

Who Are the Young People Involved in the Youth Advocate Program in Pennsylvania, and How Are They Doing?

Report on the First Visits

Brief Report #1 of the Youth Advocate Programs Outcomes Project

Submitted to:
Youth Advocate Program
Harrisburg, PA

Submitted by:
Center for Outcome Analysis
426B Darby Road
Havertown, PA 19083
610-668-9001
www.eoutcome.org

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This report describes the kinds of young people who are involved with the Youth Advocate Program in 2005, what supports they are getting, and some early but very strong findings about the outcomes of their involvement.

This is only the first in a series of reports, all of which will be aimed at getting the answer to one single and simple question:

“Are they better off?”

For all kinds of accountability, any social program needs to be able to show that the people involved in it actually benefit from it. We ask, “Are they better off?” because of their participation in the Youth Advocate Program, and then, if so, we ask,

“In what way(s)?”

“How much?”

“At what costs to families and taxpayers?”

In 2004, the YAP contracted with the Center for Outcome Analysis (COA) to get answers to these questions. We began a collaboration that is expected to last many years. We intend to measure, year after year, what benefits, if any, the participants get from taking part in the YAP. Do their lives and the lives of their families get better? Do they adapt better to their schools and communities? Do they grow and learn and become more independent? Do they achieve the goals that they and their families want to achieve?

To begin this long-term work, we needed to visit with every participant and collect good solid scientific information from the young people, their families, and the people who worked most closely with them. This is called “baseline data” by social scientists, but in regular English, this is the “before” measurement.

To get this done, COA adapted its measurement scales for the YAP and its participants. COA has measurement scales and instruments and forms that have been developed and tested over a 30 year period. These instruments can be seen at www.eoutcome.org. The version compiled for the YAP efforts is attached to this Brief Report as Appendix A.

The Center for Outcome Analysis conducted training of YAP workers so that they could collect the quality information. But no YAP worker was permitted to collect information from any participants to whom they provided supports. This avoided conflict of interest to the greatest extent possible. This method has been used by COA and other scientific groups for evaluation of public programs for many years, with excellent success. The data were collected from May to December 2005.

This Brief Report summarizes what we have learned from this first round of visits. The data we collected were computerized by COA and analyzed independently of the YAP to assure objectivity.

Soon we will visit every participant again. This will give us “before and after” information, so that we can find out whether the participants’ lives are improving over the months they are involved with YAP, and, if so, in what way(s), and how much.

So this Brief Report is mostly descriptive. What kinds of young men and women are involved? What are their disabilities and abilities? How old are they, what are their individual program goals, where do they live, what are their behavioral skills and repertoires, what challenges do they present, what are the qualities of their lives, and what kinds and amounts of supports do they receive?

Finally, although we cannot yet do the full “before and after” outcomes analysis, we used a few scales that asked people what they remembered from before they got involved with the YAP. This enables us to report preliminary data on outcomes (changes in people’s lives since they got involved), and they are quite encouraging.

Results

The Youths: Descriptive Information

The first round of visits with YAP participants included 128 people. Not all data could be collected for every person, so in the tables that follow, the numbers will not always add up to 128.

Figure 1
Gender, Ethnicity, Age

Male	85%
Minority	20%
Average Age	9

The ages of the participating children range from 2 to 17 years old, with a mean age of 9 years. These children reflect the Pennsylvania ethnic makeup fairly well – about 80% of the participants are Caucasian-American, 7% identify as African-American, 5% as Hispanic-American, 2% Asian-American, 2% Native-Indian-American, and the remaining 4% report some ethnic combination .

The following table shows the percentage of participants who report “major” or “minor” disabilities. (Families were asked to self-define these terms, according to common sense and experience – the things they found to be larger or smaller challenges.)

