

White Paper

**Transition Age Youth in Oregon:
Considerations for a
Statewide Model of Care**

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Service Delivery Concerns

Multiple system barriers at the federal, state and community level contribute to the problems transition age youth ages 16 – 24 face in Oregon. These transition age youth are 80% *less* likely than any population in Oregon with mental health needs to receive services. Barriers to service include: Eligibility guidelines for financial and housing services; differences in ‘eligible’ diagnoses between child and adult mental health providers; conflicting roles among service providers; a lack of age appropriate community resources and a (youth) culture that is often difficult to engage in services. While these are difficult issues to resolve, a concerted effort must be made. The State of Oregon pays millions of dollars each year to treat these youth as children and adolescents. Then at the point in their lives when intervention can have a profound impact on their lives and their ability to live as independent, productive adults the existing systems fail to provide adequate services to them.

The State of Oregon pays millions of dollars each year to treat these youth as children and adolescents. Then at the point when intervention can have a profound impact, we fail to provide adequate services.

In adolescent mental health the early symptoms of mental illness are not easily diagnosed. The under-developed symptoms of mental illness often overlap with the normal turmoil of adolescence.¹ Behavioral difficulties or drug and alcohol use frequently cloud the underlying symptoms. When service providers lack the clear criteria for psychotic or other formal thought disorders the diagnostic uncertainty is often a barrier to providing adequate care. For parents and guardians, fear of what the youth *might do* often results in adolescents being placed in restrictive residential treatment programs or in attempts to obtain a court order for civil commitment.

According to the Journal of General Psychiatry² “Virtually all persons who met criteria for a DSM IV psychiatric disorder at age 26 had met diagnostic criteria for a mental illness at an earlier age. Most notably childhood conduct disorder and oppositional defiant disorder was part of the developmental history of the majority of all adult disorders.” Unfortunately, neither conduct disorder or oppositional defiant disorder meets criteria for adult mental health services.

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Although some people develop mental illness in adulthood, more often the onset of Severe Emotional and Behavioral Disorders (SEBD) interferes with critical periods of development during childhood and adolescence. The onset of mental illness in adolescence often has a long-term impact on the individual’s capacity to function as an adult.

¹ Singh, Swarn; Evans, Navina; Sireling, Lester; Stuart, Helen (2005) Mind the Gap: The Interface Between Child and Adult Mental Health Services Psychiatric Bulletin 29, pp292-294.

² Kim-Cohen, J; Caspi, Avshalom; Moffitt, Terrie; Harrington, HonaLee; Milne, Barry; Poulton, Richie (July 2003) Prior Juvenile Diagnoses in Adults with Mental Disorder Archives of General Psychiatry, Vol 60

What the Outcomes Look Like

Most young people expect that upon turning 18 they will get jobs, find girlfriends or boyfriends, rent apartments, buy cars and most of their problems will disappear. Instead, multiple studies on young adults with SEBD demonstrate that without adequate treatment and support systems in place the possibility of these young people fulfilling their dreams is unlikely. Instead, left untreated these are the young people who become homeless, drug addicted or unable to complete school or hold a job. Often they become involved in criminal activity and may eventually be court mandated into care.

The Bazelon Center for Mental Health Law reports the following:

- Only about 50% of youth with SEBD (as compared to 81% of the general population) obtain a high school diploma.
- Of those who were unable to successfully complete high school 73% had been arrested at least once in the three to five years after leaving school.
- Adolescents transitioning into adulthood with SEBD are three times *more* likely to be involved in criminal activity than those adolescents without a mental illness.
- Young adults with SEBD are four times *less* likely to be engaged in any gainful activities including employment, enrollment in college or a trade school than their peers - even when socioeconomic status was held constant between the two groups.
- It is estimated that as many as 70% of youth in the Juvenile Justice system suffer from a mental disorder, with 25% of those experiencing disorders so severe that their ability to function is significantly impaired.
- An estimated 20% of youth receiving treatment for emotional or behavioral problems have either contemplated suicide or attempted suicide.
- Suicide is the second leading cause of death among young adults in Oregon.

