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# Client Views of Engagement in the RAISE Connection Early Psychosis Recovery Program

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## Abstract

**Objective—**This study describes clients' reports of factors that facilitated or impeded engagement in services offered by the Recovery After an Initial Schizophrenia Episode (RAISE) Connection Program for youth and young adults experiencing early psychosis and was part of the larger RAISE Implementation and Engagement Study (RAISE-IES).

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Previous Presentations: Some of the data reported herein was included as part of an oral presentation at the American Psychiatric Association's 2014 Annual Meeting in New York City, May 3–7, 2014.

**Method—**Semi-structured interviews with 32 clients and thematic qualitative analyses were used to examine participants' experiences of program services, staff practices, their own engagement behaviors, and related factors such as expectations, family, illness, and setting.

**Results—**Clients' statements indicated that central engagement factors include: services and staff interactions that are highly individualized, respectful, warm, and flexible; clients' life goals being the center of services; family member engagement; personal attributes and program location and setting factors.

**Conclusions—**These interviews help explain the Connection Program's effectiveness regarding client engagement and deepen our understanding of treatment engagement for youth and young adults experiencing early psychosis. The individualized, flexible, recovery-focused and assertive model of services and client-staff interaction, incorporating shared decision making and focus on client life goals should be implemented and sustained in services for this population.

Treating psychosis early can optimize the affected person's recovery, functioning, illness course, and well-being (1). Care delays and gaps may increase the likelihood of prolonged disability. Engaging people in treatment is a multi-faceted process impacted by logistical (service availability, location, transportation, costs), psychological (health beliefs), interpersonal (client-provider fit, communication) and other factors (2, 3). For young people coping with first or early episodes of psychotic experiences (early psychosis), engagement is further shaped by relative maturity, understanding of their experiences, legal status, autonomy needs, prior experiences with care, and family relationships (4, 5).

The Connection Program is an innovative multi-service intervention, for teens and young adults experiencing early psychosis suggestive of schizophrenia, which combines critical time intervention (6), best practices regarding early psychosis treatment (7, 8), shared decision making (9) and ongoing engagement outreach. It offers counseling, medication management, vocational and educational assistance, case management, and crisis services with a highly individualized client-centered community-based team approach. Details of the Program may be found at http://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml. Its programming, implementation and effectiveness were evaluated in RAISE-IES, described elsewhere in this issue (10, 11).

Among its aims, RAISE-IES evaluated the Connection Program model's recommended practices for engaging and retaining clients in treatment. Fewer than 10% of clients dropped out of Connection Program services during their treatment period of up to two years. This is a lower rate of dropout than previously identified in the literature. Other studies of first episode populations have reported an average of 30% disengagement over three to thirty months (varied by study; 12).

This study was designed to understand how clients experienced the program and its practices, with a focus on engagement, in order to contextualize the RAISE-IES retention rates. Specifically, it aimed to identify engagement facilitators and barriers among individuals with early psychosis.

## Methods

This engagement study used semi-structured interviews with Connection Program clients, their family members, clinicians, administrators, and outside referring agency representatives. Only client interviews are presented here. The Institutional Review Boards of New York State Psychiatric Institute and University of Maryland pre-approved all study procedures. The NIMH Data and Safety Monitoring Board provided study oversight.

### Sampling Frame, Eligibility, and Recruitment

This study involved participants from among the 65 clients enrolled in the two RAISE-IES Connection Program sites (Baltimore, MD and Manhattan, NY). RAISE-IES inclusion criteria, recruitment procedures, and client demographics may be found elsewhere in this issue (10). To create a broad-based sample for the engagement study, we sought to interview some Connection Program clients ”earlier” (2–9 months post enrollment) and others “later” (12–24 months) in their program involvement. We also sought to enroll both some who were “well engaged” and others “not well engaged” in Connection Program services, rated just before engagement study recruitment by their site’s clinical Team Leader. Together this created four groups of participants: two tenure levels × two engagement levels, roughly half from each site.

