geared toward students with mild mental and learning disabilities (IDEA, 2004). The core objectives of this educational tool are to establish present levels of student competency, to determine IEP (Individual Education Program) goals and objectives, to guide program planning and instructional content, and to measure student progress towards a set of standards (The Council for Exceptional Children, www.cec.sped.org). The LCCE curriculum includes an assessment of a person’s competencies in daily living skills, personal-social skills, and occupational guidance and preparation.

Each assessment is completed yearly for TTIP participants and the LCCE is completed at the beginning and the end of the school year.

Access to Services

Local public school districts refer youth to the TTIP program. Participants are also referred from Serendipity Center’s K-12 therapeutic school.

Other [transitional and vocational] programs are not equipped to deal with true behavioral disorders or mental health that really gets in the way of functioning like schizophrenia...

Program Model

I think it is the practice and preparation that makes a difference. Sometimes it takes a year for these kids to integrate that information into their functioning. Hooking them up with continuous support systems is really important. The family work if possible has been a success in helping with transitions and supporting families in getting the resources they need.

TTIP was created because there were no other educational/school based programs available to address independent living skills and mental health simultaneously in the Portland Metro area. Prior to TTIP, young people leaving their educational setting were often referred to existing job

training programs but were unsuccessful because these programs were not equipped to address their mental illness and/or developmental disability. Program staff believe youth who are dually eligible need more time between high school and independence to learn daily living skills. TTIP provides services on the school calendar from September to June. The space where TTIP is housed is in the same location as the Serendipity Center's K-12 program but it is in a separate building. Youth spend some of the week in the TTIP classroom working on educational credits or skills they have identified in their individualized transition plans and some of the time in the community practicing independent living skills. A typical classroom day at TTIP includes time dedicated to socialization, vocation, health and wellness, computer and technology, and individual study hall time.

A unique component of the TTIP model is that participants have on-site access to mental health clinicians who provide clinical case management. The clinician works with the youth, caregivers, and TTIP staff to implement the goals from the youth's individualized education plan and/or individualized transition plan. Youth are able to "drop-in" to see their clinician as needed and can call the clinician from the TTIP classroom. The clinicians also work with the instructional staff on strategies to address behavior in the classroom. The instructional staff report having access to the assistance of the clinicians has been quite helpful in managing behavior in the classroom.

A philosophy of TTIP is to treat young people as emerging adults. Unlike the behavioral management strategies and supervision policies typical of a K-12 educational setting, TTIP participants are responsible for making decisions about attending TTIP activities and may leave the campus unescorted. TTIP is also different because staff will discuss with students the consequences for poor decisions or that result from inappropriate behavior versus punishing students by suspension. Staff reported the TTIP teachers do an impressive job of talking through conflicts with participants and relating the event to what might have happened if the conflict occurred on a job site. TTIP staff be-

lieve in individualized planning based on the participant's needs, skills, and desires and TTIP staff work closely with them to identify their strengths and interests and attempt to find resources to explore these options.

TTIP provides individualized curriculum based on a participant's strengths and needs. For example, at one time during the day one participant could be exploring rental options, another practicing job interviewing skills, and another working on a math worksheet. Young people do participate together in a morning group in which they practice social skills and check in on daily issues.

Person Centered Practices

Every participant at TTIP has either an individualized educational plan (IEP) or an individualized transition plan (ITP). Youth participate in meetings to develop their plan and to assess progress and needed changes. When youth begin the TTIP program they are interviewed by staff and complete a youth worksheet that asks them to record their interests and goals.

I think the fact that TTIP is part of a therapeutic program and that clinical case management services are provided is a core ingredient – not only so the students feel supported and have a case manager and that there is another person in the pot to help them problem solve but also that there is a person in the pot who is able to truly understand their mental health piece and is truly there as a consultant to staff – no matter what staff they are.

Community Integration/Independence

Increasing independent living skills by increasing youth's exposure to the community is a primary goal of the TTIP program. Participants practice daily living skills like riding the bus, grocery shopping, and accessing services in the community. The TTIP staff work with the community to match youth with businesses for volunteer and internship opportunities. Youth also go on field trips throughout

the school year and have guest speakers related to daily living skills, personal social needs, and occupational and educational opportunities.

Staff Training and Qualifications

The TTIP program staff consists of a primary teacher who is responsible for implementing the program, a teacher's aide to assist in the classroom, and clinical case managers who are licensed clinicians available to provide services to the youth, families, and staff. The TTIP program is also supported by the administrative staff of the Serendipity Center, Inc.

How we helped staff look at these kids differently was through staff meetings and through asking staff to give kids a chance... they need to know they are treated like young adults.

Family and Caregiver Involvement

Caregivers are involved in the planning services for youth. When a youth is enrolled in TTIP they are invited to complete a parent/guardian worksheet for transition plan development which asks caregivers about the youth's needs, such as public transportation and medical insurance. There is phone in the TTIP classroom which allows caregivers easy access to communicate with the youth or the classroom staff. Clinical case managers also work with caregivers in planning and implementing services.

Finance

The TTIP program was originally funded by a private foundation grant and is now funded by tuition dollars from the student's local school district.

System Collaboration

The TTIP staff work with a variety of community service providers through the individualized educational or transitional planning meetings. TTIP

also invites community providers into the classroom to help youth learn about accessing services.

Best Practices and Recommendations

- Three principles of TTIP are:
 - Treating participants as emerging adults,
 - Individualized planning, and
 - Involving participants in goal setting and curriculum planning.
- Develop curriculum that is individualized based on the participant's strengths and needs and is also flexible with the changing interests and development of young adults.
- It is important to involve families and young adults in planning services. This includes providing a way families and young adults can easily communicate with providers by having a phone in the classroom.
- IEPs include transition goals.
- Partnering with other programs is recommended since the resources of programs are limited and attempting to provide a wide variety of needed supports may dilute the effective delivery of its primary service.

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CHRISTIECARE MOSAIC PROGRAM

“We really try to figure out some sort of place where they can meet a positive peer group that fits with them and what their interests are. We try and figure out how to get them connected with other people that are their age that they might be able to maintain a positive relationship with.”

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Overview—Program Description

In 2007, ChristieCare of Oregon opened Mosaic, a community-based group home designed to support 17-24 year olds. The young adults who enter the Mosaic Program come directly to Mosaic from a locked residential treatment facility or hospital. Most have a history of severe mental health issues, have spent much of their lives in institutional settings, and are at high risk for long-term institutionalization, homelessness, incarceration, and addiction. The Mosaic Program is designed to help these residents gain the skills necessary to live safe and productive lives. The average length of stay is approximately one year but varies greatly based on individual need.

To be eligible for the Mosaic Program, a youth must be diagnosed with a major axis I diagnosis, have an extensive history of institutional care and multiple placements, and an ability to remain safe without constant supervision. Though the Mosaic Program is not licensed or funded through Developmental Disabilities and is not a dual diagnosis program, approximately 70% of the residents have had a significant developmental disability in addition to mental health issues. These residents have traumatic brain injuries, pervasive developmental

disorders (e.g. Aspergers), fetal alcohol and drug effects, significant learning disabilities, or IQ's in the low 70's. For a variety of reasons these residents have been found ineligible for DD services prior to entering Mosaic and are being served through Addictions and Mental Health.

Screening and Assessment

Prior to screening an individual for the Mosaic Program, the program manager and therapist conduct a thorough review of the individual's clinical record. Since the individuals referred to the Mosaic Program have an extensive history of mental health treatment, their records frequently contain numerous psychological evaluations, assessments, and summaries. After reviewing the records to determine the individual's strengths, limitations, diagnosis, trauma and placement history, communication style, and cognitive abilities, the program manager, therapist, and county case manager determine whether a formal screening will take place.

Once a resident enters the Mosaic Program, a suicide risk assessment is completed immediately and a basic service plan is developed. Direct care staff are given a packet of information about the individual's diagnosis, history, trauma history, goals, favorite activities, what makes them angry, what has worked well and not worked for them in the past, and a basic crisis plan. In addition, staff are given information about the individual's IQ, reading and writing levels, receptive and expressive language abilities, and strategies for minimizing the impact of these difficulties (staff may be instructed to create alternate formats for forms or to read paperwork aloud to the resident before asking for a signature). Within 30 days, the Mo-

saic therapist completes a comprehensive assessment and service plan, and the resident's diagnosis is carefully reviewed. In institutional settings, it becomes difficult to determine what diagnoses are accurate and what diagnoses are the result of the environmental chaos, the inability to provide individualized treatment, and the lack of individual control which can occur in treatment facilities. Once these individuals have some control over their lives in a community-based setting, it is common for their diagnostic presentation to change significantly.

Access

Referrals for the Mosaic Program come directly through the Addictions and Mental Health Division of the Oregon Department of Human Services. At any given time there are 40-50 referrals waiting for an opening. In addition, family members, foster providers, caseworkers, and young adults who are homeless or about to be homeless frequently call the program trying to access services. The difficulty of gaining access to the program is compounded by the low turnover rate. Because Mosaic is the first program in which many residents have felt safe, comfortable, and successful, and because of systemic barriers to service, they frequently acknowledge they are afraid or do not feel ready to leave the program.

It is really hard to go from having staff available 24/7 to living in your own apartment. I think people could move on faster if we had a step-down so there were maybe staff during the day to provide support, but not 24/7.

Program Model

Inherent to the success of the Mosaic Program is the philosophy that guides every interaction and decision that is made. The Mosaic Program embraces Trauma Informed Care, Re-ED™ and is committed to providing an environment that respects the individuals' culture, developmental level and strengths. Mosaic focuses on empowering individuals to take control of their lives. Understanding

the profound impact of trauma and institutionalization is vital to the success of the program. When residents first move into Mosaic, they do not know how to solve conflicts without staff intervention or violence. At Mosaic, staff provide help to residents to think of ways to approach their peers and teach them the basic skills of collaboration and assertive communication. Program decisions are made in community meetings where the residents, not the staff identify solutions. This empowers the residents and takes away power struggles. Residents decide how to spend recreation funds, what the schedule is, how to ensure licensing requirements are followed, and how to resolve conflicts. During these meetings, staff offer assistance with mediation and participate by ensuring the residents find solutions that are safe and in line with the program philosophy and licensing requirements.

Mosaic Program staff believe individuals learn through real life experiences, positive relationships, and when they are having fun. One example is the way the program handles food. Instead of posting menus, assigning jobs and offering skills groups, each resident is given a share of the grocery money each week. Residents make their own individual menus by filling in categories that meet RDA guidelines, make their own shopping list based on their menu, do their own shopping while staying within budget, and cook their own meals with support as necessary.

Therapy: The therapist at the Mosaic Program meets with each resident on a weekly basis or more frequently if needed. Therapy sessions are flexible, unconventional, and provided in a way that makes the residents feel comfortable and relaxed. For example they meet at a coffee shop, play basketball, go for walks, or go to a park. Once the residents start to realize the program will not force them to do things that don't work for them and will not force goals on them, the residents become much more open and seek out assistance on a regular basis. While the Mosaic Program therapist provides the majority of mental health treatment and assessments, some services are accessed through county or other outpatient providers. These services include substance abuse treatment, psychi-

atric services, and all medical services.

Education: Mosaic residents have moved from facility to facility during their elementary and high school years and are behind in school, their records have not been transferred between school districts, and credits have been lost. When an individual enters the Mosaic Program, staff work with them to determine their goals for education and for their career. Staff assist and encourage residents in gathering necessary information from previous schools, take them to meet with the school district or college, and assist in getting enrolled in appropriate community-based services.

