ntac
National Technical
Assistance Center
for State Mental Health Planning

Service Systems Supports During the Transition from Adolescence to Adulthood: Parent Perspectives

June 2002

Prepared by:
Maryann Davis, Ph.D.
Marian Butler

Prepared for:
National Technical Assistance Center
for State Mental Health Planning (NTAC)

Table of Contents

List of Tables and Figures

Tables

Figures

Preface

This report marks another important step in the ongoing efforts of the National Technical Assistance Center for State Mental Health Planning (NTAC) to focus attention on the need to improve and expand services and supports for young people with serious emotional disturbances who are making the transition from adolescence to adulthood. With funding from the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration, the National Association of State Mental Health Program Directors (NASMHPD) convened a National Experts Meeting on this topic in June 2000 in Washington D.C. The meeting brought together family members, youth and experts in the field of transition to discuss and assess the status of progress in developing effective, comprehensive transition programs in public mental health systems. The event resulted in the drafting of an initial report, *Developing Partnerships for Youth with Serious Emotional Disturbances in Transition to Adulthood* (National Association of State Mental Health Program Directors, 2001).

Meeting participants agreed that there was a need to learn more about the status of transition initiatives across the country and a need to identify both the factors that support the improvement and expansion of transition services, as well as those factors that serve as barriers to progress in this area. To accomplish these goals, NTAC collaborated with the Center for Mental Health Services Research (CMHSR) of the University of Massachusetts Medical School to implement a CMHS-funded survey of members of NASMHPD's Children, Youth and Families Division. The resulting report, *State Efforts To Expand Transition Supports for Adolescents Receiving Public Mental Health Services* (National Association of State Mental Health Program Directors, 2001), described and assessed the information gleaned from interviews and provided a new stepping stone in efforts to ensure that youths with serious emotional disturbances have access to effective and comprehensive transition services and supports.

NTAC continued its collaboration with CMHSR and funded a national survey of members of the Federation of Families for Children's Mental Health on the transition of children from adolescence to adulthood - from the parent's perspective. This report, *Service Systems Supports During the Transition from Adolescence to Adulthood: Parent Perspectives*, describes how parents feel about the quality of transition supports their child receives from various service systems, barriers to services, other system components they thought were important, and policy considerations.

Acknowledgments

Rebecca G. Crocker, NTAC's media/meeting coordinator, for her design, layout and production oversight.

We believe that readers will find this report to be both informative and inspiring. We hope that it will contribute to the growing knowledge base about transition, as well as to efforts to improve and expand transition services in public mental health systems across the country.

—Kevin Ann Huckshorn, R.N., M.S.N., I.C.A.D.C. Director
NASMHPD Office of Technical Assistance

Executive Summary

The Center for Mental Health Services Research (CMHSR) at the University of Massachusetts Medical School and the National Technical Assistance Center (NTAC) of the National Association of State Mental Health Program Directors (NASMHPD) funded a national survey of members of the Federation of Families for Children's Mental Health on the topic of the transition of children with severe emotional or behavioral difficulties (SED) from adolescence to adulthood. The survey, circulated nationally to parents of youth ages 16–25 with SED, asked parents about the quality of transition support their child had received from various service systems, barriers to services, system components they thought were important and policy considerations. The following is a summary of the findings of the survey.

Service Systems Supports During the Transition Period

- The transition from adolescence to adulthood is a major struggle for families of children with SED.

- Few parents found service systems to be helpful during this transition.

Child Systems

Parents were asked to rate the quality of various child-serving systems on items that focus groups had identified as important to help parents and their child during the transition period.

- They rated only child vocational rehabilitation services as helpful on most transition-related issues.

- Overall, they rated child vocational rehabilitation services higher than mental health, education, special education, child welfare and juvenile justice services.

- Parents of youth under age 18 reported that none of their children had accessed vocational rehabilitation services, thus the positive rating comes from parents of older youth.

- They rated child mental health and special education services neither good nor bad on most transition-related issues, but poor on preparing adolescents to function as adults.

- Overall, they gave negative ratings to regular education, child welfare, and juvenile justice.

- They rated all child-serving agencies as poor in helping to prepare youth for impending insurance/entitlement changes.

- They rated all child-serving systems except vocational rehabilitation inadequate in preparing youth for independent living and employment.

- The age, gender, and racial background of youth influenced ratings of mental health and special education services.

    1. Parents of 18-20 year-olds rated mental health services lower and parents of those under 18 rated mental health services higher than parents of those over 20.

    2. Parents of youth under 20 rated special education higher than parents of youth over 20.

    3. Parents of young women rated mental health services higher than parents of young men.

    4. Parents of African American youth rated mental health services higher than parents of Caucasian youth.

Adult Systems

Parents were asked to rate various adult-serving systems (defined as services provided to those over age 18) on the same issues.

- They rated the adult mental health system lower overall than the children's mental health system.

- They rated the adult vocational rehabilitation system lower than the adolescent rehabilitation system. Surprisingly, they did not rate vocational services positively, even for helping youth to prepare for employment.

- They rated colleges quite positively.

- The few parents who rated the substance abuse system tended to rate it as helpful.

- Generally, the age, gender, and racial background of the youths did not affect their parents' ratings of adult systems.

Barriers to Services

Parents were asked to rate the barriers they or their children encountered in accessing services.

- The most common barrier to services is simply the stigma young people feel in accessing services that could label them as mentally ill.

- Services typically did not address issues that are relevant to young people, such as getting a job or finding a place to live.

- Services did not sufficiently or appropriately include parents.

- Lack of information on available services or resources commonly caused frustration for parents.

- The degree to which participants perceived barriers to services varied greatly depending on the age, gender, and racial background of the youth.

  1. Many parents of the oldest youths (21 and over) reported that services served much older clients than their child and that the services were too rigid.

  2. Parents of boys reported insufficient information as a barrier more often than did parents of girls.

  3. Parents of Caucasian and Latino youth more often reported stigma as a barrier than did parents of African American youth.

  4. More parents of African American youth than parents of other youth reported that services served clients with more severe mental illness than their child had.

Important Service Components

Parents were asked to rate the relative importance of a number of service components that are specifically related to transition or that were mentioned by focus groups.

- They rated all service components, on average, as "important."

- They rated vocational and independent living preparation or assistance, along with affordable housing, as the most important components.

- They consistently rated support/advocacy groups and opportunities to shape services as more important for their children than for themselves.

- They considered receiving information about services and resources a high priority.

- Their ratings of the importance of various system components varied greatly by the age, gender, and racial background of their child.

  1. Parents of older youth (18 and older) were more interested in advocacy groups for both parents and youth, a single system covering ages 16–25, and transportation assistance.

2. Parents of girls were more interested than parents of boys in supported housing and less interested in positive peer support forums and a single system covering ages 16–25.

3. Parents of youth of different racial backgrounds sometimes rated the importance of various components differently, indicating that effective transition supports should reflect these kinds of differences.

Important Service Policy Considerations

Parents were asked to rate the importance of various policy considerations regarding services during the transition stage.

- They gave all policy considerations an average rating of at least "important."

- They rated including parents as much as possible in services for their children in transition as "most important."

- They rated policies that minimize out-of-home placements "second most important."

- They rated eliminating barriers to accessing adult services "third most important."

- With few exceptions, parents of youth of different ages, genders, and racial background rated the importance of these policy considerations similarly.

Conclusions

Parents of youth with SED need systems to be more useful in helping their children make the difficult transition from adolescence to adulthood. Parents felt that all child and adult systems needed particular improvement in helping young people prepare for the tasks of adulthood: living independently, working, and supporting themselves. Systems that focused on these tasks received higher ratings, and service components that reflected these concrete tasks were rated as most important. These systems and service components need to be made more available and should be given the highest priority in future system planning for youth ages 16-25. There is also a great need, by parents and their children, for improved information about resources and system changes as the child matures into adulthood.

In order for systems to be more effective and useful, parents, youth, and professionals from the various child- and adult-serving systems need to work *together* to create more effective service systems. This should occur at every level: policy, program development, oversight, and treatment. At the treatment level, parents must be part of the treatment planning process when the youth believes them to be an essential part of the team.

While there may be legal complexities to parental involvement in an adult child's treatment, it is clearly necessary to include parents as much as possible and for their participation to be considered important to the child's well-being.

Parents' perspectives often differed in important ways depending on the age, gender, and racial background of their child. Changes in service systems should take these differences into account.

The issue of stigma is a particular barrier among this age group. Adolescents and young adults generally want nothing more than to blend in with, and be admired by, their peers; thus, the degree to which SED remains stigmatizing is often the major factor that keeps young people from accessing potentially helpful services. Adults who work with these young people must do whatever they can to reduce the stigma of having a serious emotional disturbance and should structure services that help young people blend in as much as possible.

In addition, according to the characteristics of those who participated in this survey (see the "Who Responded to the Survey?" section in this report), the survey represents a culturally and geographically diverse population representing a variety of ages. However, several factors within the survey responses indicate the participants may be from predominantly middle or upper class backgrounds. While there may be a relative lack of socioeconomic diversity represented here, the report clearly shows that these families are struggling with the existing mental health support systems during the transition period. It is reasonable to believe that families who have fewer socioeconomic resources are struggling even more.

Recommendations

Based on these findings, administrators, policy makers and providers of services to families of children with SED who are making the transition to adulthood should consider implementing the following recommendations:

- make the improvement of transition supports a high priority that results in both human and fiscal resources being dedicated to its improvement;

- provide sufficient support and leadership to result in action;

- include all relevant child- and adult-serving agencies in these efforts;

- review practices and policies related to transition supports that are helpful to or hinder youth and families;

- involve parents and youth in all levels of the system for discussion and action concerning transition supports to ensure that the voices of youth and family members are incorporated into policies and service models;

- evaluate the degree to which services prepare youth for adult functioning;

- provide appropriate transition-specific training and ongoing support to individuals working with youth and families so they can be sources of information and effective advocates for the individuals they are working with;

- provide information to youth and families on system capabilities, benefits and functions;

- provide youth and families with the necessary information to navigate between the child serving agencies and the adult serving agencies, and the gaps and barriers between these two systems;

- create an anti-stigma campaign to reduce the stigma of mental illness; and

- continue to research parents' perspectives of the impact of service systems on helping youth in transition, with a special emphasis on obtaining feedback from lower-income families.

Introduction

During the past several years, interest has grown in helping adolescents with serious emotional disturbance (SED) make the transition to adulthood. Longitudinal studies have provided ample evidence that, in general, adolescents served by mental health systems or in special education fare poorly in the tasks of young adulthood (reviewed in Davis & Vander Stoep, 1997). Studies that have looked at service utilization after youth "age out" of children's systems indicate that few of these youths have access to continuing services, even though they may want them (Evans et al., 1996; Greenbaum, 2000; Silver, 1995). Many young people and their parents report that services that could support the transition into adulthood are either not available or are not appealing (Adams, Nolte, & Schalansky, 2000; Davis & Vander Stoep, 1996).

