

CMS

CENTERS for MEDICARE & MEDICAID SERVICES



**U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services**

Denver Region

FINAL REPORT

**Montana Home and Community-Based Services
Children's Autism Waiver**

Control number 0667.R00.01

February 16, 2011

Executive Summary:

The Centers for Medicare & Medicaid Services (CMS) conducted a quality review of the Montana Home and Community-Based Services (HCBS) Children's Autism Waiver (CAW), CMS control number 0667.R00.01. As a result of the review, the State demonstrated substantial compliance with all six assurances required for waiver approval, as set forth in 42 CFR §441, subpart G. The review was conducted in accordance with the Interim Procedural Guidance (IPG), which has been in effect for assessing home and community-based waiver programs since January of 2004, and has since been revised. One of the main purposes of the IPG is to standardize the approach CMS utilized when assessing waiver programs as it transitions its quality oversight approach to one that incorporates both the assurance of statutory requirements and promotion of quality improvement.

The CAW is a new waiver approved with a January 1, 2009 effective date, and is due to expire on December 31, 2011. The State submitted one amendment that was recently approved by CMS. The waiver is administered and operated through the Developmental Disabilities Program (DDP) under the Disability Services Division, a division within the single State Medicaid agency (SMA) in the Department of Public Health and Human Services (Department). This waiver was initiated as a result of State legislation in order to provide home and community-based waiver services to children age 15 months through seven years of age diagnosed in the autism spectrum disorder with adaptive behavior deficits who, but for the provision of such services, would require the ICF/MR level of care.

The State described its waiver in the initial application as providing services “designed to improve skills in receptive and expressive communication, social interaction and activities of daily living, while reducing the inappropriate or problematic behaviors often associated with autism using training techniques based on applied behavioral analysis . . . Child and family service providers funded under the DD Comprehensive Services waiver have provided services to children with autism for many years. Until now, however, the State of Montana has not offered a systematic, comprehensive treatment approach designed to maximize the developmental potential of very young children with autism, or ASD. When approved, this waiver will give Montana children diagnosed with ASD an optimal opportunity to enjoy a higher quality of life.”

The State designed the waiver so that a child receives three full years of waiver services. Thus, the State does not enroll children in the waiver past four years of age, since they would not be able to receive services for the full three years. It is highly recommended that the State re-evaluate the effectiveness of this waiver design feature and its impact on the children's ability to maintain any benefits received from the waiver once the three years is over. The waiver offers the following services for waiver participants statewide: Children's Autism Training; Respite; Waiver Funded Children's Case Management; Adaptive Equipment/Environmental Modifications; Extended State Plan Occupational Therapy, Physical Therapy, and Speech Therapy; Transportation; Individual Goods and Services; and, Program Design and Monitoring.

Initially, the State did not offer self-direction; however, as part of the amendment, the State added self-direction for respite and transportation services under both the employer and budget

authorities. To aid families in self-directing these services to include assistance with IRS tax requirements and other implications, the State will provide Financial Management Services administratively through a contracted private entity. The Division also contracts to conduct initial and on-going level of care activities. It should also be noted that the State received technical assistance (TA) from the CMS contractor, Thomson-Reuters, which sub-contracted with Human Services Research Institute (HSRI) for this particular waiver.

Introduction:

Pursuant to §1915(c) of the Social Security Act, the Secretary of the Department of Health and Human Services has the authority to waive certain Medicaid statutory requirements to enable a State to provide a broad array of home and community-based services as an alternative to institutionalization. The CMS has been delegated the responsibility and authority to approve State HCBS waiver programs.

The CMS must assess each home and community-based waiver program in order to determine that State assurances are met. This assessment, i.e., review, also serves to inform CMS and the State of possible issues that may negatively impact the approval of the upcoming renewal application. In accordance with federal regulations at 42 CFR §430.25 (h) (3), the renewal request must be submitted to CMS at least 90 days before the currently approved waiver expires.

