

**PLEASE ANSWER AS MANY QUESTIONS AS YOU CAN.
SOME QUESTIONS MAY NOT APPLY TO EVERYONE.**

Our first questions are about your son or daughter's physical health.

- 1. What is your son or daughter's approximate height and weight?**

Height _____ Weight _____

- 2. Does your son or daughter currently smoke on a regular basis?**

_____ No (*Skip to Q.3*) _____ Yes (*Answer Q.2a*)

- 2a. How many years has he/she been smoking?**

_____ Number of years

- 3. How would you rate your son or daughter's overall health at the present time?**

(Check only one.)

_____ Excellent
_____ Very good
_____ Good
_____ Fair
_____ Poor

- 4. Does your son or daughter have any trouble walking one block because of a health problem?**

_____ No _____ Yes

- 5. Does your son or daughter have trouble walking uphill or climbing a few flights of stairs because of a health problem?**

_____ No _____ Yes

- 6. Does your son or daughter exercise on a regular basis? (*A "regular basis" is weekly or more often, and does ***not*** include walking just to get somewhere; must be for exercise.*)**

_____ No _____ Yes

7. Below is a list of common, serious health problems. For each one, please check 'yes' if your son or daughter has ever been told by a doctor that he/she has this health problem. (Note: If it is an occasional problem, check 'Yes'.)

To the best of your knowledge, has your son or daughter ever been told by a doctor that he/she has any of the following diagnoses?			
Diagnosis	Check (✓) if YES	Diagnosis	Check (✓) if YES
a. Allergies		p. High cholesterol	
b. Anemia		q. Kidney/bladder problems	
c. Arthritis		r. Liver problems (chronic)	
d. Asthma		s. Memory problems	
e. Back problems (serious)		t. Multiple sclerosis	
f. Cancer		u. Osteoporosis or brittle bones	
g. Colitis		v. Parkinson's disease	
h. Dental problems (persistent trouble with his/her teeth)		w. Recurring stomach trouble, indigestion, or diarrhea	
i. Diabetes		x. Shortness of breath	
j. Emphysema or chronic bronchitis		y. Skin problems	
k. Foot problems (persistent trouble with bunions, ingrown toenails, etc.)		z. Stroke	
l. Hearing problems or hearing loss		aa. Thyroid problem	
m. Heart attack		bb. Ulcer	
n. Heart disease		cc. Visual impairment (uncorrected)	
o. High blood pressure or hypertension		dd. Other (specify): _____	

8. Many people with a disability take a variety of prescription medications. We are interested in the medications your son or daughter is currently taking.

Does your son or daughter currently take prescription medications?

- No (*Skip to Q.9*)
- Yes (*Please complete the table below.*)
- Don't know (*Skip to Q.9*)

Name of medication	Purpose <u>primarily</u> prescribed for:	How effective is it? (<i>Circle one per medication</i>)		
		Not at all effective	Some-what	Very effective
a.		0	1	2
b.		0	1	2
c.		0	1	2
d.		0	1	2
e.		0	1	2
f.		0	1	2
g.		0	1	2
h.		0	1	2
i.		0	1	2

9. We are interested in the services your son or daughter currently receives.

Indicate all the services received currently:	Is the service received?	If no →	If this service is NOT RECEIVED , is it needed or not needed? <i>(Circle one response)</i>	
CASE MANAGEMENT SERVICES which involve a person who helps to coordinate services, may help find a job, find housing, or help with daily living activities?	Yes No →	If no →	Needed	Not needed
RECREATIONAL OR SOCIAL ACTIVITIES provided by an organization or agency, such as bowling, dances, or other organized activities?	Yes No →	If no →	Needed	Not needed
TRANSPORTATION SERVICES ?	Yes No →	If no →	Needed	Not needed
INCOME SUPPORT SERVICES , such as SSDI (Social Security Disability Insurance) or SSI (Supplemental Security Income)?	Yes No →	If no →	Needed	Not needed
MEDICAL ASSISTANCE OR MEDICAID?	Yes No →	If no →	Needed	Not needed
CRISIS INTERVENTION PROGRAMS including crisis respite services?	Yes No →	If no →	Needed	Not needed
PSYCHOLOGICAL OR PSYCHIATRIC SERVICES , such as therapy, counseling, medication review, or behavioral consultation?	Yes No →	If no →	Needed	Not needed
PHYSICAL THERAPY which is a specialized service to help with gross motor skills, but <u>not</u> general exercise?	Yes No →	If no →	Needed	Not needed
OCCUPATIONAL THERAPY which is a specialized service to help with small motor exercises, such as writing, using scissors, or self-help skills?	Yes No →	If no →	Needed	Not needed
SPEECH THERAPY?	Yes No →	If no →	Needed	Not needed
RESPITE SERVICES?	Yes No →	If no →	Needed	Not needed

10. Next, we are interested in things that your son or daughter may do for you. Please indicate if he/she gives you no help, a little, some, or a lot of help with the following tasks.

How much does your son or daughter:	None	A little	Some	A lot
a. Help you out with indoor household tasks (e.g., cleaning, vacuuming, etc.)?	0	1	2	3
b. Help you with outdoor household tasks (e.g., yard work, shoveling snow, etc.)?	0	1	2	3
c. Help you by preparing meals?	0	1	2	3
d. Drive you places that you need to go (e.g., to an appointment, shopping, etc.)?	0	1	2	3
e. Share household expenses?	0	1	2	3
f. Help you with your shopping for food, groceries and other things?	0	1	2	3
g. Help you out when you're sick?	0	1	2	3
h. Listen to your problems and provide advice?	0	1	2	3
i. Provide companionship?	0	1	2	3

11. These questions pertain to how you feel about your son or daughter.

Please read each of the following statements and answer either “true” or “false” depending on how accurate you feel the statement is for you.

