



ISSUE BRIEF

Age and Developmental Considerations in Early Psychosis

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Introduction

Adolescence and young adulthood is a time of profoundly significant and interactive biological, psychological and social developmental changes which create the underpinning for successful adult functioning. In designing and providing early psychosis services to persons who are navigating these developmental changes, it is important to understand the normal process of development, how psychosis occurs, ways in which psychosis can impede developmental progression, and ways to facilitate healthy development.

Early psychosis programs vary in the age ranges that they serve, but sometimes serve people as young as 12 and as old as 40. While developmental functioning is correlated with age, it is not the same as age and should be assessed separately. Clinicians must tailor care to the individual's changing biology, stage of psychosocial development, and to socio-cultural considerations. Focusing primarily on symptoms, while overlooking the critical importance of development, may impede successful negotiation of core developmental tasks, endanger effective engagement in the treatment program, and ultimately result in functional difficulties that might be avoided. On the other hand, if early psychosis programs are intentional and thoughtful about how their interventions facilitate developmental progression, service design will simultaneously contribute to both development and symptom mastery.

This issue brief explores how to recognize and tailor early psychosis programs to these developmental challenges and opportunities in order to maximize program effectiveness.

Goals of Early Psychosis Programs

Early intervention for psychosis programs (EIPs) target individuals who are experiencing the early stages of psychosis, usually focusing on non-affective psychosis. These programs try to identify individuals, most often adolescents and young adults, as soon as possible once symptoms begin and to provide evidence-driven care to treat the illness and keep the person on a normal developmental path. The first two to five years after the illness develops are considered a “critical period” during which time the level of functioning the person attains may establish a long-term trajectory (Birchwood et al, 1998; Carpenter & Straus, 1991; Crumlish et al, 2009). In order to maximize functioning, EIP teams provide developmentally tailored clinical care, including work and school support, medical care, specialized psychoeducation and counseling, family psychoeducation, practical assistance and advocacy. Strategies focus on facilitating engagement, shared decision making, hopefulness and resilience. Teams partner with families and other supporters to educate them about the condition and to assist them in negotiating the complex process of supporting a young person who is in early recovery from psychosis and simultaneously encountering important developmental tasks. Regardless of age, every individual faces a new set of developmental tasks. This is true for parents, young spouses, and siblings as well as for the individual experiencing psychosis. EIPs seek mastery of developmental milestones by encouraging engagement in developmentally appropriate activities, ranging from attaining a bus pass to finishing college, negotiating individuation to establishing healthy adult relationship skills. (Melton et al., 2013).



The Biology of Psychotic Disorders

People with schizophrenia spectrum disorders or other psychoses vary widely in their symptoms, how they respond to treatment, and their outcomes (van Os, 2016). Current understanding of the nature and origin of psychosis integrates biological, social and psychological factors (Roper, 2015). This wide variation reflects a complex and interactive process of brain development and may have to do with a combination of factors such as genetics, adverse events, inflammatory responses, and abnormal neuronal pruning. As science grows in its understanding of the causes and process of psychosis development, preventive strategies may become more accurate in identifying individuals who will ultimately develop psychosis and more effective in preventing its occurrence.

BRAIN CHANGES LEADING TO PSYCHOSIS

Throughout early life, a child's brain is constantly developing and modifying neural connections while navigating the world. The process of interacting with the environment and learning from experience strengthens neural connections, whereas infrequently-used connections tend to weaken over time. Around age eleven or twelve for females and males, respectively, the brain reaches maximum capacity for these neural connections. As a child approaches adolescence—a critical developmental process—synaptic pruning begins to take place to alleviate the brain's overburdened volume of connections. Under-utilized or irrelevant excitatory synaptic connections are removed from the brain to optimize mental efficiency (Selemon, 2015; Luciana, 2015). The connections that remain are the ones that have been strengthened due to frequent use and association from learning. This process helps maintain a refined balance of excitatory and inhibitory synaptic connections, allowing for an environment of neural equilibrium and efficiency (Luciana, 2015). Synaptic pruning continues into the 20s, and occurs in the same order as brain development, with the prefrontal cortex being the final cortical region to reach maturity, which does not take place until early adulthood (Luciana, 2015).

EPIGENETICS AND THE ROLE OF ENVIRONMENTAL FACTORS

The brain's architecture is in constant remodeling throughout early childhood, adolescence and young adulthood. While there is a strong genetic link in schizophrenia, there are roughly 20 genes that each appear to modestly contribute to the risk (Selemon, 2015), and gene expression may be switched on or switched off based on environmental factors (epigenetics) and some genes when "switched on" may impact other genes (referred to as epistasis) during critical periods (Coyle, 2016; Gejman, 2010). Research indicates that once a person's genetic complement is established, the expression of their genes is largely shaped by environmental (epigenetic) interactions throughout development (Coyle, 2016; Gejman, 2010) which may lead to imbalanced neurochemical activities, reduction in brain matter volume, and atypical functioning, increasing vulnerability to psychosis (Coyle, 2016; Selemon, 2008). Researchers have concluded that those who experienced psychosis were 2.72 times more likely to have experienced adverse childhood events (ACEs) than individuals without psychosis. (Roper et al., 2015; Varese et al., 2012). Many studies suggest that these types of occurrences may lead to changes in the hypothalamic-pituitary-adrenal axis (HPA), creating higher stress sensitivity, which

may also explain why later recent adverse events are often associated proximally with onset of psychosis. (Elzinga et al., 2008, Holtzman et al., 2012, McCrory et al., 2012, Roper et al., 2015).

