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CHILD/ADOLESCENT SERVICES FOCUS GROUPS SUMMARY REPORT

Prepared for DMH Unified Behavioral Health Planning Process

EXECUTIVE SUMMARY

- Youth, youth in transition and parents had unique perspectives on the adolescent mental health system, but had a number of similar ideas about how the mental health system needs to change in order to better address their needs.
- Parents and youth wanted a consumer/family-driven service system, which would provide families with accurate information about available services, more help and involvement in coordinating care, and more opportunities for social and peer support. This kind of system would also have less restrictive eligibility and fewer program rules.
- Families wanted more opportunities for “supported normalization,” including social activities for the child and the whole family, preparation for independent living and adulthood, and specialized education.
- Although parents and youth have a desire to do the same things as their peers, they both seemed to prefer specialized activities and schools for the individualized attention and avoidance of stress. Mainstream settings were often a challenge because children struggle with peer ostracism and bullying, parents deal with disruptions (due to a child’s symptoms) that can visibly upset other people/parents, and staff at programs and schools are unfamiliar with their needs.

INTRODUCTION

The Massachusetts Department of Mental Health (DMH) contracted with CQI to conduct a series of focus groups with mental health consumers and family members across the state to inform their Unified Behavioral Health planning process.

This report presents common themes that arose across seven focus groups held with youth, young adults who had transitioned from child system to the adult system (“youth

in transition”), and parents of youth about the child/adolescent mental health system. All participants in these focus groups were asked to reflect on their experiences in the child/adolescent mental health system, and to focus in one or more specific topics such as normalization, coordination of care, person-centeredness, service gaps, and supports for parents.

Youth, youth in transition and parents of youth view the mental health services from their unique vantage points.

Youth talked about the mental health services in terms of their *day-to-day experiences* in programs and their struggles to develop as teenagers while dealing with a serious emotional disturbance or mental illness.

Youth in transition could look back and think about the ways the mental health services could have addressed their needs to be prepared for adulthood. They gave a retrospective view of what worked and did not work for them.

Parents, on the other hand, were struggling to get their child’s and family’s needs met by a complicated, and often fragmented system. They could identify gaps in the system and pinpoint ways the system worked for and against them, as they tried to get their child’s complex needs addressed.

While each group’s view of the system was unique, several themes cut across the groups. Together, their perspectives provide an overview of critical areas of need in the child/adolescent mental health system.

FOCUS GROUP PARTICIPANTS

Two focus groups were held with youth/adolescents, and included twenty-three (23) adolescents aged 14-18 from Boston and Lawrence. The majority of the youth lived in or had lived in a residential program and also had experienced a psychiatric hospitalization. Two focus groups were held with youth in transition, and included sixteen (16) youth aged 18-29. Three focus groups were held with parents of youth, and included twenty-nine (29) participants. Parents had biological, adoptive or foster children, ranging in age from 4-19 years, with a variety of emotional, mental health and/or development disorders. Parents said their children lived with one or more chronic and serious condition, such as Asperger’s/Autism, ADD/ADHD, bipolar disorder, or oppositional defiance disorder. These conditions greatly impacted the child’s and family’s daily functioning.

COMMON THEMES

Themes fell into three categories: consumer-driven care, normalization, and programs and services.

Consumer-Driven Care

Parents and youth wanted services to be more consumer-oriented. They needed more information about their care options and the system, more help with coordination, fewer arbitrary rules, and more opportunities for social and peer support.

Information. Parents and youth wanted to be better informed of available resources so they could access appropriate services and be informed consumers. Both parents and youth in transition said that they received little information from state agencies (i.e., DMH, DSS, DMR) about these resources. Several young adults said that DMH had provided them with information but did not inform them of exactly what services a program could or would provide. They felt that sometimes or often the information was inaccurate. Parents said DMH often provided them with lists of programs, but when they called they found that programs were frequently full or unavailable. It was clearly frustrating for the youth and parents to not be able to take control of their situation because of a lack of information.

Coordination of care. Parents found that state agencies do not work in a coordinated fashion to meet their complex needs. Since youth often had multiple needs and diagnoses, parents were not sure which agency to approach for help; several found that when they did approach an agency, they would be told they were not eligible for services, but were then not connected to the appropriate agency or provider.

Most parents said state agencies never treated them with the attitude, “How can we help you?” State agencies need to improve the application process so it is consumer-friendly, as well as to help with parents to figure out the available services that are appropriate for their family. One parent described how she wished DMH would work with consumers to identify services:

“I have a dream that it would be like Citizen’s Bank. I would walk in and they would say, ‘What can we do to help?’ They would have a menu of services and we would sit down and talk about what would best meet my needs.”

Parents and youth also needed more help from DMH in coordinating their care. Parents often did not feel they got that help because DMH case managers often dealt with eligibility and referrals rather than comprehensive service planning with the family. Youth in transition said case managers were helpful for coordinating services, but they wanted more information about what case managers do and how DMH is set up.

Wraparound or holistic programs, such the federally-mandated Early Intervention program for youth with or at risk for a disability, were cited as helpful models that promote coordination. Parents said longer-term supports were most beneficial.

Overemphasis on strict and/or arbitrary rules. Youth, youth in transition, and parents all said the mental health system has an over reliance on strict and arbitrary rules. Parents said eligibility rules were often inflexible and therefore blind to their child's actual needs and to whether a program would benefit them.

Overly strict and inflexible rules also inhibited youth development because they often failed take into account the youth's or family's individualized needs. Youth said they understood the need for rules related to their safety, but said many other rules seemed unnecessarily punitive.