	False	True
a. I worry about what will happen to my son/daughter when I can no longer take care of him/her.	0	1
b. I have accepted the fact that my son/daughter might have to live out his/her life in some special setting (such as a group home).	0	1
c. It bothers me that my son/daughter will always be this way.	0	1
d. My son/daughter doesn't do as much as he/she should be able to do.	0	1
e. My son/daughter is over-protected.	0	1
f. My son/daughter has too much time on his/her hands.	0	1
g. I am disappointed that my son/daughter does not lead a normal life.	0	1
h. Time drags for my son/daughter, especially free time.	0	1
i. I worry about what will be done with my son/daughter when he/she gets older.	0	1
j. My son/daughter will always be a problem to us.	0	1

12. Please circle the number that corresponds to the answer that best describes your response to each statement. (Please circle only one per row.)

<p style="text-align: center;"> 0 = Not At All 1 = Somewhat 2 = Extremely </p>	Not At All	Somewhat	Extremely
a. I feel resentful of other relatives who could, but who do not do things for my son/daughter.	0	1	2
b. I feel that my son/daughter makes requests which I perceive to be over and above what he/she needs.	0	1	2
c. Because of my involvement with my son/daughter, I don't have enough time for myself.	0	1	2
d. I feel stressed between trying to give to my son/daughter as well as to other family responsibilities, job, etc.	0	1	2
e. I feel embarrassed over my son/daughter's behavior.	0	1	2
f. I feel guilty about my interactions with my son/daughter.	0	1	2
g. I feel that I don't do as much for my son/daughter as I could or should.	0	1	2
h. I feel angry about my interactions with my son/daughter.	0	1	2
i. I feel that in the past, I haven't done as much for my son/daughter as I could have or should have.	0	1	2

0 = Not At All 1 = Somewhat 2 = Extremely		Not At All	Somewhat	Extremely
j.	I feel nervous or depressed about my interactions with my son/daughter.	0	1	2
k.	I feel that my son/daughter currently affects my relationships with other family members and friends in a negative way.	0	1	2
l.	I feel resentful about my interactions with my son/daughter.	0	1	2
m.	I am afraid of what the future holds for my son/daughter.	0	1	2
n.	I feel pleased about my interactions with my son/daughter.	0	1	2
o.	It's painful to watch my son/daughter age.	0	1	2
p.	I feel useful in my interactions with my son/daughter.	0	1	2
q.	I feel my son/daughter is dependent.	0	1	2
r.	I feel strained in my interactions with my son/daughter.	0	1	2
s.	I feel that my health has suffered because of my involvement with my son/daughter.	0	1	2
t.	I feel that I am contributing to the well-being of my son/daughter.	0	1	2

<p style="text-align: center;">0 = Not At All 1 = Somewhat 2 = Extremely</p>	Not At All	Somewhat	Extremely
u. I feel that the present situation with my son/daughter doesn't allow me as much privacy as I'd like.	0	1	2
v. I feel that my social life has suffered because of my involvement with my son/daughter.	0	1	2
w. I wish that my son/daughter and I had a better relationship.	0	1	2
x. I feel that my son/daughter doesn't appreciate what I do for him/her as much as I would like.	0	1	2
y. I feel uncomfortable when I have friends over.	0	1	2
z. I feel that my son/daughter tries to manipulate me.	0	1	2
aa. I feel that my son/daughter seems to expect me to take care of him/her as if I were the only one he/she could depend on.	0	1	2
bb. I feel that I don't have enough money to support my son/daughter in addition to the rest of our expenses.	0	1	2
cc. I feel that I would like to be able to provide more money to support my son/daughter than I am able to now.	0	1	2
dd. I worry about what will happen to my son/daughter when I can no longer care for him/her.	0	1	2

13. Sometime people discover strengths and skills they never knew they had when a family member has a long-term disability. How about you? *(Please circle only one per row.)*

How much have you . . .	Not at All	Just a Little	Somewhat	Very Much
a. Become more aware of your inner strengths?	0	1	2	3
b. Become more self-confident?	0	1	2	3
c. Gotten a better idea of what is important in life?	0	1	2	3
d. Gained a sense of fulfilling your duty?	0	1	2	3
e. Grown as a person?	0	1	2	3
f. Learned to do things you didn't do before?	0	1	2	3
g. Become closer to your family?	0	1	2	3
h. Become more sensitive to persons with disabilities?	0	1	2	3
i. Made new friends?	0	1	2	3
j. Become more patient?	0	1	2	3

14. What have been the positive things you have experienced in coping with your son's or daughter's condition?

15. What have been the negative things you have experienced in coping with your son's or daughter's condition?

If there anything else you'd like to tell us about your son or daughter, please feel free to comment here:

Thank you for taking the time to complete these questions!

*Please return this survey in the business-reply envelope provided,
along with your completed WLS survey.*

*If you happen to have misplaced or already used the business-reply envelope,
please call 1-866-891-2492 to request that a new envelope be sent to you,
or use a regular envelope to mail the survey directly to:*

University of Wisconsin Survey Center
630 W. Mifflin St. Room B174
Madison, WI 53703-2636