Employment: Young adults in Mosaic want to work, but they experience barriers including the lack of vocational and social skills, poor hand writing, difficulty reading, difficulty using computers, and the lack of employment experience. In addition, residents frequently have no references to list on their applications other than caseworkers, probation officers, or therapists. They do not have appropriate interview clothes and lack the confidence necessary to pass an interview. The community-based programs designed to provide services and supports may be stigmatizing and embarrassing for young adults. The Mosaic Program attempts to utilize non-stigmatizing community-based services or works to set up individualized vocational training and employment by contacting employers and setting up supported employment.

Daily Living Skills: Many residents entering Mosaic, have had all their meals served cafeteria style on paper or plastic plates and they have never completed normal activities such as cooking, laundry, washing dishes, scheduling their own doctor's appointment, or using a phone book or public transportation. Mosaic staff provide one-on-one assistance and training while they learn new skills. Residents who have already learned these skills frequently step in and teach new residents.

Developmentally Appropriate Supports: When working with the 17 to 24 year old population, Mosaic Program staff report that it is absolutely crucial to understand the developmental stages of adolescents and young adults because

it is easy to forget the natural stages of growing up and to pathologize normal behaviors for youth aged 17 to 24. Examples are staying up until 3:00 in the morning and sleeping through morning appointments; eating junk food; listening to peers rather than adults; changing goals, careers, and identities regularly; trying to figure out their identity; preferring to communicate through Facebook, Twitter, and text messages; neglecting dental needs but having cool shoes; skipping a doctor's appointment to go on a date; and feeling like the world is ending when a relationship ends. Mosaic is designed to be flexible and adapt to the unique needs of this population. One example of this flexibility is the program has a cell phone that one staff member carries at all times so that residents can text staff to check in if they don't want to call.

Person-Centered Practices

The Mosaic Program provides person-centered practices beginning with the initial screening and continuing throughout the resident's stay at Mosaic. During screenings, the residents are asked what are their goals, dreams, values, what works well for them, and what doesn't work well. The program manager or therapist frequently ask the residents what is working, what is getting in the way of them accomplishing their goals, what irritates or frustrates them, how things could improve, etc. The program is committed to honoring the individual's goals and tailoring the program to meet their needs. In addition, forms, policies, and other written materials use the language, terminology, and format that each resident will understand.

Okay, what are you going to do with your life? What are your goals? What are your dreams? And if it is school or a trade school or if it is getting a job or if they need volunteer experience or whatever, we figure out what they are interested in and then present them with the different options that they have. They pretty much go from there.

Community Integration/Independence

The Mosaic Program assists the resident in connecting with as many community resources as possible while trying to connect them with peers in the community who have similar interests. A goal of the program is to help them develop natural supports that they can continue to access once they move out of Mosaic. For example, if a resident has a question about birth control, rather than answering the question, program staff will assist them in setting up a meeting with Planned Parenthood. The residents are encouraged to go visit and connect with as many community based resources as possible: Worksource, community centers, colleges, local churches, fitness clubs, etc. In addition, the program helps the residents connect with other young people who have similar interests. For some residents, this means joining a local club, taking a class at a community center, going to game nights, joining three-on-three basketball tournaments, etc.

Staff Training and Qualifications

The Mosaic Program has a high staff-to-resident ratio with three staff during waking hours and two overnight staff for five residents. In addition, the program manager is at the house 40 hours-a-week and the therapist is there 20 hours-a-week. Staff generally have a bachelors degree or at least three years of relevant experience and meet the criteria for a Qualified Mental Health Associate.

Newly hired staff go through intensive trainings including suicide/risk assessment, crisis intervention, Trauma-Informed Care, Re-ED™, and human development. In addition, each staff member is individually trained on the program philosophy, policies, and how to work with each resident based on their strengths, needs, goals, trauma history, diagnosis, and learning style.

Training on specific diagnoses or developmental disabilities is provided on an on-going basis and staff are asked to read articles, websites, chapters in books, and parts of the DSM-IV-TR. Each staff member receives weekly supervision and attends staff meetings. Prior to a new resident moving

into the Mosaic Program, the program manager or therapist provides a training on the individual's specific diagnosis and cognitive abilities so that staff are able to provide individualized services.

Mosaic staff are cross-trained to work in ChristieCare's residential treatment facilities. Staff regularly work shifts in locked treatment facilities in order to help them gain an understanding of where the Mosaic residents spent their childhood and the effects of institutionalization and to help them gain perspective.

Caregiver Involvement

Most of the Mosaic residents have very few family members or other significant people involved in their lives. When a resident enters the program, the manager or therapist ask them what family members or friends they want to have involved in their life, and who they want to participate in their meetings. The Mosaic Program attempts to identify barriers to involvement and makes efforts of eliminate those barriers. For example, many family members may not be able to afford long distance calls, gas, or bus tickets to visit their child. The Mosaic Program attempts to be as family friendly as possible by offering visiting hours from 7 a.m. to 9 p.m. seven days-a-week. In most cases, the family member can set up the visits directly with the resident rather than having to go through the staff. If a family member only has a cell phone and cannot afford to call during business hours, the manager or therapist will call them after hours when their minutes are free so they can fully participate in the conversation without worrying about their bill. Another strategy for engaging family members has been to call them when things are going well or to tell them how well the resident is doing. Staff report that family members are not used to getting these types of phone calls and generally get really quiet and then ask questions like: "What happened? Is everything OK? What did he do this time?"

...That's when I call them and say, 'Hey, I just wanted to let you know so-and-so is doing a great job and we are really im-

pressed,' they are just silent because they can't believe it. I had a mom start crying. She said, 'As soon as I realized who was calling me, I started to panic.' When I said, 'No, I just called to let you know that he is doing great and that he is doing this and this and this.' I think that really helps.

Funding

The Mosaic Program is licensed through multiple sources and funded through multiple funding streams. The funding for the Mosaic Program comes from Oregon Addictions and Mental Health, Clackamas County, Social Security, Housing Assistance, and various other sources. Because The Mosaic Program is the first of its kind in Oregon, systemic barriers frequently result in difficulties around receiving payments for services in a timely manner. Addictions and Mental Health recognizes the need to address these barriers while expanding services for this population.

System Collaboration

Because young adults are an underserved population and can get caught between the children's system and the adult system, system collaboration is challenging, yet vital. Each system and service area has a unique set of eligibility criteria that frequently prevent young adults from being able to access services. When a resident enters Mosaic, staff assist them trying to get SSI, Medicaid, outpatient services, etc. Staff provide assistance in navigating the system and work with adult providers to gain access to services. When a resident is getting ready to move out, Mosaic staff take them to the services they will be utilizing, explain their unique needs to the providers, and continue to be available after the residents leaves to help solve problems as they arise.

We want them to figure out where they would go if they were on their own, make those connections, with the idea that they can't stay with us forever. That is why we use Worksource Oregon... and places like that, even though we can help them make a resume. We want them to associate with a place in the community where they can go for help later.

Best Practices and Recommendations

- Understand the typical developmental stage of young adults and be flexible.
- Understand the effects of childhood trauma, loss, institutionalization, frequent moves, and growing up in treatment environments.
- Have a great sense of humor and help them see the humor in life.
- Give youth as much control over their environment and the program as possible.
- Understand the effects of stigma: college resource centers, vocational rehab, and other services all have signs and labels stating that people there are "disabled." Help find services that are not stigmatizing or find a way to reduce the stigma.
- Individualize everything.
- Before starting a program, ensure funding is streamlined, licensing is appropriate, and contracts meet the needs of this population.
- Ensure leaders in the program are well trained in the children's mental health system and in developmental disabilities programs and services.

FRANCIS FOUNDATION

“If we step in and tell people what to do, that is not a really good idea in terms of attachment or relationships or trauma with many of these people. I think the thing that has helped most of our people is to have a real life.”

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Overview—Program Description

The Francis Foundation, a private non-profit organization in Middlesex, Vermont has been providing clinically intensive therapeutic services and therapeutic foster care to people who are dually eligible since 1999. Services include individual and family therapy, psychiatric assessment, medication management, and health and wellness assessments. The majority of people served by the Francis Foundation are between the ages of 16 to 24, but have ranged from age 9 to 40. All clients served by the Francis Foundation have previously been placed in hospitals, institutions, or residential schools. To be served by the Francis Foundation a youth must have a developmental disability and have exhausted all other options for service.

The Francis Foundation serves youth throughout the state of Vermont. The Francis Foundation serves approximately 20 people at any given time and will stay connected with their clients into adulthood.

Many of the kids who went through the program remain in the program because they have developmental disabilities and because they have gotten accustomed to

us and have done well with us, and are in these therapeutic foster homes. In terms of attachments, it doesn't make sense to break those up and ship them somewhere else.

Screening and Assessment

In Vermont, assessing if someone has a developmental disability is the responsibility of the community mental health centers. Common developmental disabilities seen at the Francis Foundation include intellectual disability, autism, Asperger's syndrome, and pervasive developmental disorder.

All youth served by the Francis Foundation are assessed by a staff psychiatrist. Common mental health disorders addressed at the Francis Foundation include bipolar, schizophrenia, and seasonal affective disorders. Many youth at the Francis Foundation have disorder diagnoses. “If it was a straight bipolar disorder and they are on lithium, they should be settled down and not have to come to us.”

There is a consulting psychologist at the Francis Foundation who can conduct substance abuse assessment or other related assessments as needed. The Francis Foundation approaches assessment as an ongoing process, conducted weekly, daily or as often as it is needed.

Access

Referrals primarily come from the ten local mental health agencies throughout the state. The Francis Foundation is well known in Vermont because the program director has been providing these services for 37 years and does quarterly trainings for the mental health agencies. There

is a wait list for the Francis Foundation and the program director reported that approximately 50 youth are residing in residential programs out of state because there are not enough services in Vermont. Youth who are residing in the state and on the wait list continue to receive services through their local mental health agency until they can be served by the Francis Foundation. The Francis Foundation, as the director stated is the “last stop on the train schedule” so if a person can be served by another agency they would not be eligible for the Francis Foundation.

Program Model

The Francis Foundation is a “clinically intensive” program and the primary services are therapy and therapeutic foster placements. All youth served by the Francis Foundation are in therapeutic foster care, though some youth have contact with their biological families. When a youth is referred to the program, the Francis Foundation looks for an appropriate therapeutic foster placement. The Francis Foundation staff believe strongly that youth need secure and healthy attachments and therefore they work diligently to find placements that match the youth’s needs and then provide therapeutic services to the youth and caregivers to support the placement.

To me the most important thing, really, is the relationship and the match between the kid and the foster care provider. We have everything from a single guy, to couples, to families, to a couple of women, or couple of guys that provide this foster care. It doesn’t make sense to put an active kid in with older people or a very quiet person who likes to stay home with someone who likes to be out and active. Then you have to match their personalities and attachment styles, to a certain degree. That is the most important beginning, is to make that good match. If you get the right people, this thing goes pretty well, and if you don’t, this thing never works.

Youth and caregivers in the program receive

intensive therapeutic services in the home, school, and office to address wellness and mental health needs. The Francis Foundation also provides 24 hour crisis services. The Francis Foundation contracts with a psychologist and psychiatrist to provide assessments, supervision, and medication management. Youth who have not graduated high school attend a school that was originally started by the Francis Foundation and now is a separate private school still based on the same model as the Francis Foundation. The Francis Foundation provides training and clinical supervision to the school staff so youth experience interventions that are consistent between home and school. For youth who have graduated from high school, the state provides funds for day programs that focus on vocational skills. All youth who have completed their education spend some part of their day doing vocational training. The therapeutic foster placements supported by the Francis Foundation are also known as developmental homes and youth are able to stay there indefinitely if the youth, family, and staff feel it is successful.