State Waiver Name:	<u>Montana Children’s Autism Waiver</u>
Administrative Agency:	<u>Montana Department of Public Health and Human Services</u>
Operating Agency:	<u>Disability Services Division, Developmental Disabilities Program (DDP)</u>
State Waiver Contacts:	<u>Perry Jones, DDP Waiver Specialist</u>
Target Population:	<u>Children between the ages of 15 months through seven years of age diagnosed in the autism spectrum disorder who have adaptive behavior deficits</u>
Levels of Care:	<u>ICF/MR</u>
Number of Waiver Participants:	<u>For all three years of the waiver, the State requested and was approved to serve 55 unduplicated recipients.</u>

Average Per Capita Waiver Costs: Current Waiver Year 2, the initial annual estimated average waiver cost per person (Factor D was approved at \$45,854.16.

Effective Dates of Waiver: 1/1/09 – 12/31/11

Approved Waiver Services: Children’s Autism Training; Respite; Waiver Funded Children’s Case Management (WCCM); Adaptive Equipment/Environmental Modifications; Extended State Plan Occupational Therapy, Physical Therapy, and Speech Therapy; Transportation; Individual Goods and Services; and, Program Design and Monitoring;

CMS Contact: Di Friedli, Health Insurance Specialist, Denver Regional Office

I. State Conducts Level of Care Determinations Consistent with the Need for Institutionalization

The State must demonstrate that it implements the processes and instrument(s) specified in the approved waiver for evaluating/reevaluating an applicant's/waiver participant's level of care consistent with care provided in a hospital, nursing facility, or ICF/MR.

Authority: 42 CFR §441.301-303; State Medicaid Manual (SMM) 4442.5; 1915(c) Version 3.5 HCBS Waiver Application and corresponding Instructions, Technical Guide & Review Criteria.

CMS Finding: The State substantially meets the assurance.

Evidence Supporting this Conclusion:

The State provided sufficient evidence to support compliance with this assurance. More specifically, the State reviewed 100% of the initial level of care evaluations and reevaluations. The performance measure (PM) data and frequency of analysis were consistent with the quality improvement strategy (QIS) for this waiver agreement. For PM data that had less than 100% compliance, the State included remediation activities and, when applicable, system improvement activities.

As part of its QIS, the State developed a Children's Autism Waiver review tool, which is a Microsoft Excel spreadsheet to aid in documenting PM data. Their Quality Improvement Specialists utilized this review tool to complete the annual quality assurance (QA) reviews of each service provider in the five DDP regions throughout the State. It was noted that the State's first effort to design PMs and data collection tools as well as collecting and analyzing the data, which was described as being very labor intensive, provided valuable experience that was used to refine and strengthen each of the components for the next reporting cycle.

As a result of the findings submitted for this review, the State sent the providers a cover letter and a provider-specific spreadsheet of the data and its results along with Quality Assurance Observation Sheets (QAOS), where needed. The State indicated the QAOS serves to "identify deficiencies, recognize exemplary performance and provides a written record of Department and provider efforts to ameliorate deficiencies when compliance is less than 100%." The State entered the QAOS information into the spreadsheet and updated it when the remediation activities were completed. The initial evidence report to CMS ensuring that all findings were remediated was somewhat lacking because the State was waiting to receive feedback from the providers on the QAOS. However, the State submitted a revised report to CMS with updates on the remediation activities taken ensuring compliance.

The State did a good job of using its data findings to make system improvements to the waiver through an amendment, which has since been approved. In some cases, the State simplified its quality assurance (QA) review data requirements; in other cases, it modified PMs to align more precisely with the waiver assurances and increase the face validity of the measure. The State also refined some of its waiver practices related to conducting level of care determinations.

CMS Recommendations: There are no recommendations at this time.

II. Service Plans are Responsive to Waiver Participant Needs

The State must demonstrate that it has designed and implemented an adequate system for reviewing the adequacy of service plans for waiver participants.

Authority: 42 CFR §441.301-303; SMM 4442.6; SMM 4442.7; 1915(c) Version 3.5 HCBS Waiver Application and corresponding Instructions, Technical Guide & Review Criteria.

CMS Finding: The State substantially meets the assurance.