Clients were eligible for the engagement study if they were enrolled in the NY or MD Connection Program while it was a research study, fit into one of the four tenure-by-engagement groups, cleared by the Team Leader as clinically stable enough to participate, and willing and able to give informed consent. Research staff approached clients at the end of a parent study research or clinical appointment, or by phone. Funded by a federal contract, RAISE-IES was conducted under NIH Clinical Exemption of the Paperwork Reduction Act (PRA). This engagement study was also conducted under exemption of the PRA, since we interviewed nine or fewer individuals in each of our four distinct participant groups.

### Interview Procedures

Interviews took place in person, May 2012 to April 2013, in a private setting using IRB approved informed consent procedures. They followed a semi-structured guide focusing on client experiences and opinions about the Connection Program services, staff, practices, family engagement, and their own engagement with services. Each audio-recorded interview lasted 30–60 minutes. Each participant received $15. At the close of each interview, interviewers offered to send participants a copy of their interview’s transcript to keep and to submit comments/correction about; 25 participants requested and were sent transcripts; none returned comments.

### Data Analysis

Interview audio files were professionally transcribed, then proofread by a research team member. Proofreaders made preliminary notes of engagement facilitators, barriers, and other issues in each interview, from which four members of the study team drafted initial coding categories. Examples include “Team was engaging: competent,” “Symptoms and

Engagement," and "Client feels obliged to attend." This initial code list was revised and refined during the steps below.

Analysis was completed in two phases. First, using Atlas.ti 7 (13), two trained team members independently coded all transcript passages related to services engagement and compared their results. Differences were minor, with occasional identification of a new code. After discussing to consensus, the code list and definitions were refined accordingly and the final coding of each Client transcript was double checked for errors.

Second, in close discussion with other members of the study team, the first author consolidated codes into categories focused on the study purpose of identifying factors affecting engagement, specified as "facilitators" or "obstacles". This involved refining coding structure and definitions to encompass all data, combining to increase parsimony, and checking code and quotation distributions in Atlas.ti for anomalies, errors, and completeness. Next, again led by the first author, members of the team examined all codes' relationship to each other as affecting engagement, both via discussion and exploration via Atlas.ti "network view." This led to grouping them by topical families that form the "domains" presented in the Results section.

This process also included frequent comparison with the transcripts, independent comment on transcripts by a RAISE-IES investigator which we considered in our analysis, and ample team discussion. Atlas.ti software was used to track coding changes, interpretation notes, and code interrelationships. An online supplement (Table 3; access at) provides further detail of the specific codes comprising each engagement domain and theme.

## Results

### Final Sample

We interviewed 32 of 65 Connection Program clients (see Table 1 for demographics): 18 well-engaged with Connection Program services and 14 not; 13 early in their Connection Program involvement and 18 later. Fourteen additional clients were considered but not interviewed: 4 declined, 4 could not be reached to invite, 2 were not cleared by the clinician, and 4 did not fit a sample group for which we were seeking participants.

Four domains of factors influencing client engagement emerged from the data analysis procedures described above: individualized care, program attributes, family member engagement, and personal attributes (See Box 1). All results reported were well saturated in the client interview data. Quotations come from a wide variety of participants; all are represented at some point. Please see <<online Table 2>> for additional examples of the quotations (data) behind each domain.

### Individualized Care

Interviewees described the highly individualized care that teams provide as pivotal to their engagement in three ways: focus on life goals, effectiveness, and warm respect.

**Focus on life goals—**Most (27/32) interviewees said the Connection Program was engaging because staff took their life goals seriously, "helped me out with some of my life problems" and seemed dedicated to helping them "get back on track", most often related to relationships, jobs or education. For example one interviewee said, "What I like about the program is that it covers a lot of places, like they help you look for a job, they help you go look for school if you're in school, they cover like everything that's going on in your life." Or, as another phrased it, "…you have some clear goals, you're struggling with some things really energetically, you're trying to go places. The Connection team [asks] are there ways that they could help you?" These life goals were also important to the initial engagement of individuals who did not see themselves as needing psychiatric care.

