F⊛CAL P⊛INT

YOUTH, YOUNG ADULTS, & MENTAL HEALTH

EARLY PSYCHOSIS INTERVENTION

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Photo: Some members of EASA Young Adult Leadership Council

INTRODUCTION

EARLY PSYCHOSIS INTERVENTION

The transition years are an exciting and turbulent time, full of firsts – the first time driving alone, the first romantic relationship, the first job, leaving home for the first time. It is also the time when people often first experience the dramatic break in reality of psychosis, characterized by hallucinations, delusions, and changes in how the brain processes information. Throughout history psychosis has traumatized and permanently disrupted people's lives, but early psychosis intervention is showing that much of this trauma and disability can be prevented. Early psychosis intervention services are rapidly becoming available in every state of the US, and thousands of people who have lived through psychosis are speaking out and proving that we have every reason for hope.

This issue of *Focal Point* is dedicated to early psychosis intervention. It begins with overviews by McGorry and Stavely, and Azrin, Goldstein, and Heinssen, of how early psychosis research and treatment has evolved, internationally and in the US. The voices of young adult leaders (Buekea and Caruso with the EASA Young Adult Leadership Council) and family members (Purdy and Purdy) who have experienced early psychosis intervention illustrate the importance and hopefulness of this effort. Pruitt and Blajeski describe research that highlights the importance of family and culture in help-seeking during first episode psychosis. Addington describes efforts to ensure and measure service quality and effectiveness.

This issue also contains a series of articles describing some of the effective strategies emerging in the early psychosis field, including Cognitive Behavioral Therapy (Deal and Alt), the Individual Placement and Support approach to employment and education (Melton and Reese), and the role of sensory preferences from an occupational therapy perspective (Gottlob and Roush).

Our role as co-editors of this issue is the culmination of a journey which began in 2001. At the time, Ryan Melton and I were part of a small team in Oregon implementing the Early Assessment and Sup-

port Alliance (EASA), the first implementation of early psychosis intervention in the US public mental health system. In 2007 our responsibilities grew from work in the original five counties to coordinating the first statewide roll-out of early psychosis implementation. In 2013 we formed the EASA Center for Excellence at Portland State University. From this center of excellence, we continue to collaborate and support service development in Oregon and throughout the country.

Throughout this journey our graduates and family members have become great advocates for our common vision. We aspire to ensure rapid access to services that are voluntary, strengths-based, well-grounded in evidence, and guided by individual and family partnerships and shared decision making.

We are grateful to those who wrote for this issue. They are some of the finest colleagues we have gained along the way. We also acknowledge the contributions of many who are not represented here. We are in the midst of a dynamic and growing movement – and we are thrilled to be part of it.

AUTHOR

Tamara Sale is Director of the EASA Center for Excellence at Portland State University.

Register for Free Online Training & CEUs for Service Providers

The Pathways Transition Training Partnership invites service providers to participate in Promoting Positive Pathways to Adulthood, a series of ten, free, hour-long online training modules to increase skills to work effectively with young people with mental health conditions. See: **http://pathwaysrtc.pdx.edu/proj-pttp**

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Early Psychosis Intervention: The International Context

The outlook for a young person in the early stages of a psychotic illness today can – and should – be very different from that of just three decades ago. During the 1980s, the first clinical studies highlighting the special needs of young people experiencing a first episode of psychosis caught the attention of clinicians and researchers, beginning with our research group here in Australia. Interest expanded rapidly around the world in understanding the biological and social factors that underpin psychotic illnesses, and in better ways to treat them. Since then, we have learned much about how these illnesses evolve and their neurobiology, which has allowed the development of better medical treatments. Clinical research has led to the development of services specifically designed around the unique needs of these vulnerable young people. We now know that experiencing a psychotic illness like schizophrenia does not inevitably lead to a lifetime of disability and dependence. Instead, timely and appropriate early intervention has the potential to eliminate, or at the very least reduce, the negative effects of these illnesses. This has led to a radical shift in our approach to the care of those living with psychosis: instead of simply managing symptoms, the focus of treatment is now intervening early with a strong emphasis on promoting recovery to enable the young person to live a meaningful and contributing life within the community.

The key aims of early intervention are to prevent illness, or when illness occurs, to minimize its impact. This is particularly important for psychosis, since one of the main reasons why these illnesses can be so devastating is that they typically appear during late adolescence and early adulthood. Disrupting life during this crucial transitional period can be devastating to young people's normal development process of finishing their education and beginning their working lives, developing intimate relationships, and establishing themselves as independent adults. If the illness is untreated, or poorly treated, this disruption can lead to long-term and even life-long disability.

UNDERSTANDING HOW ILLNESS DEVELOPS, AND HOW BEST TO TREAT IT

Long-term studies have shown that schizophrenia almost always follows a long period of increasingly distressing symptoms, such as poor concentration, disturbed sleep, lack of energy, social withdrawal, depression, and anxiety. Over time, these symptoms slowly intensify; low-grade psychotic symptoms such as visual distortions, hallucinations, and early delusional thought processes appear; and the young person's ability to

> **Treatment is no longer aimed at simply controlling symptoms, but also at helping maintain or regain developmental trajectory**

function in daily life is increasingly affected. Eventually, the psychotic symptoms increase to the point that a first psychotic episode occurs in which the person loses touch with reality. We now know that much of the disability associated with psychotic illness develops during this pre-onset period, well before the first episode,[1] and that the most important risk factor for a poor outcome is a long duration of untreated illness. This is why early intervention is so important.

It is now possible to identify young people with early symptoms which are beginning to impact their functioning but which are not yet severe enough to prevent them from distinguishing reality. Appropriate care to reinforce functioning and prevent symptom deterioration for these "at clinical high risk" individuals may potentially prevent the onset of psychosis, or minimize the devastating consequences which come when individuals lose touch with reality in a first episode of psychosis. Moreover, for those who do experience a first episode of psychosis, treatment is no longer aimed at simply controlling their symptoms, but also at helping maintain or regain their developmental trajectory so they can make the best possible social and vocational recovery and enjoy a productive and meaningful life.

EARLY INTERVENTION: BEST PRACTICES

Young people in the early stages of a serious mental illness most often present with a complex mix of relatively non-specific, but distressing, symptoms that wax and wane and develop further over time. This means that different treatment approaches are required than those used for people with well-established illness, who are usually older. Care for young people should reflect their different social, vocational, and developmental needs, be acceptable within the cultures of youth and the community, appropriate for their stage of illness, and have a strong focus on recovery. Care is best provided in a specialist youth mental health service that is able to offer multidisciplinary mental health care in a youth-friendly, stigma-free setting, with strong links to locally available services for young people, such as social services, schools, tertiary training institutions, and educational and vocational support organizations.

For young people experiencing the early stages of a psychotic illness, these services offer three core functions: (a) early detection; (b) acute care during and immediately following a crisis; and (c) recovery-focused continuing care, featuring multimodal interventions to enable young people to maintain or regain their social, academic, and career trajectory during the critical first 2–5 years following the onset of illness.

USING THE MOST APPROPRIATE TREATMENT FOR THE STAGE OF ILLNESS

The type of interventions selected depend on each individual young person's symptom profile, whether or not they are at risk of self-harm or suicide, or harming another person; any substance use or comorbid illness; and their family history, among other factors. However, this staged approach to care has three major benefits over traditional care. Firstly, the very early stages of a potentially serious mental illness are recognized as requiring treatment. Secondly, but no less importantly, treating early means that more benign treatments can be used first, which minimizes the risk of any side-effects associated with the treatments used for later stages of illness, and particularly the inappropriate use of medications. Thirdly, early treatment can prevent, or greatly reduce, the risk of ongoing disability if illness does develop or progress.

INTERVENTIONS FOR YOUNG PEOPLE AT RISK OF PSYCHOSIS

A number of interventions for young people at clinical high risk for psychosis have been tested in clinical trials looking at the use of medication (low-dose antipsychotics and/or antidepressants), psychosocial treatments, or both, to prevent the onset of psychosis. An assessment of these studies has concluded that they are all effective; however, because even low doses of antipsychotic medications can cause serious side-effects, psychosocial interventions, including supportive therapy and Cognitive Behavioral Therapy (CBT), illness education, family work, group work and other benign interventions, such as dietary supplementation with fish oil, are currently recommended as first line therapy at this stage of illness.[2] Drug therapies should only be considered if symptoms and impairment persist or worsen. This is particularly important because the majority of these young people will not go on to develop schizophrenia, although a significant number will continue to need professional mental health care, particularly for depression and anxiety.