Recent evidence suggests that psychosis may result from an inflammatory process which attacks and abnormally prunes neurons in the prefrontal cortex of the brain, an area responsible for executive function and “top down” regulation of our emotional centers. When this reaches a critical state, it is believed that clear problems with thinking, reasoning, organizing thoughts (the so called “negative” symptoms), as well as abnormal interpretation of sensory phenomena (hallucinations) and odd explanations for how things work (delusions) emerge (Sekar, 2015). Excessive synaptic pruning can also result in detrimental reductions in gray matter volume and decreased neurological activity, significantly reducing the number of excitatory synaptic connections. This may help explain deficits in executive functioning seen in schizophrenia, such as poor decision making, attention, and planning (Selemon, 2015; Luciana, 2015).

Recent research has also focused on the role of elevated immune responses as a possible cause of over pruning. In addition, inadequate transmission of the excitatory neurotransmitter glutamate may play important roles in creating psychosis. It is likely that these new areas of research will improve our understanding of brain development, help better identify individuals who will experience psychosis and enable more effective early interventions. (Sekar, 2016; Coyle, 2016; Howes, 2015).

Another important area of research is the role of substance use on increasing the risk of psychosis. A meta-analysis of cannabis and other drug use found that those who used cannabis developed psychosis 2.7 years earlier than those who did not. Debates remain about causation. (Large et al., 2011). Certain other drugs such as methamphetamine also cause significant risk of psychosis. As states legalize marijuana and it becomes even more easily accessible and potent, increasing incidence of psychosis and earlier age of onset may result. This research will have important policy implications.

MEDICINES AND SIDE EFFECTS

Despite recent promising research indicating that hyperactive pruning of critical neuronal connections in the brain may be an underlying process in psychosis in adolescents and emerging adults, no treatments targeting this process currently exist. Instead, treatment focuses on reducing symptoms, allowing young people to enjoy some reprieve from internal (psychological) and external (psychosocial) stressors and a series of psychosocial interventions and supports to build on existing strengths in order to compensate for what may be temporary thinking deficits.

Antipsychotic medications are the primary biological method for controlling psychosis symptoms. Antipsychotics act mainly by blocking dopamine receptors in the brain and are often useful in addressing the fears, hallucinations, and odd explanatory beliefs of people who are experiencing psychosis. By blocking those dopamine pathways in areas of the brain which provide emotional



salience to sensory phenomenon (things we hear, see, feel) as important or frightening, people often feel more at ease. This calm comes at a price. Dopaminergic neurons are also responsible for our sense of pleasure, for wakefulness/arousal in the frontal lobes, and for controlling fine motor movements. Thus, great attention must be paid to finding which medication is “just right,” what dose is “just right,” and for how long this “just right” medication should be maintained. Effective medication management obtained through a shared decision making framework is critical for supporting healthy development for people with psychosis.

Finding the right balance is especially important for children and adolescents because they are at higher risk of a variety of side effects to antipsychotics. Table 1 lists the some of the side effects for which adolescents have a higher risk:

Table 1. Youth side effects from antipsychotics (from McClellan et al., 2007).

Children and adolescents are at increased risk for:
Weight and Dyslipidemia
Sedation
Movement Disorders (specifically extrapyramidal symptoms, EPS)
Withdrawal Dyskinesia (abnormal body movements as medications are halted or tapered)
Prolactin-Related Problems (especially post-pubertal women)
Suicidal Ideation / Behavior
Changes in sexual responsiveness and relations

The most commonly used antipsychotics with young people experiencing psychosis are the “atypical,” or “second-generation antipsychotics” (SGAs) (Sikich, 2008). One reason these medications are used so often is that young people are at slightly higher risk of developing movement disorders while taking antipsychotics than are adults. The higher affinity for dopamine receptors that modulate motor movements among older antipsychotics (so called “typical” or “first generation antipsychotics” or FGAs) makes them less preferable as first-line agents due this potentially permanent side-effect, which may involve abnormal twitching movements of the tongue, lips, or extremities (tardive dyskinesia).

While a full review of medications and side effects is beyond the scope of this issue brief, a few developmental considerations are important to consider with regard to the SGAs. SGAs are often associated with marked weight gain. While there may not be physiological differences in how the medicine affects young people versus older people, it is believed that the impact of antipsychotics may be more severe in older children and teens because parental monitoring means they may be more likely to receive their medicine. Weight gain and dyslipidemia can be early markers of the development of type II diabetes and long-term cardiovascular risk (Nielsen, 2014). Thus, early psychosis teams working with young people who are on these medications may need to help individuals develop strategies for mitigating these side-effects, including teaching healthy eating and increasing physical activity. This can be a challenge for young people whose metabolism

prior to medication allowed them to “eat whatever I want, whenever I want” and who now have to change their eating habits. Teens may be particularly concerned and ashamed about how their body changes on antipsychotics, especially individuals who are weight conscious and pride themselves on a ‘healthful’ appearance. Great attention should be paid to working with young people to minimize these physical changes by mitigating side-effects and by helping them to learn to accommodate to their changing body. Knowledge of recreational opportunities in their communities and support in adopting holistic health strategies (such as negotiating groceries, cooking with their families and navigating stressful school cafeterias) can be helpful.