Paradoxically, a few (7/32) interviewees also described life priorities as competing with program engagement. For example, one client said, "sometimes I struggle with like the actual [services] that they want me to partake in because I'm really focused on like finding a job and that to me is a high priority for me and my family."

**Effectiveness—**Many interviewees (18/32) described positive results as engaging. They said things like "I want to keep coming because it just it helps me. It's as simple as that.", or "After a while I got to realize how the program was working for me … so that's when I really got into it". Some cited specifics such as "I feel a lot healthier", "help[ing] me to feel okay with who I am right now", "not feeling constantly anxious", "realiz[ing] that I don't really need [smoking marijuana] to keep on, or "They have changed my medicine which was [is] better." Conversely, not perceiving effectiveness reduced engagement. For example, one client reduced the frequency of her appointments because "I didn't feel that much was coming out of my sessions with [a new clinician]. "

**Warm respect—**The Connection Program model emphasizes staff warmth and respect for clients; interviewees describe a staff combination of friendliness, interest, patience, and sincerity as very important to their engagement (28/32). They cited experiences where staff "take my opinion seriously" with "no judgment at all" as strongly engaging. This was conveyed by staff doing things that showed "they listened", "really cared", were "very helpful" and would go "above and beyond." Having 24/7 crisis access to familiar staff members was mentioned several times. Clients also perceived staff and program flexibility (17/32), especially regarding appointment times, locations, and late arrival, as embodying respect and as facilitating rapport and trust (9/32). One interviewee summarized:

> They were there for me. …if it was just another program I wouldn't of honestly cared, I would of just disappeared… But…they put the time and effort into trying to help me [and] all they ask from me is just to be better … to see how I feel…. So I did understand, like I really do got to shape it up and come in.

Another, recalled:

> They are very kind people and very inviting, very caring, very genuine, very like soft spoken … uh just their demeanor that made me feel comfortable and their intentions. Their intentions were pure, they really wanted to uh, to help me….

### Program Attributes

Characteristics of the program itself impacted engagement as well. Interviewees described an overall positive program atmosphere (17/32) where things "run smoothly, things happen as they say it will," and yet are "relaxed and flexible" with no "negative feel" (. They also described several more specific program attributes:

**Team Structure—**The multi-services team approach was highly engaging. Interviewees spontaneously mentioned (12/32) that being able to access multiple services through a "one stop shop" reduced strain and encouraged attendance. For example, one client said "knowing that there was a team available and everybody had their own, their own specific role to help me with my life, it felt it felt um like very it gave me ease of mind." A few (5/32) said they found meeting with the whole team at once could be overwhelming, especially at the beginning or when feeling unwell.

**Setting and location—**Interviewees described concrete attributes such as location (23/32), setting (5/32), and transportation (18/32) as affecting engagement. How nearby, easy to get to, safe-feeling, and pleasant the program location was for an interviewee affected how easy it was for them to engage. Similarly, transportation was described as either facilitating or impeding engagement depending on how stressful, affordable, safe, and convenient it was for each person. Several clients (4/32) noted that symptoms can make riding public transit and driving stressful and even prohibitive. Related, a few (5/32) interviewees emphasized that the more institutional, hospital-like, and "psychiatric" they found the location, building or décor, the less engaging, especially if they had negative associations with it, such as having been involuntarily hospitalized in the same building.

**Medication management approach—**Clients described the Connection Program model for managing medication as very engaging (23/32). A handful (6/32) commented that having medication services within the program facilitated access, and the study paying for uncovered medication costs reduced hassle and expense and conveyed caring.

