

National Family Advocacy Support and Training (FAST) Project

A project of PACER Center funded by the Administration on Developmental Disabilities as a Project of National Significance.

National Family Support Survey Consent Information Sheet

You are invited to be in a national research study of supports for families of youth with disabilities. You were selected as a possible participant because you are a parent or primary caregiver of a young person with disabilities between 12 and 22 years old. Please read this form and ask any questions you have before agreeing to be in the study. The survey must be returned by August 13, 2010, to Shauna McDonald by mail: PACER Center, 8161 Normandale Blvd., Minneapolis, MN 55437, or by fax: 952.838.0199.

The Family Advocacy and Support Training (FAST) Project is funded by the Administration on Developmental Disabilities (ADD) as a Project of National Significance. FAST is a project of PACER Center in Minnesota in collaboration with Parent Centers throughout the United States and Territories and with the help of the University of Minnesota.

This survey is being conducted by: Sheryl A. Larson, Ph.D., and K. Charlie Lakin, Ph.D., University of Minnesota, Research and Training Center on Community Living. The FAST Project is coordinated by Shauna McDonald and Paula Goldberg, Executive Director, PACER Center.

Background Information

The purpose of this study is to learn about the information and supports young adults with disabilities and their families need to prepare for moving into adulthood.

Procedures:

If you agree to be in this study, we will ask you to complete the National Family Support Survey. You can complete and submit the survey on-line or you can provide your answers on paper and return it to Sheryl Larson, ICI @ University of Minnesota, 214 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Larso072@umn.edu.

Risks and Benefits of being in the Study

Risks:

We do not anticipate there being any risks involved in completing this confidential survey.

Benefits:

You will receive no direct benefit from completing the survey. Your answers to the questions will help the Administration on Developmental Disabilities, parent centers, and researchers to understand the information and supports families need to plan for the transition of youth with disabilities into adult role. You may find that the questions cause you to think about topics you haven't considered before, or to seek more information from your local Parent Center.

Compensation:

No compensation will be provided for completing the survey.

Confidentiality:

Your answers to the survey questions will be kept private. Reports describing the results of the survey will not identify specific individuals. Research records will be stored securely and only researchers will have access to the records.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the United States Department of Health and Human Services, the University of Minnesota, PACER Center or your local Parent Center. If you do participate, you can leave questions blank or decide not to submit your answers without affecting those relationships.

Contacts and Questions:

The researchers conducting this study are: Sheryl Larson and Charlie Lakin. You may ask any questions you have now. If you have questions later, *please* contact Sherri Larson at the Research and Training Center on Community Living, 612-624-6024, larso072@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), *you are encouraged* to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You may keep this form for your records if you wish.

When you submit your responses to the survey you are saying you choose to participate in this study.

For more information about the Family Advocacy and Support Training Project, Contact Shauna McDonald at PACER Center, Inc.

8161 Normandale Boulevard

Minneapolis, MN 55437-1044

952-838-9000 voice 952-838-0190 TTY

888-248-0822

Fax: 952-838-0199

pacerc@pacerc.org

www.pacerc.org

If you decide to participate, complete and return the survey to:

Sheryl Larson

RTC on Community Integration @ U of MN

214B Pattee Hall

150 Pillsbury Drive SE

Minneapolis, MN 55455

Larso072@umn.edu

National Family Support Survey

Consent Information Sheet

FAST, a project of PACER Center, is conducting this survey to learn about the support needs of your family and your young person with disabilities. We specifically want to hear from parents or primary caregivers of young people with disabilities between 12 and 22 years old. This survey will only take a few minutes to complete.

The FAST project is funded by the United States Department of Health and Human Services, Administration on Development Disabilities (ADD) as a Project of National Significance (Project number 90DN0269).

A. General Information

1. Are you a: (Check all that apply)

- a. Parent of a young person with disabilities
- b. Grandparent of a young person with disabilities
- c. Other relative/guardian of a young person with disabilities
- d. Surrogate/Foster parent of a young person with disabilities
- e. Other _____

2. How old is your family member with a disability? _____ years

3. What is the primary disability of your family member with disabilities? (Check one)

- a. Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder
- b. Autism Spectrum Disorders (Autism or Asperger's)
- c. Blindness or Vision Impairment
- d. Deaf or Hard of Hearing
- e. Developmental Delay (for children younger than 6 years)
- f. Emotional Disturbance or Mental Illness
- g. Intellectual Disability (developmental cognitive disabilities or Down Syndrome)
- h. Multiple Disabilities
- i. Orthopedic Impairment
- j. Specific Learning Disability
- k. Speech/Language impairment
- l. Traumatic Brain Injury
- m. Other disability (Please specify) _____
- n. Don't know/prefer not to say

4. Where does your family member with a disability live? (Mark one)

- a. With me, in my home
- b. Independently in a home or apartment he or she owns or rents
- c. In the home of another family member
- d. In a special home, foster home or facility that supports children, youth or people with disabilities
- e. Other _____

For sections B through F, please choose the category for each question that best describes your opinion.