Four practice approaches used regularly by the Francis Foundation are clinical case management, training foster parents, addressing health and wellness, and addressing trauma.

In a clinical case management service model, both a case manager and a clinician work with youth together. Because both the case manager and the clinician attend all meetings together, there is always clinical input in the decisions being made about the case and there is always someone who can make decisions about the treatment plan who attends each meeting.

I often arrive at places where the people who make most of the decisions have no clinical training, could be just 22 years old and just out of undergraduate school and they are making decisions about people with developmental disabilities’ lives.

Training foster parents is a primary service provided by the Francis Foundation. To support positive and nurturing attachments between the youth and caregivers, the Francis Foundation staff

utilize strategies from Daniel Stern's (see reference list) work focused on parent-child interactions and believe that providers and caregivers need to have knowledge about trauma, brain structures (i.e. limbic systems and frontal lobe), cognitive and emotional development, and attachment. "If you want this thing to work, you have to turn the foster parents into clinicians."

Addressing a youth's nutrition and wellness is a critical service component of the Francis Foundation. The Francis Foundation believes that the connection between physical health and mental health is critical and each youth's nutrition and wellness are assessed. When youth enter the program they are asked about nutrition and exercise and provided supplements and vitamins as necessary. The staff believes that therapies and medications will not be optimally effective if the body is not stable and healthy.

We had [a person with] acute autism who was not sleeping, up around the clock, craving carbohydrates, [and] attacking people constantly. He was locked in his own portion of the hospital because they wouldn't put him in with the other people. We took him out of the hospital and put him on a wheat-free, gluten-free, dairy-free diet. We gave him light therapy, a touch of melatonin, exercise daily, and then a multi-vitamin, some vitamin D, a B complex and that kid hasn't attacked anybody since.

Understanding the role of trauma is another focus of the Francis Foundation's services and training. It is important to recognize the role of trauma and when necessary to teach youth about how current behavior can be a reaction to past events. Many youth have a history of interpersonal and institutional trauma and the Francis Foundation stresses the need for providers and caregivers to consider the role of trauma on a youth's behavior and brain development especially when implementing behavioral reward-punishment based interventions because "you can't punish trauma out of a kid...."

I recently had a kid—this is really one session that just about changed his life—he knew he had trauma, but he didn't know what it did to his brain. So he felt like he was a bad kid who was doing bad things. We said, well, wait, these behaviors that you do now, at one point in your life these were very important for you to survive. You brought that stuff from way back then up to now. So when something similar happens now, your body thinks you are going to get beat up and you react by being violent but in fact you are not in any danger... We write out the behaviors, cast everything as fight-flight-freeze, so people begin to understand how the limbic system is involved with attachment.

Person Centered Practices

The Francis Foundation provides person centered practices through three primary strategies. First, the staff and youth discuss weekly what is being done clinically and therapeutically, what services are being used, and discuss if any adjustments are needed. The Francis Foundation also uses the Strategic Self Regulation model (see resources on the Francis Foundation website at www.thefrancisfoundation.org) which can be modified to fit individual needs. Finally, all services plans are individualized with youth input.

Community Integration/Independence

The Francis Foundation supports community integration by providing therapeutic foster care versus group or institutional placements. The Francis Foundation provides services to individual families and does not organize group outings or recreational services. The Francis Foundation supports the foster families with resources to engage the youth in the community. For example, the Francis Foundation secured funds to pay for one youth to visit the local amusement park.

Staff Training and Qualifications

The Francis Foundation staff consists of co-directors (clinical and administrative), case managers, therapists, a day program coordinator, and an office administrator. The Francis Foundation also has a consulting psychologist and psychiatrist. The staff complete a three day training and quarterly full day trainings and receive regular supervision. Weekly, the staff meet with the consulting psychologist to talk about each person they are working with, what they are doing, results, and recommended changes. Staff training addresses attachment, learned helplessness, cognitive and emotional development, and trauma.

Training Model

Dr. Vecchione provides supervision and training to the Francis Foundation staff and also trains clinicians nationally about providing mental health interventions to persons with developmental disabilities. He reported that most clinicians are not trained to do this, and many providers think that people with developmental disabilities will not benefit from mental health interventions because when they have tried to apply traditional mental health interventions it goes something like this:

A client comes in your office and you say, 'How was your week?' They say, 'Good.' 'How is your mom?' They say, 'Good.' You say, 'How is school?' They say, 'Good.' Then you have got 49 minutes and 50 seconds left of therapy to do, but nowhere to go.

Dr. Vecchione's trainings cover four topics he thinks are important for success in work with people who are dually eligible; these include attachment as the primary motivation for behavior, learned helplessness, cognitive development, and emotional development. He states that traditional mental health models need to be modified. In order to modify them, clinicians need training to understand how the brain works and how people remember. It is not effective to ask a person who has

difficulty with memory to recall something that happened last week or expect them to remember what you told them last week.

Guardian and Caregivers

All of the youth served by the Francis Foundation are living in therapeutic foster care. A few youth have biological families who are involved. These youth spend a few days per week with the biological family and the rest of the week with the therapeutic foster family.

Providing therapy to caregivers is a primary service of the Francis Foundation. Caregivers receive weekly therapy in the home with a goal to "keep the foster care providers thinking about things the right way, and the other is to provide some growth and development through therapy with the person we are serving." Caregivers are given information about trauma, cognitive and emotional development, brain functioning, and attachment.

The Francis Foundation also provides crisis support 24 hours per day – 7 days a week. Caregivers or youth can call the Francis Foundation crisis support if a youth or caregiver is having a difficult time and a clinician will go to the home to intervene.

Finance

The Francis Foundation is funded through a Medicaid waiver through the Vermont Department of Developmental Disabilities. Because of the funding source, it is sometimes more difficult to get reimbursed for therapy services versus case management services or foster care. Overall the director reported that funding has minimal impact on services.

System Collaboration

One strategy Vermont uses to increase collaboration between the mental health and developmental disability systems is to hire a psychiatrist that provides consultation and services for this

population. She provides services to local agencies and to individuals in the state.

Best Practices and Recommendations

- Expect services to be intensive especially at the beginning when youth are coming from institutional settings. Do not offer services until you are ready to invest the time that is needed for the person to be successful.
- The entire team, all people working with the

youth, need to be trained about attachment, learned helplessness, cognitive development, emotional development and trauma. This includes the clinicians, educators, and foster families.

- Assess and address nutrition and physical activity.
- Provide 24 hour crisis response to families to prevent hospitalization and support stable placements.

TRILLIUM FAMILY SERVICES

"I think of us as a family nest. I have a really small office and many staff and residents often just sit around and talk about life in general. If we have something pertinent to talk about we will go for a walk and get coffee or hold a formal group. It is really a nice family setting. Eventually we help them move out of the nest like a fledgling and encourage them to spread their wings."

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Overview—Program Description

In 2007, Trillium Family Services started its Youth Adult Program (YAP), a residential program in Albany, Oregon, for youth between the ages of 17 and 24 with significant mental health issues, some of whom also developed mental disabilities. This program was developed as a temporary, transitional program where youth are provided with opportunities to learn employment and life skills to support independent living. The program serves

four residents at a time and a fifth resident participates while living in a transitional apartment in the community.

Prior to starting the program, youth come from a variety of settings including the juvenile justice system, other residential programs, foster homes, homeless shelters or the streets, and their family homes. Youth stay in the program from six to sixteen months with an average stay of nine to twelve months. Types of developmental disabilities that youth exhibit include mild intellectual disability, autism, and pervasive developmental disorder. Mental illnesses that youth are experiencing include bipolar, schizo affective, and attention deficient disorders, with bipolar disorder being the most common. Trillium's YAP has served thirteen youth since it began and nine of those youth have exited the program. Approximately 40% of youth served have both a mental health and developmental disability.

We teach participants how to cook, clean, socially interact, build resumes, look for jobs, manage their medications, manage

their mental health issues, connect with local resources, obtain their GED or diploma or further their education.

Screening and Assessment

Most youth enter the YAP program having been assessed for developmental disability and mental health challenges by their county mental health agency or the county developmental disability office sometime in their immediate past. At the time of entry into the program, the county completes intake assessments and care plans are completed by the staff at the YAP. Mental health status is monitored monthly by the county mental health agency unless the youth or staff is concerned about their current wellness and a request is made to reassess the youth earlier. The YAP staff create new care plans with residents every six months to reassess how their goals may have changed or which ones have been reached.

We haven't worried that much about substance abuse yet in our program; however, if it arises it will be taken care of on a case by case basis. There was one girl who ran away and started using. She was with us for nine months and her longest stay previously at other programs was two and half months. When we went to see her after she was picked up she said 'I shouldn't have left' and asked to come back to the program. We measured that as a success, we measure success differently with each client.

Access

People hear about Trillium's program from community providers, word of mouth, and by program staff giving presentations and trainings in communities throughout the state. The Addictions and Mental Health Department of the State of Oregon is the referral agent for the program and all interested youth and families or service providers contact this department for a referral into the pro-

gram. Although referrals are provided by a state agency, the final decision on who will receive services is made by the program staff with State and County approval. The current wait time to enter Trillium's program is six to eighteen months. To be eligible for YAP, youth must be between the ages of 17 to 24 and have a DSM-IV Axis I diagnosis; however, Trillium cannot accept youth who are registered sex offenders because the program is located near a school. Trillium works hard to "live in harmony" with the surrounding community and for this reason excludes youth who are highly aggressive.

Program Model

Trillium's YAP is a residential program designed to meet the needs of youth in transition. Often, the youth served by Trillium's YAP have been in a more restrictive residential setting, are receiving services through the educational system and are interested in transitioning to a less restrictive setting. YAP provides opportunities for youth to develop or enhance daily living skills, social skills, educational achievements, and employment skills while supporting youth in accessing needed mental health services.

We provide love, nurturing, compassion, understanding and the ability to fail while learning from their mistakes so they may move forward as healthy successful young adults.

Daily Living Skills. Youth at Trillium have access to groups that teach about cooking, cleaning, going to the store and other daily living skills. The staff at Trillium educate the youth about what public assistance they should apply for and how to access services, but the youth are responsible for arranging all appointments and transportation.

Social. Each morning, youth and staff attend house community meetings to check in about their activities and to plan for the day. Other community meetings are held bi-weekly to discuss house and life issues, make apologies, give compliments, and so on. On Sundays, there is a goals

group where residents share the status of their goals. In addition, there are intervention groups throughout the week that address areas of interest to the residents.

Education. Youth under 18 have to spend time in school, due to federal law. The Trillium YAP staff assists those older than 18 in reaching their educational goals. Many youth enroll in the local community college GED program and youth with a developmental disability attend a program at the community college or high school designed specifically for people with developmental disabilities.

Employment. To support a youth's employment goals, Trillium's YAP provides education and support about resume building and helps residents find volunteer opportunities. Youth are also referred to the state Vocational Rehabilitation program. Trillium staff would like to open a small business that youth could work at to gain work experience.

Mental Health. Youth receive psychiatric services and therapy from the county mental health agency and Trillium YAP staff provides counseling about the meaning of their disorders and how their disorders affect their lives. The staff report teaching about and modeling healthy communication is critical and especially helpful with persons with developmental disabilities to support verbalizing instead of "going to the secondary feeling of anger." Mental health strategies that YAP utilizes include techniques from Collaborative Problem Solving (CPS), Anger Replacement Therapy (ART), Chain of Analysis, and Motivational Interviewing as described below.