Medical providers—physicians, nurses and advanced practice nurses involved in prescribing and monitoring medications can also help by first selecting those medications which have less risk of causing weight gain. While no medications are risk-free and all second-generation antipsychotics are associated with weight gain, at the time of writing this publication, the literature suggests that “lower metabolic profile” drugs in this class include: Aripiprazole (Abilify), Lurasidone (Latuda), and Ziprasidone (Geodon). A brochure listing common side effects for many antipsychotic medications may be found on the NASMHPD web site [see *Optimizing Medication Management for Persons Who Experienced a First Episode of Psychosis*, a 2016 publication found at <http://www.nasmhpd.org/nasmhppublisher>].

Two other important side-effects to consider in young people include: prolactin-related adverse events and sexual side-effects. Prolactin is a hormone that is released from the anterior pituitary gland to stimulate the production of breast milk. Under normal conditions, prolactin production and release is regulated by nipple stimulation through nursing. Some antipsychotics agents, particularly those with high affinity for Dopamine 2 (D2) receptors in the brain—this includes Risperidone (Risperdal) and Paliperidone (Invega)—block the normal regulation of prolactin production. Thus, prolactin levels can rise and cause both young men and young women problems that include: decreased libido (all genders), gynecomastia (breast development in males), galactorrhea (expression of milk from the nipple), interruption of menses (females) and even prolactinomas—tumors as prolactin producing cells in the pituitary gland proliferate (Pérez-Iglesias, 2012). Obviously the development of these side-effects in people of any age would be alarming, but particularly so for those in middle school or high school—as preoccupation with bodily changes, a longing to fit in, to have one’s body match an ideal image and to keep pace of one’s peers may be extremely important. Early psychosis team members attuned to this may help reduce the impact by encouraging young people to share in decision-making around changing medications or problem solve ways to deal with certain, lower intensity, prolactin-related problems.

Some young people may experience sexual dysfunction not mediated by prolactin, but instead by blockade of other neurotransmitters. An example of this occurs when alpha-1-adrenergic receptors are blocked by drugs such as Risperidone (Risperdal); in males this can cause retrograde ejaculation wherein during ejaculation, semen does not travel the normal path up the urethra, but instead passes back into the bladder (Haefliger, 2006). This may be particularly unnerving to young people who are just developing an understanding of how their bodies do and should work. Medical personnel should be sensitive to how uncomfortable a young person may feel discussing these issues and ensure a safe space and time to minimize awkwardness and to explore whether this is occurring.

Impact of Psychosis on Normal Psychosocial Development

There is little literature about how psychosis, or treatment for psychosis, impacts normal adolescent development. However, there is a great deal of literature about adolescent and young adult development which is directly relevant to early psychosis programs. Long-term exposure to symptoms of psychosis can significantly impact quality of life and functioning in social and intimate relationships, education, vocation, and finances, all of which are directly connected with normal developmental processes. Early treatment of first episode psychosis can positively affect these areas (Oldis et al., 2016, Birchwood 2001, McGorry et al., 1996).

Psychosis is very challenging for individuals to navigate, but societal views of psychosis, including views within the mental health system have in many ways been equally challenging. For too many in the past, “to be a mental patient,” meant a life of social exclusion, discrimination, loss of control, poverty and side effects (Unziker, 1984). Early psychosis programs reject this historical narrative. Young people who are seeking to educate themselves about schizophrenia will rapidly encounter the words “chronic,”

“severe” and “disabling.” These negative societal views can impact a young person’s identity formation, and result in internalized stigma that has been shown to have a strong negative impact on psychosocial well-being, symptom severity and treatment adherence (Livingston & Boyd, 2010; Corrigan et al., 2006). Thus, early psychosis programs must create a positive and hopeful context which



counteracts negative views of likely outcomes and shifts the focus to strengths, skills, and developmental progression. Table 2 below lists the core psychosocial developmental tasks of adolescents and young adults:

Table 2: Ten Core Developmental Tasks in Adolescence

Adjust to sexually maturing bodies and feelings: behaviors, identity, skills for romantic relationships
Develop and apply abstract thinking and planning skills
Learn to take others' perspectives into account
Develop and learn to apply new coping skills such as decision making, problem solving and conflict resolution
Identify personally meaningful moral standards, values, and belief systems
Develop understanding and begin to express more complex emotional experiences
Learn to form friendships that are mutually close and supportive
Establish key aspects of identity: gender, positive view of ethnicity, etc.
Learn to meet the demands of increasingly mature roles and responsibilities
Renegotiate relationships with adults in parenting roles

(Adapted from Simpson, 2001).

Psychosis complicates these already complex tasks, and may directly impact areas such as the ability to think abstractly and plan or interact socially. However, because psychosis impacts a developmental area does not mean that the person's capacity in that area is eliminated. A combination of early identification, treatment for symptoms, reinforcement of existing strengths and social supports, along with targeted counseling, coaching, accommodations and skill building may support young people to continue moving forward developmentally. Many of the interventions currently provided in early psychosis programs focus explicitly on the core developmental tasks on this list. Some, such as structured problem solving and supported education and employment, while not necessarily framed as developmental interventions, clearly fill that function.



Young people need support to accomplish these tasks under any circumstance. Throughout adolescence and young adult years, parents and other adult supporters play a significant role in modeling, coaching and supporting mastery of these tasks. They provide caring and connection. They are important observers, monitoring the young person's well-being, progress and level of challenge compared to their ability. Parents and supportive adults provide guidance and limits. They model and provide consultation about developmental areas such as decision making, values and skills, setting goals, and how to operate in the larger world. Finally, they provide for basic needs and offer a supportive home and network of adults who care. (Simpson, 2001)

SEXUALITY

Sexuality is of great significance throughout development from early adolescence through adulthood. Early psychosis programs must be prepared to talk about and help young people accept their maturing bodies, negotiate sexual feelings, and learn healthy ways to engage in romantic relationships and sexual behavior. Team members should be prepared with condoms and connections with ongoing family planning resources. Early psychosis programs need to provide a safe and accepting environment in which youth can freely disclose their realities and explore their decisions without fear of judgment.

