ISSUE BRIEF

What Comes After Early Intervention?

Step-Down, Discharge and Continuity of Care in Early Intervention in Psychosis Programs for First Episode Psychosis

Abstract: Optimizing step-down, discharge and continuity of care policy and practice in multidisciplinary early intervention in psychosis (EIP) programs that address first episode psychosis (FEP) is a relatively under-developed but critical component of specialized early intervention. This issue brief reviews the relevant research literature and provides general guidance on challenges and decision-points involved in step-down/discharge planning and policy development.

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Acknowledgments: The author would like to thank Diana Perkins & Sylvia Saade (OASIS), Lisa Dixon & Liza Watkins (OnTrack), Tamara Sale (EASA), Adriana Furuzawa and Dina Tyler (Felton PREP), Shirley Helm (Thresholds), and Cherise Rosen (University of Illinois) for their assistance.

Technical Assistance Material Developed for SAMHSA/CMHS under Contract Reference:HHSS283201200002I/Task Order No. HHSS28342002T

Introduction

Over the past two decades, a substantial body of research has emerged that attests to the effectiveness of specialty early intervention in psychosis (EIP) services (often referred to as coordinated specialty care (CSC) in the United States) for persons experiencing a first episode of psychosis (FEP). EIP/FEP programs are typically structured through a closely coordinated, multidisciplinary treatment team with specialized training in psychosis; examples of U.S. EIP/FEP models include NAVIGATE, OnTrack, EASA, PREP, BeST and EDAPT. While there has been some variability in the exact service components tested in different clinical trials, the majority of studies have found significant improvements in key domains including symptoms, hospitalization, housing, social and vocational functioning, and work and school outcomes at the time of discharge. Effective EIP/FEP programs also facilitate timely access to services, helping reduce the average duration of untreated psychosis, and support strong family engagement and involvement.

A major goal of EIP/FEP is not just improving short-to-medium-term outcomes, however, but more fundamentally altering young people's trajectories as they move forward with their lives.

Overview Information
A major goal of specialty early intervention services is a significant impact on long-term outcomes
So far the research literature suggests that some initial client gains may be lost over the long-term
These patterns raise significant questions about optimal service length, discharge and continuity of care
Preliminary evidence on extended services (3-5 years total duration) suggests that they may more fundamentally improve client trajectories
Discharge and service length is an important piece of program development and quality improvement

While programs vary in the length of treatment, many have a standard service period of approximately 2 years. Data from 5- to 10-year follow-up studies suggests that once clients are discharged from specialty services, some of these initial gains may disappear over time. Promising preliminary results from early intervention services that extend the standard service period beyond two years have raised the possibility that extended care may often be needed to more fundamentally alter trajectories and help sustain clients' initial gains over the long haul. Given current findings, discharge or step-down policy and practice is an important emerging focus area for EIP/FEP program development and, regardless of when it takes place, raises key considerations.

Client Perspectives

Amy: "If my program hadn't let me stay in for another year, I'm not sure what would have happened... I actually feel like I was around my worst at the end of year two—I just needed more time. I'm doing really well now."

Brian: "I think that, for me, anyway, it really wouldn't have mattered. Once we got the right combination of meds, and with a little extra help and some time off school, I was fine and ready to get back to a normal life."

THE GOAL OF THIS INFORMATION BRIEF IS THREEFOLD:

1. Summarize the literature on long-term early intervention outcomes, as well as service extension trials;
2. Review research on step-down and discharge in EIP/FEP, as well as relevant discharge models that have been developed outside of EIP/FEP settings; and
3. Highlight the experiences of a selection of existing early intervention programs with diverse approaches to step-down, discharge and continuity of care.

This information is intended to serve as an initial resource for programs in the process of designing or refining discharge and/or continuity of care policies and protocols.

What does available follow-up data from EIP/FEP randomized control trials (RCTs) tell us?

As suggested above, the early intervention long-term outcomes literature is sobering. Depending on the study, available research suggests that many initial gains in symptoms and functioning have disappeared by 5- or 10-year follow-up. In the two available randomized control trials (OPUS and LEO), follow-up differences appeared to be mostly due to the loss or attenuation of client's functioning and outcomes from the discharge on. These studies are discussed individually below:

- **OPUS.** The Danish OPUS study is the largest randomized controlled trial of EIP/FEP services to date, with 10 year follow-up data now available. 547 representative patients with first episode psychosis were randomized to specialized multi-disciplinary team based EIP/FEP services versus treatment in a standard Danish community mental health setting. After 2 years, the EIP/FEP participants demonstrated significant gains in symptoms, global functioning, substance use, treatment non-adherence and decreased hospitalization rates and family burden. At five year follow up (Bertelsen et al., 2008), the EIP/FEP patients' advantage over controls in symptoms, global functioning, substance use and overall medication use, had disappeared. EIP/FEP patients were still likely to have experienced significantly fewer hospitalizations, but there were no differences in work or school attendance. There were also no significant differences between the groups in terms of early course (i.e., episodic exacerbations versus continuous) or whether or not participants had been psychotic at any point during the previous two years. These results held at 10 year follow up, with no differences between EIP/FEP participants and controls with the exception of fewer days spent in supported housing by the early intervention group (Secher et al., 2014).

