

Executive Summary
Preliminary Report on Child Outcomes in Montana's Childhood Autism Waiver
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At this time, children represented in this report have been participating in Montana's Childhood Autism Waiver (CAW) for an average of 15 months, or roughly only one third of the total program length. Thus, any report on their progress is preliminary. In addition, a complete data set is not available. Rather information from different data sources, both qualitative and quantitative, has been used to construct this report. However, the results from the different data sources reflect each other, leading to the conclusion that this is a valid report.

Each major finding is reported below:

- Training provided for agency staff resulted in increased skills for clinicians in working with young children with autism—this has been described “as the biggest systems change in memory”.
- Before participating in the CAW, children were learning on average two weeks of information for every month they were alive. Since CAW participation, they are learning, on average almost six weeks of information for every month they are alive.
- Since participating in the CAW, 100% of the children engage in more social play.
- Since participating in the CAW, 99% of the children have more access to the community.
- Since participating in the CAW, 92% of the children have a decrease in challenging behaviors.
- Since participating in the CAW, 88% of the children have had an increase in their verbal skills.
- Since participating in the CAW, 75% of the children are toilet trained.
- Since participating in the CAW, 59% of the children have a decrease in sleep problems.
- In addition, increases in: on-task behavior, direction following, the number of foods eaten and safety skills have been reported.
- Also, reports of children being calmer and less self-injurious have been made.
- Parents report that the program has resulted in significant changes and their child's functioning and in the overall quality of their family's life. (For excerpts of family letters see page two of this summary.)

These data underscore the projections that agencies are making that between 10% and 20% of the children who have participated in the CAW will be able to attend general education services without support.

Each of these finding indicates that the CAW is potentially a very effective program. However, it must be kept in mind that these data are preliminary. For example, it is possible that as children are in the program longer, their growth rate will slow. Regardless, these data indicate that the program, thus far, is effective. Further, these important child outcomes do not mediate known challenges of the implementation of the CAW program, that include: 1) the challenge of hiring, training and keeping good CAT trainers; 2) for school age children the challenge of finding 20 hours a week for this type of interventions; 3) for families there is considerable stress having a professional in your house 20 hours a week; and , 4) not all families want the allowable type of intervention and wish that funds could be used for interventions from other philosophies. All that being said, however, at this time, the data indicate that this is a promising program that should not only be kept but be expanded.

EXERPTS FROM PARENT LETTERS

Letter from a parent in Billings

“The time she has spent with the therapists, trainers and aides, the medical she has received, and the training which I have received in seminars and classes due to the additional support provided by CAW has been of great value to XX and to our entire family as well as everyone in the community she comes into contact with. Thank you for allowing her this opportunity to find the keys by which we can open the doors so she may reach her full potential.”

Letter from a parent in Billings

“We are finally getting our little boy back...We continue to have hope for the future of this program. If you could only see through the eyes and hearts of my husband and myself, you would realize how extremely important the Children’s Autism Waiver is in the State of Montana. The number of lives that are being changed is truly unbelievable.”

Letter from a parent in Billings

“The education and the feedback that has been provided has been useful also when we reach various bumps in the road. I know that with the staff at XX and our CAT we will get XX to succeed beyond what we even know at this time. On behalf of our family I would like to thank all those who are trying to keep this program implemented for our community.”

Letter from a parent in Helena:

“Thank you again for all the wonderful support you have given us. I really don’t know where we would be if we didn’t have you in our lives.”

Letter from a parent in Missoula

“Six months ago she couldn’t tell me what she wanted and now we can’t get her to stop talking. She no longer throws fits and is able to tell me what she wants and needs so life is easier for everyone.”

Letter from a parent in Lolo

“As a family, we are astounded at what a difference this program has made for XX, and therefore our whole family too. XX is currently a 5 year old, attending Kindergarten, and is able to follow along with most of the activities in the class with a help of an aide. A year ago, XX was not able to follow instructions at all, he could not participate with any activities...Thank you for this service. Thank you for changing lives.”

Letter from a parent in Polson:

“I believe this has changed XX entire life. If you can not function in society... you are not going to have a meaningful life. XX use to have a 20 minute melt down every time someone knocked on the door. He now runs to the door when he hears it, says hello to whoever is there and looks forward to the visit. The changes in his life have been a gift for all of us. Thank you for this amazing program. My hope and prayer is that every child who suffers with autism could receive the same gift. I believe this is a huge saving in future costs to schools and government services later. I do not believe XX will need any special services in school or at home by the time he completes this program.”