These statistics are even more troubling for youth struggling with dual diagnoses, or for gay, lesbian, bisexual and transgender youth. Within these populations, attempted suicide rates rise to almost 30%.

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The Need for Access to Culturally Relevant Systems of Care

Because of eligibility differences between systems of care, no state has found a way to provide adequate and culturally relevant mental health

services to youth once they reach an age only served by the adult mental health system.³

Multiple barriers can be found throughout systems of care. Some of these barriers may be found in Administrative Rule or Statute, but often they have simply evolved over time within the agency's policy and practice. For example, in Oregon, when a young person with SEBD is determined eligible for developmental disability services, they are not eligible for certain services from mental health. Even though the client may be dually diagnosed, it is expected that SPD (Services to People with Disabilities) will serve them. Likewise, if mental health serves a client, SPD typically does not. Yet in order to be determined eligible for many structured housing options through adult mental health, the client must be eligible for Social Security (*ie.disabled*).

Specific Populations

For youth who are in the custody of Child Welfare, guardianship beyond the 18th birthday is not recognized as beneficial by most adult mental health providers. In fact child welfare involvement can be a barrier to receiving services as an adult. The adult system would prefer clients with SEBD to have a court assigned legal guardian who holds a higher level of decision-making authority over the individual. The paradox is this: If child welfare discontinues guardianship (so the youth can be managed under an adult system) they lose access to many important resources such as education and medical coverage that would otherwise be available to them through age twenty-one.

These youth should serve as a model for deciding how we can best serve the transition age population.

Homeless youth present another set of issues. They represent one of the most at risk transition age populations. Despite the seriousness of their problems they often fail to receive mental health care. Culturally inappropriate services and inflexible guidelines are not suited to the needs of homeless youth. These youth need intensive services that are integrated into a continuum of care. When substance abuse or cognitive deficits also exist, their transition needs are prolonged and involve complex systems of care. These homeless youth have been described as “victims of piecemeal interventions”.⁴ “As with most young adults, they seldom fit into traditional molds. Services must be flexible and forgiving, allowing them the opportunity to try and fail and try again... just as they would be allowed to do within a family context.” Oregon's homeless youth should serve as a model for best serving the transition age population. The basic

³ -Davis, Maryann; Sondheimer, Diane (2005) State Child Mental Health Efforts to Support Youth in Transition to Adulthood Journal of Behavioral Health Services & Research 32:1 pp.27-42

⁴ Cauce, Ana Mari; Morgan, Charles J.; (1994) Effectiveness of Intensive Case Management for Homeless Adolescents: Results of a 3-month follow-up. Journal of Emotional & Behavioral Disorders Vol.2:4,

needs for autonomy, individuation and culturally meaningful social supports are developmentally the same as for other transition age youth who are not homeless.

Often forgotten are transition age youth incarcerated on criminal charges. In a study of 531 incarcerated youth following their release from an Oregon correctional facility (OYA), youth who accessed mental health services during the first six months following discharge were 2.25 times more likely to be engaged in meaningful ways with their community and 2.38 times less likely to return to OYA. These results speak not only to the prevalence of SEBD among incarcerated youth, but also point to the practice of focusing only on vocational training as being insufficient for most of these youth.⁵

We have such limited resources available to young adults with SEBD that the only option is often having them admitted to adult psychiatric wards or adult structured housing programs. It is unrealistic, culturally insensitive, and developmentally inappropriate to expect an 18 year old youth to reside with middle age adults who have chronic mental illness. We may only be succeeding in setting the youth on a lifelong path of aversion to mental health care.⁶

Providing Services

Transition programs are described as offering supports in the following areas:

- Completion of high school or equivalent diploma
- Post secondary education or vocational skill development
- Supported access and maintenance of employment
- Independent living skills
- Developing social support networks in the community
- Obtaining age-appropriate mental health services
- Youth participation in planning for coordination of services and supports