We use reality therapy based on the here and now. For example if you put your fist through the wall, you either have to patch it yourself and it has got to look exactly like the wall did before, or you pay for the damage and then the money gets added to the recreation fund. Depending on the frequency and severity of these occurrences, the local authorities may be called to cite the resident. This is different than residential care where if a client puts his or her fist through the wall they might be restrained

or put in detention, seclusion or time out. There isn't a realistic consequence to the behavior.

Collaborative Problem Solving (CPS) is a manualized treatment program developed to address oppositional defiant disorder by teaching parents and children collaborative strategies to positively meet expectations and reduce frustration (see <http://www.ccps.info/cpsentials/index.html>). CPS is widely used in educational and residential settings to reduce conflict. The CPS approach is considered different from other anger management strategies because it focuses on the adult and youth working together to solve the conflict or problem by implementing three steps that include 1) collecting information about the problem, 2) defining the problem, and 3) working together to identify solutions to the problem. YAP staff use these techniques and also teach them to the youth in the program.

Anger Replacement Therapy (ART) is a manualized treatment program designed for aggressive youth age 12 to 17 and has been used in residential, educational and juvenile justice settings. ART was designed to be implemented during 10 weeks and 30 sessions and addresses social skill trainings, anger control trainings and moral reasoning training (National Center for Mental Health Promotion and Youth Violence Prevention, 2009).

Chain Analysis is the process of looking at a behavior and its chain of events in reverse to see how they evolved. The individual and staff look at the key times or periods when coping skills could have been used to modify the outcome, then concentrate on building coping skills to help modify the behavior next time it occurs.

Motivational Interviewing (MI) refers to a counseling approach developed by psychologists William R Miller and Stephen Rollnick. It is a client-centered, semi-directive method of engaging intrinsic motivation to change behavior by developing discrepancy and exploring and resolving ambivalence within the client. Motivational Interviewing is non-judgmental, non-confrontational, and non-adversarial (Miller & Rollnick, 2002).

Transition. Trillium starts working with youth

on transitioning out of the program as soon as they enter the program by asking what their goals are regarding their desired living situation. The staff work with the county of origin on the transition plan but because youth are engaged in the community where Trillium is located, many want to stay. For persons with a developmental disability, it is recommended that transition planning intensify six months before they are scheduled to leave the program because there are fewer placement options available. Some possible transition options are adult group homes, supported housing, Job Corps, or their own apartment.

Person-Centered Practices

When youth enter the program they work with staff to identify short and long term goals including what it will take to meet their goals and what help they will need from staff. Goals are evaluated monthly. Every youth has a goal related to medication management. Trillium's YAP staff expect youth to learn what medications they are taking, why they are taking them, and how to take them. If a youth does not want to take their medications or if they want to change the medication they are encouraged to contact their doctor to make a plan. Youth are responsible for reordering their medications.

Community Integration/Independence

The Trillium YAP is a residential program in a house that doesn't look like a group home from the outside. Trillium's YAP program is a temporary transition program so it is important that the program blend with the community and encourage community engagement. The house is purposely not labeled with the program name. There are no group vans and residents are rarely seen doing group activities. The program is also located within walking distance from mental health services, the community college, and the hospital.

The residents don't want the stigma. They don't want to be labeled as someone who is in a mental health program. We have a

resident who won't even answer the phone because she doesn't like saying the name of the program. They like the anonymity with the house. It doesn't say Group Home across the front. It looks like a normal house. The residents are outside washing the car or playing basketball.

Staff Training and Qualifications

Trillium's YAP employs ten staff, eight of whom are direct service staff. YAP staff must have a high school diploma, complete Trillium's mandatory training, and have experience working with youth. The staff range in age from 20 to 66. Trillium provides annual and quarterly trainings for staff that include content on PTSD and trauma. The program supervisor recommends staff have training about youth in transition and especially how to engage with this population. Staff often attend trainings within Trillium's other programs and services. For example, the staff from the YAP program may spend a day at the more restrictive psychiatric care unit at Trillium's residential facilities. The supervisor shared that this cross training has been helpful for staff to "remember other possibilities" and other levels of care that youth have experienced and how the YAP is trying to provide less restrictive care.

Caregiver Involvement

The program supervisor reports that less than half of the residents have families or caregivers who are involved in their lives. Approximately 75% of the residents have been in foster care in their lifetime and some residents have "wraparound" or community teams and staff attend these meetings. Families can receive family therapy from the county mental health provider but no specific services are offered to caregivers at YAP.

Finance

Trillium's program is funded through Rehabilitative Services, Medicaid, Oregon Health Plan and

Supplemental Security Income. Trillium’s YAP staff often helps residents qualify for multiple funding streams.

Residents do not have to have Medicaid or OHP; we usually do all of that for them when they enter the program. Honestly, when I opened the program we didn’t know anything about how to do this and now we are gurus of this specific age bracket.

System Collaboration

The program supervisor reports that there is work to be done to improve system collaboration. It is not uncommon when a youth enters Trillium’s YAP that the other service providers such as probation or the department of human services end contact with the youth. The YAP does note that some community teams are more collaborative than others.

We have been working to open doors and try to keep them open. We also connect people with each other. People don’t seem to know each other even though we are supposed to be working together.

Best Practices and Recommendations

- Having residents with similar abilities enhances group cohesion.
- Serving only four to five residents at a time allows the individual attention necessary to promote youth’s goals.
- When doing transition planning with persons with developmental disabilities it is helpful to intensify six months prior to the youth’s planned exit because of the limited residential options available.
- Staff need to know how to engage with this population to promote independence and understand that letting a youth fail is important.

Citations

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VERMONT CRISIS INTERVENTION NETWORK

“I think our approach of individualized consultation is just a fantastic way to go. If there is an issue, that people are struggling with in the home, we have a team of sophisticated clinicians who can come and assist right in the home, help people figure stuff out.”

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Overview—Program Description

The Vermont Crisis Intervention Network (VCIN) has provided three levels of service to the state of Vermont since 1991. Level I provides prevention services through training professionals about developmental disabilities and about co-occurring mental health and developmental disabilities. Level II provides early intervention services through on-site consultation to professionals, individuals, and families about a particular person

or situation. Level III provides intervention services through two crisis beds available for short term residential service.

Any human service agency in Vermont can request Level I training services. The VCIN staff train regularly about how to identify and address the mental health challenges of someone with a developmental disability. The VCIN staff is also available to provide trainings tailored to a specific person or community. Level II and III services are available to anyone in Vermont who has a diagnosed developmental disability and a request for services is often made by the local mental health agency but individuals and families can also request Level II and III services.

VCIN sees approximately 105 people per year for Level II services and typically services last three to five months. Level III, residential crisis beds, serves approximately 35 different people in these crisis beds per year and the average stay is 20 days. Approximately 30-35% of the population served by VCIN is dually eligible.

Screening and Assessment

VCIN does not provide developmental disability assessments since to receive services a person has to already have been diagnosed with a developmental disability. VCIN staff often assesses for psychiatric disorders or other mental health needs when providing Level II or III services. VCIN does not have a uniform assessment tool but the director recommends utilizing such tools as the Psychopathology Inventory for Mentally Retarded Adults (PIMRA) and the Reiss Screen for Maladaptive Behavior. The PIMRA is an instrument used to diagnose mental disorders in people with IQs of 60 to 80 who are 16 years or older. The PIMRA includes two structured interviews, one with a caregiver or teacher and one with the person with the developmental disability. It is expected that it will take approximately 20 minutes to complete the instrument (Matson, Kazdin, & Senatore, 1984). The Reiss Screen for Maladaptive Behavior screens for mental health challenges in people who are 16 years and older who have mental retardation (Hevercamp & Reiss, 1997). The measure takes

about 10 minutes and is completed by a caregiver, supervisor, or teacher. The screening rates 36 symptoms on a scale from “no problem” to “a major problem” (Hevercamp & Reiss, 1997). The director of VCIN cautions that most of the subscales for either of these instruments have established validity but that they are useful for frontline providers and new clinicians.

Access to Services

People know about VCIN because they have a contract with every local mental health agency in Vermont to provide services and a resource guide is available with VCIN’s information. Services are often requested by professionals but “[if] a family called us and said, ‘my child is having some issues and we would like some help from you,’ if we can assess that there is some documented developmental disability, then we can usually go and be of help.”

Program Services

The VCIN program uses a bio-psycho-social model for delivering services. They provide psychological and psychiatric services as needed including prescribing medication. VCIN does not provide long term services. VCIN provides three levels of services which are described below:

Level I – Training. VCIN has a staff of experts who are available to go out to communities and provide training about developmental disabilities and psychiatric disorders. Although they teach about a number of topics, some the focus is on information about how to identify and address psychiatric disorders in people with developmental disabilities. As part of the bio-psycho-social approach, VCIN also provides training about using a skills-deficit model. This model focuses on identifying skills that the individual can develop in order to enhance their coping and social skills. This is all in an effort to minimize problematic behavior and promote successful social behavior. VCIN can also develop trainings to meet specific needs of an individual, family, or community.

What we really need to employ is a skills-deficit kind of model, to look at the situation and see what kinds of skills the person is deficit in (e.g. anger control skills) and what they can be taught in order to have their coping skills, coping strategies and those kinds of things enhanced so that the problematic behavior is minimized in that way. We are huge proponents of positive behavior supports and targeted cognitive behavior therapy around those issues.

Level II – On-site Consultation. VCIN considers their Level II on-site case consultation service a best practice. Most of VCIN’s clinical staff time is dedicated to providing consultation. When a request is made for consultation VCIN staff goes to the community and works with individuals, families, and providers. Staff may provide diagnostic services, medication prescriptions, therapeutic intervention techniques, and/or long term planning support. Individuals, families, or professionals can request a consultation, and as long as there is a documented developmental disability the VCIN can provide this service at no charge. Most often local providers are involved in the case, but it is not a requirement to receive level II services.

Level III – Residential. VCIN manages two residential beds for short term crisis placement, located in two houses with one bed each. One is located in central Vermont and the other is in the southern part of the state. Level III services are accessed when someone needs psychiatric or behavioral stabilization or is homeless because the current caregiver is unable to provide adequate care. By providing crisis residential services VCIN is preventing homelessness or unnecessary admission to the Vermont State Hospital or other inpatient psychiatric facilities. The crisis residential program has 24-hour direct staffing and serves 35 individuals per year for an average stay of 20 days.

Person Centered Practices

VCIN provides person-centered practice in both level II and III services. In level II, VCIN staff go to the family or community requesting assis-

tance with the intention to support “...the team to figure out how they can best meet the person’s needs.” In level III, only one person is served in a home at a time. Each Monday there is a clinical planning meeting that the resident, family, caregivers, guardians, and/or agency staff usually attend. At this meeting the clinical staff provides consultation to the entire team regarding any clinical concerns as well as supporting plans to move the individual back into the community.

Community Integration/Independence

The purpose of VCIN’s services is to support people in getting the care they need in their home communities and to prevent institutionalization or inappropriate hospitalizations. When providing training and consultation services staff are working in local communities to increase the capacity to serve people who are dually eligible. The level III residential services are located in two different areas of the state to be as accessible as possible and are intended as only a short-term stay away from the home community.

Staff Roles and Training

VCIN employs a clinical staff that is made up of two full-time psychologists, a part time psychologist, and a part time psychiatrist. The clinical staff is responsible for all level I and II services and the clinical services provided in level III. The level III residential services are provided by approximately three staff per day.

