MINUTES OF THE MEETING
OF THE
ASSEMBLY COMMITTEE ON HEALTH AND HUMAN SERVICES

Seventy-Sixth Session
March 28, 2011

The Committee on Health and Human Services was called to order by Chair April Mastroluca at 1:35 p.m. on Monday, March 28, 2011, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4401 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada, and Room 124 of the Greenhaw Technical Arts Building, 1500 College Parkway, Elko, Nevada. Copies of the minutes, including the Agenda (Exhibit A), the Attendance Roster (Exhibit B), and other substantive exhibits, are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/76th2011/committees/. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (email: publications@lcb.state.nv.us; telephone: 775-684-6835).

COMMITTEE MEMBERS PRESENT:

Assemblywoman April Mastroluca, Chair
Assemblywoman Peggy Pierce, Vice Chair
Assemblyman Elliot T. Anderson
Assemblywoman Teresa Benitez-Thompson
Assemblyman Steven Brooks
Assemblyman Richard Carrillo
Assemblywoman Lucy Flores
Assemblyman Jason Frierson
Assemblyman Pete Goicoechea
Assemblyman John Hambrick
Assemblyman Scott Hammond
Assemblyman Pete Livermore
Assemblyman Mark Sherwood
Assemblywoman Debbie Smith

COMMITTEE MEMBERS ABSENT:

None

GUEST LEGISLATORS PRESENT:

None

STAFF MEMBERS PRESENT:

Kirsten Coulombe, Committee Policy Analyst
Risa Lang, Committee Counsel
Linda Whimple, Committee Secretary
Olivia Lloyd, Committee Assistant

OTHERS PRESENT:

Dawn Gibbons, representing Intermountain West Communications Company
Ralph Toddre, Commissioner, Nevada Commission on Autism Spectrum Disorders
Ronald Leaf, Ph.D., Director, Autism Partnership
Mary Liveratti, Deputy Director, Programs, Department of Health and Human Services
Korri Ward, Advocate, Northern Nevada Autism Network
Jan M. Crandy, Commissioner, Nevada Commission on Autism Spectrum Disorders
Antonio Quiroz, Private Citizen, Las Vegas
Joey Alexander, representing Autism Screams

Chair Mastroluca:
[Roll was called.] Today we are going to have a presentation on autism spectrum disorders (ASD). This is in preparation for Wednesday's hearing. We have three bills on autism that will be coming up. Before we start the presentation, we are going to do some Committee bill introductions. Members should have copies at their desk. As we have discussed in the past, this vote is allowing us to send these to the floor, and they will come back to us so we can have hearings on them.

The first one is bill draft request (BDR) 38-201. With permission of the Committee, I would like to do it as one introduction, and the other four as a separate introduction. They are all on the same topic and they all came from the Legislative Commission's Committee to Study Group Homes that met during the 2009-2010 Interim.

Assemblyman Hambrick:
If it would be appropriate, perhaps I could move that they be accepted en masse as presented, because I do not think anyone would be voting against the introduction of a bill, as we did behind the bar earlier in the day, unless the Chair would prefer to have them read individually.

Chair Mastroluca:
I want to do the four group home bills together as one, and then the other BDR, because they are two separate topics.

BDR 38-201—Revises provisions relating to background checks for certain persons who work with children. (Later introduced as Assembly Bill 536.)

I will accept a motion to introduce BDR 38-201.

ASSEMBLYMAN BROOKS MOVED FOR COMMITTEE INTRODUCTION OF BDR 38-201.

ASSEMBLYMAN ANDERSON SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

BDR 40-671—Increases penalties for operating certain group homes without a license. (Later introduced as Assembly Bill 534.)

BDR 38-672—Revises provisions governing certain facilities for juveniles. (Later introduced as Assembly Bill 532.)

BDR 40-673—Provides certain financial protections for residents of group homes and similar facilities. (Later introduced as Assembly Bill 533.)

BDR 40-674—Revises provisions governing the referral of persons to residential facilities for groups. (Later introduced as Assembly Bill 535.)

Chair Mastroluca:
I will now accept a motion to introduce the group home bills.

ASSEMBLYMAN HAMMOND MOVED FOR COMMITTEE INTRODUCTION OF BDR 40-671, BDR 38-672, BDR 40-673, AND BDR 40-674.

ASSEMBLYMAN CARRILLO SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

Chair Mastroluca:
Thank you very much. Those bills will go down to the floor for our second floor session today and come back to the Committee.

I am going to start the meeting and then turn it over to Assemblywoman Pierce as I need to go introduce a bill.

Ms. Gibbons and Mr. Toddre, welcome to the Committee. Please begin.

Dawn Gibbons, representing Intermountain West Communications Company:
I am representing the NBC affiliates in the state of Nevada: Channel 4 in Reno, Channel 10 in Elko, and of course, Channel 3 in Las Vegas. More importantly, I am here as a former First Lady of Nevada, a former legislator, and as an advocate for autism. Ralph Toddre, President of Intermountain West Communications Company, the parent company of the Nevada NBC affiliates, was a founding member of Autism Speaks, the founder of the Autism Coalition of Nevada, and a member of the Nevada Commission on Autism Spectrum Disorders.

We have been here many times before and are very passionate about this issue. Oftentimes we find that we are the voice of the parents of autistic children who are really too tired and unable to come to the Legislature and educate you on this issue. Fortunately we do have Ralph Toddre, who is very articulate, and can express what it is to raise an autistic child, the kind of resources that are needed, and the fact that if we do not do anything, the result is even worse. I am going to turn this over now to Ralph Toddre.

[Assemblywoman Pierce assumed the Chair.]

Ralph Toddre, Commissioner, Nevada Commission on Autism Spectrum Disorders:
I have been coming here for quite a while and see a lot of new faces. I would like to welcome all the new legislators, and hopefully we will be able to give you a good idea of what we are dealing with.

