

# 2009 Community Needs Assessment

## 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. How many children with autism do you have or are you caring for?

1

2

3

4 or more

2. If you have more than one child with autism, please refer to the oldest child that is diagnosed with autism when answering the following questions.....

What is the age of your oldest child diagnosed with autism?

age

3. Is your child with autism a:

boy

girl

4. Who was the first to express concern regarding your child's development?

yourself/spouse

another family member

friend

pediatrician

Other (please specify)

5. Please tell us how much time elapsed between the initial concern and the time it took to get a diagnosis for your child.

months

years

# 2009 Community Needs Assessment

6. Did you have a difficult time getting the diagnosis for your child?

yes

no

7. Please describe what recommendations or steps to take, if any, your doctor provided you at the time of diagnosis:

8. Please provide any additional comments you may have about your family's experience having your child diagnosed with autism spectrum disorder:

## 3. Services

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

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

- |                                                                      |                                                |                                                           |
|----------------------------------------------------------------------|------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Early Intervention programs                 | <input type="checkbox"/> Family support        | <input type="checkbox"/> Inclusion programs               |
| <input type="checkbox"/> Autism Specific Early Intervention programs | <input type="checkbox"/> MRDD services         | <input type="checkbox"/> Transitional programs            |
| <input type="checkbox"/> Public pre-school                           | <input type="checkbox"/> Behavior intervention | <input type="checkbox"/> Residential services             |
| <input type="checkbox"/> Public school                               | <input type="checkbox"/> Speech                | <input type="checkbox"/> Vocational programs              |
| <input type="checkbox"/> Respite                                     | <input type="checkbox"/> Occupational Therapy  | <input type="checkbox"/> Life skills programs or services |
| <input type="checkbox"/> Day care                                    | <input type="checkbox"/> Physical Therapy      | <input type="checkbox"/> Social skills training           |
| <input type="checkbox"/> IEP advocacy                                | <input type="checkbox"/> Recreational programs | <input type="checkbox"/> NONE                             |
| <input type="checkbox"/> Parent training                             | <input type="checkbox"/> Camps                 |                                                           |

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:

# 2009 Community Needs Assessment

3. What services or programs, if any, is your 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. Education and Community opportunities

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

# 2009 Community Needs Assessment

1. What school does your child attend? (If your child does not currently attend school, please type "not attend")

2. Please tell us how satisfied you are with your child (children's) IEP team:

Very Satisfied

Satisfied

Unsatisfied

Very Unsatisfied

Please Explain

3. Do you feel you need support to adequately advocate for your child's educational needs?

Yes

No

Please Explain

4. Some families have described difficulty finding adequate care for their child (children) before/after school. We would like to know how various families are acquiring care.....Who/what services (if any) do you currently use for before/after school care for your child (children)? Was finding adequate before/after school care difficult and/or are there still challenges?

5. How satisfied are you with extended school year services (ESY)?

Very Satisfied

Satisfied

Unsatisfied

Very Unsatisfied

Please Explain

6. Now, thinking of recreational activities at school.....

On average, how many times per month does your child participate in recreational or extra-curricular activities at school?

Times per month

7. Ideally, about how many times would you like for your child to participate per month?

Ideal Per month

# 2009 Community Needs Assessment

8. What, if any activities does your child participate in at school? (IF NONE, PLEASE TYPE IN NONE)

Activity 1

Activity 2

Activity 3

Activity 4

Activity 5

9. Now, thinking of recreational/community activities.....

On average, how many times per month does your child participate in recreational or other community activities other than school/work?

Times per month

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

Very Satisfied       Satisfied       Unsatisfied       Very Unsatisfied

11. 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

12. 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 transportation Cost Attitude/receptivity of community groups

Lack of weekend activities

Location of activities       Lack of participation by non-disabled peers

Other (please specify)

13. 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.....

# 2009 Community Needs Assessment

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

Rarely

Sometimes

Often

Everyday

# 2009 Community Needs Assessment

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

Rarely

Sometimes

Often

Everyday

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

Rarely

Sometimes

Often

Everyday

12. What are the ages of the other child(children) in the household that besides your 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 child (children) 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)

# 2009 Community Needs Assessment

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

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

Yes

No

4. How is the child (children) with autism spectrum disorder related to you:

Your Child

Your Step-child

Your Grandchild

Your sibling

Other (please specify)

5. Are you:

married/living with significant other

separated/divorced

single/never married

widow/er

Other (please specify)

6. What is the public school system where you live?

7. What is your age?

Age

8. 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

## 2009 Community Needs Assessment

9. How often would you access picture communication software (such as Boardmaker) from your home or office computer, if it were available free of charge through The Great Lakes Center for Autism website?

Once a week or more often

Once or twice a month

Less often than once a month

Never

Other (please specify)

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

No

Yes

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

11. 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)