



Survey of Families with Respite Reductions and Termination September 2009

A survey was distributed to families whose respite services were interrupted or greatly reduced because of the notices from Illinois DHS that our respite and case management contracts were suspended. Surveys were mailed to families in the townships with no Mental Health Boards and to families in Cicero, Berwyn and Oak Park, whose Mental Health Board funding covers only small percentages of the cost of our services.

Ratings on Impact of Respite Service Interruption

Total percentages for any one area of inquiry may exceed 100% because of rounding to the nearest whole

Statements	Strongly Agree	Agree
<i>Without respite, it is more difficult to meet all the care taking needs of my child</i>	73%	19%
<i>My child has had a negative experience because of the CSS respite cuts</i>	43%	15%
<i>My child has asked when he will be able to see his respite staff again</i>	62%	16%
<i>Without respite, my child has demonstrated angry or negative behavior at home that we do not usually see</i>	32%	24%
<i>I have not been able to participate in planned activities for myself because of the loss of respite</i>	72%	21%
<i>The quality of life for my family has been reduced during this absence of respite</i>	56%	26%
<i>The quality of life for my child has been reduced during this absence of respite</i>	59%	21%
<i>I have not had assistance for medical appointments because of the loss of respite</i>	39%	19%

In addition to the ratings, there were two open ended statements in the survey document. Below are the responses from families to the two statements.

- **I have noticed an additional behavior from my child:**
 - He hits himself a lot of time on the head, he bites his hand, bruises his fingers.
 - He felt that his mentor had left him. He complains that he wishes he had friends he can hang around with. He looked forward to his outings.
 - She is more depressed and lonely and does not understand what happened.
 - Our daughter does not stop asking for her respite worker throughout every day.

- **Losing respite has hurt my family in the following manner:**
 - Reimbursement for respite allows me to pay for before school care, so I can go to work. Discontinuing this has created yet another financial burden.
 - The lack of respite has put a lot of stress on our marriage and stress within our family. Interrupting the state funding to an agency such as CSS was an extremely poor decision on the part of our government.
 - Our daughter thinks she has done something wrong and this is why she does not have services. It is a challenge for us to convince her otherwise.
 - He misses his respite worker and constantly asks about him.
 - We cannot hold a conversation without him interrupting or having to ask him repeatedly to quiet down. The only down time I now have is when he is asleep.
 - Without respite, my son would not be able to get out and associate with others on his own. He is no trouble at home but needs to get out once and awhile. I am ninety one years old with taking care of our house and my son and I can not get out with him except when we go shopping. He looks forward to respite. I feel that he is like glued to me. I feel guilty leaving him behind when I have an outing, so I just cancel my plans. I feel we need free time apart from each other. Because he depends on me, I sometimes make him go on an outing with his older sister and her family, but I know he doesn't care for that. I am a widow, and I too depend on the program.
 - Less time to have quality interactions with other children. Overall, my child has not participated in outside activities as he normally would thanks to respite workers!
 - I have not been able comply with my working hours by which the economic crisis affected me twice. It has been a stressful situation.
 - I am depressed a lot therefore I need help. I help my son go to the bathroom and get dressed and he does not know how to tie his shoes. I cannot even go to the store because if he has to go to the bathroom I will not be able to leave him alone
 - We have NO OTHER HELP. This causes much more stress for us. We are already overworked and have no time at all for ourselves or each other. We are not in good health and not having respite only makes things worse.

The comments from families indicate the positive impact of our services and the stress caused by service interruptions.