- **LEO.** The Lambeth Early Onset (LEO) was a randomized controlled trial of 2 year EIP/FEP services in the United Kingdom (UK) with both 18 month and 5 year follow-up data (144 total participants). At 18 months, EIP/FEP participants reported significantly better social relationships, global functioning, time spent in educational or vocational activity, higher quality of life, and higher service satisfaction compared to controls (Garety et al., 2006). In addition, EIP/FEP participants demonstrated higher service engagement and significant reductions in hospital use (Craig et al., 2004). 5-year follow up data was limited to hospitalization rates, and number of bed days. At 5 years, there were no longer significant differences between EIP/FEP participants and controls (Gafoor et al., 2010).

KEY POINTS: Longitudinal Data

- Longitudinal data from randomized control trials (RCTs) of EIP/FEP suggest that many initial gains are lost by 5-year follow-up

- These findings can be interpreted in different ways. Possible explanations include:
  - Insufficient specialty EIP/FEP treatment length
  - Insufficient vocational skill-building during the EIP/FEP period
  - Insufficient supports during discharge
  - Failure of EIP/FEP programs to reduce duration of untreated psychosis (DUP)
  - Lower quality of standard care in the community reduces initial gains

Interpretation of the above findings has varied. Possible explanations include: insufficient length of treatment; insufficient support for functional skill-building and/or vocational development capable of laying the groundwork for longer-term recovery, not just short term success; insufficient supports during the discharge process resulting in significant disruptions to continuity of care and negative impacts on service engagement; and failure of specialty EIP/FEP services to adequately shorten duration of untreated psychosis, which may affect long-term more than short-term outcomes. Each of these points is discussed below:

- **Insufficient EIP/FEP Treatment Length.** The “critical period” for intervention and support following a first episode of psychosis may be longer than two years, at least for a sub-group of clients. Concerns about treatment length have been at least partially validated by service extension trials—see below.

- **Insufficient Vocational Skill-Building.** In some cases, short-term functional gains may not contribute to, or correlate with, longer-term gains. For instance, a student enrolled in an unpaid internship may actually be laying a stronger foundation for future career success than someone who finds full-time work in a minimum-wage job. Some EIP/FEP programs may not be facilitating skill-building and foundational vocational development as well as they could. Unfortunately, no direct evidence is available to confirm or refute this hypothesis.

- **Insufficient Discharge Supports.** The process and immediate aftermath of discharge may significantly disrupt the relationships that clients and families have built with the EIP/FEP team and have broader impact on continuity of care, thereby negatively impacting service engagement and subsequent outcomes. One study of the post-discharge experiences of EIP/FEP clients in the UK, for example, found that their positive experiences of EIP/FEP created unrealistic expectations for future services, and that adequate planning for continuity of care prior to discharge did not always take place (Lester et al., 2012).

- **Failure of EIP/FEP to Reduce Duration of Untreated Psychosis (DUP).** A further possibility is that some EIP/FEP programs may be implementing effective early intervention services but nevertheless failing to reach clients as early as desirable following an initial break and thereby reducing DUP. This hypothesis is borne out by evidence that reductions in DUP even in the absence of specialized EIP/FEP services significantly impact some long-term outcomes (Pentilla et al., 2014). In the OPUS trial, average client DUP was relatively long (median = 53 weeks) compared to some other trials, and OPUS lacked an early detection component (Secher et al., 2014). In comparison, the Norwegian TIPS early detection trial, which did not include any service or treatment component (the goal was to get individuals into standard care as quickly following onset as possible) was 22 weeks.

- **Lower Standard of Care in the Community.** Finally, it is possible that the lower standard of care in community mental health services and inability of clients to access high quality supports after discharge, including ongoing rehabilitative supports, may contribute to the loss of initial gains. A large body of empirical work supports the idea that standard services are often sub-optimal, and established evidence-based practices such as supported employment may be very difficult to access.

What do we know about the impact of EIP/FEP service extensions?