INTERVENTIONS FOR FIRST EPISODE OF PSYCHOSIS

Treating a first episode of psychosis requires great sensitivity and clinical skill, and ideally care for these young people should be managed in specialized services separately from older people at later stages of illness. At this stage, low-dose antipsychotic medications and a range of intensive psychological and social interventions are essential to maximize recovery and minimize ongoing symptoms and disability. Most young people who experience their first episode of psychosis do recover. However, they remain at high risk for relapse, with around 50% relapsing within three years, and if they discontinue their treatment, as many do, at least 80% will relapse within five years.[3]

Intensive psychosocial interventions to promote, support, and maintain a meaningful recovery are crucial for young people with early psychosis. Ideally, these interventions should be offered to all these young people for the critical period of the first five years after diagnosis, when the risk of ongoing and entrenched functional disability is highest. Strategies targeted at maximizing functional recovery, such as those aimed at relapse prevention and vocational interventions, are key here, and complement and enhance each other. When combined with an appropriate approach to medication, including guided dose reduction or discontinuation for some young people, these approaches can significantly improve the outcome for many young people.

PHYSICAL HEALTH IN THOSE WITH A PSYCHOTIC ILLNESS

Young people who are taking antipsychotic medication are at increased risk of weight gain and metabolic abnormalities, which may appear in the first few weeks of treatment. Causes include genetic predisposition, poor nutrition, lack of exercise, smoking, and substance abuse, as well as the side effects of antipsychotic medication. Moreover, there is strong evidence to suggest that people with psychotic illnesses receive inferior quality physical health care compared to those with chronic physical illnesses.[4] Apart from these effects on physical health, the weight gain associated with antipsychotic treatment can affect a young person's self-esteem, increase self-stigma, and increase the chances of discontinuing medication, which increases the risk of relapse. Together, these factors mean that it is crucial to take measures to prevent and treat weight gain, preferably prior to it becoming an issue.

Early treatment can prevent, or greatly reduce, the risk of ongoing disability if illness does develop or progress

CONCLUSION

From its small-scale, experimental beginnings in just a few clinics around the world, it is pleasing to see that the early intervention approach, with its pre-emptive, recovery-oriented focus, has now spread to hundreds of clinics world-wide. It has proven its value in a range of long-term follow-up studies from around the world, which show significantly better clinical and functional outcomes for young people in the early stages of a psychotic illness treated within specialized early intervention services, compared to those treated in standard mental health services.[5] An added benefit is that early intervention services have been shown to be more cost-effective than traditional services. Finally, and more importantly, they are highly valued by young people and their families.

The early intervention approach has now spread to hundreds of clinics world-wide

Over 20 years ago now, the Early Psychosis Prevention and Intervention Clinic (EPPIC) was established in Melbourne, Australia. Similar approaches were quickly adopted in centers in the United Kingdom (UK) and in Denmark, and rapidly spread throughout the UK, Scandinavia, and to the Asia-Pacific region in the years that followed. Although a number of researchers in the United States (US) have been key leaders in early psychosis research, the healthcare funding structure in the US has limited the extent of service reform. The first early intervention service in the US, the Early Assessment and Support Alliance (EASA) in Oregon, was established 15 years ago to develop a systematized effort to prevent early trauma and disability caused by schizophrenia and related conditions, and a number of US academic centers also operate early intervention services. Recent results from the Recovery After an Initial Episode of Psychosis (RAISE) studies in the US have clearly demonstrated the effectiveness of early intervention, and the US is now investing in system reform.

Finally, early intervention is not a new approach in medicine. In oncology, for example, the enormous improvements in recovery and outcomes for many different cancer treatments have come not from dramatic breakthroughs or novel treatments, but from intervening much earlier with existing treatments, and delivering them in a more sustained and comprehensive fashion for as long as they are needed. Mental health professionals still have much to learn from the lessons gained from early intervention approaches in physical medicine. Early intervention for psychosis has clearly proven its value; to reap the full social and economic benefits of this approach we now need to expand early intervention to cover the full spectrum of mental ill-health in young people. For this approach to be effective, it must be offered in services that operate with a culture of hope and optimism, and provide intensive evidence-based biopsychosocial care featuring collaboration with young people and their families, in an environment that is stigma-free and youth-friendly. All of these elements are crucial to the success of this service model.

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Expansion of Coordinated Specialty Care for First-Episode Psychosis in the US

Each year approximately 100,000 young people in the US experience a first episode of psychosis (FEP). Long delays between the onset of psychosis and effective treatment (the duration of untreated psychosis, or DUP) are the norm. A 2015 study of more than 400 people in the US with early psychosis found that half were ill for nearly 18 months before beginning treatment for psychosis.[1] This is almost six times the World Health Organization's quality standard of a maximum 12 weeks DUP.

Research shows that integrated FEP care effectively reduces symptoms of psychosis and improves functioning.[2] In the United States, this type of care is referred to as Coordinated Specialty Care (CSC). CSC programs are delivered by multidisciplinary teams offering rapid initiation of care and treatments demonstrated effective in promoting recovery in people with FEP. These treatments include personalized medication management, resilience-focused psychotherapy, family education and support, and educational and employment support.[3]

Psychiatric and primary medical care are closely coordinated to optimize the client's overall mental and physical health. Treatment planning occurs within a shared decision-making framework; clients select the services that best address their life goals and treatment preferences.

RECENT COORDINATED SPECIALTY CARE (CSC) RESEARCH IN THE UNITED STATES

Despite the evidence from abroad suggesting the benefit of multicomponent interventions for FEP, until recently these programs have been unavailable in US community settings, with a few exceptions, (e.g., in Oregon and California). In 2008, the National Institute of Mental Health (NIMH) launched the *Recovery After an Initial Schizophrenia Episode* (RAISE) initiative in order to develop, implement, and test team-based, multi-element treatment programs for FEP in real world community clinics. In 2009, the NIMH funded two research projects as part of the RAISE initiative: the Early Treatment Program (RAISE-ETP) and the Implementation and Evaluation Study (RAISE-IES).

The RAISE-ETP study involved 404 people with FEP (average age 23 years) and compared the effectiveness of CSC to typical FEP care delivered in US community clinics. Over 100 clinicians from 17 clinics across the US were trained to deliver a CSC program called NAVIGATE that included four core interventions: resilience-focused psychotherapy, family education and support, supported education and employment, and personalized medication management for FEP. Compared to clients who received usual FEP care, NAVIGATE participants remained in treatment longer and experienced significantly greater improvements in quality of life, symptoms, and involvement in work or school.[4] Individuals with a shorter DUP benefited much more from NAVIGATE than those with a longer DUP, demonstrating the importance of receiving CSC early in the course of illness.

The RAISE-IES project developed and tested strategies for delivering CSC programs in publicly-funded mental health clinics. In partnership with state mental health authorities in New York and Maryland, RAISE-IES researchers demonstrated that CSC programs could be implemented in community clinics and successfully engage and retain in treatment young people with FEP (average age 22 years). Participants in the Connection Program (the CSC approach implemented in RAISE-IES)

achieved a reduction in clinical symptoms, improved social and occupational functioning, and increased rates of school and work participation.[5] The Connection Program was subsequently implemented broadly in both states.

Also funded by the NIMH, the Specialized Treatment in Early Psychosis (STEP) study launched in 2006 and compared CSC to typical FEP care in a randomized control trial within a Connecticut community mental health center. Among the 120 participants experiencing FEP (average age 23 years), those in CSC experienced significantly greater symptom improvement, fewer hospitalizations, and more school and work participation compared to those in usual FEP treatment.[6]

The RAISE and STEP projects demonstrate that US community clinics can deliver CSC, producing greater improvements in clients' symptoms and functioning compared to usual FEP care. The benefits of CSC were markedly increased when treatment was delivered soon after the onset of psychosis.

KEY FEATURES OF COORDINATED SPECIALTY CARE (CSC)

CSC programs offer a menu of evidence-based services that support recovery, delivered in an integrated fashion within a shared decision-making framework. CSC teams are comprised of a team of clinicians from different disciplines who are trained in the principles of early psychosis care and in specific evidence-based FEP services. People with lived experience of FEP can effectively deliver CSC services such as supported employment and education and add unique value to recovery-oriented programs. Peers can also help ensure the program feels user-friendly to young people.

CSC programs aim to reduce DUP by rapidly identifying people with FEP in the community and engaging them in CSC services. To achieve this, the CSC team cultivates relationships with multiple referral pathways,

such as inpatient facilities, emergency departments and crisis teams, community mental health clinics, primary care practices, college counseling centers and others.