PEER RELATIONSHIPS

During young adolescence, peer relationships begin to take on increasing importance in the person's sense of identity and focus. Over time friendships become more reciprocal and move from a focus on shared activities to focusing more on ideas and feelings, mutual trust and understanding. Friendships provide many critical roles, reinforcing the person's emerging positive self-esteem and sense of identity, giving the person opportunities to interact in new social contexts, and providing companionship. Transitions across settings (which are common in young adulthood) both reinforce the strength and continuity of friendships which persist in spite of geographic mobility and create challenges for learning how to establish new friendships (Simpson, 2001).

Social withdrawal and challenges with social cognition are common in schizophrenia (Couture et al., 2006). Individuals experiencing psychosis struggle with whether and how to discuss their experiences with friends, and they may experience internalized stigma (Livingston & Boyd, 2010). Individuals experiencing early signs of psychosis may also be more susceptible to bullying (Campbell & Morrison, 2007; Bebbington et al., 2004). Further, delayed school progression and achievement of independence may cause the person to feel left-behind, ashamed and alienated, and lead the person to withdraw even further (Garrison & Felice, 2009). Early psychosis programs must offer a safe environment in which these issues are explored and where individuals can work on developing the courage and skills to interact socially. Programs encourage new and ongoing connections to positive peer relationships, and help individuals find others with similar experiences who can provide encouragement, acceptance and respect (Buekea & Caruso, 2016).

DEVELOPMENT OF A POSITIVE ADULT IDENTITY

As adolescents move into young adulthood, they begin to develop an identity that integrates individuality with a feeling of connection to valued individuals and groups. Tasks involved in this process include developing a positive identity around gender, physical attributes, sexuality, ethnicity, and other parts of one's identity. In this process individuals also develop more sensitivity to others' unique identities. (Simpson, 2001)

The addition of perceived negative societal attitudes around diagnoses such as "psychosis" or "schizophrenia" and terms like "mental illness" can present a tremendous challenge in this process of forming a positive self-identity (Livingston & Boyd, 2010; Corrigan, 2006). When a person rejects these labels, they are often told that they are "in denial" or "lack insight." Supporting the young person in developing a positive sense of self and agency within the context of having a mental illness requires significant reframing,



persistence, and active effort. Additional struggles with body image and medication side effects, learning and earning grades, job loss, legal involvement, the lasting effects of trauma, and negative labeling and/or rejection by their community of origin may make developing a positive sense of self and belief in a positive future difficult.

The individual's perception of negative appraisal by others and discrimination can create significant anxiety and additional risk factors that may become a major focus for therapy. For example, youth who have a gender non-conforming identity face significant social pressures which often extend to their immediate family, and may put them at higher risk of bullying, suicidality and homelessness (Moe, 2016; Almeida et al., 2009). Peer support from individuals with similar experiences can acknowledge the difficulty of self-acceptance in light of ignorant social disapproval and provide role models for coping and resilience by finding other ways of approaching and conceptualizing their situation (Buekea & Caruso, 2016).

CULTURAL CONSIDERATIONS

Psychosis may be seen within a spiritual or specific cultural context. It is thus important to explore the person's and family's beliefs, values and perceptions without imposing preconceptions (Tervalon & Murray-Garcia, 1998; Huguelet et al., 2011). For example, while auditory hallucinations have been heavily stigmatized within Western culture, some non-Western cultures have more positive interpretations of the same phenomena. A culture's perception of psychosis can significantly impact the way individuals navigate these experiences, and may influence how practitioners frame and approach treatment. For example, the individual and/or family may frame the experience in spiritual terms, engage alternative healers or healing processes, or use different language to describe symptoms. The goal of early psychosis programs is not to replace these beliefs, but to come to a shared approach which honors and reinforces their beliefs and identity.

TAKING ON ADULT ROLES

In order to be successful as an adult, individuals must be competent in and committed to obtaining and sustaining a wide range of knowledge and skills, including self-care activities. Culturally-sanctioned expectations include taking on more family responsibilities, time management, obtaining groceries, cooking and nutrition, paying bills, household management, transportation, follow-through on wellness activities, and school and work-related activities. Mastering these tasks is by no means easy for any teen or young adult, as the sudden shift to legal adult is not accompanied by a sudden shift in capacity or knowledge. For many this is a process of trial-and-error. A combination of hopelessness, disrupted school and work progression, and dependence on disability payments and other financial supports can work against young adults achieving some of their most important developmental milestones, and can lead to a lifetime constricted by poverty and dependence (Melton et al., 2013). A critical role of EIPs is to assist the person in staying on their developmental course while accommodating the challenges of psychosis and avoiding these negative outcomes.