Evidence Supporting Conclusion:

As noted in the previous assurance, the State did a good job of submitting data, its analysis, remediation activities and, where applicable, system improvements for all assurances including this one. A 100% review of all files was conducted. Overall, the compliance rate for the PMs in this assurance was high. There was one systemic change made regarding service plans based on its quality reviews and the data from discovery activities to simplify one of the PMs to record one element instead of multiple elements measuring if service plan meetings were held in the required timeframe.

CMS Recommendations: There are no recommendations at this time.

III. Qualified Providers Serve Waiver Participants

The State must demonstrate that it has designed and implemented an adequate system for assuring that all waiver services are provided by qualified providers.

Authority: 42 CFR §441.302; SMM 4442.4; 1915(c) Version 3.5 HCBS Waiver Application and corresponding Instructions, Technical Guide & Review Criteria.

CMS Finding: The State demonstrates the assurance, but CMS recommends an improvement.

Evidence Supporting Conclusion:

The State's analysis of their data revealed a couple of areas of improvement in their QIS for this assurance. Before going into more detail, the State used a 100% review and provided a summary of their data, their analysis, remediation activities and, where applicable, system improvement for all PMs. In terms of system improvement activities, the State modified its QA review tool to capture data if the children's autism trainer is in compliance with DDP policy, and also changed language to be more direct about capturing data on medication assistance.

Especially if the State chooses to serve more children, in order to recruit and retain providers, CMS recommends that the State include geographic rate adjustments for rural and frontier areas of the State similar to the methods used in the Montana Individuals with Developmental

Disabilities Comprehensive HCBS Waiver, or the Montana Community Alternatives to the Psychiatric Residential Treatment Facilities Demonstration Grant.

CMS Recommendation:

In the upcoming renewal, to assist in provider recruitment and retention consider adding a geographic rate adjustment for the rural and frontier areas of the State. For more information, please refer to pages 251-252 of the Version 3.5 HCBS Instructions and Technical Review Guide.

IV. Health and Welfare of Waiver Participants

The State must demonstrate that, on an on-going basis, it identifies, addresses, and seeks to prevent instances of abuse, neglect and exploitation.

Authority: 42 CFR §441.302-303; SMM 4442.4; SMM 4442.9; 1915(c) Version 3.5 HCBS Waiver Application and corresponding Instructions, Technical Guide & Review Criteria.

CMS Finding: The State demonstrates the assurance, but CMS recommends improvements.

Evidence Supporting Conclusion:

The unit of analysis for this assurance is the waiver participant. However, the PMs and evidence provided were focused more on providers and processes. For example, the first PM was regarding staff knowledge and the data reported for this PM indicated that 16 staff interviews out of 54 total interviews could not be scheduled and/or completed with the Children's Autism Trainer (CAT). Despite focusing on the provider, there was no information provided why a significant number of the interviews weren't conducted or any follow up action provided. Further, the State took a percentage based on only the 38 interviews, which skews the results of this PM because the total percentage should be based on 54 interviews that should have been conducted and not on the 38 that were.

The second PM was ensuring that service provider agencies have a comprehensive Incident Management Policy inclusive of the components of the DDP Incident Management Policy. Again, the focus for this assurance should be based on the waiver participant, not the provider. Further, the data provided demonstrated a substantial lack of compliance, yet there was no system improvement activity, which one would expect due to the potential health and welfare issues of not reporting critical incidents at all or timely, not investigating them, etc. There was only a remediation activity of sending out QAOS to the non-compliant provider agencies.

The third PM was that the Incident Management Committee Meetings review included documented critical incidents as defined in DDP policy. However, this PM is process in nature and focuses on the provider agencies. Rather, it should be re-designed in a way to provide the State with more outcome oriented information such as the types of incidents involving the children, if incidents were reported timely, the number of unreported critical incidents, and the like. These same issues apply to the fourth PM, which captured data whether provider agency

training programs were in compliance with the Administrative Rules of Montana governing the use of aversive procedures.

