Family Empowerment Satisfaction Team
2008 Report
Young Adult Survey
Assessment of Support Services
In Montgomery County
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Background

The Family Empowerment Satisfaction Team (FEST) Montgomery County is an independent, non-profit advocacy program of the Family and Youth Division of the Mental Health Association of Southeastern Pennsylvania. FEST conducts surveys with Montgomery County families and youth who are receiving or recently received behavioral health services about their experiences - what worked and what can be improved.

FEST develops questionnaires and questions for interviews and focus groups with stakeholder involvement. These tools are used to survey and obtain family and youth feedback about accessibility, appropriateness and effectiveness of services as well as their satisfaction with county behavioral health services. After analyzing the data collected, FEST reports the findings to Montgomery County Behavioral Health and other stakeholders – providers, families, and youth - to provide family and youth input into the county’s quality improvement efforts. The goal is to help make behavioral health services more family and youth driven.

The FEST 2008 Young Adult Survey was developed to identify the support services available to young adults with behavioral health disorders in Montgomery County. The survey asks young adults for their perception of the assistance they need and their experience with services they receive. For this effort “young adults”, also referred to as “transition age youth”, were identified as individuals between the ages of 16 and 24. They are in a phase of life where they must take on challenges of adulthood that may include living independently of their families for the first time, forming new relationships with peers, leaving a structured environment of school, and taking on the demands of work or preparation for a career by attending college or another post-secondary learning experience prior to finding suitable employment. These changes are a part of “growing up” for all youth. However, the challenges can be even greater for individuals with behavioral health problems.

The young adult population with severe behavioral health needs is especially vulnerable during this transition period. Treatment and support services may not be available, appropriate for their needs, or easily accessible. The decline in use of behavioral health services is notable in 18 to 21 year-olds, coinciding with the typical cut-off from services received as a teen. Young adults are faced with navigating adult service options that are fragmented and complex. At age 18, individuals who received treatment for behavioral health challenges during childhood may no longer be eligible for publically funded services such as Medicaid and Social Security and may not meet admission criteria for independent living programs and vocational rehabilitation. Services provided through the schools end with graduation. Parents’ private insurance plans may no longer provide coverage for their children after age 18, unless they continue as full-time students.¹

In addition to the young adults who are transitioning out of services or losing insurance coverage, young adults who have never been diagnosed with a psychiatric illness may begin to suffer from the disabling effects of a serious mental illness. Research indicates that half of all lifetime cases of mental illness begin by age 14 and three quarters by age 24. Long delays often occur before individuals seek initial treatment for the illness.² Symptoms may have gone undiagnosed or misdiagnosed in the earlier teen years, but may become more severe as a young adult, at which time an individual may seek treatment. The symptoms of schizophrenia usually begin in late adolescence or early adulthood, and among mood disorders, one half of adults with clinical depression report an onset before age 20, while bipolar disorder typically develops late in adolescence or in early adulthood.³

In 2007, Montgomery County Behavioral Health established a Transition Age Task Force to examine whether the needs of young adults with behavioral health challenges were being met by existing services in

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Montgomery County. The Task Force concluded that young adults or individuals providing support for young adults should be surveyed to identify their perception of services and assistance they need. Members of the Task Force created and tested the original tool for the needs survey (further developed by FEST) and recommended that the county pursue this survey. Montgomery County Behavioral Health requested that FEST, which serves as an independent source for collecting and analyzing data, conduct the survey and report the findings to the county office, young adults and other stakeholders. FEST uses quantitative and qualitative methods and employs Appreciative Inquiry strategies. Appreciative Inquiry is a well-established approach to organizational change that identifies and builds upon what is working well. As with all FEST projects, all completed surveys remain confidential, and, in presenting the qualitative data derived from open-ended questions, all identifying information has been removed to protect confidentiality.

Objectives

1) The primary objective of this survey, as stated by the county office, was to obtain stakeholder input into gaps in services for young adults.

2) A 2nd objective was prompted by the county’s discovery that another county entity was developing a survey for this population. As this was seen as duplicative, the questions from the second questionnaire were incorporated into the existing Young Adult Survey.

To meet the first objective, FEST has preserved the integrity of the initial Young Adult Survey by treating it and the revisions as two individual surveys in the analysis and reporting of the data.

