MINTUES OF THE
TASK FORCE FOR THE FUND FOR A HEALTHY NEVADA
March 27, 2000

A meeting of the Task Force for the Fund for a Healthy Nevada (created as a result of Assembly Bill 474 – 1999) was called to order by Co-Chair Vivian Freeman at 10:35 a.m. on March 27, 2000, at the Legislative Building, 401 South Carson Street, Room 3138, Carson City, Nevada. The meeting was video-conferenced to the Grant Sawyer State Office Building, 555 East Washington Avenue, Room 4401, Las Vegas, Nevada. Exhibit A is the Meeting Notice and Agenda; Exhibit B is the Attendance Rosters.

TASK FORCE MEMBERS PRESENT IN CARSON CITY:

Assemblywoman Vivian Freeman, Presiding Co-Chair
Assemblywoman Barbara Buckley, Co-Chair
Ms. Maureen Brower
Dr. John Ellerton
Mr. Ed Fend
Dr. Elizabeth Fildes
Mr. Ron Mestre

TASK FORCE MEMBERS PRESENT IN LAS VEGAS:

Senator Raymond Rawson

TASK FORCE MEMBERS EXCUSED:

Mr. Bill Welch

LCB AND DHR STAFF MEMBERS PRESENT:

Kimberly Morgan, Chief Deputy Legislative Counsel, LCB Legal Division
Leslie Hamner, Senior Deputy Legislative Counsel, LCB Legal Division
Ginny Wiswell, Program Analyst, LCB Fiscal Division
Charlene Adamson, Project Specialist, LCB Legal Division
Marilyn Jayne & Carol Thomsen, LCB Legal Division
Charlotte Crawford, Director, DHR
Yvonne Silva, Administrator, Health Division, DHR
Dr. Carlos Brandenburg, Administrator, MHDS, DHR
Les Gruner, Northern Regional Deputy, CFSD, DHR
Janelle Mulvenon, Community Connections, DHR
Debbra King, Administrative Services Officer, DHR

Co-Chair Freeman asked members to consider a motion to approve the minutes of the previous Task Force meetings.

> MS. BUCKLEY MOVED TO APPROVE THE MINUTES OF THE DECEMBER 16, 1999, AND FEBRUARY 22, 2000, MEETINGS OF THE TASK FORCE FOR THE FUND FOR A HEALTHY NEVADA.
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> DR. ELLERTON SECONDED THE MOTION.
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> THE MOTION CARRIED UNANIMOUSLY VIA VOICE VOTE.

Co-Chair Freeman then invited Anne Cathcart, Special Assistant Attorney General, Attorney General's (AG's) Office, to come forward and present the status report on the National Tobacco Settlement, (Exhibit C). Ms. Cathcart indicated at the previous Task Force meeting, a number of questions arose regarding when Nevada could anticipate receipt of payments from the tobacco settlement, and to what extent the amounts could be calculated prior to receipt. As the AG's office was legal counsel to the Task Force, and also represented the State of Nevada's interest in the tobacco litigation and settlement, it wanted to take the opportunity to clarify some of the financial aspects of the settlement agreement.

First, Ms. Cathcart stated, it should be pointed out that anticipated payments were subject to a variety of adjustments, either upward or downward, for such as accumulated interest, investment fees, estimated federal income tax withholding, and interest or investment income. She explained that some types of payments were subject to different adjustments, which were described further in Exhibit C. Secondly, there had been, and might continue to be, legal or other challenges to the tobacco settlement agreement which could affect payments to the states from tobacco companies. However, explained Ms. Cathcart, such challenges were being vigorously defended nationwide and in Nevada. The third and final major point was that Nevada was to receive three different types of direct payments from the tobacco manufactures over the calendar years indicated in the settlement. She noted that for a variety of reasons, it was always possible that tobacco manufactures might choose to make a particular payment earlier than its due date. For example, as members were aware, the initial payment due on January 10, 2000, was actually made to the states on December 31, 1999.

According to Ms. Cathcart, there were three different types of payments, with the first being the initial payments. Those payments would only last a few years and each initial payment was due by January 10 of that particular year, and would be subject to three different types of adjustments. The first was the volume adjustment, which had been the most widely publicized during the past few months because it resulted in an approximately 13.5 percent downward adjustment to the State's base payment. Ms. Cathcart indicated that adjustment would be made each year to the initial payment based upon the percentage of increase or decrease in nationwide cigarette sales during the previous year.

Continuing, Ms. Cathcart explained the second adjustment was the non-settling states reduction, which would apply if there were any states after December 31, 2001, that had not settled and achieved state specific finality. The third adjustment was the offset for miscalculated or disputed payments, and she explained there had been a dispute in which the states questioned part of the basis upon which the January 10, 2000, initial payment was calculated. Ms. Cathcart stated there could be a subsequent adjustment when the figures were corrected fully or partially by an independent auditor.

The second type of payment was the annual payment, which Ms. Cathcart explained could conceivably be received forever. The annual payment had been calculated through the first 25 years. Those annual payments were due by April 15 of each year, and the base payment amounts were also subject to at least eight upward or downward adjustments (Exhibit C). Perhaps the most important of those, advised Ms. Cathcart, were the volume adjustment based upon cigarette sales during the previous year, and the inflation adjustment. Under the master settlement agreement, the base payment amount due every year would be based upon the increase in the annual Consumer Price Index (CPI), which would always be a minimum of 3 percent. Ms. Cathcart then introduced John Albrecht, Senior Deputy Attorney General, who would explain the non-participating manufacturers' adjustment.

Mr. Albrecht advised the main point of the non-participating manufacturers' adjustment was that the AG's Office would take steps to reasonably enforce the model statute, (A.B. 667), approved by the 1999 Legislature. Basically, the model statute required that non-participating manufacturers pay 1 cent per cigarette sold in Nevada into an escrow account, which had to be established by April 15, 2000. He indicated the AG's Office had already notified the non-participating manufacturers about the requirement, which went into effect May 24, 1999, and was ongoing. The AG's Office could then bring an action against the non-participating manufacturers for reimbursement to the state, similar to the agreement reached in the master settlement agreement for participating manufacturers. Mr. Albrecht indicated if the market share decreased as a result of advertising restrictions, a portion of that market share might go to non-participating manufacturers, and the state was attempting to insure it could eventually collect from those non-participating manufactures, which was the goal of the model statute. Further, he indicated there might be other monies collected from non-participating manufacturers which would cause an increase in the payment, however, he did not feel it would be a significant amount.

Senator Rawson stated he assumed the volume adjustment was just for cigarettes sold in the United States, and he wondered if the AG's Office had the ability to go after profit from offshore sales. Mr. Albrecht noted the AG's Office would approach any non-participating manufacturer that sold cigarettes within the State of Nevada, therefore, if a foreign company was selling cigarettes in Nevada, it would be required to set up an escrow account as a non-participating manufacturer. To that extent, Nevada was going after sales by foreign companies.

Mr. Mestre asked if Nevada was attempting to stop the Internet sale of cigarettes, or possibly place restrictions on that activity, because such sales would not count in the volume. Mr. Albrecht stated if a non-participating manufacturer sold cigarettes within the State of Nevada, that manufacturer would still be required to set up an escrow account. For example, if a non-participating manufacturer were selling cigarettes over the Internet in the State of Nevada, the AG's Office would pursue that company in order to ensure it was paying the required 1 cent per cigarette into an escrow account.

Mr. Mestre then asked if a retailer in the State of Virginia was selling cigarettes via the Internet, would that sale count toward Virginia rather than Nevada. Mr. Albrecht replied the volume was set by national sales rather than state sales, and Nevada received a percentage based on the original settlement. He advised that in the original settlement, a factor had been negotiated for every state, and Nevada received approximately .6 percent of the entire $2.8 billion per year.

Mr. Fend asked if a company moved overseas, how would the adjusted volume be incorporated to include what was being made on sales of cigarettes produced overseas, but exported and sold in the United States. Ms. Cathcart stated, as she understood it, the volume adjustment was based solely on sales within the United States and did not take into account anything that was being sold outside the United States. It was possible that statutes could change with future legislation or other developments. She noted there was a possibility that the whole picture of cigarette sales would change, however, that would not alter the terms of the national settlement agreement, which was based on nationwide sales.

Co-Chair Freeman indicated the question regarding Internet sales was very interesting and, in fact, that was a "hot" topic currently under discussion in Washington, D.C. She felt that might be a factor in future Task Force action, and asked Ms. Cathcart to keep the members updated on current affairs. Ms. Cathcart advised the National Association of Attorneys General had a team working on current issues and any other issues related to the tobacco settlement. Periodically, it was the intention of the AG's Office to update legislators as to the current status.

Ms. Cathcart continued her discussion of the status report (Exhibit C), stating there was a previously settled states reduction, which had already been calculated into the base payments, so there would be no additional calculation or reduction in that area. The non-settling states reduction would probably not apply because there were only two states that had not achieved "state specific finality," meaning that litigation had not been finalized, but was expected to be finalized in the near future. Therefore, stated Ms. Cathcart, it did not appear there would be a reduction in that area. The federal tobacco legislation offset adjustment would depend upon whether or not there was federal legislation that would affect payments to states. Ms. Cathcart noted that was an extremely complex area, and she would be happy to provide the Task Force with a flowchart of "trigger points" that would have to commence in order for such an offset to occur. Because it was so complex, the National Association of Attorneys General did not feel it would ever come into play.

According to Ms. Cathcart, there were two other potential offsets that could occur, but were considered unlikely. Those were the litigating releasing parties offset and the claims over offset (Exhibit C). Those offsets concerned litigation brought within a particular state against a tobacco manufacturer by a political subdivision of the state, or the tobacco manufacturer was brought into the litigation in some manner and would possibly become liable for payments, either to the political subdivision or other entity. In that circumstance, there could be a reduction in the payments made from the tobacco settlement manufacturers to Nevada. She reiterated it appeared very unlikely those two offsets would occur.

The final category of payments to the state was strategic contribution payments, which would not begin until the year 2008 and would last for 10 years through the year 2017. Nevada would receive a base amount in each of those 10 years of approximately $8.87 million. Ms. Cathcart explained that strategic contribution payments reflected the contribution which each state made toward resolution of the tobacco litigation. Strategic contribution payments were subject to an inflation adjustment only, which Ms. Cathcart advised should go up rather than down.

Dr. Fildes inquired if there was an update regarding the American Legacy Foundation, and how available monies could be accessed. Mr. Albrecht replied that the American Legacy Foundation was created under the settlement, and a portion of its money was to be used for tobacco prevention problems. The foundation had publicized its grant request, with response due in May 2000. He advised the State Health Division had submitted a letter of intent for either program grant or planning grant funds. Mr. Albrecht noted the grant proposal had been written so that funds from the Task Force could be used as a match for American Legacy Foundation funding which would, in affect, add $1 million to existing funds for use in youth tobacco prevention programs.

Ms. Buckley indicated that since the last meeting of the Task Force, the U.S. Supreme court had issued a negative ruling, as anticipated, regarding the Food and Drug Administration's involvement in tobacco sales, and inquired if that would affect the Youth Enforcement Program coordinated by the AG's Office. Mr. Albrecht indicated the AG's Office felt it had sufficient funding to keep the program operating for approximately 2 months. He hoped to have the appropriate fiscal information within 1 week, and explained the AG's Office had submitted a grant application through the Health Division to the Centers for Disease Control (CDC). Further, Mr. Albrecht indicated he might approach the Task Force for funding in the future. Co-Chair Freeman asked Mr. Albrecht to keep the Task Force apprised of the status of the program and whether or not to place it on a future agenda for review. Mr. Albrecht indicated he felt review of the Youth Enforcement Program should be placed on the agenda for the May 1, 2000, meeting of the Task Force.

Brian Krolicki, State Treasurer, submitted Exhibit D to the Task Force, and indicated he would speak more specifically as to the actual monies available to the Task Force to complete its responsibilities. Mr. Krolicki indicated that 50 percent of tobacco receipt monies which had been deposited into the Trust Fund for a Healthy Nevada were as depicted on the first page of Exhibit D. There was an initial payment for 1998, received December 14, 1999, in the amount of $4,029,739, and the initial payment for the year 2000 in the amount of $6,558,754, was received December 31, 1999, and the anticipated amount to be received by the Task Force via the April 15, 2000, payment was $10.6 million. As members were aware, Mr. Krolicki noted there were two one-shot allocations the fund was responsible for:

1. A $5 million payment to the Department of Employment, Training and Rehabilitation (DETR) for accessible space; and,
2. A $1 million payment to the University of Nevada School of Medicine.

Mr. Krolicki explained the total receipt would be $15.2 for Fiscal Year (FY) 2000, and per Nevada Revised Statutes (NRS), he indicated the administrative fee capability of 2 percent would translate to $304,677. For FY 2001, the total receipt would be $18.8 million, with a 2 percent administrative fee of approximately $377,777.

Dr. Ellerton stated Exhibit D was different than the report received from the Department of Human Resources (DHR), and asked which report was viable. Mr. Krolicki stated some of the numbers did have a variability about them; the projected numbers in Exhibit D were from a study prepared by Goldman, Sachs and Company, and the exhibit depicted the Treasurer's best estimate as to the amount that would be received, including all the variables involved. The one component not included was interest being earned on the fund within the general portfolio.

Ms. Morgan asked Mr. Krolicki to give the Task Force a "ball park" figure regarding possible interest. Mr. Krolicki stated the numbers included in Exhibit E, which would be presented and discussed by Charlotte Crawford, Director, DHR, depicted projected interest components for FY 2000 and FY 2001, however, he cautioned there would be variability depending upon when the one-shot allocations were drawn from the fund. He advised the best estimate at the current time was $475,000 interest component for FY 2000, and $755,249 for FY 2001.

Co-Chair Freeman asked if, at some point, Mr. Krolicki could provide the Task Force with a report regarding the method used for investment of the tobacco money. At a previous Task Force meeting, Mr. Krolicki had mentioned a "tobacco bond," and Co-Chair Freeman asked for an explanation. Mr. Krolicki indicated he was still in pursuit of a plan that would be appropriate for Nevada to securitize the tobacco payments. Ms. Cathcart's presentation noted the variability in the different revenues involved, and what securitization could do was reduce the risk associated with the concern regarding tobacco companies over the next 25 years.

According to Mr. Krolicki, tobacco companies were extremely viable, because very few industries could afford a quarter of a trillion dollar settlement and still be conducting business in a healthy manner, however, the risk could be avoided and shifted to bond holders. He noted the Nevada AG's Office, along with other attorneys general, was in pursuit of making the tobacco companies uncomfortable by lessening the consumption of their products in Nevada and other states. However, at the same time, it was necessary for the tobacco companies to remain healthy enough to provide the settlement payments the next 25 years, and essentially into perpetuity. Mr. Krolicki indicated that discomfort had led many of his colleagues in other state treasuries throughout the nation to pursue tobacco securitization. He commented that was a method to control the money and not worry about the industry for many years.

Continuing, Mr. Krolicki explained Nevada's portion of the settlement proceeds for the next 25 years was approximately $1.2 billion. The State could not, however, sell $1.2 billion in bonds, but with a present value discount, along with other cost considerations, the state could consider an approximately $500 million bond proceed pool, with half of that amount available via an escrow account or separate trust fund. Mr. Krolicki felt that was an extremely prudent, conservative way to approach those monies, and he hoped to present a comprehensive plan to the Task Force within the next 3 months. Co-Chair Freeman asked that he keep staff apprised of his progress in that area.

Mr. Krolicki stated investment of the monies was similar to other portfolio funds, which were all fixed income. He indicated he was looking for ways to perhaps exercise the portfolio very conservatively, but in a sound manner, especially since it was a 25-year portfolio. Mr. Krolicki felt there should be some component of the monies in the equity market, for example. The Treasurer's Office was looking for a way to diversify the portfolio, to ensure that the money was working as hard as possible, so additional funds would be available for future programs.