Interviewees emphasized that the medication shared decision making practices promoted engagement (17/32). They liked that staff (especially psychiatrists) discussed medication concerns non-judgmentally, saying things like, "[the psychiatrist] works with you more, like instead of just kind of telling you what your needs are, she [says] we'll see what we can do together." Being able to be frank, to be taken seriously, and to get sincere responses were key. For example, one said "I told them I wasn't taking my medication and they didn't press me like you [have to] take your medication or you shouldn't do that…. but I kind of realized that I really do need it." Conversely, interviewees felt less collaboration when medication interactions felt less open: "I wish it was a little bit more compromising … like you get a little bit more of your say and less of their… agenda".

**Active outreach—**The Connection Program model stresses active ongoing outreach. About one third of interviewees (10/32) commented on its relationship to engagement. They found staff outreach to be persistent, individualized, sometimes surprising, and highly effective in keeping them involved on a practical level. For some, the calls, visits, and offers

of assistance also increased their *desire* to engage because of what the outreach conveyed. For example, a client said, "…they would make the effort and I like that. Instead of waiting for me to come to them, they would come to me, call me, ask me what's wrong you know….so now I like to come and I look forward to talking with them."

### Family member influences

Interacting with the factors above, many interviewees described family influences as important to their engagement (18/32). Almost all had at least one family member (usually parent(s) in contact with the Connection Program team, reminding them of appointments, encouraging attendance, providing transportation, and/or expressing concern about their well-being. A few (3/32) reported starting at the Connection Program primarily to reassure "my family that I was doing something to try not to have them worry about me."

**Promoting engagement—**In most instances family impact on engagement was predominantly positive, regarding practical assistance and emotional support: "My mom comes with me every time…, I actually like her support….having my mom come makes it feel less of a struggle."

**Deterring engagement—**Occasionally it could also be an obstacle, especially when relatives were not supportive of mental health care. For example, one client described her mother's involvement as embarrassingly argumentative with staff, saying "I almost gave up, I was like, I actually don't want to come here anymore…." Interviewees reporting family tensions (8/32) said that Connection Program staff often educated family members and helped the clients form their own opinions, listen, and/or navigate family relationships and boundaries.

### Personal attributes

Most interviewees (23/32) described personal attributes that affected their engagement. Ambivalence about engaging in treatment (11/32) was often an obstacle, combining worry and fear about symptoms, unfamiliar mental health concepts, stigma, an uncertain future, and past negative experiences. At the same time, self-concern regarding symptoms and functioning led some interviewees (10/32) to want services, highlighting that distress can facilitate engagement. One succinctly expressed this tension: "Really, really I didn't want to get involved with the program but I knew it was going to better me so I had no choice but to go to the program." Interviewees described information, reassurance, patience, and focus on getting help with personal life goals as helpful in overcoming ambivalence. Some acknowledged a conscious decision: "I'm already used to the program, I just got to open myself up I guess… it's just if I want to do [that] or not."

A few clients (6/32) described self-reliance as affecting their engagement, in two different ways: self-reliance qua taking responsibility for one's health prompted engagement, but self-reliance as striving to solve problems without others' help can discourage it. For example, one person said "I was [at] a really low point where I didn't think I could really help myself. That's why I was seeking professional help and trying to use resources to the best of my

ability," while another declined some services because, "…so far what they've offered I've just been kind of like I guess I can do it myself."

In addition, clients' symptoms, delusions, depression, fears, lethargy, and self-consciousness were sometimes described as making engagement difficult (11/32). Individual examples included sleeping a lot, being unable to attend cognitively, and feeling disoriented, irritable, or paranoid.