Early empirical support for the hypothesis that extended service periods might render EIP/FEP gains more sustainable came from Ontario's Prevention and Early Intervention Program for Psychoses (PEPP) program. Researchers studied a 5-year PEPP service model, with higher intensity EIP/FEP services offered for two years followed by lower-intensity services with the same treatment team for an additional three years (Norman, 2011). While the project did not include a control group, the researchers found that improvement in symptoms were maintained between the 2 and 5-year time-points, and global functioning actually continued to improve. In addition, when compared to OPUS clients at 5 years, average positive symptoms, functioning and hospitalization for PEPP clients were significantly better. A follow-up PEPP RCT in Montreal is currently underway (Lutgens et al., 2015).

KEY POINTS: EIP/FEP Extension

- Both published EIP/FEP extension trials suggest that additional years of treatment (ranging from 1-3) may improve longer-term outcomes
- Because of differences between research trials and real-world community services, which may be more flexible and/or embedded in centers prepared to provide ongoing care, it is not completely clear how these findings translate to community settings
- Findings nevertheless underscore the potential importance of extending EIP/FEP services beyond two years

Meanwhile, the Hong Kong-based EASY EIP/FEP service has published the results of a 1-year service extension RCT (Chang et al., 2016). Researchers extended a 2-year EIP/FEP service with an additional year of case management. At the end of the 1-year extension, extension clients showed significantly better global functioning, independent living skills, and work productivity as well as fewer negative and depressive symptoms than individuals who didn't receive the extension. An additional 5-year extended EIP/FEP trial is currently underway in Denmark (Melau et al., 2011).

While the evidence base remains incomplete, these studies raise serious questions about the optimal length of EIP/FEP treatment and the differential long-term impact of EIP/FEP services with varying program lengths. When thinking about real-world community-based services in the US, additional factors may come into play. For instance, EIP/FEP services embedded within a generalist community mental health center may be able to maintain continuity of care relatively easily so long as clients remain at the center.

What do we know about step-down and/or discharge from EIP/FEP Programs?

Beyond the type of quantitative follow-up data referenced above, the literature on clients' and families' discharge and post-discharge experiences is surprisingly sparse. Analyses of post-discharge data suggest that certain sub-groups may be most at risk for relapse and that most relapses requiring re-hospitalization occur within the first year following discharge (Kam et al., 2013). Predictors of post-discharge relapse include substance use, minority status and prior number of hospitalizations. Qualitative research confirms that clients and families are not always adequately prepared for mainstream mental health services and may perceive this transition as a negative experience or involving the loss of important relationships (Lester et al., 2012).

KEY POINTS: Discharge & Step-Down in Coordinated Specialty Care

- Discharge and step-down are under-researched topics
- Limited research suggests significant challenges in successfully navigating discharges
- The development of interventions and/or supports based outside of EIP/FEP may help support clients through and following discharge
  - Examples include online interventions and non-clinical supports operated outside EIP/FEP clinics

Informal interviews with current and former EIP/FEP administrators conducted in the preparation of this document suggest that optimal step-down and/or discharge policies and procedures remain an ongoing challenge (see also program Q & A's at end of the brief). EIP/FEP clinicians may feel that certain clients need more time, clients may express a strong desire to continue working with clinicians with whom they have formed a strong working alliance, and/or clinicians and administrators may be aware that community-based treatment as usual in their area or region is unlikely or unable to provide the quality of care they would like to see former clients receiving. Family members may also find it to be very jarring to move from EIP/FEP services that actively embrace family involvement to standard services that do not.

Spotlights:

HORYZON Moderated Online Social Therapy

What: Innovative online platform for current and discharged EIP/FEP clients including peer-to-peer social networking, individually tailored interactive interventions, and expert moderation.

Impact: Proof that online interventions for EIP/FEP clients are safe and feasible; increase client empowerment and social connectedness; and decrease depression.

UThink Residential & Recovery Learning Programs

What: Residential and non-residential recovery learning interventions based in non-clinical charities and designed to support peer-to-peer relationship building and community inclusion outside of EIP/FEP services

Impact: Increased confidence and self-esteem, and improved social life and the development of new interests and work/school aspirations.

Rather than focusing on step-down or discharge per se, some EIP/FEP researchers have instead focused on alternative types of interventions designed to maintain continuity of services and/or continuity of social support. A team of digital intervention researchers in Australia, for example, developed "HORYZON," a moderated online platform supporting peer-to-peer social networking, and psychosocial intervention designed to span pre- and post-discharge from specialty EIP/FEP (Alvarez-Jimenez et al., 2013). Engagement with HORYZON increased participants' sense of social connectedness and empowerment and decreased depressive symptoms. The British project UThink included both residential and recovery learning interventions based outside of EIP/FEP services that were designed to complement specialty clinical services and promote social networking and community inclusion independent of early intervention clinics (Thomas & Pilgrim, 2010; Thomas et al., 2012). One goal of the project was to help young people develop skills and relationships that could sustain them outside of EIP/FEP services and following discharge.