CSC programs are designed to be youth friendly, flexible, and engaging, which is enhanced by locating the program separate from adult mental health programs. Appointments are offered at times convenient for clients, given their school or work commitments, and in the community, as well as in the office. During the initial appointment and throughout treatment, clients and families receive consistent messages that the clients' personal recovery goals drive the course of treatment.

Weekly team meetings and frequent communication among team members help to maintain focus on addressing each client's recovery goals and to sustain high-quality services. Services are organized to provide rapid response, coordination, and continuity of care.

FUNDING AND EXPANSION OF COORDINATED SPECIALTY CARE IN THE US

The US Congress allocated an additional $24.8M in fiscal year 2014 for evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders. These set-aside funds, administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) through the Community Mental Health Services Block Grant program, directed new resources to each state and US territory for early intervention models such as those tested by the RAISE and STEP projects. Congress continued the block grant set-aside for fiscal year 2015 and doubled the set-aside amount for fiscal year 2016. A number of states have provided matching funds to leverage the block grant set-aside funds and further expand their CSC programs. Thirty-two states have announced plans to initiate or expand early treatment programs for FEP, a 16-fold increase over the number of states with such plans before the launch of the RAISE initiative.

Medicaid is a major source of reimbursement to states for mental health and related services. In October of 2015, the Centers for Medicare and Medicaid Services (CMS) signaled its support of Medicaid coverage for CSC in its Joint Informational Bulletin to state Medicaid Directors, *Coverage of Early Intervention Services for First Episode Psychosis*.[7] Issued by CMS, NIMH, and SAMHSA, the bulletin described mechanisms for funding and expanding programs.

The two RAISE projects produced an abundance of user-friendly materials to speed dissemination of CSC programs in community settings. These resources – freely available from the NIMH website[8] – include CSC program planning and decision support tools, training

and implementation manuals, *Voices of Recovery* videos, and resources for supervising staff and monitoring treatment fidelity. Combined with CSC technical assistance and training activities jointly sponsored by SAMHSA and NIMH in 2014-2015, these resources have been widely used in the development of CSC programs across the US.

The expansion of CSC in the US is also aided by the efforts of the Prodrome and Early Psychosis Program Network (PEPPNET), a consortium of researchers, government agencies, clinician experts, and advocates for early psychosis intervention and prevention. PEPPNET is developing clinical best practice guidelines and metrics and addressing the evolving needs and barriers to CSC program implementation.

FUTURE RESEARCH DIRECTIONS AND CONCLUSION

New research findings, federal funding for early psychosis treatment programs, and an abundance of CSC implementation and training resources have stimulated rapid expansion of CSC programs across the US. NIMH has also launched research initiatives aimed at reducing the duration of untreated psychosis; learning more about long-term outcomes after discharge from CSC; and accurately identifying individuals at high risk for psychosis and intervening to prevent clinical worsening or conversion to a psychotic disorder. Also, NIMH is building on the rapid expansion of CSC programs across the US to establish the Early Psychosis Intervention Network (EPINET) to use data collected during routine care for scientific inquiry and create a vibrant learning healthcare environment. EPINET will accelerate research and set new standards for early psychosis care by facilitating practice-based research collaboration among clinicians, academic researchers, and CSC service users.

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FOCAL POINT 11

The EASA Young Adult

We are the EASA Young Adult Leadership Council. We are from different cultures and we range in age. All of us have been affected socially, emotionally, and mentally by the break from our previous perceptions of reality, called "psychosis." We have felt alone, afraid, and misunderstood. We have also felt stronger in the end for having had those experiences. Our group includes a high school student, college graduates, and individuals pursuing professional paths such as peer support, occupational therapy, music, and law. We offer mirrors of hope and inspiration to each other. We have a common vision: "Uniting the voices and strengths of young adults and their allies in order to create a thriving community and revolution of hope."

EASA teams work to be welcoming, respectful, and honest. They listen and keep you in the lead. They give the message: "This is a normal experience and we are here to help you." EASA includes mental health professionals, supported employment and education specialists, peer support specialists, occupational therapists, psychiatrists, and nurses. Shared decision making is at the core, and recognizes the diverse needs and perspectives of each person:

> "It's your battle but others are there to support you."

> "I needed a place to live and someone to work with my family."

> "The information I needed as a high school freshman was different than what I would have needed if I were a pre-med student."

> "I wanted to read and explore the research articles. I understood them."

Navigating our way from fear to hope, self-acceptance, independence and wellness takes trust, patience, and persistence:

Photo: Some members of the EASA Young Adult Leadership Council

> "Experiencing a mental illness is a really scary thing. You think you are alone and the path is dark. Even the recovery path can be scary because there's the potential for relapse. You have to trust yourself and you have to trust what other people are telling you."

> "Helping me to understand what I was experiencing made a huge difference."

> "They were there for me when I went to the hospital, and didn't let me forget that I wanted to go to college."

> "There's this idea that we're the microwave generation so that we expect everything to happen fast…It really takes patience and determination to…walk through recovery."

We have struggled with our relationship with medicine. "Medication can be very empowering if the decision is truly made by the individual. Pressure can be subtle. The information can be stacked to make it look like the only option. If one option isn't working it's important to explore others that might."

Leadership Council:
Our Experiences and Vision
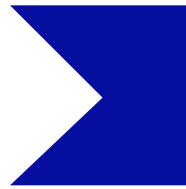
We will make decisions that others disagree with, and it is important for us to be able to be honest and discuss our decisions without feeling shamed, blamed, or threatened.

EASA is not perfect. Some of us struggled with the early signs of psychosis for a long time before we found EASA. EASA teams vary and can be improved. We have struggled finding long-term support after leaving EASA's two-year program. We have at times been denied critically important care when leaving EASA because we had private insurance. We have found a larger system of care focused largely on maintenance and not much on career development, independence, and shared decision making.

Many of us have experienced ignorance and discrimination in school, employment, and housing. Some of us have experienced homelessness, involuntary hospitalizations, and criminalization. At times we have felt marginalized, reduced to the role of "pill swallower" and not having our full humanity recognized and honored. We have struggled to find our voices and to stand up for our rights. We are beginning to use our experience to develop policy recommendations and to help create a more educated and accepting community.

In spite of these obstacles, we have experienced graduations, new jobs and career paths, finding our ways back from relapses, new independence, new relationships, marriage, and becoming new parents. We have appreciated the opportunity to be on a professional leadership board which is both safe for self-disclosure and serious in its mission.

Our greatest passion as a group is reaching out to others who are new to journeys like ours to let them know: You are not alone. There is hope. You deserve respect. You have many strengths and they will serve you well. It matters what you think, even when others disagree.

We believe that the early psychosis field has the potential to radically change people's experiences for the better. "It is the difference between thriving and surviving." It is important for us all to come together in order to really create a revolution of hope. That revolution will involve more than just offering a service package for a couple of years. It will mean a different attitude and sense of ownership, confronting discrimination and injustice, valuing the importance of lived experience, and working in support of each other to change attitudes and practices in all the settings we encounter.

AUTHORS

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Nybelle Caruso is a student pursuing her BS, a peer support mental health professional, and member of the EASA Young Adult Leadership Council.

Nicholas and Nybelle helped to weave the voices of EASA's Young Adult Leadership Council into a "united voice."

> **It's your battle but others are there to support you.**

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FOCAL POINT   13

Our Experience with EASA

My son recently told me that one night while he was trying to sleep, he was thinking how unique he was to have schizophrenia. The National Institute for Mental Health (NIMH) states that 1% of the population of the United States has the disease.[1] My son is right, he is unique, kind, funny, intelligent, musically gifted, and a generous person who happens to have schizophrenia. He has two parents, three older sisters, grandparents, and extended family who love him. The world is a better place because my son is in it. That is what those statistics represent, but seem to hide. While all of these young people are uniquely affected by their illness, for the most part, they all want what everyone universally wants: to be loved and understood by their friends and family; to have meaningful, fulfilling work; and to contribute to the greater good of society. In other words, to seek out and achieve what makes them healthy and happy.

Our son was hospitalized for the first time in January of 2012 for a psychotic episode. There would be many more hospital stays and a few months in jail in the following years. As parents, you try to keep your children safe from all the known dangers you can. No one prepares you for keeping your kid safe from the dangers of his own mind.