Ms. Crawford stated that Exhibit E contained the dollar amounts in the account as of March 26, 2000. She indicated DHR had worked carefully with the Treasurer's Office and the numbers matched. The exhibit also indicated the projected dollar amounts with the additional payment in April 2000, in each of the accounts within the Fund for a Healthy Nevada for expenditure. She noted the exhibit also depicted the amounts in two categories, with a reserve of 20 percent, and without reserve, in each of the four programs: (1) Senior Prescription Program, 30 percent; (2) Aging Division – Independent Living, 30 percent; (3) Prevent/Reduce Use of Tobacco, 20 percent; and, (4) Improve Health for Children and Disabled, 20 percent. The decision of whether or not to reserve 20 percent of the funds for a "holdover" would be made by the Task Force. The amount available for allocation was $15,404,180 in FY 2000 and $19,266,314 in FY 2001.

Ms. Crawford then addressed the 2 percent administrative costs for the Fund for a Healthy Nevada (Exhibit E), which was $304,677 in FY 2000, and $377,777 in FY 2001. The Department would request the support of the Task Force in looking at the mandates of A.B. 474 within the four different programs. The 30 percent Senior Prescription Program was a program that the Department, with the Governor's approval, had moved forward on. She explained the Request for Proposal (RFP) for the Senior Prescription Program had recently been released and April 21, 2000, was the deadline for the letters of intent to be received.

Ms. Crawford advised she would discuss the actual format of the program under the "Public Comment" portion of the agenda. She informed the Task Force it did, however, require that DHR have some staff in order to develop the program; the Department anticipated the program would be contracted to a provider of senior prescription insurance coverage. The DHR would, however, be required to perform eligibility determinations, track and make payments on behalf of those individuals, and provide for the overall accountability of the program, as well as ensure the performance of the contractor. Additionally, Ms. Crawford pointed out, the DHR would carry out the mandate assigned it in A.B. 474 regarding the two 20 percent accounts allocated by the Task Force. Requirements for each of those programs was that the Task Force:

1. Take public testimony;
2. Evaluate and prioritize the needs in each of those areas;
3. Develop a procedure for awarding and making decisions regarding the funds;
4. Complete at least one round of competitive bid granting for the funds;
5. Award the funds and provide accountability as the funds were distributed;
6. Evaluate the programs after funds had been provided; and,
7. Provide a report to the full Legislature and the Governor at the 2001 session.

According to Ms. Crawford, each of those tasks assigned to the Task Force would be supported by DHR. Additionally, a 30 percent fund for Independent Living for Seniors was assigned to the Aging Division, which would complete the same process as that indicated for the Task Force. She advised DHR simply did not have the resources to assure it could responsibly and effectively comply with those mandates. Contained in Exhibit E was a matrix that identified five and one-quarter positions evaluated by DHR and determined to be the minimal number of staff that could responsibly execute the mandates of the program. The positions of Management Analyst IV, Management Analyst II, Auditor II, and a one-quarter time Management Assistant, were those that were needed to support the tasks included in the Senior Prescription Program, as well as support for the two 20 percent programs assigned to the Task Force.

To identify the staff needs, Ms. Crawford explained the DHR had balanced each mandate included in A.B. 474 against each requested position and described how it would work to fulfill those mandates. The Grants Analyst and Auditor I positions would work to fulfill the responsibilities assigned to the Aging Division of DHR to award the 30 percent grant for the Senior Independent Living Program. She emphasized there was a long list of mandated activities, and when considering the total dollars available, approximately $15 million in FY 2000 and $20 million in FY 2001, to be awarded or expended by the Task Force through the four programs, a certain level of accounting would be required, along with assurance that the tasks would be carried out. In order to accomplish that, Ms. Crawford stressed the Department must have the resources to assure that the mandates were executed.

In previous discussions with the Task Force Co-Chairs, it was requested that DHR defer the request for the two positions for the Aging Division (Grants Analyst and Auditor I), and Ms. Crawford indicated DHR would be glad to comply, in order that the Task Force have additional time to consider the positions. The three and one-quarter positions for the Senior Pharmacy Program, however, were needed by the DHR and in order to accomplish that, the Department would approach the Interim Finance Committee (IFC) with a work program request in order to receive the authority to hire for those positions. Per Ms. Crawford, the DHR would like to have those positions in place May 1, 2000, and had scheduled the Management Analysts, and the one-quarter time Management Assistant II positions be filled by May 1, 2000. It would be fairly remarkable to actually achieve support and approval for those positions by that deadline, because of the process involved. She indicated that was a target date in order to have staff in place to execute the Senior Pharmacy Program as quickly as possible and begin providing benefits. The Auditor position would not be requested until January 2001, at which time there would be audit needs throughout the program.

Ms. Crawford stated she was asking for the support of the Task Force as she approached the IFC. Support for those positions would be gleaned from the 2 percent administrative funds available to the Treasurer's Office. Mr. Krolicki indicated to DHR that if its interpretation were correct regarding the distribution of tasks, he would allow the Department to use the dollars it indicated were needed for administration. Ms. Crawford remarked that the Co-Chairs had also asked her to consider an alternative source of funding, which would be a revenue-earned account within DHR that would not be retained by the Department, but passed back into the General Fund. Ms. Crawford stated she would be glad to bring forward at the IFC meeting both resources that might be available, the revenue-earned account, or use of the 2 percent administrative funds, and allow the IFC to decide which funds it felt should most appropriately be used to support the positions. While she respected the Co-Chair's concern regarding use of the 2 percent administrative funds, the actual assignment of tasks to the DHR were considerably greater than those which would be executed by the Treasurer's Office in appropriately conducting and carrying out the mandates of A.B. 474.

Once again, Ms. Crawford asked for the support of the Task Force for the three and one-quarter positions (Management Analyst IV, Management Analyst II, Auditor II, and one-quarter time Management Assistant II), and to reflect that support when she approached IFC. Further, she indicated she would withdraw the request for the two positions for the Aging Division (Grants Analyst and Auditor I), which would be submitted after the Task Force had reviewed its grant process.

Co-Chair Freeman asked Mr. Krolicki to verify what Ms. Crawford had related to the Task Force regarding use of the administrative funds. Mr. Krolicki acknowledged that as the Treasurer's Office envisioned the administration of the fund, it would have little burden in that aspect. It was his greatest hope that the 2 percent administrative funds available to the Treasurer's Office would not be consumed at all, however, there was a "gray area" regarding the actual administration of the accounts on a daily basis. According to Mr. Krolicki, he envisioned a "one-shot" transfer of the appropriate level of funding to the DHR to track compliance with the mandates, while the Treasurer's Office would track the "global" number. If that was the way the administrative funds were finally enacted, Mr. Krolicki stated his office would forgo receipt of any portion of the 2 percent funding. There was, however, some question as to the best method of facilitating transfer of those monies or the pursuit of other financial options, but the Treasurer's Office would be pleased to provide cooperation, such as an inter-local agreement to transfer funds. He felt that was a decision best left to the Task Force and the IFC.

Co-Chair Freeman stated she had some concern regarding what the Senior Prescription Program and Independent Living Program would include, and emphasized the Task Force needed that information prior to making a decision regarding staff needs. Ms. Crawford commented she would give the Task Force a presentation regarding the Senior Prescription Program under the "Public Comment" section of the agenda.

Dr. Ellerton asked for clarification regarding the positions, noting that positions had also been requested in the CDC grant application submitted by the DHR. If the positions were the same or similar, as it appeared, he wondered how the funding would be resolved. Ms. Crawford noted the CDC positions previously discussed with the Task Force were those that had the responsibility of carrying out the strategic planning for the tobacco fund. What DHR had offered to the Task Force was the use of a collaborative model of strategic planning, which it felt the Task Force might be interested in pursuing. If that action were approved, the CDC positions would be used for the strategic planning requirements of both the Health Division and the Task Force. She noted that DHR specifically indicated the CDC positions could not be used for the actual follow-up, evaluation, and execution of programs. Ms. Crawford advised the Task Force that Yvonne Sylva, Administrator, Health Division, DHR, was present and could clarify any questions regarding the CDC positions. Ms. Crawford reiterated those positions were allocated and dedicated to complete the CDC requirements. The DHR had offered the possibility of completing the strategic planning on a collaborative basis with the Task Force, however, she noted the Task Force indicated it was not interested in such a collaborative effort.

Dr. Ellerton then asked if he misunderstood the CDC grant application, which used the Task Force as justification for a number of requests, and indicated it created a substantial demand on the tobacco program and the Health Division. He noted the application used that as a reason for requesting funds for administrative positions rather than programs. Electing to respond was Ms. Sylva, who stated the CDC grant was initially compiled prior to LCB's agreement to partner with the DHR in providing assistance and support to the Task Force regarding meetings, preparation of minutes, et cetera. Items included in the initial grant application had since been removed and a revised budget had been submitted to the CDC. She reiterated there was no duplication of full-time employee (FTE) positions, and never were they included in the grant application with the intent of implementing programs, but rather in the aspect of support.

Ms. Buckley asked if the Health Division was successful in its grant application. Ms. Sylva indicated the Division had received notice that it would be receiving a reduced amount, however, it was an ongoing grant. Ms. Buckley then asked if, based on the fact that the grant request did include staff time needed to support the effort, those funds would be available to support some of the requested staff positions. For example, Exhibit E indicated that the Management Analyst IV would, "Arrange for public hearings…," which was, in fact, being handled by LCB staff. To the extent there was some duplicative need to coordinate substantive presentations, Ms. Buckley asked if the CDC grant would pay for support of that effort. Ms. Sylva asserted the CDC grant, as originally proposed, included additional staff support, however, the initial grant request and the ultimate funding received were very different. Those pieces had been removed, given the fact that LCB was providing support to the Task Force, along with the fact that it had chosen not to "go down the same path" as the Health Division regarding the strategic planning process. The proposed Management Analyst IV position would be located within the Director's Office to provide the coordinated planning, which was not a Health Division, nor a CDC activity. Ms. Buckley once again inquired if funding for that position was available from the CDC grant monies; Ms. Sylva replied in the negative.

Ms. Brower stated since the CDC grant proposal had been changed, could the Task Force receive a copy of the final application, and the actual award granted by the CDC, so it would be aware of the actual positions available under the grant. Ms. Sylva replied in the affirmative, and noted the focus of the CDC grant was much broader than that of the Task Force. However, she indicated the Division would provide information regarding the scope of the program addressed by the CDC grant.

Ms. Buckley commented that regarding the issue of using a portion of the 2 percent administrative fees to fund personnel, she was strongly opposed to the Task Force moving in that direction. She believed the legislative intent was that all tobacco proceeds would be used for either health or educational purposes, and every dollar spent on administration meant a dollar less for the senior programs, respite programs, and other needs. Ms. Buckley acknowledged there might be additional costs and indicated she would like DHR to pursue other options. She felt IFC should review the need for the positions, and what funding options might be available. It was difficult for the Task Force to make a decision regarding positions without first hearing the details of the Senior Prescription Program, such as the number of projected eligibles, or what type of screening process would be needed. Ms. Buckley remarked that she would feel most comfortable at the present time if the Task Force:

- Provided support for the Department in its request to have sufficient support for the Senior Prescription Program;
- Reaffirmed how important the program was to the Task Force, and the need for DHR to have sufficient staff to insure it was running a "topnotch" program;
- Ask the IFC to determine the necessity of the requested staff, and support the request if the positions were needed; and,
- Affirmed its position that the 2 percent administrative fees could not be used for that type of administrative costs.

Ms. Buckley asserted that the statute was written to include a 2 percent administrative fee for use by the Treasurer's Office, not for administration pertaining to other programs. On the other hand, she felt the Task Force should make sure that DHR received the support it needed to administer the Senior Prescription Program in a manner that would assist as many seniors as possible. That was her outlook on the request by DHR to utilize the 2 percent administrative fund for additional staff positions, however, she noted it should be a full committee decision.

Co-Chair Freeman asked Ms. Buckley to submit a motion for the member's consideration.

MS. BUCKLEY MOVED THAT THE TASK FORCE:

(1) SUPPORT THE DEPARTMENT IN ITS REQUEST TO HAVE SUFFICIENT STAFF AND SUPPORT TO RUN THE PRESCRIPTION PROGRAM;

(2) ASK THE INTERIM FINANCE COMMITTEE TO DETERMINE WHAT STAFF POSITIONS WERE NECESSARY TO DO SO, AND CONSIDER THE DIFFERENT OPTIONS THAT MIGHT BE AVAILABLE TO FUND ANY NEEDED POSITIONS; AND,

(3) INFORM THE INTERIM FINANCE COMMITTEE THE TASK FORCE CONSIDERED THAT THE 2 PERCENT ADMINISTRATIVE FEE SHOULD NOT BE USED FOR THE DEPARTMENT'S ADMINISTRATIVE COSTS.

DR. ELLERTON SECONDED THE MOTION.

Mr. Mestre asked what would occur if the IFC disapproved the Department's request for additional positions, and what would be the responsibility of the Task Force. Co-Chair Freeman advised the Task Force could review the request if necessary.

THE MOTION CARRIED UNANIMOUSLY VIA VOICE VOTE.

Ms. Crawford presented Task Force members with a copy of the RFP for the Senior Prescription Program (Exhibit F) for their perusal.

Co-Chair Freeman then announced that the Task Force would consider the main topic for consideration: An Overview of

Existing Health Services for Persons with Disabilities in Nevada and Identification of Gaps in Those Services and of Their Future Needs.

Next to address the Task Force was Donny Loux, Chief, Office of Community Based Services (OCBS), Department of Employment, Rehabilitation and Training (DETR). She clarified that her agency worked with persons with physical disabilities, as well as sensory and neurological impairments. She presented a packet to members, Exhibit G, which explained OCBS was an agency with an approximately $9 million budget which administered four federal and five State programs under the guidance of persons with disabilities and their families. According to Ms. Loux, all services provided under those programs were privatized via non-profit or for-profit organizations within the community. The responsibilities and functions of OCBS were primarily in the administration and "flow-through" of federal and State funds to various organizations to conduct needs assessments, trends analysis, develop programs designed to fill gaps in services, and build service capacity within the identified needs.

Ms. Loux stated OCBS also conducted policy research analysis and collaborated with other State agencies and with private and non-profit organizations in the community to develop leadership opportunities for persons with disabilities and their families. Funds from the majority of OCBS's programs were pooled so that leaders with disabilities and their family members could receive the training necessary to assist their peers. According to Ms. Loux, OCBS also provided information dissemination and oversight monitoring of the provider organizations to ensure quality, and also coordinated services to ensure there was no duplication. The agency's mission was to provide equal opportunity and life choices for persons with disabilities.

Continuing her review of Exhibit G, Ms. Loux stated OCBS's target population consisted of persons who could not obtain services through any other entitlement or government program, who worked, had families that worked, or were working when they became disabled. The service philosophy was that services were most effective when carried out in the community that would be impacted, and consumers of OCBS's services were required be involved in all levels of policy and decision-making. Because OCBS programs were privatized, either via non-profit or for-profit agencies, Ms. Loux stated those agencies were in turn able to attract a great deal of money to further the mission and available services.

Ms. Loux indicated the services provided by OCBS's private and public sector partners included:

- The creation of a comprehensive housing development organization designed to attract various funds for housing from agencies such as the Department of Housing and Urban Development (HUD), the Nevada Division of Housing, et cetera. Money had been secured to either build or have approved 165 units of assisted living, or apartments that were designed for the accessibility needs of persons with disabilities. Persons living in such assisted living housing areas shared their resources for personal assistance or personal care, in order that 24-hour care would be available for all residents.
- A program that allowed low-income persons with disabilities who had difficulty with credit to purchase their own homes. The service assisted with down payments through collaboration with various state and federal programs, allowing disabled persons to purchase homes at a much lower rate with reduced payments.

According to Ms. Loux, personal assistance services were perhaps the most important to persons of any age with disabilities. Those were the services that assisted with the activities of daily living such as getting in and out of bed, meal preparation, bathing, and dressing, et cetera. Once a disabled person was out of bed, bathed, dressed and fed, they then could get into their vehicle and drive to work. She reiterated OCBS assistance was for those persons who could not quality for Medicaid or Medicaid waiver services because of income level, or because they were living with family.

Ms. Loux explained telecommunications services assisted deaf persons, speech and hearing impaired persons, or persons with any disability who could not use the phone. The Northern and Southern Nevada Centers for Independent Living provided free telephone-telecommunication devices. That program was funded through a surcharge on telephone access lines. Relay services for persons with sensory or speech impairments were also available.