RENEGOTIATION OF RELATIONSHIPS WITH PARENTS

Throughout adolescence and young adulthood the role of the young adult's parental figure(s) is of critical importance. Flexibility in executing this role is essential. Parents struggle to provide the ongoing love and connection that young people need while also dealing with differences in perception, emerging values which may be different from those of the family, and sometimes with anger and withdrawal from the family. Given the changing situation, parents may constantly be renegotiating their relationship with their adolescent or young adult. As the various processes of identity formation and assumption of adult roles proceed, uneven progress may require alternating between strong guidance and reassurance, supporting independent action, and providing distance for autonomous development. Consistently, however, parents or those in parental roles provide love and connection, resources and advocacy. Parents are important observers, monitoring the young person's physical and emotional well-being. They provide guidance and limits, modeling and consultation. (Simpson, 2001). When psychosis develops, families often must return to an earlier stage of development in which the young person is more dependent and less able to perform expected roles. This adjustment requires new knowledge and skills, and may create conflict among members of the family who have different expectations of the person's performance and appropriate response to family members. EIPs are essential in reinforcing each family member's role while helping them to maintain hope, communicate and come to agreement with each other, and adapt to their loved one's changing needs.

Parenting youth through adolescence and young adulthood requires ongoing adjustment to give and accept higher levels of independence and choice. When psychosis occurs, parental involvement is often the critical determinant of whether the illness is identified and

whether the individual receives care. Parents are often far more engaged in treatment-seeking than their child, both because they recognize a problem and because psychosis interferes with the young person's ability to seek help (Cairns et al., 2015). Throughout recovery, parents and other members of the social support network are an important part of the environment in which the individual can find safety, financial and emotional stability, an environment where one can explore one's emerging identity and be supported by people who believe in them. The role that family and support systems play in an individual's life can be beneficial as they help to provide continued guidance and advocacy throughout the lifespan. Families assist their young people in building community connections that will help to provide positive peer and adult relationships. (Simpson 2001)



Organizational Implications for Early Psychosis Programming

PHILOSOPHY AND METHODS

Early psychosis programs must be adept in: understanding psychosis; recognizing and mitigating the impact of trauma (Bloom, 2013); and being attentive to participants' unique needs and the developmental tasks that they face. Early psychosis treatment should focus on resiliency and support the person in achieving role functioning and a rewarding and meaningful life. Services may need to be adapted based on the person's developmental stage and ability to process abstract information. For example, some adolescents may be better able to connect through physical activity than through a face-to-face conversation. Programs and their partners should be safe places of caring in which young people can develop competence in ordinary tasks, as well as understanding and managing psychosis. Programs help young people build confidence and reinforce their sense of self-worth by adapting to their interests and ways of relating, while focusing on strengths, fostering a positive view of the situation, letting them know they are not alone, and working to minimize internalized stigma. Early psychosis programs work to reinforce and build social connectedness, and explore and reinforce the individual's emerging positive identity and value system. (Mueser et al., 2015)

STAFF TRAINING

It is rare for clinical team members working for early psychosis programs to come to the job with the full complement of knowledge that they may need. Most staff will need additional training in areas where they have less experience. All team members should be trained in a core set of knowledge, practices and principles, including a solid knowledge of adolescent and young adult development, psychosis, outreach and engagement techniques, and methods of facilitating voice and empowerment. (Sale & Blajeski, 2014)

ENGAGEMENT AND CONTINUITY OF CARE

Engagement and continuity of care are major issues for teenagers and young adults. Under ordinary circumstances, they are still learning consistency and planning. Programs should be prepared to deal in a constructive, proactive and non-punitive fashion with lack of consistent follow-through and ambivalence about treatment participation. Young adults move frequently, and so programs need to make special efforts to facilitate successful transitions across settings and—to the degree possible—to maintain continuity of caregivers.



INVOLVEMENT OF PEERS THROUGHOUT THE PROGRAM

The role of peers is central in the lives of adolescents and young adults, and peer involvement should be visible and meaningful in all elements of early psychosis service development and delivery (Jones, 2015). Programs may need to encourage and facilitate maintenance of pre-existing friendships and peer relationships, including discussions and problem solving/role playing around how and when to disclose about participation in the program and experiences of psychosis. Friends may benefit from strategic coaching focused on understanding what their friend has experienced and what friends can do to support recovery. Individuals who have experienced psychosis, including formal peer support specialists, may also play an important role in helping participants overcome negative preconceptions and adapt to their experiences in a positive way.

PHYSICAL AND COMMUNICATION INFRASTRUCTURE

Youths' cultural norms can depart significantly from parental and agency norms including: communication preferences regarding in-person versus electronic communication such as texting; ways of meeting/gathering; sexual and gender expectations; and language and cultural references such as music and video games with which youth are familiar but older people often are not. It is important for agency leadership and early psychosis staff to accommodate these differences, and to consult young people to understand their perceptions and needs. Many youth no longer talk on the telephone and the common

methods and expectations around use of technology can change rapidly. Keeping up with phenomena such as texting and use of social media can be a challenge for HIPAA related policies, but being able to use these technologies may greatly enhance effective and timely communication.



Young people's experience of the program's physical environment also contributes to both successful engagement and communicating respect, empowerment and the message that the individual is valued. Programs housed in locations with a large number of clients who are older and more likely to have more severe illness may communicate an unintentional message about the course of the disorder and not create a sense of identification with the program clientele. Likewise, programs serving younger children should be sensitive to the appropriateness of a pediatric environment if they are also serving adolescents and young adults. Where a separate

location is not possible, discussing the young person's reactions to the program's clientele will help to surface these issues and may generate strategies to resolve any concerns (such as changing the art in the waiting room or providing access to computers). Youth consultants can be helpful in creating an inviting and empowering environment in the physical space, suggesting the most effective ways for clinicians to introduce themselves, and how best to configure the internet environment. Since individuals with psychosis may be vulnerable to normal stressors, agencies should work to create welcoming and soothing environments, minimizing punitive or negative messages. (Sale & Blajeski, 2016)

SYSTEMS PARTNERSHIP AND ADVOCACY

Early psychosis programs often interface with both child and adult systems, including secondary schools and colleges, youth and adult providers. By focusing on the community's shared interest in healthy development of teenagers into adulthood, early psychosis programs can help bring the community together in support of their young people. Providing positive stories and reframing psychosis as a common and treatable condition may help dispel negative preconceptions and assumed disability, thereby providing a nurturing environment that promotes personal growth.