B. Youth Development

These questions are about preparing your family member for adult living.

As your family member moves towards the adult years, how important is it for you to know how to get supports for:		Very Important	Somewhat Important	Not Important
1.	Helping your son or daughter develop skills for living on their own			
2.	Helping your son or daughter develop skills for self-care, hygiene and safety			
3.	Helping your son or daughter find and participate in recreation, hobbies and other activities or interests			
4.	Helping your son or daughter improve social skills and build lifelong friendships			
5.	Preparing your son or daughter for healthy, loving adult relationships			
6.	Finding a support group for your son or daughter			

How would you rate the supports you get in these areas?		I get support about this. The quality of this support is:				I do not need support on this	I need support on this but have none
		Excellent	Good	Fair	Poor		
7.	Helping your son or daughter develop skills for living on their own						
8.	Helping your son or daughter develop skills for self-care, hygiene, and safety						
9.	Helping your son or daughter find and participate in recreation, hobbies, and other activities or interests						
10.	Helping your son or daughter improve social skills and build lifelong friendships						
11.	Preparing your son or daughter for healthy, loving adult relationships						
12.	Finding a support group for your son or daughter						

C. Family Support and Leadership

These questions are about supports and leadership skills your family may need

As your family member moves towards the adult years, how important is it for you to know how to get supports for:		Very Important	Somewhat Important	Not Important
1.	How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)			
2.	Preparing others to fulfill your role in the future			
3.	Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter			
4.	Advocating for your son or daughter's rights			
5.	Success stories from other parents or adults with the same disabilities as your son or daughter			
6.	Finding a support group for yourself			

How would you rate the supports you get in these areas?	I get support about this. The quality of this support is:				I do not need support on this	I need support on this but have none
	Excellent	Good	Fair	Poor		
7.	How your role as a parent legally changes when your son or daughter turns 18 (guardianship, conservatorship, power of attorney)					
8.	Preparing others to fulfill your role in the future					
9.	Obtaining personal care, child care, respite services, in-home health care supports for your son or daughter					
10.	Advocating for your son or daughter's rights					
11.	Success stories from other parents or adults with the same disabilities as your son or daughter					
12.	Finding support group for yourself					

D. Career Development and Employment

These questions are about preparing your family member to work when they become an adult.

As your family member moves towards the adult years, how important is it for you to know how to get supports for:		Very Important	Somewhat Important	Not Important
1.	Finding and choosing vocational education, job training and employment programs for your son or daughter			
2.	Helping your son or daughter be prepared to work			
3.	Helping your son or daughter find and keep a job			

How would you rate the supports you get in these areas?	I get support about this. The quality of this support is:				I do not need support on this	I need support on this but have none
	Excellent	Good	Fair	Poor		
4.	Finding and choosing vocational education, job training and employment programs for your son or daughter					
5.	Helping your son or daughter be prepared to work					
6.	Helping your son or daughter find and keep a job					

E. Adult Services

These questions are about main services your son or daughter may need as an adult.

As your family member moves towards the adult years, how important is it for you to know how to get supports for:		Very Important	Somewhat Important	Not Important
1.	Helping your son or daughter with housing and support services			
2.	Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself			
3.	Obtaining medical care and health insurance for your son or daughter			
4.	Obtaining mental health services for your son or daughter			
5.	Providing transportation for your son or daughter			

How would you rate the supports you get in these areas?	I get support about this. The quality of this support is:				I do not need support on this	I need support on this but have none
	Excellent	Good	Fair	Poor		
6. Helping your son or daughter with housing and support services						
7. Financial assistance or income support programs for your son or daughter if he/she is unable to fully support him/ herself						
8. Obtaining medical care and health insurance for your son or daughter						
9. Obtaining mental health services for your son or daughter						
10. Providing transportation for your son or daughter						

F. Education

These questions are about succeeding at school and choosing a post-secondary option.