What can we learn from step-down and/or discharge models developed outside of EIP/FEP?

Time-limited service programs are not unique to EIP/FEP. A number of other multi-disciplinary high intensity service models, including assertive community treatment (ACT), California's full-service partnerships (FSPs), and a variety of transition age youth (TAY) services have long been forced to grapple with the challenges of successfully transitioning clients into different, external and/or less intensive services. Consequently, there is a much more developed literature on discharge and transition from such services and discussion of various strategies. Below is a brief review of some of these approaches.

Assertive Community Treatment Step-Down: Assertive community treatment (ACT) is often described as either a precursor to or practice component of specialty EIP care. Unlike EIP/FEP, however, ACT was originally designed to serve clients for indefinite periods of time (Hackman & Stowell, 2009). Step-down, therefore, rarely follows a set time-based algorithm and is rather determined by perceived readiness and/or fiscal constraints requiring discharge. Descriptive studies of ACT staff members' experiences of and concern about step-down underscore the difficulties of transitioning clients out of more intensive team-based services. ACT clinicians consistently express concerns about client wellbeing following discharge, the disruption of strong working relationships, and the hit-or-miss realities of the public mental health system (Chen & Herman, 2009; Finnerty et al., 2014; Bromley et al., 2015). In order to guide step-down decisions, researchers at the University of North Carolina have developed the Transition Readiness Scale (TRS), a tool which includes careful assessment of current needs, functioning, supports and service utilization (Donahue et al., 2012). Research to date suggests that the TRS helps successfully identify clients ready for step-down.

Critical Time Intervention: Critical Time Intervention (CTI) is an evidence-based practice explicitly designed to facilitate periods of transition, including the period immediately following discharge from an inpatient setting, transitional housing or prison (Herman & Mandiburg, 2010). CTI is a phased approach, and from the outset prepares clients for discharge to other services and seeks to establish solid ties to people and organizations that will ultimately serve as clients' primary source of treatment and/or support. Reviews of the evidence base supporting CTI have consistently found significant impacts on client outcomes and service engagement (Center for Evidence-Based Policy, 2013; SAMHSA, 2006). Some EIP/FEP programs utilize an explicit CTI model, including OnTrackNY (see also OnTrack Q & A at the end of the brief).

Peer Navigators: Peer navigator or mental health navigator interventions generally draw their inspiration from the "patient navigator" models developed within physical health settings such as primary care clinics and oncology centers (Pederson & Hack, 2010). Peer navigators can be distinguished from other "peer" roles in that they typically assist clients to engage with particular mental health or social services and physically accompany them to appointments, assist with registration, scheduling and transportation, and ensure that clients are successfully linked to particular services, engaged with (new) clinicians or support staff, and are able to successfully navigate systems and spaces. For example, a peer navigator in the context of EIP/FEP discharge might: help clients connect with primary care or other health services, and attend initial appointments; work out transportation possibilities and travel with the client (e.g., on public transportation) to ensure that they can locate services and are comfortable getting to meetings or appointments; and encourage initial relationship-building and engagement. Across domains, the positive impact of patient navigation models has repeatedly been demonstrated (Corrigan et al., 2014; Manderson et al., 2012; Robinson-White et al., 2010). Researchers at Orygen Youth Health in Australia actually proposed an EIP/FEP discharge peer navigator intervention, but for logistical reasons were unable to recruit for the trial (Jo Robinson, personal communication).

Implications for Planners & Administrators: Step-Down, Discharge and Continuity of Care Questions & Decision Points

Throughout this author's conversations with EIP/FEP clinicians and administrators, it has been clear that many questions and challenges remain, not only within research circles, but for program leaders faced with the challenge of developing and implementing real-world discharge policy and negotiating state or county contracts. Even for many of those who would like to extend the length of their programs or provide follow-up services, challenges related to funding were a consistent theme. Both the clinicians and peer and family advocates who were interviewed for this brief affirmed the anxiety that many actively-engaged clients and families often feel about discharge. At the same time, they noted a sub-group of clients who have never adequately engaged and for whom the challenge instead centers on preventing premature discharge due to disengagement. A list of major discharge-related questions and decision-points has been included on the next page to help structure planning and policy development. Also, following the References section, please see the Appendix of Q & A interviews with representatives from a sampling of EIP/FEP programs.

