



UNIVERSITY of MARYLAND
SCHOOL OF PHARMACY

**Prioritizing Outcomes, Needs, ExEctations
and RecoRery
(PIONEER) Study**



A Survey for Caregivers

Study Identification Number:

What Outcomes Are Most Important to You?

When selecting a treatment for children, caregivers often are faced with a difficult decision. There may be many outcomes that you like and others you want to avoid. Below we list some outcomes that people may think about when choosing a treatment for their child.

For each question,

- A) Select the box for the **ONE** that is **MOST IMPORTANT**,
- B) Select the box for the **ONE** that is **LEAST IMPORTANT**.

CHOOSE ONLY 1 MOST AND 1 LEAST IMPORTANT

Here is an **EXAMPLE** to get you going:

When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is not behaving in ways that could hurt him/her.	
	The child is not behaving in ways that can hurt other children.	
X	The child gets an IEP.	
	The caregiver is able to bring the child to social events.	X
	The child is able to stay in school all day with no problems.	
	The child gets good grades in school.	

- 1) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is not behaving in ways that could hurt him/her.	
	The child is not behaving in ways that can hurt other children.	
	The child gets an IEP.	
	The caregiver is able to bring the child to social events.	
	The child is able to stay in school all day with no problems.	
	The child gets good grades in school.	

- 2) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is able to keep friends for a long time.	
	The child is able to manage his/her money as an adult.	
	The child is able to stay in school all day with no problems.	
	The child is in a school for children with special needs.	
	Family supports the caregiver's treatment decisions.	
	The caregiver is able to bring the child to social events.	

- 3) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	Family outings are not cancelled because of the child's behavior.	
	The caregiver is able to bring the child to social events.	
	The child is able to hold a paying job as an adult.	
	The child is able to keep friends for a long time.	
	The child gets an IEP.	
	Friends going through the same thing support the caregiver.	

- 4) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is able to live on his/her own as an adult.	
	The child gets an IEP.	
	The child is able to manage healthcare decisions in the future.	
	The child is able to stay in school all day with no problems.	
	The child is able to keep friends for a long time.	
	The child is not a risk to the safety of siblings at home.	

- 5) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child gets good grades in school.	
	The child is able to keep friends for a long time.	
	The child is not behaving in ways that can hurt other children.	
	The child is able to live on his/her own as an adult.	
	Friends going through the same thing support the caregiver.	
	The child is able to manage his/her money as an adult.	

- 6) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	Friends going through the same thing support the caregiver.	
	The child is not behaving in ways that could hurt him/her.	
	The child is in a school for children with special needs.	
	Family supports the caregiver's treatment decisions.	
	The child is able to live on his/her own as an adult.	
	The child gets an IEP.	

- 7) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is able to manage his/her money as an adult.	
	The child is able to stay in school all day with no problems.	
	The child is able to live on his/her own as an adult.	
	The child is able to hold a paying job as an adult.	
	Family outings are not cancelled because of the child's behavior.	
	The child is not behaving in ways that could hurt him/her.	

- 8) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The caregiver is able to bring the child to social events.	
	The child is not a risk to the safety of siblings at home.	
	Friends going through the same thing support the caregiver.	
	The child is able to manage his/her money as an adult.	
	The child is not behaving in ways that could hurt him/her.	
	The child is able to manage healthcare decisions in the future.	

- 9) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is in a school for children with special needs.	
	The child gets good grades in school.	
	The child is able to keep friends for a long time.	
	The child is not behaving in ways that could hurt him/her.	
	The child is not a risk to the safety of siblings at home.	
	Family outings are not cancelled because of the child's behavior.	

10) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is not a risk to the safety of siblings at home.	
	Family supports the caregiver's treatment decisions.	
	Family outings are not cancelled because of the child's behavior.	
	The child gets an IEP.	
	The child is able to manage his/her money as an adult.	
	The child is not behaving in ways that can hurt other children.	

11) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	Family supports the caregiver's treatment decisions.	
	The child is able to hold a paying job as an adult.	
	The child is not behaving in ways that could hurt him/her.	
	The child is able to manage healthcare decisions in the future.	
	The child is not behaving in ways that can hurt other children.	
	The child is able to keep friends for a long time.	

12) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is able to stay in school all day with no problems.	
	Friends going through the same thing support the caregiver.	
	The child is not a risk to the safety of siblings at home.	
	The child is not behaving in ways that can hurt other children.	
	The child is in a school for children with special needs.	
	The child is able to hold a paying job as an adult.	

13) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is not behaving in ways that can hurt other children.	
	The child is in a school for children with special needs.	
	The caregiver is able to bring the child to social events.	
	Family outings are not cancelled because of the child's behavior.	
	The child is able to manage healthcare decisions in the future.	
	The child is able to live on his/her own as an adult.	

14) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child gets an IEP.	
	The child is able to manage healthcare decisions in the future.	
	The child is able to manage his/her money as an adult.	
	The child gets good grades in school.	
	The child is able to hold a paying job as an adult.	
	The child is in a school for children with special needs.	

15) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is able to manage healthcare decisions in the future.	
	Family outings are not cancelled because of the child's behavior.	
	Family supports the caregiver's treatment decisions.	
	Friends going through the same thing support the caregiver.	
	The child gets good grades in school.	
	The child is able to stay in school all day with no problems.	

16) When you think about choosing a treatment for your child, of the 6 items shown here, which is the **MOST** and **LEAST IMPORTANT**?

Most Important		Least Important
	The child is able to hold a paying job as an adult.	
	The child is able to live on his/her own as an adult.	
	The child gets good grades in school.	
	The child is not a risk to the safety of siblings at home.	
	The caregiver is able to bring the child to social events.	
	Family supports the caregiver's treatment decisions.	

The next questions are to learn a little about YOU.



1) How are you related to your child?

☐ Mother

☐ Uncle/Aunt

☐ Father

☐ Foster Parent

☐ Grandparent

☐ Other, please specify: _____

2) What is your age? _____ (years)

3) What is your gender?

☐ Male

☐ Female

4) What is your race?

☐ White, not of Hispanic origin

☐ Hispanic

☐ Black, not of Hispanic origin

☐ Native American/Alaskan Native

☐ Black, of Hispanic origin

☐ Other, please specify: _____

☐ Asian/Pacific Islander

5) What is your marital status?

☐ Married

☐ Widowed

☐ Never married

☐ Other. Please specify: _____

☐ Divorced/Separated

☐ Don't know

6) What is the highest grade of school that YOU have completed?

☐ Less than high school

☐ Postgraduate

☐ High school

☐ Don't know

☐ College

7) Are you working now?

☐ Working, please specify:

☐ Retired, please specify former job:

☐ Not working

8) What is your family's yearly household income?

☐ \$7,500 or less

☐ \$35,001 to \$50,000

☐ \$7,501 to \$15,000

☐ \$50,001 to \$75,000

☐ \$15,001 to \$25,000

☐ \$75,001 or over

☐ \$25,001 to \$35,000

☐ Don't know

9) Which state are you currently residing in? _____

10) Which type of community do you live in?

☐ Urban

☐ Suburban

☐ Rural

The next questions are to learn a little about your CHILD.



1) What is your child's age? _____ (years)

2) What is your child's gender?

☐ Male

☐ Female

3) What race is your child?

☐ White, not of Hispanic origin

☐ Hispanic

☐ Black, not of Hispanic origin

☐ Native American/Alaskan Native

☐ Black, of Hispanic origin

☐ Other, please specify: _____

☐ Asian/Pacific Islander

4) What grade is your child currently in (if your child is no longer in school specify highest grade attained)? _____ Grade

5) What **developmental disorder(s)** does your child have? Please check all that apply.

☐ Intellectual Disability (e.g.,
problems with reasoning)

☐ Autism Spectrum Disorder

☐ Communication Disorder (e.g.,
muffled speech, cannot hold a
conversation)

☐ Specific Learning Disorder

☐ Motor Disorder

☐ Other developmental disorder. please
specify: _____

6) Which of the following describes your child?

☐ Verbal

☐ Non-Verbal

7) What **mental health diagnoses** does your child have? Please check all that apply.

☐ Anxiety Disorder

☐ Conduct Disorder

☐ Bipolar Disorder

☐ Schizophrenia/Psychoses

☐ Depression

☐ Oppositional Defiant Disorder

☐ Attention Deficit Hyperactivity
Disorder/Attention Deficit
Disorder

☐ Other mental health diagnoses. please
specify: _____

8) What **mental health services** or treatment does your child currently receive? Please check all that apply.

☐ Medication

☐ Other, please specify: _____

☐ Counseling

☐ Behavior management therapy

9) Has your child been hospitalized for a mental health-related condition (e.g., aggressive behavior, mood)?

☐ Yes, please state the reason for hospitalization: _____



If **YES**, How long ago was your child hospitalized (ex: yesterday, 1 month, 3 years, 10 years, etc.)? _____

☐ No

10) Which of the following types of aggressive behaviors have you seen in your child? Check all that apply.

☐ Aggression towards self (e.g., self-
injury)

☐ Aggression towards others

☐ Aggression towards property

☐ My child does not have aggressive behavior

11) Who is the main caregiver of your child, i.e. the person responsible for making health care decisions?

☐ Mother

☐ Uncle/Aunt

☐ Father

☐ Foster Parent

☐ Grandparent

☐ Other, please specify: _____

12) How many people are living in the same house with your child, including yourself? _____

13) Who lives in the same house with your child? Please check all that apply.

☐ Yourself

☐ Step-mother or father's significant other

☐ Mother

☐ Step-father or mother's significant other

☐ Father

☐ Other, please specify: _____

☐ Siblings, how many _____

☐ Don't know

14) What type of health insurance do you have for your child? Check all that apply.

☐ Public (e.g., Medical assistance)

☐ None

☐ Private (e.g., Blue Cross Blue Shield)

☐ Other, please specify: _____

15) Does anyone help you manage your child's healthcare needs?

☐ Yes, please specify: _____

☐ No

16) Does your child need 24-hour supervision or care?

☐ Yes

☐ No

17) Do you get any financial or other support for healthcare services for your child?

☐ Yes, please specify: _____

☐ No

☐ Don't know

THANK YOU!