Procedures

Sample

Individuals of transition age (ages 16 -24) in Montgomery County who have received or are receiving behavioral health services or are self-identified as having behavioral health challenges

Two methods were employed to identify young adults for the sample in this effort
- Contacting young adults who had received or were receiving county behavioral health services
- Communicating through providers and organizations that serve transition-age individuals who meet the criteria

Development of Tool

- The Transition Age Task Force designed original tool with stakeholder input, tested it with young adults receiving case management, and incorporated feedback from young adults in revising tool
- FEST reviewed the survey after it was revised and recommended changes in the instructions that would make them easier to follow and improvements in the overall format of the tool
- FEST and Task Force further refined tool, and Task Force created flyer to distribute with survey

Methods

1) The county office provided FEST with database of 1314 names and addresses of young adults who were receiving or had received county behavioral health services, and FEST removed names with undeliverable addresses. FEST divided the updated database into two equal groups through random assignment. The first group of 598 surveys was mailed in July, 2008, and the remaining 597 were mailed in September 2008. The decision on two mailing was prompted by FEST’s concern that responses might be affected by summer activities.

2) FEST strategized with county representatives to create categories of providers/organizations for the county office to contact to aid with the distribution of surveys to sample the population not in database.

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– FEST and county staff identified Child Welfare, Substance Abuse, Educational Facilities, Healthcare Providers, Juvenile Probation, Mental Health Providers, Community-Based Organizations, Vocational/ Employment Assistance, Shelters, MR/Developmental Disabilities as service categories for the county to contact
– FEST coded surveys for each of these 10 categories for the purpose of data entry when completed surveys were mailed to FEST.

3) FEST mailed the initial 598 surveys along with the flyer, a Family and Youth Division brochure, and return envelope in July, 2008, and provided surveys with 10 category codes to the county office.

4) FEST revised the survey before the second mailing to accommodate a second county survey targeting the same transition age population. FEST mailed the remaining 597 surveys during September, 2008, and ended data collection in November 2008.

Results
All surveys, regardless of method of distribution, were returned to FEST via mail. Codes on surveys permitted identification of surveys mailed by FEST and those distributed through the county so data could be entered accordingly. A total N=73 completed surveys were returned, of those 50 were from the FEST mailings and 23 were from category “D”, Drug and Alcohol.

Of the 50 surveys returned from the combined FEST mailings, 24 surveys were from FEST’s September mailing which had been revised to include five interagency questions. No surveys with category codes were returned.

Demographics
The demographic information was provided on 63 or about 86% of the total number of surveys received.

a) What is your age?
The age distribution for 62 young adults in the survey is

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<tr>
<td><strong>Total</strong></td>
<td><strong>62</strong></td>
</tr>
</tbody>
</table>

b) What is your gender?
The gender of 63 respondents was almost equal.

Male - 30  48%  Female - 33  52%
c) In what town or township do you live?

<table>
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<tr>
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<th>Count</th>
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<td>Whitemarsh</td>
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<td>Douglasville Union</td>
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<tr>
<td>Willow Grove / Upper Moreland</td>
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</table>

d) Do you live with?

Young Adults (63) reported that they lived with:
- Family - 42 (67%)
- Friends - 4 (6%)
- Alone - 4 (6%)
- Homeless - 3 (5%)
- Other - 10 (16%)

e) Are you satisfied with this living situation?

87% of the 63 reported being satisfied or somewhat satisfied with their living situation.
- Yes - 39 (62%)
- No - 7 (11%)
- Somewhat - 16 (25%)
- No Response - 1 (2%)

2) Please complete this section if you are filling this out for a young adult

What is your relationship to the young adult for whom you are completing this questionnaire?

- Parent or caregiver of a young adult - 24 (89%)
- Provider of mental health services for a young adult - 0 (0%)
- Other person who gives support to a young adult - 3 (11%)
- Total - 27 (100%)

3) Each question begins with “Do you” if answered by a young adult or “Does the young adult you are filling this out for” if answered by an individual providing support to a young adult.
Table 1

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<th>D&amp;A</th>
<th>FEST</th>
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<th>All</th>
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Summary of Findings

In Table 1, 30% of all respondents reported they were receiving assistance for education while a greater number, 55%, said they were not. The number of Yes responses was similar throughout all questions with one notable exception. 55% of all answered Yes, when asked if they wanted assistance or more help in this area.

The data presented in Table 2 identifies that 12% of all respondents were receiving assistance for employment, while 68% were not. 48% answered Yes they want assistance or more help in this area. When
young adults were asked if they find it difficult getting the assistance needed, 44% of the FEST group responded Yes, while only 17% of the D&A group answered Yes.