Youth participation is one of the most important goals in the development of a model of care for transition age youth. Without the ability to actively engage the young person in their own life, the supports we put in place are laden with adult authority and rigid rules. Frequently this is a set up for failure. Culturally appropriate and evidence-based models are needed for this age group. The composition of supportive teams must be a

⁵ Bullis, Michael; Yovanoff, Paul (2006) Experiences of Formerly Incarcerated Youth Journal of Emotional and Behavioral Disorders 14:2, 71-85

⁶ Singh, Swarn; Evans, Navina; Sireling, Lester; Stuart, Helen (2005) Mind the Gap: The Interface Between Child and Adult Mental Health Services Psychiatric Bulletin 29, pp292-294.

collaborative process between the youth and the care coordinator. Family-driven and client-directed care becomes a critical balancing act depending on the support available and the youth's ability to engage in the process.⁷

Another option to consider is the development of *Specialist Care Coordinators* who are able to work with both adult and children's mental health services. Bridging the gap between these providers will require adult services to adopt a more family-based system of care with a flexible approach to service delivery and eligibility criteria. Adolescent providers will need to let go of their reluctance to believe that these youth (who have never been considered safe enough to live in the community) will probably not meet criteria for civil commitment and now *must* be given the opportunity to live independently.

Necessary Supports

Flexible housing options must be a priority for developing any statewide model of care for transition age youth with SEBD. "Housing provides the stability that makes it possible for an individual to live, learn and work productively in the community. Without housing, much of an individual's existence is dictated by the need to find shelter, meals and other items necessary for survival."⁸ Oregon law prohibits a 17 year old from entering into a legally binding contract (ie. rental or purchase agreement). Without programs that are willing to co-sign housing agreements, access to HUD or other subsidized housing programs is severely limited for these youth. Age 17 is often the very age these young adults need to be learning and allowed to practice independent living skills.

A continuum of housing options must be made available. These housing options could include individual 'scatter site' apartments with wrap around supports, to Single Resident Occupancies (SROs) and group living environments. Available housing could then be matched to the youth's needs and abilities. Many of these youth are coming out of psychiatric residential programs where they have spent the majority of their childhood and adolescence. Their needs and abilities are varied. They may need to transition slowly through the entire continuum of housing options.

Eligibility for financial supports to youth actively involved in transitional services should be re-evaluated. Currently, unless a youth is continued under the guardianship of Child Welfare beyond their 18th birthday they are no longer eligible for Oregon Health Plan and General Assistance is

⁷ Armstrong, Dedrick & Greenbaum Factors Associated with Community Adjustment of Young Adults with Serious Emotional Disturbance Journal of Emotional and Behavioral Disorders vol 11, No 2 (Summer 2003)

⁸ Platte, Melissa; Kroner, Mark J.; Oritz, Robert Vocational and Transitional Services for Adolescents with Emotional and Behavioral Disorders: Strategies & Best Practices. Research Press: Behavioral Institute for Children (1993) Ch.5 pp 91-105

not available to them. The only other financial option is for them is to be determined eligible for Social Security as a youth, then re-qualify as an adult based on a severe and persistent (mental) disability. Unfortunately, Social Security eligibility requires the client to demonstrate (repeatedly) that the majority of his or her functioning is significantly impaired. The (application) process in itself can be disabling, contributing to a deficit-based self-image and often laying the foundation for a lifetime of disability claims. In the long run, short-term financial and medical assistance makes more sense and is the least demeaning to the client.

Of primary importance are programs that have a ‘no eject - no reject’ approach to services.⁹ In order to provide an unconditional safety net of services available to meet the client’s needs, we have to meet them where they are and when they are ready to accept assistance. Eligibility for services is often based on the mental health diagnosis and does not factor in the developmental and functional limitations of this age group.

Youth with SEBD respond differently... if the job or roommate is not to their liking, they simply quit or leave.

