

HHS Public Access

Author manuscript *Psychiatr Serv.* Author manuscript; available in PMC 2023 June 20.

Published in final edited form as:

Psychiatr Serv. 2021 April 01; 72(4): 399–407. doi:10.1176/appi.ps.202000241.

Clients' Preferences for Family Involvement and Subsequent Family Contact Patterns within OnTrackNY Early Psychosis Services

Nev Jones, PhD¹, Cale Basaraba, MPH², Sarah Piscitelli, MA², Thomas Jewell, PhD², Ilana Nossel, MD², Iruma Bello, PhD², Franco Mascayano, MPH², Jennifer Scodes, MS², Leslie Marino, MD², Melanie Wall, PhD², Lisa B. Dixon, MD MPH²

¹Department of Psychiatry & Behavioral Neurosciences, University of South Florida, Tampa, FL

²Division of Behavioral Health Services and Policies, New York State Psychiatric Institute, New York, New York

Abstract

Objective: Little is known about client preferences for family involvement and family contact in naturalistic, community-based Coordinated Specialty Care (CSC) settings. The study's primary goal was to characterize clients' preferences, and longitudinal patterns of family contact with providers across the OnTrackNY network.

Methods: Clinical administrative data collected at three month intervals and spanning 21 OnTrackNY CSC sites was used to analyze client preferences, family contact patterns and their correlates during the initial 12 month service period. Clients discharged prior to 12 months were included as a comparison group.

Results: The majority of clients requested some form of family involvement and rates of family contact ranged from 74.3% and 84.1% within each three month assessment period. Variables associated with both client preferences and contact patterns included baseline insurance status, housing status, race, frequency of contact with family, and employment. Preferences for no or limited family involvement were associated with higher rates of early discharge.

Conclusions: Structuring family involvement around clients' preferences does not appear to negatively impact, and may bolster, family contact. Additional mixed methods research is needed to deepen our understanding of the contexts and reasoning underlying both preferences and subsequent levels of family involvement.

Introduction

Family members are a major source of emotional and material support for individuals with psychotic disorders across the lifespan^{1–5}. For example, the CATIE trial found that nearly half of participants with an average 8 year duration of illness lived with family members⁶. Families are often the first to notice early signs and symptoms⁷ and play a pivotal role in initial pathways to care among youth with a first episode of psychosis (FEP) ^{8–12}.

Corresponding author: Nev Jones, nev.inbox@gmail.com, genevra@usf.edu.

Family support bolsters client outcomes, including improved functioning and reduced rates of relapse^{13–17}.

Family psychoeducation, which provides information, problem solving, and crisis intervention is a robust evidence based practice shown to improve outcomes and reduce relapse among adults with schizophrenia^{18–20}. Despite the evidence supporting family participation in care, however, gaps exist in typical adult service settings, with both quantitative and qualitative studies attesting to numerous barriers to involvement^{21–27}. The full family psychoeducation model is virtually non-existent in usual services; even minimal family contact in adult settings rarely exceeds $20-30\%^{21-24}$.

Dixon and colleagues developed a family involvement intervention (REcovery ORiented DEcision making for Relative's support (REORDER)) premised on a structured dialogue concerning clients' preferences for both the degree and form of family involvement in their care followed by a similar dialogue with family members^{28–9}. Results from a randomized trial of REORDER compared with enhanced TAU services (including access to a skilled family therapist), found marked increases in family contact and improved indicators of recovery within the experimental group²⁸. Trial findings strongly support the idea that clients welcome family involvement if the nature of involvement is under their control and choices are offered.

In most Early Intervention in Psychosis services (EIP), family psychoeducation is the primary family treatment component⁻³³. The OPUS trial, integrating family psychoeducation, found that enrolled families reported higher satisfaction and lower caregiving burden³⁴; similarly, the Italian GET-UP trial found that enrolled family members experienced decreased family burden and emotional distress and greater service satisfaction over 9 months ³⁵. A recent meta-analysis found that family psychoeducation is highly effective in reducing relapse in FEP¹³.

Although family psychoeducation is an effective intervention, it is unclear if there are barriers to its uptake in FEP programs—similar to those observed in adult programs. Only a handful of EIP studies have reported family involvement rates. Internationally, the Italian GET-UP trial found that 91.9% of families participated in at least one family psychoeducation session and 72.7% received more than 10³⁵. A Canadian study of individualized family intervention reported a 72% participation rate: of 71 families, 27 were unavailable/out of area, 25 did not participate due to client preferences and 8 preferred not to be involved³⁶. A 2017 meta-analysis of family interventions in FEP summarizes family-carer intervention completion rates across trials from 42–100%, with longer interventions associated with higher drop-out³⁷.

Turning to the US, the RAISE Early Treatment Program trial found that monthly family participation within the first year of treatment fluctuated between 22.5 and 48.4%³⁸. A pilot evaluation of community-based CSC programs in Washington State found that 82% of clients' families participated in at least one family psychoeducation session during the initial 12 months of treatment³⁹. The Arizona EPICENTER implementation reported 22% participation in individual family psychoeducation and 44% in group family

psychoeducation⁴⁰. Although there are approximately 285 CSC programs in the US, we were unable to locate family involvement data for other community based programs.