As you can see on the graph in your packet (Exhibit C), in 1975, the prevalence level for autism was 1 in 5,000. You can see how that has grown over the years. The Centers for Disease Control and Prevention (CDC) state that autism now affects 1 in every 110 American children, including 1 in 70 boys (Exhibit D). This represents a staggering 57 percent increase from 2002 to 2006, and a 600 percent increase in just the past 20 years. Other significant findings include that a broader definition of autism spectrum disorder (ASD) does not account for the increase, and while improved and earlier diagnosis accounts for some of the increase, it does not fully account for it. Thus, a true increase in the risk of ASD cannot be ruled out. Even though parents typically express concerns about their child's developmental progress before age three, the average age of diagnosis is not until 53 months, although diagnoses are occurring earlier than found in the 2002 study. The report uses the same methodology that produced the CDC's 2007 prevalence findings of 1 in 150 children with autism. These new findings reinforce that autism is an urgent and growing public health crisis that affects most individuals across their lifespan and demands a commensurate level of action from both the public and private sectors.

[Mr. Toddre read from prepared text (Exhibit E).] Now please take a few minutes, watch the screen, and meet autism. [Video presentation showed the experiences of mothers of autistic children.]

I am the parent of two children with autism. I would now like to introduce you to someone who has been a wonderful help to many of our children. Dr. Ronald Leaf is a world-renowned autism expert. He has authored books on treatment, school-based applied behavior analysis (ABA), and most recently, social skills training. He is a researcher and a treatment provider. He works with school districts across the country to improve classrooms for students with autism. He has provided treatment to children and adults, and he is the director of Autism Partnership, which serves individuals with autism around the world. He has been very good to Nevada, and we are grateful to have him here today.

Ronald Leaf, Ph.D., Director, Autism Partnership:
I am the director of Autism Partnership, and a licensed psychologist in the state of California. It is a pleasure to be here; I am glad I was invited by Jan Crandy to be able to present.

About 40 years ago, I was on my way to law school—I wanted to be a politician. I happened to take a class at the University of California, Los Angeles (UCLA) because it fit my schedule. By taking this class, I only had to go to class on Tuesdays and Thursdays. I did not know that it would change my life forever. The professor, Ivar Lovaas, was a pioneer in the treatment of autism, and when I took the class, it changed the course of my life. At that time, autism was a very serious disorder—not that it is not today—but there was very little hope in what could happen in the treatment of autism.

I have a unique perspective in having worked and done research with a wide variety of children with ASD. I have worked with 6-month-olds to 60-year-olds.

I have worked with children, adolescents, and adults with tremendous cognitive impairments, and I have worked with children, adolescents, and adults who have superior intelligence. I have worked with those groups, many having life-threatening behavior issues. I have also worked in a variety of settings: state hospitals, clinics, research settings, schools, and homes. I have had the unique opportunity of living with children and adults with autism. I have also served in a variety of capacities: clinician, researcher, expert witness, and administrator. Through these experiences, I have learned a great deal; of course, I have a great deal more to learn. These experiences have resulted in me having tremendous optimism, but also great sadness. Pessimism: there is a tremendous amount of misinformation regarding autism and its treatment, which compromises the lives of children and their families. Optimism: there are treatments that could make a dramatic difference in the lives of children and their families. Such treatments result in tremendous financial savings for society, and at least of equal importance, result in children and families having a significantly higher quality of life. Tragically, however, when such treatments are not provided, there are tremendous costs financially and emotionally, and devastation for all.

I had an experience last week, which is so representative. We were called into an intervention on the East Coast with a ten-year-old boy. He had been expelled from school and told he may not go back the rest of the year, because of the tremendous aggression he showed and injury to his peers and teacher. His parents were at their wits' end, thinking about a home placement, and it was ripping the family apart, not to speak of the impact on this child's very life. In one week we were able to work with him, and put him back on the road. In one week we were able to get him back in school. In one week we were able to help the parents and give them support so that they could work with him more effectively. At the end of that week, I had to ask the question, what would have happened if we had provided this treatment two years earlier, or four years earlier? We certainly would not have been there, and the cost—in terms of educational cost, and medical cost—would have been very different.

What is sad and tragic for me is that I see children, adolescents, and adults, and wonder, "What if . . .? What if they had gotten the proper treatment?" I know today, when I see a seven-year-old, a six-year-old, I know there are two roads that he can go on. With the right treatment, it is very likely this child, as an adult, will have a job, will be in a relationship, and will probably attend a university. I also know that without that treatment, it is going to be a very different road. This will be someone that we impaired the rest of his life. At the end I will present some evidence to back that claim.

Let me now take the opportunity to focus more specifically on what we do and my perspective on autism (Exhibit F). I will bypass some of my slides (Exhibit G), but I will point them out, because they have already been covered and I do not want to take too much of your time by covering them again. As a short history, autism was identified in 1943 by Leo Kanner. He had 11 children that he felt did not meet the criteria of mental retardation or schizophrenia, so autism was born. It was not that autism did not occur before then, but that is when it had its own diagnosis.

The ratio of boys to girls is 4:1. We do not know why. It is just a boy disorder. As covered previously, there is a rapid increase in prevalence—which makes me feel rather old—and when I started it was 2 in 10,000, and today we are talking about 1 in 110. It has been quite a change with quite a bit of speculation about why that is. As I said previously, there are tremendous amounts of misinformation about autism and treatments.

One piece of misinformation has to do with the cause of autism. Let me share with you that we do not know the cause of autism. It is a worthwhile endeavor to keep looking for the cause. It is a very difficult one to find. It is very hard to parse nature versus nurture. I only wish that we had spent the same amount of money looking at the cause as we have on the treatment and training people to treat autism.