In the qualitative results, few individuals identified education or employment as either additional supports they were receiving or another support that would improve the quality of life. In reference to education, one individual stated, “I am going to receive education by Cyber School since medical problems prevent me from going to school.”

The need for assistance with finding employment was often expressed in statements about individual circumstances that were creating barriers such as “Make it easier for felons to get jobs”, “Because of my bipolar disorder I have trouble finding work I would like more assistance finding work I can do where I don’t have to deal with a lot of people”.

Table 3

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Table 4

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Table 5
Transportation

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<th>find the assistance has been helpful</th>
<th>feel this assistance is meeting needs</th>
<th>make the choice to get this help</th>
<th>want assistance or more help in this area</th>
<th>find it difficult getting the assistance needed</th>
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<td>100% 100% 100%</td>
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Summary of Findings
In Table 3, 67% of the young adults surveyed said they were not receiving assistance for housing. When asked if they wanted assistance or more help in this area, 46% of the FEST group answered Yes and 42% said they found it difficult to get assistance. In comparison, only 22% of the D&A group reported needing assistance in this area. The data in Table 4 shows only 14% of all respondents receive assistance for skills to help them live independently. However 60% of the FEST respondents wanted assistance or more help. Only 35% of the D&A group said Yes. Table 5 shows that under 30% of all young adults surveyed reported receiving transportation assistance. 52% of the FEST group said they would like assistance or more help in this area, and 44% reported finding it difficult to get help. Only 17% of the D&A group responded that they would like assistance or more help.

Finding suitable housing emerged as an issue that a number of people thought would improve their quality of life. A few people simply wrote housing or “section 8”, others asked for specific types of housing support including “More intake residential housing for dual diagnosis that is not in West Philadelphia”, and housing concerns overlapping with gaining skills to live independently, such as “Needs more help with possible group home/or roommate in future to help with independent living”. Very few people gave information about transportation needs. However, one individual viewed receiving transportation as an additional support. A parent thought her child would benefit from taking the step to drive, reporting “Fears driving unable yet to get license - using bus”.

Table 6
Therapy

<table>
<thead>
<tr>
<th>THERAPY</th>
<th>receive any type of assistance for the following items</th>
<th>find the assistance has been helpful</th>
<th>feel this assistance is meeting needs</th>
<th>make the choice to get this help</th>
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Table 7
FEST Montgomery County
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9
Summary of Findings

In general, the data in all areas of health related needs, therapy (Table 6), drug and alcohol treatment (Table 7), and benefits (Table 8), demonstrates the high number of young adults who are receiving assistance and/or want additional assistance or help in this area. The findings show 55% of all young adults in this survey receive assistance in the area of therapy; and close to 50% find the assistance helpful, feel it is meeting needs, and make the choice to get this help. Almost half of the FEST group indicated wanting assistance or more help in this area, while significantly fewer, 17%, of responders from the D&A group indicated Yes.

Naturally one would expect a high rate of drug and alcohol related assistance in the D&A group. 65% answered Yes to receiving assistance, 65% find the assistance has been helpful, 78% feel this assistance is meeting their needs, and 52% report making the choice to get this help. 35% said they need assistance or more help in this area. It is notable in reviewing the data, that, when asked if they were receiving assistance in this area, 30% of D&A group answered No or Doesn’t apply. Among young adults in the FEST group, only 14% reported receiving assistance in this area.
The data in Table 8, benefits for disabilities, reveals 74% of the FEST respondents receive assistance in this area, and, although not as high, 43% of the D&A group reported getting assistance in this area. 72% of the FEST group has found the assistance helpful, which is 40% higher than those responding Yes in the D&A group. The gap between the two groups decreases when asked if they want assistance or more help in this area. 43% of D&A group and 56% of the FEST group responded Yes.

Many young adults or their supporters addressed health concerns when answering the open-ended questions. Some of the additional supports listed were “I use AA as a support”, “I attend Narcotics Anonymous Daily (by choice)”, “Psychiatric help”, “Visual impairment services & Developmental disabled services”, “Wrap-around behavioral specialist rehabilitative help”. In the health related category there was a lengthy list of additional supports that were needed. Examples include “My Medical Assistance ran out and I still very much need it”, “Outpatient Drug & Alcohol counseling, Medical Assistance”, “Better pool of psychiatrists/psychologists that accept Medicaid. We go out of network & pay privately to ensure continuity of care”. “She needs motor skills, physical & Occupational Therapy, help with independence” and “Inability to see specialist/experts not covered by insurance” are examples of other issues addressed. In addition to medical assistance, individuals reported needing assistance in obtaining benefits such as cash assistance and food stamps.