Senator Rawson pointed out the Task Force should review the waiting list for such services, because even though the availability of services was increasing, the waiting list was also growing. He felt everyone should realize those important services were falling behind the need. Ms. Loux concurred, and indicated in the low-income home ownership program, there was a waiting list of approximately 25 persons. There was somewhere in the vicinity of 300 to 400 persons waiting for assisted housing, which consisted not only of financial assistance, but also the need to construct such apartment buildings. It was a matter of, (1) how fast money could be secured; (2) how fast buildings could be constructed; and, (3) how fast the additional money could be secured for the adaptability and accessibility required by most programs.

Mr. Fend stated Exhibit G indicated there were additional units for disabled persons under construction in Las Vegas, and there were completed buildings in the north. He asked when a contractor was building those units, was it assured they would contain the necessary requirements and/or provisions regarding accessibility. He emphasized that the same level of accessibility was frequently necessary for senior citizens. Ms. Loux replied in the affirmative, and stated all clients in independent living programs were assessed for needed items such as "reachers" and "grabbers," and every apartment was equipped for total accessibility throughout. In addition, she noted that before HUD would approve financing, it was necessary to prove that all required services and adaptations were provided.

In the personal assistance service category, Ms. Loux noted there was a waiting list of 162 persons. Eligibility for personal assistance service was gained via three methods:

1. Persons eligible for Medicaid were provided personal assistance services under the Medicaid State Plan.
2. Persons 65 years of age or older became eligible under the Community Home-Based Initiatives Program (CHIP) waiver, and in so doing, would become eligible for all Medicaid services, including personal assistance. That program, however, currently had a waiting list of approximately 700 persons.
3. Eligibility for the OCBS programs for persons who could not qualify for other programs because of income levels, family or parental support, or because they had worked prior to becoming disabled.

Ms. Loux advised there was no waiting list for telecommunications services, because OCBS simply presented the need for telecommunication devices to the Public Service Commission for funding. She explained independent living services included two areas, persons that could not quality for Medicaid or Medicaid waiver services, or persons for whom Medicaid did not provide that service. Such services included home and vehicle modification, and Ms. Loux noted approximately one-third of the persons requiring independent living services were seniors.

Ms. Buckley indicated it was apparent that the Legislature had not funded enough programs to handle the waiting lists, and perhaps the administration had not done all it could when processing the various waiver requests. She felt it was important to note that when the Task Force allocated money, it should not eliminate the obligation of the State to care for those individuals on waiting lists for services. The tobacco money might not always be available, and Ms. Buckley indicated it would be a disservice if the State felt it did not have to fund some programs. She noted the Task Force might wish to augment the money and services available in certain programs, and asked Ms. Loux for her thoughts regarding the priorities it should set in allocating money to best meet the existing needs.

Ms. Loux stated that generally the services needed by persons with disabilities, their families, and seniors were available, however, were terribly under-funded. While it was not the purview of the Task Force to ensure that waiting lists were eliminated and all needed funding was available, she emphasized there were some services that were simply not available at all, or available on a very limited basis. One such service was respite care for persons who did not qualify for other programs. According to Ms. Loux, there was simply no respite care available for some families with mentally retarded or senior members. She stated pediatric brain injury and autism services were desperately needed, along with specialized services and providers in the rural areas. Ms. Loux explained there was currently an initiative in Congress regarding a Medicaid buy-in program for persons attempting to return to work. Health insurance was a problem for persons with disabilities who were attempting to reenter the workforce, or foster families who needed assistance with health insurance for children. She suggested perhaps a fund could be established that seniors, persons with disabilities, or families with foster children could draw from.

Co-Chair Freeman asked Ms. Loux if she felt the most pressing needs included respite care, rural needs, and assistance for foster care families. Ms. Loux indicated affordable housing needs, health care needs, and family respite services were the number one areas of need. Other areas of concern were pediatric and specialized behavioral services, along with programs for persons with autism, regardless of age. She stated even when services were available through existing Medicaid programs, rural residents were often required to travel great distances to benefit from those services.

Co-Chair Freeman advised Ms. Loux that it would be very helpful to the Task Force to know what she felt were the top priorities, and requested an accounting of the dollar amounts needed and where added funding would fit into her program. Ms. Loux indicated she would provide that information.

Mr. Fend stated he recently listened to a presentation regarding the services that were available in rural areas, such as health facilities, long-term care facilities, et cetera. The presentation pointed out the shortfalls in the rural areas for any type of medical facilities or independent living facilities. Ms. Loux suggested the Task Force review the issues of persons with disabilities and seniors together, because they were so similar.

Jon Sasser, Esq., Legal Services Statewide Advocacy Coordinator, advised the Task Force he represented three legal services programs that represented low-income Nevadans. He stated his role was to point out where the gaps in coverage and services existed within the Medicaid program, by far the largest program serving the medical needs of persons with disabilities, so the Task Force would have an idea of the "lay of the land," as it began to prioritize the needs for expenditure of the tobacco fund money. He presented Exhibit H for review by the Task Force.

According to Mr. Sasser, there were three general areas of qualification currently available from Medicaid in terms of services for persons with disabilities:

1. Supplemental Security Income (SSI) recipient. That was the federal program for aged, blind and disabled individuals who were low-income and did not work enough in their lifetimes to qualify for Social Security Disability Income (SSDI). There were approximately 16,000 SSI recipients in the State of Nevada. The income requirement for that category was a maximum monthly income of $500 or lower in order to qualify.
2. Nursing home residents. Medicaid covered nursing home residents with incomes up to approximately $1,500 per month, or 300 percent of SSI.
3. Waiver programs for persons with physical disabilities. Persons with disabilities whose income fell above $500 per month were ineligible for Medicaid unless they were able to obtain one of the "slots" in a waiver program. Such programs had long waiting lists in terms of persons needing to be served.

Ms. Sasser indicated there were a number of residents in Nevada who were unable to afford medical insurance, and who were also ineligible for Medicaid. In Nevada, only about 26 percent of persons under the age of 65 and living in families below the poverty level, were covered by Medicaid programs, which ranked Nevada 51st among all states, with the national average being approximately 45.6 percent; only 4.7 percent of Nevadans were covered by Medicaid, with the national average being 9.3 percent. Mr. Sasser indicated Nevada was last of all the states in terms of per capita expenditures on Medicaid, which were over $600 per month in other states and just over $300 per month in Nevada.

Mr. Sasser stated it should not be surprising, with the low level of Medicaid spending, that there were many persons with disabilities who could not receive coverage. The main reason was that Nevada was one of only 13 states that did not offer Medicaid for the medically needy. In Nevada, in terms of qualification, only income and resources were considered, rather than the size of the medical bills. Mr. Sasser stated a person might have a decent income, but if he incurred large medical bills, as persons with disabilities did, he would not qualify for Medicaid in Nevada. As a result, Nevada spent much less, but had more disabled persons who did not qualify for Medicaid coverage, than almost any other state. That created a particular hardship for persons who had worked all their lives then became disabled, because they could not receive Medicare for 2 years after receiving SSI or SSDI benefits. During that 2-year waiting period, in many states such persons would be covered by Medicaid, however, in Nevada they were not.

Another important gap, reported Mr. Sasser, was the failure to take advantage of federal options to serve those who were disabled and returned to work. In December 1999 the President signed the "Ticket to Work and Work Incentives Improvement Act of 1999," which gave even greater flexibility to states in terms of covering Medicaid recipients returning to work who lived in families where income did not exceed 250 percent of the federal poverty level. That would help those persons who might be sitting home being nonproductive citizens, but could not go back to work because they could not make it without medical insurance. If they could qualify for medical insurance through an employer, that insurance often did not offer personal care assistance (PCA) services to aid the disabled person in getting up and out to work each day, and without those services, such persons could not afford to work.

Mr. Sasser further explained that the new federal option would allow disabled persons to go back to work, as it would pick up 50 percent of the costs. That program was the Medicaid Buy-in Program, an option the State of Nevada had chosen not to take advantage of. There were some disabled persons eligible under Medicaid, however, the services needed by those persons were often considered "optional," which Nevada had chosen not to offer under its Medicaid program. Adult dental services were probably the largest and most important of the needed services, along with podiatrist and chiropractic services. According to Mr. Sasser, many adult services, such as prescription drugs and doctor visits were limited severely in terms of the number of prescriptions or visits allowed each month.

Per Mr. Sasser, some persons had a Medicaid card, but were unable to locate a provider who was willing to accept Medicaid, due to the low reimbursement rates and the perceived "red tape" in terms of receiving payment. Perhaps one of the most dramatic problems, stated Mr. Sasser, was the waiting list for waiver services for persons within the $500 to $1,500 per month income level, who were attempting to survive in the community without Medicaid services. There was an alarming growth in the waiting list for that program, with only approximately 113 persons currently being served. He noted in October 1999, there were 160 persons on the waiting list, from October to December 1999, the number increased to 187, and from December

1999 to March 2000, it increased to 229 persons. Even though more persons would be approved for waiver services once the new amended waiver program was approved at the federal level, Mr. Sasser noted Nevada was falling further and further behind in terms of keeping up with the waiting list and the need.

Mr. Sasser indicated some persons on Medicaid received services that had proven to be inadequate, and there had been a great deal of controversy within the disabled community regarding the quality of PCA services. Medicaid chose to provide those services through independent contractors at $9.48 per hour without the requirement of standard credentials, training, background checks, or benefits. Also, he explained the number of hours had been limited based on a daily cap, with no backup services provided. There was an exception to the Nurse Practitioners Act, which allowed a layperson to perform certain procedures, such as the irrigation of catheters. Mr. Sasser indicated there were some signs of improvement, and in 1999 the Legislature approved an increase to $14.50 per hour for PCA services. There had been a number of hearings held on regulations regarding those programs, and some positive changes were under consideration which, hopefully, would be finalized soon. Included in the positive changes were:

- Greater flexibility for PCA's who provided services outside the home;
- Allowance for more family members to play the role of PCA in conformance with federal regulations; and,
- Broadening the types of services that could be performed, such as light housework.

Another controversial area, according to Mr. Sasser, was whether or not Nevada's waiver programs included sufficient services to support those more severely disabled individuals. During the 1997 Session, a bill was passed that created an Independent Choices Waiver, however, the funds reverted between 1997 and 1999, and an expansion of the current waiver, with increased services, was approved by the 1999 Legislature. That amended waiver was currently awaiting approval at the federal level, and hopefully, it would provide some significant progress in terms of the ability to serve more severely disabled individuals. Mr. Sasser pointed out there was some concern about the proposed waiver, however, because the income caps were not as high as those in the Independent Choices Waiver.

Finally, Mr. Sasser stated there were a number of special needs within the Medicaid population where the services were simply not adequate to cover the needs today. He commended the Task Force for having an RFP process to bring innovative grant applications forward. It seemed to Mr. Sasser that perhaps the Task Force should consider creating a point system that gave extra points for proposals which:

- Had the ability to leverage other funding from either public or private sources;
- Would foster long-term savings;
- Would significantly enhance the quality of life for beneficiaries; and,
- Would promote services in the least restrictive/most integrated settings.

The target population in terms of priorities, indicated Mr. Sasser, were those individuals whose income level was between $500 and $1,500 per month, and who were attempting to survive outside the institutional setting. If such persons failed in that effort, they would be placed in nursing homes, where payment of the bill would be via the Medicaid program, and if greater help was provided in the way of respite care, assisted living, and other programs, perhaps those persons could remain in the community.

Co-Chair Freeman stated the Task Force valued Mr. Sasser's input and asked him to work with the Task Force during the RFP process. She indicated perhaps there were state programs available that could assist with those issues.

Senator Rawson commented regarding the possibility of bond sales, as previously discussed by Mr. Krolicki, and which might bring in a significant amount of money ($500 million) now. He indicated he was unsure if that possibility had been discussed thoroughly, however, the implication of such a bond program was a permanent endowment fund that would provide $50 million in perpetuity. Senator Rawson felt that program might provide additional money to allocate to some of the problem areas. He noted that Exhibit H, submitted by Mr. Sasser, was a very powerful document, which detailed many of the problem areas.

Ms. Buckley stated she felt the possibility of bond sales was interesting, however, what caused her some concern was the idea that the State might ultimately lose half of the settlement through the risk of bonding. Certainly, that aspect could be explored in future presentations, and perhaps those risks could be balanced against lower cigarette sales. She pointed out the bigger risk was what the Legislature would do with $500 million, i.e., would it devote that money to health and senior programs, or would there be some desire to divert those funds into other problem areas, rather than the programs being considered by the Task Force for funding with the tobacco proceeds. That was the only caveat she could see to the bond issue. Senator Rawson replied if the state actually had $500 million in the bank today, it could possibly do better than it would through the tobacco settlement, and he felt the bond issue should be explored.

Paul Gowins advised the Task Force he would present testimony on behalf of the Disability Forum, and provided written copy of his presentation, Exhibit I. He stated he brought a concept forward that had been utilized in several states, which was to set aside approximately $1 million to provide low-interest loans to people with disabilities. Through the experience of a small pilot project which began in 1992, it was found that such a program was a very effective method of providing assisted technology and services to persons with disabilities. Those persons normally would not have access to such a loan because they were middle-income workers who might lack the ability to repay, and also because of the lack of understanding regarding the need.

According to Mr. Gowins, Bank of America stepped forward in 1992 to initiate the program with $147,000 federal money set aside for what was basically a guaranteed loan program. For example, a person could approach the bank with a request to purchase vehicle modifications costing $5,000. He explained that added to the purchase price of a vehicle was the cost to modify it for use by a disabled person. Most banks were unfamiliar with that type of service, and would not loan over the margin price of the vehicle. With the affordable low-cost loan program, money would be utilized to guarantee that loans would be repaid. He explained that currently the bank required a 50 percent guarantee, where funds were held as collateral. Because payments could be spread out, a $5,000 loan for modifications should be affordable for the disabled person.

Mr. Gowins explained under the existing program, Bank of America loaned at the prime rate, which saved the individual money, and also executed a more lenient approach to the criteria for loan approval. In the past, individuals had been required to go through the normal loan process, which often led to refusal. He indicated the concept was very straight forward, and Exhibit I detailed the program currently in use by the State of Maine, which funded its program with a $5 million bond issue in 1989, thereby allowing it to expand its program and offer larger loans. Nevada's loan cap was currently $5,000, and the suggestion was to raise the cap to $20,000.

Continuing, Mr. Gowins addressed the possibility of small business loans, noting that compliance with the Americans with Disabilities Act (ADA) was not a problem for larger businesses, but the smaller employer could not afford to meet that requirement. By creating such a loan program, small businesses could provide reasonable accommodations. He stated the demand for consumer loans was an interesting concept, because even though programs such as Medicaid would pay for some devices, if a disabled person wanted or needed something different, those programs often would not pay.

Mr. Gowins stated loan services were not just for persons between the ages of 60 to 65, but were utilized by families with children that needed special devices, persons on fixed incomes, and the elderly, and provided access to needed devices. He asked the Task Force to review the concept and put it on its list of RFP's. The benefits would coincide with many issues of concern before the Task Force, and the program could be established with "one-shot" funding. The program could also provide access to services for individuals outside the poverty level.

Mr. Fend inquired if a bond request had been considered to provide funding for such a loan program. Mr. Gowins stated it was considered originally when the pilot program began in 1992. That was the method used by the State of Maine in its loan program, and it had been discussed at two sessions of the Legislature; however, there did not appear to be much of an appetite for a bond mechanism to fund the program. Mr. Gowins explained that the Assistive Technology Loan Program had provided the administrative money because the project was so small. Mr. Fend noted a bond would not be subject to the restrictions required by use of state funds, and even if there was a deficit in spending, the bond would still function, which he felt was important. The Task Force was required to allocate several initial, up-front expenditures from the tobacco money, and he felt the bond issue was a logical step to enlarge the existing program.

Ms. Brower asked Mr. Gowins if he had been through the process of purchasing a van and modifying it for his use, to which he replied in the affirmative. She then asked if that allowed Mr. Gowins to go to work and make a living. Mr. Gowins replied the $5,000 loan for the modification of his vehicle made it work for him, thereby allowing him to go to work. Often, a person could qualify for a loan for the vehicle, but not for the required modifications. Mr. Gowins offered another example, explaining that of purchasing used equipment such as wheelchairs, which was not covered by most insurance companies, and the loan program could be utilized for purchase of specialized equipment. He also felt that disabled persons, along with seniors, should be included in the Prescription Program because the needs were almost identical. Mr. Gowins reiterated he would ask the Task Force to review a RFP in the area of a low-income loan program for disabled persons.

