



Montana's Children's Autism Waiver Update January 23, 2012

Submitted by:

Jackie Emerson
DPHHS

Ann Garfinkle, PhD
University of Montana

Background

In 2009, DPHHS began the Children's Autism Waiver (CAW). The CAW responds to the needs of Montana's children and families by providing a cutting edge, evidence-based, intensive program for 50 children aged 15 months to eight years of age who are diagnosed with autism and have delays in adaptive behavior. The program is based on the nationally recommended practices for children with autism, including Applied Behavior Analysis. The program consists of individualized program design and monitoring, case management, and 20 hours a week of instruction for the child.

To support the implementation of the program, DPHHS contracted with the University of Montana (UM) to provide Technical Assistance and Professional Development. In addition, DPHHS contracted with the UM to design an evaluation program.

Method

Fifty children, qualifying with a diagnosis of autism and delays in adaptive functioning, across the State of Montana, were randomly selected to participate in the program. Community providers from the Developmental Disabilities Program Child and Family Services were contracted with to provide the services. Training included statewide plenary training and individualized training for agencies. However, the bulk of the training was conducted using an innovative shoulder-to-shoulder approach. This approach combined video tape review, observation and coaching, modeling, data review, and program development.

To evaluate the program a variety of types of measures (i.e., norm referenced, curriculum-based measures) across a number of variables (i.e., symptom-related, development, and functional) were measured. While a comprehensive evaluation of the project will be conducted when children complete the program (meaning receive three years of CAW services), preliminary data have been collected. A report of this data has submitted previously and is available at

<http://www.dphhs.mt.gov/dsd/ddp/autism.shtml>

Results

Previously reported data indicate that in the developmental domains most affected by autism (i.e., social skills, communication skills and adaptive functioning) all children were making progress. Most notably, in these three domains, norm-reference tests indicated that on average, participating children's rate of development nearly tripled. It is not known, however, if this rate will hold steady through the children's participation in the program.

Although no children have yet completed the full three years of treatment, four children have exited due to age (i.e., the children turned 8 before they received 3 full years of service). Preliminary outcome

data are available on these four children and are presented below. It should be noted that it is not known how representative these four children are of the entire sample of 50 children.

Below are outcome data for the four children, all four children are white males:

What percent of the three year program did the children complete?

Participant	Percent of three year program completed
Child 1	83%
Child 2	93%
Child 3	64%
Child 4	64%

What functional skills did the children learn?

All four children made gains in the following area:

- Communication skills
- Social skills
- Self- help (all four children are toilet trained)
- Self- regulation

How did program participation affect the children’s challenging behavior?

All four children demonstrated decreases in the following behaviors:

- Tantrums
- Impulsivity
- Aggression
- Screaming

What percentage of treatment goals did the children master?

(Treatment goals are developed by the child’s team and are individualized for that child.)

Participant	Percent of goals mastered
Child 1	85%
Child 2	81%
Child 3	87%
Child 4	73%

In terms of symptom severity, how are these children described at exit?

(This data is based on the results of the Children’s Autism Rating Scale [CARS], which is a well-accepted, psychometrically strong assessment of autism symptomology.)

Participant	Description of Symptom Severity
Child 1	Normal range
Child 2	Severely autistic
Child 3	Mildly autistic
Child 4	Normal range

Discussion/Analysis/Impact

For children who have completed at least two years of CAW services, service providers were able to deliver an average of 17.97 hours a week of direct intervention to each participating child. To do so, they had to overcome barriers of an undertrained workforce, long distances and children with many scheduled therapies and school activities. Providers are encouraged to continue to deliver 20 hours a week of service, as the number of hours in service is thought to have a direct relationship to the eventual outcome.

Based on the data presented previously and above, it is anticipated that some of the children will achieve what is called a "best outcome". Autism is considered a life-long developmental disability and as such there is no cure. However, a "best outcome" label is used to describe children who demonstrate a normal IQ, can access the general education curriculum, and whose autism symptoms have decreased to the extent that they no longer fall in the clinical scale of autism. The data above describes two children that have met this criteria. Based on preliminary data, as many as 20% of the children receiving CAW service may reach this outcome. If average lifetime costs for serving an individual with autism are used, for *each child* obtaining a best outcome, the State could save approximately \$2M in lifetime costs. Appropriations to DDP to serve 50 individuals for one year of this waiver totals \$2.1M. The State general fund portion is \$709,000.

The budget for each child's service plan averages \$42,111. Approximately 94% of the cost of the service goes into direct provision of the 3 main services: Program Design and Monitoring of the individualized autism training plan, Children's Autism Training which provides the direct autism intervention, and Case Management to provide case coordination for the overall plan of care. Only 16% of the budget goes to Case Management. The remaining 6% of the funds purchase support services such as adaptive equipment and environmental modifications, respite, transportation, and therapies.

The expertise required to provide autism waiver services has increased the sophistication of Montana's workforce. **The technical assistance and professional development provided has been described by a provider as "the single best systems change effort put into practice in my 30 years in the system."**

The preliminary outcomes of the evaluation project have been reprinted by at least three web-based media outlets, have resulted in newspaper articles in many of Montana's major cities and have been picked up by the Associated Press. Other states that have seen the outcomes have asked Montana for support in their waiver programs.

Waiting List Numbers

Over the three years of the waiver, there have been 224 children on the waiting list. Of that number,

- 50 children are currently receiving CAW services;
- 58 are currently waiting for an opportunity – this number is in flux as new children become eligible and others age off;
- 89 children have aged off the list (turned five and been removed from the waiting list) without being selected for an opening;
- four children turned age eight and were transitioned out of the waiver; and
- 19 children were selected for the waiver but did not fully participate, eight of these families cited the time commitment of the program or family related stress as the reason for not

participating; five families found services through other means (i.e., insurance); three families moved out of state; and three families were not interested .

Future Direction

By July of 2012, more than 30 of the children currently in the CAW will have completed their autism waiver services with another 12 finishing services by the end of the calendar year. This means that more than 42 children from the waiting list will be given an opportunity to receive services over the next year.

A data collection system is currently being developed based on the evaluation protocol designed by the UM. This system will allow the Department to sustain the ability to aggregate, summarize, analyze, and report data and outcomes. **A report of outcomes from the first group of program completers (i.e., children receiving the full three years of service) will be available for the 2013 Montana Legislature.**

Also included in the future of the service are pioneering work with distance technologies for hard-to-serve families, continued professional development for core personnel who are ready to progress, and standardized transition planning training so children don't lose skills. It will also be important to communicate and coordinate with other states and national groups to report Montana's results and to stay current with the latest developments in the field of autism intervention.

All those involved with the autism waiver services have been encouraged by the progress made across the system as well as in the lives of the Montana children and families served.