

Youth Advocate Program

Family Survey

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The Center for Outcome Analysis

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Consent Form for Interview About the Youth Advocate Program

We of the Youth Advocate Program and the Center for Outcome Analysis are asking you to talk with us about your quality of life – what’s good, and not so good – in [your life and your family’s life/your life and your child’s life].

Before you agree, we have to tell you:

1. The purpose of the work: To measure how well YAP is doing in helping young people with disabilities.
2. Why we need evidence: Getting solid evidence of how YAP works well is very important for keeping the program going, getting funding – and for making it better.
3. What we’re going to ask you to do: To complete a private survey about [your life/your child’s life] and services – and your own life.
4. The risks to you (if any): We don’t know of any risks in doing this survey. It will not have any effect on [your/your child’s] qualification for services.
5. The benefits to you (if any): Learning about how YAP is working will help YAP get more funding and keep going. Also, you can make a copy of the information in the survey, and it should be useful in your future IEP meetings.
6. The possible benefits to all other people: Evidence of YAP’s effectiveness will help all current recipients and future ones too.
7. That you can refuse, and that’s no problem: There will be absolutely no problem to you or anyone else if you decide not to take part.
8. That you can agree, then change your mind and stop, and that’s no problem: There will be absolutely no problem if you stop anytime during the interview.
9. That we will keep everything private, including who you are and what you say: We will keep your name, and the names of the people supporting you, completely private, and we will never tell anyone what you yourself say.

IF YOU AGREE to do this interview, please sign or check the space below.

General Information

The Young Person Receiving Youth Advocate Program Services:

First Name

M.I.

Last Name

Person's Complete Mailing Address, Including Apartment #, Line 1

Person's Complete Mailing Address, Including Apartment #, Line 2

City or Town

State

Zip Code

Telephone Number of the Home

The YAP Person Conducting This Interview:

Interviewer

Title or Relationship to Person

____/____/____

Today's Date

Individual Descriptive Information About the Young Person

1. DATE OF BIRTH

____ - ____ - ____

Month Day Year

2. AGE

3. GENDER

_____ 1 Male

_____ 2 Female

4. PRIMARY ETHNICITY

_____ 1 Indian/Native American/Alaskan

_____ 2 Asian/Pacific

_____ 3 White, Caucasian

_____ 4 Black, African-American

_____ 5 Hispanic, Latino

_____ 6 Other

_____ 7 Combination of two or more

_____ 9 Unknown

5. Have [you/the young person] ever been given any of these labels or diagnoses? (Please define Minor and Major any way)

you like.)

0 = No disability

1 = Minor disability

2 = Major disability

- _____ 5A. Ambulation (Walking)
- _____ 5B. Asperger Syndrome
- _____ 5C. Autism
- _____ 5D. Behavior: Aggressive or Destructive
- _____ 5E. Behavior: Self Abusive
- _____ 5F. Brain Injury
- _____ 5G. Cerebral Palsy
- _____ 5H. Communication
- _____ 5I. Down Syndrome
- _____ 5J. Fetal Alcohol Syndrome
- _____ 5K. Fragile X Syndrome
- _____ 5L. Health Problems: _____
- _____ 5M. Hearing
- _____ 5N. Landau-Kleffner Syndrome
- _____ 5O. Mental Illness: _____
- _____ 5P. Mental Retardation
- _____ 5Q. Multiple Developmental Disorders
- _____ 5R. Pervasive Developmental Disorder (PDD)
- _____ 5S. Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)
- _____ 5T. Physical Disability Other Than Ambulation: _____
- _____ 5U. Rett's Syndrome
- _____ 5V. Seizures
- _____ 5W. Severe Regulatory and Attention Disorders
- _____ 5X. Substance Abuse _____
- _____ 5Y. Vision
- _____ 5Z. Other Diagnosed: _____
- _____ 5AA. Other, Not Diagnosed, but suspected: _____

Living Situation and History

1. TYPE OF HOME

1 Parents' Home

2 Other Relatives' Home

_____ 3 Foster Home, non-relatives

4 Foster Home, relatives

5 Other _____

2. HOW MANY PEOPLE LIVE IN THIS HOME?

2A. _____ People with disabilities (including this person)

2B. _____ People without disabilities (unpaid cohabitants, including friends, parents, and other family members.)

3. HAS THE YOUNG PERSON EVER BEEN REMOVED FROM FAMILY HOME?

1 Yes

_____ 2 No

4A. If Yes, Please explain why.

5. HOW MANY TIMES IN THE PAST YEAR HAS THIS PERSON CHANGED RESIDENTIAL PLACEMENT, FOSTER HOMES, OR FACILITY?

_____ times

YAP Services

(1) If someone other than the young person is answering all or most of these questions, What is your relationship to the YAP Service recipient?

1. Mother
2. Father
3. Mother and Father (responding together)
4. Sister or Brother
- _____ 5. Grandmother or Grandfather
6. Aunt or Uncle
7. Not Related --- Guardian or Conservator
8. Foster Parent
9. Special Needs Adoptive Parent
10. Other (PLEASE SPECIFY): _____

(2) About how many months has your family gotten help from the Youth Advocate Program?

_____ months

(3) Has the young person had any similar support before (wrap, wraparound, TSS)?

1 Yes

_____ 2 No

(4) Family's Quality of Life, BEFORE YAP and NOW

Please rate each aspect of family life below, both

- "BEFORE" getting involved with the Youth Advocate Program, and
- "NOW" that your family is receiving Youth Advocate Program supports

Any item that doesn't apply to your family can be left blank or marked "N/A" for Not Applicable.