As your family member moves towards the adult years, how important is it for you to know how to get supports for:		Very Important	Somewhat Important	Not Important
1.	Helping your son or daughter succeed at school and prepare for post-secondary education			
2.	Finding and choosing postsecondary education options for your son or daughter			

How would you rate the supports you get in these areas?	I get support about this. The quality of this support is:				I do not need support on this	I need support on this but have none
	Excellent	Good	Fair	Poor		
3.	Helping your son or daughter succeed at school and prepare for post-secondary education					
4.	Finding and choosing postsecondary education options for your son or daughter					

G. Information Sources

Which of these resources have you used to find information about supports for your family member as he or she moves towards adulthood? (Mark all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Advocacy organization | <input type="checkbox"/> Public health nurse, nurse, doctor or other medical provider |
| <input type="checkbox"/> Books, magazines, TV, radio | <input type="checkbox"/> Recreation program, Special Olympics |
| <input type="checkbox"/> Centers for Independent Livingd. College or University | <input type="checkbox"/> Religious organization |
| <input type="checkbox"/> Community organization or center | <input type="checkbox"/> Self-advocacy group for people with disabilities |
| <input type="checkbox"/> County or regional welfare or social services agency, social worker or case manager | <input type="checkbox"/> Service provider agency |
| <input type="checkbox"/> Cultural center or organization | <input type="checkbox"/> State Developmental Disabilities, Ombudsman's, Department of Human Services or Department of Health Office |
| <input type="checkbox"/> Developmental Disability Council | <input type="checkbox"/> Support groups or another parent |
| <input type="checkbox"/> Disability organization | <input type="checkbox"/> Teacher, social worker, counselor, or other school staff |
| <input type="checkbox"/> Friend/family member | <input type="checkbox"/> Vocational Rehabilitation Service |
| <input type="checkbox"/> Internet (if you have a favorite site list it here)_____ | <input type="checkbox"/> Workshops and/or conferences |
| <input type="checkbox"/> Library | <input type="checkbox"/> Other (describe) _____ |
| <input type="checkbox"/> Parent Center | <input type="checkbox"/> None/I don't Know |
| <input type="checkbox"/> Protection and Advocacy Office (Law) | |

H. Current Supports

Which of the following service(s) does your family member with a disability currently receive? (Mark all that apply)

- | | |
|--|---|
| <input type="checkbox"/> School (Kindergarten through grade 12) | <input type="checkbox"/> Assistive technology (e.g., augmentative communication device) |
| <input type="checkbox"/> School (Technical, vocational, community college, college, university) | <input type="checkbox"/> Behavioral or mental health services |
| <input type="checkbox"/> Case management or service coordination | <input type="checkbox"/> Non-vocational day program for adults |
| <input type="checkbox"/> Supports at home (such as a home health aide, or personal care attendant) | <input type="checkbox"/> Job coach, employment or vocational rehabilitation services |
| <input type="checkbox"/> Respite care/family support | <input type="checkbox"/> Parent training and education |
| <input type="checkbox"/> Homemaker/chore services | <input type="checkbox"/> Specialized transportation services |
| <input type="checkbox"/> Out-of-home residential supports (such as a foster home or group home) | <input type="checkbox"/> Specialist services such as occupational, physical or speech therapy |
| <input type="checkbox"/> Supports to help my family member live in his/her own home (such as budgeting help, shopping, or meal planning) | <input type="checkbox"/> Health insurance coverage |
| <input type="checkbox"/> Adaptive aids or equipment | <input type="checkbox"/> Medicaid |
| <input type="checkbox"/> Environmental modifications (including modifications to the person's home or vehicle) | <input type="checkbox"/> Other |
| | <input type="checkbox"/> None of the above |

I. Demographic Information

The following information helps us understand how families with different characteristics think about the topics on this survey. This information is confidential and will only be provided in a summary format of all respondents. This section is optional.

Questions about you

1. In which state do you live? _____
2. What is your zip code? _____
3. Which best describes your household income? (Mark one)
____ a. Less than \$20,000 per year
____ b. \$20,000 to \$50,000 per year
____ c. More than \$50,000 per year
4. What is your marital status? (Mark one)
____ a. Single
____ b. Married/Partnered
____ c. Formerly married/partnered

Questions about your family member with a disability (If you have more than one family member with a disability tell us about the one you thought of most when answering the questions on the survey)

5. What is your son or daughter's gender? (Mark one)
____ a. male
____ b. female
6. What is your son or daughter's race? (Mark ONE or MORE races)
____ a. American Indian or Alaska Native
____ b. Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese or Other Asian)
____ c. Black or African American
____ d. Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, or Other Pacific Islander)
____ e. White
____ f. Other race not listed (Specify _____)
____ g. Don't know/prefer not to say
7. What is your son or daughter's ethnicity? (Mark one)
____ a. Hispanic/Latino
____ b. Not Hispanic/Latino
____ c. Don't know/prefer not to say
8. What is your son or daughter's primary language? What language does s/he understand best? (Mark one)
____ a. English
____ b. Other (specify) _____

Thank you for completing this survey.

If you have questions about this survey contact Shauna McDonald

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Click **SUBMIT** to complete the electronic survey.

Or

Return the paper survey to:

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214B Pattee Hall

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