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AVAILABLE SERVICES IN THE UNITED STATESFor the degree of Master of Science

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ESSENTIAL COMPONENTS OF EARLY INTERVENTION PROGRAMS FOR
PSYCHOSIS: A QUALITATIVE STUDY OF AVAILABLE SERVICES IN THE
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ABSTRACT

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Programs providing interventions for early psychosis are becoming commonplace in the United States (US); however the terrain of existing services within programs remains undocumented. Unlike other countries, the US does not have a systematic approach to defining and treating this population. We examined program characteristics, clinical services, and treatment population parameters for early intervention programs across the US. A semi-structured telephone interview was conducted with program directors between July 2013 and April 2014. Content analysis was used to identify the presence or absence of 32 evidenced based practices recently recommended for early intervention programs (Addington, et al., 2013). Frequent client requests were identified and functional definitions of the population served were assessed. A total of 34 eligible programs were identified; 31 (91.2%) program representatives agreed to be interviewed. Of the 32 essential components, the most prevalent were individual psychoeducation and outcomes tracking; the least prevalent were outreach services and communication with inpatient units. The population was most frequently defined by age restrictions, and restrictions on the duration of psychosis. Emergent themes of client requests included functional and social recovery as well as help meeting practical needs. Findings have the

ability to assist researchers and policy-makers in determining best practice models and creating measures of fidelity. This study provides critical feedback on services for the early psychosis population and identifies research to practice gaps and areas for improvement moving forward.

CHAPTER 1. INTRODUCTION

Early intervention programs for psychosis provide a number of benefits including reduced morbidity, more rapid recovery, better long-term prognoses, preserved social skills, higher quality of life, and a decreased need for hospitalization (Edwards, Harris, & Bapat, 2005; Garety et al., 2006; Marshall & Rathbone, 2011; McGorry, Killackey, & Yung, 2008). Indeed, the mounting evidence in support for early intervention redefines the question from “should we intervene early in psychosis” to “what kind of interventions should we intervene with?” (Reading & Birchwood, 2005; Ruggeri & Tansella, 2011). While early intervention programs generally provide treatment and secondary prevention aimed at reducing relapse, coping with symptoms, and sustaining recovery following the initial onset of psychosis (McGorry et al., 2008; Owen, 2003; Reading & Birchwood, 2005), little is known about the actual content of early intervention services being delivered in the community and how the target population is being defined.

Early psychosis can be thought of as an umbrella term, capturing a range of experiences from early warning signs of psychosis (clinical high risk/prodromal), to a full-blown psychotic episode (first episode psychosis), and even multiple episodes early in the course of an illness. Three broad operational definitions are frequently used for the early psychosis population: first treatment contact, duration of antipsychotic medication

use, and duration of psychosis (Breitborde, Srihari, & Woods, 2009; Kirch, Keith, & Matthews, 1992). This lack of a clear definition can be problematic for determining study eligibility criteria and for understanding best treatment options (Breitborde et al., 2009; Keshavan & Schooler, 1992; Kirch et al., 1992). For example, intervention studies may be as specific as requiring subjects to be diagnosed with non-affective psychosis within the last 12 months, without any prior antipsychotic treatment, or as broad as including anyone within 5 years of an initial onset (Bird et al., 2010; Malla, Norman, Manchanda, & Townsend, 2002). The identification of functional definitions being used in early intervention settings may help to narrow the focus to a single definition, which could improve comparability across programs and external validity of future early intervention studies.

Research findings support a number of key elements of early intervention programs, however the best combination of services has yet to be identified (Edwards et al., 2005; Garety et al., 2006; Malla, Norman, McLean, Scholten, & Townsend, 2003; McGorry et al., 2008; Reading & Birchwood, 2005; Srihari, Shah, & Keshavan, 2012). The literature shows variability in the implementation of early intervention services, with many programs providing differing treatment options (Catts et al., 2010; Ghio et al., 2012). Some programs stress the importance of case management, while others focus more on medication management, or social and functional recovery (Garety et al., 2006; Malla et al., 2003; Spencer, Birchwood, & McGovern, 2001). Although variation exists, most studies indicate the potential for key components such as: pharmacological interventions, cognitive-behavioral treatment, family interventions, and vocational services (J. Addington et al., 2005; Allott et al., 2011; Bertolote & McGorry, 2005; De

Masi et al., 2008; Department of Health, 2001; Hill et al., 2012; Initiative to Reduce the Impact of Schizophrenia, 2012; Spencer et al., 2001). The extent to which each of these key components is used in practice has yet to be assessed, and the importance of other components has yet to be fully examined.