According to Naomi Zigmond (2006) “Developmentally, the average youth exiting high school who enter the job market do not have occupational aspirations. Instead they view work as a means to an end. Work equates to purchasing power... the power to own a car, buy a stereo or live independently with friends. Therefore, they will stick with a job whether they like it or not to maintain that power over their own lives. Youth with SEBD respond differently. If the job or a roommate is not to their liking, they simply quit or leave. They are not in jobs or relationships long enough to achieve advancement, benefit from the stability and continue to develop the maturity necessary to improve their standard of living.”¹⁰

Executive functioning and adaptive living skills are compromised in this population. In other words, simply providing traditional (adult) mental health services will not address other critical areas of development that were missed with the early onset of their illness. The goal for a self-determined life style is contingent on a skill set that is developed over time. Interestingly, individuals who show improvement in adaptive behavior demonstrate better overall outcomes in achieving independence. Adaptive behavior is shown to be the strongest predictor of success in this population.¹¹ Utilization of scales to measure adaptive behavior such as

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⁹ Youth in Transition: The Challenge Facing Connecticut: A Report on the Statewide Consensus-Building Project (May, 2000) Submitted by North Central Regional Mental Health Board, Newington, Connecticut

¹⁰ Zigmond, Naomi (2006) Twenty-Four Months After High School: Paths Taken by Youth Diagnosed With Severe Emotional and Behavioral Disorders Journal of Emotional and Behavioral Disorders 14:2, 99-107

¹¹ Armstrong, Kathleen; Dedrick, Robert; Greenbaum, Paul (2003) Factors Associated with Community Adjustment of Young Adults with Serious Emotional Disturbance: A Longitudinal Analysis Journal of Emotional and Behavioral Disorders Vol 11:2 66-76

the Vineland and the Index of Community Adjustment would provide a relevant starting place for working with transition age youth.

Service Delivery Models

Numerous projects have been undertaken across the country to better serve this population. Unfortunately many of the models attempt to ‘fit’ the young adult into a slightly modified program that would be more appropriate for a teenager. Evidence-Based Practices are in short supply for this very specialized age group. Most well known are the efforts of Hewitt (Rusty) Clark and his work with the development of the TIPS model in Connecticut. This model emphasizes engagement of the youth, individual and tailored services, client-driven care and support systems to facilitate the young person’s future (as opposed to directing it).

Casey Family Programs has a model called It is My Life, which assists youth transitioning out of foster care. The model allows the youth to choose one of four different developmental levels for assessing their abilities. Supplemental materials are available to assist with building specific skill sets such as parenting.

Cascadia, located in the Portland Metro area does good work with transition age youth. They utilize a combination of outreach, engagement and structure. They emphasize the client’s right to legitimate choices by allowing them to experience natural consequences while still maintaining the connection to their programs. The EAST Program also does an excellent job of this and provides services to youth experiencing a first psychotic break. Other providers such as Outside Inn, Central City Concern and P:EAR are doing some excellent work with these marginalized populations. Yet the systems of care necessary to adequately serve transition age youth remains fragmented.

Another model that is not being used in working with transition age youth, but could prove very beneficial in day-to-day interactions with this population is the Collaborative Problem Solving Model developed by Ross Greene, PhD and Stuart Ablon, PhD. The foundation of this model challenges our thinking that *children (people) would do well if they wanted to* and instead employs a strengths-based belief that *children (people) do well if they can*© .¹² This shift in thinking supports research that suggests when people of all ages have adequate information regarding their options and are supported in their decision making, they are likely to make healthier and more positive choices. The Collaborative Problem Solving model emphasizes strength

¹² Greene, Ross W., Ablon, J. Stuart Treating Explosive Kids: The Collaborative Problem-Solving Approach The Guilford Press, New York (2006)

based outcomes to measure success such as the development of communication or adaptive skills as opposed to measuring the reduction of dysfunctional behaviors.

One model, sometimes used in transition programs is derived from the Program for Assertive Community Treatment (P)ACT model. This is a well-known, evidence-based practice often used with adults who have chronic mental illness. (P)ACT is appropriate for the most difficult to treat symptoms and those with the greatest level of functional impairment. These are two very important considerations when looking at options for developing a model of care for this population. Some important qualities of this model include the following:

The foundation of this model focuses on the belief that children do well if they can.