Shaun Griffin, Executive Director, Community Chest, addressed the Task Force regarding the need for respite services, and provided members with Exhibit J, his written testimony. He explained that the University of Nevada and Community Chest interviewed 88 families, 17 agencies who provided respite care, and 68 caregivers over a 6-month period. Mr. Griffin indicated he had personally interviewed the respite care directors throughout the state. Many of those individuals were running agencies out of their homes with no funding and no help, but were providing that service because someone in their life suffered from a disability. The need existed in all age groups, be it a child with autism or an aging parent. According to Mr. Griffin, the directors spent the majority of their time "chasing" funding, because there were no available funds in the State of Nevada for respite care.

Mr. Griffin stated Community Chest administered a small amount of federal "flow-through" money to families attempting to receive respite care. When he interviewed the respite care directors, they indicated they were so overwhelmed with survival, they did not know such an idea or program existed. Mr. Griffin commented that in rural counties it was even difficult to find funding to provide a visiting community health nurse, and when families in the rural areas were notified they received respite care, they were quite overwhelmed. He felt it was imperative that as a State, and as human beings, those individuals were provided with some help.

Mr. Griffin then read verbatim from a letter he received on March 2, 2000, from a mother in need of respite care for her son:

> "I am requesting respite care for my son – he has autism and two neurological disabilities. I have been running a home treatment program for him for 3 years. This treatment could make the difference between totally dependent life in an institution and a productive and happy life in society for my son. Since there is no autism treatment in Las Vegas, we were lucky to be accepted by UCLA's autism program. We fly a consultant in every month to review an update my son's treatment. This part of the program alone costs $1,200 each month. My son's program each year costs $25,000.
>
> "With our obligations to our children and the children in the community, my husband and I have no personal time together. We are both under great stress to deal with the everyday demands of having a disabled son and a gifted daughter. Since early intervention in both cases is critical to our children meeting their full potential, we have been going all out for the last several years to work with them. This has almost thrown a fatal shot in our marriage. I desperately want to keep our family together, but realize that we need some time to rebuild the marriage. I would also like to give more attention to my daughter who, at six, is expected to always happily yield to her brother's needs."

Mr. Griffin stressed that was the part of the process that was most difficult, and explained that all respite applications in some way addressed the strain on the parents' relationship and the possibility of a break-up in the family. He felt there were no more eloquent words he could share with the Task Force, and there was some variation of the same story in every single letter he received.

Ginny Oldham, a single mother residing in Las Vegas, read verbatim from prepared testimony, Exhibit K, explaining her circumstances regarding her son, Joshua, and reminding the Task Force that respite care was a critical need, which could make a difference. She stated the need was real, and she needed respite services, along with her parents. The family had two boys in the home that required constant vigilance, and Ms. Oldham explained it was not only funding that was needed, but also well-trained people to provide the respite service. She stated legislation would be forthcoming that would ask for a statewide, lifespan respite opportunity for Nevada, which would require a vote of confidence and the ongoing money to keep respite available for those in need. She explained when she was not in the home, her parents cared for her autistic son, who required 24-hour care, and she emphasized that her family needed help in the form of a service that would not "die" away.

Ralph Baker, Ph.D., Chairman, Nevada Council on Independent Living, advised the Task Force he was present to ask that a portion of the tobacco settlement monies be allocated to meet the independent living needs of disabled Nevadans. He explained that the Independent Living Council currently oversaw a small budget of approximately $500,000 per year, which was used to provide independent living services to persons with disabilities who were unable to obtain such services through other programs.

According to Dr. Baker, "independent living services," were those services which allowed persons with disabilities to function more independently in the community; to carry out basic daily activities with a minimum amount of assistance. Those services were quite often the difference between the disabled person living in the community or living in an institutional setting. Dr. Baker commented that with those services, a person had access to the community and was able to drive, feed and bathe himself rather than relying totally on other people. Also, with such services a disabled person and his family could achieve unity rather than suffering the stress of coping with the mere basics of existence, and could communicate with others rather than facing a life of silence and isolation.

Dr. Baker explained those independent living services included:

- Building wheelchair ramps;
- Installing grab bars and handrails;
- Widening doors;
- Making bathrooms accessible;
- Installing lifts in vans or carriers for wheelchairs or scooters;
- Installing hand controls so a disabled person could drive;
- Provide assistive technology such as environmental controls, communication devices, or phone and doorbell flashers for the hearing impaired; and,
- Provide medical equipment such as wheelchairs, scooters, walkers, shower benches or equipment repairs.

Again, reiterated Dr. Baker, the Independent Living Program provided services only to those who could not access services via any other resource. The program also funded Independent Living Advocates, both in the northern and southern regions of the State. Those advocates helped disabled persons locate and secure independent living services through existing community resources, if available.

Dr. Baker gave two examples of individuals who had received Independent Living Program services:

1. A client who was 4 years of age when his mother first applied. He was currently 7 years of age, and suffered from shaken baby syndrome with resulting multiple disabilities. He was functionally limited in self-care, mobility, socialization, and communication. Independent living provided an array of services, and a technology assessment was provided to assist the client in identifying the technology needed. The client was provided assistance with a bathroom modification, which enhanced his ability for self-care. His mother requested a ramp from Medicaid so she no longer had to carry him down the stairs of her mobile home; she was denied that service from Medicaid and Independent Living provided the ramp and sidewalk which allowed the client to get safely out of the home and also get to his grandmother's home next door, who was also his caregiver. The client was considered for a surplus vehicle, and since his mother lived in a rural area and had no other transportation, she was awarded the vehicle. The client's independence was greatly improved and his family was satisfied with the services.

2. A 73-year-old male with multiple disabilities resulting from a stroke. The client was functionally limited in self-care and mobility. He was provided a technology assessment to identify his independent living needs and the technology needed to assure his home safety. As a result of the assessment, he was provided a ramp so he could safely exit his home; he was also provided with grab bars, pivot poles, shower bench, hand-held showerhead, and other bath equipment so he could bathe safely and independently.

According to Dr. Baker, those were but two of a hundred examples he could give the Task Force to explain what independent services were all about; they were pretty basic services, but were essential. For the past 3 years, the Independent Living Program had 50 to 75 more service requests than it could fund. The program would hopefully provide independent living services to 78 people; unfortunately, there were an additional 136 persons with disabilities waiting for those services.

Dr. Baker explained that the average cost per person was approximately $3,900, which could range from as little as $250 for a minor home modification to as much as $15,000 to $20,000 for a vehicle modification or environmental control system. Over the past 3 years, the average cost to serve independent living clients had increased 90 percent, and the average cost was projected to increase from the current $3,900 to approximately $7,500 by the year 2004.

It was the request of the Independent Living Council that a portion of the tobacco settlement monies be allocated to provide independent living services to the severely disabled Nevadans who were in dire need of such services and were waiting to receive them. Dr. Baker stated it was hoped that with additional funding, the Council could meet the current and future needs of children, adults, and seniors with disabilities. As with the current program, the funding would also be for individuals who could not access independent living services from any other resource.

In conclusion, Dr. Baker advised the Council was not asking for money for frivolous items, but rather for funding so that people could get out of bed, have accessible facilities, get in and out of their homes, turn on the lights, or answer a phone; the basic but essential needs. Dr. Baker then introduced Jesse Hunter to the Task Force.

Mr. Hunter explained that 2 years ago his daughter fell while hiking and became a quadriplegic with a traumatic brain injury. At that time, his wife was forced to quit work to become her caregiver, and the family income was considerably reduced. Mr. Hunter stated that community-based services provided help during that time, and began communication while his daughter was in her initial rehabilitation program in California. During that time, his family was put in contact with persons who could help and provide insight as to what the family's needs would be. Because of the help from community- based services, Mr. Hunter indicated he was able to add modifications to his house, along with the purchase of an appropriate van prior to his daughter's return to the home. She was able to enter a local rehabilitation program that would prepare her to reenter the community immediately upon return because of the assistance provided. Mr. Hunter reiterated his family would not have known what to do without the assistance provided. Because of his daughter's immediate entrance into a rehabilitation program, and the family's ability to add the necessary modifications to the home, she had returned to college.

The next person to address the Task Force was Les Gruner, Acting Deputy, Northern Region of the Division of Child and Family Services (DCFS), DHR. Mr. Gruner explained he would provide an overview of child and adolescent mental health services for persons with disabilities, and presented Exhibit L. He introduced Laurel Swetnam, Program Manager, Early Childhood Services in Las Vegas, who would address the Task Force on issues specific to early childhood development.

Mr. Gruner explained the DCFS was created by the 1991 Legislature at the recommendation of the DHR. The Department recognized that children served by the State's youth correction, child welfare, and children's mental health systems would often move back and forth from system to system, especially those children with emotional disorders. The services for those children were often fragmented and uncoordinated. Mr. Gruner indicated when the DCFS was created the State's child welfare system was placed within it, as well as youth parole, correctional facilities for delinquent youth, and the children's mental health programs in Washoe and Clark Counties. Children's health services in rural Nevada remained with the then Division of Mental Hygiene.

The creation of DCFS, indicated Mr. Gruner, was effective in accomplishing a myriad of important objectives in improving mental health services to children, (Exhibit L). In 1977 a regional administrative structure was created via the Regional Resource Council, which consisted of child welfare, youth corrections, and children's mental health supervisors, in order to facilitate a more effective service delivery. According to Mr. Gruner, most Nevada children in out-of-state residential treatment facilities were also returned in 1997, and maintained in their communities with intensive service and resource coordination through the Regional Resource Council.

Mr. Gruner noted that the DCFS Regional Mental Health Treatment Service had primary responsibility for providing services to children and/or adolescents with severe emotional disturbance (SED) within the child welfare and juvenile justice systems, and also through community based programs in the Reno and Las Vegas areas. In rural areas, that service was provided by the Division of Mental Health and Developmental Services (MHDS), complimented by the DCFS Intensive Family Services Program. Through DCFS, a continuum of mental health services was provided to SED children and adolescents, as depicted in Exhibit L.

According to Mr. Gruner, included in the exhibit was a copy of testimony presented to a previous Task Force hearing by Dr. Christa Peterson, regarding children with emotional disturbance, with the target population being severely emotionally disturbed children. Such children suffered a significant loss of function in daily life, were at major risk for lifelong problems, and might be unable to work or contribute to society as adults. He went on to explain the reasons children developed emotional disturbances, and the impact on the family of children who suffered from SED. Mr. Gruner noted that Exhibit L illustrated the broad range of mental health services currently available in Washoe and Clark Counties through DCFS, along with the coordinated treatment of rural youth where necessary.

Mr. Gruner informed the Task Force that the total number of children served by DCFS and MHDS in FY 1999 was 8,781, with 5,500 identified as SED. There was a waiting list for the array of DCFS services offered, as depicted in the exhibit (Tables 3 and 4). He stated over 7,400 children were served each year through DCFS programs, and approximately 1,300 children were served each year through MHDS in rural Nevada. Exhibit L also contained illustrations (Tables 5 and 6) regarding mental health expenditures and funding, based on FY 1999 actual expenditures.

Ms. Swetnam presented a packet of information to Task Force members, (Exhibit M), which explained that early childhood behavioral health services were somewhat different than those for older children. Early Childhood Services was part of DCFS, and had developed a program in southern Nevada called "New Wish," which provided a potential template for meeting some of the needs of Nevada's youngest children. Unlike older children whose problems were often identified in the school setting, Ms. Swetnam indicated young children with behavioral problems were often not identified at all. Medical practitioners were not routinely trained to screen younger children for problems, and she felt more young children went unidentified than older children.

According to Ms. Swetnam, working with young children meant working with the needs of the family unit. In southern Nevada, a continuum of services had been built up over the years, which was used somewhat as a national model, as depicted in Exhibit M. She indicated there was a high grade of services available within DCFS for young children:

- Mental health services;
- Developmental services;
- Crisis services;
- Respite services; and,
- Therapeutic day treatment.

Those services allowed Early Childhood Services to meet the needs of some families who fell between systems. Ms. Swetnam stated in 1997, a grant was received from the Substance Abuse/Mental Health Services Administration for a 4-year research project entitled "New Wish." The purpose of that project was to test the idea that if services for young children and their families were placed in community settings frequented by them, better use of the facilities would occur, with better outcomes. There was a control group in that program which would provide excellent outcome data in approximately 1 year.

Ms. Swetnam commented that Early Childhood Services typically served families that suffered a variety of disabilities. Most families had children who were either SED, or suffered from developmental delays. There were also families facing challenges that put the children at risk of out-of-home placement. She explained of the children with disabilities served, 20 percent of the parents either had mental health issues or disabilities. It was know on a national level that there were some populations that absolutely could not access services, even in community settings, and the purpose of "New Wish" was to go into the community and locate such families. Early Childhood Services partnered with Head Start, which served a population that was traditionally in need of services, and placed mental health counselors who were cross-trained in substance abuse treatment into the Head Start setting via the "New Wish" project.

The children at the Head Start sites were screened by mental health counselors on a weekly basis, and mental health activities were provided for the children, with consult regarding any children experiencing difficulties. Ms. Swetnam explained each site had multiple groups each week to offer support to families, and in addition, there were services provided on an individual basis to children and families, either on-site or in the home. The access rate for families with serious needs had been six times higher at the integrated services sites as compared to other groups, which indicated that access had been greatly improved.

Continuing, Ms. Swetnam asked the Task Force to consider how the model project, "New Wish," might be supported on a community basis, in order to provide integrated behavioral health care services to daycare centers in high-risk neighborhoods, and also consider the benefits such a program would provide for families. She noted those families were not likely to be competent at utilizing resources available in the community, where programs were already inadequate. If Early Childhood Services were able to expand the model, Ms. Swetnam estimated it could serve approximately 1,000 children and/or their families in southern Nevada alone.

Dr. Fildes asked what were the most likely causes of emotional disturbance among children and/or adolescents, and what was being done to assist in that area. Ms. Swetnam replied that in young children, there were a number of idiologies that could be identified. Some children were clearly born with development disabilities with behavioral ramifications, and many children were exposed to family violence or trauma in the home, which caused emotional behavior problems. Also, she noted some children suffered experiences such as traffic accidents, or suffered divorce in the family which caused emotional trauma. Ms. Swetnam advised the State did provide services for children who otherwise did not have insurance, but they were not identified well in the community setting, nor was there a community-wide mechanism to educate childcare providers, which was where the greatest volume of children were located on a daily basis. Research showed that early childhood behavioral problems became elementary school behavioral problems, with a propensity toward involvement in the juvenile justice system. Such behavioral problems were not simply outgrown.

Mr. Gruner added that the risk of abuse and neglect in society today, from a national perspective, revealed that in 1986 there were approximately 280,000 children in foster care, and today that number was over 500,000. He emphasized that abuse and neglect contributed towards children experiencing emotional problems. Co-Chair Freeman inquired if there was any state-specific data available regarding that issue, and Mr. Gruner indicated the State of Nevada had approximately 5,000 children in foster care at the present time.

Carlos Brandenburg, Ph.D, Administrator, Division of Mental Health and Developmental Services (MHDS), DHR, indicated he would present the Task Force with an overview of Exhibit N, "2000 Mental Health Needs Assessment." He explained the purpose of MHDS was to develop and operate programs to assist individuals with mental illness or in need of developmental services live as productive and independent a life as possible. Dr. Brandenburg indicated there were four agencies that provided mental health services in the state:

1. Nevada Mental Health Institute, located in northern Nevada, provided a combination of both in and outpatient care at

one location.
2. Southern Nevada Adult Mental Health Services, which operated from four different locations in Clark County and offered a variety of in and outpatient services.
3. Lakes Crossing, a facility for the mentally disordered offender, i.e., those offenders who had been adjudicated by the courts as being either incompetent to stand trial, or needed an evaluation of competency prior to standing trial.
4. Rural Clinics operated throughout Nevada, with 16 outpatient clinics located within the 17 counties.

Dr. Brandenburg explained Southern Nevada Adult Mental Health Services was staffed for 86 beds and Nevada Mental Health Institute was staff for 50 beds, however, was licensed for 74 beds. Both facilities provided psychiatric emergency service via a triage unit, which provided 7-day, 24-hour triage services to the community. Those were ambulatory sites, where a client could walk in at anytime, day or night, and receive services from a professional. Adjacent to the psychiatric emergency service was a 10-bed observation unit, where a person could be hospitalized up to 72 hours without admission to an inpatient hospital.