As described on slide 4, the U.S. Senate Subcommittee on Children and Families hearing on August 2, 2010 brought together researchers from federal health organizations and institutes to highlight the state of scientific findings regarding environmental contributions to autism and other neurodevelopmental disorders. According to these experts, "emerging scientific findings suggest that a combination of genetic and environmental factors could affect neurological development, but additional research is needed." Expert witnesses also said that autism likely has a number of causes. When I read that, my comment was, "Really? We spent money and time saying this? We have known this for 30 years."

We do not know the cause of autism. It is a very complex disorder and has a tremendous amount of factors. I turn to ask the question, "What are your expectations? What are society's expectations of children with autism?" I think we have a choice, as slide 5 indicates. I think there is a choice of which road children are going to go down. I am optimistic to say that with good treatment, it is a very different choice. Children indeed can graduate from high school, can go on to college, and after college have gainful employment—clearly not all children, but the vast majority of children, if they get the correct treatment. The same thing in relationships. What is our choice? Without the right treatment, these children will have a life of loneliness. Tragically, the depression rate as adults is astronomical, and so is the suicide rate. It does not have to be this way. With the right treatment, children, adolescents, and adults can have meaningful friendships, but it requires the right treatment.

Look at the next slide, which is on the evolution of expectations. If we look at the history of autism—although it was identified in the 1940s—actual treatment did not occur until the early 1960s. In the 1960s, autism was a lifelong sentence. The expectations were bleak at best. Parents were told—when they had a child with autism—that the best thing they could do for their child was to send him to a state institution, that he would go from a toddler ward, to a child ward, to an adolescent ward, to an adult ward, and to a geriatric ward. That was the state of what we felt the outcome of autism was. It was a serious, lifelong disorder with very little hope of any improvement. The research of that day showed that only 5 percent of children would have any hope of any improvement.

We moved to the 1970s with a little more hope, as we started doing the deinstitutionalization, and children, adolescents, and adults were now living in group homes. But, again, the prognosis was bleak. The 1980s saw a slight change. With the work of Ivar Lovaas, my mentor, we saw that children could make substantial and significant improvements. Children could learn to communicate, have friends, and have recreational skills. The 1990s brought new studies showing the same kind of evidence. In 2000, we started getting acceptance of the treatment that I do, called applied behavior analysis. What is 2010 going to bring? I am not sure, but I hope we keep on moving in our expectations and our outcomes.

I would like to refer to a study that I was proud to be a part of at UCLA, which started turning the course of autism in the 1980s. It was a study done by Ivar Lovaas as published in 1987, and then there was a follow-up replication study in 1993. I would like to spend a few minutes detailing that study, because I think it is critical in what we still know today, and is the foundation of what we do that is effective.

We treated 38 children at UCLA. Half of the children were placed in an experimental group where they received an average of 40 hours a week of treatment, and half went into a control group where they received an average of 10 hours a week of treatment. Treatment began before the age of four. This study was funded with a grant from the National Institute of Mental Health that wanted to know what the outcomes could be with early intervention. The children received treatment for two or more years. Interventions occurred across the environments that the children were in: homes, clinics, schools, and the community. I again want to note that at that time—we are talking about the 1980s—the outcome was somewhat bleak. At the end of treatment, these children were assessed independently. Someone outside our project did the assessment and the evaluation. The children were placed in three outcome groups. One was called the poor outcome group. These were children whose IQs remained in the profound or severe ranges, who were in school placements for classrooms with autism, and whose diagnosis remained unchanged. They presented with autistic disorder. The middle group was called the fair outcome group. Their IQs had moved to the moderate and mild ranges. They were no longer in classrooms for autism. They were in communication classrooms and diagnostically they presented as another disorder no longer autism, but primarily a communication disorder. The best outcome group was called "recovered." Their IQs were in the normal range. They were in general education without supports, and they no longer presented with any of the symptoms or characteristics of autism. They were indistinguishable.

Let us look at the data. Those children who received intensive intervention an average of 40 hours a week, and only received applied behavior analysis—no other treatments, no speech therapy, no occupational therapy, no medical, no dietary treatments, no medicine—had a dramatic outcome. Nine of the nineteen children were indistinguishable. They were classified as "recovered." Eight of the children—although not making indistinguishability—also did rather well. There were only two children who remained as presenting with autism.

Let us compare that to the control group, the group that received an average of ten hours, the group that had other treatments in an eclectic approach with many different treatments. How did they fare? The data is quite clear. There was a substantial difference. Not one child moved to the best outcome group. More than half remained in the lowest group, and eight were moved to the middle group. We added a control group that received zero hours—no treatment, only an eclectic approach—and their outcomes were the same as the group that received an average of ten hours. It was a dramatic finding. It was dramatic because no one thought that children with autism could move to such a tremendous outcome. In fact, when we did the study, we were accused of fraudulent data. We were then accused of only selecting the most high-functioning children. Luckily, replication studies that followed showed this was not true, that indeed, children, if they receive intensive and quality treatment, can make tremendous progress.

I think the other thing that is dramatic to point out is that children who received an average of ten hours and the children who received zero hours, did the same. My conclusion from that was, let us save the time and money and not provide minimal treatment. There is what we call a "dosage of fact," just like in medicine. You need the proper dosage to get the right outcomes, and often if the dosage is far less, it is not worth it from an emotional or economic standpoint.

I would like to present a video demonstrating one of the children from that outcome group, a child that again changed the course of my career because I was lucky enough to be part of his treatment. This child, when I first saw him, had no language, was incredibly aggressive, self-injurious, and dangerous to himself, his parents, and the community. When I first saw him, I feared I was not ready to treat him. Luckily, my mentor insisted that I treat him, and I want to show you a little bit of his story. [Video presentation showed Ian's progress.] I am pleased to tell you he did drink the beer and the booze at college. I got to see him recently. He is now in his mid-thirties—which ages me quite a bit again. He went to college, has his master's degree, has full-time employment in upper management, has been in long-lasting relationships, and is an avid skier. I want to point out that he is not unusual in what we see at UCLA. Forty-seven percent of the children we treated had the same kind of outcomes that he had. I would also point out that when we started with him, he had no language. He was aggressive, had no friendships or social skills, and was severely impacted. But because of the treatment, he was able to have such an outcome.

