

# Transition Age Youth (TAY) Needs Assessment

## Executive Summary

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### **Background**

The Carroll County Systems of Care group was formed to identify strategies to address three tasks/populations in Carroll County: 1) respite training, 2) substance affected newborns, and 3) transition age youth. In November 2008, the Systems of Care group established a TAY Planning Committee comprised of members from the Carroll County Core Services Agency, Get Connected, and the Local Management Board (LMB). The purpose of the TAY planning committee was to develop a plan to identify existing services for TAY and families, to pinpoint gaps in services, and to recommend strategies to close those gaps. Through a series of preliminary meetings and after a review of existing TAY literature, the planning team opted to form a TAY Advisory Committee comprised of county services providers, parents and youth to identify the needs of TAY and families.

This report summarizes findings from two TAY Advisory Committee meetings held in February and June, 2009, as well as focus groups with transition age youth and parents conducted in March, 2009. In the February meeting, participants suggested that focus groups would be the best way to learn about the perspectives and needs of TAY and parents. Data from the February meeting and the focus groups were summarized in separate reports and combined into a PowerPoint that was presented at the June TAY Advisory Committee meeting. The same presentation was also made to the Carroll County Local Management Board at their monthly meeting in May, 2009. Please see the appendices for a copy of the presentation.

### **Defining Transition Age Youth:**

Maryland defines TAY as all youth ages 18-21. For the purposes of this project, TAY were defined as youth ages 16 – 24 who are or were in the child-serving systems and have faced one or more of the following concerns: mental health disorder, substance abuse or developmental disabilities.

### **Broad Evaluation Questions Explored in Data Collection Activities**

Five primary questions were asked during our data collection efforts. They included:

*What are the....*

1. *Gaps in current knowledge about TAY in Carroll County?*
2. *Existing services for TAY in Carroll County?*
3. *Current challenges facing TAY and their families in Carroll County?*
4. *Needs of TAY and families in Carroll County?*
5. *Recommendations for improving services and accessibility to services for TAY in Carroll County?*

### **Methods**

Three data collection efforts were undertaken, two participatory meetings and focus groups with transition age youth and families.

1. TAY Advisory Committee Meeting #1 2/2/09 (N=35)
  - 25 providers completed an On-the-Wall Survey and engaged in interactive discussions following presentations by youth and parent speakers

- 10 other participants attended including TAY Planning Committee Members, parents, and youth
- 2. Focus Groups with Parents and Youth: 3/12/09 at the Carroll County Non-Profit Center
  - 9 Youth and 8 Parents
- 3. TAY Advisory Committee Meeting #2 6/4/09 (N=15)
  - 12 providers and parents participated in interactive discussions that focused on drawing conclusions from the data and making recommendations to improve services

Please see the appendices for summaries of each data collection activity. The next section presents participant characteristics followed by highlights of the findings by key evaluation question. Please note that the highlights focus exclusively on the first TAY Advisory Committee meeting and the focus groups because that is where the data was collected. The purpose of the second TAY meeting was to present the data, draw conclusions, and make recommendations for moving forward.

## Findings

### Participant Characteristics

Participants of the February TAY meeting represented a range of providers (see Table 1) who had extensive experience working with transition age youth. Indeed, 80% reported having a “great deal of experience” working with TAY and 50% had a family member or an extended family member that is, will be, or had been a TAY.

**Table 1**

<b>Provider Characteristics: Number of Participants Representing...</b>	<b>(N=25)</b>
• ...Developmental Disabilities	8
• ...Education	5
• ...Mental Health	4
• ...Substance Abuse	2
• ...Other	6

Focus group demographics are shown in Table 2 below. Parent participants described having youth with a wide range of circumstances, challenges, and opportunities including:

- Son graduated, working at CVS
- Two children with development disabilities
- Daughter at Carroll Community College
- Son diagnosed with ADHD and Asperger’s
- Son with psychotic episodes
- Foster daughter attending Junction
- Daughter with Fetal Alcohol Syndrome

**Table 2**

	<b>Parents (N=8)</b>	<b>Youth (N=9)*</b>
Gender	• Female (n=8)	• Female (n=5)
Age	• 30-39 (n=1) • 40-49 (n=4) • 50-59 (n=3)	• 16-18 (n=4) • 19-24 (n=2) • 25-29 (n=1)
Race	• All White	• All White

Evaluation Question #1: Gaps in Current Knowledge/ Strategies to Fill Gaps

This evaluation question was addressed in the February TAY meeting. In the On-the-Wall Survey, fewer than 50% of providers “agreed” that Carroll County provides needed services to TAY and over 60% “disagreed” that we have a strong understanding of TAY and their families (who they are & what they need). Participants indicated that they wanted to learn from TAY and families about:

- Why some TAY/families will not accept available services (10)
- Problems with system navigation (5)
- What they want/need (4)
- What is going well (3)
- Housing issues (3)
- Available transportation (2)