BEFORE 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good	NOW 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good	This is about the entire family, not just the youth with a disability:
		Health
		Mental health
		Getting help in a crisis
		Home situation
		School situation
		Family enjoying activities together in the community
		Stress
		Having help & support for young person with special needs
		Having a friend(s) who understands
		Family members having leisure time to themselves
		Privacy
		Getting needed services
		Family spending time together
		Confidence about coping with challenges
		Plans and hopes for the future
		Overall Quality of Family Life

(5) Young person’s Quality of Life, BEFORE YAP and NOW

Please ask these questions of the young person if possible – Otherwise, please ask a family member to answer as they believe the young person would.

Rate each aspect the young person’s life below, both

- “BEFORE” getting involved with the Youth Advocate Program, and
- “NOW” that your family is receiving Youth Advocate Program supports

Any item that doesn’t apply to your young person can be left blank or marked “N/A” for Not Applicable.

BEFORE 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good	NOW 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good	This is about the youth with a disability:
		Getting help whenever I need it
		Running my own life, making choices
		Not doing activities if I don’t want to
		Relationships with friends
		Having hobbies I enjoy
		Privacy
		Safety at home
		Safety at school
		Happiness at home
		Happiness at school
		Safety in neighborhood
		Happiness in neighborhood
		Getting out in my community
		How I feel about trying new things
		Overall quality of life

Who answered most of these questions?

- _____ 1 The young person
 _____ 2 Someone else

(6) Relationship between Family and YAP wraparound worker (also called Therapeutic Support Staff or TSS):

(Note: If more than one TSS worker works with [you/your child], please rate the TSS worker who works with him/her the MOST.)

Any item that doesn't apply to your family can be left blank or marked "N/A" for Not Applicable.

1=Strongly Disagree 2=Disagree 3=In-Between 4=Agree 5=Strongly Agree	
	Support Person (TSS) is respectful of family's needs, ideas and opinions
	Support Person (TSS) is nonjudgmental
	Support Person (TSS) listens to what family members have to say
	Support Person (TSS) is dependable
	Support Person (TSS) is punctual
	Support Person (TSS) keeps young person safe
	Support Person (TSS) is easy to reach when needed
	Support Person (TSS) uses language family understands
	Support Person (TSS) is respectful of family's privacy
	Support Person (TSS) is flexible and willing to learn new things from the family
	Support Person (TSS) is respectful of family culture and traditions

(7) Relationship between Young person and Support Person (TSS):

(Note: If more than one SUPPORT PERSON (TSS) Support Person works with [you/your child], please rate the TSS Support Person who works with [you/him/her] the MOST.)

Any item that doesn't apply to [you/your child] can be left blank or marked "N/A" for Not Applicable.

1=Strongly Disagree 2=Disagree 3=In-Between 4=Agree 5=Strongly Agree	
	Support Person (TSS) treats child with dignity
	Support Person (TSS) speaks respectfully in child's presence (e.g. does not speak about child to others as if child were not there)
	Support Person (TSS) advocates for child's needs when working with teachers, community members, other service providers
	Support Person (TSS) helps others to appreciate child's strengths
	Support Person (TSS) helps child interact and communicate with others (rather than speaking and acting for the child)
	Support Person (TSS) has skills and training needed to help the child
	Support Person (TSS) continues to learn new things by communicating and observing the child
	Support Person (TSS) adjusts to the child's changing needs and interests
	Support Person (TSS) supports child to make progress at home
	Support Person (TSS) supports child to make progress at school
	Support Person (TSS) supports child to be included in community activities
	Support Person (TSS) supports child to make friends

8. Elements of the Treatment Planning Process

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Please rate how whether you agree or disagree with these statements about individual planning with (you/your child/relative/ward).

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

9. Individual Goals When First Started With YAP

What were the top 5 goals the young person and the family had, <u>when they began with YAP?</u> Short Description of Top 5 Goals in the Original Treatment Plan	Progress Toward Meeting this Goal Since Starting With YAP 1=Major Loss 2=Some Loss 3=No change 4=Some Gain 5=Major Gain 99=Don't Know
1	
2	
3	
4	
5	

(10) FIVE MOST IMPORTANT THINGS FOR THE YOUNG PERSON

- In the section below we would like to know what the **five** most important things are concerning the young person’s well-being. **Please choose only five.**
- Please read through the list below and determine which of these is the #1 most important thing to you about your child’s well-being. Please write a "1" next to that item. Then, please write a "2" next to the SECOND most important thing to you. Please continue writing numbers up to 5, for the fifth most important thing to you.

<p>How Important to You? 1=Most Important 2=Second 3=Third 4=Fourth 5=Fifth most Important Please choose only Five.</p>	
	Academic achievement (doing well in school)
	Assistive devices
	Being kept busy
	Being with peers
	Choicemaking
	Comfort
	Community acceptance
	Development, learning
	Development of speech and language
	Dignity, respect
	Exercise, fitness
	Freedom from abuse
	Friends
	Girlfriends/Boyfriends
	Health
	Integration, inclusion
	Love
	Medical attention
	Permanence of home
	Recreation
	Religion, worship
	Safety
	Self-esteem
	Self-care skill development
	Self-determination
	Supports for problematic behavior

Who answered most of these questions?

- _____ 1 The young person
 _____ 2 Someone else

COMMENTS

(1) Any comments you have about the YAP Wraparound Service Program?

(2) Were there things or services or supports that you have been able to obtain via the YAP wraparound services program that you probably could not have gotten otherwise? One example is fine.

(3) Were there things or services or supports that you have NOT been able to obtain via the YAP wraparound services program that you really needed? One example is fine.

(4) If you had one wish for your child, what would it be?

(4a) Who answered this last question?

_____ 1 The young person
_____ 2 Someone else

How many minutes did it take to complete this survey?

_____ minutes

THANK YOU!