Figure 2
Disabilities Reported by Families

Disability	Major Disability	Minor Disability
Autism	37.5	26.6
Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)	33.6	12.5
Communication	32.8	25.0
Pervasive Developmental Disorder (PDD)	22.7	12.5
Asperger's Syndrome	17.2	5.5
Behavior: Aggressive or Destructive	14.8	28.9
Health Problems	11.7	14.1
Severe Regulatory and Attention Disorders	11.7	12.5
Other Diagnosed	11.7	7.8
Multisystem Developmental Disorders	8.6	7.8
Mental Retardation	7.8	14.8
Seizures	6.3	11.7
Behavior: Self Abusive	3.9	19.5
Brain Injury	3.1	1.6
Mental Illness	3.1	2.3
Physical Disability Other Than Ambulation	3.1	3.9
Ambulation (Walking)	2.3	3.9
Cerebral Palsy	2.3	0.0
Hearing	2.3	6.3
Vision	2.3	14.1
Other, not Diagnosed, but Suspected	2.3	3.9
Substance Abuse	1.6	0.0
Down's Syndrome	0.8	0.0
Landau-Kleffner Syndrome	0.8	0.8
Rett's Syndrome	0.8	0.0
Fragile X Syndrome	0.1	1.6
Fetal Alcohol Syndrome	0.0	1.6

The five most frequently reported major disabilities were Autism, Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), Communication, Pervasive Developmental Disorder (PDD), and Asperger's Syndrome. A wide variety of other disabilities were reported as minor and major. About a fifth of the youth were reported to have some level of mental retardation, about a tenth had

physical or ambulation difficulties, and about a fourth were reported to have self-abusive behaviors.

The majority of the participants (92%) live at home with their families as we would expect by their age. Only 15 families reported that their child had ever been removed from the family home for treatment.

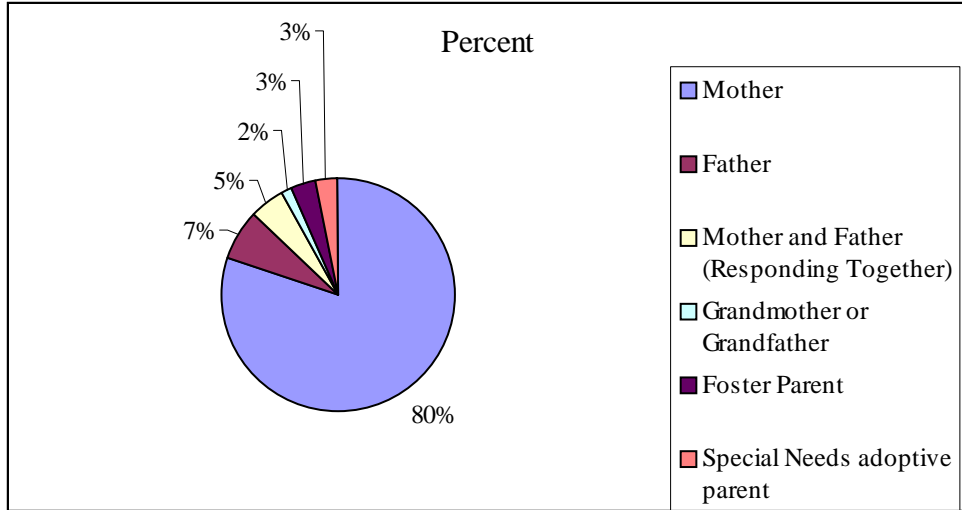
The primary respondents for this survey were the family members, and they were primarily mothers.

Figure 3
If someone other than the young person is answering all or most of these questions, What is your relationship to the YAP service recipient?

Relationship of the Respondent to the Participating Young Person	Number	Percent
Mother	100	78.1
Father	9	7.0
Mother and Father (Responding Together)	6	4.7
Grandmother or Grandfather	2	1.6
Foster Parent	4	3.1
Special Needs adoptive parent	4	3.1
Other (PLEASE SPECIFY)	2	1.6
Left Blank	1	.8
Total	128	100.0

Displayed in chart form:

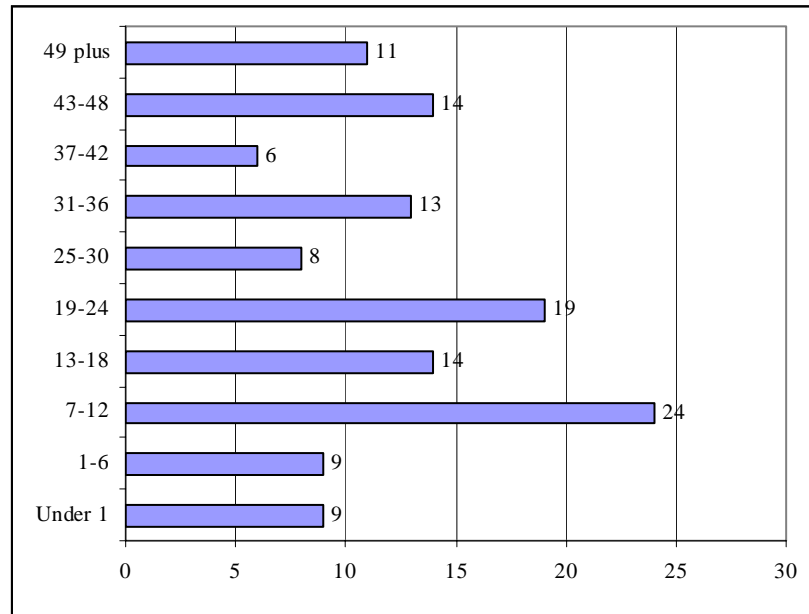
Figure 4
Relationship of Respondents to the Young Participant



Results About Participation in the YAP Network

We asked, “About how many months has your family gotten help from the Youth Advocate Program?” The answers ranged from less than 1 month to 84 months, with an average of about 25 months, or just over 2 years.

Figure 5
Months of Participation in YAP Supports



Are the Families and the Youths “Better Off”?

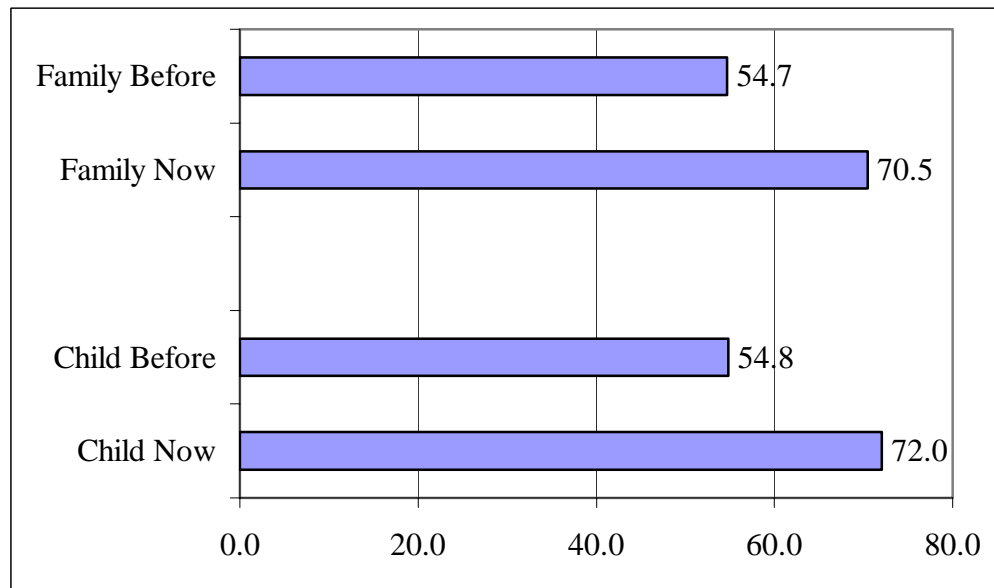
On page 4 of Appendix A, survey item (4) is about the Family’s Quality of Life, BEFORE getting involved with YAP and NOW. Families rated their Qualities of Life in 16 areas, Before getting involved with YAP, and NOW, during their involvement.

On Page 5 of Appendix A, we asked similar questions about the Youth’s Qualities of Life, BEFORE YAP and NOW, in 15 areas.

The results from these scales are impressive. We combined all the items from the Family QOL section into a single 100 point scale, and did the same for the Youth QOL section. Higher scores mean higher Quality of Life overall. The

highest possible is 100, the lowest 0. The graph below summarizes what we found on the Family and the Youth scales.

Figure 6
Family and Youth Overall Quality of Life Scale: Before and Now, During YAP



Both the families and the children scales showed more than 15 points gain out of 100 points. In long experience with these scales, we know enough to interpret these changes as very large. We conclude that the families believe that they are much better off since getting involved with YAP, and they believe their children are too.¹

These findings are particularly important, in the view of the Independent Evaluators. Even though they rely on memory, these are more than mere “satisfaction” findings. A family could be very satisfied with services received, even if there are no real changes in Quality of Life. This is a very common finding in pure satisfaction research (Nerney & Conroy, 2003).