The treatment we do is applied behavior analysis. It is the most evidence-based treatment there is. Applied behavior analysis is not just for autism. If you went and saw a psychologist in Nevada, there is a 50 percent likelihood that you would get someone that does applied behavior analysis, too. It is not a new approach. This approach has been around since the late 1800s. It is an approach that is incredibly optimistic; it is an approach that works with individuals and looks at their uniqueness, helps them cope with everyday life, and helps them with necessary skills.

Being a psychologist, when I look at applied behavior analysis, it is simply an outstanding teaching coaching intervention and—I want to point out—is the most evidence-based treatment there is. I am biased, I know. This is what I have done in my career. But I look at journals on an ongoing basis, and the evidence is quite clear about what best practice is.

Let me point out what the slide "Cure of the Year" means. Twenty years ago every year there was a cure in autism. My mother would call me, excited, every year and say, "Did you hear about this new treatment that is a cure?" Well, then it became the "flavor of the month," and now we call it the "panacea of the week." We have to be careful. We have to be careful about what we choose for our children, adolescents, and adults to receive. There are a plethora of treatments out there. Tonight, go online and you will see hundreds of treatments that are being offered in the treatment of autism. Autism Month—you will hear it constantly. I caution you to look at those treatments that are evidence-based—those treatments that have gone through empirical investigation, those treatments that are in reputable journals with double-blind studies, those treatments that have experimental design and statistical significance. The evidence will be very clear. There are very few treatments out there that are effective in the treatment of autism. Most everything you will hear sounds good, and the people that are doing it mean well, but the evidence is not there for the treatment.

We also need to be careful, not only about the single treatments, the animal therapies, the medications, the dietary treatments, and the educational strategies that are not effective, but when we put them together. Today it is commonly accepted as necessary—an eclectic approach. I work in school districts across the country, where I need to fight the battle against the eclectic approach. Let me point out to you there is not one single shred of evidence an eclectic approach works. An eclectic approach is a mish-mash of different treatments, all often sabotaging each other and often ineffective. There are a number of research studies that have looked at eclectic approaches and all have shown that they are not effective. Nonetheless today we have eclectic approaches being provided to children, adolescents, and adults with autism, and we have those treatments that are "Cures of the Year."

I want to point out a study that I am quite proud of. We have just been accepted for publication in *Education & Treatment of Children* journal. I will not go through the particulars, but the evidence was that 70 percent of the children we treated who got intensive treatment—70 percent—their IQ is in the normal range today. Seventy percent of the children that we provide treatment for today are in general education classrooms, half with minimal supports, and half with no supports. Seven out of ten children that we see, if they receive intensive and early intervention—and early intervention is under the age of eight—are able to make a dramatic outcome. We are talking about a difference in life.

I want to show two videos to illustrate that. The first video you are going to see is rather disturbing. This is an adult who did not receive treatment. [Video presentation showed an adult striking himself.] He will do that throughout his day if he is not placed in restraints. Because of the lack of treatment, this is someone who has been hospitalized on an ongoing basis. This is someone whose quality of life is incredibly restricted. This is someone that with the right treatment, this would not be his life. He would not be a cost to taxpayers. He would not have devastated his family, which resulted in a divorce. This was someone that had a very good profile. We do have indicators of who would do well. This is someone who most likely would have gone to the university. His life would have been quite different.

Let me finish by showing you a variety of the children who were in our study, and where they are today. [Video presentation showed a child communicating with others.] He is having a full conversation about what he is doing and what occurs in school. [Continued video presentation showing three young women talking.] This is a group of three adolescents with autism. Again, they were severely impacted at the beginning of treatment. There is a discussion. They all have crushes on boys, and so the discussion is, what do you talk to a boy about? [End of video presentation.] My question is, what would have happened if they had not received treatment? We know from the evidence the answer is very clear. They would not be having these discussions. They would still be severely impacted today. Luckily they did receive treatment, luckily for them, and luckily for their families. We can make a difference. Thank you for letting me present.

Assemblyman Hambrick:
It is very difficult to formulate questions after seeing something like this, but obviously it is necessary to educate ourselves to as we go through this process. As these youngsters and adults reach different plateaus, are these plateaus then permanent? Would they be able to maintain certain plateaus? Hopefully, expectations would increase, such as the young man with the master's degree.

Ronald Leaf:
I have two responses to that. First, I think we always keep on learning. All of us can keep on learning, and so can our students. Second, we do not see regression. If you do treatment correctly, regression is minimal at best. We are teaching them skills that will be life-lasting. When they acquire the intervention to have friendships, they have turned a corner. They now want friends, and they are not going to go back on that. We have not seen that kind of regression. We have seen treatment withdrawn more and more over time, and our goal is that our children as adolescents no longer receive treatment. That group of three you just saw are no longer receiving treatment. The one who said, "You know, they will have to listen to you anyway," now has a boyfriend, and we no longer see her because it is not necessary. None of those students are being seen anymore.

Vice Chair Pierce:
Thank you very much.

Mary Liveratti, Deputy Director, Programs, Department of Health and Human Services:

You should have some information in your packets. I am going to talk briefly about the programs for children with autism we have in the Department of Health and Human Services.