In 1993, Clark, Unger, and Stewart reviewed the characteristics shared by successful programs that serve this group. In 2000, Clark, Deschenes, and Jones developed system-of-care values that can be used to create effective programs. Testimonials of young people from these types of programs are impressive and indicate that good programming can work with this age group (Clark & Davis, 2000).

Taken together, these studies suggest that (1) many youth with SED need help making the transition into adulthood, and (2) researchers have delineated the kinds of programs that appeal to this group and that seem to work, but (3) significant barriers exist to access quality programs. Also, while young people have communicated about their experience of moving from adolescence to young adulthood, including the role of services in that transition, much less is known about their parents' perspective on the process (Adams, Nolte, & Schalansky, 2000; Davis & Vander Stoep, 1996).

The Child and Family Branch of the Center for Mental Health Services (CMHS) and the National Technical Assistance Center (NTAC) of the National Association of State Mental Health Program Directors (NASMHPD) felt that there was enough interest in this topic to hold a consensus meeting in June 2000. This meeting brought together families, youth, and experts in the field of transition, as well as representatives from federal agencies (NASMHPD, 2000). On the basis of testimonials from youth and families and studies of the transitioning population, the group concluded that there was cause for concern. The consensus was that youth with SED in transition are at great risk for ineffective functioning as adults and that appropriate and appealing supports, and the coordination of such supports, are virtually nonexistent. A few states did report significant progress in addressing these needs, although they noted that these were just beginning steps.

The meeting highlighted the need to formulate an accurate picture of what families experience when children with SED who have used public mental health services make the transition from adolescence to young adulthood. In spring 2001, CMHS and NTAC funded a national survey of members of the Federation of Families for Children's Mental Health to obtain a broad and systematic impression of youths' and families' experience in this situation. This report describes the survey and summarizes its findings.

Development of the Survey

Maryann Davis, Ph.D., of the Center for Mental Health Services Research at the University of Massachusetts Medical School, held three focus groups with parents of transition-age youth with emotional or behavioral difficulties to identify the topics to be covered in the survey and refine the wording of the survey questions (see Appendix A). Two focus groups were held at the Building on Family Strengths Conference 2000, convened by the Research and Training Center on Family Support and Children's Mental Health at Portland State University in Oregon. The groups identified topics of interest and established priorities. On the basis of this information, Dr. Davis drafted the survey instrument. A third parent focus group took place in the Worcester, MA area to refine the wording of the questions.

The survey consisted of the following five sections:

- basic characteristics of respondents and the child they reported on;
- experiences of respondents with their child in child and adult services, including:
    1. which services they had used, and
    2. ratings of the helpfulness of the various services on specific transition-related issues;
- barriers respondents or their child had experienced;
- service components respondents thought were important for transition support; and
- policy considerations that respondents thought were important.

Procedure

Families First of Alexandria, a chapter of the Federation of Families for Children's Mental Health, conducted the survey. Families First of Alexandria mailed surveys to Federation chapters in 25 states and the District of Columbia (see Figure 1). The states were chosen, using Healthy Children 2000 data, to represent a diversity in child-health-related characteristics including: infant mortality rate, teenage pregnancy rate, and overall rating of child health. In addition, the choices reflected two (Connecticut and Idaho) of the four states that have consolidated children's agencies (Rhode Island and Delaware are the other two) in which child mental health services are housed with other child-serving agencies, such as child welfare.

Families First of Alexandria contacted two Federation chapters in each state, and each chapter received 25 surveys. The chapters were asked to circulate the surveys to member families known to have a transition-age child. Two letters, one from the local Federation chapter and one from Families First of Alexandria and Dr. Davis accompanied each survey. Participants were to receive $10 for completing and returning the survey to the local chapter. Completed surveys were then forwarded to Families First of Alexandria for reimbursement. Families First of Alexandria mailed out 1,000 surveys; respondents returned 70 surveys, conservatively a 7 percent response rate.

To obtain an accurate return rate, researchers contacted all the Federation chapters that had received surveys. They asked how many surveys they had distributed and how many had

been returned to them. Many of the chapters did not respond. Numerous chapters indicated that they had not been able to distribute any of the surveys, primarily because of a lack of resources to do so. A few chapters could provide accurate counts, which varied from response rates of 0%-100%. Given that numerous chapters did not distribute any surveys, and numerous chapters could not be reached to determine how many surveys were distributed, it is safe to say that the actual response rate was higher than 7%, but the actual response rate is unknown.

In view of the small number of returns, it was decided to circulate the survey at the eighth annual Building on Family Strengths Conference 2001 at Portland State University. About 450 people attend the conference each year, including professionals and family members interested in hearing about or presenting research relating to the family interests of children and youth with emotional or behavioral difficulties. Attendees at the conference returned another 45 surveys, yielding a total of 115 surveys from 28 states.

Figure 1
States in Which Chapters of the Federation of Families for Children's Mental Health Received Surveys for Distribution

■ States that responded

Who Responded to the Survey?

Respondents were overwhelmingly mothers, and they were primarily reporting about sons. Fifty-six percent of the respondents were parents of children over 18 years old. Not quite half of the respondents were parenting a youth of minority racial background (see Table 1). Since only one grandmother responded, this report will refer to all respondents throughout as "parents."

Table 1
Percent Distribution of Demographic Characteristics of Respondents

Characteristic	Percent
Relationship to Youth	
Mother	96
Father	3
Grandmother	1
Age of Youth	
<18 years	44
18–20 years	24
21+ years	32
Racial Background of Youth	
Caucasian	59
African American	27
Latino	11
Bi-/multiracial	3
Hawaiian/Pacific Islander/Asian	<1
Gender of Youth	
Male	71
Female	29

Child System Involvement

The survey asked respondents to identify the children's agencies in which their child had been involved. This report uses "systems" to refer to state agencies, such as public children's mental health agencies or the state vocational rehabilitation system. Ninety percent of these youth had been involved with some public system (see Table 2), typically special education and the mental health system. The vast majority (80%) of the youth had been involved with more than one system.

Table 2
Child Public System Involvement of Respondents' Children

State Agency	Percentage of Respondents
Special education	79
Mental health	69
Juvenile justice	46
Health services	44
Substance abuse	36
Vocational rehabilitation	22
Child welfare/protective services	22
Multisystem involvement	
One system	10
2–4 systems	49
>4 systems	31

Effects of Child's Age, Gender, and Racial Background

The youngest group of youth (under 18 years) did not access the vocational rehabilitation system at all, and many fewer boys than girls received services from the public health system (see Table 3).

Because the number of children of multiracial or Asian/Pacific Islander background was so small, this report limits its analyses of racial background effects to differences among Caucasian, African American, and Latino youths. In general, youth of Latino background were less involved with children's systems. Caucasian and African American youth were commonly involved with special education and mental health systems. Caucasian youth

accessed public health systems, and they were the only ones to access vocational rehabilitation systems.

Table 3
Effects of Youth's Age, Gender, and Racial Background
On Child Public System Involvement

Characteristic and Agency	Percentage	Characteristic and Agency	Percentage
Age		*Racial Background (cont'd)*	
Vocational rehabilitation		Mental health	
<18	0	Caucasian	77
18–20	41	African American	77
21+	39	Latino	0
Gender		Vocational rehabilitation	
Males	29	Caucasian	35
Females	81	African American	0
Racial Background		Latino	0
No Agency Involvement		Health	
Caucasian	3	Caucasian	71
African-American	17	African American	10
Latino	45	Latino	0
Special education			
Caucasian	86		
African American	83		
Latino	9		

Note: Racial Background, n = 65 for Caucasian, n = 30 for African American, and n = 12 for Latino on Health and n=11 for remaining Latino categories.

Types of Child Services Received

Parents were asked what types of child services or treatments their child had received. The most common service was school support. Less than half (35%) had been in a psychiatric hospital and more than half had received outpatient therapy (66%) or psychopharmacological treatment (58%). Again, the majority of youth had received multiple treatments or services.

Adult System Involvement

Parent reports on children who were 18 or older (56%) indicated that the majority (70%) had accessed an adult system. Fewer youth had been involved in adult public systems (70% of those 18 and older) than child public systems (90% of all youth). Of these young adults, 44 percent had been involved with vocational rehabilitation, 31% with mental health services, 22% with state-supported health services, 19% with the substance abuse system, and 16% with corrections. Overall, 25% had been involved with one adult system, 30% with two, and 14% with three.

Adult Service or Treatment Involvement

Many more young people over age 18 had received no adult treatment (32%) than had received no children's treatment (1%). Generally, if youth had not accessed an adult system, they received no adult treatment; 89% of those who did not access adult systems received no adult treatment. This is in contrast to the child system in which all of those who had not accessed the child system still received child treatment.

Nonetheless, the majority had received some adult treatment. The same number had received adult vocational counseling as had received child vocational counseling; however, these were not necessarily the same people - only about half received both. For each other type of adult treatment that had a comparable child counterpart, including alcohol and drug treatment, fewer youth had accessed the adult service. Substance abuse and dependence disorders rise sharply after age 18 among youth with SED (Greenbaum, 2000); the smaller number of youths accessing those adult services than child treatment services (22% versus 34%) indicates a barrier to access for the older youth. Only 13% had been in a psychiatric hospital. Again, of those who accessed some treatment, the majority accessed more than one service.

Effects of Age, Gender, and Racial Background

There were few effects of age and gender on involvement with adult systems (see Table 4). Almost a third of those ages 21-and-over accessed the substance abuse system, while few 18- to 20-year-olds did. Many more young women than men were involved with the mental health and health systems.

Very few African American youth accessed any adult system, and only about half of Latino youth did, compared with 87% of Caucasian youth. No Latino youth and only 9% of African American youth accessed the adult vocational rehabilitation system, compared with 66% of Caucasian youth. No other effects of racial background reached statistical significance,

although there were trends in adult mental health, substance abuse, corrections involvement, and health services.

Table 4
Effects of Age, Gender, and Racial Background on Adult Public System Involvement

Characteristic and Agency	Percentage	Characteristic and Agency	Percentage
Age		*Racial Background (cont'd)*	
Substance abuse services		Mental health*	
18—20	4	Caucasian	44
21+	32	African American	1
Gender		Latino	9
Mental health		Substance abuse*	
Males	14	Caucasian	18
Females	80	African American	0
Health		Latino	45
Males	8	Corrections*	
Females	67	Caucasian	8
Racial Background		African American	9
No service system involvement		Latino	45
Caucasian	13	Health*	
African American	73	Caucasian	34
Latino	45	African American	9
Vocational rehabilitation		Latino	0
Caucasian	66	*Did not reach statistical significance but were trends (p=) 0.029, 0.052, 0.005, 0.033 respectively).	
African American	9		
Latino	0		

Note: Racial Background, Caucasian n = 39 for no service system involvement and mental health and n = 38 for remaining categories; n = 11 for African American and n = 11 for Latino.