The RAISE Connection Program (now OnTrackNY), integrated the client-driven, shared decision making approach developed in REORDER^{28,41–43}. At program enrollment, a semistructured assessment tool and decision aids are used to collaboratively map out client preferences regarding family involvement. Involvement can take a number of forms, and clients can impose nuanced constraints such as involvement in only some aspects of care.. In the initial RAISE Connection trial, higher family involvement was associated with client age (less than 18 years old), more severe psychiatric symptoms, and absence of substance use⁴³. The effectiveness of client-driven family involvement in CSC has not been studied to date.

Study Rationale and Aim

To better understand family involvement in CSC, we examined the participation of families, and correlates of participation, within the client preference driven model implemented within OnTrackNY. Specific aims were to:

- 1. Characterize clients' family involvement preferences at enrollment and associated baseline variables;
- 2. Characterize family contact pattern with CSC teams over the initial 12 months of treatment and associated variables;
- **3.** Examine the relationship between clients' preferences at enrollment and family contact patterns over 12 months of follow-up

2. Materials and methods

2.1. Research design and sample

We report on a prospective CSC cohort using administrative data from the OnTrackNY network, encompassing 21 programs in New York State^{41,44}. Between October 2013 and December 2018, the network served approximately 1350 individuals with FEP between the ages of 16–30 with a recent-onset (<2 years) non-affective psychotic disorder. Additional publications describe the development and implementation of the OnTrackNY network in detail^{41,42,44}.

Client-reported data are collected at admission and quarterly using standardized providerreported admission, follow-up and discharge data collection forms for purposes of quality improvement. All identifiable information are removed from the datasets, and the deidentified data are approved by the [deidentified IRB]. This study includes 761 participants who enrolled between August 2015 (when data collection of the main outcomes began) and December 2017 to allow for each participant to be eligible for 1-year of follow-up data.

2.2. Outcomes

The two target outcomes are:

1. *Client preferences regarding family involvement* in their care, with three categorical options: no-involvement, involvement with conditions (e.g. client

requests family involvement in some aspects of care but not others); and unconditional involvement. Collected at baseline.

2. *Family contact with the CSC team:* presence of one or more contacts between family member(s) and CSC team members during the preceding 3 months. Collected quarterly during follow-up.

2.3. Baseline Correlates

Analyses also includeded sociodemographic variables, family support system variables (e.g., contact with family, living situation, identified designated support person and homelessness), functioning and clinical status (e.g., hospitalization, medication adherence, time to first mental health contact, family involvement in pathway to care, substance abuse). A comprehensive list of these variables and their respective categories is available in Table 1 and additional information on variable structure located in Supplemental Information.

The standardized clinical measured utilized was the Mental Illness Research, Education, and Clinical Centers Global Assessment of Functioning scale (MIRECC-GAF), which includes three sub-scales: Symptoms (MIRECC-GAF Symptoms), Social Functioning (MIRECC-GAF SF), and Occupational Functioning (MIRECC-GAF OF). The MIRECC-GAF OF has 10 anchor points reflecting average level of functioning in their primary role as worker, student or homemaker during the 30 days prior to assessment. The MIRECC-GAF SF is similarly structured and considers social interactionns, relationship quality and quantity, and interpersonal conflicts in the previous 30 days. The MIRECC-GAF Symptoms captures patients' worst level of functioning during the previous 30 days based on suicidality, mood, anxiety and psychotic symptoms. Subscales are scored from 0 to 100.

2.3. Data Analysis

Analyses utilize a censored sample of OnTrackNY clients who were eligible to have received services for 12 months (n=761).

To assess the associations between both primary outcomes (client's family involvement preference at enrollment and family contact with teams over initial 12-months of follow-up) and baseline variables, descriptive summaries of baseline measures were computed stratified by baseline involvement preference (3-levels: no involvement, conditional involvement, unconditional involvement) and then by family contact pattern (4-levels: always, mixed, never, early discharge). The family contact patterns across 1-year of follow-up are characterized in the follow way: 'always' includes those who had family involvement for all follow-up data in the first year, 'mixed' includes those who had a mix of family involvement and non-involvement in the first year, 'never' includes those who never had family involvement in the first year, and 'early discharge' includes participants who disengaged from the program prior to 1 year length of stay. The descriptive summaries include proportions for categorical measures, means and standard deviations for normally distributed continuous measures, and medians and interquartile ranges for skewed-continuous measures. The associations between groups and the baseline measures were assessed using chi-square tests, one-way ANOVAs, and Kruskal-Wallis tests depending on the distribution of the baseline correlate.

All statistical tests were two-sided with significance level of 5%. Due to the novelty of the primary outcomes examined in the current study and lack of prior research utilizing analogous datapoints, we conceptualized our analyses as exploratory and hypothesis generating, therefore, we did not employ tests for multiple comparisons. All analyses were run using SAS version 9.4.