Recently, Addington, MacKenzie, Norman, Wang and Bond (2013) used a systematic literature review and Delphi consensus process to develop a model of evidence-based, essential components for first episode psychosis services. Utilizing a librarian search specialist, the research team identified peer reviewed articles focusing on components of early psychosis intervention programs. Identified articles were reviewed independently by team members, who met to come to consensus on components identified and terminology used. Once all components were identified, a level of evidence was assigned to each component based on the quality and quantity of the research supported by the literature (see Table 1). Using a Delphi consensus model, experts were presented an operational definition of the component along with supporting evidence and were then asked to rate the importance of 75 components on a 5-point scale. After each round of rating, consensus was calculated using the semi-interquartile range (SIR); a component had to receive a SIR level of $\leq .5$ on a rating of 5 for importance in order to be included on the final list. The resulting 32 components can be seen in Table 1.

D.E. Addington et al. (2013) indicate that the essential components list may lead to the development of an evidence-based fidelity scale; however, little is known about the extent to which these components are currently used in treatment settings. Further, unlike some countries (e.g., Australia (Edwards & McGorry, 2002; McGorry, Edwards, Mihalopoulos, & Harrigan, 1996), Italy (De Masi et al., 2008), UK (Department of

Health, 2001)) the US does not have a systematic approach to defining and treating this population. Indeed, no study within the United States has examined services currently being offered at early intervention programs nationwide.

In the current study, we examined the extent to which these essential components are being implemented in early intervention programs across the United States. We believe that this list of 32 components has the capacity to act as a comprehensive starting point for a previously unexamined area. Moreover, as this list was derived from an empirically sound, systematic literature review and consensus process with FEP experts, this list may also allow for examination and understanding of the gap between research and practice that may be occurring within the United States early intervention programs. In addition to documenting the use of the 32 evidence based components, we also explored additional services being offered in these programs and definitions of the target populations served.

CHAPTER 2. METHODS

2.1 Sample

Early intervention programs were identified via literature reviews, online searches and snowball sampling. Programs were eligible for inclusion if they provided specialized services for early intervention. Programs providing assessment, without intervention, were excluded. Whenever possible, study eligibility was assessed based on publically available information (i.e. websites, brochures). When eligibility could not be determined from external sources, programs were contacted directly for eligibility screening. For each identified program, we attempted to interview one key personnel (e.g., program directors, medical directors) willing to complete a telephone interview and be audio recorded. Participants were recruited through a combination of telephone calls and e-mail.

2.2 Measures

We developed a semi-structured interview guide (available from the first author) with items asking about each of the 32 essential practices outlined by D.E. Addington et al. (2013). Additionally, two open-ended questions were examined for insight into the needs and strengths of early intervention programs (“What are the most common requests you are getting from clients?” and “What components or aspects of your program do you think are essential?”). The interview guide was piloted on an early intervention program

staff member to ensure completeness and was revised as necessary throughout the interview process. At the suggestion of an early participant, we created an on-line survey to ask the direct, closed-ended questions. Participants were offered the option of completing a full telephone interview or the online survey, followed by an abbreviated telephone interview. After conducting approximately 8 interviews, the research team coded three transcripts to ensure completeness and clarity of the interview guide. Upon review, a number of components were found to require clarification. These items were revised for the remaining interviews. Items affected by these changes included: communication protocol with inpatient units, outreach services, use of single antipsychotic, timely contact after referral, and monitoring other medication side effects.

All interviews were conducted by a doctoral student in clinical psychology, were digitally recorded, and professionally transcribed. All participants were offered compensation of \$20.00. The procedures were approved by the Indiana University IRB.