- (P)ACT provides a multidisciplinary approach with service provided as long as needed. The services are not brokered, rather the ACT team itself is the service delivery vehicle in this model.
- (P)ACT often utilizes a ‘flexible fund’ which provides for the individualized and tailored needs of the client.
- Low caseloads and shared responsibility among team members
- Treatment and services are individualized
- Active engagement as part of a team with respect for the individuals right to choice and privacy
- Services are available on a 24 hour basis
- Services are typically delivered in the recipients’ natural settings.
- All aspects of (P)ACT are developed through utilizing a working knowledge of cultural considerations as well as the community and family norms to provide culturally relevant services.
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Statewide Efforts are Called For

In Oregon, the Secure Adolescent Inpatient Program (SAIP) unit provides the highest level of psychiatric residential care to adolescents. The cost of caring for one adolescent in the SAIP unit for one year is almost a quarter of a million dollars in treatment costs alone. The average daily census is 15 adolescents or 2.7 million dollars per year. Finding appropriate discharge options for these adolescents as they approach their 18th birthday is extremely difficult at best. The lack of resources in our state often results in longer than necessary lengths of stay, discharge plans that are less than ideal or even civil commitment.

The cost of caring for one adolescent in Oregon’s highest level of secure psychiatric care is almost a quarter million dollars a year.

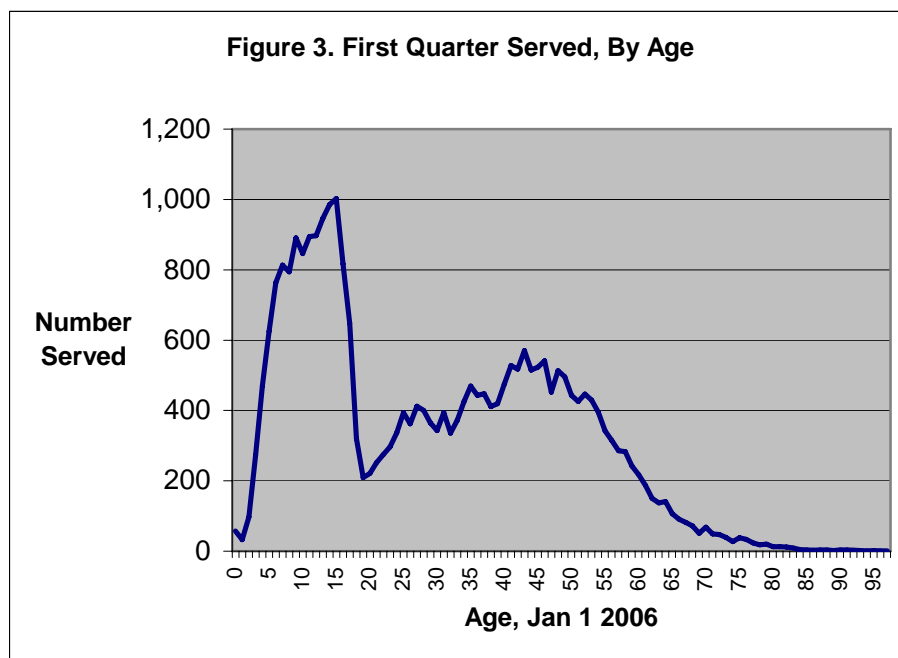
Nationally, more than 3 million transition age youth are diagnosed annually with SEBD. Many of these also struggle with addiction or other dual diagnoses.¹³ At any given time in Oregon there are approximately

¹³ Edgar & Siegal (1995)

one hundred youth in care facilities who are diagnosed with SEBD and are within six months of reaching their 18th birthday. One provider in Oregon is actively in the process of opening a transition age group home that will house *five* young adults. Currently there are no other psychiatric residential programs in the state appropriately designed to serve young people with SEBD between the ages of 16 – 24.