Despite the need to revise the PMs in this assurance, there were no critical incidents involving the children or anything that jeopardized their health and welfare, per ongoing monitoring of this waiver between CMS and the State. In fact, this waiver has been very beneficial for many families in getting their child the needed individualized and behavioral services and supports.

CMS Recommendations:

- 1) The PMs for this assurance are more appropriate under the Qualified Providers assurance and should be moved there in the next amendment or renewal, whichever is submitted first.
- 2) Since the State is receiving TA from HSRI, it is recommended that the State redo the PMs in this assurance ensuring that the unit of analysis is the waiver participants. Examples of PMs appropriate under this assurance include, but are not limited to, the number and percent of waiver participants who received age-appropriate preventive health care; number and percent of medication errors; number and percent of restraint usage and time-outs that were not implemented in accordance with the individualized service/behavior support plans; number and percent of unreported critical incidents; etc.

V. State Medicaid Agency Retains Administrative Authority over the Waiver Program

The State must demonstrate that it retains ultimate administrative authority over the waiver program and that its administration of the waiver program is consistent with its approved waiver application.

Authority: 42 CFR §431 et seq.; 42 CFR §441.301-303; SMM 4442.6; SMM 4442.7; 1915(c) Version 3.5 HCBS Waiver Application and corresponding Instructions, Technical Guide & Review Criteria.

CMS Finding: The State demonstrates the assurance, but CMS recommends an improvement.

Evidence Supporting Conclusion:

In the State's response to the CMS concerns of the lack of remediation activities documented in the initial evidence report submitted on 9/20/10, the State indicated that the Quality Assurance Observation Sheets (QAOS) were issued to all entities responsible for activities specified on the performance measures when the outcomes were less than 100%. QAOS sheets have been returned to the DDP reviewing authorities and as of 11/19/10, findings have been closed. However, the State indicated a closed finding means that either the deficiency has been resolved, or will be resolved by a certain date; the methods and timeframes for which have been accepted by the Department.

Closing a finding before the issue, or deficiency as the State calls it, is resolved by a certain date is concerning because there is no documented follow up on the State's tracking system to

ensure that the issue was, in fact, sufficiently addressed at that later time. Many times something comes up that delays or changes the nature of the corrective action. By keeping the finding open, this ensures timely and adequate follow-up to ensure the issues were fully remediated. Also, it should be noted that the CMS previously expressed concern the way the State wrote its PMs for this assurance in that they lacked the critical link to the SMA oversight. The State already addressed this concern in the recent amendment and revised the PMs for this assurance.

CMS Recommendation:

Keep an issue that “will be resolved by a certain date” open until that date has passed and the issue has been fully remediated.

VI. State Provides Financial Accountability for the Waiver

The State must demonstrate that it has designed and implemented an adequate system for assuring financial accountability of the waiver program.

Authority: 42 CFR §441.302-303; 42 CFR §441.308; 42 CFR §447.10; 42 CFR §447.200-205; 42 CFR §433; 45 CFR §74; SMM 2700.6; SMM 2500; SMM 4442.8-10; 1915(c) Version 3.5 HCBS Waiver Application and corresponding Instructions, Technical Guide & Review Criteria.

CMS Finding: The State demonstrates the assurance, but CMS recommends an improvement.

Evidence Supporting Documentation:

This assurance was the weakest in terms of evidence submitted. Although the State was conducting more activities than what they originally included in its evidence report, there was only one PM that involved reviewing parent survey information whether services and supports were delivered in accordance with the plan of care. CMS reminded the State that PMs based on survey data should be used in conjunction with other PMs, and that the one PM it did have for this waiver was not an assurance that claims were coded and paid for appropriately. As a result, the State added another PM in its amendment that the Department assures financial accountability in the reimbursement of services using a 100% annual review with the sources of data noted as contact notes, staff log notes, employee timesheets and payroll records.

CMS Recommendation:

As previously noted in other sections of this report, the State added self-direction as part of the amendment to this waiver, and therefore a PM should be added ensuring the FMS is processing payroll and reimbursing employees according to the submitted timesheets and individual cost plans.