We have three programs right now that have autism services. We have one in the Division of Mental Health and Developmental Services (MHDS), known as Self-Directed Autism Services. We have a program that is referred to as Autism Treatment Assistance Program (ATAP) under the Aging and Disability Services Division. Under our Health Division we have Early Intervention Services. Mental Health and Developmental Services provides autism services for children up to the age of 11. Currently we have 174 children receiving services. We have a waiting list of about 134 for autism services. The current funding is through the Temporary Assistance to Needy Families (TANF) funds, which come into the Division of Welfare and Supportive Services and are transferred over to MHDS for these services, and then we have some General Fund support. In the next biennium we do not have any funding for this program. The TANF funds are going away because our TANF caseload has gone so high that we need it for its primary purpose. We were using some reserve funds. Those reserve funds will be gone and are not available to be transferred to sister agencies.

So what is going to happen to those children? We have had a lot of questions about that, and I want to let you know that children that are currently receiving services will continue to receive services from MHDS. No new children will be added; in fact, at this point there is a waiting list and we are not adding children. Since this only goes until the age of 11, children will eventually age out of this program, or sometimes they drop out for other reasons.

We serve children 18 months to 19 years old in our ATAP program. Right now they have 110 children that they can serve under their funding. They have a waiting list of about 215 children. We are proposing to keep the funding for this program going. It will be less than it was in the current biennium. We have approximately $1.9 million for the current state fiscal year (FY) 2011. In FY 2012, we will have about $1.2 million. In FY 2013, it goes up slightly, but again, is about $1.2 million.

To give you some brief background, this program started in 2007. It was an end-of-the-year bill that provided funding to Aging and Disability Services for autism services. It was only a one-shot funding, so we only had it for the first two years. In the 2009 Session, the autism families came to the Legislature and said, “Please do not stop this program,” so funding was continued into this biennium. The program is not currently in statute, so it is a program that we have been doing for four years now, added to other services that we do. So Aging and Disability Services does have funding for the $1.2 million, and they are asking for a position to help manage this program. We do not have dedicated staff who have been overseeing this, because it had been a one-shot program, although it has been going on for four years.

Under the Health Division, our Early Intervention Services are available to children from birth to three years old. That program is more extensive. It is not just autism services, so we treat children with a number of developmental delays, including Down syndrome, spina bifida, autism, blindness, deafness, or anything that is going to contribute to a developmental delay for those children, including if they are having trouble walking and talking. In FY 2010, we had 117 children that were diagnosed and treated with autism services through Early Intervention Services. There are currently about 329 children on the waiting list. Not all those children have autism, per se. It could be any diagnosis. We are increasing some of our money because we did have some American Reinvestment and Recovery Act (ARRA) money that was given to us for these services. Of course, that went away, so we are replacing those funds with some money from the General Fund. That is my presentation for this afternoon. If you have any questions, I would be happy to answer them.

[Assemblywoman Mastroluca reassumed the Chair.]

Chair Mastroluca:
Thank you very much. Is there any concern about duplication of services with having different autism programs for different reasons in different divisions?

Mary Liveratti:
We formed a work group in our department to look at autism services. Jan Crandy, who is sitting next to me, has very much wanted to have one autism program so that families are not confused by having to go to different agencies. Since MHDS is phasing its program out, ATAP, under Aging and Disability Services, will be a primary program, but we will still have services under Early Intervention Services. Because we accept federal money under Early Intervention Services under Part C of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), we have to meet all of the federal mandates for that program. We looked to see if there was a way that we could somehow have the children shifted over. What we have come up with for this next biennium is to have a pilot project started to see how we can coordinate it. Right now, if we just go over to the ATAP program, we would have to comply with all the federal regulations that come with it. Many times these children are also receiving other services, not just autism services. It is really a complicated

system that we need to take a look at, because we would not want to provide any disincentive for children, or affect their services. Going forward, we are looking at one autism service, primarily the Aging and Disability Services ATAP program.

Assemblyman Brooks:
Ms. Liveratti, you are an awesome deputy director, and I am so glad this program is under you. I know that you will make sure that it lives on wherever it needs to, because I know that is where your heart is.

You mentioned about 130 individuals who were on the waiting list for TANF funds, and you said the people who were on TANF funds would be transferred to Mental Health and Developmental Services. What happens to the 130 children who were on the waiting list?

Mary Liveratti:
We decided that for continuity of care, it would make more sense to keep those children with MHDS. The ones on the waiting list will be given the choice, if they want to come over and be on services with ATAP. They will have to go on the waiting list, but they will be put on the list based on their original application with MHDS so they do not lose their standing on the waiting list. We have to ask them if they will let us release their name to put them on the waiting list. It is their choice. One of the children who is currently being served will continue to be served at MHDS because we feel there would be more continuity of care by keeping him there, and he will age out, so he will not be there forever. Well, actually, I should correct myself. He may be there for a long time because children that age out of this will be eligible for other developmental services if they are not, like Dr. Leaf said, to the point where they can live normal lives. Many of them will still need some of the services that are available under Developmental Services at MHDS as they get older and reach adulthood.

Korri Ward, Advocate, Northern Nevada Autism Network:
My testimony was initially on "How is autism impacting education in Nevada?" and as I wrote it, I realized maybe it is more about "How is education impacting autism in Nevada?" (Exhibit H). I am the chairman of the Nevada Commission on Autism Spectrum Disorders Education Subcommittee. Formerly, I was the chairman of the Nevada Autism Task Force Education Subcommittee. We have provided the *2008 Report of the Nevada Autism Task Force*, and some of the things I am going to talk about are in that report (Exhibit I). Rorie Fitzpatrick from the Department of Education will be here on Wednesday to speak on the day the bills are introduced.

I am a secondary math and science teacher and taught for seven years in Clark County. I quit my teaching job to advocate in the educational and medical systems for my twin sons, Douglas and Derrick, both of whom have autism. They are now 17 years old.