Out-of-Pocket Expenditures

Almost half of the parents had paid for help that their child could not have received otherwise (i.e., insurance would not pay for it, and a public agency did not provide it). Most of these parents felt that the assistance was helpful. The high incidence of out-of-pocket expenditures indicates a widespread lack of funding for appropriate services for this age group.

Who Do the Survey Respondents Represent?

There are two points to understand to characterize who these respondents represent: (1) characteristics of those who responded, and (2) characteristics of those who did not respond. As described in the previous section, those who responded were largely mothers reporting about their sons. Almost half of the youths were of minority background, and they had had extensive involvement with public child and adult systems.

There are also two additional characteristics that describe this group of respondents: (1) an overwhelming majority of the youths had accessed the adult system, and (2) more than half of those over age 17 had attended college. These two findings suggest that the respondents are a subgroup of youth with SED. The national literature indicates that the majority of youth with SED who receive child mental health or special education services do not go on to receive adult mental health services. The sample may represent youth whose disabilities are more severe than the typical group of youth with SED and who therefore are more likely to use adult services. Or, it is possible that their parents - and perhaps the young people themselves - have been relatively effective advocates, opening doors that might not otherwise open. The finding that almost half the parents have paid for help tends to support the latter interpretation. Further, respondents were either members of the Federation or attendees at a conference focused on building family strengths, again suggesting that these are parents who are effective advocates for their children.

The percentage of those attending some college in this sample (54%) is very high in comparison to the figures from national studies that have reported rates of 4-13% (reviewed in Davis & Vanderstoep, 1997). This further suggests that these respondents represent a subgroup of parents of youth with SED. It is likely that these families have or find the resources to support their child in their motivation to attend college. They may be from a higher socioeconomic status than the average family of youth with SED (Silver et al, 1985). Taken together, the characteristics of respondents suggest that they represent parents who are good advocates for their child, and who may have higher educational attainment and income than the average family of youth with SED in public systems.

Considering the second factor, the characteristics of those who did not respond to the survey are more complicated. Clearly, the majority of individuals who received the survey chose not to respond to it. It is probable that those who responded to the survey were motivated by strong feelings about their experiences during their child's transition to adulthood. Thus, respondents may represent parents who are good at negotiating systems to help their child, and those who have experienced significant frustration during the transition period.

The results of this survey, then, do not reveal how many parents find transition services to be satisfactory and may underrepresent their experiences. Nor do the results reflect input from families that are less able to advocate for their child. However, the survey respondents are an important group of parents, and their experiences are consistent with what many parents have communicated to the authors over the past several years. Many parents commented on the survey that if their own experience as good advocates for their child was so negative, other parents must have had even worse experiences.

Results

Weighted Results

This survey was intended to provide a national sample. States were carefully chosen to capture national characteristics; however, because response rates did not correspond to the population size (i.e., 20 parents responded from Washington, D.C., while only 1 responded from Texas), the researchers weighted the responses so that each state contributed answers in proportion to its population. The details of this weighting formula can be found in Appendix B. These results are intended to provide a national picture. The researchers conducted no regional analyses.

Statistics

Basic descriptive and nonparametric statistics were used to summarize and analyze the survey findings. Details of the statistical analyses are given in appendix B. In general, findings that had a significance level less than 0.002 or 0.001 are reported. These levels help to ensure that the many repeated analyses are not increasing the likelihood of spurious findings.

Ratings of Systems Support During the Transition Period

- The transition from adolescence to adulthood is a major struggle for families of children with SED.

The survey asked parents to rate, on a five-point scale, how the transition period has been for their family. A score of 1 meant terrible, 3 meant neither good nor bad, and 5 meant wonderful. Respondents indicated that this period was a struggle for their families. The majority (60%) rated this item 1 or 2, most of the rest (39%) rated it 3, and only 1 percent rated it higher.

- Few parents found service systems to be helpful during this transition.

The survey also asked parents to rate "the system" overall on the help their child received during the transition. The majority (66%) rated the help as 1 or 2; 22% rated it 3; and 12% rated it 4 or 5.

Ratings on Specific Transition Issues for Each Type of Child System

The survey asked parents to rate, on a scale of 1 (terrible) to 5 (wonderful), each public child system on 12 items. Table 5 shows average response and standard deviation for each question. The average ratings ranged from 1 to 3.7 (3 = neutral).

- Parents rated only the child vocational rehabilitation system as helpful on most transition-related issues.

- Overall, parents rated the child vocational rehabilitation system the highest of any child system.

Parents rated the child vocational rehabilitation system highest overall. Parents' average ratings were above neutral on several items: treating a child in a way that was consistent with his or her level of functioning; knowing about the needs of this group of young people; being respectful of parents and youth; including parents in transition planning and treatment; and preparing youth for independent living and employment. Vocational rehabilitation's only low rating was for preparing youth for the impending insurance/eligibility changes. It should be noted that none of the parents of children under 18 reported involvement of their child with child vocational rehabilitation systems. The majority of parents who rated this system (92%) rated it from the perspective of their older child having accessed the vocational rehabilitation system both before and after age 18. These parents rated adult vocational rehabilitation systems lower than the child system. Perhaps in retrospect the child vocational rehabilitation system seemed particularly effective.

- Parents rated child mental health and special education systems neither good nor bad on most transition-related issues but poor on preparing adolescents for adult functioning.

Although child mental health rated higher than some other child-serving systems, it is disheartening to see that even the highest rated items, which reflect aspects of the system-of-care principles established by Stroul and Friedman (1986), did not average higher than a neutral score. For example, being respectful of parents and youth, and including parents in transition planning and treatment, each of which is a value of the system-of-care-established by the Child and Adolescent Service System Program (Stroul & Friedman, 1986), were rated 2.8–3.1 (neither good nor bad). These items, along with treating children in a way that is consistent with their level of functioning, were the highest rated items within mental health systems. Parents rated mental health lowest on preparing youth for work, independent living, fiscal responsibility, and for insurance/entitlement changes (average rating around 2).

Parents rated special education highest on: treating children in a way that is consistent with the child's level of functioning; being respectful of parents; and including them in transition planning and treatment (average rating around 3). Similar to their ratings of mental health, parents rated special education lowest on: preparing the child for work; independent living; fiscal responsibility; and for insurance/entitlement changes (average rating around 2).

- Overall, parents rated regular education, child welfare, and juvenile justice very low.

Respondents' perceptions of education, child welfare, and the juvenile justice system were so low that in no case did any of them even reach the neutral level.

- Parents rated all the child-serving systems low in helping to prepare youth for impending insurance/entitlement changes.

The highest rating in this category was a 1.9 for the child mental health system.

- Parents rated all child-serving systems except vocational rehabilitation inadequate in preparing youth for independent living and employment.

The vocational rehabilitation system received a 3.2 rating for both categories of preparing youth for independent living and for employment.

Table 5
Parent Ratings of Child Public Systems

Perceptions of the system	Child Mental Health	Educa-tion	Special Educa-tion	Voc. Rehab.	Child Welfare	Juvenile Justice
	Mean (standard deviation) (1=terrible, 5=wonderful)					
1. Did it know how other systems could be helpful?	2.5 (1.0)	1.6 (0.7	2.5 (1.2)	2.9 (1.2)	1.4 (0.8)	1.6 (0.9)
2. Did it treat your child in a way that was consistent with his/her level of functioning?	3.0 (0.0)	2.0 (0.8)	3.1 (1.2)	3.2 (1.0)	1.7 (0.9)	2.3 (1.5)
3. Did it know about the needs of this group of young people?	2.9 (1.3)	1.7 (0.9)	2.6 (1.0)	3.2 (1.4)	1.3 (0.7)	2.2 (1.4)
4. Did it help you prepare for system changes during transition?	2.3 (1.5)	1.5 (0.7)	2.4 (1.5)	2.5 (1.5)	1.3 (0.7)	1.2 (0.6)
5. Did it guide you to relevant information and resources?	2.2 (1.2)	1.5 (0.7)	2.3 (1.3)	2.5 (1.7)	1.2 (0.7)	2.0 (1.4)
6. Was it respectful of you?	2.9 (1.6)	2.0 (1.4)	2.9 (1.4)	3.6 (1.6)	1.6 (1.1)	2.2 (1.3)
7. Was it respectful of your child?	3.1 (1.5)	1.7 (1.1)	2.7 (1.4)	3.7 (1.3)	1.5 (0.9)	2.1 (1.2)
8. Did it include you in your child's transition planning and treatment?	2.8 (1.4)	1.9 (1.4)	2.9 (1.3)	3.4 (1.8)	1.4 (0.8)	1.4 (0.8)
9. Did it help prepare your child for living on her/his own?	2.0 (1.1)	1.3 (0.6)	1.9 (1.1)	3.2 (1.6)	1.2 (0.4)	1.2 (0.6)
10. Did it help prepare your child for being employed?	1.9 (1.1)	1.8 (1.3)	2.1 (1.2)	3.2 (1.5)	1.0 (0.2)	1.2 (0.5)
11. Did it help prepare your child for being fiscally responsible?	1.8 (1.2)	1.3 (0.5)	1.8 (1.2)	2.7 (1.7)	1.0 (0.2)	1.5 (1.1)
12. Did it help prepare your child for changes in insurance/entitlement?	1.9 (1.3	1.2 (0.4)	1.2 (0.5)	2.1 (1.8)	1.1 (0.5)	1.0 (0.3)

Effects of Age, Gender, and Racial Background

- Generally, age, gender, and racial background of the youth did not affect parents' ratings of children's systems.

Because the education, child welfare, and juvenile justice systems all received low ratings, researchers did not examine the effects of age, gender, or racial background on the ratings. For the child mental health, special education, and vocational rehabilitation systems, they calculated an average rating for each respondent by summing the total ratings for that system and dividing by the number of ratings provided (some parents did not rate each system on every item). Only one or two parents of Latino youth rated any one of these systems; thus, the effects of racial background were analyzed only for Caucasian and African American youths. However, the result of the analysis showed that, generally, youths' age, gender, and racial background had no effect on parents' ratings of children's systems.

Ratings on Specific Transition Issues for Each Type of Adult System

Parents rated each adult system on specific issues related to transition, using the same scale they used for the children's systems. These results are summarized in Table 6.

- Parents rated the adult mental health system lower overall than the children's mental health system.

Average ratings for the adult mental health system were around 2 or lower on: helping parents prepare for system changes during transition; guiding parents to relevant information and resources; preparing youth for employment and fiscal responsibility; and preparing youth for insurance/entitlement changes. Parents rated it highest for treating youth in a way that is consistent with their level of functioning and being respectful of youth.

- Parents rated the adult vocational rehabilitation system lower than the adolescent system. Vocational services did not receive positive ratings for helping to prepare youth for employment.