2.3 Data Analysis

Transcripts were analyzed using directed content analysis, allowing coding to begin with pre-defined categories of interest, then expand through emergent processes (Hsieh & Shannon, 2005). Pre-defined categories were generated from the list of 32 essential evidence-based components (D. E. Addington et al., 2013). All transcripts were coded for the presence or absence of each of the pre-defined categories by two independent coders (both doctoral students in clinical psychology); for each transcript, coders came to consensus.

Data for the presence and absence of the identified components, program characteristics, and program eligibility criteria were entered into SPSS 20.0. We examined descriptive statistics for all programs to explore use of essential components and to summarize program eligibility definitions.

For the open-ended questions regarding staff perceptions of essential components and common client requests, we used emergent content analysis (Hsieh & Shannon, 2005). Responses to these questions were extracted from the transcripts, and systematically reviewed by the first author. Iterative readings of the text allowed for the emergence of a number of themes. Once a coding scheme had been developed, codes were systematically applied.

CHAPTER 3. RESULTS

3.1 Participants

A total of 47 programs were identified; this included a combination of first episode psychosis programs, clinical high-risk programs (i.e., no prior psychotic episode, but exhibiting high-risk symptoms) and programs accepting both populations. Of the 47 programs identified, 34 were considered eligible for the study. Programs were excluded for: closing prior to contact (N=2), not providing interventions (N=6), not having a specialized treatment team (N=1), or still being in the planning phases (N=2). The final 2 programs did not have sufficient publically available evidence to determine eligibility and no contact information was available for either program. Of the 34 eligible programs, representatives from 31 (91.2%) programs agreed to be interviewed and were included for analyses.

3.2 Program Characteristics

More than half of the programs were conducting research in addition to providing treatment (N=19, 61.3%). Of the 31 programs included, 11 programs served the first episode psychosis population, 8 served the clinical high-risk population and the majority of programs (N=12, 38.7%) served both populations. Most programs were located on the West coast (see Table 2), with the East coast being the second most prevalent region. The

Midwest and South had very few programs. The number of program locations per region can also be found in Table 2. More than half of programs were directly providing key auxiliary services (i.e., substance abuse support, supported employment and education) allowing for full integration of treatment services.

3.3 Essential Component Use

Overall, use of essential components was common across programs (see Table 3). All programs reported using two components: individual psychoeducation and outcomes tracking. At least 80% of programs endorsed using an additional 16 components, including: comprehensive assessments upon enrollment (96.8%), family therapy (96.8%), weekly team meetings (96.8%), and care plans including psychosocial needs (93.5%; see Table 3 for additional components). The remaining 14 components were used by 71% or fewer programs (see Table 3). The only component used by less than half of the programs was having a communication protocol with inpatient units (45.2%). This component may be reported less frequently as it required a clarification on an iteration of the interview guide.

3.4 Population Definitions

Almost all programs had an age restriction (96.8%; see Table 4). The lowest age for most programs (N=13; 43.3%) was between 10 and 12 years old, but some programs had age limits starting at 16-18 years old. The upper end of the age restriction for most programs (N = 18; 60.0%) was between 25 and 32 years old, with the highest age being mid-40's. All but 2 programs restricted admissions on the basis of the duration of

psychosis (see Table 4). The most common restriction was psychotic symptoms for less than 1 year (34.5%). Most programs did not place a restriction on antipsychotic medication use (71.0%), prior treatment history (74.2%) or substance use (71.0%).

3.5 Emergent Themes of Client Request

A number of themes emerged from participant reports on clients' requests, including functional recovery, social recovery, practical needs, symptom reduction, and diet/exercise. The most common theme that emerged from the data was the concept of functional recovery, evident in 20 programs. The category included returning back to school or work, applying to college, or determining the supports needed to allow clients to remain in work and school settings. Thus, for the majority of programs, clients are requesting help with returning back to normal role functioning.

Social recovery was another highly emergent theme. More than half of the programs mentioned client requests that included a social element (N=14). This ranged from social skills group requests, to help making friends or dating.

The remaining themes of client requests that emerged were endorsed less frequently, each less than 10 times. Seven programs identified clients wanting help with practical needs such as finding house or obtaining Medicaid coverage/social security benefits. Symptom reduction, or means of coping with symptoms was a theme that emerged from 6 programs and largely pertained to positive symptoms (i.e. reducing the voices/hallucinations). Two programs mentioned diet/exercise as a, as well as community-based services. Four programs did not have an answer, and one described CBT.