Step-Down & Discharge Decision Points and Questions

- [ ] **Program Length:** In light of the existing research literature, local stakeholder priorities and fiscal constraints, what program length seems most feasible? 2, 3 or 5 years?

- [ ] **Flexibility:** Will the program flexibly accommodate clients who seem to need services for a longer period, or will it be necessary to discharge by a fixed program cut-off?

- [ ] **Individualization:** Will the program individualize step-down or discharge for each client, or follow a single protocol?

- [ ] **Gradation:** Will service intensity be gradually decreased, or will services be equally intense right up to the point of discharge? If graded, what components will be offered less frequently or dropped over time? To what extent will this vary with the individual client?

- [ ] **Managing Expectations:** What role will information about or planning for discharge and/or step-down play in service delivery and psychoeducation involving clients and family members? Will this begin with initial contact or be introduced at a later time-point?

- [ ] **Building Enduring Skills & External Supports:** How will the program maximize clients' development of skills that are anticipated to contribute to long-term social and/or career development, as well as the development of relationships and social networks external to the EIP/FEP service?

- [ ] **Discharge Planning:** How will the program prepare clients and families for discharge? Will a discharge assessment be used? What supports will be put in place to ensure continuity of care? What efforts will be taken to address non-clinical gaps or needs including social or family support, housing, and educational/vocational support?

- [ ] **Post-Discharge Follow-Up:** Will the program follow up with clients and families to check in? If significant problems are reported, will the program have resources or the ability to respond or assist in any form?

- [ ] **Discharge Evaluation:** How will the program evaluate the impact of its discharge strategy and the subsequent experiences of clients and family members? How will this information be incorporated back into program improvement or refinement?

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Appendix

DISCHARGE & STEP-DOWN Q & A WITH A SAMPLING OF ESTABLISHED U.S. EIP/FEP PROGRAMS

OnTrackNY

OASIS

Felton PREP

EASA

Q & A

Respondent & Name of Program: Liza Watkins, OnTrackNY

Question: *Please describe your general approach to client step-down/discharge.*

Response: Transitioning out of the OnTrackNY program is a critical phase in the treatment process. When we developed our program parameters, we articulated a policy that we expected that for each team, clients would receive OnTrackNY services for an average of 2 years. We understood that that the optimal length of Coordinated Specialty Care (CSC) (i.e., EIP/FEP) treatment was unknown. The literature, if it suggested anything, underscored the lack of maintenance of early benefits of EIP/FEP programs after program completion (see TIPS, LEO and OPUS studies). Further, we had learned from our experience in RAISE that there would be extraordinary diversity in how clients related to the program, how they understood the value of treatment, and the meaning of discharge. We also understood that we would fail to engage a minority of clients, that some clients would need to move and leave treatment for reasons that were essentially unrelated to treatment, and that others would need to test out distance from treatment as a part of their learning what they needed. Therefore, we made the "average of 2 year rule" fully cognizant that this average would allow our teams to work with clients as individuals while creating some overall metric which our funder required; this service was not "forever." Programs needed to be accountable for transition, and the goal of transition is fully compatible with a recovery framework. We fully understood and anticipated that some clients might stay less than two years, while others might receive services beyond two years. We understood that discharges would not be uniform. We recommended, however, that early transition (defined as anytime during the second year prior to the specified end of the two-year expected tenure) be considered carefully and executed on a limited basis.

As per our manuals, the transition planning process begins around six months before discharge to ensure a smooth transition and is guided by a "core session" focused on the topic of transitioning from the team. Coordinated by the Primary Clinician, this session guides the timing of a more formal assessment using the Transition Planning Tool. The Transition Planning Tool considers input from all key stakeholders, including the client, his/her family, and other members of the OnTrackNY team. In short, the tool is used to help determine whether the client is, or is not, in need of continued and ongoing assistance from the OnTrackNY program. Clinicians help participants and their families to reassess their needs and preferences, and equip them with knowledge about mental health services and the mental health care system that will help guide their selection of the most appropriate service options. The Transition Planning Tool was created based on a comparable tool developed as a part of New York State's initiative to make Assertive Community Treatment (ACT) Teams time-limited services.

The Primary Clinician plays a central role in the transition process by helping the participant and family to develop a plan for obtaining care in the community and to make that plan become a reality. The Primary Clinician also coordinates with other team members to ensure the plan is comprehensive, incorporating medication, school/work, and recovery goals. Transitioning from the team should be viewed as positive, meaningful, and something to work toward, rather than something to be dreaded or avoided. Participants and families need to know that they will be ready to take the step to community care because they will be properly prepared to navigate a world that is unfamiliar to them. OnTrackNY clinicians help create and test a transition plan to ensure wellness post discharge from the team.