PARTICIPATORY DECISION MAKING

Psychosis is often a major blow to identity development, autonomy and independence. It is important for programs to consistently reinforce the person's and family's strengths and resilience and to offer exposure to individuals and messages that give a realistic sense of hopefulness. It is critical that young people, no matter their age or developmental status, have ample opportunity to have their voices heard, define their own goals and priorities, express their values and preferences and participate fully in shared decision making processes. Shared decision making processes involve use of an explicit structure to facilitate discussion between clients and treatment staff addressing important treatment decisions. The skills to use shared decision making will often need to be taught. (Drake et al., 2009; Orygen, 2016). In addition, clinicians should routinely request and integrate feedback into clinical care in order to ensure engagement, effectiveness and retention in services (Duncan & Miller, 2000).

REINFORCING RESILIENCE AND PROVIDING DEVELOPMENTAL SKILLS AND TOOLS

By thoroughly exploring and building on the individual's strengths, needs and priorities within the context of the person's current developmental stage, programs can help reinforce a positive identity, facilitate developmental progression and strengthen resilience. Methods that early psychosis programs commonly teach—such as cognitive

restructuring, emotional regulation, motivational interviewing around behavior change, structured problem solving and decision making methods, social skills training and rehearsal, stress management and conflict resolution skills—are useful in navigating illness and of great value developmentally. Psychoeducation and counseling for both the individual and family should focus on the symptoms of psychosis and how to manage them, and also on normal development and related skills.



NEGOTIATING INDIVIDUATION AND FAMILY DIFFERENCES

It is not uncommon for individuals to disclose preferences and values, and make decisions, that differ from those of their families. They may or may not be prepared to share these with family members. Thus, early psychosis clinicians face a delicate balance, providing a safe and validating environment for both the young person and the family while respecting confidentiality, educating everyone about the normal developmental progression, encouraging safe and honest communication and teaching skills of shared decision making, communication and conflict resolution. Through family guidelines, education and coaching, families are encouraged to provide a safe space and to reduce external pressures when young people are in the early stages of illness, but to relax those protections and encourage more independence, accountability and risk taking as recovery progresses. Young people often resist parents in ways that they do not resist others, and a partnership in which both young people and their parents are encouraged to communicate freely to clinicians can be helpful in reframing issues and finding common ground.



TALKING ABOUT DIAGNOSIS

Receiving a diagnosis and recognizing that navigating adolescence and young adulthood may be more difficult than it might be for one's peers may be discouraging, especially in combination with school, work and relationship difficulties. Rejection of a negatively-viewed diagnosis may be a healthy response by an individual who is working to form a positive self-identity and should be explored, with the goal of establishing a shared and positive explanatory model that facilitates symptom mastery and developmental progress. The person may begin to feel that he or she is incapable of achieving adult roles and relationships, and suggestions to pursue disability payments can compound the discouragement. It is critical that young people have access to role models who have worked their way through the same types of challenges, and that programs adopt a strong orientation based on strengths, resilience and skill building, with rapid access to supported employment and education.

BECOMING TRAUMA RESPONSIVE

While not all individuals have histories of trauma, a variety of factors may make them more sensitive to stressors. Psychosis itself can be traumatizing, for both the individual and for the family. Also, the organization and team members can be impacted by recent and historical traumatic events. A trauma-informed approach includes addressing systemic and individual interactions in a way that builds a sense of safety, trustworthiness and transparency, mutual self-help and peer support, collaboration and mutuality. The focus on empowerment, voice and choice (which are important developmentally) are also key principles in trauma informed care. Finally, organizations must make active effort to understand and move past cultural, historical and gender issues. While the tenants of trauma-informed care are not specifically developmental, failure to address them will likely have an impact on the program's ability to engage with the individual and family in a way that is experienced as empowering. (SAMHSA, 2014)

Programs must intentionally integrate trauma-responsive practices that recognize and mitigate recent traumas (such as police involvement and hospital visits) as well as addressing traumatic experiences that may have been experienced earlier in life. It is important to recognize that the experience of psychosis can itself be traumatizing. Given the extent to which stress can exacerbate symptoms and provoke relapse, it may be helpful to assist the individual in stress management and relapse prevention. Returning to prior functioning and developmental progression is a gradual process. Families and young adults need education to understand this and to temporarily reduce external pressures and stressors, increasing them gradually as the person recovers.

STRATEGIES FOR COGNITIVE CHALLENGES

Many people who experience psychosis experience significant cognitive challenges in processing speed, attention, memory, reasoning, problem solving and social cognition. These challenges may make abstract thinking, planning and reciprocal relationships more difficult. However, while these functions may be affected, they are by no means lost. The growing field of cognitive remediation is demonstrating that individuals can improve their cognition through targeted learning strategies which address specific areas of cognition, including intentional efforts to generalize in a real world setting (McGurk, 2007; Wykes, 2011). People with schizophrenia and related disorders can and do learn to address these challenges. Sometimes, in part related to their experience of psychosis, they can be extraordinarily creative. Early psychosis programs should offer specific tools, strategies and accommodations for cognitive abilities that may need strengthening.