3. Results

Family Involvement Preferences and Correlates.

At enrollment, 59% (450/761) of participants requested unconditional family involvement, 35% (266/761) involvement with conditions, and 5.9% no involvement. Baseline variables examined in relation to involvement preferences are reported in Table 1. There were significant differences in baseline family involvement preferences for family and support system measures, medication adherence, substance use, employment and secondary/ post-secondary educational participation. Compared to clients requesting conditional or unconditional involvement, clients in the 'no involvement' group were more likely to be older, employed and have graduated from college; they were also less likely to have a designated support person, and more likely to be homeless, live alone, or live with non-family members. Family member involvement in pathways to care was significantly less likely in the 'no involvement' group compared to the other groups, although there was no difference in time from onset to first mental health contact between groups. In general, metrics for the conditional involvement group fell in-between the unconditional and no involvement groups. In addition, family involvement preference was significantly associated with early discharge, with a higher proportion of early discharges in the 'no involvement' group. Prior hospitalizations and GAF scores were not significantly related to family involvement preference.

Family Contact with CSC Teams.

Within the same cohort (n = 761), 67% (n=506) remained enrolled for 12 months. Rates of family contact significantly decreased over time: 84%, 78%, 74% and 73% had family contact at 3 months, 6 months, 9 months, and 12 months, respectively (Cochran-Armitage z = 4.90, N = 761, p < .001). When assessing longitudinal family contact patterns: 42% had contact at least once at every follow-up ('always'; 323/761), 3% had no contact at all follow-up points ('never'; 22/761), 21% had mixed pattern of family contact ('mixed'; 161/761), and 34% disengaged from the program early ('early discharge'; 255/761).

Group differences in baseline characteristics for the three family contact patterns and those with early discharge are reported in Table 2. Racial differences were marked: families of white (non-Hispanic) clients represented a third of those 'always involved' but only 5% of those never involved. Additional cross-tabulations showed Black (non-Hispanic) race/ ethnicity was significantly associated with indicators of insurance status ($\chi 2 = 14.3$, N = 761, df = 1, p = .003) and criminal justice involvement ($\chi^2 = 3.9$, N = 761, df = 1, p = .047). Age, gender, insurance status, current family contact, living status, designation of a support person, homelessness, medication adherence, family involvement in pathways to care, and baseline employment all differed significantly across involvement patterns. Clients with

Page 6

family never involved were more likely to be older, employed at baseline, and had higher baseline occupational functioning in comparison to the other family contact patterns, while those with continuous family involvement were more likely to be younger, male, living with their parents, and to have higher symptom burden, and markedly worse occupational functioning. Mixed involvement metrics generally fell in-between the continuous and no involvement groups, though were typically much closer to the former.

Relationship between baseline preferences and 12 month family contact pattern.

There was a significant association between baseline client preferences and family contact pattern (χ^2 = 48.2, N = 761, df = 6, p <.001). Nearly half of those specifying 'no involvement' discharged prior to 12 months; conversely, families of clients who preferred unconditional involvement were the most likely to remain continuously involved (48% versus 37% and 18% in the 'involvement with conditions' and 'no involvement' groups, respectively). However, the combined proportion of either always having family contact or mixed contact were nearly equal for the conditional and unconditional involvement groups (60% versus 68% respectively). Even among families of clients who preferred unconditional involvement, a small proportion (1%) nevertheless did not make contact at any point during the first year. Additionally, about a third of families of clients who expressed a preference for 'no involvement' nevertheless had contact with teams at all or some timepoints (34%).

4. Discussion

We investigated client preferences for family involvement at enrollment and patterns of family contact over 12 months of follow-up, across a large, community-based CSC network. Most clients preferred family involvement, but a significant subset (41%) requested constraints or conditions. Almost all families were involved at least some of the time during the first year of treatment. Both preferences for no family involvement and patterns of no family contact in the first year of treatment were more likely for older clients with higher rates of employment and/or occupational functioning and greater likelihood of living alone or independently from parents. Black families were more likely to fall in the no involvement and mixed involvement groups. Rates of private insurance were nearly twice as high among clients with continuous family involvement compared to those with never involved families.

Clinical Implications

A major contribution of the current study is the reporting of data concerning client preferences for family involvement within one of the largest implementations of CSC in the US. While a significant number of clients requested constraints or conditions, the rates for the continuously involved and mixed involvement families of clients requesting conditions were very similar (61% vs 68%), suggesting that they do not adversely affect family involvement and may in fact increase them. Ultimately, the comparative effectiveness of different family involvement strategies will be of considerable clinical importance to the field. While the OnTrackNY statistics appear promising, limitations of the datapoints used in both the current study and other identified reports as well as differences in both timescale and constructs measured, preclude making meaningful comparisons between outcomes. Future research efforts should better delineate the kind, type and circumstances of family

Racial/ethnic differences in family involvement have been noted in the literature^{38,45–47}. We found significant but attenuated differences in client preferences by racial/ethnic group, but more robust differences in actual family involvement. Black participants were significantly more likely to disengage early and to fall into the 'never' and 'mixed' involvement groups, mirroring recent analyses of the RAISE Navigate trial³⁸ While these findings may be mediated or moderated by socioeconomic differences^{48–50}, they foreground the importance of meeting the needs of minority clients and families at elevated risk of disengagement and premature discharge.