To say we were completely unprepared for our son's onset of schizophrenia is a huge understatement. That first full-blown psychosis had us searching the phone book looking for emergency numbers in the wee hours of the morning. We watched helpless as our boy ran around saying he could flip cars over with his mind and fight off aliens coming to get us. We also had to keep redirecting him away from the knives in the kitchen because he wanted to cut out an evil third eye he insisted he had. No amount of reasoning changed the situation. When I finally called the local free psychiatric clinic listed in the phone book, the person on the other end of the phone said we could bring him in for a free evaluation, if he would come willingly. Then he said the famous words repeated to us many times in the coming years, "If he becomes a danger to himself or others, call 911." What a ludicrous statement, I remember thinking at the time; I am not going to call the police on my sweet son. However, a few hours later, that is exactly what I was doing. We would have to call the police many times, each time heartbreaking, but we could not control the situation on our own.

During that first hospitalization, one of the nurses in the psychiatric center told us about a workshop that Early Assessment and Support Alliance (EASA) was hosting that very weekend. We were desperate for help, and could not wait to get there. We sat at a table with another couple who had a son in the hospital with ours. Right away, we had a connection with others who were in the same horror we were, and desperate for help, direction, and most of all, hope. The psychiatrist at the workshop spoke about mental illness and the brain and described the services EASA offered. A mother spoke about her son and his experiences with psychosis and the help received from EASA. Her son's story had a nice ending, so we were extremely optimistic.

Our son's journey was not to be so easy. He willingly took his medication while it was court-mandated, but refused it as soon as he was no longer on probation. The months became a year of sleepless nights of worry, with him sometimes home, sometimes walking the streets all night or sleeping in a park under a tree. During all this stress and dysfunction EASA staff was always there for our son and for us, trying to connect with our son and assist us in trying to cope with what was happening. When our son was in jail, his EASA caseworker was the first person allowed to see him. This was his turning point; he told her everything and asked for help. We attended Multi-family Group at EASA. Family group is just that, a group for the client, family, and friends of the EASA client that meets twice a month. Family group is designed to help people help themselves by helping others. You talk out your issues and problems from the last two weeks and give each other ideas on what might help. This core of parents, who, like us, needed to feel accepted by others going through the same experiences, became our lifeline. Here, there was no judgment. Here was compassion, understanding, support, and comradery within the hell our lives had become. These lovely parents, and EASA staff leading the group, taught us something about ourselves we did not know: we could endure; we could survive; we could even laugh with each other in the midst of it all. The families came from all walks-of-life, all income levels, with different belief systems, to learn how to help our loved ones, even when they didn't want help. Even now, with our son's time finished in the program, we stay connected to EASA, continuing to go to Multi-family Group and speaking at workshops.

Young people going through the EASA program are enrolled for two years, sometimes with additional vocational support after that time. In those two years, clients have access to caring staff who provide therapy, medication management, help looking for employment, and a website full of great learning material.[2]

Clients can also attend conferences to hear from peers and learn about advances in healing and help for those dealing with a mental illness. The approach to helping those who come through the program's doors is one of compassion and education that works with the individual client, never losing sight of the dignity each of them needs to feel worthwhile and valued. In addition, the entire family can participate in EASA Multi-family Group. The help from the EASA staff is unparalleled. Once a client graduates from the program, there are services available at the local county level, but moving from the individual care of EASA to a one-size-fits-all approach with the local county program can be tough.

Our son has had some difficult hurdles to climb over since his illness manifested itself. Today he is doing well, taking a medication that is working for him, and living in a semi-staffed home the county operates. He and a friend plan to move into an apartment together in the near future. Independence is a viable goal. He still attends Multi-family Group on occasion and speaks at the EASA workshops telling his story, encouraging others that they too can get through this difficult journey, and come out the other side a better, stronger individual. EASA is definitely leading the way to give young people like our son, and their families, hope that their lives can be just as rich and rewarding as anyone's.

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DATA TRENDS

SEEKING HELP FOR FAMILY MEMBERS EXPERIENCING THEIR FIRST EPISODE OF PSYCHOSIS

A recent qualitative study found that the very presence of family or support professionals determined a process of help-seeking.

Families often play a critical role in identifying and seeking help for psychosis. When a young person first experiences psychosis, family members are often confused and frustrated in attempting to make sense of the changes occurring in their loved one.[1] Resulting delays in accessing care are associated with negative outcomes such as worse psychiatric and social functioning.[2]

A recent qualitative study on the duration of untreated psychosis (DUP) period for young people served by the Early Assessment and Support Alliance (EASA) in Oregon found that the very presence of family or support professionals determined a process of help-seeking.[3] For all but one young adult (away at college with little family contact), a family member or professional counselor was available to assist the young person resulting in an eventual visit to a mental health professional. Conversely, being physically away from family led to the longest period of DUP.

A meta-synthesis[1] of articles on family members' experiences in seeking help when their loved ones experienced their first-episode of psychosis, and a qualitative study of young people served by the Early Assessment and Support Alliance (EASA) in Oregon emphasize the importance of families and the challenges they face in seeking care.[3] The meta-synthesis included studies from urban and rural communities in Australia, Canada, Brazil, Hong Kong, New Zealand, the United Kingdom, and the United States, and the qualitative study focused on the duration of untreated psychosis and causes among individuals receiving early psychosis services from EASA in the US. Considering the central importance of family members for seeking help with early psychosis, we will now summarize four themes from the meta-synthesis.

RESULTING THEMES

The first theme was, "*'Not Knowing' – trying to make sense and looking for answers*."[1] Family members may vary in their decision to seek treatment for their young person due to their level of understanding of psychosis – misinterpreting changes such as blank stares, reports of hearing voices, or odd mood shifts as normal teenage behavior or underestimating the seriousness of symptoms.[1,4] Cultural beliefs about mental illness and religion may also impact how families interpret behavior and the appropriate response.[5] Some family members may seek answers through discussions with extended family or engaging a religious leader. These help-seeking choices may be affected both by cultural norms and by distrust of mental health service providers stemming from historical systematic oppressions.[1,4,5]

Family members talked about experiencing feelings of desperation as they struggled to make sense of the behavioral changes. For some, these feelings were expressed through justifying, ignoring, or minimizing symptoms, while other family members distanced themselves from the young person as a coping strategy.

The second theme was the "*Crisis point – the cry for help*."[1] After a period of interpretation or informal help-seeking, there was often a "dramatic shift in help-seeking behavior" after reaching a personal limit of feeling overwhelmed and recognizing a need for professional help, or seeing behavior as dangerous. Two families in the EASA study[3] did not recognize the need for professional care until the young adults' mental health difficulties led to a medical emergency, resulting in a stronger sense that "something was wrong" than the appearance of hallucinations and delusions. Similarly, some families who experienced the impact of oppression were found to have "high coping strategies" which functioned until the young person's psychosis symptoms escalated into a dangerous situation and overwhelmed these families.[1,6,7] Finally, frustration around seeking help occurred when there was limited understanding of psychosis symptoms, and barriers to accessing mental health services from front-line service providers.

The third theme, "*Impact on the family member*,"[1] included emotional impact, family relationship impact, and stigmatization. Obtaining help brought relief, yet involuntary hospitalization resulted in traumatization and possible stigmatization. The help decreased the negative impact on the family members and increased their knowledge around psychosis. This resulted in increased hope within the family, which had a relationship-mending effect.