¹ Both changes are statistically significant, using the Paired-t test, beyond the .0001 level. This means the odds that such large changes happened by chance alone are less than 1 in 10,000.

These, then, are the first concrete outcome data for the Youth Advocate Program. They are very encouraging. The families and the young people are very significantly “better off” now than they were before getting involved with YAP.

Next, we need to find out if these trends continue year after year.

Although we have summarized the results for this first Brief Report, we can also break down these results by the exact areas of Quality of Life. This will enable YAP workers and families can see where success is highest, and where more attention might be needed. We will do this analysis and provide another Brief Report upon request. Depending on schedules, this kind of feedback to YAP questions about the data can take anywhere from an hour to a week. The main point is that, now that the Baseline data are in hand, further analyses can be done quickly.

Relationships Between Families/Youths and YAP Workers

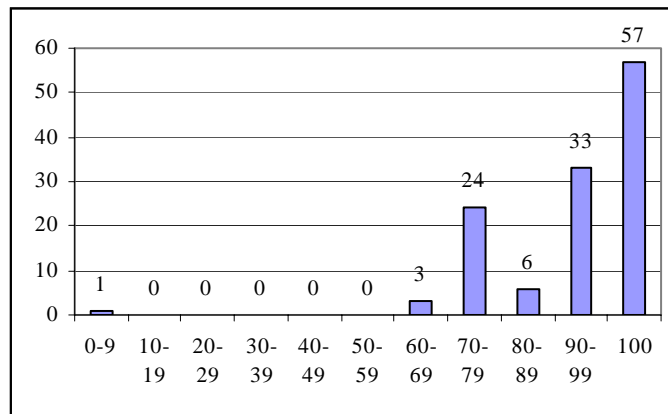
On page 6 of Appendix A are the questions and scales we asked about the relationships between the families and the youth and the YAP Support Workers, sometimes call Therapeutic Support or TSS workers.

The literature on Quality of services and supports over a 40 year period, from institutions to nursing homes to community living and self-determination strongly suggest that the relationships are “where the rubber meets the road” in quality of supports and services. These scales were included because of this

knowledge about the importance of relationships in delivering high quality supports and services.

Once again, we put all the items together and calculated one single score for the Family's and the Youth's relationship with the YAP workers. We graphed the results as though they were "grades" in school. There were a lot of 100 point grades, so we broke them out separately. If 90 and above were an "A," then the YAP worker relationships with families would be a strong "A" overall. There were a few "Bs" (6) and some "Cs" (24), with only a handful or borderline failing "grades."

Figure 7
100 Point Scale of the Quality of the Family's Relationship with Primary YAP Worker



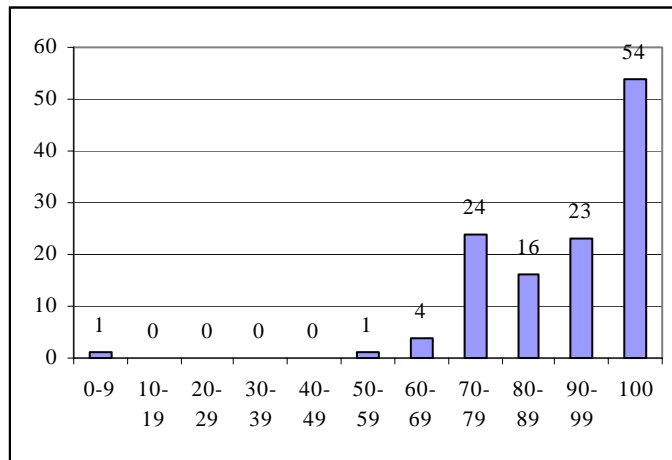
The way to read this graph is to look at how many families scored their relationship with the worker toward the high, or 100 point, end of the scale. A lot of the families (57 out of 128) rated every item at the highest possible, for an overall total of 100 points. Another 33 families gave ratings that totaled above the 90% level. These are powerfully positive findings.

The lack of low ratings is also very important. Only one family gave a very low rating, over on the left of the graph. What do the ratings mean in the 70 to 79 percent range? We would suggest further interviews of those specific families. The first thing to answer is the simplest question – were these 24 families just “hard graders,” or did they really have lower qualities of worker relationships than the other families?

Again, these findings can be broken down by items within the Worker Relationship scales, and we can learn more about which aspects of relationships are the strongest, and which might need more attention.