The following are areas in preparation for transition that the Primary Clinician should review with participants and their families:

1. Review of experience with the OnTrackNY program (The goal of this review is to identify services and supports that the participant would like to maintain, as well as those they would like to initiate in the community.)
2. Review of practical considerations that may impact community care options
3. Development of a transition plan, including treatment options, role of family and other supports
4. Utilizing recovery coaching interventions for focused work to enable the participant to implement a transition plan
5. Identifying and reviewing tools in the toolbox
   i. Conducting skills check-up and honing skills for implementing transition plan
   ii. Arranging community field trips
   iii. Helping the family prepare for transition

Clinicians are asked to accompany participants to appointments with potential new providers when appropriate and to actively engage them to ensure key information is shared. It is required that OnTrackNY clinicians follow up with the participants one month post-discharge to verify whether they are linked with new providers or could benefit from follow up.

A current question for us is the extent to which the process that we outline in our manuals is actually followed. Since we know that many discharges occur before the two year point, and our program is just in its toddlerhood (we may have moved beyond infancy!), we don't have a tremendous amount of experience with this. We are in the process of looking at our data and trying to understand how best to track and monitor discharge activities and outcomes.

Question: *More informally, what challenges have you encountered navigating the discharge process?*

Response: We have encountered challenges related to finding recovery-oriented treatment options in the community. We hear from our clinicians that many providers that accept some participants' insurance would not want to work with young people with psychotic disorders or may not have a recovery focus in their practice. In addition, there are few resources related to supported employment and education which makes it challenging to create a strong discharge plan for someone who is doing well but would like to continue receiving this kind of support in the community. In general, clinicians are less familiar with creating and executing successful transition plans than they are with other phases of treatment, so our training and technical assistance team checks in about this topic frequently and conducts care reviews.

Question: *Do you have any "lessons learned" or strategies you'd be willing to share?*

Response: We would be eager to connect with other training entities for EIP/FEP programs and other providers and discuss the challenges of the discharge process. Some of our lessons learned have been alluded to above:

- Discharge is exceedingly heterogeneous and we need a flexible approach to discharge. Perhaps a way to think about it is that we need a taxonomy of discharge.
- It is challenging to navigate the fine line between periods of disengagement and discharge; we run into agency rules that we often have to bend.
- Discharge can lead to readmission which, while it creates some challenges, is generally welcomed.
- One subtype of discharge that is vexing is the "going back to school" subtype. We need a way to deal with geographic dislocation that is often positive. This could include tele-psychiatry and working with local teams.
- A consistent and structured approach to discharge for the individual who has had a full course of treatment is likely very helpful. Teams do ask for it.
- Clients like to come back and connect with teams and there may be value to ongoing peer led or other types of groups.
- It is important to collect data.
- Insurance is a huge barrier to getting good follow up care.
- We need to work together on this issue and learn from clients.
- We think that peers may be helpful, and we plan to have peers work on this aspect of treatment.

Respondent & Name of Program: Sylvia Saade, UNC Outreach and Support Intervention Services (OASIS), North Carolina

Question: *Please describe your general approach to client step-down/discharge.*

Response:

STEP–DOWN: The UNC OASIS program's approach to step-down and discharge is based on the **Phases of Recovery**** from a psychotic illness. Those phases are the Acute Phase, the Early Recovery Phase, the Sustained Recovery Phase, and the Maintenance Phase. Phases are defined by symptoms and functional recoveries (over a period of 5 to 7 years). Step-down (i.e., intensity of psychosocial interventions, individual therapy, family engagement, medication management) is related to what phase the client is in. For example, in the maintenance phase, clients stay in our program but we see them only twice a year for review of their progress, meds refill if needed, and relapse prevention plan with client and also with significant person(s) in their life. Should a crisis occur in the person's life and symptoms return, the client will move to an earlier stage (e.g., acute phase) where for a month or 2 or more, the interventions are intensified: individual therapy once/week, family meetings once/week, etc.

DISCHARGE: Here is the discharge policy and criteria for our program:

- The first 5 years are critical for individuals with a first onset of psychosis. This is the period where the potential for relapse into another psychotic episode is high. Subsequently, participants at the OASIS program are encouraged to continue their treatment for at least 5 years.
- Discharge from the OASIS program will occur with one or more of the following criteria:
  - **a.** The individual has moved out of the area and cannot transport himself/herself to OASIS for treatment. In this case, consultation with providers in the client's new catchment area will be provided when requested by the client.
  - **b.** The individual's diagnosis is clarified and the final diagnosis does not meet criterion for continued participation in the program and our program cannot meet the clinical needs of the individual.
  - **c.** The individual chooses to transfer to another provider in the community.
  - **d.** The individual refuses further treatment. Clinicians will attempt to re-involve the individual in the program and would be discharged after 3 months of failed attempts.
    - The individual that develops a more severe course of the illness after 5 years of interventions will be transferred to an outpatient setting that deals with chronic severe psychotic illnesses. An individual that has been in the Maintenance Phase of recovery after the 5 to 7 years can remain in our program. We actually have not been discharging them.