Other services provided on an outpatient basis included medication clinics, outpatient therapy, psychosocial services to train clients in pre-vocation, as well as vocational training, and personal service coordination, which was basically case management on a ratio of 1:35 where the client was actually monitored in the community. Dr. Brandenburg indicated mental health services were also provided in the Clark County Jail, Las Vegas City Jail, and the Washoe County Jail. Homeless outreach services were available in Las Vegas, as well as intensive case management, with a caseload ratio of 1:15. The average clients in that category were those that had been historically involved in the criminal justice system, or those that required extra monitoring in the community with the hope of keeping them out of the criminal justice system.

Dr. Brandenburg stated MHDS had received funding for assertive community treatment via the Parents and Children Together (PACT) Program, as well as a residential treatment program with a 16-bed unit in the south and an 8-bed unit in the north. That was a step-up or step-down program, which allowed clients to bypass hospitals and enter the treatment unit if necessary. Other services included Senior Mental Health Outreach in Clark County, as well as a 24-hour Suicide Crisis Hotline funded by the 1999 Legislature. According to Dr. Brandenburg, MHDS was the “safety net” for the severely mentally ill adult throughout the Washoe and Clark County areas. Also, services were provided to the seriously emotionally disturbed youngsters in rural clinics via outpatient services. Dr. Brandenburg noted 30 percent of the rural Nevada population consisted of children with serious emotional disturbances.

Dr. Brandenburg informed Task Force members that pages 6 through 11 of <u>Exhibit N</u> provided the needs assessment for southern Nevada; pages 12 through 14 depicted needs assessment for the Nevada Mental Health Institute; pages 14 and 15 indicated the needs for the Lakes Crossing facility; and pages 15 through 18 contained the needs for rural clinics. That would provide the Task Force with an overview of the current needs throughout the state, as well as the current demographic information.

Currently, explained Dr. Brandenburg, there was a gap in the service delivery system in the area of residential support, or housing. There was a waiting list for residential support throughout the state. Another gap existed in the area of treatment for co-occurring disorders, or those individuals who were mentally ill and also had substance abuse problems. There was a tremendous need for treatment in that area, and Dr. Brandenburg emphasized MHDS was working closely with the Bureau of Alcohol and Drug Abuse (BADA) to address that gap in the service delivery system. Other gaps included consumer-based services, and intensive case management services in northern Nevada. Included in <u>Exhibit N</u> was a cost analysis of the service delivery system.

Dr. Brandenburg explained that waiting lists occurred basically in the area of residential support services and vocational training. However, there was a waiting list of approximately 114 persons for the medication clinic at the Nevada Mental Health Institute. That waiting list was for individuals who had not been seen by a psychiatrist within 30 to 60 days. He noted two vacant positions had been recently filled, which should somewhat alleviate the waiting list.

Ms. Buckley asked if the Task Force wished to fund a program without supplanting State funded programs, or what should be State funded programs, what would Dr. Brandenburg suggest. Dr. Brandenburg indicated he would ask for consideration of services on the developmental side; the mental health side had been adequately funded over the past three sessions of the Legislature. He stated he could not provide specifics, but felt respite care for the mentally ill was a high-priority.

Dr. Fildes inquired about the cost of <u>Exhibit N</u>. Dr. Brandenburg advised MHDS had been funded for quality assurance and planning staff positions, and part of that job was the collection of needs assessment on a biannual basis. MHDS used that information in budget preparation, and identified resources so managers could allocate them appropriately. Dr. Brandenburg noted data was collected on a monthly basis in terms of caseload and outcome measures. He emphasized that without data he could not run a system, and without outcome measures, he could not indicate how successful the programs were. He indicated MHDS felt it was an extremely important part of managing a very important system.

Senator Rawson stated there were various estimates of the number of homeless persons who were mentally ill or suffered from substance abuse, and asked if those numbers were included in the needs assessment (Exhibit N). Dr. Brandenburg advised those individual were actually included in the needs assessment, due to the fact MHDS worked very closely with the Mobilized Assistance Shelter for the Homeless (MASH) component in Clark County. He felt MHDS had a good "handle" on the number of homeless individuals who were mentally ill in Clark County, and had found that between 45 to 60 percent of those individuals suffering from mental illness also suffered from a co-occurring disorder. Having a mental health worker actually located at the MASH unit allowed MHDS to monitor the homeless in Clark County, however, the same could not be said for Washoe County or the rural areas.

Alan Chapman, West Hills Hospital/Willow Springs Center, declared that he would review the needs and gaps that the private sector felt were not being met. Currently, there was one private, for-profit facility in Las Vegas that offered a full continuum of services, minus residential care, for ages 5 to 95. Also, Mr. Chapman stated there was the Nevada Children's Center which had an after-school program for children ages 5 to 11, and a special needs program of approximately 3 to 4 hours in length. He explained there was recreational treatment available in the Las Vegas area. West Care was a private, non-profit organization that offered a day-treatment program consisting of approximately 5 hours per day, mainly for adolescents who were chemically dependent, along with a children's runaway shelter program.

Mr. Chapman indicated there were many private foster care group homes, however, they also had an extensive waiting list. Boys' Town in southern Nevada was a residential treatment Center, Level III, which meant it was an unsecured center. St. Jude's was a private, non-profit organization that also offered a Level III facility. West Hills Hospital was currently the only freestanding, private psychiatric hospital in northern Nevada, and was a Level IV, acute secured unit. Mr. Chapman explained West Hills Hospital handled patients from ages 3 to 96, and was a full continuum program that covered acute inpatient, as well as day hospital programs. Those programs included chemical dependency, partial programs, and individual therapy.

According to Mr. Chapman, the average length of the stay for youth with severe emotional disturbance was approximately 8 days. The Willow Springs Center was a 72-bed residential treatment center, Level IV, for ages 4 to 18 years, with an average length of stay from 30 to 160 days. SageWind Treatment Center was also located in the Reno area, and was an 18-bed adolescent substance abuse program. Mr. Chapman explained there were other various groups including:

- The Maple Star Nevada, Incorporated group homes, which handled small group homes for adolescents;
- Northern Nevada Medical Center provided a Senior Bridges Program, specifically for seniors with psychiatric and medical problems;
- Washoe Medical Center had a 7-bed, Level III, adolescent program for ages 13 to 18, and was an open unit for voluntary commitment; and,
- Rite of Passage was located in northern Nevada, and was a program for adjudicated adolescents. There was a boot camp model in Schurz, Nevada and an adolescent treatment center model in Yerington, with various group homes in the Minden/Gardnerville area.

Mr. Chapman reported gaps existed, along with the need for additional Level IV residential treatment centers. His organization was constantly asked to expand its services in the area of specialized treatment programs for sexual offenders, as well as dual-diagnosed children. There were also gaps in outpatient substance abuse programs for children and adolescents, along with alternative schools for emotionally disturbed children. Mr. Chapman stated if he could submit a "wish list," he would stress that preventative programs regarding youth violence, and suicide-specific programs be included. Currently, he explained, there were no complete diagnostic and evaluation programs for children ages 9 to 17. A recent study indicated that 20 percent of children in that age group had diagnosable behavior disorders, and only 10 percent were receiving treatment. Another major "wish" would be educational programs for health care professionals, not only at the community college level, but also at the university level. He indicated one of the major problems being encountered was a lack of health care professionals willing to work with children's behavioral health programs.

Co-Chair Freeman remarked that the 1999 Legislature funded a suicide hotline, and agreed that trained health care professionals were needed. She felt that perhaps funding from the Millennium Scholarship Fund could be used for that type of educational service, and suggested Mr. Chapman address the Governor's staff regarding that possibility. Mr. Chapman replied that he certainly viewed that as an option and he would proceed accordingly.

Janelle Mulvenon, Administrator, Community Connections, DHR, indicated one of the programs or grants administered by

Community Connections was the Individuals with Disabilities Education Act (IDEA) grant. That grant was responsible for the implementation of a statewide early intervention system. Ms. Mulvenon declared that she would provide an overview of existing available services for children with disabilities, age birth to 3, and the support provided to the families, (Exhibit O).

Ms. Mulvenon remarked there were several early intervention programs statewide that provided services:

1. The Infant Enhancement Program based in the neonatal intensive care units at Washoe Medical Center and St. Mary's Hospital in Reno;
2. The First Step Program, which provided services in the urban and Las Vegas areas;
3. The Home Activities Program for Parents and Youngsters (HAPPY), which provided services in areas up to 50 miles from Reno, and rural services in the rural northern and northeastern counties; and,
4. The Special Children's Clinic in Reno and Las Vegas, which served the urban areas.

Under IDEA, each state was required to establish an eligibility definition, noted Ms. Mulvenon, and in Nevada a child had to be between birth and 3 years of age and meet one of the criteria depicted on page 3 of Exhibit O. She indicated eligibility would be determined if a child:

- Exhibited a 50 percent delay in one area;
- Had a 25 percent delay in two or more areas;
- Had a diagnosed physical condition and/or syndrome that resulted in a high probability of a developmental delay;
- Had experienced a biological insult that would increase the probability of delay as a result of complications during pregnancy or during the birthing process; or,
- Had a mother 15 years of age of younger.

Ms. Mulvenon explained that upon a determination of eligibility by the multi-disciplinary team, which included the parents, an Individualized Family Service Plan (IFSP) was developed. The team determined what services would benefit the child and increase developmental skills. Part C of IDEA required 17 services be provided and available if deemed appropriate, as outlined in Exhibit O. All services were provided at no cost to the parents. She noted it would be a rare occurrence for one child to receive all 17 services but, obviously, depending upon the complexity of the child's need, more services would be provided.

According to Ms. Mulvenon, the type of personnel involved in the program was delineated by IDEA (Exhibit O), with the number of personnel involved in each case dependent upon the child's need. She advised that early intervention services were provided in a variety of locations including the home, childcare and clinic settings. In addition, the programs were striving to provide services during family routines and activities.

At this point in her testimony, Ms. Mulvenon provided a short video for the Task Force to view; the story of a child named "Jacob," who, with his family and physical therapist worked together to integrate therapy goals into everyday routines, activities, and places. Ms. Mulvenon explained the video emphasized that early intervention services were provided in many locations throughout the community, not just the clinic or childcare setting, or the home.

Included in Exhibit O was information regarding the projected cost of services, however, Ms. Mulvenon cautioned that the information was extremely elementary and very simplistic. Because of limited resources, Community Connections had been unable to break out the various costs, and was unable to factor out the difference between urban and rural costs, the future increased service cost rates, or the number of new families moving into Nevada with children eligible for services under IDEA. Ms. Mulvenon explained that the most conservative birth rate had been used in compiling the information contained in the exhibit.

Ms. Mulvenon noted that one variable remained, and that was the continued increase in the number of children waiting for services. As of January 31, 2000, there were 219 children on the waiting list, and on March 1, 2000, that number increased to 250 children waiting for early intervention services. Ms. Mulvenon acknowledged that the average wait was between 3 to 6 months, and IDEA stipulated that the child and its family must not wait longer than 45 days. The early intervention programs reported high caseloads, which also impacted the quality of services being provided. Under IDEA, the law required utilization of various funding sources, including state and federal funds, and Medicaid. However, advised Ms. Mulvenon, incentives were needed for the recruitment of additional private providers. The Special Children's Clinics in Las Vegas and Reno reported receipt of only an approximately 14 percent rate of return from insurance billings. In summary, Ms. Mulvenon stated the goal of statewide early intervention programs was to enhance each child's ability so they could live a full and rich life.

Gloria Dopf, Director, Special Education, Nevada Department of Education, advised the Task Force she would address the governing structure of special education, funding, demographics, and issues relative to programs for students with autism. According to Ms. Dopf, Community Connections was responsible for the infant and toddler programs, for children under 3 years of age, and once a disabled child advanced beyond that age, the responsibility fell to the Department of Education. She explained the Department had the oversight responsibility for education programs with direct services to the 17 local school districts. It was the entity that received IDEA funds under Part B, the federal funds available for special education, and also administered the state funding for special education.

Funding became a critical framework for specific programs for children with disabilities such as autism. Ms. Dopf indicated the State of Nevada had provided dedicated funding via Special Education Unit Funding through the Distributive School Account (DSA), which were the funds made available to the school districts for operation of programs. The school district, on behalf of the child, received a basic support guarantee, which was part of the DSA and, in addition, each school district received a certain number of units allocated by the Legislature to operate special education programs. Ms. Dopf remarked that those units were defined essentially as instructional programs for the eligible population, along with any related services that population might require. The unit funding funded approximately one-half of the teacher salary. The unit was funded in the amount of $28,000 for the current school year, and $29,000 for the next school year. Ms. Dopf noted that the average teacher salary, plus fringe benefits, was approximately $56,000, so for every unit received by a district, it had to pay an equal amount for the classroom teacher for special education programs. At the current time, stated Ms. Dopf, the school districts had received approximately $56 million for special education units, which meant the districts had to match the amount via their general funds for the program. Ms. Dopf pointed out that IDEA funding was driven by a per-pupil amount, and a count of children served was turned in by the school districts on December 1 of each year.

According to Ms. Dopf, the State and federal programs included all special education children within all disability areas. Autism was one of 10 identified areas within the State of Nevada for federal funding purposes, along with several others, including children with physical disabilities or emotional disturbances. Developmental delay was a category of service where the school district had the option of either identifying the child via one of the discrete disability areas such as autism, mental retardation, et cetera, or if the child was under the age of 6, the district might use a more developmental categorization. The districts received federal funds in the amount of approximately $22 million, or approximately $550 per pupil. The state units were not funded on a per-pupil basis, but were used to run the instructional programs, and the State Board of Education set caseload maximums for the operation of those units according to the different disability areas.

Continuing, Ms. Dopf explained that the December 1, 1999, count of children in the special education programs indicated there was in excess of 35,000 children receiving special education through the 17 school districts, based upon the Individualized Education Plan (IEP). Of those, 327 had specific identifiers as autism in the age group of 3 to 21. Ms. Dopf further explained that by using a developmentally delayed descriptor in the 3 to 5 year old category, 2,392 children were identified as developmentally delayed. For the range of 3 to 8 years of age, there were 212 children identified with autism. The services received by those children were driven by an IEP, developed by a team that included the parents, and identified the individual instructional needs of that child. The IEP also identified what additional services the child would need in order to benefit from the specialized instruction. Ms. Dopf noted that typical related services throughout the programs included:

- Speech therapy;
- Occupational therapy;
- Physical therapy;
- Specialized psychological assessment; and,
- Medical assessment, if deemed necessary for educational decision-making.

Ms. Dopf indicated it had been known for many years that children with autism created a unique challenge for school systems and other service systems that worked with meeting the needs of those children. In order to plan for Nevada, the Department of Education entered into a joint effort with Community Connections, to put together a broad-based task force to review the issue of improving services for students with autism. Ms. Dopf indicated she would be happy to supply a copy of that report to the Task Force for the Fund for a Healthy Nevada for review by members. In January 2000, that task force published a report that identified programming issues for children with autism across the spectrum of services provided by both agencies, as well as the direction in which the State should proceed for improvement of services. Both agencies had agreed upon an action plan, and were working toward fulfillment of those commitments. Subsequent to the task force, the Department developed a model program application for IDEA Part B funds specific to early childhood. Ms. Dopf reported the Department provided a minimum of $100,000 per year on a 3-year cycle to school districts, on a competitive basis, to apply for a program of improving services to children with autism. It was required that the project use a research-based approach, however, the Department did not specify which model; parental participation was also a required component, along with a training component. The Department also required that it have an opportunity to view model sites.

According to Ms. Dopf, Clark County, Washoe County, and Carson City school districts were the recipients of those funds, and were in the second year of the cycle. Each of those districts developed models unique to its method of structuring programs. There was also an evaluation component to the project, in order to evaluate the success. Ms. Dopf stated the Department hoped that from those model sites, it could replicate what worked best for students throughout the state and provide additional funding from the "pot" of money that had been set aside from the federal grant. The Department also allocated "mini" grants of $500, available per teacher to purchase articles that might not be budgeted, but would assist them in the success of their program. Ms. Dopf stated during the current school year, there were five districts participating in that program.