The staff at VCIN are hired with a background and extensive knowledge in serving people with co-occurring disorders.

Family and Caregiver Involvement

Caregivers are actively involved in the onsite consultation and residential service by providing information about the person and the situation that prompted the consultation and having input into an intervention plan. The VCIN director states that the involvement of caregivers is critical to providing effective services. Since VCIN’s purpose is to

provide consultation to allow people to be served in their local community, caregivers need to have an active part in developing an intervention plan so that it is sustainable when VCIN staff withdraw from the situation.

They are completely involved with us. Without them it is nothing. How could anyone make any kind of planning that made any sense that wasn't individualized or person-centered.

VCIN's goal in working with caregivers is to give them "some ideas around making life better for the person that lives with them and for themselves." To help caregivers, VCIN provides psychiatric services including assessments and medication recommendations. VCIN also teaches caregivers to address common psychological needs such as anxiety, anger, and/or depression. VCIN has also assisted families in making decisions about long term living arrangements. When the need arises, VCIN is able to send staff into the home to provide extensive direct services to the caregivers.

Finance

VCIN is funded through a Medicaid waiver. For each person diagnosed with a developmental disability, a percentage of the allocated financial support is designated for crisis services. All but one of the mental health agencies throughout the state use these funds designated for crisis service to support VCIN. VCIN is implementing a new revenue stream by charging \$225.00 per night for the crisis beds. The director states that no family would be denied service based on their inability to pay. This type of funding strategy has allowed services to be flexible to the needs of each community because there is almost no billing necessary.

System Collaboration

In Vermont, each county has a designated mental health agency that provides mental health and

developmental disability services. One strategy VCIN provides to support collaborations between the mental health and developmental disabilities service division is to provide training and consultation to both systems. Most of the requests for consultation and training originate from the developmental services division within the county mental health services agency but in the 18 years that the program has operated there have been many requests from mental health programs. The director reports that there is a need for clinicians who can serve dually eligible people and they hope that by providing training, more clinicians will be available and this will increase system collaboration.

Best Practices and Recommendations

- Services are more effective if they are provided on-site in the community where the individual and family reside.
- Mental health professionals need training about how to assess and work with persons with developmental disabilities. With assistance in modifying interventions mental health professionals often find working with persons who are dually eligible quite rewarding.

Citations

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THE CENTER FOR START SERVICES

"I think the focus has been too much on this special needs of this population, instead of on the failings of the system to accommodate people who don't fit in particular program models. I think a best practice strategy has to include really looking at changing the way systems collaborate and communicate."

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Overview—Program Description

The START model is a systems linkage outreach model which emphasizes individual cross-system crisis prevention and intervention planning. The Center for START Services, located at the University of New Hampshire provides technical support, training, and expert consultation to START teams and other programs throughout the United States and Canada. This model has been used in Massachusetts since 1989 and has been implemented in a number of other states including North Carolina, Tennessee, Ohio, and Connecticut. In addition, communities in about 20 states in the United States have developed services based on the model.

The START program (Systematic, Therapeutic, Assessment, Respite and Treatment) is based on three primary components. First, it calls for establishing a cross-system infrastructure of linkages and collaborative relationships that bring together public and private service providers. Second, an interdisciplinary clinical team is formed that is available to give consultation, training, and help with treatment planning in the local community. Third, the model calls for strong respite and crisis re-

sponse services to be available for individual use. Staff at the Center for START Services are available to help evaluate the services requirements of people with complex needs and to provide technical support to local teams to enhance their capacity to serve this population.

The director of The Center for START Services, Dr. Joan Beasley is a licensed mental health counselor with a PhD in mental health policy and developmental disability policy. She has assisted state governments and local systems to develop services based on the START model since 1989. Dr. Beasley developed the model based on her experiences serving children and adults with both developmental disabilities and mental health needs. Dr. Beasley conducted a four-year study of family experiences and outcomes associated with the Massachusetts START program with promising results, including a reduction in emergency service use and improved satisfaction with services received.

Access to Services

Center staff report that there is a problem with access to services across the states because young people whose IQ is slightly above 70 do not have access to the services that serve individuals with intellectual disability. As a result, these youth are served in the mental health system, but they are not well-served. They have many difficulties because traditional mental health providers are not trained to modify their approach to serve this population. For example, it is difficult to diagnose obsessive-compulsive disorder in somebody with autism. As a result, some of these young people end up in restrictive settings such as psychiatric hospitals or jail, or may become homeless.

Program Services

The START model is an evidence-based model (See Center for START Services at the University of New Hampshire). The approach was developed to address the existing focus on the special needs of this population, instead of on the failings of the system to accommodate people who don't fit other established program models. The director noted that it is critical to change the way systems collaborate and communicate because people with multiple issues use multiple systems. Language barriers, miscommunications, and lack of collaboration result in people getting very poor services. One element of the START model is to make sure that there are no barriers and the collaboration takes place on multiple levels. This includes stakeholders, such as funders and decision makers, individuals, their teams, and their families. A second element is to conduct a multi-modal, comprehensive assessment of every individual, including their history – what worked, what didn't work, what they looked like when they were doing well, what happened to them, what are the issues that have affected this person throughout their life.

Person Centered Practices

The START model requires that each individual's strengths, wishes and needs are articulated and a working agreement is developed between the individual, the caregivers, and the system of support to collaborate to prevent an individual problem becoming a crisis. A focus of this model is on helping to reintegrate people into the community and keep them out of crisis. The START model includes a focus on natural supports and building on individual strengths, positive behavioral approaches, and providing support to the caregivers, especially family caregivers, so that individuals can stay in their natural environments.

Key aspects of this model are its focus on the individual and their wishes and needs, as well as on giving people a meaningful day of work as part of the rehabilitative process. Teams are encouraged to use interest inventories and talk about what the person needs to build their resilience and coping

strategies. The START model “includes attention to rehabilitative, recreational and social supports as key to appropriate mental health care, rather than identifying the proper medication or the proper therapy.”

Center staff make recommendations to teams and provide technical assistance, as well as helping states plan for and fund needed resources. The teams develop concrete plans to prioritize the individual's needs in the recovery process. They also work closely with the individual and their family to get feedback on how things are going, using a service experience survey that was developed at the Human Services Research Institutes “to create a feedback loop between the service recipient and their system, not just on their wishes and dreams, but actually on what has been accomplished and how they feel about it.”

In the director's experience, it has been important that state and local decision makers buy into this type of person-centered care and that the people in charge of resources believe in it and see the benefits of it. Outcome data is essential so that providers know whether or not people are benefiting. The director notes that “what drives decisions about funding is how many people are ending up in the ER, how many people are ending up in institutions, or in out-of-state placements.” In some states, such as Massachusetts, the mental health providers receive an enhanced rate through Medicaid to cover the costs of ongoing collaboration between systems in order to support individuals. In some states the state pays for bridge meetings, so that the mental health providers have the opportunity to be part of the team, talk about the person's wishes and dreams and how things are going, and promote these directions. This is seen as an effective strategy to avoid team members functioning in isolation or as part of a silo.

Community Integration/Independence

The purpose of the START model is to coordinate services across agencies for people who are dually eligible to increase accessibility to services. By increasing service accessibility the need for crisis services are reduced and consumers are able to

receive services and support in their communities. The START model was developed to better serve consumers in their community and to include consumer voice in decisions about services and the evaluation of service effectiveness.

Staff Roles and Training

The director commented that most state systems lack expertise to serve this dually eligible population and few institutions of higher learning train professionals to serve young people with co-occurring disorders. A particular challenge is how to distinguish typical adolescent and young adult developmental issues from mental health issues. Most trainings use positive behavior support strategies. There is some awareness of person-centered planning and many states use the Child and Adolescent Needs and Strengths measure (Lyons, 2008).

A team of experts from the Center for START Services provides technical support and training in the areas of psychiatry, psychology, assessment, service development, and family support. They also provide training and technical assistance to states on how to develop a service linkage approach to supporting this population, how to develop respite programming, and systemic clinical consultation. The focus of training provided by Center staff is to improve the capacity of the system as a whole through enhancements, rather than to develop a separate system. They also do training on how to work with families and how to write crisis plans. The director believes that training should not just be didactic, but that case conferencing and debriefing are important components.

The director recommended caution in working with consultants because there is no formalized training in how to do this work and there are no clear standards for people who are recognized as having expertise or who the expert is. A goal in developing the Center for START Services was to provide cost effective forums, technical support, advice, and training opportunities.

Training on trauma-informed care is needed

because many of the individuals who have the most severe behavioral issues and the most severe personality-related issues are victims of trauma, abuse, and neglect. Their needs are the most complex and Center staff have found that there is the least expertise available to support individuals affected by past trauma. Experts from the Center for START services have expertise in treating trauma and they recommend incorporating the person's history of trauma into the program planning and treatment planning.

Family and Caregiver Involvement

The START models focuses on families as an important means of support for young people with co-occurring disorders. Approximately 44% of the young adults that have received services through the START program are family members, with the another 36% in foster care or group care settings. Services provided to families include planned respite services specifically designed for this population. They also provide cross-systems crisis planning, so that families know who to call and when to call them, to get more effective services. Teams functioning under the START model incorporate service linkage into the case manager's role and case managers often accompany the family and the individual to psychiatric appointments, to improve communication and cooperation.

The director reported that families who responded to their survey said that they wanted one contact person and therefore, the START model includes a designated person who helps the family navigate the system and who has expertise in dual diagnose. Additionally, she reported that she has learned from her research that families want to be heard and they want technical assistance. She reports that when there is more than one person in the family household who helps to care for the individual with disabilities, "they are far more likely to use planned services, to access the system appropriately and effectively, and far less likely to need emergency services." She has also found that the reverse is true – that families with a single source of care giving are less likely to use the sys-

tem in a planful way and are more likely to use the emergency room and other acute care services. The director has concluded that the more overwhelmed families have trouble navigating the system and they don't have the personal resources to figure out whom to call for help. "They are so busy managing the care giving process that they can't access the system." Based on this research, the director modified the START model and increased outreach services to single caregiver families. In Tennessee where the TN-START program has been implemented, instead of having the families call the team, the team calls the families. Some families do not have phones, so the team does home visits. This was seen as good use of resources because:

Just because you don't hear from them doesn't mean they are not having a problem. It can mean just the opposite. It can mean they are having such a big problem that they don't have the time to call you.

The director reported that staff also may assist families by attending doctor's appointments with the family so that information is better reported. They may provide training to families with regard to medications, treatment, and service options.

Funding

The services that are available for dually eligible young adults are usually publically funded by the state, often through a Medicaid waiver focused on individuals with developmental disabilities. Depending on how the state creates the waiver, it may restrict the population served. For example, if the young person does not have an IQ below 70, s/he may not be served. In some states, funding for individuals with developmental disabilities may not include vocational services, habilitative services, residential supports, respite services and family support services. The other challenge for youth is that when they turn 18 (or 22 in some states), and they leave the child system, there is no guarantee that they will be immediately accepted for adult services. For example, the director described

a family where the individual was in a residential school until the age of 18, then returned home and was wait-listed for developmental disability services: "He had nothing while he was waiting. He went from a full compilation of services to nothing." This age group may be on a wait list for a long time and there have been a number of lawsuits about this in various states. Being on a wait list means that the individuals met the criteria for services but have no entitlement to receive services if resources are lacking. Connecticut is doing early identification at age 16 so that by the time the young person comes of age, the system has prepared the needed resources. With this approach, the adult service providers have input into the long-term goals such as vocational training. Involving the adult system and starting earlier allows for step-down planning for youth who are in out-of-home placement. This can make the transition to the adult system more seamless.