BUILDING A POSITIVE SELF-IDENTITY

The process of forming a positive identity and becoming an adult is much longer than the two to five years that most early psychosis programs last. Social recognition and reinforcement of the individual's strengths and resilience may assist the individual to develop a grounded and positive self-view outside of the treatment environment. Role models who have overcome negative societal views and self-stigma can be greatly supportive in helping individuals to develop language and ways of thinking about their experiences. Practices such as self-compassion meditation, leadership opportunities, and highlighting creative gifts such as art, music, sports and hobbies may all be important in helping the person create a lasting and sustaining positive self-identity.



PEER SUPPORT

The importance of peers in the lives of adolescents and young adults has significant implications for how early psychosis programs are designed and operate. Including younger adults and near-age peers in service delivery may increase the program's ability to relate to their young clientele. Early psychosis programs are helpful in coaching young people in how to approach social relationships, learning and practicing new

skills, and exploring how and when to disclose to friends. By reinforcing normal activities which involve peers, programs can encourage continuation of peer relationships and establishment of new friendships. Also, many early psychosis programs provide social and leadership opportunities which allow individuals to develop friendships and practice skills within an accepting and non-stigmatizing group environment. (Jones, 2015)

SUBSTANCE USE

Substance use is common in adolescent and young adult peer groups, and is very common among persons with early psychosis, with most studies reporting rates of over 40% (Wade et al., 2009; Addington & Addington, 2007). Individuals with psychosis most commonly begin using substances prior to entering early psychosis

programs rather than after, and they most commonly report using substances to relieve dysphoria, anxiety and boredom rather than psychotic symptoms. Early psychosis programs must be prepared to assess and treat substance use among their participants, and clinicians should be skilled in motivational interviewing and harm reduction approaches (Wade et al., 2009). Given the importance of peers, individuals wanting to reduce use when many of their peers continue use, will need support in establishing a peer network that is not focused on substance use.

PSYCHIATRY AND NURSING

Together with other team members, medical professionals play an important role in teaching about health and lifestyle choices, sexuality, shared decision making and self-advocacy within healthcare systems. Prescribing decisions are collaborative and need to take into account issues such as school and work timing and the impact of side effects. Psychiatrists and nurses need to be prepared to engage flexibly and in a way that values the young person's experiences and stage of development. Examples include: spending time engaging an ambivalent young person around interests such as music, sports or comics; hanging the doctor's high school diploma on the wall next to the medical diploma; and being willing to continue to work with young people even when they are unsure or make choices not to use medicine. Family members and other team members may participate in psychiatric appointments and will be an important source of information and follow-through for the team. Medical professionals need to be particularly conscious of the psychological impacts of diagnosis and medication for young people and families. Grief and fear for the future are common reactions to hearing a diagnosis and the choice to go on medicine may suggest a level of permanency and loss of control. (Jenkins & Carpenter-Song, 2009; Buekea & Caruso, 2016)



Nursing roles are often overlooked but can be extremely important in routine monitoring of metabolic disorder and other side effects, as well as health education and intervention around nutrition, sexuality, tobacco, healthy lifestyles, communication with primary care, and problem solving around medication and lab access. (Melton, Sale et al., 2013; Melton and Practice Guideline Writing Committee, 2013)

SCHOOL AND WORK SUPPORT

Individualized Placement and Support (IPS) generally provides the framework for early psychosis educational and employment services, but must be adapted to be developmentally appropriate. IPS specialists work within the early psychosis team to provide specialized support for work and school. (Bond et al., 2015; Twanly, 2003; Killackey, 2008; Dudley et al., 2014). Teenagers and young adults have not had an opportunity to form an adult identity as a worker, and they are in the early stages of contemplating a career path. A focus on rapid placement, which is one of the tenants of IPS, was meant to prevent delayed job search based on perceptions of incapacity or lack of “work readiness.” This approach will be particularly helpful for a young person who lacks any job experience and needs to build a resume and experience as a worker, or where there is clarity about short-term school and work goals. On the other hand, strengths assessment, career planning and unpaid opportunities such as informational interviewing and internships may help plot a longer-term career trajectory which is more likely to support overall recovery. Evidence around supported employment is more robust than for supported education, but it is essential that programs not sacrifice one for the other. Teens and young adults may want part-time or summer work while going to school. Thus, being able to seamlessly support young people in both settings is important. (Melton & Reese, 2016)

Supported employment and education specialists may be working with high school students under the age 18, as well as people over 18. Benefits planning, which is part of the IPS model, looks different for younger people than for older individuals. Teenagers may be less concerned about benefits because the jobs they seek usually do not provide them, and they are generally covered by their parents’ insurance. Individuals not covered by a parent’s policy are more likely to be uninsured and may have generally thought very little about benefits. Whereas much of the IPS literature discusses benefits planning related to Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) benefits, benefits planning with young adults is more likely to focus on which jobs have the best flexibility, insurance, vacation, and school reimbursement. Social Security and other income supports may play into the conversation, but they are not developmentally normal options and may create significant work disincentives, as well as suggesting long term disability. Balancing needs for income and the potentially-negative consequences of enrolling in the disability system can be challenging. Financial aid is also an important conversation for those who are going to school.