At times, rules interfered with normal psychosocial development. Youth were very concerned about not being able to make and keep friends, and rules often prevented them from having ongoing friendships. For instance, youth often could talk on the phone only with people on their official call list, which might not include their friends. Also, they were not allowed to keep in contact with friends they made in programs once they moved on to another program. Overall, youth preferred programs that were less rule-oriented, which helped them develop their growing need for independence and personal decision making.

Youth in transition echoed this concern, saying that adolescent programs were overly structured and rule-oriented which inhibited their development into young adults. Programs need to focus on individuals, rather than relying on blanket policies or rules.

Peer and social support. Both youth and parents emphasized that support from their peers helped them to deal with the struggles of living a serious emotional disturbance or mental illness. Youth said they appreciated the support of other youth at their programs, who had gone through similar experiences. One youth said, *"It made me realize I'm not alone, that there are people like me who are going through similar things."* Youth regretted not being able to maintain those supportive relationships as they or others moved through the system. Many were had strained relationships with peers and family members from home, and they felt that programs allowed them the first opportunity to have supportive relationships with peers. Youth said that therapeutic as well as recreational groups were very helpful, and allowed them to get much needed peer support.

Youth in transition said that support groups with peers, where they could get feedback from those with similar experiences, were often more helpful to them than individual therapy. They also had a desire for more peer counselors.

Parents said that peer advocates helped them to identify programs and services that were both available and a good match for their child. Some peer advocates also accompanied parents to meetings with providers as a source of support or advocacy. Other parents often had the most up-to-date information on what services were available. Parent support groups were also very helpful for information, empathy, and problem-solving.

Peer support and opportunities to socialize with others who have had similar experiences are both important coping mechanisms for youth and parents.

Supported Normalization

Parents and youth wanted to access activities that promoted youth development and normalization, such as social activities, vocational programs, and school/educational opportunities. Often these programs were difficult for them to access because of the symptoms of the child. Parents and youth wanted to fully participate in normalizing activities, but in a supported environment where staff understood and addressed their unique needs.

Social activities. Parents and youth were interested in more opportunities for activities that ‘normal’ kids get to do, such as outdoor activities, camp, games, trips to the beach, bowling, and parties. Parents felt that activities were best when well-trained clinical staff were present.

Although youth, youth in transition, and parents wanted to be integrated in the community, they felt that specialized programs best met their needs. Youth became involved in the mental health system because they were not able to fully participate in mainstream activities. Programs should provide opportunities for integration, while recognizing that integration needs are different for each child.

Preparation for independent living/adulthood. Parents and youth in transition said they needed programs to help youth develop skills for living independently as adults. Parents and youth said vocational programs were needed. Youth wanted opportunities to make money, and parents wanted them to develop skills for independent living so they could succeed as adults.

Youth in transition said that adolescent programs that are overly structured did not adequately prepare them for adulthood. The transition from highly structured to much less structure as young adults made the adjustment to adulthood particularly difficult. Programs for adolescents should help youth develop decision making and independent living skills.

Specialized education. Youth and parents seem to prefer specialized schools, as public schools often did not meet their needs. For some youth, the stigma they faced at school was overwhelming. Children faced ostracism and bullying from peers. In addition, school staff lacked an understanding of serious emotional problems, and did not provide enough individual attention. At specialized schools, youth could get the individual attention and support they needed to succeed. One youth said, “*The smaller alternative schools are better. There’s more support and focus on you.*” Youth and parents felt that families know what setting will work best for them, and want to have that choice.

Parents also said that children often needed specialized afterschool programs, which provided the necessary structure that working or tired parents wanted. Local afterschool

programs often did not work for them, as they were difficult or impossible to access since parents worked and could not transport the child back to their hometown right after school.

Programs and Services

Staff sensitivity and understanding. Parents and youth discussed instances in which they were treated disrespectfully by providers or DMH staff. They felt staff need more training in how to respect and support families (but not blame or control). Some parents and children felt that some providers sent them the message that they were “bad parents” or “bad kids.” They felt some staff quickly formed negative opinions or judgments about them, which was unhelpful while they were seeking support. One youth said, “*The [hospital] staff treated you normally, but here [at the group home] they think you’re bad kids.*”

Staff, particularly support staff at housing programs, need to be better trained on the appropriate techniques for working with children with various diagnoses. For instance, a child who has ADD might respond differently to stimulation than a child with bipolar disorder or autism. Staff need to be sensitive to the fact that certain techniques work better with some kids than others, depending on their unique diagnosis, history, and preferences. Staff should reach out to parents and children to better understand what works for each child.

Staff also need to be more sensitive when working with parents and child in crisis. This is a critical time for families and they deserve to be treated with courtesy and support by their providers.

Additional critical areas of support. Parent, youth, and youth in transition had several critical areas, unique to each group, where they needed more support.

- Parents wanted additional respite, expanded programming for children under age seven, and substance abuse programming for adolescents. Parents also said mentoring was particularly helpful when all children in the family had a mentor.
- Youth in transition cited a need for more specialized housing for their age group.
- Youth said they wanted more social and physical activities, as well as opportunities to develop friendships inside and outside of programs.

DISCUSSION

Parents and youth face many challenges. Dealing with a serious behavioral or mental health issue and learning to navigate the system is very difficult for families. Ideally, system access and navigation should be a seamless process both to reduce stress on families and to have their needs addressed in a timely fashion.

Fundamentally, youth and family want to be acknowledged on an individual level and have their concerns taken seriously. As such their needs and desires should drive all aspects of the child/adolescent behavioral health system.