Surprisingly, adult vocational rehabilitation was not rated positively for helping prepare youth for employment. The highest ratings were for: being respectful of parents and youth; including parents in transition planning and treatment; knowing about the needs of this group of youth; and knowing how other systems could be helpful (all averaging 3 or above). The lowest ratings were for preparing youth to live on their own and to be fiscally responsible, and preparing them for insurance/entitlement changes (averaging 2 or less). These lower ratings, relative to the ratings of the child vocational rehabilitation system, do not appear to be the result of comparing the two systems because there were no differences in the ratings of adult vocational rehabilitation systems by parents whose children had and had not accessed the child system. The adult vocational rehabilitation system was rated comparably by both groups of parents.

- Parents, particularly parents of African American youth, rated colleges quite high.

Parents rated colleges quite high on several items: knowing about the needs of this group of youth; being respectful of parents and youth; helping prepare youth for living on their own; and helping parents prepare for system changes during transition (averaging 3 or higher). Colleges did not receive a low rating on any item (averaging 2.4 or higher on all items). It should be noted that 54% of parents of youth over age 17 rated college. This indicates that around half of those youths attended college, a remarkably high percentage among youth with serious emotional disturbance. National studies reported 4-13% of youth with serious emotional disturbance attend some college (reviewed by Davis and Vander Sloep 1997). The U.S. Census Bureau found that 46% of 18-24-year-olds had attended some college (U.S. Census Bureau, March 2000). This finding suggests that these parents represent families of a higher socioeconomic status than the general population of youth with serious emotional disturbance.

- The few parents who rated the substance abuse system tended to rate it as helpful.

Only 14 parents rated the substance abuse system (compared with almost twice as many responses for the other systems), and there was more variability in the answers. However, the average ratings were quite high. Parents rated it highest for: being respectful of youth and parents; knowing how other systems could be helpful; knowing about the needs of this group of youth; and treating youth in a manner consistent with their level of functioning. The only low average rating was for helping to prepare parents for system changes during transition.

Table 6
Parent Ratings of Adult Public Systems

Perceptions of the system	Adult Mental Health	College	Vocational Rehab.	Substance Abuse
	Mean (standard deviation) (1=terrible, 5=wonderful)			
1. Did it know how other systems could be helpful?	2.5 (1.5)	2.8 (1.5)	3.0 (1.6)	3.3 (1.7)
2. Did it treat your child in a way that was consistent with his/her level of functioning?	2.9 (1.0)	2.7 (1.3)	2.9 (1.5)	3.0 (2.1)
3. Did it know about the needs of this group of young people?		3.7 (1.1)	3.2 (1.2)	3.3 (1.7)
4. Did it help you prepare for system changes during transition?	1.8 (0.9)	3.0 (1.5)	2.6 (1.5)	2.1 (1.3)
5. Did it guide you to relevant information and resources?	1.8 (.9)	2.6 (1.3)	2.9 (1.6)	2.8 (2.1)
6. Was it respectful of you?	2.2 (1.1)	3.4 (1.6)	3.2 (1.5)	3.1 (1.9)
7. Was it respectful of your child?	2.7 (1.4)	3.9 (1.0)	3.5 (1.2)	3.4 (1.5)
8. Did it include you in your child's transition planning and treatment?	2.1 (1.8)	2.7 (1.6)	3.1 (1.5)	2.8 (2.0)
9. Did it help prepare your child for living on her/his own?	2.2 (1.3)	3.3 (1.3)	2.0 (.9)	2.9 (2.0)
10. Did it help prepare your child for being employed?	1.9 (1.1)	2.5 (1.3)	2.3 (.8)	2.9 (2.1)
11. Did it help prepare your child for being fiscally responsible?	1.6 (0.9)	2.4 (1.3)	1.9 (0.9)	2.9 (2.1)
12. Did it help prepare your child for changes in insurance/entitlement?	1.6 (0.9)	2.4 (1.3)	1.9 (0.8)	2.9 (2.0)

Effects of Age, Gender, and Racial Background

- Generally, age, gender, and racial background of the youth did not affect parents' ratings of adult systems.

Because the number of parents who rated substance abuse services was so small, no analysis was done of the effects of age, gender, or racial background for that system. For the other systems, the average system rating was calculated for each parent. Only one parent of Latino youth rated each system, so analysis of the effects of racial background was limited to Caucasian and African American youth.

The youth's age or gender had no effect on parents' ratings of adult systems. Parents of African American youth rated colleges high (3.9+/-0.3) compared with parents of Caucasian youth.

**Barriers to Services Encountered During the
Transition from Adolescence to Adulthood**

Parents were asked about the barriers they encountered in seeking services for their children. The focus groups had identified certain barriers as being particularly relevant to youth during the transition period.

- The most common barrier to receiving services is the stigma young people feel in accessing services that could label them as mentally ill.

As shown in Table 7, 61.6% of respondents listed stigma as the most common barrier to receiving services.

- Services typically did not address issues that were relevant to young people, such as getting a job or finding a place to live.

More than half the parents felt that some services did not address issues relevant to young people. This finding is consistent with reports that adult services are geared toward the older adult population and adolescent services are designed for younger adolescents.

- Services did not sufficiently or appropriately include parents.

Half the parents had encountered services that did not sufficiently or appropriately include them.
- It was common for parents to feel frustrated by the lack of information on available services or resources.

Many parents expressed frustration over what they perceived as a lack of information on available services or resources.

Table 7

Percentage of Parents Reporting Having Encountered Barriers to Services

Barrier	Percentage
Young person saw the service as stigmatizing.	61.6
The service did not deal with issues relevant to young people.	51.5
The service did not sufficiently/appropriately involve parents.	50.0
There was no source of information on available services or resources.	49.0
There was no payor (insurance/entitlement/public service) for the service.	42.3
Service providers were too rigid.	38.1
The service was not culturally competent/sensitive.	37.6
The service was too inconvenient to get to (because of hours or location).	37.4
Changes in insurance coverage related to the child's age eliminated a service he/she was getting.	29.5
Most people in the service were considerably older or younger than the child.	26.1
Most people in the service had more severe mental illness.	18.3
Other	17.4

Effects of Age, Gender, and Racial Background

- The degree to which barriers had been encountered varied greatly depending on the age, gender, and racial background of youth.

This finding suggests that barriers differentially affect subgroups of youth and parents during the transition period. As systems address barriers to transition support services the impact of the changes should be evaluated for these different groups.

- Parents of the oldest youths (ages 21 and over) commonly reported services that: served much older clients than their child; were too rigid; and did not sufficiently involve parents.

As shown in Table 8, parents of the oldest youths had more experience with services that served much older clients than their child and services that were too rigid. These parents also overwhelmingly reported that services did not sufficiently involve parents. This finding is consistent with the way adult services are structured: They are not age-graded, and most people who use them are ages 30–50. Adult services in general are also less individually

tailored than children's services. Together, these findings indicate that older youths are highly likely to encounter services that are developmentally inappropriate.

- Parents of boys reported insufficient information as a barrier more than did parents of girls.

Parents of boys rated the quality of information provision in child and adult services as more problematic when rating children's systems, and they reported insufficient information as a barrier more often than parents of girls. There were no other gender differences.

- More parents of African American youth than parents of other youth reported that services served clients with more severe mental illness than their child.

Fifty-three percent of African American respondents reported dissatisfaction with the service because its clients generally had more severe mental illness than their child, while only 8% of Caucasian parents and no Latino parents reported this dissatisfaction.

- Parents of Caucasian and Latino youth reported stigma as a barrier more than did parents of African American youth.

Ninety-one percent of Latino respondents and 80% of Caucasian respondents reported that their child's perception of stigma attached to the service was a barrier, while only 10% of African American respondents reported this barrier.

Table 8

Effects of Youth's Age, Gender, and Racial Background on Barriers Encountered

Characteristic and Barrier	Percentage Reporting Barrier
Age	
Most people in the service were considerably older or younger than the reporting parent's child.	
<18	6
18–20	22
21+	57
Service providers were too rigid.	
<18	27
18–20	25
21+	64
Service did not sufficiently/appropriately involve parents.	
<18	43
18–20	36
21+	72
Service was not culturally competent/sensitive.	
<18	33
18–20	18
21+	58
Gender	
There was no source of information on available services or resources.	
Males	59
Females	24
Racial Background	
Most people in the service had more severe mental illness.	
Caucasian	8
African American	53
Latino	0
Young people saw the service as stigmatizing.	
Caucasian	80
African American	10
Latino	91

Important Service Components for Transition Support

Parents were asked to rate the importance of various service components in addressing the demands of transition. Parents were not asked about the need for traditional mental health treatment such as outpatient therapy, psychiatric hospitalization, or residential care, as it is assumed that any mental health system is likely to have some of these components. Rather, the questions focused on components more specifically related to transition, or on common elements that were either helpful or lacking. Each component was rated as 1=little importance, 2 = helpful, 3 = important, 4 = most important.

- On average, all service components were rated "important."

As shown in Table 9, none of the components were, on average, rated lower than 3.

- Parents rated vocational and independent living preparation or assistance, along with affordable housing, as the most important components.

All three components received a rating of 3.76 - 3.77, indicating that their significance as transition factors was relatively high.

- Parents consistently rated support/advocacy groups and opportunities to shape services as more important for their children than for themselves.

Advocacy groups for young adults received a rating of 3.67; advocacy groups for parents received the slightly lower rating of 3.43.

- Parents consider being provided with information about services and resources a high priority.

Ease of access to information about the system and its services received a fairly high rating of 3.72.

Table 9

Parent Ratings of the Importance of Various Components of Transition Support

System Component	Mean (SD)
	(1=little importance, 4=most important)
Affordable housing	3.77 (0.52)
Independent living skills preparation	3.77 (0.55)
Career/vocational training	3.77 (0.58)
Career/vocational development assistance (choosing a vocation that matches interests and skills)	3.76 (0.48)
An easily accessible source of information (i.e., guide to what to expect, services, legal rights)	3.72 (0.52)
Advocacy groups for young adults	3.67 (0.54)
Supported work/job coaching	3.60 (0.81)
Positive peer support forums	3.59 (0.61)
Assistance with financial issues/insurance coverage for young person	3.56 (0.78)
A single system covering ages 16–25	3.56 (0.83)
Forum for young people to help develop and evaluate services	3.55 (0.65)
Forum for parents/family members to help develop and evaluate services	3.44 (0.74)
Advocacy groups for parents	3.43 (0.82)
Supported housing (housing in which trained helpers provide assistance/supervision)	3.38 (1.0)
Respite (brief care for the child that provides relief for the parent)	3.31 (0.93)
Service coordination (case management)	3.25 (0.85)
Transportation assistance	3.15 (0.92)

Effects of Age, Gender, and Racial Background

- Parents' ratings of the importance of various system components varied greatly by the age, gender, and racial background of their child.

This finding illustrates the importance of individualized and culturally competent transition support services. The array of transition support services available should meet the needs of young men and women, from different cultural backgrounds, and change as they move from early to late transition stages.

- Parents of the older groups of youth (ages 18 and older) were more interested in advocacy groups for both parents and youth, a single system covering ages 16–25, and transportation assistance.