3.6 Emergent Themes of Program Identified Essential Components

When program directors were asked to describe which aspects of their program they considered “essential,” most responses could be mapped onto the components described by D.E. Addington et al. (2013), including medication management, individual therapy, and family therapy, which emerged in more than half of all the program transcripts.

The remaining, “new” themes included case management, practical needs, social skills and CBT. Case management was a core theme for some programs (N=8; 25.8%). Participants discussed the importance in coordinating the needs of the clients, “Case management is really pivotal because if they don’t have housing or basic needs met, you’re not [going to] get them anywhere”. Additionally, participants discussed case managers providing many of the education and community advocacy services for clients. Practical needs, social skills and CBT also emerged as perceived essential components. In addition, client engagement was presented as an essential element in 4 of the responses. These programs often indicated that they believed successful outcomes were at least in part tied to their ability to engage and maintain clients in services, “If you said what was the one thing you could do that would have the largest effect on people's distress and function, I would say, building an alliance around stable care.”

CHAPTER 4. DISCUSSION

This is the first study we are aware of that maps the terrain of early intervention programs for psychosis in the US. Programs report using most of the 32 essential components identified by D.E. Addington et al. (2013). The most prevalent components were individual psychoeducation and outcomes tracking; programs are clearly striving to make a measureable impact on improving outcomes and individuals' understanding of their emerging disorders.

The typical US early psychosis program appears to be providing a range of services, including treatment lasting at least 2 years, family and individual interventions, medication management, integrated addictions treatments and thorough assessments. Given that clients are perceived as most frequently requesting help with social and vocational functioning, it may be beneficial for programs to consider incorporating (or expanding) supported employment and education components. Providing additional research into the development and implementation of interventions aimed at the improvement of social cognition in this population, such as Social Cognition Skills Training, SocialVille online gaming or Social Cognition and Interaction training may also lead to great social and functional recovery for individuals (Bartholomeusz et al., 2013; Horan et al., 2011; Nahum et al., 2014).

The least reported components were outreach services and communication protocols with inpatient units. It is possible that both of these components were under-reported due to a large number of programs (two-thirds of the sample) providing services to the clinical high risk population; these individuals usually experience less severe symptoms and may not be perceived as requiring intensive outreach services. Additionally this population has not been hospitalized with an episode of psychosis, making the inclusion of inpatient communications an ineffective means of program recruitment. Outreach services can be labor intensive and may be difficult to fund. However, given the importance of treatment engagement in this population (Lecomte et al., 2008; McGorry, Killackey, & Yung, 2007), it may be beneficial for more programs to offer outreach services to foster a sense of security and enhance treatment engagement.

Almost all programs reported age restrictions, ranging (at the extremes) from 10 to 45 years of age, yet age is not recognized as a defining feature of the population. Although psychosis most commonly begins in early adulthood (Kessler et al., 2007), the onset of a psychotic disorder may occur at a variety of ages. Another defining factor of program eligibility is the duration of untreated psychosis; almost all programs limit eligibility in this domain, with most serving clients within one year of the initial onset episode, but wide variation was observed. Few programs reported placing restrictions on antipsychotic medication use or prior treatment; although there may be reasons for research protocols to limit exposure to prior antipsychotics and treatments, our findings suggest that this practice may restrict the external generalizability of such studies.

The limitations of this study should be considered. Although we attempted to find all programs in the US providing early intervention services, there may have been difficulties in discovering all of the programs (e.g., programs may not have an internet presence). We attempted to reduce the likelihood of missed programs through extensive snowball sampling and literature review. In addition we were highly successful in obtaining interviews with eligible programs that we did identify (response rate of 91.2%), suggesting a fairly representative sample for this study. While we had a guide for the essential components (D.E. Addington et al., 2013), this list was generated with first episode psychosis programs in mind, and our sample included programs serving clinical high risk as well. Qualitative coding of the presence or absence of components involved a degree of subjectivity. We attempted to reduce the level of subjectivity by engaging in independent, duplicate coding followed by consensus meetings for each program interviewed, as well as thorough development of a codebook. Finally it should be noted that these results are based on self-report of program staff. Self-report can be an effective means of initial investigation in an unknown area, however once fidelity measures have been established for early intervention programs in the US, work should be done to determine degree of observed use for these components.