Ms. Dopf noted that the Task Force had heard previous testimony about the many needs of children, the needs of children with autism, and the fact that those needs were not being met. She advised that the Department was working toward improvement of services, and not every specific model was available in every locale statewide. In the rural areas, where there might be only one child with autism, it was difficult to structure a program viable for that child, while continuing to maintain the other programs. While the Department provided consultants to those districts for advisement, Ms. Dopf noted there were still significant needs.

In conclusion, Ms. Dopf wished to explain some of the needs identified by the Community Connections and Department of Education's Autism Task Force regarding the needs of children with autism that had not yet been initiated. One was the concept of wrap-around services for the child, no matter what the age. She explained service systems were not necessarily developed to "wrap" the services around the child's needs, but rather each individual agency provided an individual service. Another was to provide the intensity of services needed for some of the models, such as the discrete trial analysis, which had been discussed in relation to autism. Ms. Dopf remarked those were some of the types of services that did not lend themselves well to a school district service system, or the systems available in rural locales. A more intensive system was needed, both in terms of training and availability to match services with the child's need. She felt there was also a need for additional services categorized as emergencies by the parents, whether it was respite care or other emergency services.

Co-Chair Freeman instructed Ms. Dopf to provide the Task Force with a plan of what it could do to assist State programs, given the funds it had available. Ms. Dopf indicated she would provide that information.

David Luke, Ph.D., informed the Task Force he worked within the Developmental Services area of MHDS, and provided a packet to members, Exhibit P. Dr. Luke explained Developmental Services had a budget of approximately $48 million to provide services to persons with mental retardation and related conditions. Those were persons who very often had problems from birth or very early in life, which caused difficulty in learning and created the need for various assistance and support throughout their lives. He indicated Nevada Developmental Services had regionalized its service system and provided services through three regional centers:

1. Desert Regional Center, Las Vegas;
2. Sierra Regional Center, Washoe County; and,
3. Rural Regional Center, Carson City, with outreach offices in Elko, Fallon, and Winnemucca.

According to Dr. Luke, Developmental Services provided service coordination by assisting a person in qualifying for, and arranging receipt of, needed services. Those services might consist of respite care, job or day training activities, or residential assistance. MHDS also worked with Medicaid and there was a specific Home and Community Based Waiver available for persons with mental retardation and related conditions; that waiver would provide funding for up to 1,000 persons throughout the next approximately 2 years. Currently, there were approximately 800 persons enrolled in that waiver and receiving services.

Dr. Luke stated that during the last two sessions, both the Legislature and the Administration had been extremely helpful in addressing some of the waiting list needs occurring in the service system. During the 1997 session, an initiative for family support was presented, and funding was received in the respite care area, along with funding for a program entitled Family Preservation Fund. During the 1999 session, Dr. Luke indicated there was a major emphasis on providing funding for the waiting list for residential placement. Funding was provided for 210 new placements, which were currently being phased in and would continue throughout the current biennium.

According to Dr. Luke, the range of disabilities and the range of services required individualization for each participant. For example, a person with "profound" mental retardation might need constant attention and medical involvement; a person with "severe" mental retardation might need constant supervision throughout his life; and, a person with "mild" mental retardation might hold a job, but require assistance on a part-time basis with such things as budgeting his income and payment of bills.

The challenge to Nevada Developmental Services was to individualize services, and the outcome measure was whether or not a person continued to function in the community setting. The goal was to avoid placement in facilities if at all possible. Dr. Luke noted that care in intermediate care facilities for persons with mental retardation cost from $200 to $350 per day, and considering that service for the lifetime of a person would be several million dollars.

Dr. Luke indicated there were 2,466 persons currently in service throughout Nevada, and of those, approximately 24 percent were children. He noted Developmental Services was seeing an increasing trend of children becoming a higher proportion of the service population. Everyone in the service system received service coordination, and Dr. Luke noted there were 474 families receiving respite funds of approximately $1,000 per year to purchase relief or respite care in the home, which would equate to 100 hours of respite service at $10.00 per hour.

Ms. Buckley asked if there were non-profit organizations that provided housing and supportive services for individuals with developmental disabilities in a smaller setting that was institutional in nature. Dr. Luke replied of the 954 individuals in residential care, 85 percent were under private arrangements, either in a group home setting, an intermediate care facility located in the community that was six beds or smaller, or in the home setting with a private provider assisting at whatever level was needed. He advised that some persons shared homes and private providers. Ms. Buckley then inquired what non-profit organizations were active in that area, owning small facilities. Dr. Luke commented there were probably cases where non-profits owned or leased facilities. He advised there was an organization entitled Trinity Services that operated intermediate care facilities in northern Nevada, and there were several for-profit organizations, such as Educare, which provided services throughout the state; Danville Services, which worked from the State of Utah and was operational in the Las Vegas area; and, the REM Organization, that provided service in both northern and southern Nevada. Dr. Luke advised that Disability Resources was also a non-profit organization, however, it did not provide intermediate care, only in-home care.

Ms. Buckley commented that the Task Force was just beginning its struggle to determine what programs could be funded in order to make the most difference, while not duplicating current State funding efforts. She indicated that she worked with non-profit housing providers for homeless women and children, and working individuals attempting to get "back on their feet." The city and county committees that provided grant funds would give the non-profit organizations $100,000 grants to purchase housing, such as a four-plex building, which could be renovated and used for supportive housing. It did not pay for any other services, but at least it relieved the non-profit organization of a lease payment, which was a start in attempting to expand services. Ms. Buckley questioned whether that model might provide any guidance in the Developmental Service area. Dr. Luke remarked there might be cases where the model would provide guidance, and noted that day program service providers were almost entirely private, not-for-profit. He stated Developmental Services had been attempting to focus on client choice and had not asked providers to acquire additional facilities, so the client could have a choice of where to live, and also be able to move and not feel encumbered by the provider.

In terms of the services provided by Developmental Services, Dr. Luke indicated the State had a plan in place and was progressing to the stage of providing the services that would normally be accepted, such as services funded by Medicaid and matched by state funding. There was one other program approved by the Legislature several years ago called the Family Preservation Fund. That fund provided a direct grant to families that cared for a profoundly or severely disabled family member at home. Currently, he noted there were approximately 200 individuals receiving that grant of approximately $300 per month, and he felt it might well be one of the most cost effective programs offered by the state. Every one of those individuals would qualify for residential care from the state, which would essentially cost $300 a day, rather than $300 per month.

Co-Chair Freeman asked Dr. Luke to identify the amount of money that would be required if the Task Force decided to help in the area of the profoundly or severely disabled. Dr. Luke indicated he was unsure of the amount, as it would be somewhat of a new program. The existing program operated on a fixed amount of money each fiscal year, and that money was divided among all families that met the qualifications, with no strings attached. Unlike Medicaid funding, the grant funding could be used by the families for whatever purpose they saw fit. Dr. Luke felt that Nevada might face some very demanding future financial burdens in the area of the profoundly and severely disabled, because there was currently a very low utilization rate in the expensive care programs, and the more that could be done to support families and maintain community integration in a satisfactory manner would be wise.

Ms. Brower asked whether the funds from the Family Preservation Program were allocated to families that were keeping a member at home who might otherwise be in an institutional setting. Dr. Luke replied in the affirmative. Dr. Fildes stated that the Task Force would like to challenge non-profit and private organizations, along with governmental agencies that served the same population to come together and decide the best method to invest the limited resources available to serve the clients. Dr. Luke indicated MHDS would be glad to participate in such a venture.

Brian Lahern, Ph.D., Executive Director, Washoe Association for Retarded Citizens, Incorporated, indicated he represented the perspective that had been developed over several years by a coalition of virtually all the providers of developmental disability services within Nevada, and provided Exhibit Q to the Task Force.

Dr. Lahern pointed out that developmental disabilities were one of the areas of disability in which there was a direct connection between smoking and the disability. A study by the National Centers for Health Statistics, along with the Rollins School of Public Health at Emory University, identified the fact that there was a 50 percent increase in the prevalence of mental retardation among mothers who smoked during pregnancy. According to Dr. Lahern, children whose mothers smoked at least one pack a day during pregnancy had more than a 75 percent increase in the occurrence of mental retardation. He noted mental retardation was but one of a number of different developmental disabilities. Autism was one of the disabling diseases, however, physical disabilities were included, as were disabilities that occurred as a consequence of something genetic that went wrong during pregnancy, or a problem that occurred immediately after birth. He stated three of every 100 live births were children with developmental disabilities that would require some degree of public support in order to maintain themselves in as independent a manner as possible for the rest of their lives.

Dr. Lahern noted that previous testimony indicated there were 35,000 children with developmental disabilities in special education programs in the State of Nevada, and indicated the school system was identifying approximately 1.8 percent of the children in need. He indicated .15 of 1 percent of the national incidence figures was being served by mental health and developmental services. The last two legislative sessions had been supportive in the area of mental health and developmental disability services, however, that assistance had not been as effective as anticipated, and the job was nowhere near done. Dr. Lahern noted that in 1996, Nevada was 51st in the nation in the overall level of funding for people with developmental disabilities. At that time, it was suggested that if the amount of funding received by Nevada was doubled in the area of developmental services, it would still leave the state in 51st or 50th position, behind the State of Mississippi and the District of Columbia.

According to Dr. Lahern, he mentioned the connection with smoking, not because he felt developmental disabilities deserved more support, but rather to bring to light the fact that the developmental services area was the most poorly funded service in the nation, even though it was better funded than other disability service areas. He indicated the Washoe Association for Retarded Citizens attempted to identify those critical needs and the support available for services. The Association paid out $1.2 million a year for services to persons who needed vocational training to assist them in becoming independent in the community. Dr. Lahern advised the Association received State funding in the amount of $503,000, and had to develop other funding sources for the additional $700,000 in order to provide the services that disabled persons could legally demand and receive from the State at a cost vastly in excess of the $503,000. That notwithstanding, Dr. Lahern reported the last three legislative sessions had not produced a rate increase for providers in the community, and he felt Nevada was now in the process of destroying the very system that was a model of the type of services that should be provided for persons with needs in the community. He emphasized that the Association's programming was efficient, and cost-effective, and also noted the State's role in providing oversight and flow through funding was appropriate.

Continuing, Dr. Lahern stated he felt the Task Force needed to look at services such as the Family Preservation Program and respite programs. Those were services where the natural inclination of the family to provide support could be enhanced by the services available through the Association, at the lowest possible level of State financial involvement. He indicated in the Family Preservation Program, persons who were willing to provide care to seriously disabled family members were identified, and given funding to spend in the manner they felt was most important in keeping the disabled family member out of an institutional setting. That same principle, explained Dr. Lahern, applied to respite care. That issue was so critically important, because most families wanted to keep their disabled family members at home, however, those caretakers often suffered "burnout" and needed respite care.

Dr. Lahern remarked the decision of whether Task Force action would be supplanting or not supplanting to State funding was difficult to determine. He asked if the Task Force felt it would be supplanting if it funded a service that was available under Medicaid, but not available to those not eligible for Medicaid benefits. He would argue that any service not currently in existence and not funded with State money could be supported by the Task Force without supplanting. He suggested the Task Force review the respite care area, noting that such care existed in small pockets throughout Nevada and needed centralized organization; he felt there was also a need to provide training for respite care providers.

Dr. Lahern suggested the establishment of a "clearinghouse" or centralized location for persons with disabilities, which would also provide data collection to reflect where needs existed. Because such data was unavailable, the needs were constantly underestimated. Dr. Lahern remarked that even with the fine data-gathering capacity of MHDS, the waiting list for developmental disability services had not been eradicated, even though MHDS was accepting clients as rapidly as possible. He reiterated the State simply did not have a handle on expansive data collection, and if there was a "clearinghouse" for disabilities, which was somewhat removed from the politics of budget development, a real picture of what was available could be developed, leading to rational decisions by the Legislature regarding funding.

Dr. Lahern stated that A.B. 280 of the 1999 Legislature was a bill which directed there be positive behavioral supports for children in the school system, and included a comprehensive method of providing training for persons in that area. Unfortunately, the bill did not include the funding for that training, and his Association, along with Opportunity Village, had put forth approximately $10,000 to bring in qualified persons to provide a 3-year training program in positive behavioral supports. That program was training a team of persons from the school districts, from local providers, and from developmental centers. The State, he emphasized, was not funding any portion of that program. A centralized organization would create a way for families to access those providers. Persons who contacted the system seeking assistance found that often the system did not even know how to contact itself, i.e., Medicaid would be unable to provide information regarding other available services. Dr. Lahern noted that agencies seldom talked to each other and the result was there was no place to access the availability of full-menu services, or even a starting point, because that information was not readily available to the consumer. He suggested the focus of the "clearinghouse" could be something such as a web site on the Internet that contained all information from the various State agencies. Such a site would allow a person to contact one agency that could provide all the necessary information via such a web site.

Continuing, Dr. Lahern indicated if there was an attempt to honestly build a system, it should include a method to preserve the system currently in existence at all levels, and not let it fall apart because of lack of support from the State. His association actually subsidized the State, rather than being a consumer of raw State dollars with no benefits returned. There should also be an emphasis on the type of services that kept persons with their families via the use of such as a voucher program. He noted 100 hours a year of respite services was 2 hours per week for families who might not have had such freedom in the past several years.

Dr. Lahern noted that Mr. Sasser had been quite correct in his statement that Nevada did not maximize its Medicaid draw, which was a place the State could secure federal dollars for 50 cents on the dollar, and questioned why the State would not draw every federal dollar it possibly could. He noted other services certainly exercised that option, and felt it should be policy that the State drew federal funding to the maximum in the disability services area. Finally, Dr. Lahern commented Nevada was the worst state in the nation in terms of funding for disability services, and many other states had been the victim of large class action lawsuits which forced those states to provide the appropriate services. Nevada had been awakened to the possibility of lawsuits, and the waiting list issue had been addressed during the 1999 Legislature. He felt the State needed to do more in that area, and perhaps lawsuits might be the answer if action was not taken in a proactive and consciously humane manner on behalf of the citizens with disabilities.

Co-Chair Freeman inquired if the coalition was still in existence. Dr. Lahern indicated the coalition did still exist as an organization, however, had not met since the last legislative session. Co-Chair Freeman stated she became familiar with the coalition during the previous interim, and felt it was because of that coalition that funding had been brought forward for the mental health system. Dr. Lahern remarked there was a Legislative Mental Health Task Force in southern Nevada that worked closely with the northern Nevada coalition.

Jeff Engelke, explained Educare was a private, for-profit agency that served individuals on a statewide basis. He presented Exhibit R to the Task Force and referenced the chart contained therein regarding the State fiscal effort rankings, which depicted Nevada in 51st place. Mr. Engelke stated there had been some effort by the Legislature in past years to address the issue of developmental services, however, it was not difficult for agencies to arrive at a needs or deficiency list. Exhibit R contained specific examples which would help the Task Force form a clear picture of the issue. He indicated the existing service establishment was inadequate and it would be an admirable goal to augment that service area. He noted the Task Force would be financially unable to effectively address all the needs it was presented, and would be required to prioritize those needs. According to Mr. Engelke, Educare felt rate increases, training, a children's residential treatment facility, and sex offenders unit were all areas of critical need for Nevada, and were absent from its service delivery system. He recommended the Task Force address the respite care issue, and provide funding in an effort to make a difference to families who needed that service. Mr. Engelke stated Nevada should not be ranked in 51st place in every area, and hoped the Task Force would select an area to fund that would make a difference to persons impacted by need for those services.

Dr. Stephen McFarlane, Chairman, Department of Speech Pathology and Audiology, University School of Medicine, informed the Task Force he would represent the Dean of the Medical School, Dr. Robert Miller. He introduced his colleague, Dr. Jeffrey Elias, Associate Director, Sanford Center for Aging, located on campus at the University of Nevada, Reno. Dr. McFarlane explained the Sanford Center was established via an endowment of approximately $11 million, and worked with the geriatric element of the population.