The difference in responses between parents of the youngest group (<18) and parents of the two older groups reflect the difficulties that young people encounter when they are no longer served in the child system: they gave higher ratings to advocacy, coordination between the child and adult systems, and the need for transportation to adult endeavors such as work (see Table 10).

- Parents of girls were more interested than parents of boys in supported housing and less interested in positive peer support forums and a single system covering ages 16–25.

The reasons for the different responses from parents of boys and girls are not clear, but the fact that these differences exist in the responses suggests that local systems may want to explore gender differences in the interest in and use of various service components.

- Parents of youth of different racial backgrounds rated the importance of various components differently, indicating that good transition supports should reflect these kinds of differences.

The child's racial background had a significant effect on parents' ratings of seven service components. It is clear that local systems must closely evaluate the differing needs of various ethnic groups in order to support young people in transition to adulthood. Many of these differences may reflect cultural practices around the movement from adolescence to adulthood, so supportive services should be particularly sensitive in this area.

Table 10
Effects of Youth's Age, Gender, and Racial Background on Ratings of System Components for Transition Support

Characteristic and System Component	Mean (SD)	Characteristic and System Component	Mean (SD)
	(1=little importance, 4=most important)		
Age		*Racial Background*	
Advocacy groups for young adults		An easily accessible source of information	
<18	3.44 (0.57)	Caucasian	3.92 (0.28)
18–20	3.87 (0.46)	African American	3.20 (0.66)
21+	3.82 (0.69)	Latino	3.53 (0.55)
Advocacy groups for parents		Supported housing	
<18	3.18 (0.92)	Caucasian	3.73 (0.67)
18–20	3.83 (0.58)	African American	2.81 (1.30)
21+	3.46 (0.69)	Latino	3.43 (0.59)
Single system covering ages 16–25		Career/vocational training	
<18	3.23 (0.93)	Caucasian	3.80 (0.50)
18–20	3.76 (0.70)	African American	3.95 (0.30)
21+	3.86 (0.57)	Latino	3.09 (1.04)
Transportation assistance		Supported work/job coaching	
<18	2.86 (0.80)	Caucasian	3.77 (0.60)
18–20	3.53 (0.79)	African American	3.77 (0.48)
21+	3.19 (1.08)	Latino	2.22 (1.18)
Gender		Advocacy groups for parents	
Positive peer support forums		Caucasian	3.59 (0.61)
Males	3.68 (0.61)		
		African American	2.84 (1.03)
Females	3.34 (0.54)		
		Latino	4.00 (0.0)
Supported housing			
Males	3.17 (1.10)	Positive peer support forums	
		Caucasian	3.47 (0.61)
Females	3.87 (0.43)	African American	3.91 (0.42)
		Latino	3.47 (0.59)
Single system covering ages 16–25			
Males	3.63 (0.84)	Respite	
		Caucasian	3.57 (0.72)
Females	3.30 (0.80)	African American	2.67 (1.11)
		Latino	3.56 (0.52)

Important Policy Considerations for Transition Support

Parents were asked to rate the importance of various policy considerations regarding services during the transition stage. The focus groups had identified a number of policy issues they felt would help improve systems for youth in transition. Using the same four-point scale as for system components, the survey asked parents about the relative importance of each of these policy considerations.

- All policy considerations averaged a rating of at least "important."

All items averaged a score of no less than "important" (see Table 11), with the highest ranked component receiving an average rating of 3.77 and the lowest receiving an average rating of 3.27.

- The highest rated policy component was including parents as much as possible in services for their children in transition.

- The second rated component was establishing policies that minimize out-of-home placements.

- The third rated component was eliminating barriers to accessing adult services.

- The lowest rated policy consideration (although still rated important) was minimizing services that do not prepare youth for life in their communities.

The low rating for this policy consideration seems to contradict parents' high ratings for service components that directly prepare youth for adult life. The question with a double negative was not clearly stated, though, so some of the respondents may have misunderstood it.

Table 11

Parent Ratings of the Importance of Various Policies Affecting Transition Support

Policy (1=little importance, 4=most important)	Mean (SD)
Include parents as much as possible in services for their children in transition.	3.77 (0.48)
Increase supports in order to minimize out-of-home placements.	3.70 (0.53)
Eliminate barriers to accessing adult services.	3.67 (0.58)
Teach providers how transition affects every area of life for a significant period of time.	3.65 (0.52)
Change law enforcement so that it is more informed and more flexible about addressing mental health issues and responding in a developmentally appropriate way.	3.65 (0.63)
Make all providers knowledgeable about this developmental stage.	3.63 (0.51)
Coordinate public and private systems to address transition needs.	3.63 (0.58)
Sensitize providers to cultural and family differences regarding the transition to adulthood.	3.56 (0.62)
Continue to include parents in services and treatment for young people over age 18.	3.53 (0.65)
Make young people's input a guide to service development.	3.53 (0.73)
Measure young adult outcomes to guide system change.	3.47 (0.71)
Emphasize peer support in services.	3.46 (0.77)
Make sure child and adult supports and treatment help them fit in with their peers.	3.46 (0.79)
Minimize services that do not prepare youth for life in their communities.	3.27 (0.78)

Effects of Age, Gender, and Racial Background

- With few exceptions, parents of youth of different ages, genders, and racial background rated the importance of these policy considerations similarly.

Parents of older youth were more interested in policies to encourage law enforcement changes than parents of the younger two groups (see Table 12). Parents of boys rated making providers knowledgeable about this developmental stage more important than did parents of girls. Parents of Latino youth rated the factors of teaching providers how transition affects every area of life for a significant period of time and coordinating public and private systems around transition issues as less important than did the parents of other youth. There were no other effects of the child's age, gender, or racial background. Thus, with few exceptions, parents were consistent in their ratings of the importance of the various policy considerations.

Table 12
Effects of Youth's Age, Gender, and Racial Background
on Ratings of Policy Considerations

Characteristic and Policy Component	Mean (SD)
(1=little importance, 4=most important)	
Age	
Change law enforcement.	
<18	3.57 (0.50)
18–20	3.39 (0.97)
21+	3.95 (0.24)
Gender	
Make all providers knowledgeable about this developmental stage.	
Males	3.75 (0.47)
Females	3.35 (0.50)
Racial Background	
Teach providers how transition affects every area of life for a significant period of time.	
Caucasian	3.72 (0.45)
African American	3.69 (0.60)
Latino	3.11 (0.33)
Coordinate public and private systems to address transition needs.	
Caucasian	3.82 (0.39)
African American	3.42 (0.55)
Latino	3.11 (1.04)

Conclusions

Parents of all youth who are in transition to adulthood strive to help their children develop into well-adjusted adults. Parents of youth with serious emotional or behavioral difficulties have many additional hurdles to overcome in helping their children with this task. Many youth with SED receive some supports from various helping systems, so it seems natural for parents to expect those systems to help prepare them and their child for the tremendous change from dependence to independence. However, it is clear from the survey reviewed in this report that parents are often very disappointed in the help they receive or in the fact that they do not receive help at all.

Survey respondents said that systems needed improvement especially in helping young people prepare for the tasks of adulthood: living independently, working, and supporting themselves. Systems that focused on these tasks (vocational rehabilitation and colleges) were rated higher, and these service components were given the highest priority. Treatment professionals tend to focus on treatment, educators tend to focus on completing courses and classroom management, child welfare tends to focus on safe environments, and juvenile justice focuses on rehabilitation or containment. Each child-serving system has important priorities. But focusing on the fact that every child will eventually become an adult has not been a high enough priority. Similarly, adult systems work primarily with older adults, who have already established independent living skills and perhaps need rehabilitation. Thus, preparation for adult functioning has been embraced by neither child nor adult systems.

Parents in this survey also repeatedly emphasized the need, for the child and for themselves, for improved information about resources and system changes as their child matures into adulthood. Parents would like more efforts to include them in their children's treatment, in both child and adult services. While there may be legal complexities to parental involvement in an adult child's treatment, it is clearly worthwhile to include parents as much as possible and to see their participation as important to their child's well-being. Parents want systems to help more and not to interfere with their own efforts to help their child. They want the same things for their children: peer support, advocacy organizations, information, and access to resources. Most of the parents who responded to the survey have discovered the power of information and advocacy, and they want more of both for themselves and their children.

Parents' perspectives differed in important ways depending on the age, gender, and racial background of their child. Many of the age differences probably reflected different experiences in the child and adult systems, and the needs of younger and older transitioning youth. As systems review their transition practices and policies, it is important that they be aware of some of the gender and racial differences and ensure that youth and parent voices are sufficiently diverse to help guide these changes.

Finally, the issue of stigma is a particular barrier for youth of this age group. Adolescents and young adults generally want nothing more than to blend in with, and be admired by, their peers. The degree to which SED remains stigmatizing prevents many young people from accessing potentially helpful services. Adults who work in any way with these young people must do all they can to reduce the stigma of SED and promote services that help young

people blend in as much as possible. There is much work to be done to improve transition supports to youth with SED and their parents.

Recommendations

Based on these findings, administrators, policy makers and providers of services to families of children with SED who are making the transition to adulthood should consider implementing the following recommendations:

- make the improvement of transition supports a high priority that results in both human and fiscal resources being dedicated to its improvement;

- provide sufficient support and leadership to result in action;

- include all relevant child- and adult-serving agencies in these efforts;

- review practices and policies related to transition supports that are helpful to or hinder youth and families;

- involve parents and youth in all levels of the system for discussion and action concerning transition supports to ensure that the voices of youth and family members are incorporated into policies and service models;

- evaluate the degree to which services prepare youth for adult functioning;

- provide appropriate transition-specific training and ongoing support to individuals working with youth and families so they can be sources of information and effective advocates for the individuals they are working with;

- provide information to youth and families on system capabilities, benefits and functions;

- provide youth and families with the necessary information to navigate between the child serving agencies and the adult serving agencies, and the gaps and barriers between these two systems;

- create an anti-stigma campaign to reduce the stigma of mental illness; and

- continue to research parents' perspectives of the impact of service systems on helping youth in transition, with a special emphasis on obtaining feedback from lower-income families.

References

Adams, J., Nolte, M., & Schalansky, J. (2000). Who will hear our voices? In H. B. Clark and M. Davis (Eds.). *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties* (pp. 181-193). Baltimore: Paul H. Brookes, Co.

Clark, H., & Davis, M. (2000). *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties.* Baltimore: Paul H. Brookes, Co.

Clark, H., Deschenes, N., & Jones, J. (2000). A framework for the development and operation of a transition system. In H. B. Clark and M. Davis (Eds.). *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties* (pp. 29-51). Baltimore: Paul H. Brookes, Co.

Clark, H., Unger, K. & Stewart, E. (1993). Transition of youth and young adults with emotional/behavioral disorders into employment, education and independent living. *Community Alternatives International Journal of Family Care, 5,* 21-46.