The current Education Subcommittee of the Commission has representation from five school districts. I contacted all 17 districts, and 5 are actively involved. The districts have been helpful and cooperative in sharing information. My testimony is based on our discussions and the information provided by the school districts participating in the Subcommittee.

Currently, there is a lack of uniformity among Nevada's school districts regarding assessments and evaluations for children with autism. Not all the school districts use the same assessments, and where that plays a role is when people move around or when children move between agencies. The Education Subcommittee has discussed the need for statewide standards and consistency regarding assessments and evaluations. Some districts are very good at providing autism eligibility at intake, while others are still waiting until the child is reevaulated at six years old. That delay creates a lot of problems for parents when they are told, "Oh, just wait, just wait, just wait." All that time treatment is not being done.

Standardized assessments and evaluations across schools districts and state agencies would reduce the need for multiple assessments on the same child. For example, when a child has been assessed and determined to have an autism spectrum disorder by a sister agency or school district, the prior evaluation should be valued and accepted, and the child should be made eligible without further autism-specific assessments being done.

The ongoing practice of multiple assessments is costly, creates an undue burden on the family, can make the family doubt the diagnosis, and delays treatment and services.

Oftentimes, three-year reevaluations do not include assessments across all domains. Some parents report being asked to decline further evaluation because the child's eligibility is not expected to change. I did that a lot of times. "Oh, it is going to be so hard to assess them. Why do you not sign here?" The response would be, "OK."

The *Nevada Administrative Code* (NAC) Chapter 388 currently outlines the areas to be assessed at intake: cognitive, social, emotional conditions in multiple settings, adaptive skills, speech, language, other communication skills, and behavior problems, among others. So it is already there. We just need to see consistency across the state. We are not asking school districts to do anything else other than agree on what assessments they want. This information will assist parents and Individualized Education Program (IEP) teams in identifying how the child learns, hence improving the child's outcome. Long-term data will help school districts and teachers identify the most effective educational methodologies to improve student outcomes.

All districts report the need to increase training opportunities for teachers and paraprofessionals who work with children with autism. Clark County School District reports a 30 percent turnover for teachers in autism-specific classrooms. Clark County School District also reports an enrollment of 2,225 with autism in 2008, and 2,852 students with autism in 2010. This is a 28 percent increase in the number of students with autism, and a 30 percent decrease in autism-specific teachers.

School districts statewide are seeing an increase in the number of students with autism. From 2008 to 2010 the number of children aged 3 to 21 with a single label of autism in Nevada schools increased from 2,875 to 3,668. This is a staggering 28 percent increase in two years.

The Subcommittee discussed the need to improve consistency in school districts' reporting of children identified as having autism. The children on this graph are the children that have autism only (Exhibit J). My son, who has cerebral palsy and autism, would be labeled as having multiple disabilities and not be on this chart. The data from the Nevada Department of Education, as shocking as it is, does not reflect all students with autism. The data reflects only the students that have a single label of autism. In some districts, the child may be put in the "developmental delay" category until he is reevaluated at age six. In other districts, a child with multiple diagnoses may be reported in the "multiple disability" category.

A child's eligibility will impact the education methodologies provided to that student. With this in mind, it is important that all children suspected of having autism are provided a standardized assessment in a timely manner, and that eligibility is reported as "autism."

There is a need to count the number of people with an autism spectrum disorder in Nevada. A few years ago, the Nevada Governor's Council on Developmental Disabilities funded a grant to the University of Nevada, Reno (UNR) to determine the number of people with autism in Nevada. The researchers indicated that the use of "developmental delay" and "multiple disabilities" instead of "autism" hindered their ability to achieve an accurate count. By counting the number of children and students diagnosed with autism spectrum disorder over time, we can find out if the number is rising, dropping, or staying the same. We can also compare the number of children with ASD in different areas of the state, and in different groups of people. This information can help school districts, state agencies, and communities plan for services and apply for grants. How is education impacting autism in Nevada? To answer this question, we need an accurate count, and standardized assessments. Thank you.

Chair Mastroluca:
Are there any questions? [There was no response.] Thank you very much.

Jan M. Crandy, Commissioner, Nevada Commission on Autism Spectrum Disorders:
We have made positive moves and progress in Nevada in serving and addressing the impact of autism, but we are not getting to the kids early enough. The kids are not getting the treatment that Ronald Leaf talked about. The average number of hours the children in Early Intervention Services are getting is seven hours a week, and that is with an eclectic approach. It has been hard to get them to do ABA.

Last session we passed Assembly Bill No. 359 of the 75th Session, which required screening for autism at age levels and frequencies recommended by the American Academy of Pediatrics. It recommended that each child be screened two times for autism before his second birthday, regardless of whether he failed the first screening or not. After Mary Liveratti looked at the chart that came from Early Intervention Services (Exhibit K), she thought the number of 3,805 kids might be wrong. They told her today that they serve 2,100 kids, so it is questionable how many kids Early Intervention Services serves statewide.

My next exhibit (Exhibit L) shows the number of kids that were screened by Early Intervention Services. The first column shows that the total number of completed screenings is 859. If they are doing them two times, is that two times, or is that one time for each kid? Even if they did 859, they did not screen every child who came through that door for autism. There were 268 kids that failed the screen. On the next column, 40 kids received a diagnosis. We are not identifying these kids early enough.

The next page of the exhibit shows how much money Early Intervention Services has spent on autism. I want to point out how many hours were spent on intensive behavioral services for 117 kids at $25 per hour. It averages less than seven hours per kid. [Table entitled "FY10 – Extra Hours of Services Provided to Children with Autism Diagnosis" indicates 2359.37 hours of service provided for intensive behavioral services (IBS).] I wish they would not call it "intensive." I understand the lack of money and the lack of resources to be able to do this, but if kids get identified, at least parents know the research so they can help get funds to put their child closer to the research-based hours. The next page is "Is Nevada Providing Early Identification?" If we take the population of children aged 0 to 2 in Nevada and look at it with the CDC prevalence rate of 1 in 110, we should have 1,099 kids identified with ASD in this age group. If we take the 3-year-olds and do the same thing, we should have another 364 kids identified. The Department of Education identified 156 kids statewide. Early Intervention Services identified 117 kids for 2010, whereas in 2009 they identified 144. So are we doing better?