According to Dr. McFarlane, under Dr. Miller, the School of Medicine was a statewide institution with clinical operations in northern and southern Nevada, along with rural outreach programs. It was an institution that worked to help educate physicians and other healthcare providers throughout the state, and provided backup and specialty information for treatment of various types of disorders. He indicated he would like to give the Task Force an example of the School of Medicine's capabilities:

> The institution was presented with a child who was diagnosed with a relatively rare neurological disease which occurred during the first 10 years of life, and limited the lifespan to approximately age 20. It was a disease that progressed rather rapidly through the motor control system and the child lost his ability to walk and the ability to speak because his vocal cords became paralyzed. The School of Medicine worked with a number of agencies, the school system, the Department of Education, Developmental Disabilities, and a number of other agencies to create a system for the child and educate him in the use of the system, which would allow him to continue in school. His parents were also involved in learning to work with the system, along with the teachers, in order that the child could maximize his educational experience and quality of life for the time he had. It was an extremely successful project.

Dr. McFarlane explained there were a number of other neurological diseases that "fell through the cracks," and needed more services than those provided by the school system alone. He remarked that it took interaction to make such projects successful and help ameliorate the tragedy of those types of disorders and diseases.

Another area of concern, noted Dr. McFarlane, was fetal alcohol syndrome, which was a little known area a few years ago. That syndrome had become a major cause of hearing loss and other types of developmental disability in children. He emphasized the need to pull together some existing programs, and the School of Medicine would propose a Chronic Disease and Disabilities Management Program, which would build on existing programs within the State and expand those services to include those persons who "fell through the cracks." There were a number of individual success stories, however, Dr. McFarlane indicated that should become the rule rather than the exception. He stressed again that the School of Medicine went through the entire spectrum from pediatrics, to the middle years, to geriatrics.

Co-Chair Freeman indicated there were Task Force members who were involved with the Medical School, Dr. Fildes and Dr. Ellerton, and suggested perhaps they could assist with any future presentations regarding the proposed program.

Dr. Elias submitted Exhibit S, which he explained was a report that detailed the framework for understanding disability and aging in Nevada. He stated the report was organized around the idea developed by the MacArthur Studies of Successful Aging, where it was pointed out there were three key factors involved in probability of disability as a person aged:

1. The impact of disease, or several diseases at once;
2. The impact of lifestyle factors, exercise, diet, health habits; and,
3. Naturally occurring, age-related physiological changes.

In an attempt to secure an indication of how well Nevadans were doing in each area, Dr. Elias stated he reviewed several national databases for statistics. The exhibit depicted the age-related causes of death from the National Vital Statistics Report, which pointed out the impact of disease in Nevada. It also contained information from a report by the National Center for Chronic Disease, Prevention and Health Promotion, which reviewed 21 targeted health behaviors around the nation and specific to Nevada.

Referring to Exhibit S, Dr. Elias noted the report provided the following estimates with respect to factors that contributed to health:

- Access to Care (10 percent);
- Genetics (20 percent);
- Environment (20 percent); and,
- Health Behaviors (50 percent).

With respect to age-adjusted causes of death, Dr. Elias reported the major causes of death were determined to be heart disease and cancer, with Nevada on par with the rest of the states with respect to the death rate. Nevada did, however, stand out with respect to Chronic Obstructive Pulmonary Disease (COPD) at 1.46 times the national rate, and death from chronic liver disease at 1.7 times the national rate. What Dr. Elias claimed was of particular interest, and perhaps alarming, was that with respect to death by accident and adverse effects, Nevada was 1.21 times the national norm; injury by firearms 1.84 times the national norm; led the nation in suicide at 2.08 times the national norm; death by motor vehicle accident, 1.356 times the national norm; and, homicide and legal intervention, 1.36 times the national norm.

Continuing, Dr. Elias noted in terms of behavioral risk in disease, Nevada was above the national norm on 11 of 21, and in particular was alcohol consumption, where Nevada was at 62.9 percent while the median was 53.5 percent in number of individuals reporting consumption of alcohol. Nevada was 1.92 percent and the nation was 14.4 percent in numbers of individuals reporting binge drinking, and was 27.8 percent with the national median at 23.3 percent in numbers of individual smoking cigarettes. Dr. Elias commented if those behavioral measures were combined with the death rates, the high rate for death from liver disease and COPD was not surprising, however, it was not quite clear why the death and disability rate was so high from accidents. He pointed out that the exhibit contained a discussion regarding depression and how that related to chronic disease. Some estimates concerning older individuals suggested that by the year 2010, the impact of depression would be the same as the impact of cancer with respect to disabilities. Because of the high rate of suicide in Nevada, Dr. Elias indicated it was an area that required attention.

Co-Chair Freeman stated Exhibit S was very interesting, and hoped the Task Force could assist in the various health issues such as suicide and binge drinking. She asked Dr. Elias to provide specific information regarding the role the Task Force could play in those areas. Dr. McFarlane indicated a suicide study group had been in existence in southern Nevada for approximately 1 year. The information gleaned from that group would be helpful for use in an intervention program, which was his meaning regarding the possibility of building on existing programs. The Sanford Center was making great strides in working with the community in terms of helping the geriatric population reach possible potentials.

Co-Chair Freeman then asked Charlotte Crawford, Director, DHR, to report on Medicaid coverage and waivers regarding services to persons with disabilities. Ms. Crawford reviewed Exhibit T, a report entitled "Department of Human Resources/Nevada Medicaid/Individuals with Disability," which was an overview of Nevada Medicaid as it pertained to the disabled. Referencing the exhibit, she explained of the total 98,839 individuals covered by Medicaid in FY 1999, 19,841 were individuals that were determined to be disabled, which represented 20.1 percent of the caseload. Of the total $455,758,797 expenditure, $185,018,955 was expended on individuals who were categorized as disabled, or 40.6 percent of the expenditures.

Continuing, Ms. Crawford explained the exhibit contained a chart that reflected the trends in enrollment of individuals who were disabled. From FY 1993 at 13.3 of the Medicaid population being composed of individuals with disabilities, to FY 1999 at 20.1 percent in the same category, which indicated an increase in the percentage of the Medicaid caseload that was disabled. Ms. Crawford stated over that time frame there had also been reductions in the growth pattern of the overall caseload, with expenditures in FY 1993 at 36 percent for individuals who were disabled, and in FY 1999, that figure was 46.6 percent. In FY 1993, the average annual expenditure per disabled recipient was $10,097, which decreased to $9,325 in FY 1999. What became clear was that what was driving the increase in cost was not the per-individual cost for disabled recipients, but rather the increase in the number of enrollees.

According to Ms. Crawford, the questions regarding Medicaid were: (1) who was disabled; (2) what did "disabled" mean; and, (3) how was "disability" defined. She called attention to the fact that the rules were different for aged, blind and disabled individuals. Disability was basically determined by the Social Security Administration, however, mandated for Medicaid coverage were individuals who were determined disabled and received SSI benefits. Ms. Crawford indicated the actual administration and SSI rules regarding adults and children, and what the disability determination contained, were attached to Exhibit T. She explained that for an adult, the law defined "disability" as:

> "The inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, you must have a severe impairment, which makes you unable to do your previous work or any other substantial gainful activity which exists in the national economy."

For a child, the definition was:

> "If you are under the age of 18, we will consider you disabled if you have a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitation, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months."

Ms. Crawford explained there were a great number of procedures, definitions, and actual lists of impairments that were not contained in the exhibit, however, one of the important characteristics of a disability determination was that regardless of a person's medical, physical, or mental condition, if that person was working and gainfully employed, or a child engaged in gainful activity, he could not be determined "disabled."

Per Ms. Crawford, there were several categories regarding determination of disability, which included SSI clients, or those living in the community who would be deemed eligible for SSI should they apply. That definition would include a person who met the disability requirements, but had some characteristic regarding income or resources that prohibited receipt of SSI benefits. She further explained that the medical facility clause, commonly referred to as "institutional cases," were those cases in which an individual, by virtue of meeting the criteria for admission to an approved medical facility, was determined to be disabled. Those were the two primary eligibility determinates, and the Katie Beckett Program was for families, regardless of income, who had a child that met the disability determination, and who would otherwise have to be served in a medical facility, but was being served at home. Nevada Medicaid required those families to participate in some payment for that program. The home and community based waiver recipients were those eligible persons who had income up to 300 percent of SSI and were eligible for, or might be housed in, a medical facility, but who could reside in the home with specialized care for less cost.

Ms. Crawford went on to describe the benefits and/or services covered by Medicaid as depicted in Exhibit T. She stated the exhibit indicated the expenditures on behalf of individuals who were categorically disabled, and described the population associated with the Nevada Service Delivery Systems. By virtue of the definitions as quoted above, Ms. Crawford indicated any individual with a medical impairment that rendered them unable to work could be qualified under Medicaid, and many disabled individuals on Medicaid caseloads were not from a recognized group, but might have some other type of medical condition. It should be noted that approximately 64 percent of the expenditures were accounted for by individuals who were disabled and living independently in the community, rather than an institutional setting. Ms. Crawford explained the various Medicaid covered services available on behalf of disabled eligibles, as defined in the exhibit. Also addressed were the expenditures for services targeted to the treatment of a disabling condition without regard to qualifying eligibility category.

As indicated in Exhibit T, Ms. Crawford noted Medicaid expenditures for those individuals in intermediate care facilities for the mentally retarded was close to $30 million, and the majority of those individuals were categorically disabled by virtue of admission to a medical facility. Case management expenditures of $9 million were made on behalf of seriously mentally ill individuals, seriously emotionally disturbed children, developmentally delayed children, and individuals with mental retardation or delayed conditions. Not all expenditures in case management were for individuals that were disabled, however. Ms. Crawford explained individuals did come to services that were targeted to a disability, but who might not be categorically disabled.

According to Ms. Crawford, a residential treatment center was a "step-down" inpatient psychiatric service for children, and less than half of the expenditures in that category were for disabled children. The home and community based waiver program provided home and community based services to individuals with mental retardation and related conditions, who were categorically disabled. Ms. Crawford remarked that Medicaid did participate with local school districts in the payment of Medicaid for qualified students in the receipt of special education support services. She noted school districts provided the matching dollars; there was a great deal of opportunity to bring in federal funding in the special education area. The exhibit also contained categories for psychiatric hospital inpatient and rehabilitation hospital inpatient expenditures. Along with the programs supported by Medicaid, there were additional service areas associated with disability groups that were also supported by Medicaid, which was a substantial payment source for low-income, handicapped, and disabled individuals.

Ms. Crawford stated the waiver programs included the Home and Community Based Waiver for persons with mental retardation and related conditions. It was for individuals who would require the services of an intermediate care facility for the mentally retarded, were it not for the availability of those community services offered by the waiver program. That was the most evolved of the four waiver programs, and was the first developed in Nevada. It was a very extensive, well organized, and well-funded program which had evolved over the years as an extremely effective alternative to institutionalization. There were 798 persons served by that waiver, and 256 on the waiting list, with an average waiting period of 10 months. The waiver program also provided services for persons with physical disability; it was the youngest of the waivers and the least developed, currently serving 113 persons. That waiver only covered three service areas at the present time: (1) Case management; (2) Homemaker services; and, (3) Personal emergency response. The waiver for persons with physical disabilities had been revised and submitted for approval. Services would be added and additional individuals would be served. Ms. Crawford commented there had been a great deal of testimony from individuals with physical disabilities regarding their needs, which was an area where the waiver program was the least developed, and faced the biggest challenges. Without community based services, individuals in that category would be at risk of long-term care placement.

Co-Chair Freeman then opened the "Public Comment" portion of the agenda, beginning with those persons wishing to testify from Las Vegas.

Dr. Maury Astley, Executive Director, Nevada Dental Association, stated he represented 85 percent of the dentists in Nevada. Dentists were involved in several programs where they donated their time, such as the Donate a Dental Service Program, where 87 dentists had agreed to help disabled patients who did not have insurance or Medicaid coverage. Often, such programs aided persons seeking employment, because of the resulting improvement in their appearance. He indicated dentists also donated time to children's programs, such as the "Miles for Smiles" bus program in the north and south.

Dr. Astley stated the Nevada Dental Association and the American Dental Association were keeping abreast of the programs being funded in other states with tobacco settlement money. One area that needed additional funding was oral health, and the problems caused by use of tobacco, particularly the use of "spit" or "chew" tobacco products. Dr. Astley indicated when people stopped smoking cigarettes, they often turned to "spit" tobacco as an alternative, and some youth viewed that as a "macho" practice. He felt it was an area where real problems were developing. He commented the Dental Association would like to see some money earmarked for education for both school children and adults. According to Dr. Astley, the Nevada Dental Association would propose a grant to produce brochures that depicted the dangers of tobacco product use, and which could be handed out in dental offices and schools.

Mr. Mestre inquired whether or not most dentists accepted Medicaid patients. Dr. Astley replied that there were a number of dentists who handled those patients. Recent reports indicated approximately $12 million was being spent on Medicaid patients.

Jan Crandy informed the Task Force she was the parent of a child who suffered from autism. She stated she had spoken before the Legislative Committee on Health Care, asking that committee to draft legislation relative to autism, as it was an underserved population within the State of Nevada. According to Ms. Crandy, autism affected 1 in 500 children and was on the rise. She noted Nevada was very short in the area of available programs. Autism was the third most common developmental disability, even more prevalent than Down Syndrome, and Ms. Crandy noted that earlier testimony by Nevada Early Intervention Programs indicated there were no behaviorists available in Nevada. Autism was a disease that affected a child's behavior and communication skills, and there were 236 school age children in Nevada suffering from the disease. She felt Nevada should sponsor an autism awareness campaign.

Senator Rawson advised if there was language Ms. Crandy wished to see incorporated in the proposed legislation, she should provide that information to the Task Force so it could be forwarded to LCB. Ms. Crandy asked if autism could be placed on the agenda of future Task Force meetings for consideration of tobacco settlement funding. Senator Rawson advised the Task Force would give her request serious consideration.

Ms. Crawford presented Exhibit U, a description of the Senior Prescription Program to the Task Force, and explained that was the program identified for 30 percent funding in A.B. 474, which included the directive to the Department of Human Resources (DHR) to construct the program. The Request for Proposal (RFP) for the program had been released and much of the basic structure of the program was included in NRS. She explained that any individual aged 62 or older, who had been a Nevada resident for a period of at least 1 year and was not eligible for Medicaid, would be eligible for the prescription benefit based on income level requirements. Benefits were based on a sliding scale, as identified in Exhibit U, and were available to individuals with an income level of up to $21,500.

Ms. Crawford indicated different income categories qualified for a different percentage of subsidy for payment of the premium. The maximum allowance was $40 per month, because the maximum amount the program could provide in subsidy was $480 per year per individual to support the purchase of prescription insurance. Currently, noted Ms. Crawford, there was no stand-alone prescription product insurance available, and the RFP indicated a sole statewide provider of senior prescriptions and pharmacy services insurance product would be selected. The RFP's would be evaluated on the overall best value, considering such issues as the formulary, the availability, the accessibility, emergency services, response time, and the availability of physicians able to prescribe medication. Also taken into consideration would be the length of time it took to deliver medication and the policy regarding out-of-state service.

Ms. Crawford offered to provide Task Force members with a copy of the RFP. In addition, she noted coverage would be provided for no more than 10,000 seniors, given the cap of $480 per year, even though there were more than 10,000 seniors within the income categories. She explained that open enrollment would be offered once per year, and the subsidies would be awarded from the lowest income level up to the maximum until the available funding was exhausted. Once a senior qualified for the program, they would remain so unless they failed to pay their portion of the premium or lost their qualification for some other reason. The DHR was charged with determining eligibility, and proposed to conduct the eligibility determination on a self-declaration with an audit of the declaration, because of the receipt of a substantial number of applications within a very short period of time. The Department had also set up a process whereby it could interface with the Department of Taxation and county assessor's offices, in order to insure a coordinated application, because those agencies offered similar programs to similar target groups. All agencies involved worked together in the development of the RFP process and continued to work on the application and processing. Ms. Crawford indicated there was also coordination with the Medicaid program because individuals who might be qualified under those programs, might also qualify for the prescription program. DHR was making every effort not to duplicate requested information as it attempted to process the applications.

Ms. Crawford stated once an individual was determined eligible, the contracted insurance provider would be given the names in order to work in recruiting the individuals into the program, and the individual would have to make a decision whether or not they wanted the product, along with whether or not they could afford the premium cost above the allotted subsidy. She reiterated the maximum was set by statute, and DHR could not exceed $480 per year per individual. Once a person was signed up for the program, DHR would pay the insurance provider the state's portion of the premium to subsidize each approved recipient on an ongoing basis.