Evaluation Question #2: Existing Services

Participants of both the February TAY meeting and the focus groups were asked to mention the agencies that came to mind when they thought about transition age youth. In Table 3 below, the numbers represent the number of times a particular agency was mentioned. Interestingly, the agency most familiar to providers – DORS – was not mentioned at all by parents and was minimally mentioned by the youth. When asked this question, parents tended to focus on the quality of services in general rather than specific service providers

**Table 3**

Agencies Mentioned More Than Once	Providers	Parents	Youth
• DORS	10		2
• CHANGE, Inc.	3	1	1
• Get Connected	2	1	2
• Target	2		
• Junction	2		
• ARC of Carroll County	2		1
• CCPS – Carroll Springs	2	1	
• YSB	1	1	
• CC Hospital – Drug Rehab			2

In the February meeting, providers were asked to indicate which agencies do the best job providing services for TAY in Carroll County. They were also asked which agencies need work. Respondents indicated that Get Connected and Service Coordination did the best job and that transportation was the area that needed the most work.

**Table 4**

Agency	Best Job	Needs Work
• Transportation/CATS (12)		XXXXXXXXXXXX
• Get Connected (8)	XXXXXXXX	
• Service Coordination/DDS (6)	XXXXXX	
• DORS (4)	XXXX	XXXX
• CCPS (3)	XXX	XXXX
• Housing (2)		XX
• Target, Inc (2)	XX	
• ARC of Carroll County (2)	XX	
• CHANGE, Inc. (2)	XX	

Similarly, focus group participants were asked to indicate which agencies provided the most and least helpful services for TAY in Carroll County. As illustrated in Table 5 and in sharp contrast with providers, neither parents nor youth mentioned transportation in response to this question (though they did mention it later). However, they did, like providers, express the most satisfaction with Get Connected. Finally, while providers expressed concerns about CCPS, the parents were far more likely to do so.

**Table 5**

Agency	Most Helpful	Least Helpful
• DORS	YY	PYYY
• CHANGE, Inc.	PY*	Y
• Get Connected	PYY	
• CCPS	PY	PPPPPY
• YSB	P	
• CC Hospital	YY	

\*P=Parent Comment and Y=Youth Comment

Evaluation Question #3: Current Challenges Facing TAY and Families in Carroll County

Providers, parents and youth were asked to talk about the main challenges facing TAY and families in Carroll County. As indicated in Table 6, providers described ‘transition issues’ in general as the greatest challenge. A sampling of ‘transition issues’ includes:

- *Parents are written out of treatment options when their children turn 18*
- *Parents are exhausted by the time the youth are 18*
- *Youth may be 18-21 years old and legally an adult, but they are not emotionally or developmentally an adult – we can’t expect them to carry the load of an adult*
- *Ages 18-21 is a void – youth cannot access services, isolated due to lack of transportation*
- *Families are resistant to services*
- *There is a resistance with 18-22 year olds because their families have not received good services in the past and the youth no longer want to deal with service providers*

When asked about challenges specific to ‘access,’ providers mentioned funding streams (15), parent/child follow through (9), and lack of knowledge about accessible services (6). Ironically, they made little mention of transportation.

**Table 6**

Challenges	Providers
• Transition Issues	XXXXXXXXXX
• Services not tailored to TAY	XXXXXX
• Transportation	XX
• Lack of coordination	XX
• Difficult to navigate services	X
• Waiting lists	X

Focus groups participants were asked to talk about the current challenges facing TAY and families. The access related issues are presented in Table 7. In response to this question, parents, and less so the youth, picked up on the transportation theme. In addition, parents and youth mentioned ‘lack of services,’ and ‘long waiting lists’ as barriers to access. Parents also indicated ‘having to fight for services.’ This latter point is an interesting contrast to providers’ interest in wanting to better understand ‘why some TAY/families will not accept available services’ (from Evaluation Question 1).

**Table 7**

Access Issues	Parents	Youth
• Transportation	XXXXXXXXXX	XXXX
• Lack of services	XXXXXXXXXX	XXX
• Long waiting lists	XXX	XXXX
• Have to fight for services	XXXX	
• Cost	XXX	X
• Unaware of services	XX	X
• TAY issues all consuming	XX	X

Finally, parents were asked what services, agencies, and/or supports they utilized outside of Carroll County. While a range of services was listed, the most frequently mentioned was mental Health (5). The services mentioned just once included medication management, dental care, educational services, substance abuse treatment, respite care, and primary care doctors.

Evaluation Question #4: Needs of TAY & Families in Carroll County

Providers, parents, and youth were asked to share their insights about the key needs of TAY and families. Table 8 lists the themes that emerged from their responses. Each 'x' indicates a comment made by a respondent. Not surprisingly, there are far more comments made by providers than by parents and youth simply because more providers participated in the data collection.

