

## 1. 2009 Community Needs Assessment

The Great Lakes Center for Autism (GLCA) works to help enhance the existing services for care and treatment already available in our community and surface additional services that need to be developed.

In the past three years, the GLCA has raised and distributed over \$225,000 to 17 different local organizations that serve families affected by Autism. By answering this survey about your family's needs you will help the GLCA identify gaps within local services as well as assist in defining how and where to use newly raised funds.

Thank you very much for taking the time to fill out this survey.

## 2. Diagnosis

Please think about the experience you had when getting a diagnosis of Autism Spectrum Disorder

1. What is the age of your adult child with autism?

age

2. Is your adult child with autism a:

boy

girl

3. Please provide any comments you may have/remember about your family's experience when your adult child was diagnosed with autism spectrum disorder:

### 3. Services

Please think about and tell us about the types of programs, supports, or services your adult child is or has been involved in.....

1. Please tell us what types of programs or services your adult child currently receives support from (CHECK ALL THAT APPLY):

- |  |  |   |
|--|--|---|
| <input type="checkbox"/> Respite               | <input type="checkbox"/> Speech                | <input type="checkbox"/> Residential services             |
| <input type="checkbox"/> Adult Day care        | <input type="checkbox"/> Occupational Therapy  | <input type="checkbox"/> Vocational programs              |
| <input type="checkbox"/> Parent training       | <input type="checkbox"/> Physical Therapy      | <input type="checkbox"/> Life skills programs or services |
| <input type="checkbox"/> Family support        | <input type="checkbox"/> Recreational programs | <input type="checkbox"/> Social skills training           |
| <input type="checkbox"/> MRDD services         | <input type="checkbox"/> Camps                 | <input type="checkbox"/> NONE                             |
| <input type="checkbox"/> Behavior intervention | <input type="checkbox"/> Transitional programs |   |

Other (please specify)

2. If you answered none to Q1, please describe why your family member does not receive support and/or services from any program:

3. What services or programs, if any, is your adult child currently on a waiting list for and for how long have they been waiting? (IF NOT ON WAITING LIST, TYPE "NONE" ON LAST LINE)

Service/program	<input type="text"/>
Service/program	<input type="text"/>
Service/program	<input type="text"/>
NOT ON ANY WAITING LIST	<input type="text"/>

4. Which of the following describes your family's use of respite services?

- We have access to respite services, we use respite services, and feel we have an adequate amount of hours.
- We have access to respite services, we use respite services but would like more.
- We have access to respite services but we do not use respite services
- We do not have access to respite services but we would like to use respite services
- We do not have access to respite services and we do not feel the need for them at this time

Other (please specify)

5. If you have access to respite services, how many hours do you have per month? (if you do not have access, type "0")

hours per month

6. How many hours of respite do you actually use per month? (if you do not have access to respite hours type "0")

hours per month

7. How many hours of respite do you feel would be ideal to have access to each month?

Ideal hours per month

8. Please share any additional comments or concerns regarding availability, cost, quality of care, etc... you may have about respite services:

9. Thinking of all services, programs, and supports your family has accessed, please describe any other of your experience(s) both positive and challenging, with any services, programs, supports (as much as you can) that have been provided to your child:

## 4. Community opportunities

Please tell us about your child's community experiences/opportunities.....

1. Thinking of recreational/community activities, on average, how many times per month does your adult child participate in recreational or other community activities?

Times per month

2. How satisfied are you with your child's participation in those activities?

Very Satisfied

Satisfied

Unsatisfied

Very Unsatisfied

3. Are you aware that there are a number of activities (dances, bowling, horseback riding, skiing, drop-in centers such as Life Art) arranged for persons with developmental disabilities, acquired brain injuries, and/or chronic health conditions?

Yes

No

4. To what extent do you believe the following factors are obstacles to your child's participation in recreational and other community activities? (check all that apply)

Lack of information

Lack of weekend activities

Location of activities

Lack of transportation Cost Attitude/receptivity of community groups

Lack of participation by non-disabled peers

Other (please specify)

5. Please describe any additional comments or concerns you may have regarding recreation or community activities for your child:

## 5. Coping as a family

Please tell us how your family handles the challenges of autism.....

1. Do you receive adequate emotional support to help with the day-to-day stresses of caring for your adult child?

Yes

No

2. What sources of support, if any, do you have?(PLEASE CHECK ALL THAT APPLY)

Spouse

Church

other child (children) living at home

On-line support

other child (children) not living at home

Other families in a similar situation

Friends

Professionals

Extended Family

Support Group

Other (please specify)

3. Please describe any suggestions you may have for improving the support you receive.

4. How often do you feel that the time you spend with your adult child takes away from your own basic needs (sleep, meals)?

Rarely

Sometimes

Often

Everyday

5. How often do you feel that in addition to caring for your adult child, you don't have enough energy to meet other responsibilities for family or work

Rarely

Sometimes

Often

Everyday

6. How often do you feel your adult child's needs or behaviors affect your ability to take your family member into the community?

Rarely

Sometimes

Often

Everyday

7. How often do you feel your adult child's needs or behaviors affect your relationship with family and/or friends

Rarely

Sometimes

Often

Everyday

8. How often do you feel uncertain about what to do with your adult child?

Rarely

Sometimes

Often

Everyday

9. How often do you feel that you have lost control of your life due to the needs of your adult child?

Rarely

Sometimes

Often

Everyday

10. How often do you feel that you do not have enough outside support to care for your adult child?

Rarely

Sometimes

Often

Everyday

11. How often do you feel that you will be unable to take care of your adult child much longer?

Rarely

Sometimes

Often

Everyday

12. What are the ages of the other child(children) in the household that besides your adult child with autism? (if no other children please type "0")

Child 1

Child 2

Child 3

Child 4

Child 5

13. Do you feel your other child (children) have adequate support to deal with their sibling (s) with autism?

Yes

No

Please Explain:

14. Please describe what change, service, or support would most improve your family situation and reduce stress:

## 6. Family and Demographic information

We realize some of these questions, may be personal. We want to assure you again, all information is kept STRICTLY confidential. This information will help assess the needs of families within our community and allow us to identify providers to meet these needs. Please answer as much as you can.

1. Does your adult child with autism spectrum disorder have medical insurance?

Yes, has adequate medical insurance that covers most needs

Yes, has medical insurance but leaves many needs uncovered

No, does not have medical insurance

Other (please specify)

2. Please provide any specific needs that go unmet do to inadequate insurance or a lack of insurance:

3. Does your child have a doctor that understands his/her unique needs

Yes

No

4. How has caring for your child changed as they have gotten older?

Much MORE difficult

Somewhat MORE difficult

Not changed at all

Somewhat LESS difficult

Much LESS difficult

Please Explain

5. Are you:

married/living with significant other

separated/divorced

single/never married

widow/er

Other (please specify)

6. What is your age?

Age

7. Thinking about all of your family's needs when caring for your child with autism, what are the three most important needs that are not currently being met?

Need not being met

Need not being met

Need not being met

8. Did you learn about this survey through an organization or school?

No

Yes

If yes, please specify, specifically what school or organization:

9. Please share any other comments/concerns/ideas you may have about the support your family finds helpful or about unmet needs your family has:

## 7. THANK YOU

Thank you so very much for taking the time to fill out this survey. For any questions and/or feedback, please contact Catina Harding at [catina@bex.net](mailto:catina@bex.net)