Question: *What challenges have you encountered navigating the discharge process?*

Response: There has been a lot of dialogue throughout the 10 years of the OASIS existence on the timing of discharge versus criterion of discharge. At the beginning of our program, in 2005 through 2008, we initially agreed on 3 years and then we noticed that is was too early as our clients and their families would call us for readmission due to relapses (e.g., stopping their meds, or even providers in the community would tell them they have been misdiagnosed, and clients dealing with the challenges of life, etc.). We then had to adjust our criteria accordingly and realized that functional recovery may take much longer—and the stress of finding themselves, their career, education, employment etc. takes longer than one to two years…dealing with the anxiety and stress are big challenges.

ABOVE CONCLUSIONS REACHED BASED ON:

- Research on functional recovery;
- Our clinical experience with our own clients and their families;
- The lack of education of providers in the community on FEP; and
- Our formulation of the Phases of Recovery

Question: *Do you have any "lessons learned" you'd be willing to share?*

Response: See above. In addition, education of providers in the community on first episode psychosis and the possibility of recovery is a MUST and remains quite challenging.

****Note:** OASIS staff have kindly agreed to provide their Phases of Recovery guidebook to interested EIP/FEP programs. Please contact:

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UNC / OASIS Program Director

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Q & A

Respondent & Name of Program: Dina Tyler, Felton Institute PREP

Question: *Please describe your general approach to client step-down/discharge.*

Response: Our discharge process is based on a PREP "Phases of Treatment" model that our program developed. The phases we include are, "Assess, Stabilize, Implement, Reinforce, and Plan." PREP is designed to be a two-year program. Staff begin discharge planning within the final six months of the program. Clients can be formally discharged if they meet the following criteria:

- ☑ Client is in the PLAN phase of the Phases of Treatment
- ☑ Relapse Prevention Plan developed or finalized
- ☑ Relapse Prevention Plan shared with key supports (family, other providers)
- ☑ Family Meeting conducted with client and family to review discharge plan
- ☑ Client has demonstrated independence in accessing treatment and necessary adjunctive appointments (e.g., regular blood draws if taking Clozaril) OR has identified individual in place to support this effort
- ☑ Client is connected with treatment providers in the community as necessary OR has referral details for relevant resources if client decides not to connect with treatment providers outside PREP
- ☑ Crisis Information provided for emergency access to services
- ☑ Release of Information on file for new treatment providers and dated six months post discharge
- ☑ Client has been stable (no major fluctuation in symptoms, no recent medication changes, no hospitalizations) for six weeks prior to discharge
- ☑ Exit interview offered and conducted

In some situations, we have been able to extend services a bit beyond the 2 year marker, and some people have been discharged in less than 2 years (e.g., due to having successfully moved through the Phases of Treatment, because the client actively seeks discharge or moves out of the area, or in some cases prolonged disengagement from services).

In terms of the transition out, we hold a graduation ceremony twice a year for young adults that have completed the PREP program. The graduation is open to any family members and friends the client wants to invite. We also invite any former staff that have worked with the client in the past. At the graduation, key staff members pick a word that encompasses the strengths of each PREP graduate and present it on a stone to each of them. PREP graduates also pick a word that sums up their experience at PREP and leave it at PREP. Current PREP participants also write a joint poem giving advice to the graduates that is read at the graduation. Graduates and their families are invited to speak or share how PREP has helped them. All current PREP clients are also welcome to attend the graduation.

At one of our sites, we also have a graduate alumni program. Young adults that graduate from PREP and want to get involved in mental health work or advocacy are provided access to trainings, mentoring and volunteer- or stipend-based opportunities. For young adults that are interested in becoming peer specialists, we have helped them access peer specialist trainings, WRAP facilitation trainings, and Hearing Voices Network facilitator trainings. For those who are interested in stigma reduction work and public speaking, we have provided Coming Out Proud disclosure trainings[1], and actively reach out about opportunities to speak with the media. We have also created a volunteer social media internship for a graduate to help spread stigma-reducing information and messages through public media. In addition, we help connect PREP graduates with other local/national stigma reduction projects and assist with applications to youth advisory boards. For young adults that are interested in policy advocacy and systems change, we help connect graduates with local/national advocacy efforts and organizations that foster youth leadership and policy work.