The final theme was "*The role of interactions in help-seeking*."[1] This theme addressed the interaction between families, informal sources of help, and helping professionals. Informal sources were sought to provide a reassuring explanation to diminish uneasy feelings. Parents also found support from school social workers who helped link them to mental health organizations. Trust in helping professions increased when issues of culture were addressed and parents were validated around their concerns. A key factor was clear communication between the family and helping professionals.
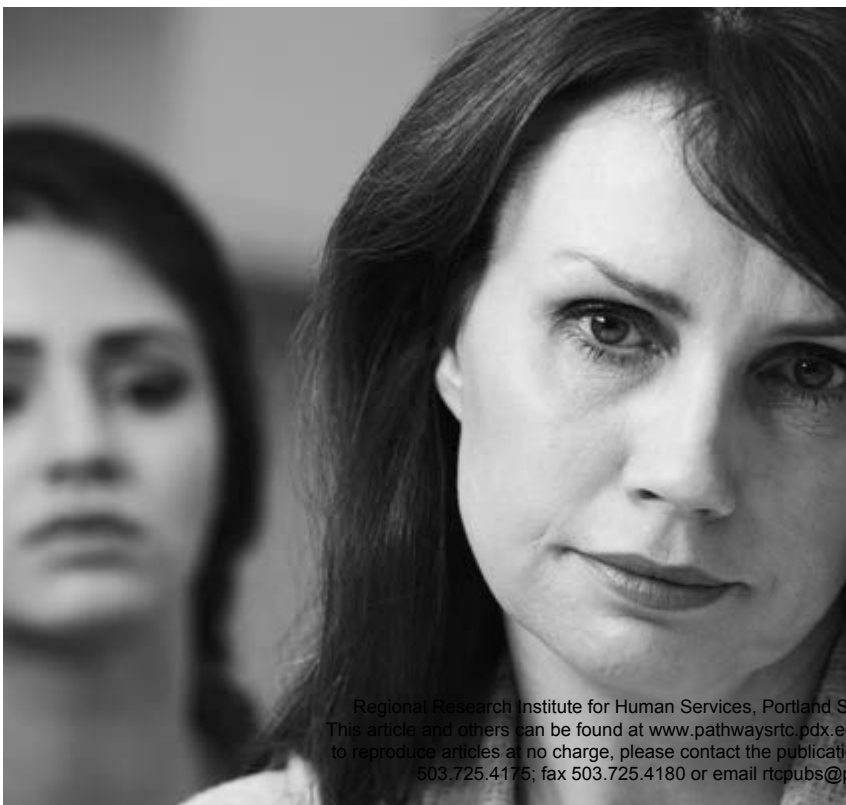
Obtaining help brought relief, yet involuntary hospitalization resulted in traumatization and possible stigmatization.

PRACTICAL IMPLICATIONS

The presence of family members or other supporters can determine whether the person gets help and how long it takes. Family-level factors such as cultural beliefs, interpretation of behavior, and awareness of mental illness affect DUP length. The meta-synthesis concluded that all four themes influence family members seeking help. The interaction of service providers with families is paramount in all aspects of the process of seeking help. Reducing the length of DUP during the help-seeking period will depend heavily on recognizing emerging psychosis within the family. Efforts to reduce DUP must recognize that help-seeking for psychosis varies within communities that experience marginalization. Addressing factors that facilitate rapid help-seeking by significant others will ideally shorten delays in seeking care.

Addressing spiritual beliefs, cultural traditions, the historical impact of oppression, and stigma may decrease or eliminate delay in seeking help.[1,6,7] Education needs to be accessible, easy to understand, and non-threatening, and dispel cultural fears and stigma around first episodes of psychosis. Supportive interactions between service providers and family members are key in increasing early intervention and sustained help.

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The interaction of service providers with families is paramount in all aspects of the process of seeking help.

Assessment of Quality in First Episode Psychosis Services

The rapid creation of First Episode Psychosis Services (FEPS) throughout the US raises the challenge of how to offer optimal access to evidence-based services in a consistent and reliable way that has the support of funders, providers, and consumers. Recent health services research supports reliable and valid process and outcome measurement of first episode psychosis services.[1-3]

Large scale research studies show that FEPS can deliver a range of improved outcomes from shorter duration of early psychosis and reduced rates of hospitalization to improved quality of life in a variety of health systems.[4-6] With a significant body of evidence supporting such services, the challenge is changing from demonstrating effectiveness in research to ensuring access and quality in the real world. A number of relevant frameworks for health services implementation have identified which strategies are most effective as they apply to mental health initiatives. Two key areas of focus in successful implementation are developing the skills of front line clinicians and fidelity monitoring and evaluation; these focal areas require specific knowledge and tools based on the research evidence supporting FEPS effectiveness.[7] Most of the major mental health implementation initiatives have used three core approaches to support skills development and to support fidelity monitoring and evaluation. These approaches are: the use of educational materials; training and supervision; and consultation or technical assistance. Fidelity monitoring and feedback are supported by fidelity scale development and performance measures.

First episode psychosis services comprise a number of essential components that need to be delivered over time and are adapted to the varying needs of individual patients and families.[8] In the United States, a survey of 31 programs showed that most of these components are delivered in a high proportion of services.[8] Such surveys are useful for validating the list of evidence-based components and getting the big picture of service implementation.

In the US, Oregon's Early Assessment and Support Alliance (EASA) has been the earliest adopter of these evidence-based implementation strategies in order to develop and maintain a statewide dissemination of early intervention services.[9] EASA has a technical support center, the EASA Center for Excellence, which has developed a fidelity scale that is used to evaluate the county programs on a two year review cycle.

The EASA initiative in Oregon covers some of the key requirements for broad scale program implementation. This includes a technical support center and provision of evidence-based services delivered in the context of the existing US health care system. EASA includes fidelity scales and performance measures or quality indicators as key implementation tools.

Fidelity scales provide a list of objective criteria by which a program or intervention is judged to adhere to evidence-based practices. Fidelity measures are comprised of process measures and structural measures that together assess the degree to which a program delivers evidence-based components of care. Fidelity scales have been widely used in mental health services research, implementation, and quality control. They can be developed based on the effective components of a program model that has research evidence to support its effectiveness or they can be derived from the entire literature on the efficacy of programs or components of programs. There has been limited application of fidelity scales in first episode psychosis research and implementation but that is changing rapidly.

Performance measures or quality indicators are broader in application and can be used at the individual, program, or health system level. In order to evaluate programs, a number of domains can be assessed including: accessibility, efficiency, appropriateness, and outcome. Since fidelity scales address the process of care, they are best linked with performance measures or indicators that measure outcomes in order to assess the overall quality of health care. These indicators have been described as "Norms, criteria, standards and other direct qualitative and quantitative measures used in determining the quality of health care."[10]

Fidelity scale development for first episode psychosis services was first undertaken in the United Kingdom. The Early Intervention Services (EIS) fidelity scale was developed using an expert clinician consensus process and refined by researchers. The scale has been applied in one program evaluation in the UK but has not been described in the peer reviewed literature. In the US, Oregon EASA developed a fidelity scale using a process of expert committees tied to practice guideline development. It has been used in support of program implementation and quality control.

A different approach to fidelity scale development was used to develop the First Episode Psychosis Services Fidelity Scale (FEPS-FS). The scale was developed by first identifying effective treatments from the research literature then measuring the strength of that evidence. In the second step, a group of international experts was provided with the results of the first stage and asked to identify what it considered to be the essential evidence-based components.[8] This list formed the basis for developing a 31-item fidelity scale with definitions of each component paired with a 1 to 5 rating scale. This scale has been tested in six programs in both the United States and Canada and found to be reliable and to have face validity. This fidelity scale had fewer items than the ones mentioned above, but a higher proportion of items that were common to all the scales.
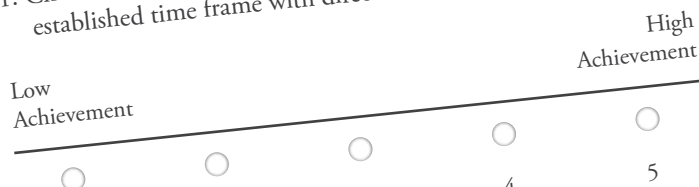
In summary, funding and establishment of First Episode Psychosis Services offers the opportunity for patients and families to access programs that provide optimal evidence-based care for a first episode of psychosis. The use of performance measures and fidelity scales can ensure that these programs meet standards of care.

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Services Fidelity Scale

1: Clients have completed program intake procedures within established time frame with direction from program staff.

Low
Achievement

High
Achievement

1   2   3   4   5

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PROJECTS AND STAFF

PROJECT FUTURES: FOSTERING UNITY TOWARDS UPLIFTING RESILIENCE, EDUCATION, AND SUCCESS tests an approach to enhancing self-determination and community participation to help young adults with a history of mental health challenges to build skills to navigate the university system and increase postsecondary success and engagement.

Jessica Schmidt, Principal Investigator; Shannon Turner, Project Manager; Sarah Geenen, Laurie Powers, Project Consultants; Molly Oberweiser-Kennedy, Graduate Research Assistant.

EASA CONNECTIONS brings together young adults who have been part of Oregon's early psychosis initiative to develop and test a peer-delivered series of web-based decision support tools for new individuals entering into early psychosis services.

Tamara Sale and Ryan Melton, Co-Principal Investigators; Dora Raymaker, Project Manager; Christina Wall, Young Adult Coordinator.

TEC-PD: TECHNOLOGY-ENHANCED COACHING FOR POSITIVE DEVELOPMENT tests a workforce intervention using state-of-the-art technology to implement high-quality coaching and supervision with practitioners employing the Transition to Independence Process intervention with emerging adults with serious mental health challenges.

Janet Walker, Principal Investigator; Celeste Seibel, Project Manager.