The finding that CSC clients displaying signs of greater independence at baseline, as indicated by higher likelihood of being older, employed, greater educational attainment, and greater likelihood of living independently, are more likely to prefer no or conditional family involvement is unsurprising. Similarly, we would expect less need for family involvement among clients with fewer needs, i.e. higher occupational and social functioning, employment and educational attainment and lower rates of severe symptoms. More surprisingly, however, preferences for less family involvement were also predicted by public insurance, potentially a proxy for lower socioeconomic status, and by race (being black versus white). This suggests hidden sub-groups within this cohort—one potentially reflecting greater client independence and lower needs, and another reflecting lower family involvement due to the additional barriers that socioeconomic disadvantage (and its intersections with race and cultural stigma) may present^{48–51}. Future research can better identify these potential sub-groups, as lack of involvement may reflect a logical outcome for low needs clients, but evidence of disparities driven by socioeconomics and/or race for others.

The fact that nearly half of those who preferred no family involvement disengaged prior to one year could suggest that 'no involvement' preferences are a red flag for potential disengagement; however, given the patterns described above, they may also be driven by lower needs and higher functioning associated with "positive" early discharges due to a desire for a lower level of care (e.g., medication management only). A more nuanced understanding of variable length of engagement with EIP/CSC is important and will depend on identifying diverse latent groups and latent trajectories among clients.

While there was a small sub-group with no family involvement, compared to family involvement in mainstream community mental health services^{43,52}, family involvement across OnTrackNY is exceptionally high. Other CSC programs could potentially learn from and replicate these practices. While the current dataset did not allow for investigation of comparative involvement in and preferences for individualized family involvement versus involvement in group interventions (such as multi-family groups, commonly implemented in EIP/CSC programs), such research could help explain how to best meet the needs of family members.

Limitations

Due to the observational nature of our data, causal inferences cannot be made. Further, there are likely multiple complex interactions between measures; however, small cell sizes within our sample precluded more complex modeling of these relationships. Potentially important metrics were not available in the dataset, including more comprehensive indicators of family socioeconomics and acculturation, as well as perceived family conflict^{21,23}. The only available family involvement metric within the dataset ('any contact within the prior quarter') is blunt, and does not allow for examination of diverging patterns of contact, nor distinguish between deep and sustained versus more superficial involvement. The first person experience of involvement, both from client and family member perspectives, is also absent and future research would benefit from strategic use of mixed methods to deepen our understanding of client and family involvement decisions and associated impact.

Finally, preferences are dynamic rather than static and measurement of changes in preferences over time is important; this study focuses on preferences during enrollment and this is both a limitation and issue worthy of significant attention in future studies.

Conclusions

Overall, we found that the overwhelming majority of clients prefer at least some degree of family involvement, and overall rates of family involvement are high, in both cases exceeding those identified in older clients with SMI. While exploratory and observational, patterns of relationships between variables seem to suggest that clients who had achieved greater independence from their families at baseline were more likely to prefer less involvement, and for families to in turn be less involved over the initial year of treatment. We also found lower rates of family involvement for African-American clients and clients who were uninsured or publicly (versus privately) insured, suggesting potential racial and socioeconomic inequities in involvement capacity. Expanded research on the optimization of the involvement of diverse members remains a priority for the field.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Disclosures:

The authors report no financial relationships with commercial interests. Editor Emeritus Howard H. Goldman, M.D., Ph.D., served as decision editor on the manuscript.

References

- 1. Cloutier M, Aigbogun MS, Guerin A, et al., Legacy SN, Henderson C, François C. The economic burden of schizophrenia in the United States in 2013. J Clin Psychiat 2013; 77:764–71.
- García JI, Chang CL, Young JS, et al. Family support predicts psychiatric medication usage among Mexican American individuals with schizophrenia. Soc Psychiatry Psychiatr Epidemiol 2006; 41: 624–31. [PubMed: 16733631]
- Gutiérrez-Maldonado J, Caqueo-Urízar A, Kavan. Burden of care and general health in families of patients with schizophrenia. Soc Psychiatry Psychiatr Epidemiol 2005;40: 899–904. [PubMed: 16245190]