Turning to the next page of the exhibit, using the CDC prevalence rates by age group, we estimate that in 2009, 5,702 Nevada children ages 0 to 21 had an autism spectrum disorder. This translates to something like 1 in 166 through the population. We should be serving 5,702 kids who have autism spectrum disorder. We are providing funding to help pay for treatment for less than 9 percent of this group. I am including children served by the MHDS program (174), ATAP (110), other programs from the MHDS Regional Centers (123), and programs funded by Clark County School District (90). Based on the funding in the proposed budget, only 83 slots will be designated statewide for autism services, which is less than 2 percent of the population of Nevada children with ASD.

I gave you an overview of the MHDS-directed program on the next page. I will not go through everything, but the research shows that 90 percent of children who do not receive treatment, like Ron said, are going to need a lifetime of some level of support. It is not a fiscally healthy choice for Nevada not to be funding treatment as early as possible.

The next page is on the Autism Treatment Assistance Program (ATAP), which has served 206 kids to date. Kids are moving out of that program. It is designed to be a treatment assistance program, not a lifelong program. It is about treating kids, getting the best outcomes, using evidence-based treatments proven to be effective, and targeting specific behaviors that could reduce the need for and level of lifelong support for these kids.

The Autism Treatment Assistance Program has built an infrastructure and established a data system to demonstrate outcomes, including developing support manuals.

In terms of capacity building, we have done a two-year pilot study with Washoe County School District providing training to staff and treatment to children. This program has grown and they are renewing it for an additional five children for the next two years. We have a collaboration with the

Elko County School District; 88 individuals are receiving training. We have trained teams of interventionists and are growing a pool of interventionists in Nevada.

Reporting outcomes, 51 children statewide demonstrated signs of aggression at intake; as of today, 40 of those 51 children show reduced or eliminated signs of aggression. This represents an improvement in 78 percent of those children. We have had seven children exit the program and attend regular education classes due to the success of the treatment. One child, currently funded by ATAP, was in an out-of-state placement at a cost to Medicaid of $12,180 per month. The child is now back at home and doing better, at a cost to ATAP of $778 per month. Applied behavioral analysis has reduced some of his aggressive behavior, so we are saving the state money.

Chair Mastroluca:
Would you repeat that, please?

Jan M. Crandy:
We have a number of kids that we are keeping out of out-of-state placements or out-of-home placements that are funded, but to place one child in Texas rehab runs about $12,000 per month. We have returned this child home, we are paying $778 for this child to get ABA every month, and we have corrected some of his behaviors so that he is going to be able to stay in his home. This family has three children that have an autism spectrum disorder. We are funding two of those kids. I happen to know the person that went there the first time, and the kid broke a pool cue and went after him. He said that that is the first time he has ever been scared working with a kid with autism. And what a difference; I mean, he is staying home. So we are targeting specific behaviors. That is probably not a kid who is going to be a best-outcome kid, but we are going to lower the level of support that we are going to have to pay for the rest of his life to take care of him.

Clark County School District gave me a figure of what it costs for an autism classroom. The average cost to educate one child with autism for 15 years in an autism classroom is $160,906. If they are in regular education, we do not have that cost, which is a savings.

The next page is an overview of what happens when a child comes into ATAP, all of the assessments that are required. Children are scored, and their score determines their position on the waiting list. We look for an IQ test, we do Vineland Scores, and a Pervasive Development Disorders Behavior Inventory. This assessment will tell you if treatment is effective. We also take data and we look at it every year. We have a lot of data targets. This shows us real-life outcomes. Every year we reevaluate to see where the kid is. Some targets are age-specific, but if a child is older, he has to be assessed on all of them.

We also do justification for continuation of the program. If the child is making minimum gains, he probably does belong at MHDS. He is going to need lifelong support. Again, the goal of ATAP is to get kids to the highest level of functioning, so we do not have to take care of them in the future.

The next exhibit (Exhibit M) shows targets for a child to be able to stay in his home—if a child can wait appropriately, express his wants and needs, toilet independently, follow two-step instructions, and has some language. This study looked at 26 kids who were in treatment for one year. At intake, 2 kids, and then at the follow-up, 19 of those kids met those targets. So you can see the difference that those skills made at a follow-up one year later.

I also gave you a couple of specific examples to show you what it looks like. This little girl—her name is Chloe—is in a regular education classroom 92 percent of the time. We exited her in December. She had an IQ gain of 17 points. She received 34 months of funding and her parents were able to fund some additional treatment hours. These are her gains. We are not having to treat her anymore. We are done after 34 months. On the next page, you can see Chloe's real-life outcomes. At the end of follow-up, she has met the targets and she can talk.

We started a little boy named Ethan at age two. This is the key. We have to get these kids at an earlier age. He was tested by Early Intervention Services, and they tested his IQ at 55. He started in January of 2010. In November he was assessed by Child Find. Clark County School District now does his assessment. His IQ is 98. This child received an average of 34 hours of treatment. He made an IQ point gain of 43. Look at his communication skills. He was at 12 months when he started, and now he is at 26 months. His receptive language was at 6 months and now it is at 28 months. Ethan's dad testified during the budget hearing that his child was being self-injurious and he was below weight because he did not eat food. The chart on the next page shows the acquisition of novel food. The ABA program can also work on desensitizing kids to different things—fears, eating food, or textures. So in the beginning of his treatment—and this is what we are talking about when we look at acquisition rates—he made very slow progress but then it starts moving up. And now that little boy is eating food and he has gained weight. He is not going to need a feeding tube because he is eating regular food.