Friedli, Diana R. (CMS/WC)

From: Friedli, Diana R. (CMS/WC)
Sent: Friday, February 11, 2011 10:57 AM
To: Allen, Richard C. (CMS/CMCHO); Marchioni, Mary A. (CMS/WC)
Cc: Travis, Ondrea D. (CMS/CMCS); Turner, Trudy J. (CMS/WC)
Subject: RE: Please review - MT 0667 Final Report
Attachments: PreliminaryRptonChildOutcomesinCAW012111.pdf

You're right, Richard, there is very little controversy with this waiver. In fact, Jeff Sturm, the DD Director, and I recently spoke, and Jeff said that the legislature and parents are very happy with the waiver. There was a draft report recently issued by the University of Montana at Missoula indicating the waiver is effective in addressing the kids' needs that I attached, if interested.

From: Allen, Richard C. (CMS/CMCHO)
Sent: Friday, February 11, 2011 10:51 AM
To: Friedli, Diana R. (CMS/WC); Marchioni, Mary A. (CMS/WC)
Cc: Travis, Ondrea D. (CMS/CMCS); Turner, Trudy J. (CMS/WC)
Subject: RE: Please review - MT 0667 Final Report

Di, this report looks good to me and will sign after Mary has reviewed. This waiver covers 55 children between ages 15 months to 7 years and appears to be working well without a lot of controversy. By contrast there is so much controversy in the Colorado Autism waiver. I will certainly be using this waiver as a comparison to the Colorado waiver and be thinking about why all the controversy exists in one and not the other. Richard

From: Friedli, Diana R. (CMS/WC)
Sent: Thursday, February 10, 2011 2:56 PM
To: Allen, Richard C. (CMS/CMCHO); Marchioni, Mary A. (CMS/WC)
Cc: Travis, Ondrea D. (CMS/CMCS); Turner, Trudy J. (CMS/WC)
Subject: Please review - MT 0667 Final Report

Hello again,

Please review and comment on the attached MT Children's Autism Waiver final report. They were in compliance with all six assurances, and they agreed with all of our recommendations. Since I just sent you a Colorado PACE letter that needs to be reviewed and issued pretty soon due to its impact on this year's PACE rates, I dated this report for Wednesday, the 16th.

Thanks. Di



Please consider the environment before printing this e-mail!

DRAFT

Preliminary Report on Child Outcomes in Montana's Childhood Autism Waiver

Submitted by:

Ann N. Garfinkle, Ph.D.

University of Montana—Missoula

This is a preliminary report of the effectiveness of Montana's Childhood Autism Waiver (CAW). The CAW is a waiver program overseen by the Developmental Disabilities Program of Montana's Department of Public Health and Human Services (DPHHS). The services are provided by private agencies (i.e., providers) across the state that have contracts with DPHHS. Services consists of a number of functions including case management, respite, and the heart of the CAW, 20 hours per week of intervention based on applied behavior analytic techniques. These techniques are considered by the field to be current recommended practices.

This report is preliminary in three ways: 1) CAW services are designed as a three year program (children who receive the service are eligible for three years of services and must exit either when they reach their three years or when they turn eight), however, none of the children have yet completed three years of intervention and thus no conclusions can be made about the ultimate effectiveness of the program; and 2) the planned formal program evaluation is largely based on evaluating children's skill before and after program participation, and thus is not yet available; and, 3) the data used for this report not only is based on children still receiving services but is also based on an incomplete data set. Not all the children receiving services were reported on for this report and not all children receiving services were reported on in a consistent matter. However, this preliminary report is thought to be both a reliable and valid report on the effectiveness of the waiver so far.

Agencies (providers of CAW services) responded to the call for preliminary data on children receiving waiver services in a variety of ways. Thus, four different types of data were provided for this report: 1) quantitative data based on norm-referenced assessments, 2) qualitative impressions on core skills and behaviors, 3) qualitative summaries based on field observations and progress notes, and 4) parent reports in the form of letters. Each type of data is analyzed such that the analysis is suitable for the type of data presented. Each type of data will be presented in turn. Each will have a brief explanation of the data analysis technique used followed by the actual data and a short discussion of the findings. Next the data will be looked at as a whole and discussed thusly. Finally some limitations and caveats about this data and its interpretation will be given.