- Hayes L, Hawthorne G, Farhall J, et al. Quality of life and social isolation among caregivers of adults with schizophrenia: Policy and outcomes. Community Ment Health J 2015; 51: 591–7. [PubMed: 25690154]
- Perlick DA, Rosenheck RA, Kaczynski R, et al. Special section on CATIE baseline data: components and correlates of family burden in schizophrenia. Psychiatr Serv 2006; 57: 1117–25. [PubMed: 16870962]
- Tsai J, Stroup TS, Rosenheck RA. Housing arrangements among a national sample of adults with chronic schizophrenia living in the United States: A descriptive study. J Com Psychology 2011; 39: 76–88.
- 7. Norman RM, Malla AK, Manchanda R, et al. Social support and three-year symptom and admission outcomes for first episode psychosis. Schiz Res 2005 ;80: 227–34.
- Cabassa LJ, Piscitelli S, Haselden M, et al. Understanding pathways to care of individuals entering a specialized early intervention service for first-episode psychosis. Psychiatr Serv 2018; 69: 648–56. [PubMed: 29493414]
- Cocchi A, Meneghelli A, Erlicher A, et al A. Patterns of referral in first-episode schizophrenia and ultra high-risk individuals: results from an early intervention program in Italy. Soc Psychiatry Psychiatr Epidemiol 2013; 48: 1905–16. [PubMed: 23832100]
- Del Vecchio V, Luciano M, Sampogna G, et al. . The role of relatives in pathways to care of patients with a first episode of psychosis. Int J Soc Psychiatry 2015; 61: 631–7. [PubMed: 25614470]
- 11. Lucksted A, Stevenson J, Nossel I, et al. Family member engagement with early psychosis specialty care. Early intervention in psychiatry 2018; 12: 922–7. [PubMed: 27863039]
- MacDonald K, Fainman-Adelman N, Anderson KK, Iyer SN. Pathways to mental health services for young people: a systematic review. Soc Psychiatry Psychiatr Epidemiol 2018; 53: 1005–38. [PubMed: 30136192]
- Camacho-Gomez M, Castellvi P. Effectiveness of family intervention for preventing relapse in first-episode psychosis until 24 months of follow-up: a systematic review with meta-analysis of randomized controlled trials. . Schiz Bull 2020; 46: 98–109.
- Haselden M, Corbeil T, Tang F, et al. Family involvement in psychiatric hospitalizations: associations with discharge planning and prompt follow-up care. Psychiatr Serv 2019;70: 860–6. [PubMed: 31310186]
- Lee G, Barrowclough C, Lobban F. Positive affect in the family environment protects against relapse in first-episode psychosis. Soc Psychiatry Psychiatr Epidemiol 2014; 49: 367–76. [PubMed: 24081324]
- Norman RM, Windell D, Manchanda R, et al. Social support and functional outcomes in an early intervention program. Schiz Res 2012; 140: 37–40.
- 17. Pitschel-Walz G, Leucht S, Bäuml J, Kissling W, Engel RR. The effect of family interventions on relapse and rehospitalization in schizophrenia—a meta-analysis. Schiz Bull 2001; 27: 73–92.
- 18. Lehman AF, Kreyenbuhl J, Buchanan RW, et al. The schizophrenia patient outcomes research team (PORT): Updated treatment recommendations 2003. Schiz Bull 2004; 30 :193–217.
- 19. Kuipers E, Yesufu-Udechuku A, Taylor C, et al. Management of psychosis and schizophrenia in adults: summary of updated NICE guidance. BMJ 2014; 348:g1173.
- 20. Gaebel W, Weinmann S, Sartorius N, Rutz W, McIntyre JS. Schizophrenia practice guidelines: international survey and comparison. Br J Psychiatry 2005; 187: 248–55. [PubMed: 16135862]
- 21. Cohen AN, Drapalski AL, Glynn SM, et al. Preferences for family involvement in care among consumers with serious mental illness. Psychiatr Serv 2013; 64: 257–63. [PubMed: 23242515]
- 22. Drapalski A, Leith J, Dixon L. Involving families in the care of persons with schizophrenia and other serious mental illnesses: History, evidence, and recommendations. Clin Schizophr Relat Psychoses 2009; 3 :39–49.
- 23. Fang LJ, Dixon LB. Family contact, experience of family relationships, and views about family involvement in treatment among VA consumers with serious mental illness. Journal of Rehabilitation Research and Development 2007; 44: 801–7. [PubMed: 18075938]