S/PAC: SYSTEM/POLICY ASSESSMENT AND CHANGE PROJECT documents and analyzes processes, strategies, and outcomes by which organized groups of young adults engage in policy analysis and action relevant to transition, and develops knowledge about key systems factors at the state level affecting transition services.

Nancy Koroloff and Barbara Friesen, Co-Principal Investigators; Nicholas Buekea, Research Assistant; Pauline Jivanjee, Project Consultant.

AMP+: DEVELOPING THE YOUNG ADULT PEER SUPPORT WORKFORCE tests a workforce intervention focused on training and coaching peer support providers who work with emerging adults with serious mental health conditions, and prepares agencies to supervise and support them.

Janet Walker, Principal Investigator; Celeste Seibel, Project Manager; Sharice Jackson, Research Analyst; Mary Beth Welch, Peer Support Training Specialist; Jesse Homan, Graduate Research Assistant.

MENTEE-NOMINATED MENTORING adapts and tests a promising mentoring approach – youth-initiated mentoring – for young people who are living in residential treatment settings after stepping down from more acute psychiatric care.

Jennifer Blakeslee and Tom Keller, Co-Principal Investigators; Celeste Seibel, Project Manager; Janet Walker, Project Collaborator.

THE PATHWAYS TRANSITION TRAINING PARTNERSHIP has formed partnerships with service provider organizations that are participating in testing the effectiveness of an online training program, will survey service providers regarding their training needs and preferences, and develop new training materials in response.

Eileen Brennan and Pauline Jivanjee, Co-Principal Investigators; Maria Carolina Gonzalez-Prats, Graduate Research Assistant.

A CURIOUS LENS:

Cognitive Behavioral Therapy for Recovery and Resiliency

The Experience: Imagine you are boarding a bus. You step onto the bus and pay your fare. You look up to the faces of other passengers; many of them glance over as you find your seat, and a few people stare. Someone catches your eye and you're convinced he is part of a governmental conspiracy that you have been suspicious of for some time. These paranoid thoughts dart in and out of your head, making you increasingly uncomfortable, scared, and confused about how you became a target. You quickly scan the rest of the seats and notice more and more people staring at you. Beads of sweat start to collect on your forehead. You hear a voice saying "We will get you, we will get you." You're not sure where it is coming from, but assume it must be one of the riders behind you. At the next stop, you exit the bus, constantly looking over your shoulder to make sure no one is following you.

Sounds scary? Imagine navigating a world where everyone tries to convince you that there is no conspiracy, asks "Have you slept enough?" or offers their opinion that "You sound crazy."

Living with psychosis symptoms can be confusing. Individuals often receive terrifying and contradictory messages from their sensory world coupled with invalidating feedback from others' responses to their stories and beliefs. It's easy to feel isolated and misunderstood when you are told that what you experience isn't "real," and is "an illness."

Cognitive Behavioral Therapy for Psychosis (CBTp) is an opportunity to see these experiences in a new light. CBTp is a collaborative approach which aims to increase our awareness of how our thoughts, feelings, and behaviors are linked when we respond to and interpret internal and external events. Through this approach individuals gain perspective into how they view their experiences and life events. CBT is a well-established treatment for anxiety and depression.[1] It is now broadly recommended as a first line treatment for psychosis by the National Institute for Health and Care Excellence in the United Kingdom[2] and the Schizophrenia Patient Outcomes Research Team (PORT) report in the US.[3]

CBT for psychosis differs slightly from CBT for anxiety and depression in that the initial focus is not to reduce symptoms, but rather to reduce the distress caused by the symptoms. Symptoms are not conceptualized as challenges to be eliminated, but are explored as warning signs that something else may be off for the

person experiencing them. For example, a client may stop spending time with friends due to the voices she hears throughout the day and as a result she feels lonely and sad. A CBTp clinician might work with this client on coping skills (behavioral intervention) to manage and distract herself from the auditory hallucinations. This would allow her to spend time with friends again and feel less sad and lonely.

The clinician may also work with the client around her understanding of the voices (cognitive intervention) to increase insight and identify more helpful and accurate thoughts. This client may still hear the voices, but her functioning is less impaired due to the coping skills and an improved way of making sense of the voices. At the heart of this journey of exploration is normalization. Psychotic symptoms are part of the continuum of human experience – any person is capable of these symptoms given the right circumstances (e.g., stress, drugs, trauma). Understanding this can normalize the clients' experiences and empower them to feel less alone. Clients are able to begin shifting their interpretation of their symptoms and associated thoughts, emotions, and behavioral responses, in order to move toward productive and affirming goals.

The real-life scenario above was drawn from the experiences of a young man who was experiencing frightening and unusual beliefs on a daily basis. He began missing school and was isolated from his friends. Each week, we worked through these distorted thoughts and interpretations to help him better distinguish his symptoms of psychosis from reality. Slowly but surely, he was able to identify his triggers and use adaptive coping skills to manage his stress. He began to see the relationship between specific triggers, stress, and his symptoms. He learned skills such as finding evidence for and against his interpretation, keeping a coping card of his alternative beliefs about people on the bus, deep breathing, and wearing headphones to distract from potentially distressing voices. Over time, he was able to reduce the impact and severity of his symptoms.

These cognitive and behavioral changes were possible because of a relationship with the clinician built on collaboration, mutual respect, trust, and communicating that these experiences are not abnormal. CBTp gives clients a safe space to talk about confusing and scary experiences while working together with a clinician to identify solutions. Curiosity and openness are at the core of CBTp, with the ultimate goal being to understand the client's experience and together choose an appropriate intervention.[4] The clinician also uses questioning in order to increase the client's insight into how earlier life experiences have contributed to the way she makes sense of the world today. This roadmap serves as a way for both the clinician and the client to navigate current patterns of thinking, feeling, and behaving.

Through exploration, psychoeducation, and emphasizing that unusual and distressing beliefs are within the normal continuum of human experience, clients are able to reframe and understand experiences within a different, more normalized context. CBTp clinicians strive to understand and empathize with their clients' reality, whether it is entangled in systems of delusions or based on hallucinations, and identify how to decrease the distress. Morrison states that many symptoms of psychosis can be thought of as intrusions into

PSYCHOTIC SYMPTOMS ARE PART OF THE CONTINUUM OF HUMAN EXPERIENCE – ANY PERSON IS CAPABLE OF THESE SYMPTOMS GIVEN THE RIGHT CIRCUMSTANCES

the awareness – and that it is the interpretation of this intrusion that causes distress and impaired functioning.[5] As clients work towards learning how to manage their distress, the next step can be to explore how the meaning attributed to symptoms is an underlying source of the maintenance of certain patterns of thinking and behavior. The clients and clinicians work as a team, with the clients in the driver's seat, to untangle distress and barriers, increase clients' understanding of what is happening, and learn how they may respond. The goal of this work is to support clients to return to functioning as they once were, and hopefully to continue thriving in life.

CBTp encourages us to be open and at the same time think critically. Participants are supported in looking for evidence and also validated in their challenges to make sense of confusing experiences. Their experience is normalized, helping them to feel less alone in their journey. They are given hope through a here-and-now, problem-solving method in which they are their own experts in the search for meaning and understanding. Together these pieces allow clients experiencing psychosis to lead more functional lives, far from their previous disconnected and disorganized realities. The framework that CBTp offers to both clinicians and clients within the clinical setting can also be beneficial in more global contexts. Perhaps if our society learned to be more open, accepting, and validating towards individuals with psychosis, we could move away from stigma and towards community acceptance and understanding that individuals who experience psychosis can and do recover.

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PERHAPS IF OUR SOCIETY LEARNED TO BE MORE OPEN AND VALIDATING TOWARDS INDIVIDUALS WITH PSYCHOSIS, WE COULD MOVE AWAY FROM STIGMA AND TOWARDS COMMUNITY ACCEPTANCE

Individual Placement and Support Model of Supported Employment:

Modifications for First Episode Psychosis Programs

During her sophomore year at college, Holly began experiencing significant psychotic symptoms. She believed that her history professor was shape-shifting and having an affair with several students in her dorm. Holly spoke out about her experience, and school administrators asked that she withdraw from the school and seek psychiatric help. Ultimately Holly was referred to an early psychosis program. After a short trial of medication Holly told her counselor she would like to return to school. In exploring that option the school was reluctant to re-enroll her given her current symptoms, which were improved, but still present. Holly agreed to put her goal of returning to school off for a year while she explored vocational options, although she was unsure if she really wanted to work for a while or put her efforts towards going back to school right away. Her counselor referred her to the early psychosis program's Employment Specialist (ES), John who followed the Individual Placement and Support (IPS) model of supported employment.[1] At Holly's request, John met her at the college career center instead of the mental health center since it felt like a less stigmatizing environment. They completed some online career inventories and explored the job market.