Quantitative data based on norm-referenced assessments. In this preliminary call for information, agencies provided information using a variety of published norm-referenced assessments including, the Vineland, the Learning Accomplishment Profile, and the Battelle Developmental Inventory. These tests were administered at program entry and then again in October, 2010 (in preparation for this report). Data for 15 children are reported this way. The average time in CAW services, represented by these data, is 15 months (with a range of 9 months to 28 months). Thus, on average these data represent children who are a little more than a third of their way through the program. Since data was from different assessments, all scores were translated into age equivalency scores. Scores in communication, social/emotional, and self help/adaptive domains were the focus. This is because two of the three primary deficits in autism are in

the communication and social domains (the third deficit area is restricted repertoire for which no norm-referenced test exists). And, self help/ adaptive was a focus because a requirement for program entry was documented deficits in this area. Next, age equivalency scores were translated into rate of growth scores. This was done by taking the age equivalency score and dividing it by the child's actual chronological score at the time of testing. The result is a figure representing the amount of information the child learned for each month he was alive. For example, a score of one would mean that for each month the child was living he learned a month's worth of information. A score of less than one indicates that the child is learning less than a month's worth of information for each month he is alive. A score higher than one indicates that he is learning more than a month's information for each month he is alive. Figure 1. below represents the average rate of growth for the children in the CAW program before and during the program. A net rate of change due to waiver participation is also provided.

Figure 1. Average actual monthly rate of growth per month in CAW participants

Domain	Prior to CAW	October 2010 Update	Overall Rate Change
Communication	.5	1.4	.9
Social/Emotional	.4	1.4	1.0
Self help/Adaptive	.5	1.3	.8

Thus, as a result of waiver participation, children's rate of growth increased markedly. Prior to participation in the waiver children were approximately half of what typically developing children were learning in the same time period. At the October evaluation time, children were learning more than a month's worth of information for each month of intervention.

Qualitative impressions on core skills and behaviors. In response to the request for information about the progress of the children receiving waiver services, an agency created a form using valued outcomes (i.e., toilet training, language, sleep, social skills, community access, and challenging behaviors) that asked providers to rate the child at the start of waiver service and again in October 2010. Other agencies also used this form in their reporting. All told 24, children were described using this approach. At the time of this evaluation, the average time spent in the waiver services was 15 months (with a range of 5 months – 22 months). Again, on average, the children are only about a third of the way through the program. This tool asks providers to describe children's progress. Responses were coded with children who had like progress. For example, children who were described as "not toilet trained" at the start of the waiver and as "toilet trained" at the October progress report were coded together. This was done for all possible categories. In Figure 2 below percentages of children that fit into each category are provided.

Figure 2. The percentage of children in each category of valued outcomes.

Valued Outcomes	Category of Results	Category of Results	Category of Results
Toilet Training	Not trained (pre and Oct.)	Not trained (pre) to trained (Oct.)	Trained (pre and Oct.)
	25%	58%	17%
Language	Non-verbal (pre and Oct.)	Non-verbal (pre) to verbal (Oct.)	Verbal (pre) to more verbal (Oct.)
	13%	38%	50%
Sleep	Severe problems (pre) to mild problems (Oct.)	Problems (pre) to none (Oct.)	None (pre and Oct.)

	42%	17%	42%
Social Skills	Plays alone (pre) to side-by-side (Oct)	Side-by-side (pre) to Interactive (Oct.)	
	21%	79%	
Community Access	No/ limited access (pre and Oct)	No/limited (pre) to moderate/full (Oct)	No Change (pre to Oct)
	0%	99%	1%
Challenging Behaviors	Lots (pre) to less (Oct)	Some (pre) to none (Oct)	No change (pre to Oct)
	88%	4%	8%

Figure 2. indicates that in all categories, that the majority of children made gains in important skills that were noticeable in the child's everyday life.