- Landeweer E, Molewijk B, Hem MH, et al. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. BMC Health Serv Res 2017; 17: 349–54. [PubMed: 28506296]
- Cohen AN, Glynn SM, Murray-Swank AB, et al. The family forum: directions for the implementation of family psychoeducation for severe mental illness. Psychiatr Serv 2008 ; 59: 40–8. [PubMed: 18182538]
- 26. Dausch BM, Cohen AN, Glynn S, et al. An intervention framework for family involvement in the care of persons with psychiatric illness: Further guidance from family forum II. Am J Psychiatr Rehabil 2012; 15: 5–25.
- 27. Eassom E, Giacco D, Dirik A, et al. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open 2014; :e006108.
- Dixon LB, Glynn SM, Cohen AN, et al. Outcomes of a brief program, REORDER, to promote consumer recovery and family involvement in care. Psychiatr Serv 2014; 65: 116–20. [PubMed: 24177229]
- 29. Gioia D, Autrey S, Drapalski AL, et al. Veterans' views of a shared decision-making process: a qualitative substudy of REORDER. Am J Psychiatr Rehabil 2014; 17: 348–64.
- 30. Addington DE, McKenzie E, Norman R, et al. Essential evidence-based components of firstepisode psychosis services. Psychiatr Serv 201; 64: 452–7.
- 31. Bertolote J, McGorry P. Early intervention and recovery for young people with early psychosis: consensus statement. Br J Psychiatry 2005; 187: s116–9.
- 32. Heinssen RK, Goldstein AB, Azrin ST. Evidence-based treatments for first episode psychosis: components of coordinated specialty care. White paper. Bethesda: National Institute of Mental Health, 2014.
- Fusar-Poli P, McGorry PD, Kane JM. Improving outcomes of first-episode psychosis: an overview. World Psychiatry 2017; 16: 251–65. [PubMed: 28941089]
- 34. Jeppesen PI, Petersen L, Thorup A, et al. Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. Br J Psychiatry 2005; 187: :s85–90.
- Ruggeri M, Lasalvia A, Santonastaso P, et al. Family burden, emotional distress and service satisfaction in first episode psychosis. Data from the GET UP Trial. Front Psychol 2017; 16; 8:721.
- Addington J, McCleery A, Addington D. Three-year outcome of family work in an early psychosis program. Schiz Res 2005; 79: 107–16.
- 37. Claxton M, Onwumere J, Fornells-Ambrojo M. Do family interventions improve outcomes in early psychosis? A systematic review and meta-analysis. Front Psychol 2017; 27: 8:371.
- Oluwoye O, Stiles B, Monroe-DeVita M, et al. Racial-ethnic disparities in first-episode psychosis treatment outcomes from the RAISE-ETP study. Psychiatr Serv 2018; 69: 1138–45. [PubMed: 30152275]
- 39. Oluwoye O, Reneau H, Stokes B, et al. Preliminary Evaluation of Washington State's Early Intervention Program for First-Episode Psychosis. Psychiatr Serv 2019; 18: appi-ps.
- Breitborde NJ, Bell EK, Dawley D, et al. The Early Psychosis Intervention Center (EPICENTER): development and six-month outcomes of an American first-episode psychosis clinical service. BMC Psychiatry 2015; 15:266–71. [PubMed: 26511605]
- 41. Bello I, Lee R, Malinovsky I, et al. OnTrackNY: the development of a coordinated specialty care program for individuals experiencing early psychosis. 2017.Psych Serv 68: 318–320.
- 42. Dixon LB, Goldman HH, Bennett ME, et al. Implementing coordinated specialty care for early psychosis: the RAISE Connection Program. Psychiatr Serv 2015; 66: 691–8. [PubMed: 25772764]
- 43. Drapalski A, Piscitelli S, Lee RJ., et al. Family Involvement in the Clinical Care of Clients With First-Episode Psychosis in the RAISE Connection Program. Psychiatr Serv 2017; 69: 358–361. [PubMed: 29089013]
- 44. Mascayano F, Nossel I, Bello I, et al. . Understanding the implementation of coordinated specialty Care for Early Psychosis in New York state: A guide using the RE-AIM framework. Early Interv Psychiatry 2019;13: 715–9. [PubMed: 30672144]

- 45. Islam Z, Rabiee F, Singh SP. Black and minority ethnic groups' perception and experience of early intervention in psychosis services in the United Kingdom J Cross Cult Psychol 2015; 46: 737–53.
- 46. Snowden LR. Explaining mental health treatment disparities: Ethnic and cultural differences in family involvement. Cult Med Psychiatry 2007; 31: 389–402. [PubMed: 17874177]
- 47. Rosenfarb IS, Bellack AS, Aziz N. Family interactions and the course of schizophrenia in African American and white patients. J Abnorm Psychol 2006; 115: 112–15 [PubMed: 16492102]
- Berg AO, Aas M, Larsson S, et al. Childhood trauma mediates the association between ethnic minority status and more severe hallucinations in psychotic disorder. Psychol Med 2015; 45: 133– 42. [PubMed: 25065296]
- Jones N, Godzikovskaya J, Zhao Z, et al. Intersecting disadvantage: Unpacking poor outcomes within early intervention in psychosis services. Early Interv Psychiatry 2019;13: 488–94. [PubMed: 29076244]
- Rosen C, Jones N, Longden E, et al. Exploring the intersections of trauma, structural adversity, and psychosis among a primarily African-American sample: a mixed-methods analysis. Front Psychiatry 2017; 8:57. [PubMed: 28469582]
- Maura J, de Mamani AW. Mental health disparities, treatment engagement, and attrition among racial/ethnic minorities with severe mental illness: a review. J Clin Psychol Med Settings 2017; 24: 187–210. [PubMed: 28900779]
- Resnick SG, Rosenheck RA, Dixon L, et al. Correlates of family contact with the mental health system: Allocation of a scarce resource. Ment Health Serv Res 2005; 7: 113–21. [PubMed: 15974157]

Highlights:

- The overwhelming majority of New York CSC clients preferred at least some degree of family involvement and family contact rates were high
- Older clients with greater independence seemed to prefer less family involvement
- Family contact with program staff was lower among African-American clients and those who were uninsured or receiving public insurance
- Client preferences for family involvement were significantly associated with both family contact and early client discharge prior to 12 months of service

Table 1.