Question: *What challenges have you encountered navigating the discharge process?*

Response: We have found that two years is often not enough time to move someone through the Phases of Treatment. Due to immense needs stemming from unstable housing, relationships, school and work, and challenges engaging clients and families, it often takes a while to move into the 'implementation' and 'reinforcement' phases. We have generally had the most challenges engaging young people who already have long histories of mental health treatment and hospitalization (for diagnoses other than psychosis), criminal justice system and foster care involvement, and housing instability or homelessness.

We've also found it difficult for many clients, after they leave PREP—which provides holistic, high intensity services—to readjust to more standard community services, which are often significantly less responsive and provide fewer supports. Clients that have become very attached to the PREP community (staff as well as other clients) have definitely struggled with the transition to services that do not have the same sense of community.

[1] Coming Out Proud (now renamed Open Honest Proud) is a modularized, peer-facilitated disclosure decision-making support program developed by Dr. Patrick Corrigan at the Illinois Institute of Technology.

Question: *Do you have any "lessons learned" or strategies you'd be willing to share?*

Response: We have definitely discussed the possibility of extending the PREP program beyond two years, as well as creating a less intensive version of PREP that could be offered beyond the two year marker for those that would benefit from continued but less intensive support. Financing extended services remains a significant challenge, however.

Our team has also begun discussing the extended discharge process as a process during which we may need to do more to gradually prepare young adults to transfer into the adult system of care, with far fewer supports. For instance, we might slowly taper the number of appointment reminder calls we make, or increasingly encourage use of public transportation to appointments and activities rather than picking the client up in our own vehicle. We've also discussed the importance of strengthening client's social networks and increasing their involvement in groups and activities that they will be able to access post-discharge before they leave PREP. This way, we help them forge external ties that can help them weather the transition and provide support after PREP's more intensive supports are gone.

Q & A

Respondent & Name of Program: Tamara Sale, Early Assessment & Support Alliance (EASA), Oregon

Question: *Please describe your general approach to client step-down/discharge.*

Response: We have a transition section in our practice guidelines and a transition checklist which we ask all programs to use. We ask programs to reference/use the transition checklist from the outset, but in earnest six months prior to discharge. The transition process is intended to be gradual with follow-up care firmly established prior to discharge from EASA. The transition section encourages programs to maintain contact with alumni, to invite them to participate in targeted activities and participatory decision making opportunities, and to be available for check-ins/ short-term follow up in the case that the transition becomes problematic.

Question: *What challenges have you encountered navigating the discharge process?*

Response: There is near-universal agreement in our program (in addition to the international literature) that a two-year framework is inadequate, and we are working toward an alternative longer-term approach. We originally started with a 3-5 year approach and narrowed it back to two years because clinicians were focusing almost entirely on building alliance and not preparing people for transition. The two-year framework is short enough that clinicians are much less likely to lose sight of the transitional nature of the program. That being said, we are moving the pendulum back in the opposite direction now, recognizing that lack of follow-up after two years is highly problematic.

It is not uncommon for participants to not fully engage in treatment initially, so having a two-year framework is problematic for individuals who are not fully engaged until the six month or one-year juncture. Also, it is not uncommon for people to fall in and out of services, and these discontinuities impact what "two years" looks like. We allow a lot of flexibility at the provider level, but still interpretation can be narrower.

Also, the range of insurance and the fact that people are generally doing well clinically affects the options available for them at transition. The transition itself from a well-trusted group of clinicians who are willing to do outreach and are highly supportive of the family creates a set of risk factors for relapse. Our teams operate in a different fashion from the programs in their environments, and it is difficult for people to go from a highly responsive and comprehensive team to a much narrower, less responsive and more prescribed system.

Question: *Do you have any "lessons learned" or strategies you'd be willing to share?*

Response: We have integrated graduation ceremonies/celebrations that have become highly valued by participants and clinicians as an important milestone, and there is general agreement that there are enough benefits to the two-year framework that we don't want to lose it completely. We are talking about a combination of: 1) clarifying discharge criteria to have it more driven by the criteria for discharge than by the two year mark; and 2) integrating a more proactive and structured follow-up care component which would include routine check-ins by the program, access to long-term vocational supports and problem solving, and ongoing social support.

Lessons learned are that EIP/FEP culture and EBPs need to be infused into all ongoing services for psychosis, and we need to address accessibility of our systems, not just within these small programs but in a much broader way. It is critical for us to build systems of care which support people to work and go to school without requiring them to sacrifice private insurance coverage.