Among the top two needs identified, 'ongoing support' and 'support groups/mentoring,' there was agreement between providers, parents, and youth that these were the most critical steps to address the needs of TAY and families. With respect to the third need, 'more programs/eliminate waiting lists,' parents and providers seemed to concur that this too was an important strategy to undertake. Relative to the other strategies listed, youth expressed the greatest interest in peer support groups and opportunities for socialization, while parents selected 'ongoing support.' Providers were equally split over 'ongoing support' and 'support groups/mentoring.' They were also in favor of 'more programs/eliminate waiting lists' and 'job placement services.'

**Table 8**

Needs	Parents	Youth	Providers
• <b>Ongoing Support (n=35)</b> -- Family Navigator for TAY*; tailored services, family empowerment	XXXXXXXXXX XXXXX	XXX	XXXXXXXXXX XXXXXXX
• <b>Support Groups/Mentoring (n=29)</b> -- for parents, peer, siblings; peer socialization for youth	XXXXX	XXXXXXXXXX	XXXXXXXXXX XXXXXXX
• <b>More Programs/Eliminate Waiting Lists (n=17)</b> - life skills training, mental health services	XXXXXX	X	XXXXXXXXXX
• <b>Job Placement Services (n=14)</b> - career development/job skills; access to challenging jobs	XX	X	XXXXXXXXXX X
• <b>Housing (n=9)</b> -- residential services, supported, appropriate housing; transitional housing	XX	X	XXXXXX
• <b>Transportation (n=7)</b> – increase availability of transportation for TAY and families			XXXXXXX
• <b>Medical Services/Crisis Care – (n=7)</b> access to, health insurance	XXX	X	XXX
• <b>System of Care (n=5)</b> -- youth driven, culturally competent; integrated treatment for dually diagnosed; greater agency/system cooperation			XXXXX
• <b>Increase Awareness (n=3)</b> -- ..of services	X	XX	
• <b>CCPS (n=3)</b> -- Improve post-secondary	X	XX	

\*Parents and Youth were asked specifically about this

## Evaluation Question #5: Recommendations

Throughout the data collection activities, participants were asked to share their recommendations to improve TAY services. As is often the case, the recommendations listed below directly mirror the stated needs. The detailed suggestions, shown as sub-bullets below, were offered by TAY Advisory Committee members in both the March and the June meetings.

### **Improving TAY Services**

- Develop and/or expand ongoing (beyond age 18), tailored support/services for TAY & families
  - Develop a TAY navigator position
  - Improve collaboration and communication between agencies
  - Ensure understanding of the roles of various agencies (e.g., DORS)
- Create and/or expand support groups/opportunities for socialization for youth, parents, siblings
  - Increase inclusivity of young adults with disabilities among community groups (e.g., YMCA) and employers, include these youth in existing program
- Improve career development/job placement opportunities

### **Improve TAY Access to Services**

- Create a comprehensive and up-to-date list of available resources
- Increase awareness of services
  - CCPS – Include in students' IEPs information about DORS and transition
  - Create CHC discharge brochure, clearly define what agencies can offer
  - Increase use of technology to reach youth – e.g., through internet
  - List services on existing websites – e.g., LMB, Get Connected, CCPS Resource Directory
  - Increase outreach to non-English speaking population to improve or create awareness
- Lessen waiting lists by expanding available services
- Improve public transportation in Carroll County

## **Conclusions**

The purpose of this project was to explore the needs of TAY and their families in Carroll County. While providers, parents, and youth varied somewhat in their recommendations to improve services, there were key commonalities. It is critical to understand those commonalities and to use them as a foundation for moving forward. Keep in mind that this executive summary provides only the highlights of the findings. As planners come together over the next few months to develop strategies and action steps, it will be important to revisit the full summaries of each data collection activity, particularly the June meeting summary. In this last meeting providers talked extensively about the CCPS system; its role in working with TAY and families; concerns about CCPS fostering a sense of dependency and entitlement among parents and youth; and, collaborative efforts between CCPS and other agencies including Carroll Hospital Center and the Youth Services Bureau. In addition, transportation and housing representatives shared valuable insights that were documented in the meeting summary.

Finally, there can be an inherent tension in projects involving parents/families and providers. This was evidenced in the findings, where for example, parents reported having to fight “tooth and nail” for services and providers seeming bewildered that parents do not “accept available services.” When developing strategies to improve services, it is important to understand this disconnect given that it could stem from a genuine lack of awareness of services, or from services that don't adequately meet the needs of TAY and their families. Naturally, for planning purposes, there is great value in recognizing the distinction between a lack of awareness and concern over services. Both providers and parents/families need continued opportunities to freely speak their minds, and, just as importantly, to listen to each other. We encourage the TAY Planning Committee to continue to guide future TAY efforts in a spirit of cooperation and respect.