With these caveats in mind, this study has the potential to assist researchers, policy makers and administrators alike. We have described the variety of early psychosis intervention programs across the US, highlighting the key components being used (e.g. individual psychoeducation, outcomes tracking, comprehensive assessments), as well as areas worthy of further investigation (e.g. interventions for social and functional recovery, the role of case management and means of client engagement). Additionally, our findings

suggest that both age and duration of psychosis are key defining variables that early intervention programs are using to determine their service population. These results can provide direction for future fidelity scales and highlight areas for targeted implementation strategies as this field grows.

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APPENDIX

APPENDIX

Table 1. 32 Essential Evidence Based Components for Early Intervention

Component	Supported Evidence	Semi-Interquartile Range
Targeted public education	B	0.5
Targeted health/social provider education	B	0.5
Acceptance of referrals with potential comorbid substance abuse	C	0.5
FEP service communication protocol with inpatient units	D	0.5
Timely contact with referred individual	D	0.25
Individual centered assessments	C	0.5
Comprehensive assessment upon enrollment	C	0.5
Assessment of suicidal thinking and behavior	B	0
Care plan includes psychosocial needs	C	0.5
Informed decision making	C	0.5
Informed consent	D	0.5
Selection of antipsychotic medication	A	0.5
Mode of antipsychotic administration	C	0.5
Low dose, slow increment antipsychotic medication	A	0.37
Clozapine for treatment resistance	A	0.5
Use of single antipsychotic	A	0.5
Monitor metabolic changes	B	0.5
Monitor antipsychotic medication side effects	C	0.5
Proactive steps to prevent weight gain/metabolic effects	B	0.5
Individual psycho-education	B	0.37
Integrated mental health and addictions treatment	C	0.5
Vocational Plan	C	0.5
Supported Employment	A	0.37
Family psycho-education – MFG	A	0.5
Group family psycho-education	B	0.37
Psychiatrist as part of the team	C	0
Duration of FEP services	B	0.5
FEP staff supervision and education	C	0.5
Weekly team meetings	B	0.5
Active outreach services	C	0.5
Crisis intervention services	C	0.5
Tracking of process and outcome measures	C	0.5

^a This table is a summary of the data provided from D.E. Addington et al., (2013). Please see reference.
Note: FEP=First Episode Psychosis; MFG=Multifamily Group Psychoeducation

Table 2. United States Early Intervention Programs' General Characteristics

	N of Programs	Percent of Programs
Population Served		
First Episode Psychosis Only	11	35.5%
Clinical High Risk Only	8	25.8%
Both FEP and CHR	12	38.7%
Research or Clinical Programs		
Research Programs	19	61.3%
Clinically Programs	12	38.7%
Regional Distribution of Programs*		
East Coast	9	29.0%
West Coast	16	51.6%
Midwest	2	6.5%
South	4	12.9%
Total Number of Locations by Region		
East Coast Total Locations	12	19.7%
West Coast Total Locations	39	63.9%
Midwest Total Locations	6	9.8%
South Total Locations	4	6.6%
Services Offered In-House		
Substance Abuse Services	17	54.8%
Supported Employment & Education Services	16	51.6%

A program was only counted once, regardless of number of locations, if all locations were operating under the same modality and services.

Table 3. United States Early Intervention Programs' Use of the 32 Essential Components