Davis, M., & Vander Stoep, A. (1996). *The Transition to Adulthood Among Adolescents Who Have Serious Emotional Disturbances; At Risk for Homelessness.* Delmar, NY: National Resource Center on Homelessness and Mental Illness.

Davis, M., & Vander Stoep, A. (1997). The transition to adulthood among children and adolescents who have serious emotional disturbance. Part I: Developmental transitions. *Journal of Mental Health Administration, 24 (4),* 400-427.

Evans, M., Huz, S., McNulty, T., & Banks, S. (1996). Child, family, and system outcomes of intensive case management in New York State. *Psychiatric Quarterly, 67*, 273-286.

Greenbaum, P. (2000). National Adolescent and Child Treatment Study (NACTS): A longitudinal study of children with serious emotional and behavioral disturbance. Paper presented at *Developing partnerships for youth with serious emotional disturbance in transition to adulthood,* National Association of State Mental Health Program Directors. Washington, DC, June 19.

Silver, S. (March 1995). How to promote (and not interfere with) effective transition. Paper presented at Eighth Annual Research Conference, *A System of Care for Children's Mental Health: Expanding the Research Base*, University of South Florida, Research and Training Center for Children's Mental Health, Tampa, FL.

Stroul, B. & Friedman, R. (1986). *A System of Care for Severely Emotionally Disturbed Children and Youth.* Washington, DC: CASSO Technical Assistance Center.

U.S. Census Bureau (2000). Educational attainment in the U.S.; March 2000. *Current Population Survey*. Retrieved April 24, 2002, from, www.census.gov/population/www/ socdemo/educ-attn.html.

Appendices

Appendix A
Survey Instrument

SURVEY OF PARENTS' PERSPECTIVES ON TRANSITION

Please fill out this survey so that we can communicate your experiences and recommendations to the people who shape services for youth with emotional or behavioral difficulties. Parents of children with emotional or behavioral difficulties in transition to adulthood helped us develop this survey. We realize that filling out this survey may bring out painful or difficult memories. The thoughtfulness of your response is very much appreciated and your responses will help other families in the future.

There are five sections of this survey. Please answer as many questions as you are able to and are comfortable with. **Not knowing the answers to some of these sections is fine. Just fill out what you know (if you don't know it, skip it). Any information is helpful.**

SECTION ONE: Please tell us about yourself and your child (we'll refer to the person who you are answering this questionnaire about as "your child"). If you have more than one child aged 16–25 who has serious emotional or behavioral difficulties please fill out this survey in reference to just one of them.

Where do you live? _____ (city/town) _____ (state)

Your gender: Male__   Female__   Your child's gender: Male __   Female __

Age of your child_____   Your child's racial/ethnic background _____

Your relationship to your child: __ parent   __ grandparent   __ foster parent

__ other (please describe)_____

SECTION TWO:	**YOUR EXPERIENCE**

Please circle the number that best represents your answer.
1.   Overall, how has your child's transition from adolescence to adulthood been for your family?
1----------------------**2**------------------------------**3**---------------------------**4**-----------------------**5**
Terrible   *OK*   *Wonderful*

2. Overall, how would you rate the help your child has received from 'the system' during this transition?
1----------------------**2**------------------------------**3**---------------------------**4**----------------------**5**
Terrible   *OK*   *Wonderful*

3.   Have you paid for any help for your child that you could not have gotten from anywhere else (taxpayer dollars or insurance) during the transition to adulthood?
     Yes ___   No ___ Don't Know ___ Doesn't Apply ____

4.   If yes, was it helpful?
     Yes, very ___   Somewhat ___   No ___ Don't Know ___

5.   Was there anyone who was particularly helpful to you or your child in preparing for the transition to adulthood? If so, please describe their role (i.e. a teacher, a counselor, a religious leader).
     _____

Children's Services

6.   What state agencies has your child been involved with **as a child**; (please check all that apply)?
o no state agencies involved   o public children's mental health   o juvenile justice
o child welfare/protective services   o vocational rehabilitation   o substance abuse services
o special education   o state supported health services   o I Don't Know
o other (please describe)_____

7.   If your child has received any services or treatment under the age of 18 please check all that apply.
o school support   o outpatient psychotherapy   o vocational counseling
o psychopharmacology   o substance abuse treatment   o homebased therapy
o homeless shelter   o residential treatment   o psychiatric hospital
o supported housing   o foster care
o other (please describe) _____

8. On a scale of 1 (**terrible**) to 5 (**wonderful**), please rate each state children's agency that your child has been involved with on the items listed below. *Please leave the answer blank whenever it doesn't apply.*

Was/Did this system:	Public Child Mental Health	Regular Education	Special Education	Vocational Rehabilitation	Child Welfare/ Foster Care	Juvenile Justice
Know how other systems could be helpful?	____	____	____	____	____	____
Treat your child in a way that was consistent with his/her level of functioning?	____	____	____	____	____	____
Know about the needs of this group of young people?	____	____	____	____	____	____
Helpful in assisting you prepare for all of the 'system' changes during transition?	____	____	____	____	____	____
Guide you to relevant information and resources?	____	____	____	____	____	____
Respectful of you?	____	____	____	____	____	____
Respectful of your child?	____	____	____	____	____	____
Include you in your child's transition planning and treatment?	____	____	____	____	____	____
Help prepare your child for living on her/his own?	____	____	____	____	____	____
Help prepare your child for being employed?	____	____	____	____	____	____
Help prepare your child for being fiscally responsible?	___	____	____	____	____	____
Help prepare your child for insurance/entitlement changes?	____	____	____	____	____	____

Adult Services

9. What state agencies has your child been involved with as an adult (please check all that apply)?

o no state agencies involved   o public adult mental health   o corrections
o vocational rehabilitation   o substance abuse services   o state supported health services
o I don't know
o other (please describe)_____

10. a. Have you found that adult services have stricter eligibility criteria than children's services?
        Yes ___ No ___ Don't know ___ Doesn't apply ____

    b. If yes, has your child been denied services because of this?
        Yes ___ No ___ Don't know ___ Doesn't apply ____

    c. If yes, please give examples_____

11. Please <u>check</u> the boxes of adult services that your child has received.

o no adult services received   o residential treatment   o vocational counseling
o supported housing   o psychiatric hospital   o outpatient psychotherapy
o homeless shelter treatment   o supported employment   o drug/alcohol hospital
o drug/alcohol outpatient treatment o psychopharmacology
o other (please describe) _____

12. On a scale of 1 (**terrible**) to 5 (**wonderful**), please rate each adult agency that your child has been involved with on the items listed below. *Please leave the answer blank whenever it doesn't apply.*

Was/Did this system:	Public Adult Mental Health	College	Vocational Rehabilitation	Substance Abuse
Know how other systems could be helpful?	____	____	____	____
Treat your child in a way that was consistent with his/her level of functioning?	____	____	____	____
Know about the needs of young adults?	____	____	____	____
Helpful in assisting you to be prepared for all of the 'system' changes during transition?	____	____	____	____
Guide you to relevant information and resources?	____	____	____	____
Respectful of you?	____	____	____	____
Respectful of your child?	____	____	____	____
Include you in your child's transition planning and treatment?	____	____	____	____
Help prepare your child for living on her/his own?	____	____	____	____
Help prepare your child for being employed?	____	____	____	____
Help prepare your child for being fiscally responsible?	____	____	____	____
Help prepare your child for insurance/entitlement changes?	____	____	____	____

SECTION THREE: **BARRIERS TO APPROPRIATE SERVICES**
Have you ever encountered the following barriers in the services that you described to us above?

---

o *Service didn't deal with issues that were relevant to young people.*
o *Most people in the service were considerably older or younger than your child.*
o *Most people in service had more severe mental illness.*
o *Young person saw the service as stigmatizing.*
o *There was no payor (insurance/entitlement/public service) for the service.*
o *Changes in insurance coverage related to your child's age eliminated a service he/she was getting.*
o *There was no source of information on available services or resources.*
o *Service was too inconvenient to get to (because of hours or location).*
o *Service providers were too rigid.*
o *Service did not sufficiently/appropriately involve parents.*
o *Service was not culturally competent/sensitive.*
o *Other (please describe).*_____
_____
_____
_____
_____

How important are each of the following service components to addressing the demands of transition?
1=little importance   2=helpful   3=important   4=most important

1 2 3 4	*An easily accessible source of information (i.e., guide to what to expect, services, legal rights)*
1 2 3 4	*Supported housing (housing in which trained helpers provide assistance/supervision)*
1 2 3 4	*Affordable housing*
1 2 3 4	*Independent living skills preparation (cooking, shopping, public transportation, etc.)*
1 2 3 4	*Career/vocation development assistance (choosing vocation that matches interest and skills)*
1 2 3 4	*Career/vocational training*
1 2 3 4	*Supported work/job coaching*
1 2 3 4	*Forum for parents/family members to help develop and evaluate services*
1 2 3 4	*Forum for young people to help develop and evaluate services*
1 2 3 4	*Transportation assistance*
1 2 3 4	*Assistance with financial issues/insurance coverage regarding young person*
1 2 3 4	*Advocacy groups for parents*
1 2 3 4	*Advocacy groups for young adults*
1 2 3 4	*Positive peer support forums (i.e., clubhouses)*
1 2 3 4	*Respite; brief care for your child that provides you relief as a parent*
1 2 3 4	*Service coordination (case management)*
1 2 3 4	*A single system covering ages 16-25 years*

What priority would you give each of the following policies for a better system for youth in transition?
1=little importance   2=helpful   3=important   4=most important

1 2 3 4	*Include parents as much as possible in services for their child in transition.*
1 2 3 4	*Continue to include parents in services and treatment for young people over age 18.*
1 2 3 4	*Eliminate barriers to accessing adult services.*
1 2 3 4	*Make all providers knowledgeable about this developmental stage.*
1 2 3 4	*Teach providers how transition impacts EVERY area of life for a significant period of time.*
1 2 3 4	*Sensitize providers to cultural and family differences regarding the transition to adulthood.*
1 2 3 4	*Change law enforcement so that it is more informed and more flexible about addressing mental health issues and responding in developmentally appropriate ways.*
1 2 3 4	*Coordinate public and private systems in addressing transition needs.*
1 2 3 4	*Measure young adult outcomes to guide system change.*
1 2 3 4	*Services should emphasize peer support.*
1 2 3 4	*Young people's input should guide service development.*
1 2 3 4	*Minimize services that do not prepare youth for life in their communities.*
1 2 3 4	*Child and adult supports and treatments must help them fit in with their peers.**
1 2 3 4	*Increase supports in order to minimize out of home placements.*

Please feel free to add additional comments here and continuing on the next page ➔:

Appendix B
Technical Statistical Analyses

Statistical Analyses

Weighted Responses

The researchers received 115 responses from 28 states that represent 68% of the national population. Many states were either over or underrepresented within this sample. The weighting of responses was the product of two proportions. The first is the percent of the general population responding that a state represents. This is the percent of the national population a state represents/68 since only 68% of the population is represented in this sample. This proportion is p1. The second proportion is the percent of the respondents in a state as a proportion of the total sample. This proportion is the number of respondents from a state/115 (there were 115 respondents). This proportion is p2. The weight then is the ratio p1/p2. If this ratio is 1, that says the proportion of the reporting of the nation responding is the same as the proportion of the respondent pool. Thus the weight would be 1. If the ratio is 2, that says the proportion of respondents is less than the state general population, and the weight would be 2.