System Collaboration

Center staff believe that data on collaboration is critical—team members need to document what they are doing and who they are doing it with on an ongoing basis. Given the complexity of the needs of dually diagnosed individuals it is important to anticipate obstacles. Those obstacles need to be addressed both from an individual point of view, but also from a systems perspective. A first step is to do is an assessment of effectiveness of services in the system to determine where the gaps lie. It is helpful for state systems to use an outside person, who has an understanding of the obstacles and the ability to give the system the technical support needed.

Staff at the Center for START Services believe that what works well is to serve people in the context of their family and to understand that when a young person has a problem, it is not the individual's personal issue but it is the system's issue. As the director commented, "A crisis is a problem without the tools to address it. We all have problems, but kids get into trouble because the system does not have the tools to help them with their

problem. We should really be saying, what tools do we need to help resolve this problem?”

Best Practices and Recommendations

- Cross-system crisis prevention and intervention planning is recommended and requires the intentional development of collaborative relationships among all service providers.
- Individuals and their families will use fewer crisis services if individual planning includes clearly delineated ways of dealing with emergencies (who to call and when) as well as access to respite services when needed.
- It is important to have forums in which families have input, “and not just the squeaky wheel families.” This may result in going

door-to-door to do interviews to find out what families really need and not assuming that the families with the greatest need are being served.

- A central part in learning how to support young people with dual diagnoses includes measuring outcomes and testing the degree to which people’s lives have really changed rather than being managed.

Citation

1. Lyons, J. (2008). *CANS Bibliography*. Chicago, IL: Buddin Praed Foundation. Retrieved 05/12/2010 from www.mass.gov/Eeohhs2/docs/masshealth/memlibrary/chbi_cans-bibliography.pdf.

BEST PRACTICE SUMMARIES



During our interviews we learned about several innovative practices and programs that were not specially designed for youth who are dually eligible but could be applied to this population. Each of these practices and programs is described briefly below.

PEER SUPPORT

Westchester County Department of Community Mental Health *Westchester County, New York*

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Westchester County, New York has had a system of care for children's mental health for many years, and services for youth with dual diagnoses have evolved from the system of care model where "what drives everything are the needs of young people and their families. Then we organize our services, not only to respond to identified needs, but also to insure that we are connected to one another in the service system."

The system of care serves around 150 young people with a primary mental health diagnosis, of whom about 20% have both a developmental disability and a mental health diagnosis. The county has a planning body across county departments and community agencies that include the de-

partment of social services, mental health, Mental Retardation and Developmental Disabilities, drug and alcohol, and probation that is co-led by young people. One of the young people who have been a peer leader has a significant developmental disability. There is a Transition/Aging Out Network and a peer support movement with 60 to 65 young people who provide help and support to one another. As the children's mental health director commented,

They are typically young people, who have spent much of their years in the child-serving systems, including residential settings... Now they are coming together to help each other to become successful adults. It is a very, very diverse group. There are significant numbers of young people with developmental delays in the group. There are young people with drug and alcohol prob-

lems in the group... They come together two nights a week in one location and one night a week in the northern part of our county (recently a second night was added). Then they do things together on weekends, holidays. They serve as an extended family and support system to one another."

The director reported that the participants are spokespeople and advocates who are active on policy, planning, and training committees. They are funded to play a role in the system, and they are partners with the family movement. A large number of young people with developmental disabilities are members of the group. The members have all suffered from stigma in their lives, and they want to make sure that that doesn't happen again to themselves or one another.

YOUTH DRIVEN RESOURCE MAPPING

PACER Center PROJECT C³ Minneapolis, MN

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Project C³: Connecting Youth to Communities and Careers is a collaborative program between several Minnesota state agencies and the PACER Center. Initially funded by a grant from the US De-

partment of Labor, Office of Disability and Employment Policy, the project now receives funding from Minnesota's Department of Education and the Department of Employment and Economic Development's (DEED) Vocational Rehabilitation Services. Administrative support is provided by DEED's Office of Youth Development. Project C³ provides 8-12 week internships for Minnesota youth with disabilities between the ages 16 and 22. Interns conduct resource mapping in their communities, located throughout the state.

Resource mapping is the collection of information about services and resources in the community. This information is then entered into an interactive searchable database. Information collected and mapped by Project C³ is relevant to all youth although a concerted effort is made to include in-

formation and resources relevant for youth with disabilities. Youth are paid during the internship and can also earn academic credit.

It's a great project for youth because it yields a product that can be utilized inside their community. They are proud and excited that their work will help other youth find resources and information that will help them be successful.

Project C³ is a community directed program. Each region, defined using Minnesota workforce regions, was allotted a certain amount of funds. Project C³ staff approached local communities with about \$10,000 to pay youth interns and additional support for the administrative costs of community stakeholders who agreed to serve as lead partners implementing local program activities. Community stakeholders decide how to use the money, how to recruit the youth, the length of the project, and which community partners should be involved. Project C³ provides a trainer that can meet in person with both partner agency staff and youth interns, and who also provides technical assistance and training to community partners and youth remotely via online meetings.

Initially we attempted to enter each community with a standardized model, but it didn't work. You have to come in to the community and partner. Take the time to build relationships, visit with folks and figure out how it works best for them and the youth in their community. You tell us how it should be done.

Youth interns are responsible for collecting information and managing the data, entering the data into the searchable database, and making public presentations on the project. At the completion of the internship youth have gained valuable work experience and the community has a searchable database of resources about employment, transportation, housing, education, recreation, and health assistance created for youth by youth.

By September 30, 2009 Project C³ will have mapped youth resources in communities throughout Minnesota. The internship model, collaboration between state agencies, and local partnerships established through Project C³ activities have already begun to yield creative new work-based learning experiences for youth with disabilities in communities throughout the state.

TRANSITION TO INDEPENDENCE (TIP) MODEL

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Jewish Family and Children's Services has developed a transition program based on the Transition to Independence (TIP) Model developed by Clark and associates (see Clark & Davis, 2000) that serves approximately 60-65 young people aging out of foster care. The program is designed to serve youth aged 16-22, although most participants are 17-19. All participants have mental health needs and at the time of the study, there were two participants who also had a developmental disability. Each young person is assigned a facilitator who functions as a case manager and who works with

the young person to assure that they complete their education and have a stable living situation; have access to training and/or employment; gain daily living skills, including budgeting, cooking, and cleaning; learn skills to manage their illness; and are able to access information, resources, and benefits they are entitled to. The transition program uses a strengths discovery process in planning with youth and assessment of needs in the four domains of interdependent living (living situation; employment/career; education; and personal well-being and effectiveness in community and life functioning) and then develops an individualized services plan (ISP) with each young person. The director expressed appreciation for this model of service delivery and noted,

So far, it seems to be working pretty well. The thing I like about it the best is that it

always checks back in with the youth themselves, and says to the youth, 'What is working for you? Is this what you thought it was going to be? Is this what you think you need?' It is another important skill for them to learn.

In addition to participating in their own transition team planning process, young people participate in decision making through an advisory council and committees.

Citation

Clark, H.B., & Davis, M. (Eds). (2000). *Transition to adulthood: A resource for assisting young people with emotional or behavioral difficulties*. Baltimore, MD: Paul Brookes Publishing.

COMMUNITY CONNECTIONS

A Grace Place Adult Care Center: Connections Program Richmond, Virginia

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The Connections Program at A Grace Place is made up of five teams who provide day services for adults of all ages with developmental disabilities. Each participant chooses from three available

program models:

1. The Community-based Team that spend the majority of their time in the community at local businesses and attractions,
2. The Center-based Team that spends the majority of their time at the center in a specially designed activity room playing table games, video games, doing arts and craft projects, and meeting various medical/physical/ADL needs and taking occasional community trips, and
3. The Combo Team that is based out of an activity room but also frequently and regularly visits local businesses and attractions.

Of the 130 program participants, ten are within the 16 to 24 age range with dual diagnoses. The focus of the program is on maintaining

and increasing skills in self-care, socialization, and community living skills, with the goal of maximizing independent living skills. The program includes opportunities for social activities and recreation. Recruitment of young people to participate occurs at high schools, transition fairs, service fairs, and through case manager referrals. The program uses person-centered practice and a zero-rejection policy. All staff are trained in the Therapeutic Options model (see www.therops.com for information), which prepares staff to effectively anticipate, prevent, understand, and safely intervene regarding maladaptive behaviors, including aggression. Each new participant develops an Individualized Services Plan/Person Centered Plan (ISP/PCP) that details the participant's goals for the upcoming year including individualized strategies for reaching their goals. Each plan is updated annually or as needed when a participant's goals or situation changes. Included in the development of the ISP/PCP are the individual, their case manager, an agency representative, and any other relevant or invited parties. The ISP/PCP focuses on areas important to the individual including their interests, hopes, health, and safety. Participants do regular activities in the community and are also involved in various special events including parties, cook-outs, fashion and talent shows, special day trips, and field days. Additionally, participants are engaged in the agency's wellness and creative arts initiatives. A program emphasis is on participants volunteering to do tasks within the agency and in the community for organizations such as Meals on Wheels, the Special Olympics, and a local church. The director noted that it is important for young

people to have a sense of purpose and to be contributors and that volunteering provides opportunities for building skills and is a way of increasing their confidence.

They volunteer for others, but it is for their own benefit first and foremost. I think that instills a sense of pride and when you have a sense of pride, you work harder toward your goals. We see individuals become more independent and they often exhibit fewer maladaptive behaviors.

The participants are also encouraged to be self advocates both within the agency and at local and state events including rallies and an annual trip to the State Legislature / House of Delegates in anticipation of the State budget process. The program maintains daily communication with caregivers, by sending home notes about the activities, challenges, and successes of the day and responding to caregiver questions. There is also a quarterly newsletter and the staff organize several caregiver support events each year in which staff provide care for the program participants while the caregivers participate in classes on topics such as healthy diets and managing aggression, in addition to socializing with other caregivers. There is also an "in-home residential" program, scheduled to open this fall, where a staff member goes into the home and works with the individual. This will allow the primary caregiver time to focus on other priorities. Staff will also share skills and approaches with the caregiver to help them to better manage challenging or disruptive behaviors.

CULTURALLY SPECIFIC SERVICES

La Familia Sacramento, California

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La Familia is a non-profit children and families mental health agency that serves youth up to their 21st birthday. Of the 200 families served, approximately 5-7% are the families of youth with dual diagnoses. Using a family team approach, staff work entirely in the community, usually at the family home or the child's school.

The program serves very diverse populations and therefore, of the 15 clinicians working at the agency, eight are Spanish-speaking and five are Hmong-speaking. The director noted that the program approach is to:

Work with the parents' acculturation challenges, language barriers. Staff must understand the parent's perspective, what they want for their child... Don't use translators, if possible. Having a clinician from the adolescent's culture is very helpful when working with the family. Use the wraparound philosophy for helping the entire family, not just the youth.

La Familia staff are focused on gaining understanding of the capabilities of the youth and family and uses wraparound processes to bring together all the natural supports that can help families, including all of the relationships to support the youth "from a great uncle or the mechanic down the street that took a liking. That is the best basis of helping those families."

Program staff at La Familia emphasize the importance of close working relationship with families and by being able to work with families and young people in their homes, they have much more understanding of the families' needs and circumstances than if they met at the agency. This is enhanced by staff always speaking the families' languages. They also use art therapy to draw out young people whose communication skills are limited, for example, the director reported about an isolated young person:

I say bring him to the art therapy group and you will see a 120 percent turnaround, because it is a small group. They can use art as a medium to start talking to each other in, and you just see them change... That is an excellent place because they feel comfortable there.