Figure 8 shows the parallel findings for the relationships between the youths and the workers. These came out almost exactly the same as the family findings.

Figure 8
100 Point Scale of the Quality of the Youth’s Relationship with Primary YAP Worker



Of course, it is possible in theory that a youth would have a great relationship with a worker while the family did not – and vice versa – but the overall results do not show this to be common. The rare cases where this did happen could be identified for further study, if that might be helpful.

Is the Individual Planning Process “Person-Centered”?

Families were asked to respond to statements about the treatment planning process, to describe how they rated various aspects of the process. The survey items can be seen in Appendix A, page 7. This scale was originally designed to measure the ideal of “person-centered planning” as originally created by Beth Mount.¹ Our “Elements of the Treatment Planning Process” scale has been used all over the U.S. during the past decade, and has been shown to be a reasonably accurate reflection of the “best practice” that we generally call “person-centered planning.”

Each item is asked on a 1 to 5 point scale from Strongly Disagree to Strongly Agree. In general, agreement means that the process was person-centered. The actual average scores from YAP families are show in Figure 9.

Figure 9
Elements of the Treatment Planning Process

1=Strongly Disagree 2=Disagree 3=In-Between 4=Agree 5=Strongly Agree	
4.1	Planning really includes [my/his/her/our] dreams.
4.2	Planning tries to build networks of support from family, friends and community.
4.3	Planning meetings are comfortable and relaxed for us.
4.3	Treatment plan meeting schedules are flexible.
4.4	The planning team is creative – thinking of new ideas, new ways to get things done, different approaches.
4.4	Our planning can handle disagreements, we can get past them.
4.5	Our planning is flexible – we will try a different way if something is not working.
4.4	If others in the planning group can't agree, the family has the final word (as long as it's not dangerous or unhealthy).
4.4	Cooperation is important in our planning – no one group is 'in charge.'
4.2	Our planning works a lot on our child's relationships and friendships.

As shown above, the average family response were in the “Agree” to “Strongly Agree” range on all of the statements about the planning process. The strongest score was on flexibility and the weakest was on including children’s dreams. (We hasten to note that the “dreams” item is more applicable to teens and adults than it is to young children, who haven’t planned out what they want yet.)

We then took all the items and combined them to create an overall 0 to 100 point score. Using this method, the average rating was 84. For comparison, in an institution in Delaware the average score in 2001 was 61. In our studies of self-determination initiatives in other states, the scores on this person centered planning scale ranged from 65 to 72 before getting involved with self-determination.

Thus, the average score of 84 for YAP participants should be interpreted as good evidence of best practice in Person-Centered Planning. We will be interested to see if these score go even higher in the years to come.

Individual Goals When Beginning YAP Involvement

Every family and young person comes into the YAP support system with ideas of what they want to accomplish. This is what is clarified during the initial Person-Centered Planning process that was evaluated in the previous section.

For our Outcomes Survey, each participant listed his/her top five individual goals when they started working with YAP. The goals were listed in the words of the participants/families. We did not limit participants to a pre-defined list of goals. The data collection format is on the bottom of page 7 of Appendix A.

A review of the goals (via content analysis) showed that the largest proportion of goals were related to acquiring or improving communication skills. The next most popular group of goals concerned attention, and extended all the way from attending to specific activities, to increasing the span of attention in general. The third highest category related to social skills, friendships, and relationships. Among dozens of other kinds of goals, we noted that there were a lot related to behavior change, especially aggression and anger management

Progress Toward Individual Goals

We also asked how much progress each youth had made toward achieving each goal on a scale of one to five, ranging from major loss to major gain. The average response was above four, meaning between some gain and major gain.

Figure 10
Goal Attainment Ratings

# People With A Goal	Average Score
111	4.3
111	4.2
106	4.1
92	4.1
64	4.2

The figure shows that 111 people described their #1 goal to us, and the average progress toward that goal was 4.3 on a 5 point scale. The same 111 people listed a second goal, and progress toward that one was almost as strong, at 4.2. Moving down the table, fewer people had the higher numbers of goals, but the achievement scores remained quite high, always above 4.