For most transition age youth with SEBD the long-term outcomes upon entering adulthood are dismal. Especially those formally served in psychiatric residential treatment programs, day treatment programs and juvenile correctional facilities. Unemployment, poverty, incarceration, homelessness, substance abuse, violence and impaired personal relationships are all too often the norm for many years following their transition into adulthood. These outcomes have widespread, generational impact and the costs to society as a whole are significant. Unfortunately services currently being delivered to this age group in Oregon are negligible.

According to data from the Addictions & Mental Health Division in Oregon (2006), mental health service delivery rates drop by a dramatic 80% between the ages of 16 and 24 (See figure 3).



What is Needed

A systems of care approach to working with the multiple needs of this complex population sits at the crux of developing a statewide model for our transition age youth. Barriers between Child Welfare, Developmental Disabilities, Alcohol & Drug Treatment Providers as well as Child and Adult Mental Health Services need to be openly addressed and dismantled

at the State level. Eligibility criteria for Medicaid or General Assistance needs to be modified to provide assistance to young adults with SEBD who are actively involved in transition services. Collaborative working relationships between agencies such as mental health, child welfare, vocational rehabilitation, housing agencies, developmental disabilities and the schools must be built in order to adequately address the needs of these young people.

The development of meaningful vocational training and career exploration that is more easily accessible to youth is also needed. A lack of awareness regarding available services along with reluctance to self identify as having a disability often severely limits the options for these youth.¹⁴

Vocational Rehabilitation and mental health agencies must identify trained, culturally competent individuals to assist this population in accessing services.

A standard of care where none exists must be developed and put into action. The State of Oregon needs to move from the current reactive mode into a planful proactive process that provides support and guidance for working with these struggling youth. The transition to adulthood occurs across relationships and environments as expectations and roles change.¹⁵ The development of a statewide model for transitional age youth must include a continuum of care that meets the client where they are and develops with them over time.

A Plan for Action

In consideration of these findings the Addictions & Mental Health Division in Oregon (AMH) is moving forward with the following series of initial actions steps to dismantle barriers that limit access to care for transition age youth:

- 1.) Utilize internal workforce development resources to guide an identified team through the change processes necessary to address barriers to service within AMH.
- 2.) Develop internal AMH policies and procedures for transition age youth that will serve as a guideline for case level decision-making and future program development.
- 3.) Review and develop funding structures that serve to bridge the gap between child and adult mental health service systems.

¹⁴ Lane, Kathleen; Carter, Erik (2006) Supporting Transition-Age Youth With and At Risk for Emotional and Behavioral Disorders at the Secondary Level: A Need for Further Inquiry Journal of Emotional and Behavioral Disorders Vol 14:2

¹⁵ Thomas, Jean W.; Moloney, Mairead (2001) "Who I Am and What I Want": Adolescents' Self-Definition and Struggles The Council for Exceptional Children Vol 67:3, pp.375-389

- 4.) Identify and implement necessary changes to existing administrative rules and regulatory statutes within DHS that currently act as barriers to service for this population.
- 5.) Develop and communicate a shared criteria for services among child and adult mental health providers, alcohol and drug treatment providers and other DHS divisions in order to improve access to appropriate care.
- 6.) Work from a systems of care perspective to develop cooperative agreements for care between multiple service providers including disability services, housing, vocational resources, education, health plans and community mental health providers.

None of the above steps for action are easily accomplished. Yet according to the Harvard Business Review's On Point Publication,¹⁶ AMH already has to its advantage multiple factors that are critical for successful change:

- √ There is a sense of urgency.
- √ We have the support of a powerful guiding coalition that is clearly communicated by our Administrators, Community Partners and Mental Health Advisory Committees.
- √ As a team we are empowered by the support of our Administrators to develop a system of care to address needs specific to this population.

These efforts **will** comprise a new chapter in Mental Health Services for the State of Oregon.

¹⁶ Kotter, John P. Leading Change: Why Transformation Efforts Fail, Harvard Business Review (2005) On Point #4231