Baseline characteristics by client family involvement preferences (N=761)

	Grouped by Baseline Family Involvement Preference								
	N	to Involvement (n=45)	Conditio	nal Involvement (n=266)	Unconditi	onal Involvement (n=450)	Difference btw groups		
Measures	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	p-value		
Demographics									
Age (years)	45	23.0±3.0	266	21.6±3.2	450	20.8±3.2	<.001		
Gender							0.018		
Female	14	31%	82	31%	91	20%			
Male	31	69%	182	68%	357	79%			
Other	0	0%	2	1%	2	0%			
Race							0.036		
White (non-Hispanic)	15	33%	94	35%	108	24%			
Black (non-Hispanic)	13	29%	89	34%	161	36%			
Hispanic	11	24%	63	24%	138	31%			
Other	6	13%	20	8%	43	10%			
Insurance status							0.027		
Uninsured	4	9%	19	7%	23	5%			
Public	25	56%	111	42%	233	52%			
Private	14	31%	116	44%	180	40%			
Other	2	4.4%	20	8%	14	3%			
Primary language							<.001		
English	43	96%	251	94%	385	86%			
Spanish	0	0%	4	2%	36	8.%			
Other	2	4%	11	4%	28	6%			
Highest grade completed							0.002		
<hs< td=""><td>9</td><td>20%</td><td>60</td><td>23%</td><td>136</td><td>30%</td><td></td></hs<>	9	20%	60	23%	136	30%			
HS or GED	8	18%	49	18%	92	20%			
Some college	15	33%	117	44%	180	40%			
College graduate	13	29%	40	15%	42	9%			
Family and Support System									
Current family contact with client							<.001		
Daily	26	62%	224	85%	425	94%			
Weekly	6	14%	31	12%	19	4%			
Monthly or less	10	24%	8	3%	6	1%			
Lives with family							<.001		
Parents	27	60%	205	77%	398	88%			
Other family (not parents)	3	7%	17	6%	31	7%			

		Grouped by Baseline Family Involvement Preference							
	N	o Involvement (n=45)	Conditio	nal Involvement (n=266)	Unconditi	onal Involvement (n=450)	Difference btw groups		
Measures	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	p-value		
Alone	5	11%	25	9%	8	2%			
Other	10	22%	19	7%	13	3%			
Lives with anyone (% yes)	40	89%	241	91%	442	98%	<.001		
Has support person (% yes)	28	62%	241	91%	438	97%	<.001		
Homeless (% yes)	11	24%	21	8%	14	3%	<.001		
Clinical									
Ever hospitalized (% yes)	37	82%	226	85%	388	86%	0.726		
Number of prior hospitalizations	39	1.7±1.3	234	1.7±1.1	403	1.5±1.0	0.088		
Current prescription for antipsychotics							<.001		
Not medication adherent	8	18%	54	20%	54	12%			
Medication adherent	23	51%	159	60%	331	74%			
Not prescribed	6	13%	23	9%	20	4%			
Unknown	8	18%	30	11%	45	10%			
Time to 1st mental health contact (days) median (IQR)	44	37.0 (11.0– 183.0)	264	29.0 (2.0– 119.0)	443	25.0 (2.0–90.0)	0.224		
Family involvement in initial pathways to care referral chains (% yes)	21	47%	165	62%	326	73%	<.001		
Any substance use	33	73%	153	58%	229	51%	0.008		
Discharged within one year	22	49%	96	36%	137	30%	0.024		
Functioning									
GAF social functioning							0.223		
< 40	8	18%	31	12%	52	12%			
40–70	28	62%	178	67%	273	69%			
>=70	9	20%	56	21%	124	28%			
GAF occupational functioning							0.660		
< 40	31	69%	166	63%	301	67%			
40–70	11	24%	74	28%	105	23%			
>=70	3	7%	24	9%	44	10%			
GAF symptoms							0.367		
< 40	37	82%	214	81%	371	82%			
40-70	8	18%	47	18%	77	17%			
>=70	0	0%	5	2%	2	0%			
Employment at admission (% yes)	11	24%	53	20%	55	12%	0.006		
Early Discharge									
Discharged within one year (% yes)	22	49%	96	36%	137	30%	0.024		

 * GAF scores range from 0 to 100 with 100 representing better functioning

Table 2.