Again, we combined all five goals for each person, and calculated an overall index of Goal Attainment on a scale from 0 to 100. The average score was 79 points. This can be interpreted as quite positive. It is not unusual on this very same scale to find scores in much lower ranges. In California institutions, for example, our average score among 800 people was 46 on this scale. Later, when they came out to community homes, these scores increased to an average of 71, meaning they were experiencing much better achievement of their individual plan goals in the community than they did in institutions.

Judging by the high average score of the YAP participants, we must conclude that significant progress toward individual goals is, in fact, being made. This can be explored in far more detail in the future, but for the time being, this is a strong indicator of the “ultimate” outcome: people and their families are moving strongly toward what they, individually, want to achieve.

Valued Outcomes

We asked families to review the list below and to rank the five most important things concerning their child’s well-being. The survey item is on page 8 of Appendix A. Figure 11 shows the “scores” we calculated from these ratings. The higher the score, the higher the average importance given to that outcome area.

Figure 11
Valued Outcomes:
Important Things Concerning Young Person’s Well-being

Academic achievement (doing well in school)	1.28
Assistive devices	0.01
Being kept busy	0.25
Being with peers	0.63
Choicemaking	0.48
Comfort	0.36
Community acceptance	0.67
Development, learning	1.23
Development of speech and language	0.88
Dignity, respect	0.47
Exercise, fitness	0.19
Freedom from abuse	0.16
Friends	1.12
Girlfriends/Boyfriends	0.01
Health	0.56
Integration, inclusion	0.37
Love	0.77
Medical attention	0.20
Permanence of home	0.25
Recreation	0.12
Religion, worship	0.30
Safety	0.90
Self-esteem	0.80
Self-care skill development	1.21
Self-determination	0.13
Supports for problematic behavior	1.11

The top five scores on the list are boldfaced above. The highest-rated “valued outcome” among these 128 families was success in school, or “Academic Achievement.”

Figure 12
Top Five Valued Outcomes Across 128 Families

Academic achievement (doing well in school)	1.28
Development, learning	1.23
Self-care skill development	1.21
Friends	1.12
Supports for problematic behavior	1.11

We collected this information to inform program policy designers about the most common priorities among the families involved with YAP. Although every family, and every young person, can and do value outcomes differently, it may be useful to have an idea what the overall hopes and dreams are for the families of these young people.

However, we note that these findings do not show one to one correspondence with the individual goals that have been set in the Person-Centered Planning process. We should take these findings and interpret them with caution until we can explore the differences between the two sources of information and understand them better.

Summary

This first Brief Report of the Youth Advocate Programs Outcomes Project shows that the youths and families involved are experiencing compelling and positive outcomes. Although these results are preliminary, in the scientific sense that we have not measured “before and after,” and do not have a “control group,” we can be very confident in the conclusion that the families believe that their lives, and the lives of their children, are significantly better now than they were before getting involved with YAP.

A long and credible body of knowledge indicates that the best single predictor of “quality” in human services of any kind is the relationship of the service recipient with the primary support worker. The data from the YAP baseline study indicate extremely positive relationships between families & youths and their primary workers. This is a very positive finding, and yet the data will support further exploration and even more understanding of, and improvement of, relationships with the YAP front line workers.

We collected our scale of Person-Centered Planning, and found that the process within YAP is strong, scoring as high as we have seen in any other projects, including self-determination pilot initiatives (Conroy et al, 2002). We conclude that the YAP efforts do in fact match “best practice” in the field. Still, the data can be analyzed further to show which areas might benefit from even more attention.

The individual goals set by each participant were summarized and analyzed. We measured and scored Goal Attainment among the participants, and found strong evidence that the participants have been making very good progress toward the goals they set for themselves. This can be viewed as the “ultimate outcome” in a very real sense – it measures the extent to which people come into the program with things they want and need to accomplish, and accomplish those things. In this baseline data set, the Goal Attainment numbers are quite high.

Finally, we asked families to prioritize their most valued outcomes from a list of 25 areas. The results emphasize academics, skills, relationships, and behavior, followed closely by safety and communication. There were some differences between this way of asking about priorities and the priorities as reflected in the actual individual goals. These differences merit further study. Nonetheless, it is very useful to have a concrete idea of what families say they want the most, so we can always compare those wants to the ideas being promoted by professionals. If they are different, then it is probably the professionals who need to think about change.

References and Notes

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Appendix A

Youth Advocate Programs

Family Survey, 2005