The next page is on expressive language acquisition. We look at kids to see what their acquisition rate is. If their acquisition rate stays flat, then we know that they have peaked, and it is either time to exit them, or look at moving them to MHDS. Here is a little guy that did not talk in the beginning, and now he has over 400 expressive labels. You can hold anything up and he can tell you what it is. Treatment definitely works.

We have got to get these kids identified. We need counts. Everyone who has ASD in Nevada is not counted. When we look at those numbers and we see that the school districts are saying there are 3,368 kids, and then we know that with this prevalence rate we should have close to 6,000 kids, we are not addressing the need. We need to look at those things. We really have to fund autism, or we are going to be paying for it. People do not think that it is going to cost us? If their kid is beating them and hurting them, parents will say, “Take my kid. You guys can take care of him; here you go.” We have had some parents that have already done that. We need to be funding autism. Thank you.

Assemblywoman Pierce:
Where is the bulk of the research being done on the causes of autism?

Jan M. Crandy:
For how much money is being spent on autism, it is very little compared to what is being spent on other things. There is money being spent on research, and the Medical Investigation of Neurodevelopmental Disorders (MIND) Institute at the University of California, Davis is looking at different causes, but we need to put the money into treatment. That is really our only answer right now.

Chair Mastroluca:
Thank you very much. I appreciate the amount of information that you gave us, and I apologize for the short amount of time we gave you to put it together. You have covered a lot, and you have given the Committee a lot to think about in preparation for the hearing on Wednesday.

We have about three minutes, and I believe we still have some people for public comment in Las Vegas.

Antonio Quiroz, Private Citizen, Las Vegas:
I am here on behalf of my son and ATAP. Our three-year-old son, Andrew, was diagnosed with autism on April 14, 2010. At the time, Andrew did not have age-appropriate skills. He was nonverbal, antisocial, and could not express his wants and needs. It was heartbreaking to get the diagnosis. We knew that our time was limited as far as effectively treating our son’s condition, and immediately set out to find the best treatment available. We sought advice from other parents with children who had autism. While everyone seemed to

have a different answer, they all had one thing in common. They all believed ABA was the most effective treatment. At the time, I was unemployed and my wife was working part-time. We simply did not have the funds to provide our son with the services he so desperately needed. We heard about RAGE, Inc. and Desert Regional Center funding, and immediately signed up. We anxiously waited for approval. When we got a call from RAGE in November of 2010, we were ecstatic. We started Andrew's program the following month, and saw huge improvements. The first month he was matching colors and animals. By the second month he was able to imitate actions. By the third month he was responding to receptive commands. About two weeks ago he gave me a hug for the first time. He is now more aware, social, and just plain happier. He knows all of his colors receptively, and can pick specific items out of a field of nine. At this rate, he will know more than his classmates by the time he enters the school system, and all of this in three months with the diagnosis of a very serious neurological disorder, one that his neurologist said was severe. I know what will happen if he loses his funding. He will struggle to retain the skills that he has acquired and will most likely regress. He will go back into the bubble he came out of, and not improve intellectually or socially. He will become a burden for the state and cost you more money. As a taxpayer, I just do not see how this would make any sense. I would like to think that we are smart enough to know that we just cannot sweep these kids under the rug. There is not a big enough rug and the number of kids is not getting smaller.

Chair Mastroluca:
Thank you for your testimony. I know that you have been in Las Vegas to testify before, and I have heard the story of your son. I appreciate you sharing it. It is very emotional and touching, and I am excited to hear more about his progress.

Jan M. Crandy:
I went to this child's intake. He is two years old, and one of his self-stimulatory behaviors is playing the Angry Birds game, and it is amazing.

Chair Mastroluca:
Thank you for sharing that.

Is there anyone else who would like to give public comment, either in Carson City or Las Vegas?

Joey Alexander, representing Autism Screams:
I am an unpaid lobbyist for Autism Screams, which is my advocacy group for autism. I have a six-year-old son with autism. He has been a recent recipient of the self-directed autism funds. Thank you again. Whatever can be done to

keep the funding going for these kids is very important. When my son first started treatment, he was completely nonverbal. He is now attending regular kindergarten 98 percent of the time, and from a lot of the reports that I have been getting as of late, he is completely indistinguishable from his peers. There are still a lot of behavioral and stimulatory issues, but for the most part he is able to play and interact with his kindergarten class. This is all due to the funding that was allotted to us by the Legislature. You need to know that this funding is working, and however we can keep it going for these kids, it is very, very important. Thank you.

Chair Mastroluca:
Thank you very much for sharing.

Is there anything else to come before the Committee? [There was no response.]

The meeting is adjourned [at 3:02 p.m.].

RESPECTFULLY SUBMITTED:

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Linda Whimple
Committee Secretary

APPROVED BY:

____
Assemblywoman April Mastroluca, Chair

DATE: ____________________________

EXHIBITS

Committee Name: Committee on Health and Human Services

Date: March 28, 2011 **Time of Meeting: 1:35 p.m.**

Bill	Exhibit	Witness / Agency	Description
	A		Agenda
	B		Attendance Roster
	C	Ralph Toddre	Autism Prevalence Chart
	D	Ralph Toddre	CDC Autism Numbers
	E	Ralph Toddre	Testimony
	F	Ronald Leaf	Testimony
	G	Ronald Leaf	Slide Presentation
	H	Korri Ward	Testimony
	I	Korri Ward	*2008 Report of the Nevada Autism Task Force*
	J	Korri Ward	Chart from Department of Education
	K	Jan Crandy	SFY 2010 Chart
	L	Jan Crandy	Early Intervention Services Document
	M	Jan Crandy	ATAP Outcomes Document