Qualitative summaries based on field observations and progress notes. A third type of data is summaries of field notes and progress notes taken by the professionals who work with the children. These summaries were then analyzed using the constant comparison technique. This technique is the most commonly used way to analyze qualitative data. It involves reading each note, and deciding a "theme" it describes. Like themes are grouped together. Then, the number of notes in each theme is counted and the themes are rank ordered from most common mentions to least commonly mentioned. For this report, the notes of children before CAW services were analyzed together and the October reports were analyzed with each other, resulting in a pre-services and October comparison. Figure 3 below represents the rank order (from most to least) of themes in the field notes. In cases where the themes had the same number of mentions, they are presented in the same box.

Figure 3. Rank Order of themes in field notes and progress reports.

Rank Order	Before CAW	At October, 2010
1.	Child engaged in challenging behavior Child has poor communication skills	Child has better communication skills
2.	Child is off-task most of the time Child engages in repetitive play	Child is toilet trained
3.	Child has poor social skills Child is not toilet trained	Child plays with others Child exhibits fewer challenging behaviors Child has increased engagement in tasks Child can more easily access the community
4.	Child is highly non-compliant Child has unmet sensory needs Child has sleep issues Child has problems with transitions	Child has better self help skills Child is better able to follow instructions
5.	Child has poor self help skills Child engages in self injurious	Child has better social skills

	behaviors Child doesn't respond to his name	
6.	NA	Child is calmer Child eats a wider variety of foods Child is more flexible
7.	NA	Childs in engages in less self injurious behavior Child has fewer unmet sensory needs Child has better safety skills

This data indicates that as a result of participation in the waiver that the most noteworthy concerns were addressed and that significant changes in thus areas where made.

Parent reports in the form of letters. Although these letters could be analyzed using the constant comparison technique, the results of this analysis would not greatly differ from the data presented above. Thus, portions of the letters will directly quoted so that the parents own words show the way in which individual families have been impacted by the CAW.

Letter 1:

“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 2:

“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 3:

“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 4:

“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 5:

“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 6:

“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.”

Conclusion.

Taken together, this data suggests that the CAW is potentially an extremely effective program that is changing children’s developmental trajectories and by extension creating different lives for not only the child but the child’s family as well. These changes are triangulated across data types and data sources adding to the validity of this conclusion. While the changes on standardized tests are powerful and considered by some to be the gold standard, the importance in the changes in the everyday functioning of the children should not be down played. For it is often these changes that have the biggest impact on children and their families. Though not specifically reported above, agencies report estimates of as high as 20% of children receiving CAW services either no longer or are projected to no longer need special services in schools. This is what the field refers to as a “Best Outcome”.

Despite these promising findings and projected outcomes, one needs to consider the data with certain cautions in mind. First, these data are very preliminary and do not reflect all 50 participants who receive CAW services. Second, given the short amount of time in the program, the acceleration of the children’s growth rates may be a function of the introduction formal intervention and these may slow over time. These data should not be interpreted to mean that these children will eventually “catch up” on their development. Third, the quantitative data presented are of group averages. This was done intentionally in order to distil into a single number the effect of the program. However, whenever an average is used, there are important individual differences that get smoothed out. These individual response rates are varied with some children making many gains and others making far fewer gains. Fourth, there are known challenges to the waiver including but not limited to: 1) the challenge of hiring, training and keeping good autism 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.

Friedli, Diana R. (CMS/WC)

From: Friedli, Diana R. (CMS/WC)
Sent: Monday, February 07, 2011 2:39 PM
To: 'Jones, Perry'
Cc: Thompson, Jo; Sturm, Jeff; Schroader, Joli; Travis, Ondrea D. (CMS/CMSO)
Subject: RE: tribal notification letters re 0208 and 0371 amendment requests

MT 0667 Response

Thanks Perry. I didn't want to assume anything. You should be receiving a final report within the next week or so. Thanks again. Di

From: Jones, Perry [<mailto:pjones@mt.gov>]
Sent: Monday, February 07, 2011 2:13 PM
To: Friedli, Diana R. (CMS/WC)
Cc: Thompson, Jo; Sturm, Jeff; Schroader, Joli; Travis, Ondrea D. (CMS/CMCS)
Subject: RE: tribal notification letters re 0208 and 0371 amendment requests