IPS supported employment is an evidence-based practice that follows eight principles aimed at support-

ing individuals with severe mental illness in their efforts to return to work.[2] The principles include:

- Open to anyone who wants to work
- Focus on competitive employment
- Rapid job search
- Systematic job development
- Client preferences guide decisions
- Individualized long-term supports
- IPS integrated with treatment team
- Benefits counseling included

IPS was originally developed to help individuals with severe and persistent mental illness return to work. Because most early psychosis participants are late adolescents or young adults just beginning their careers, it is essential that the ES utilizing the IPS model also integrate the principles in supporting the individual as he or she decides to stay in, return to, or engage in high school or post-secondary education. Essentially supported education is as important as employment, and the ES should support both school and work options using the same IPS principles.

John, Holly's IPS ES, knew that Holly was studying political science, and approached a political action agency to learn if they needed support. They had an

opening for a phone surveyor calling constituents to seek support of their cause. John approached Holly about the opening. Holly expressed interest in applying but based on the stigma and discrimination she experienced at her college she would not disclose her condition to the agency. John worked with her to research the agency, helped her complete the application, and practiced a mock interview. Holly applied, interviewed, and was offered the position.

The first several weeks on the job went well for Holly. However, as the job demands increased, Holly began to experience an increase in symptoms. She reported this to John via text message and an app that tracks her specific symptoms. John immediately reported the increase of symptoms to her treatment team, who began working on coping skills and medication adjustment. The counselor suggested that Holly talk to her boss about taking a break when she experienced increased symptoms. Holly and John came up with some language she could tell her boss when she needed a break, so that she did not have to disclose her symptoms.

As Holly continued to work, her boss offered her more and more hours to meet the demand of the agency. Holly began to earn money at a rate that put her Medicaid insurance at risk. John met with Holly and her parents to review her benefits options and figured out the best way for her to continue to work the hours she desired and still earn medical benefits. With Holly's permission, John also met with her family to educate them on the options around insurance, as her family assumed the only way for Holly to continue being insured was to stay below the Medicaid income limit.

Over the next year, Holly expressed interest in returning to college to complete her degree, but she feared that if she used the disability services office (DSO), they would disclose her condition to the administration. Additionally, Holly did not see herself as having a disability and did not see the need to connect with an office with the term "disability" in its title. With Holly's consent, John began to work with the DSO to start the process of returning to school. John let the DSO know of Holly's concerns and the staff agreed to meet with her outside of the DSO office at the college coffee shop and explain her rights. They built a relationship with Holly on her own ground, and did not force her to go to the office where she already felt stigmatized.

The above scenario represents a typical supported employment referral from an early psychosis program. Although the principles of IPS are generalizable to individuals in early psychosis programs, and research supports the model's effectiveness with these individuals,[3] some modifications are needed to address the specific cultural needs of this population. The following recommendations and modifications to IPS in working with young adults with early psychosis were developed by Dartmouth University in collaboration with Oregon Department of Vocational Services, Early Assessment and Support Alliance (EASA) participants, and EASA clinical and supported employment staff.[2]

TIP 1: NORMAL DEVELOPMENT

Young adults are at a stage of developing self-identity and want to try different experiences. They may fluctuate in their desire to work or go to school. Help them explore both options and continue to engage young

people during periods of uncertainty. Do not confuse ambivalence and developing an identity with lack of motivation. Peers with work or school experiences can help engage other young adults who are unsure about their goals. Young adults may not want to disclose their condition to employers or schools for various reasons. Although it may be helpful in some cases, disclosure may not be necessary to improve vocational or educational outcomes.[4]

Holly was reluctant to explore employment given her goal of returning to college. Also, given her experience with the college she was not interested in disclosing her condition to employers. The ES viewed Holly's uncertainties as normal developmental issues and understandable given her recent situation with the college – as opposed to unwillingness or lack of motivation to work.

TIP 2: STRENGTH-BASED SERVICES

Young adults typically see themselves as healthy and invincible rather than as persons with disabilities. They are more likely to engage in services that focus on their strengths and opportunities rather than on diagnosis or disability. Help them consider short-term and long-term career goals. For some, the focus is on educational goals that match their career goals. Help young people explore career opportunities by asking questions such as:

- What would you like to be doing in two to three years?

- What is your dream job? (If the individual is unsure of this due to lack of knowledge of jobs, it is recommended the ES use online career value, personality, and interest inventories to increase the understanding of the world of work).

- Do you know of anyone who has gone to college or attended training programs?

- What are some of your interests?

- What are the things that we are working on now that you find helpful?

John worked with Holly to find employment positions that supported her interest in political science and her long-term vocational goals. He met with the hiring manager to learn about the organization and what types of individuals were successful working there. IPS for early psychosis participants keeps the focus on long-term career goals and not just establishing a job.

TIP 3: FAMILY INVOLVEMENT

With the young adult's permission, invite family members to some employment/education meetings. The young adult can define family to include friends, partners, or other supporters. Family members contribute information about the individual's strengths, skills and past education. Friends often have a strong influence in the person's life and share information from a young person's perspective. Ask the young adult "Is there anyone else who has given you helpful ideas? Would you like to invite that person to a meeting?" Educate the family about career development. For example, explain that it is normal for young people to try different jobs. Some jobs may be short-term or brief, but are still learning experiences. Educate the family about how to support the young adult in his work and school experiences. Talk with the family about whether this approach challenges the family norms and culture.

Holly's family was concerned that the only way for her to stay insured was to limit her work hours. John was able to provide them with information regarding a range of options.

TIP 4: COMMUNITY-BASED SERVICES

Young adults often shun traditional clinical settings. Create an environment that is more conducive to a younger population by creating separate waiting rooms for young people, displaying materials that are marketed towards youth, and equipping the space with computers. Community locations are often more appealing to young adults than meeting in a clinic. Ask each person where she likes to spend time and offer to meet the young person there.

John met with Holly at the community college. This normalized the job exploration process for her.

TIP 5: ENGAGEMENT AND USE OF TECHNOLOGY

Many young adults prefer to communicate through texts, emails, and instant messages rather than by phone. In addition, many job applications require online access. Social media, such as LinkedIn, provide employment connections that aid job searches. Review and revise agency policies about communicating using technology and ensure that computers used by the IPS program have access to job-seeking sites.

Holly preferred the use of text messaging to communicate with John how she was doing on the job. She also used a symptom tracker app that she could share with John and the treatment team to let them know how the stress of the job was impacting her symptoms.

TIP 6: BENEFITS COUNSELING

Help young adults consider jobs and careers as an alternative to disability benefits. Help young people consider the advantages and disadvantages of applying for disability benefits. Offer meetings with peers who can explain why they chose employment. Ultimately, honor each person's choice and continue to offer assistance with school and work.

Holly did not want to decrease her work hours to maintain her benefits. She saw this job as experience leading to a long term career path and felt decreasing hours would hurt that goal. John engaged with Holly around benefits offered by her job and benefits that would be available to any young person in her situation as opposed to limiting benefit planning to keeping Medicaid and/or Social Security.

TIP 7: WORK EXPLORATION

Young adults often have little or no employment history. Exploring the world of work through summer jobs, internships, AmeriCorps, and additional schooling or certification is normal. When young adults prefer help with permanent, competitive jobs, follow their lead and do not require or encourage non-competitive positions.

Volunteer experiences are generally discouraged in the IPS model; however, they may make sense for the young adult attempting to learn the world of work and gain experience for careers. When a person expresses a preference for an internship or volunteer job, explore available positions that will help her gain skills and experience related to her career goals.

Given Holly's limited job experience, John and Holly used an online career search system that allowed her to take interest inventories, learn about jobs she did not know existed, identify necessary skills for specific jobs of interest, and understand job availability and school options.

TIP 8: LANGUAGE MATTERS

Young adults often avoid programs that use disability-related language. For example, names such as Office for Student Disability Services, or Rehabilitation Services are sometimes discouraging. When connecting young people with these services, prepare the young person for the language and perhaps modify the pro-

cess. For example, a vocational rehabilitation counselor could meet the young adult at the mental health office or another community location.

For Holly the thought of going to a DSO was stigmatizing. John arranged for the DSO staff to meet with Holly outside of that office to build a relationship and describe what they could offer her to support her goals of returning to school.