Youth participants have been involved in program evaluation in the role of data collectors for a SAMHSA grant. The director reported that youth received extensive training to do interviews with families at the beginning of their services and at six-month intervals. She added that, "It worked out well. A couple of them went on to gain employment as youth advocates with the Mental Health Association.

DISCUSSION



Study respondents described varied examples of how the “ideal” characteristics identified in the NASMHPD report (2004) were implemented. In this section, we will summarize the ways in which respondents from selected programs described the ideal characteristics present in their programs.

Assessment and Screening

At most of the programs described, trained professionals were reported to complete screening and assessment using appropriate instruments. Some of the programs conduct their own assessments, for example, the Serendipity Transition to Independence Program uses the Adult Needs and Strengths Assessment – Transition (Burt, Carter, Christie & Rainey, 2003), the Woodcock Johnson test of academic achievement (Woodcock, McGrew, & Mather, 2001), and the Life Centered Career Education (Council for Exceptional Children, 2010) instrument to assess youth entering their program. Other programs rely on assessments completed by the referring organization supplemented with their own assessments; for example, the Intercept Center serves young people who have already been diagnosed with a developmental disability and therefore the focus is on a modi-

fied mental health evaluation to take account of the developmental disability. For this purpose, Intercept staff use the Behavior Assessment System for Children (Reynolds & Kamphaus, 1992) with the self-report section completed orally to accommodate different reading levels. They also use the National Child Traumatic Stress Center Baseline Trauma assessment (National Child Trauma Stress Network, 2004) and the Woodcock Johnson (Woodcock, McGrew, & Mather, 2001). The Mosaic Program reported caution in the use of screening instruments based on their experiences with youth transitioning from institutional care, where their functioning has been compromised by the institutional structure.

“No Reject” Stance

Mosley (2004) recommended a “no reject” stance allowing access to mental health and developmental disability services for youth who are dually eligible. Programs in our study varied in the extent to which they adhered to this principle, depending on their mission and collaborators. For example, because the Project SEARCH Program places participants in private employment situations, they work with youth who are most likely to succeed in the mainstream workforce. The

program maintains high standards of appropriate dress and behavior and if young people do not meet these standards, they may be asked to leave the program. Trillium's YAP program has few criteria for inclusion but cannot serve youth who are registered sex offenders because of the facility's proximity to a school. At the other end of the spectrum, the Francis Foundation serves young people whose needs cannot be met by any other agency and a no-reject perspective is central to this approach.

Person-Centered Services

All the programs we examined in this study were described as providing individualized or person-centered services beyond diagnostic needs. Several of these programs incorporate youth goals in multiple life domains. For example, both Mosaic and Trillium's Youth Adult Program serve young people transitioning from other settings, with services designed to support participants to complete their education, obtain employment, develop independent living skills, connect with local resources, and manage their own health and mental health needs. Similarly, Serendipity works with youth to develop these skills in a day school with therapeutic case management. Project SEARCH works with youth to identify career interests and tailors the internships to build skill sets related to the youth's interest.

Funding

Funding for most of the programs identified in this study was through Medicaid waivers at the state level. Unfortunately, restrictions in the waiver program result in some supportive services not being funded for this population. Additionally, in some states waivers will not fund services for youth with an IQ above 70 or therapy services for young people with developmental disabilities. Because of this problem, some programs are funded through state mental health funding. Some programs such as Serendipity are funded through education districts. Project SEARCH has an innovative system of "braided" funding whereby relevant service sectors fund specific program elements,

e.g., education pays for the employment preparation classes, Vocational Rehabilitation pays for job coaches, and Mental Health pays for the services of a psychiatric nurse. In general, flexible funding is desired by staff of these programs, but funding continues to be quite restrictive, resulting in constraints on what programs can offer. Another challenge is related to the transition from child-serving to adult-serving systems with different funding streams.

Cross-Training

While it is a goal to have services provided by professionals trained in both mental health and developmental disabilities interventions, at this time, most service providers are trained in one area of disability. Programs try to ensure that staff are adequately cross-trained in both disability arenas and that they understand the interaction between the two types of disabilities. For example, staff come to the Intercept Program with mental health knowledge and skills and receive additional knowledge and skills training to understand and meet the needs of youth who also have a developmental disability. The Francis Foundation provides staff training to assist service providers to modify traditional mental health interventions to be appropriate for young people who also have a developmental disability. The Vermont Crisis Intervention Network provides trainings to community professionals about how to identify and address mental health disorders in people with developmental disabilities.

Evidence-Supported Interventions

The NASMHPD Report (2004) recommended that services provided to people who are dually eligible be based on the most current research specific to the needs of this population. Programs in this study demonstrated their commitment to this principle by continually seeking new information and engaging in staff training, as described above. To meet the needs of individual young people, staff at the Mosaic Program described doing Internet research focused on specific disorders in order to find the most up-to-date diagnostic and treat-

ment information, then sharing the findings with other staff in supervision. Staff also attend conferences and trainings. The Center for START Services provides trainings and technical assistance to programs to improve cross-system collaboration and comprehensive assessment and individualized intervention planning.

Trauma-Focused Interventions

The NASMHPD recommendation that service providers be knowledgeable about the effects of trauma, interventions to address past trauma, and practices that reduce retraumatization was affirmed by several of our respondents. Because of the high rate of traumatization of this population, program directors place emphasis on training staff to offer appropriate treatment. For example, Intercept staff receive training in Trauma-Focused Cognitive Behavioral Therapy. Staff at the Mosaic Program are assigned to work briefly in an institutional setting in order to begin to understand the traumatic effects of living in a restrictive setting and the residential staff consult with a trauma consultant on a regular basis.

Caregiver Support

Some programs in our study were described as incorporating caregivers in their intervention planning and/or implementation of services. In their consultation with states and counties, the Center for START Services recommends doing outreach to families based on the belief that families need support and those who need it most are least likely to ask for assistance when they are overwhelmed with caregiving demands. Serendipity staff are in contact with caregivers regularly and there is a telephone in the classroom so that parents can call teachers directly to share their concerns. Project SEARCH staff ask caregivers to sign a contract and to attend regular meetings to support their youth's successful participation in the employment preparation program. Youth transitioning from child welfare or psychiatric facilities may have little or no contact with families and therefore the Mosaic Program reaches out to families to invite them to be involved in social and other activities.

Least Restrictive Environments

All of the programs featured in this study provide services in less restrictive settings. Serendipity, the Intercept Center, and Project SEARCH provide non-residential programs and their participants return to their own living situation each evening. The Mosaic and Trillium programs are residential programs designed to assist young people to transition from restrictive settings to community independent living. In addition to providing training and on-site consultation, the Vermont Crisis Intervention Network has two short-term residential beds for crisis placements to avoid the use of state hospital or other inpatient facilities.

Cross-System Collaboration

In line with the NASMHPD recommendation that mental health and developmental disability systems work collaboratively to provide services to individuals, the programs in this study are all based on cross-system collaborations of various types. To varying degrees, mental health and developmental disabilities systems are collaborating to meet the needs of young people served by these programs. For example, Serendipity is an educational program with a significant mental health component and relationships with community mental health agencies, as well as Vocational Rehabilitation. However, this is an area of challenge for some programs, and some respondents wished that collaboration could be stronger. The Center for START Services provides technical assistance to states and counties focused on assessing and removing barriers to communication and collaboration to strengthen services to young people with dual diagnoses. Collaborations with the criminal justice system, primary health care and public health systems, were rarely mentioned by our respondents, although it is common knowledge that members of this population are involved with the juvenile and criminal justice systems and are served in health care settings. Further development of collaborative relationships and arrangements is an area for future development.



CONCLUSION

The specific aim of this project was to identify effective programs and best practices that address the needs of youth and young adults with both mental health and developmental disabilities as they transition into adulthood. Based on a review of the literature and multiple interviews with providers, administrators, and policy makers four general conclusions were reached.

First, a body of literature is available that describes the population characteristics of youth who are dually eligible and examines prevalence rates through several lenses. Further, the literature describes and discusses the challenges that are unique to this population. Although little of this literature focuses on issues associated with transition into adulthood, there is reasonable documentation of the problems faced by young people, their families, and providers. In addition to literature that described the characteristics and needs of the population, a few articles were found that details programmatic approaches that had been either developed or modified to address the needs of these young adults (Dykstra & Charlton, 2003; Jacobson, Holburn, & Mulick, 2002). The existence of these program descriptions supports our understanding that there are a small number of leaders who are focusing their clinical and pro-

grammatic efforts toward addressing the needs of dually eligible young adults. The intervention literature is, for the most part, descriptive in nature and little research has been done to establish evidence of the effectiveness of clinical approaches or holistic programs. The available literature on effectiveness of programs report on small samples and/or depends on case examples (Prout & Nowak-Drabik, 2003).

Second, among the programs that serve young people with both mental health and developmental disability challenges, two distinct types emerged. The first type of program is organized specifically for individuals with dual diagnoses, with some serving all ages and others serving only adults or only children. Examples in this monograph would be Aurora Mental Health (Intercept Program) and Francis Foundation. This type of program usually serves a limited number of young adults and may allow them to remain in the program throughout adulthood. Most often, this type of program is supported through the development disabilities system. The second type of program supports youth and young adults with mental health challenges during transition and makes special efforts to serve youth with dual eligibility in the same program. Examples in this monograph

would be Mosaic and Project SEARCH. These programs face unique challenges related to individualizing core interventions so that they are effective with dually eligible young adults. Supportive programs for youth with mental health challenges are more commonly available than programs focused solely on individuals with dual diagnoses. However, many programs for transition aged youth have yet to recognize the needs of youth with developmental disabilities and they have not yet begun to modify or adapt their approaches to accommodate these needs. Most often, this second type of program is supported through the children's mental health system but may have limitation in regards to services after age 18.

The third conclusion is that there is an emerging understanding that youth and young adults with developmental disabilities can benefit from mental health interventions if these interventions are modified to meet their cognitive abilities. In the 1970's and early 80's, some research was conducted that suggested individuals with developmental disabilities and mental health challenges were not benefited by mental health therapies. This early research was lacking in rigor and more recent studies have found moderate effects of psychotherapeutic interventions on persons with mental retardation (Prout & Nowak-Drabik, 2003). Interviews in our study suggests that leaders in the developmental disabilities field understand that youth and young adults with developmental disabilities can benefit from clinical interventions, especially if these interventions have been modified to accommodate their developmental disabilities. Professionals in the mental health field are less clear about the potential of therapeutic interventions with youth who are dually eligible, and some still believe that mental health services to individuals with intellectual disabilities are not effective.

The fact that some mental health clinicians have been reluctant to work on mental health issues with individuals who have developmental disabilities is at least partly due to the lack of research evidence. Several of our interviewees commented on the need for this specific kind of research. Perhaps the most likely place where

evidence might be developed quickly is in the treatment of trauma. The effect of trauma on individuals with dual diagnoses and the frequency with which they experience trauma is beginning to demand attention. Issues related to trauma were brought up frequently in our interviews and several of the programs highlighted in this monograph address trauma with participants. One program (the Intercept Center at Aurora Mental Health) has developed a modified trauma intervention and is conducting research to test its effectiveness. Related to the need for modified mental health interventions is the need for assessment tools that are adapted to accurately diagnose mental health conditions in youth with dual eligibility. The existence of diagnostic shadowing has been documented as a major barrier; however, empirically supported screening tools that help providers sort out which symptoms result from the developmental disability and which suggest mental health needs are not yet available.