### Summary of Findings

When asked if they received any type of assistance for Social/Community needs, over 50% of all respondents reported No and 25% answered Yes. The individuals responding to the survey mailed by FEST expressed a greater desire than the D&A group for assistance or more help in meeting their social needs, with 50% of the FEST group saying Yes compared to only 22% of the D&A group answering Yes. The data also shows a divergence in their responses concerning the difficulty getting the assistance needed. 40% of the FEST group responded Yes while only 13% of the D&A agreed.

Several parents of transition-age youth provided examples of programs that served as additional social supports including “New Horizons - privately funded social support group” and “Trail Guides – Social”. Other social supports that respondents thought would improve the quality of life were “social group-social opportunities” and “Young Adult activities, trips, get-togethers”. One young adult suggested, “More youth oriented support group type meetings, for socializing/community involvement - that is a positive force.”
Table 10
Other

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Summary of Findings

As shown in Table 10, little quantitative data was reported concerning “Other” assistance needed or received. (perhaps because respondent not understanding what was being asked).

Although a few of the needs of two self-identified groups have been noted elsewhere, the qualitative results show young adults who are facing the additional challenges of a new family/domicile life or prison convictions could require “Other” help or additional support to address the complexity of their needs. Other assistance needs related to a new family/domicile life includes assistance with pregnancy or childcare and “Domestic Violence counseling”. Comments such as “Being on probation I need housing and financial aid” and “Prison – work, housing, Medical assistance” reiterated needs related to having been in prison.

Discussion

The multitude of changes young adults face as they make the transition from youth to adulthood may appear daunting at times. For individuals already challenged by behavioral health difficulties, the demands can become overwhelming. With the new freedom and independence, welcomed by some youth, comes the responsibility of self-sufficiency. Living with parents or other caregivers and family, attending school, and having basic needs met provide structure during childhood and adolescence. Just as these support systems diminish, the young adult is confronted with difficult decisions about employment or continuing education, housing, forming new social relationships and choices of companionship. Depending on the nature and severity of the behavioral health illness or disability, youth may have experienced an interruption in their education or delay in their maturation, creating an even greater disadvantage. Other issues such as the loss of treatment through behavioral health services for youth, the change in eligibility criteria for Medicaid services, or loss of parents’ private insurance coverage may impact their ability to receive help for ongoing problems.

The need for assistance for these transition-age youth is evident when looking at the number of issues they are facing in addition to their behavioral health challenges. The Young Adult Survey covered the major areas in which individuals are most likely to need help. The primary objective of this survey was to solicit stakeholder input into gaps in services in Montgomery County for those transition-age youth needing assistance in taking on the responsibilities and challenges of young adulthood. The intention of this undertaking was to be inclusive of all young adults who have challenges that fall within the broad spectrum of behavioral health. When interpreting the results, the diversity of this population must be taken into

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consideration as well as the likelihood that certain segments of the population were not adequately represented among the participants. Individuals who had received or were receiving county behavioral health services were mailed surveys by FEST. Originally ten categories of provider/organizations were identified as likely to reach a cross-section of young adults, including those who may have had a recent onset of a major psychiatric illness or never received treatment for an illness. Of these providers/organizations, completed surveys were limited to providers of treatment for substance abuse.

In reviewing the results, several observations warrant discussion and most likely are indicative of the general population of young adults with behavioral health challenges. In several areas of assistance, notable differences exist between young adults who completed their own surveys and the surveys completed by a person supporting a young adult. Young adults identified more needs in the areas of employment, education and better housing options. Supporters of young adults, primarily parents, focused on a long-term transition to living independently, reporting needs for assisted living and more opportunities for social interactions. (One exception involved several parents who completed surveys for children in prison or otherwise unavailable)

When reviewing the parent responses to the open-ended question about improving the young adult’s quality of life, answers included “Things that he finds fulfilling to occupy his very empty days, evens, weekends”, and activities including trips, get-togethers and dances. To move toward independent living parents expressed the need for situations such as “More intake residential housing for dual diagnosis that is not in West Philadelphia” and “supported/assisted community housing.”