Although IPS has been found to be successful with working with young adults with early psychosis, it is important to remember that mental health programs must adapt their approach to fit the developmental stage, culture, and belief systems of young adults with psychosis.

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FOR MORE INFORMATION ON THE IPS MODEL PLEASE VISIT:

http://www.dartmouthips.org/resources/programs/program-tools

Perceptions:

Using the Senses to Navigate Early Psychosis

Your experience of the world is based on how your brain makes sense of everything your body interacts with around you. Our brains are fueled by sensory input – without it, the brain has no source of information. Too little or too much sensory input can also confuse the brain, but not everyone needs the same amount for the brain to do its best work. The sensory serving sizes your individual brain craves are called sensory preferences. These preferences underlie your everyday choices that determine how, where, and with whom you spend your time. Not only do these decisions influence your favorite band or type of comfort food, but sensory experiences can also influence your mood and behavior. Differences in sensory preferences between people can be misinterpreted and lead to relationship problems or make it harder to function. People experiencing psychosis in particular tend to have distinct sensory preferences that can lead to different behaviors. Occupational therapy (OT), an integral part of many early psychosis programs, can help by identifying an individual's sensory preferences, and how to feed the brain its own unique sensory diet.

To get a better idea of how sensory preferences and psychosis can influence us, let's take a look at a typical family coming into an early psychosis program.

Zach, a high school sophomore, was very active with the drama, foreign exchange, and chess clubs his freshman year. He also ran cross country in the fall and made the school golf team in the spring. He's always been very involved and maintained As and Bs in his classes. Earlier this year he stopped going to his club activities and didn't try out for any sport teams. Zach's parents, Logan and Sierra, got emails from his teachers stating concern about Zach's school performance and his lack of engagement in class, reporting that he often appeared to be falling asleep and zoning out. Zach's grades dropped to Cs and Ds. Lately, Logan and Sierra have noticed that Zach is spending more time in his room and often appears anxious. When they try to talk to Zach about their concerns, he gets angry and locks himself in his room. Sierra notes that "Things have gotten really bad" between her and Zach. She feels as though he's always ready to pick a fight with her.

Zach's dad, Logan, works as a computer programmer. Logan's friends consider him to be very easy-going but also sometimes a bit clueless about what's going on around him. He often misses cell phone calls if he doesn't have the ringer set to loud and vibrate in his pocket. In order to get going in the morning, he uses a booming alarm clock across the room to force himself out of bed but still frequently oversleeps unless Sierra jostles him awake.

Sierra is very social, likes to stay busy, and brings lots of energy and excitement to everyday activities. Sierra and Logan both use a family calendar on the fridge,

which prevents Sierra from overbooking and provides a visual reminder for Logan. Sierra loves her job as a senior project manager. She enjoys the bustling environment, managing multiple projects and people at the same time, and the fast-paced schedule. Sierra enjoys skiing, loud rock concerts, spicy foods, and decorating the house brightly for every holiday.

SENSORY PREFERENCES AND THE EVERYDAY CHOICES WE MAKE

Just like the rest of us, Zach and his parents have very different sensory needs. Winnie Dunn,[1] an occupational therapist, developed a model describing four types of sensory preferences. Imagine a sensory cup that needs to be filled just right in order for the brain to activate and do its best work. Some people start with a cup that sits close to empty, and some a cup that's nearly overflowing. To balance the just right amount, the cup can be filled or drained by increasing or decreasing the intensity, frequency, variety, or number of sensations, such as sounds, sights, and touch on the skin. When the cup is too low, your brain isn't getting the sensory fuel it needs and transitions into hibernation mode. You may feel zoned out, irritable, or fidgety. If the cup is too full, your brain is over stimulated with sensory information and has difficulty shutting out uncomfortable or confusing sensations. This can make you feel anxious or afraid, distracted, or quick-tempered.

UNDER STIMULATED – MY EMPTY SENSORY CUP

Low registration describes a nearly empty sensory cup. Logan displays characteristics of low registration when he misses phone calls and has trouble reacting to his alarm in the morning. He often misses or takes longer to register things that others notice, and tends to have trouble reacting to information delivered quickly or subtly. Logan's low registration also helps him, because he doesn't get bothered by extra noises and sights around him. In class, Zach displays low registration when he has difficulty keeping up with what is being said, misses details or subtle information conveyed by body language or tone of voice, and appears zoned out or uninterested.

Sensation seeking individuals enjoy sensory input and actively seek it out to keep their sensory cup full. Sierra enjoys her fast-paced, bustling job that requires multitasking, is involved in physically active sports, and decorates her house brightly for the holidays. She gets bored easily in slower paced environments that don't provide her with the diverse sensory diet her system needs, and her constant search for more stimulation may be distracting to others.

OVER STIMULATED – MY SENSORY CUP RUNNETH OVER

Individuals with *sensory sensitivity* quickly and easily notice everything going on around them. This sensitivity can support attention to detail, whether it's noting a change in a friend's mood or creating detailed art. Their sensory cup is easily filled to the brim and intense stimuli can cause it to overflow, creating anxiety and distracting the brain from its other duties. They may have difficulty adapting to change and stick to precise routines.

People with *sensation avoiding preferences* actively evade sensory experiences to prevent their full cup from overflowing. They may prefer spending time alone, because social gatherings and unfamiliar places are unpredictable and can create a sense of uneasiness or irritability. In an effort to control the amount of sensory information around them, they may be skilled at creating order around themselves with precise schedules or specific ways to do daily activities.

SENSORY PROCESSING AND EARLY PSYCHOSIS

While each person has a unique combination of sensory preferences, some specific patterns emerge within groups. In comparison to the general population, individuals with schizophrenia have an emptier cup, avoid sensation more, and seek sensation less than others.[2] Roush, Parham, Downing, and Michael[3] found

the same pattern in individuals at high risk for developing psychosis when compared to peers at low risk, with the addition of more sensory sensitivity. This distinct combination of sensory preferences can create a tricky cup to fill, like pouring soda over ice so quickly that the fizz bubbles over the top. Zach is displaying this pattern when he appears to be zoning out in class (low registration), drops out of many of the activities he previously engaged in (sensory avoiding), and reacts badly to his mom (sensory sensitivity to her typical pattern of sensation seeking). To avoid overwhelming daily activities, interactions, and environments, individuals experiencing psychosis may spend more time alone in low stimulation settings to reduce the chances of unpredictable, unsettling sensory experiences that amplify psychosis symptoms.

MANAGING SENSORY NEEDS

Occupational therapists (OTs) use the *Adolescent/Adult Sensory Profile* to assess an individual's unique pattern of sensory processing.[4] OTs interpret these results to identify and implement strategies to support the individual's sensory needs in daily activities. For example, a backpack or purse can provide calming weighted pressure in class or on the bus that can help the individual to focus attention. The stash of sour candies, mints or gum in the backpack are helpful to eat when feeling low on energy or having difficulty focusing, because the chewy consistency and strong, intense flavors help to wake up and focus the brain. Integrating more movement throughout the day can fill a cup to the just right level, particularly before thinking tasks – even a lap around the house during commercials can help. In class or meetings, using something small to fidget with, like a stress ball or paper clip, or sitting in a rocking chair or on an exercise ball, can help organize thoughts and stay alert.

OTs can also use Sensory Profile results to make recommendations for how the individual's family, school, employer, and treatment team can best provide support.[5] For someone with psychosis, whose cup can quickly overflow, a switch to working the closing shift at a coffee shop avoids the crowded rush of customers while still offering opportunities to interact with others one-on-one and can include more solitary routine tasks, like stocking and cleaning. An OT may also complete the Sensory Profile with each family member. Comparing the scores of Zach and his parents, the conflict arising from Zach's irritability with his mom can be explained by their differences in sensory patterns, shifting the conflict from emotional intent to the brain's needs. These differences can be addressed by concrete strategies integrated into daily routines, such as making different rooms in the house specific to Zach and Sierra's needs. Lights and sounds in Zach's room can be subdued to meet his needs, Sierra's room can be brightly lit with music playing to meet her needs, and shared spaces, such as the living room or kitchen, can be neutral ground with sensations of all types being kept at a moderate level between each of their needs. Sierra might also give Zach extra time to process information in a quiet space rather than expecting him to answer questions or make changes to plans on the spot. His initial overreaction might actually be a sensory processing issue, and giving him quiet time allows his sensory system to calm down before responding. By understanding each other's sensory processing needs and making some small adjustments we can help everyone to feel and do better with everyday activities.

To learn more about sensory strategies to support individuals experiencing psychosis, please visit the EASA website (www.easacommunity.org) for more resources.

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