Tables reporting the statistics in which there were significant effects of age, racial background or gender only present findings meeting the p-level criteria described. All other tables simply present the distribution of ratings of all items - in the body of the report the mean and standard deviation were presented - here the actual distribution is presented. These are simply two different way to describe the distribution and variation in ratings given.

Statistical Analysis

Descriptive statistics were used to summarize the ratings and priority scores. Analyses of answers pertaining only to the adult systems were conducted only for youth over age 18. It should be noted that a scale of 1–5 or 1–4 is not actually a continuous variable; rather, it is a categorical variable. That is, there are only 5 or 4 possible answers, respectively, and thus there is no actual answer that corresponds with 3.24 (which can be a possible mean). While means and standard deviations present a picture of the central tendency and variation in scores (as described in the preceding text), it is also important to look at the actual distribution of answers, as presented below (in Table B-3 through B-11, B-13, B-15).

Nonparametric statistics were used to examine the effects of youth's age, gender, and racial background. These nonparametric statistics were chosen because the variables are not continuous. In addition, repeated analyses are likely to produce some "significant" results by chance (i.e., by chance, 1 in 20 results should be significant when the alpha is set at 0.05). Thus, within each category of questions (there were five categories), the alpha was divided by the number of analyses conducted to provide a more conservative estimate of significance and reduce the likelihood of artificial findings. As an example, there were 11 questions in the section on barriers to appropriate services, and researchers analyzed the effects of age, gender, and race for each question; thus, there were 33 analyses. They set the *p*-level of significance at <0.0015 (0.05/33). All the findings reported in the tables on age, gender, and racial background met such a standard. The statistics for these findings are presented in tables B-1, B-2 B-12, B-14, and B-16.

Researchers did analyses of the effects of age and racial background using the Kruskal-Wallis test for *K* independent groups. They analyzed the effects of gender using the Mann-Whitney *U*-test for two independent groups. When the number of individuals in the Latino group was too small (i.e., <4), they compared only Caucasian and African American youth, using the Mann-Whitney *U*-test for two independent groups.

Effects of Age, Gender, and Racial Background
on Child and Adult System Involvement

A *p*-value of 0.0012 or less was considered to be significant for examination of these demographic variables on systems involvement (0.05/(8 child systems + 6 adult systems) x 3 variables = 0.00119). The following are the statistics for each of the significant findings.

Table B-1
Child System Involvement—Racial Background

System	χ^2(df = 2)	*p* =
None	15.7	<0.001
Special education	32.8	<0.001
Mental health	24.2	<0.001
Vocational rehabilitation	19.8	<0.001
Health	39.7	<0.001

Table B-2
Adult System Involvement—Racial Background

System	χ^2(df = 2)	p =
None	17.0	<0.001
Vocational rehabilitation	16.8	<0.001

Distribution of Ratings of Child Systems

Table B-3
Child Mental Health

	1	2	3	4	5

(1=terrible, 5=wonderful)

Perceptions of the system	Percentage of respondents				
1. Did it know how other systems could be helpful?	18.8	30.9	31.4	17.8	1.2
2. Did it treat your child in a way that was consistent with his/her level of functioning?	11.6	14.2	34.3	38.0	1.9
3. Did it know about the needs of this group of young people?	25.8	5.6	29.7	35.8	3.1
4. Did it help you prepare for system changes during transition?	48.0	8.5	18.6	11.2	13.7
5. Did it guide you to relevant information and resources?	33.6	32.1	13.4	19.5	1.4
6. Was it respectful of you?	26.4	23.3	14.4	8.3	27.6
7. Was it respectful of your child?	24.2	7.0	33.8	6.5	28.4
8. Did it include you in your child's transition planning and treatment?	29.4	10.5	24.1	23.2	12.9
9. Did it help prepare your child for living on her/his own?	53.8	4.6	32.6	8.8	0.2
10. Did it help prepare your child for being employed?	51.7	14.3	22.8	10.9	0.3
11. Did it help prepare your child for being fiscally responsible?	64.2	4.7	17.3	13.5	1.3
12. Did it help prepare your child for insurance/entitlement changes?	58.9	15.2	1.0	24.5	0.3

Table B-4
Education

	1	2	3	4	5

(1=terrible, 5=wonderful)

Perceptions of the system	Percentage of respondents				
1. Did it know how other systems could be helpful?	53.8	35.4	10.6	0.1	0.0
2. Did it treat your child in a way that was consistent with his/her level of functioning?	28.1	46.7	21.8	3.4	0.0
3. Did it know about the needs of this group of young people?	61.6	10.8	26.9	0.7	0.0
4. Did it help you prepare for system changes during transition?	55.5	33.8	10.7	0.0	0.0
5. Did it guide you to relevant information and resources?	58.6	33.0	6.8	1.6	0.0
6. Was it respectful of you?	57.4	7.5	17.7	9.8	7.6
7. Was it respectful of your child?	65.9	7.6	16.4	9.2	0.8
8. Did it include you in your child's transition planning and treatment?	61.9	5.5	20.8	0.6	11.2
9. Did it help prepare your child for living on her/his own?	82.8	6.8	10.4	0.0	0.0
10. Did it help prepare your child for being employed?	62.5	18.0	8.1	3.0	8.5
11. Did it help prepare your child for being fiscally responsible?	74.2	22.7	3.1	0.0	0.0
12. Did it help prepare your child for insurance/entitlement changes?	84.4	15.6	0.0	0.0	0.0

Table B-5
Special Education

Perceptions of the system	1	2	3	4	5
					(1=terrible, 5=wonderful)
	Percentage of respondents				
1. Did it know how other systems could be helpful?	17.7	43.2	15.4	13.5	10.2
2. Did it treat your child in a way that was consistent with his/her level of functioning?	14.4	9.7	46.8	15.0	14.2
3. Did it know about the needs of this group of young people?	20.6	8.0	60.7	8.7	1.9
4. Did it help you prepare for system changes during transition?	45.0	14.8	12.7	11.9	15.5
5. Did it guide you to relevant information and resources?	31.7	34.5	17.0	6.3	10.5
6. Was it respectful of you?	24.2	14.4	27.4	17.0	17.0
7. Was it respectful of your child?	28.3	14.3	31.3	9.0	17.2
8. Did it include you in your child's transition planning and treatment?	21.2	12.9	37.3	15.3	13.4
9. Did it help prepare your child for living on her/his own?	50.9	18.9	18.4	9.9	1.9
10. Did it help prepare your child for being employed?	43.3	29.8	8.8	14.9	3.3
11. Did it help prepare your child for being fiscally responsible?	59.8	18.2	7.5	12.3	2.2
12. Did it help prepare your child for insurance/entitlement changes?	84.2	14.3	1.1	0.0	0.4

Table B-6
Adolescent Vocational Rehabilitation

Perceptions of the system	1	2	3	4	5
					(1=terrible, 5=wonderful)
	Percentage of respondents				
1. Did it know how other systems could be helpful?	7.2	35.3	29.9	12.3	15.3
2. Did it treat your child in a way that was consistent with his/her level of functioning?	2.1	20.9	49.9	11.8	15.2
3. Did it know about the needs of this group of young people?	9.4	31.0	23.3	5.7	30.6
4. Did it help you prepare for system changes during transition?	35.1	21.3	19.2	2.4	22.0
5. Did it guide you to relevant information and resources?	48.3	0.4	20.5	9.5	21.2
6. Was it respectful of you?	18.8	11.5	7.2	17.2	45.2
7. Was it respectful of your child?	3.1	22.6	16.2	14.8	43.3
8. Did it include you in your child's transition planning and treatment?	32.9	0.4	8.4	8.0	50.3
9. Did it help prepare your child for living on her/his own?	18.0	17.3	25.9	0.1	38.7
10. Did it help prepare your child for being employed?	13.4	23.4	23.9	5.8	33.5
11. Did it help prepare your child for being fiscally responsible?	42.1	4.0	21.5	3.5	28.9
12. Did it help prepare your child for insurance/entitlement changes?	71.0	3.0	0.0	0.0	25.9

Table B-7
Child Welfare

Perceptions of the system	1	2	3	4	5
		(1=terrible, 5=wonderful)			
		Percentage of respondents			
1. Did it know how other systems could be helpful?	76.3	4.4	18.4	0.8	0.0
2. Did it treat your child in a way that was consistent with his/her level of functioning?	50.0	36.1	7.7	6.2	0.0
3. Did it know about the needs of this group of young people?	80.6	7.0	11.3	1.1	0.0
4. Did it help you prepare for system changes during transition?	85.0	0.9	14.1	0.0	0.0
5. Did it guide you to relevant information and resources?	90.2	0.3	8.21	1.2	0.0
6. Was it respectful of you?	69.2	10.2	9.7	10.8	0.2
7. Was it respectful of your child?	74.5	13.1	5.8	6.4	0.2
8. Did it include you in your child's transition planning and treatment?	69.5	18.2	11.3	0.8	0.2
9. Did it help prepare your child for living on her/his own?	80.0	19.7	0.0	0.2	0.0
10. Did it help prepare your child for being employed?	96.2	3.5	0.3	0.0	0.0
11. Did it help prepare your child for being fiscally responsible?	96.8	2.9	0.3	0.0	0.0
12. Did it help prepare your child for insurance/entitlement changes?	97.6	0.0	0.0	2.4	0.0

Table B-8
Juvenile Justice

Perceptions of the system	1	2	3	4	5
		(1=terrible, 5=wonderful)			
		Percentage of respondents			
1. Did it know how other systems could be helpful?	56.1	34.0	6.7	0.7	2.5
2. Did it treat your child in a way that was consistent with his/her level of functioning?	53.5	5.5	5.5	31.9	3.7
3. Did it know about the needs of this group of young people?	54.4	6.3	7.7	29.9	1.6
4. Did it help you prepare for system changes during transition?	86.9	5.8	6.7	0.1	0.6
5. Did it guide you to relevant information and resources?	64.2	4.4	0.3	30.7	0.3
6. Was it respectful of you?	43.1	11.3	36.5	0.1	8.9
7. Was it respectful of your child?	46.7	6.9	37.3	2.6	6.5
8. Did it include you in your child's transition planning and treatment?	79.2	10.9	4.5	4.9	0.6
9. Did it help prepare your child for living on her/his own?	88.0	6.5	4.0	1.0	0.6
10. Did it help prepare your child for being employed?	85.3	13.3	0.0	0.9	0.6
11. Did it help prepare your child for being fiscally responsible?	81.9	3.3	7.8	0.0	6.9
12. Did it help prepare your child for insurance/entitlement changes?	99.4	0.0	0.0	0.0	0.6

Effects of Child's Age, Gender, and Racial Background on Ratings of Children's Systems

A *p*-value of 0.003 or less was considered to be significant for examination of these demographic variables on systems ratings (0.05/(3 child systems + 3 adult systems) x 3 variables = 0.0028). The following are the statistics for each of the significant findings. Since

the average ratings are continuous variables, parametric tests were conducted: independent sample *T*-tests for gender and racial background (Caucasian vs. African American) on ratings of child and adult systems, and for age (18–20 vs. 21+) on ratings of adult systems.