Baseline characteristics by Family Contact Pattern (n=761)

	Grouped by Family Contact Pattern								
	Alv	ways (n=323)	M	ixed (n=161)	N	Never (n=22)	Early Discharge (n=255)		Difference btw groups
Measures	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	p-value
Demographics									
Age (years)	323	20.7±3.3	161	21.9±3.0	22	22.5±2.6	255	21.3±3.3	<.001
Gender									0.021
Female	66	20%	53	33%	9	41%	59	23%	
Male	256	79%	106	66%	13	59%	195	77%	
Other	1	0%	2	1%	0	0%	1	0%	
Race									0.004
White (non-Hispanic)	105	33%	39	24%	1	5%	72	28%	
Black (non-Hispanic)	92	29%	68	42%	12	55%	91	36%	
Hispanic	94	29%	48	30%	7	32%	63	25%	
Other	32	10%	6	4%	2	9%	29	11%	
Insurance status									0.014
Uninsured	10	3%	10	6%	2	9%	24	9%	
Public	147	46%	84	52%	12	55%	126	49%	
Private	150	46%	60	37%	5	23%	95	37%	
Other	16	5%	7	4%	3	14%	10	4%	
Primary language									0.533
English	287	89%	147	91%	18	82%	227	89%	
Spanish	16	5%	7	4%	1	5%	16	6%	
Other	20	6%	7	4%	3	14%	11	4%	
Highest grade completed									0.050
<hs< td=""><td>102</td><td>32%</td><td>27</td><td>17%</td><td>3</td><td>14%</td><td>73</td><td>29%</td><td></td></hs<>	102	32%	27	17%	3	14%	73	29%	
HS or GED	61	19%	33	21%	5	23%	50	20%	
Some college	124	38%	80	50%	9	41%	99	39%	
College graduate	36	11%	21	13%	5	23%	33	13%	
Family and Support System									
Current family contact with client									<.001
Daily	299	93%	139	87%	16	73%	221	88%	
Weekly	19	6%	13	8%	2	9%	22	9%	
Monthly or less	4	1%	7	4%	4	18%	9	4%	
Lives with family									0.007
Parents	289	90%	129	80%	14	64%	198	78%	

	Grouped by Family Contact Pattern								
	Aŀ	ways (n=323)	М	ixed (n=161)	N	Never (n=22)	Ear	rly Discharge (n=255)	Difference btw groups
Measures	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	p-value
Other family (not parents)	14	4%	12	8%	3	14%	22	9%	
Alone	8	3%	9	6%	2	9%	19	8%	
Other	12	4%	11	7%	3	14%	16	6%	
Lives with anyone (% yes)	315	98%	152	94%	20	91%	236	93%	0.037
Has support person (% yes)	314	97%	144	89%	15	68%	234	92%	<.001
Homeless (% yes)	9	3%	14	9%	2	9%	21	8%	0.014
Clinical									
Ever hospitalized (% yes)	279	86%	143	89%	19	86%	210	82%	0.297
Number of prior hospitalizations	294	1.6±1.0	151	1.5±1.1	20	1.7±0.9	211	1.5±1.0	0.654
Current prescription for antipsychotics									0.009
Not medication adherent	42	13%	18	11%	4	18%	52	20%	
Medication adherent	233	72%	121	75%	14	64%	145	57%	
Not prescribed	19	6%	9	6%	2	9%	19	8%	
Unknown	29	9%	13	8%	2	9%	39	15%	
Time to 1st mental health contact (days) median (IQR)	321	25.0 (3.0– 92.0)	156	31.0 (0.0– 119.5)	22	20.0 (0.0– 70.0)	252	30.0 (4.5– 102.5)	0.419
Family involvement in initial pathways to care referral chains (% yes)	228	71%	98	61%	11	50%	175	69%	0.044
Any substance use (% yes)	178	55%	80	50%	14	64%	143	56%	0.467
Functioning									
GAF social functioning									0.096
< 40	37	12%	18	11%	1	5%	35	14%	
40–70	210	65%	108	67%	10	46%	151	60%	
>=70	76	24%	35	22%	11	50%	67	27%	
GAF occupational functioning									0.028
< 40	215	67%	105	65%	10	46%	168	66%	
40–70	89	28%	39	24%	7	32%	55	22%	
>=70	19	6%	17	11%	5	23%	30	12%	
GAF symptoms									0.018
< 40	277	86%	123	76%	17	77%	205	80%	
40–70	46	14%	37	23%	4	18%	45	18%	
>=70	0	0%	1	1%	1	5%	5	2%	

		Grouped by Family Contact Pattern										
	Al	ways (n=323)	М	ixed (n=161)	ľ	Never (n=22)	Ear	rly Discharge (n=255)	Difference btw groups			
Measures	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	N	% or Mean±SD	p-value			
Employment at admission (% yes)	39	12%	34	21%	6	27%	40	15.7%	0.029			

 ${}^{*}_{GAF}$ scores range from 0 to 100 with 100 representing better functioning

Table 3.

Client Family Involvement Preference by Family Contact Pattern

			Fa	mily Cont				
	Always		Μ	lixed	ľ	lever	Early Discharge	
Family Involvement Preference	n	row %	n	row %	n	row %	n	row %
No Involvement	8	18%	8	18%	7	16%	22	49%
Conditional Involvement	97	37%	64	24%	9	3%	96	36%
Unconditional Involvement	218	48%	89	20%	6	1%	137	30%
Total	323	42%	161	21%	22	3%	255	34%

 $\chi^2\!\!=\!\!48.15;\,df=6;\,p<0.001$