Related to the need for effective assessment tools and mental health interventions is the need to encourage more professional training programs to cross-train professionals in both mental health and developmental disabilities. The need for mental health professionals who are skilled in working with individuals with developmental disabilities was repeated in almost every interview. Many program directors report the need to "train their own" by conducting training programs in house for their staff (e.g. Francis Foundation). Others report bringing in a national consultant to work with staff and participants or sending valued staff back to school to gain mental health expertise. The NADD, An Association for Persons with Developmental Disabilities and Mental Health Needs, provides online training modules, organizes a national conference, and publishes bulletins (www.thenadd.org). Centers of Excellence in Dual Diagnosis are functioning in a few states (Ohio: [www.ohiomidd.com/Ohio_Coordinating_Center_of_Excellence_\(CCOE\)/Home.html](http://www.ohiomidd.com/Ohio_Coordinating_Center_of_Excellence_(CCOE)/Home.html), Wisconsin: <http://cow.waisman.wisc.edu/dualdiagnosis.html>) and these also provide training and disseminate information. Incentive programs, such as training

grants and trainee stipends, would increase the number of well trained service providers.

The fourth conclusion is that there are major differences between the philosophies and approaches of the mental health and developmental disabilities systems and these differences affect the type and amount of services that young people receive. The effects of these differences have been clearly described and discussed by Mosely (2004). Differing beliefs about the potential of dually eligible young adults to move into independent adulthood, along with differences in federal policy and funding streams, make productive collaboration between these two systems challenging but not impossible. Our study did not focus on finding effective collaboration between mental health and developmental disabilities at state or local level and therefore we cannot draw any conclusion about how frequently this exists. However, our interviews suggested that there are some places where good collaboration has been developed. More frequently, we heard about difficulties created by eligibility criteria and restricted funding streams. The challenge of spanning system boundaries is further complicated by the bifurcation of services between children and adults that exists in both systems but is particularly pronounced in the mental health system.

Several other issues have emerged during the writing of this monograph that were not anticipated in the original research questions. They deserve brief comments here. We noticed that many of the programs involved congregate living as opposed to living with a family or roommate in the community. Although this may have been an effect of the purposive sampling we employed, it appears that services for these young adults are often centered in group homes, residential treatment, and similar facilities. Housing and appropriate adult support are needs for all young people transitioning into adulthood and it is more difficult to find appropriate levels of support for young adults with mental health challenges. It seems, however, that when the young person also has a developmental disability, programs and providers lean toward more restrictive, congregate, care approaches, rather

than finding ways to design community based programs that prepare these young adults to achieve more optimal levels of community integration.

Related to the observation that many services are provided in restrictive living settings is the observation that this population is more likely to use the crisis service system and to receive at least of some of their services there. This is due, in part, to the difficulties some individuals with developmental disabilities may have in processing traumatic experiences and understanding their feelings and reactions (Charlton et al., 2004). It may also be related to the lack of effective mental health services that would allow young adults to identify and manage difficult feelings in a more positive way. The Vermont Crisis Intervention Network addresses this need by providing crisis training for professionals, on-site consultation, and direct intervention through available crisis beds. This network, focused on the needs of individuals with developmental disabilities, is unusual in its comprehensiveness and focus.

Our final observation focuses on the etiology of mental health disorders in persons with developmental disabilities. A review of the prevalence data calls for a discussion of the high rates of mental health challenges in this population. One explanation that is frequently offered is that individuals with developmental disabilities have more difficulty communicating and therefore are less able to process and adapt to difficult events in their lives. Another explanation offered more recently is that young adults with developmental disabilities are more likely to have spent significant time in institutions and have experienced high rates of traumatic events that are difficult for them to process. Even for young adults living in the community, the incidence of stigma and bullying is high. If this explanation is true, then we should see higher rates of mental health challenges among young adults with developmental disabilities than observed among younger children, an empirical question that has not been explored. A third explanation is that mental health challenges are physically rooted in the developmental disability and that the risk of mental illness is high for most children with de-

velopmental disabilities. If this explanation is true, then early childhood interventions should be effective. The high rates of mental health conditions in young adults with developmental disabilities may represent a failure of early childhood development systems to identify mental health challenges and intervene more effectively. Although the truth probably lies in a combination of several potential causes, further exploration into ways to prevent mental health difficulties for this population is needed.

Taken together, the conclusions and observations of this study present a sobering picture for a group of young adults whose needs for effective mental health services and sound transition supports have been overlooked or ignored. Although

the pathway to helping young adults who are dually eligible is complex, the human and financial costs of failing to provide effective services is high. Young adults with dual diagnosis are finding their way into the criminal justice system, homeless shelters, and emergency services in staggering numbers. Providers are stressed because they aren't able to serve these young adults properly and families and caregivers are demoralized by the caregiving demands and lack of hope for the future.

The programs and best practices described in this monograph provide evidence that these young adults can be effectively supported as they do their best to move successfully into a productive adult life.



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APPENDIX A

INTERVIEW PROTOCOL: TRANSITION PROGRAM ADMINISTRATORS/SERVICE PROVIDERS

Thank you again for agreeing to participate in our study on transition to adulthood services for youth age 16-24 that have developmental and mental health disabilities. These questions will help us gather information about transition services, and how they are provided and administered.

Before we begin I would like to review the cover letter sent to you earlier.

Below are the topics we would like to talk about during our conversation. We may add questions to get a clearer understanding of your answer.

First, we would like to get the following information:

<i>Position Title/Role</i> _____	<i>Length in Field</i> _____
<i>Program Name</i> _____	<i>City</i> _____

INTERVIEW SCREENING:

1. How many people do you serve who are 16-24 and have both a developmental and mental health disabilities?
2. What percentage is this population of the total population you serve?
3. What services do you provide to people in this age group who are dually eligible?

SCREENING AND ASSESSMENT:

Developmental Disability:

1. Do the people you serve receive developmental disability assessments?
2. Who completes these assessments [education level]?
3. How often are assessments completed?
4. How do you define developmental disability?
5. What developmental disabilities does your program address?

Mental Illness:

1. Do the people you serve receive mental health/illness assessments?
2. Who completes these assessments [education level]?

3. How often are assessments completed?
4. How do you define mental health/illness?
5. What mental health/illness does your program address?

Substance Use Disorders:

1. Do the people you serve receive substance use assessments?
2. Who completes these assessments [education level]?
3. How often are assessments completed?
4. How do you define substance use disorders?
5. What substance use disorder does your program address?
6. Are there strategies or ways you have assessed developmental disabilities, mental illness, and substance abuse disorders that have worked well?
7. Do you have recommendations about assessments for others who may be starting programs?

Accessibility:

1. What are your eligibility criteria for participating in your program? [Probe: age, funding source, guardianship]
2. What would cause someone to be considered ineligible to receive your services?
3. How do people know about your services?
4. What are the primary referral sources?
5. What do you think your program has done well to increase accessibility?
6. Do you have recommendations about making services accessible for others who may be starting programs?

Person-Centered:

1. Are you familiar with the term “person-centered”?
2. Do you provide “person-centered” or individualized planning services? (What name do you call this?)
 - a. Describe how individualized planning is carried out in your program?
 - b. How are families/caregivers involved in this process?
3. Are there individualized planning services/strategies that have worked well?
4. Do you have recommendations about implementing individualized services for others who may be starting programs?

Support Guardian/Caregivers:

1. What percent of the people you serve are living:
 - a. with family members?
 - b. in foster care settings?
2. Do you provide services or supports to family members/guardians/caregivers?
 - a. Describe:
3. Are there things you have done that have worked well to involve families/foster families/guardians?
4. Do you have recommendations about services to families/guardians/foster families for others who may be starting programs?

Financing:

1. How are your services funded?
 - a. Do you receive funding from both mental health and developmental disabilities?
2. How does funding impact service delivery?
 - a. Does the funding source support or constrain providing any particular services?
3. Do you have recommendations about funding strategies for others who may be starting programs?

Trained Staff:

1. Are there training and/or educational hiring requirements for your direct service staff?
 - a. Describe:
2. Do you hire mental health consultants to supplement your staff?
3. Do you hire developmental disability consultants to supplement your staff?
4. Do you hire substance use consultants to supplement your staff?
5. Do your staff receive training about mental health/illness?
 - a. Describe:
6. Do your staff receive training about developmental disabilities?
 - a. Describe:
7. Do your staff receive training about substance use?
 - a. Describe:
8. Do your staff receive training about trauma and PTSD?
 - a. Describe:
9. Do you cross-train staff?
 - a. Describe:
10. Are there things you have done that have worked well to cross-train staff?
11. Do you have recommendations about staff training for others who may be starting programs?

Best Practice/Evidence-Based:

1. How do you meet participants' needs in the following areas:
 - a. Mental Health
 - b. Trauma
 - c. Substance Abuse
 - d. Educational
 - e. Life Skills
 - f. Employment
 - g. Transition
2. Do you provide any other types of services?
 - a. If so, what are they?
3. How frequently do participants receive services?
4. Typically, how long do participants receive services through your program?
5. Of all of your services which do you consider a best practice?
 - a. Why do you think this is a best practice?
 - b. What outcomes are associated with this practice?
 - c. Has this service been evaluated?
6. Are there best practices or evidence based practices that have worked in your program?
7. Do you have recommendations about using best practices or evidence based services for others who may be starting programs? [Things you have heard about or tried?]

Least Restrictive Setting:

1. Do you feel you provide the least restrictive setting for the people you serve? Why or why not?
2. Can you provide any examples when this population is not served in the least restrictive setting?
3. What strategies or services do you provide that have promoted community integration?

System Collaboration:

1. Are there ways the mental health and developmental disability systems work together in your area?
 - a. Example:
2. What has your program done related to collaboration between the DD services/systems and MH services/systems?
3. Do you have recommendations about collaborating for others who may be starting programs?

General:

1. Is there anything else you'd like to tell us about what works well in serving young people aged 16-24 who are dually eligible?
2. Do you have any recommendations for who else we should talk to about best practices for this population?

APPENDIX B

SELECTED RESOURCES

The following sites provide information about Trauma Informed Cognitive Behavioral Therapy (TF_CBT) and TF-CBT for persons with developmental disabilities:

tfcbt.musc.edu/

mediasite.nctsn.org/NCTSN/Viewer/?peid=fb538448-fa70-4719-b73a-b9d59a067bfd

The National Child Traumatic Stress Network site offers resources about trauma including interventions for diverse populations:

www.nctsn.org

Site about modified dialectical behavior therapy for persons with developmental disabilities:

www.nctsn.org/nctsn_assets/pdfs/promising_practices/dbtsp_general.pdf

The NADD, An Association for Persons with Developmental Disabilities and Mental Health Needs website offers a variety of resources and training opportunities for providers, care givers, and families about providing services to people who have developmental disabilities and mental health needs:

www.thenadd.org

Online report: National Association of State Mental Health Program Directors. (2004). Serving individuals with co-occurring developmental disabilities and mental illnesses: Systems barriers and strategies for reform. Alexandria, VA: NASMHPD:

www.nasmhpd.org/general_files/publications/MIDD%20report102704FINAL.pdf

The following site provides information about the Life Centered Career Education curriculum used by Serendipity:

www.cec.sped.org/Content/NavigationMenu/ProfessionalDevelopment/ProfessionalTraining/LCCE/LCCE_what.htm

The Adult Needs and Strengths Assessment—Transition (ANSA-T) is an assessment instrument that provides agencies, families, care coordinators, and other helping-professionals essential information for development of individual plans of care:

www.praedfoundation.org