Hi Di,

DDP staff reviewed the recommendations in the CMS QA Review of the 0667 Waiver and agreed with the CMS recommendations for the additional performance measures. You promptly answered the 1/29/11 e-mail question related to the timeframe for incorporating new 0667 Waiver performance measures in your 1/31/11 e-mail, attached. It was our understanding that if we did not respond to the draft report by 1/30/11, the CMS draft QA report would become the final report (based on the language in the attached pdf document). At this time, the DDP considers the CMS draft report the final CMS report.

We appreciate the CMS efforts in reviewing the 0667 Waiver performance measure outcomes and providing us with constructive feedback.

Perry

From: Friedli, Diana R. (CMS/WC) [<mailto:Diana.Friedli@cms.hhs.gov>]
Sent: Monday, February 07, 2011 1:03 PM
To: Jones, Perry
Cc: Thompson, Jo; Sturm, Jeff; Schroader, Joli; Travis, Ondrea D. (CMS/CMCS)
Subject: RE: tribal notification letters re 0208 and 0371 amendment requests

Thanks Perry.

On a different topic, was the MT 0667 CAW State response to the draft report sent yet? It was due the end of January and I haven't seen anything.

From: Jones, Perry [<mailto:pjones@mt.gov>]
Sent: Monday, February 07, 2011 12:49 PM
To: Friedli, Diana R. (CMS/WC)

Cc: Thompson, Jo; Sturm, Jeff; Schroader, Joli

Subject: tribal notification letters re 0208 and 0371 amendment requests

Hi Di,

Tribal notification letters were sent Monday, 1/31/11, to all the tribal governments in Montana, serving to briefly summarize the content of the upcoming 0371 and 0208 Waiver amendment requests. Attached, please find a copy of one of the tribal letters. The waiver amendment requests will be submitted to CMS on or before 3/31/11. The waiver amendment request items, if approved, would be retroactive to 7/1/10.

Please let us know if you have any questions or concerns.

Perry

From: Friedli, Diana R. (CMS/WC) [Diana.Friedli@cms.hhs.gov]
Sent: Monday, January 31, 2011 9:12 AM
To: Jones, Perry
Cc: Sturm, Jeff; Thompson, Jo; Travis, Ondrea D. (CMS/CMSO)
Subject: RE: CMS Quality Review of DDP CAW Evidence Report dated 12 21 10

Hi Perry,

Your understanding is correct. Since the renewal application is due no later than October 1st of this year, I'm assuming you will include the PM revisions at that time.

Have a good week. Di

From: Jones, Perry [mailto:pjones@mt.gov]
Sent: Saturday, January 29, 2011 5:06 PM
To: Friedli, Diana R. (CMS/WC)
Cc: Sturm, Jeff; Thompson, Jo
Subject: CMS Quality Review of DDP CAW Evidence Report dated 12 21 10

Hi Di,

The DDP agrees with CMS recommendations related to the revision of Children's Autism Waiver performance measures. To reiterate needed revisions, performance measures are recommended in the following areas:

Section IV, page 9: Health and Welfare of Waiver Participants, items #1 and #2. These recommendations have not been incorporated at this time.

Section V, page 10: State Medicaid Agency Retains Administrative Authority over the Waiver Program. The QA review tool has been revised to capture closed findings. QAOS sheets are now referenced in the QA review tool, enabling the tracking and reporting of findings and remediation efforts for the purpose of ensuring follow up of all findings. This will also facilitate in the aggregation of this information annually and will further serve as the basis of findings and follow up remediation activities for CMS 372 Reports.

Section VI, page 10: State provides Financial Accountability for the Waiver. This recommendation has not been incorporated at this time.

It is DDP's understanding these performance measure revisions should be incorporated in either the waiver renewal request (due on or before 9/30/11) or the next amendment request, whichever comes first. Is this correct?

Thanks for your help with this.

Perry