On the other hand, respondents need for assistance converged in the areas that were health related, including medical needs. Almost half of the survey respondents reported receiving assistance in therapy and felt it was helpful. Over half of the individuals responding to the FEST mailings wanted more assistance in this area. The majority of individuals completing surveys through substance abuse providers did not want more help in therapy; however this might be explained by the fact that they were also receiving assistance in the area of drug/alcohol abuse. The other area included in the general category of health-related assistance included benefits such as insurance and SSI. The majority of participants responded that they received assistance in this area, found it helpful and was meeting needs. However the majority also wanted more help or assistance in applying for benefits. These findings for the perceived need for assistance and more help in health-related services were confirmed in the quantity of answers to the open-ended questions that were related to this topic.

Concerns included the financial aspects of care, insurance problems and the need for better quality of care. One individual summed up the issues in the statement

“More consistency in care - Family base, case management, therapist, psychiatrist - people change frequently,
Medication management - when making med changes especially during crisis - drs seem afraid to make changes because patient is told they have to leave hospital due to insurance. Plus seeing a psychiatrist once a month for 10 minutes doesn't work for patients who have complex medication regimen & too expensive to continue with dr's outside of insurance. Inability to see specialist/experts not covered by insurance.”

Two special concerns that were not specifically addressed in the survey were assigned to question in the survey grid, “Other”. Both young adults and parents of young adults had reported a variety of needs related to issues of young parents and prison convictions. Although some of the needs were reported in other survey questions, the context of the situation was not visible. However, when reviewing the qualitative data, the young adults linked the assistance needed to their situations. The following responses serve as examples for young adults with parenting roles: “Having sitter so can start looking for work”, “Helping with parenting”,” Baby help cause I pregnant”, and “I would like to receive Rental assistance, but that is harder to get w/o my daughter w/me. It's a catch 22, she's not w/me b/c I don't have a place, but I don't have a place b/c she's not w/me”.

Assistance related to prison issues included “Being on probation I need housing and financial aid” and “Make it easier for felons to get jobs”. Several parents responded for their young adult children with frustration in finding assistance as in the following. “Until NAME* was put in prison, he was part of the Mental Health

* The individual’s name was replaced with NAME to insure confidentiality

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System in Montgomery Co. since the age of 6. Because of his imprisonment he has lost all of his Medical Assistance rights. NAME has no place to live, except bringing him home. This is less than satisfactory situation for all involved. I am mailing this back to you, but will be calling the numbers listed on the green brochure \(^6\) to get help. This mailing came just in time! Thank you”.

In conclusion, the survey results identify services related to health concerns, both behavioral and medical, as the area where the greatest amount of assistance is being received and where additional help is needed by the young adults participating in this survey. Because behavioral health encompasses a very diverse group of needs, other areas of assistance appeared more important to individuals with certain types of behavioral health disabilities. These observations were made through a combination of reviewing results from All respondents and the breakdown of D&A and FEST survey data, and supplementing these quantitative results with qualitative data. Not only does the diversity of behavioral health challenges within the sample create difficulty in determining more specific areas of need, but also raises the question of the wide variation of the type of assistance desired within the sub-groups. It’s recommended that the diversity of the population and any groups of young adults who may not be represented in the survey receive greater consideration in future studies.

The second area of discussion, the special circumstances surrounding a new family/domestic life or a prison conviction, may warrant additional consideration in areas of assistance in terms of support services. It appears that these areas in themselves have a set of needs that could require additional and well coordinated support. It is encouraging to note, however, that the survey itself may have provided some hope to individuals struggling to find assistance to help them with challenges that may seem insurmountable, as noted in several responses written on the surveys. Through the brochure of services from FEST, one parent that we are aware of became aware of an existing service available in Montgomery County and made contact with PIN (Parents Involved Network) and then was directed to a service for assistance with her son. Perhaps the most important recommendation is to continue to follow through with the larger project of identifying all types of assistance already available to transition-age youth and to provide additional assistance to young adults with behavioral health challenges through creating ways to “fill in the gaps”.
References


3. Active Minds Mental Health Fact Sheets
2647 Connecticut Ave, NW Suite 200 Washington, DC 20008 (202) 332-9595
<www.activeminds.org>


6. Family & Youth Support and Advocacy Division of the Mental Health Association of Southeastern Pennsylvania, Program Brochure, Revised 09/26/2007.