OCCUPATIONAL THERAPY


While occupational therapy is currently offered only in a subset of programs, training for occupational therapists (OT) involves an understanding of development across the lifespan, including physical, cognitive, emotional, and social factors, making them important team members in an early psychosis program focused on developmental progression. After a thorough assessment including the individual's background, roles, routines, interests, meaningful activities, and previous developmental challenges, occupational therapists target intervention to the person's needs and goals (Lloyd, Waghorn, Williams, Harris, & Capra, 2008). Occupational therapists modify or grade activities to create the "just right challenge" and promote productive life roles (Brown, 2011). Occupational therapists are trained in group dynamics and may also use groups to engage young people in meaningful activities, help with strengths and identity exploration, and to improve social interaction skills. OTs offer careful attention to environmental demands and supports, sensory needs, and the skills required for living independently, and they can be very helpful in assisting with accommodations in school, work and the community.



If an individual needs to take a sabbatical from school, planning ahead is important because not doing so can create problems with readmission to school, ongoing financial aid and requirements to pay back loans. Close coordination with academic counselors and Disability Services is helpful in ensuring appropriate accommodations and planning. Young adults are sometimes reluctant to seek the support of programs using terms like "disability" and "rehabilitation," and early psychosis team members may need to explore the person's negative assumptions and the benefits of using these resources. (Reese, 2015; Melton & Reese, 2016). It may be helpful to portray use of these services as a right under federal law that is intended to reduce discrimination against persons with disabilities so that they have an equitable chance to succeed in school and life.

FAMILY PSYCHOEDUCATION AND PARTNERSHIP

Families and support systems play a pivotal role in the lives of adolescents and young adults, and in the treatment of psychosis in particular (Simpson, 2001; Lucksted et al., 2015). Individuals who report having positive family environments experienced a greater decrease in symptoms and an increase in social functioning than persons with less favorable family relations (O'Brien et al., 2006; González-Pinto et al., 2011). It is essential for parents to receive information about the young person's condition and coaching around how to communicate, set limits, and give the person enough time and space to recover. Cultural and belief differences, as well previous negative experiences with mental illness or the mental health system can interfere with the family's adjustment. Also, it is common for the experience of psychosis to generate trauma and ongoing grief, which can become a source of conflict within the family. Family conflict may reduce levels of treatment engagement (Lucksted et al., 2015) and reduce motivation to achieve (Gonzalez-Pinot, 2001, Yung et al., 2009). Additionally, the absence of family involvement can increase the chance of early relapse (Johnstone et al., 1990).



Early psychosis programs must work closely with family members in order to help them understand, adjust, cope, communicate, problem solve, and make decisions with each other. Clinicians often must coach family members to increase or decrease their level of protectiveness and monitoring, while recognizing that, in spite of developmental needs, young adults have legal rights and a level of independence which can make parental roles more difficult but no less important. Family education, coaching and problem solving play an important role in reducing conflict and improving family member skills related to supporting their loved one in a developmentally appropriate way. Individuals define who they consider to be family.

Structured multi-family psychoeducation groups have a robust evidence base and offer many advantages. First, they are effective across stages of development and provide a forum for adolescents and young adults and their families to learn communication, conflict resolution and problem solving skills. Second, they help families to better understand their own and their loved one's needs, and to create an environment which is more conducive to recovery. Third, they provide a social network of individuals who can relate to each other's situations in a helpful and non-judgmental manner.

Finally, they provide a method for effectively solving the pragmatic challenges that families may face (Pitschel-Walz et al., 2004; McFarlane, 2002).

TRANSITION PLANNING

Young people who enter a program in their teens have many years of developmental progression left before establishing solid adult roles and identities. It is important to recognize this limitation in service design while also recognizing that maintaining a transitional focus prevents individuals from turning to the program as a primary source of identity. Establishment of alumni, leadership and peer mentor roles can provide a sense of progression while offering important role models and educational opportunities for people newer to the program.

FUTURE EXPLORATION

Most evidence-based practices used in early psychosis services were developed without accounting for the essential role of psychosocial and biological development, or the need to adapt existing models accordingly. While a strong emphasis on resilience, recovery, cultural humility and shared decision making is consistent with developmental needs, current evidence-based and emerging practices should be routinely evaluated for their developmental impact and revised to align to the needs of individuals in different stages of development. To do so may require adoption of new measures and ways of conceptualizing the goals of early psychosis programs. Better understanding of brain development, the role of trauma, and the role of cognition, are rapidly emerging and likely to change the way we think about early psychosis services.

As programs become more sophisticated and intentional about integrating developmental awareness and practices, they may naturally discard well-meaning but potentially unintentionally harmful practices in favor of more effective means. A serious commitment to supporting young adult development will require our systems to ensure access to effective care beyond the first two years, and address insurance and disability systems which push young people prematurely into disability and government dependence. The EIP team will need to work with the larger treatment and support system of care that has more experience with individuals who may have developed significant disability, in order to promote a recovery orientation that expects long-term assistance with increased adult responsibility, and support for entering adult roles.

Conclusion

Early psychosis services have the opportunity to change the trajectory of a young person's life if they provide early, readily accessible and developmentally appropriate supports. By framing the goals of early psychosis programs to focus as much on developmental progression as symptom mastery, young adults and their family members may be more prepared and supported to tackle the difficulties of adulthood with less disability and need for system reliance. By creating strong coalitions of supporters, investing in effective treatment and support, and encouraging young adults to find their voices, we are entering into an exciting and transformational time for our systems and our society.



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