There were no effects of youth's age, gender, or racial background on parents' ratings of children's systems.

Distribution of Ratings of Adult Systems

<div align="center">

Table B-9
Adult Mental Health

</div>

	1	2	3	4	5
		(1=terrible, 5=wonderful)			
Perceptions of the system	**Percentage of respondents**				
1. Did it know how other systems could be helpful?	37.9	21.9	17.4	0.0	22.8
2. Did it treat your child in a way that was consistent with his/her level of functioning?	8.9	33.6	20.0	37.6	0.0
3. Did it know about the needs of this group of young people?	36.0	9.0	32.2	22.8	0.1
4. Did it help you prepare for system changes during transition?	49.5	22.4	28.1	0.0	0.1
5. Did it guide you to relevant information and resources?	49.7	16.4	33.7	0.1	0.0
6. Was it respectful of you?	38.9	10.6	41.3	9.2	0.0
7. Was it respectful of your child?	36.5	0.3	25.5	32.2	5.5
8. Did it include you in your child's transition planning and treatment?	67.5	6.6	0.0	0.3	25.7
9. Did it help prepare your child for living on her/his own?	46.6	21.9	8.0	23.5	0.0
10. Did it help prepare your child for being employed?	60.8	2.3	36.9	0.0	0.0
11. Did it help prepare your child for being fiscally responsible?	66.3	8.8	24.8	0.0	0.0
12. Did it help prepare your child for insurance/entitlement changes?	67.8	8.3	23.9	0.0	0.0

Table B-10
Adult Vocational Rehabilitation

	1	2	3	4	5
		(1=terrible, 5=wonderful)			
Perceptions of the system	**Percentage of respondents**				
1. Did it know how other systems could be helpful?	28.9	7.8	13.3	27.3	22.7
2. Did it treat your child in a way that was consistent with his/her level of functioning?	20.3	27.0	21.7	5.6	25.4
3. Did it know about the needs of this group of young people?	0.2	37.4	27.9	11.5	22.9
4. Did it help you prepare for system changes during transition?	33.8	18.6	26.0	0.1	21.5
5. Did it guide you to relevant information and resources?	28.5	10.0	31.1	1.0	29.4
6. Was it respectful of you?	22.3	1.9	35.5	13.9	26.4
7. Was it respectful of your child?	0.1	24.2	32.4	12.4	31.0
8. Did it include you in your child's transition planning and treatment?	24.6	5.6	28.4	20.4	21.0
9. Did it help prepare your child for living on her/his own?	33.0	37.1	24.1	5.1	0.6
10. Did it help prepare your child for being employed?	11.1	58.9	21.1	7.1	1.7
11. Did it help prepare your child for being fiscally responsible?	37.4	35.3	26.6	0.0	0.6
12. Did it help prepare your child for insurance/entitlement changes?	35.9	40.3	23.2	0.0	0.7

Table B-11
Colleges

	1	2	3	4	5
		(1=terrible, 5=wonderful)			
Perceptions of the system	**Percentage of respondents**				
1. Did it know how other systems could be helpful?	29.8	9.8	32.3	5.4	22.8
2. Did it treat your child in a way that was consistent with his/her level of functioning?	26.4	25.9	5.2	37.7	4.8
3. Did it know about the needs of this group of young people?	0.1	24.7	9.5	37.3	28.4
4. Did it help you prepare for system changes during transition?	7.6	52.1	2.1	5.8	32.4
5. Did it guide you to relevant information and resources?	30.9	25.7	7.4	30.6	5.4
6. Was it respectful of you?	27.9	0.7	4.1	37.2	30.1
7. Was it respectful of your child?	4.3	0.0	29.2	34.3	32.1
8. Did it include you in your child's transition planning and treatment?	38.2	0.1	38.2	0.0	23.6
9. Did it help prepare your child for living on her/his own?	5.5	33.7	4.5	33.5	22.8
10. Did it help prepare your child for being employed?	30.5	24.3	8.8	36.4	0.0
11. Did it help prepare your child for being fiscally responsible?	37.1	24.0	2.9	36.0	0.0
12. Did it help prepare your child for insurance/entitlement changes?	37.3	25.8	0.0	36.8	0.0

Effects of Child's Age, Gender, and Racial Background on Ratings of Adult Systems

There were no effects of age or gender on parents' ratings of adult systems. There was a significant effect of race on parents' ratings of colleges: $t(df = 16) = -4.6$, $p<.001$.

Barriers to Services Encountered During the Transition from Adolescence to Adulthood

Effects of Child's Age, Gender, and Racial Background on Barriers Encountered

Nonparametric tests were used to examine the effects of age, gender, and racial background. The *p*-level was set at <0.002 ($0.05/(11$ items x 3 variables$) = 0.0015$.

Table B-12
Effects of Youth's Age, Gender, and Racial Background on Barriers Encountered

Characteristic and Barrier	Statistic (df)	p =
Age	χ^2(df=2)	
Most people in the service were considerably older or younger than your child.	34.4	<0.001
Service providers were too rigid.	15.9	<0.001
Service did not sufficiently/appropriately involve parents.	12.4	0.002
Service was not culturally competent/sensitive.	13.0	0.002
Gender	**Z**	
There was no source of information on available services or resources.	-3.6	<0.001
Racial Background	χ^2(df=2)	
Most people in service had more severe mental illness.	36.7	<0.001
Young person saw the service as stigmatizing.	54.7	<0.001

Important Service Components for Transition Support

The following table summarizes the distributions of the actual ratings for each system component.

Table B-13

Distribution of Parent Ratings of the Importance of Different Components of Transition Support

System Component	Ratings			
	1 little importance	2 helpful	3 important	4 most important
Affordable housing	1.2	0.9	17.9	80.0
Independent living skills preparation	1.2	2.6	13.9	82.3
Career/vocational training	0.5	6.3	8.3	84.8
Career/vocational development assistance	0.5	0.7	20.8	77.9
An easily accessible source of information	0.7	1.3	23.6	74.4
Advocacy groups for young adults	0.3	2.7	27.1	70.1
Supported work/job coaching	5.9	2.4	17.8	73.9
Positive peer support forums	0.5	4.9	30.0	64.7
Assistance with financial issues/insurance coverage regarding young person	5.0	2.7	23.3	69.0
A single system covering ages 16-25 years	6.5	1.7	21.2	70.6
Forum for young people to help develop and evaluate services	0.6	6.5	30.0	63.0
Forum for parents/family members to help develop and evaluate services	0.0	14.9	26.0	59.0
Advocacy groups for parents	4.9	6.0	30.8	58.4
Supported housing	8.9	10.2	14.8	66.1
Respite care	7.9	8.2	28.6	55.3
Service coordination (case management)	5.5	10.1	38.5	45.8
Transportation assistance	7.7	12.0	37.5	42.8

Effects of Child's Age, Gender, and Racial Background on Barriers Encountered

Nonparametric tests were used to examine the effects of age, gender, and racial background. The p-level was set at <0.001 (0.05/(17 items x 3 variables) = 0.00098.

Table B-14
Effects of Youth's Age, Gender, and Racial Background on Ratings
Of System Components for Transition Support

Characteristic and System Component	Statistic (df)	$p =$
Age	$\chi^2(df=2)$	
Advocacy groups for young adults	22.9	<0.001
Advocacy groups for parents	16.1	<0.001
Single system covering ages 16–25	29.1	<0.001
Transportation assistance	18.6	<0.001
Gender	Z	
Positive peer support forums	-3.3	0.001
Supported housing	-3.3	0.001
Single system covering ages 16–25	-3.2	0.001
Racial Background	$\chi^2(df=2)$	
Easily accessible source of information	32.0	<0.001
Supported housing	15.3	<0.001
Career/vocational training	14.6	0.001
Supported work/job coaching	28.4	<0.001
Advocacy groups for parents	24.7	<0.001
Positive peer support forums	20.0	<0.001
Respite care	18.6	<0.001

Important Policy Considerations for Transition Support

The following table summarizes the distributions of the actual ratings for each policy item.

Table B-15
Distribution of Parent Ratings of the Importance of Different Policies
Affecting Transition Services

Policy	Rating			
	1 little importance	2 helpful	3 important	4 most important
Include parents as much as possible in services for their children in transition.	0.6	0.6	20.3	78.5
Increase supports to minimize out-of-home placements.	0.0	3.2	23.0	73.7
Eliminate barriers to accessing adult services.	1.7	0.6	26.4	71.3
Teach providers how transition affects every area of life for a significant period of time.	0.6	0.0	32.9	66.5
Change law enforcement so that it is more informed and more flexible about addressing mental health issues and responding in a developmentally appropriate way.	0.6	6.2	20.4	72.7
Make all providers knowledgeable about this developmental stage.	0.1	1.1	34.7	64.2
Coordinate public and private systems to address transition needs.	0.1	5.2	26.1	68.6
Sensitize providers to cultural and family differences regarding the transition to adulthood.	0.6	5.0	32.5	61.8
Continue to include parents in services and treatment for young people over age 18.	1.2	4.9	33.4	60.5
Use young people's input to guide service development.	0.1	13.6	19.4	67.0
Measure young adult outcomes to guide system change.	0.7	10.3	30.9	58.1
Emphasize peer support in services.	0.0	16.7	20.1	63.1
Ensure that child and adult supports and treatment help youth fit in with their peers.	0.9	15.9	19.6	63.6
Minimize services that do not prepare youth for life in their communities.	3.4	10.0	42.5	44.1

Effects of Child's Age, Gender, and Racial Background on Barriers Encountered

Nonparametric tests were used to examine the effects of age, gender, and racial background. The *p*-level was set at 0.001 (0.05/(14 items x 3 variables) = 0.0012.

Table B-16
Effects of Youth's Age, Gender, and Racial Background on Ratings of Policy Considerations

Characteristic and Policy Component	Statistic (df)	*p* =
Age	χ^2(df=2)	
Change law enforcement.	17.6	<0.001
Young people's input should guide service development.	14.4	0.001
Gender	**Z**	
Make all providers knowledgeable about this developmental stage.	-3.89	<0.001
Racial Background	χ^2(df=2)	
Continue to include parents in services and treatment for young people over age 18.	15.4	<0.001
Teach providers how transition affects every area of life for a significant period of time.	17.0	<0.001
Coordinate public and private systems to address transition needs.	13.2	0 .001