Mr. Mestre inquired when the RFP's had been sent out; Ms. Crawford replied they were sent out March 17, 2000, and on April 11, 2000, the letters of intent were due back. She stated the process was being handled as rapidly as possible, because DHR realized the need for the subsidy. Mr. Mestre asked if DHR was going to "dovetail" with other agencies, and noted when his mother was alive, she filled out many forms that required review by several persons for her bills, which were approximately $550 per month, with her income level being approximately $680 per month. Ms. Crawford indicated DHR was attempting to set up a technology system or data system in order to provide maximum interface with other related agencies.

Dr. Ellerton asked how many RFP's had been sent out by DHR. Electing to respond was Debbra King, Administrative Services Officer, DHR, who indicated approximately 36 RFP's had been distributed to those agencies on the mailing list provided by the State Purchasing Division, and 1,600 letters or synopsis of the RFP had been sent to insurance companies licensed to conduct business in the State of Nevada so they would be aware it was available. Dr. Ellerton asked for clarification regarding the issue of physicians who would prescribe the medications, and was it suggested that certain doctors would be excluded from writing prescriptions for seniors under the program. Ms. Crawford stated that was not the intention of DHR, and what was proposed was to insure compliance with the Patient Protection Act, and to evaluate the ability of the physician to be able to prescribe the needed medications.

Co-Chair Freeman stated she was interested in the formulary, and felt that the type of medications used most frequently by persons over the age of 62 should be reviewed, to determine how those medications would coincide with the available funding. Ms. Crawford advised that evaluation of the formulary was part of the overall evaluation of the RFP, in order to ensure that an appropriate array of medication was made available. Co-Chair Freeman then asked who reviewed the RFP. Ms. Crawford replied there was an evaluation team from the various agencies such as DHR and the Insurance Division. Ms. King noted in addition, the pharmacist from Medicaid would be responsible for review of the RFP's, along with a representative from the Public Employees' Health Plan. Dr. Ellerton requested that a practicing physician also review the RFP's, because in a number of managed care programs, certain prescriptions that were normally not on the formulary had been carved out in order to keep patients out of the hospital setting because it was better therapy, et cetera. He emphasized that senior recipients should not be locked into an extremely strict formulary, and noted at times physicians negotiated with the managed care companies. Ms. Crawford concurred, noting that was an excellent suggestion, which DHR would follow, as it had that experience in the Medicaid programs from both the provider and payer aspect.

Co-Chair Freeman emphasized the fact that the program was for persons from age 62 upwards, which she hoped would be factored into the consideration. Ms. Crawford remarked that in the development of the proposals, the projections, and the evaluations, DHR would be extremely sensitive to changes in insurance costs and prescribing practices for persons from the age of 62 upwards. Co-Chair Freeman then asked if the programs would also approve the use of generic drugs. Ms. Crawford noted that the statute mandated prescription drugs, however, it could be assumed that the RFP's would include some generic medications, and possibly some non-prescription but commonly used medications. Co-Chair Freeman noted there was discussion in the U.S. Congress regarding health care reform, and possible funding for senior medications, and asked if there was information available from the federal agencies. Ms. Crawford stated the President discussed a pharmacy component under Medicare, however, that was not approved last session, and had been proposed again during the current session. All indications from the sectors involved were that the program would have a much higher probability of some success in a modified form. She assured that DHR was tracking proposed legislation, because what might be done in the Medicare program could be of great interest to the state.

Co-Chair Freeman then invited persons in the audience in Carson City to approach the Task Force and present testimony.

Dee Dee Foremaster, representing the Carson City Center for Independent Living, explained she was a Resource Specialist, and knew how the systems worked. She stated she was the only Resource Specialist available in a multi-county area, Carson City, Douglas County, Storey County, and Lyon County. Ms. Foremaster indicated she was not present to speak on behalf of the Center, but rather would speak on behalf of persons with disabilities within her community. She was the person “in the trenches” and knew about the gaps that existed in the system. Ms. Foremaster advised there were persons with her who had suffered the problems caused by those gaps. She felt major gaps existed in the area of medical assistance, and one of the waiver programs for persons with disabilities had 2-year waiting lists. Ms. Foremaster advised that respite care was desperately needed, and she could not express the extreme need in that area. She knew of at least two persons who could not attend the Task Force meeting because there was no respite care available. Further, she noted the in-home services for persons from age 18 to 65 were completely lacking, and the housing situation was also deplorable. She introduced David Sorensen, who would discuss the problems with in-home support.

Co-Chair Freeman asked Ms. Foremaster if she was present during previous testimony regarding the gaps that existed in the various service areas, and asked whether Ms. Foremaster’s concerns the same as those already presented. Ms. Foremaster replied that her agency covered all ages, and all disabilities, so she was not present to address any specific disability, but would speak for the entire disabled community. Co-Chair Freeman indicated she understood, however, asked if Ms. Foremaster agreed in principle with prior testimony regarding the gaps in service. Ms. Foremaster replied in the affirmative, and indicated she would like to see some funding provided for direct services for consumers and families.

David Sorensen informed the Task Force he was a member of the Carson City Recreational Club, and a volunteer at the Carson City Center for Independent Living. He advised he was also disabled and in need of direct client services. He stated he was not eligible for aging services because of his young age and, because he possessed a high IQ, was not eligible for mental health/mental retardation services. At the current time, the Carson City Center for Independent Living was showing him how to cook, clean his apartment, do his laundry, and manage his money. Mr. Sorensen explained the physical problems he suffered, and stated without the help of those at the Center, he would be unable to hold down a job. He recommended that a portion of the tobacco settlement money be allocated to people with disabilities for recreational purposes, so those individuals would have the opportunity to involve themselves in the community. Mr. Sorensen felt that recreation provided emotional support for persons with disabilities. Funding for non-profit organizations, such as the Carson City Recreational Club, should also be considered, because those organizations provided persons with disabilities a chance to go bowling, go fishing, camping, et cetera, when otherwise they would be denied access to those activities. Ms. Foremaster advised that Mr. Sorenson was presently involved in the Support Services area of the Center, an area that was manned by volunteer workers.

William Braunly advised the Task Force he had arrived in the area approximately 3 months ago, and had been attempting to find work. His present situation was that he was living out of his truck because he had been unsuccessful in finding work. Approximately 2 weeks ago, he advised he suffered a heart attack, was hospitalized in Reno and underwent bypass surgery. Mr. Braunly emphasized he was not asking for much, just a place to park his truck and regain his health in order to work. He stated he was willing and able to work.

Co-Chair Freeman asked Ms. Crawford if DHR could provide assistance to Mr. Braunly. Ms. Foremaster indicated Medicaid paperwork to pay for his hospitalization had already been filed, however, the State did not provide medical coverage unless a person qualified under SSI. Co-Chair Freeman suggested that Ms. Foremaster speak with Ms. Crawford regarding possible avenues of assistance.

Gregory Ressler informed the Task Force he was formerly homeless and would probably be dead if it were not for Ms. Foremaster. He stated he lived in a van for approximately 1 year, and thanks to the help provided by Ms. Foremaster and the Independent Living Center, he finally qualified for SSI/SSDI benefits and was living in his own apartment. Mr. Ressler stated he suffered a traumatic brain injury in 1958, and experienced further brain surgery in August 1999. He stated he was getting by now and had a place to live, but wanted the Task Force to envision his life when he lived in his van.

Ms. Foremaster stressed that money was needed in the area of direct client services. Attempting to get Mr. Ressler off the street had been an extremely difficult undertaking, because the only program she was aware of was city welfare. That program offered $250 for housing, only if that amount could be matched by the client or another agency, and only if he could prove that he had ongoing financial support to maintain a place of residence. Ms. Foremaster explained there were some “catches” in the available programs. She was well aware of existing services, but worried about persons who were newly disabled and living on the streets. Ms. Foremaster emphasized the situation was extremely desperate for those persons, and she would appreciate assistance from any entity.

Bob Hogan, Director, NCEP Brain Injury Program in Las Vegas, advised he was also a member of the Head Injury Association of Southern Nevada, and chaired the Nevada Statewide Advisory Council on Brain Injury. He presented the following testimony:

> “I have testified in this building many times, advocating for adults with brain injuries. I’m happy to report that

> we have made great strides in that area in Nevada for rehabilitation services. Today, however, I'm here to advocate for, and alert you to, the needs of a group even less able to advocate for themselves than Nevada's brain injured adults. I'm speaking today for Nevada's children. You may be surprised to learn that brain injury is often cited as the leading cause in disability amongst American children. Yet, in the Twentieth Report to Congress by the Department of Education, Office of Special Education, of the 5.5 million kids ages 6 to 21 years old served under Part B of IDEA (Individual's With Disabilities Education Act), only 10,356 were identified as brain injured. Was this even possible – to have that small a number? I direct you to the state's Trauma Registry Statistics and what they tell us. Each year, 110 children, ages 1 to 5 were reported to have brain injury, while nearly the same number in ages 5 to 9 also suffer the same fate. 150 kids, ages 10 to 14 suffer an injury, and adolescents 15 to 18 years of age numbered a staggering 275 injuries per year. At the age of 5, a Nevada child entering school has over 100 of his peers with brain injuries. At the age of 10 the number is 230. At 15 years old, a Nevadan has 400 peers with brain injuries, and a graduating senior could count 600 classmates living with brain injuries in the State of Nevada. I say 'could count,' because most of these students are unidentified.
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> "Clark County, our largest school district by far, identifies less than 70 students with brain injuries within their system. Again I say, is this possible – yes it is – surely it is, because kids are quick to recover physically while their cognitive and behavioral problems may not surface for months or even years later. Children are not small adults; their brains are constantly changing and maturing. As the problems surface, they may not even be associated with the earlier injury. As they progress through education systems, the demand for complexity, independent learning, and higher level thinking skills increase significantly. These are just those skills most affected by a brain injury. A very interesting study done by the Vermont School System by reviewing the histories of their students found that 40 percent of those identified as learning disabled, attention deficit disorder, or behaviorally disordered, had actually suffered a brain injury sometime in their past.
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> "Many of the behavioral issues we find so difficult to manage in our communities can, I submit, be related to the brain injury. Not to frighten you, but only to dramatize a point, I state a now famous study published in the Journal of the American Medical Association. This study looked at 15 teenagers, all on death row awaiting execution for crimes of an extremely violent nature. Researchers, as you may guess, were trying to find some commonality; could it be ethnicity, social economic status, genealogy, an abusive upbringing – what could it be? There was only one characteristic common to all of these kids – 15 out of 15 or 100 percent had a brain injury. That statistic is hard to ignore. Brain injury issues, especially behavioral issues are not always well managed in today's world. For Nevada's children, these issues are not well addressed. Here in Nevada, we lack adequate rehabilitation services for children with brain injuries. We lack training for educators who are challenged with teaching these kids. We lack the information systems for parents who struggle to raise these children. But do you know what, we do have the knowledge and we do have the technology. Much of it really is pretty simple stuff – not free – but pretty simple. The most dramatic change we could make in the lives of thousands of Nevada's children to effect quality of life and educational success would be to fund appropriate rehabilitation services, information, behavioral training, and technology.
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> "I agree with many of the folks that have spoken today about looking at privatizing services rather than make more state bureaucracies. In the case of our program, the state invested $300,000 early on to start a brain injury program that has provided services, far and away, millions of dollars of services back to the state for that small investment. To recap what I heard today, again many folks said privatizing and using non-profit providers works, and I know it does, I've seen it. If you paint a picture for Nevada that is kind of a Nevada analogy, I would see a slot machine where for every dollar you put in, several hundred dollars came out. Privatizing is really the only slot machine that works over and over again, and pays off all the time.
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> "I've heard preferences today for respite care, for independent living services, for services for folks with children with autism, for Medicaid buy-in to assure health coverage, and for a central disability data system. I would add that we need pediatric brain injury services and a family preservation system for the physically disabled."

Co-Chair Freeman clarified for Mr. Hogan that the Task Force was not necessarily talking about privatization, but was discussing public/private partnerships, which she felt was something that should be done. She asked if the figures and issues Mr. Hogan discussed regarding children with brain injuries held true for northern Nevada as well as for Clark County; Mr. Hogan replied in the affirmative.

Robert Davis-Coelho, manager of the HAPPY program in Reno, advised it was a program which served the special needs children birth to 3 years of age in the rural areas. He wanted to reiterate the emphasis on prevention because of the effect of maternal smoking. Approximately one-third of the program's clientele were affected in the enormous gambit of disabilities for children because of maternal smoking, as well as emphasizing the incredible cost to the program for therapists and staff to reach the rural areas.

Co-Chair Freeman stated securing professional staff for programs was a longstanding problem area, and asked Mr. Davis-Coelho to present possible proposals to the Task Force. She noted in the rural areas, very often the issue was transportation.

Robert Desruisseaux from the Northern Nevada Center for Independent Living stated he would reiterate previous testimony, and the two reoccurring themes. One of those themes was respite care, and most speakers mentioned that service area in one aspect or another, either a service provided by a program, or the need for respite care for a certain segment of the population. Co-Chair Freeman stated there was an earlier proposal for a voucher program for respite care, and asked Mr. Desruisseaux to voice his opinion regarding such a program. Mr. Desruisseaux advised he had not heard much about that type of program, other than a program reviewed by the Center for possible pursuit of grant monies, however, felt it was a wonderful method to use for respite care. As with all programs, the reoccurring theme was the waiting lists, and Mr. Desruisseaux stated he realized that was not an issue that could be easily fixed, but was an area that needed review. Co-Chair Freeman advised the Task Force recognized that as an immediate goal, but was also attempting to construct long-range planning.

Florence LaRoy advised she was the parent of a child with a disability who was born in Nevada. Her child was now 15 years of age and had an autism spectrum disorder. She indicated he went through the service system in southern Nevada and was not diagnosed until he was approximately 5 years of age, which caused him to miss much of the early intervention services. Ms. LaRoy stated he did go through the Special Children's Clinic or the Children's Behavioral Services Program. She felt that the appropriate personnel did not have sufficient information regarding child development and, therefore, did not recognize her son's disability. She advised he was currently in the ninth grade in the Clark County School District and she felt she had a good perspective on the delivery of services experienced by her son over the years, which was very sparse. Ms. LaRoy advised she had not been able to seek out the services for her son that she felt he needed, and had taken 10 years from her career in order to stay home and provide for his needs, because she was unable to locate assistance.

In addition to being the parent of a child with a disability, Ms. LaRoy stated she was the Training Services Director for Nevada Parents Encouraging Parents, which was a statewide parent training and information center for the State of Nevada. It was a federal program and a non-profit organization, which networked with parent training information centers across the nation. Ms. LaRoy advised the program had a budget of $160,000 per year, which was very meager. She stated the program received so many calls from parents, it was almost impossible to provide the needed information and deliver the services to parents of children with disabilities. Ms. LaRoy noted the Nevada Parents Encouraging Parents program was severely under-funded, and could do more if able to hire additional staff.

Ms. LaRoy advised she was a member of a number of task force groups within the state, as well as working on a Legislative Task Force regarding the needs of children with autism. She spoke to parents on a daily basis, and her organization served families suffering from all disabilities, children age zero to 21. According to Ms. LaRoy, the program would also provide adults with needed assistance in locating the appropriate resources. She stated there were many parents frustrated over the services available in Nevada, and families thinking about relocating to Nevada were advised that Nevada did not provide the level of services available in other states. Ms. LaRoy stated there were many parents who left the state after a short period of time. There was a minimum amount of human resources available, and she would like to see Nevada provide children with the early intervention services they needed, so schools would not be required to deal with the issues. Ms. LaRoy advised there were no after-school programs available, and children with behavioral disorders were being kicked out of programs. Parents of those children did not know where to go for assistance, and experienced difficulty on their jobs. She explained that families of children with disabilities encountered a great deal of stress, and as a result of that stress, often lost jobs. It was a vicious cycle that families suffered. Ms. LaRoy indicated her organization could do more if it was appropriately funded, and also felt that appropriate services, especially in the area of autism, were definitely needed.

With no further business to come before the Task Force, Co-Chair Freeman adjourned the hearing at 5:10 p.m.

Submitted by:

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Carol Thomsen, Secretary

APPROVED:

Assemblywoman Vivian Freeman
Presiding Co-Chair