## Discussion

This study aimed to better understand the engagement experiences of clients experiencing early psychosis enrolled in the RAISE Connection Program. Its results add to understanding of engagement for this population generally, and have several services implications. First, prioritizing clients' life goals was fundamental to engagement. For many interviewees, engagement hinged substantially on receiving what could be considered non-clinical services, such as supported education and employment, especially during early program tenure. Although these services were built into the Connection Program model, they were more crucial than anticipated, likely because of their link to clients' personal growth (14) Second, in keeping with other studies of engagement and retention in care (e.g., 4, 15, 16) staff flexibility, mobility, patience, warmth, and stamina over time were helped clients navigate ambivalence, illness and life challenges and stay engaged with clinical services. Relatedly, staff members' nonjudgmental active outreach conveyed caring and respect for clients, their families, and their complex situations and helped ameliorate barriers to engagement (4, 17). Third, the shared decision-making focus of the Connection Program was experienced by clients as more engaging than adherence-focused clinical programs they had attended (see also 15,18), especially regarding medication where interviewees described staff openness to discussing concerns and even discontinuation as respectful, helpful, and adherence promoting.

These three areas embody a youth-tailored, client-centered, active and empathic program and staff approach that echo and add specificity to the growing literature on services engagement among youth with early episode psychosis (e.g., 4, 14, 15, 20). Together, as discussed by Wilson et al. (16), Edwards et al. (20), and others, such approaches can support clients in using their young-adult drive for autonomy and identity development to promote engagement with services and mental health recovery.

This study's context is relevant to interpreting its results and implications. First, since interviewees were enrolled in the Connection Program, our sample excluded people who never made contact with the program. Thus it may be especially well suited to report engagement facilitators, but less able to give a full account of barriers. Second, some clients conflated the parent study's clinical encounters and research encounters, and the research process may have played some unexamined role in engagement. Third, a limited number of participants were available for interview who fit our four categories of interest, so we did not interview all clients. Finally, the applicability of this study's results to other settings and client samples will need to be evaluated in future qualitative and quantitative work.

## Conclusions

It takes considerable personal effort to approach mental health services (Owens et al, 2002, p 731), making each facet of the experience a potential barrier or facilitator to successful engagement. The Connection Program was designed to engaging young people experiencing early episode psychosis, a group usually very hard to involve in services. In the parent RAISE-IES project the Connection Program teams were able to achieve very high rates of client engagement and retention. This related qualitative study helps to explain how and why, and deepens our understanding of engagement for this population. Its results suggest that, to maximize engagement, early psychosis treatment should provide services and staff interactions that are highly individualized, respectful, warm, and flexible, giving prominence to clients' life goals and preferences and family member engagement. While doing so is challenging, such services offer hope for maximizing recovery.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Authors B, D, and H may be part of training and consultation efforts helping others provide the type of services for individuals with first episode psychosis provided as part of the RAISE Connection Program described in this report.

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**Box 1**

## Client Engagement Factors

| |
|---|
| Individualized Care |
| Focus on life goals |
| Effectiveness |
| Warm Respect |
| Program Attributes |
| Team Structure |
| Setting and Location |
| Medication Management |
| Active Outreach |
| Family Member Influences |
| Promoting Engagement |
| Deterring Engagement |
| Personal Attributes |
| Ambivalence |
| Self-concern |
| Self-reliance |
| Symptoms |

**Table 1**

Interviewee Demographics

| | Interviewees (N=32) | % |
|---|---|---|
| Age | | |
| < 20 | 7 | 22% |
| 20–24 | 16 | 50% |
| 25–29 | 7 | 22% |
| 30–34 | 2 | 06% |
| Gender | | |
| Female | 11 | 34% |
| Male | 21 | 66% |
| Race | | |
| African American | 16 | 50% |
| Asian, Pacific Islander | 1 | 03% |
| White, Caucasian | 10 | 31% |
| Other | 5 | 16% |
| Ethnicity | | |
| Hispanic / Latino/a | 7 | 22% |
| Non-Hispanic | 24 | 75% |
| Other | 1 | 03% |
| Highest Education | | |
| Some High School | 6 | 19% |
| HS Grad / GED | 3 | 09% |
| Some College | 15 | 47% |
| College Grad or higher | 8 | 25% |