Component	Using		Not Using		Use Unknown -	
	N	%	N	%	N	%
Individual Psychoeducation	31	100.0%	0	0.0%	0	0.0%
Outcomes and Process Tracking	31	100.0%	0	0.0%	0	0.0%
Comprehensive Assessment upon Enrollment	30	96.8%	0	0.0%	1	3.2%
Family Therapy	30	96.8%	1	3.2%	0	0.0%
Weekly Team Meetings	30	96.8%	0	0.0%	1	3.2%
Care Plan Includes Psychosocial Needs	29	93.5%	0	0.0%	2	6.5%
Duration of Services Lasting at Least 2 years	29	93.5%	1	3.2%	1	3.2%
Psychiatrist as Part of Team	29	93.5%	2	6.5%	0	0.0%
Staff Supervision and Education	29	93.5%	1	3.2%	1	3.2%
Acceptance of Referrals with Substance Use	28	90.3%	3	9.7%	0	0.0%
Informed Decision Making	28	90.3%	0	0.0%	3	9.7%
Monitoring Metabolic Changes	28	90.3%	2	6.5%	1	3.2%
Assessment of Suicidal Thinking/Behavioral	27	87.1%	3	9.7%	1	3.2%
Informed Consent	27	87.1%	2	6.5%	2	6.5%
Targeted Public Education	27	87.1%	2	6.5%	2	6.5%
Targeted Health/Social Service Provider Education	26	83.9%	5	16.1%	0	0.0%
Low Dose, Slow Increment Medication (N=30)*	25	83.3%	1	3.3%	4	13.3%
Selection of Antipsychotic Meds (N=30)*	25	83.3%	2	6.7%	3	10.0%
Integrated Mental Health and Addictions	22	71.0%	9	29.0%	0	0.0%
Mode of Antipsychotic Administration (N=30)*	22	73.3%	7	23.3%	1	3.3%
Monitoring Other Side Effects	21	67.7%	2	6.5%	8	25.8%
Proactive Steps to Prevent Metabolic Effects	20	64.5%	6	19.4%	5	16.1%
Timely Contact after Referral (within 2 weeks)	20	64.5%	3	9.7%	8	25.8%
Multifamily Groups**	19	61.3%	11	35.5%	1	3.2%
Supported Employment	19	61.3%	12	38.7%	0	0.0%
Clozapine for Treatment Resistance (N=30)*	18	60.0%	7	23.3%	5	16.7%
Use of Single Antipsychotic (N=30)*	18	60.0%	3	10.0%	9	30.0%
Crisis Intervention Services	17	54.8%	13	41.9%	1	3.2%
Individually Centered Assessments	17	54.8%	14	45.2%	0	0.0%
Vocational Plan	17	54.8%	9	29.0%	5	16.1%
Outreach Services for Participants	16	51.6%	9	29.0%	6	19.4%
Communication protocol with inpatient units	14	45.2%	8	25.8%	9	29.0%

* One program did not engage in any medication management and thus they were not included in the total for these categories. All components marked with an (*) have a total N of 30.

** Multifamily group includes programs providing any multifamily style groups.

-Responses were marked unknown when programs were unsure of whether they were utilizing a component, or if their response was so unclear that a definitive response could not be determined by the coding team.

Table 4. United States Early Intervention Programs' Eligibility Criteria

Eligibility Criteria	N of Programs	Percentage of Programs
Age Restriction		
N of Programs with Age Restriction	30	96.8
Age Range Lower Limit		
10-12 Years Old	13	43.3%
13-15 Years Old	9	30.0%
16-18 Years Old	8	26.7%
Age Range Upper Limit		
25-32 Years Old	18	60.0%
33-39 Years Old	7	23.3%
40-46 Years Old	5	16.7%
Duration of Psychosis Restriction		
N of Programs with DUP Restriction	29	93.5%
DUP Restriction Length		
Unknown	9	31.0%
15 days – 12 Months	10	34.5%
13 Months – 24 Months	6	20.7%
25 Months – 36 Months	1	3.4%
37 Months or More	5	17.2%
Prior Antipsychotic Medication Restriction		
N of Programs without Medication Restriction	22	71.0%
N of Programs with Medication Restriction ^a	9	29.0%
Prior Treatment for Psychosis		
N of Programs without Treatment Restriction	23	74.2%
N of Programs with Prior Treatment Restriction ^b	4	12.9%
Unknown	4	12.9%
Substance Use Restriction		
N of Programs without Substance Use Restriction*	22	71.0%
N of Programs with Substance Use Restriction	9	29.0%

*Substance Use restriction did not include substance induced psychosis. No programs accepted individuals with substance induced psychosis.

^a Restrictions on medication included being completely medication naïve, or a restriction on the length of time antipsychotic medication could be used.

^b Restrictions on prior treatment included never receiving treatment for a psychiatric disorder, never receiving treatment for psychosis, or a specific restriction on the duration of treatment received.