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

Seventy-Fourth Session
April 6, 2007

The Committee on Health and Human Services was called to order by Chair Sheila Leslie at 12:06 p.m., on Friday, April 6, 2007, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4406 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Copies of the minutes, including the Agenda (Exhibit A), the Attendance Roster (Exhibit B), and other substantive exhibits are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/74th/committees/. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (email: publications@lcb.state.nv.us; telephone: 775-684-6835).

COMMITTEE MEMBERS PRESENT:

Assemblywoman Sheila Leslie, Chair
Assemblywoman Susan I. Gerhardt, Vice Chair
Assemblyman Bob L. Beers
Assemblyman Joseph P. (Joe) Hardy
Assemblywoman Bonnie Parnell
Assemblywoman Peggy Pierce
Assemblyman Lynn D. Stewart
Assemblywoman Valerie E. Weber
Assemblywoman RoseMary Womack

COMMITTEE MEMBERS ABSENT:

Assemblywoman Ellen Koivisto (Excused)
Assemblywoman Kathy McClain (Excused)

GUEST LEGISLATORS PRESENT:

Assemblyman Moises Denis, Clark County District No. 28

STAFF MEMBERS PRESENT:

Donald O. Williams, Research Director, Legislative Counsel Bureau
Sarah J. Lutter, Committee Policy Analyst
Bonnie Borda Hoffecker, Committee Manager
Patricia Evans, Committee Secretary
Olivia Lloyd, Committee Assistant

OTHERS PRESENT:

Carlos Brandenburg, Administrator, Division of Mental Health and Developmental Services, Department of Health and Human Services, Carson City
Cari Rovig, Executive Director, Nevada Immunization Coalitions, Reno
Alex Haartz, Administrator, Department of Health and Human Services, Health Division, Carson City
Amanda Harris, WebIZ HelpDesk Coordinator, Immunization Program, Bureau of Community Health, Department of Health and Human Services, Health Division, Carson City
Bobette Bond, Culinary Health Fund, Las Vegas
Lynn Chapman, Nevada Eagle Forum, Sparks
Lisa Foster, Saint Mary's Hospital, Reno
Angela Berg, RN Manager, Southwest Medical Associates, Las Vegas
Deborah A. Agosti, Senior Justice, Supreme Court of Nevada, Carson City
Daniel J. Klaich, Executive Vice Chancellor, Nevada System of Higher Education, Las Vegas
Mark L. Brenner, Vice President for Research and Dean of the Graduate School, University of Nevada, Reno
Susan Ford Publicover, Director, Office of Human Research Protection, University of Nevada, Reno
Charles Bernick, Director, Lou Ruvo Center for Alzheimer's Disease and Brain Aging, University of Nevada School of Medicine, Las Vegas
Debra Fredericks, Associate Director, Center for Cognitive Aging, Reno
Jane E. Fisher, Executive Director, Nevada Caregiver Support Center, Reno
Sally Crawford Ramm, Elder Rights Attorney, Department of Health and Human Services, Division for Aging Services, Reno
Marietta Bobba, Director, Washoe County Senior Services, Reno
Janice R. Ayres, Executive Director and CEO, Nevada 15 Rural Counties' RSVP Program, Inc., Carson City
W. Larry Williams, Associate Professor, Department of Psychology, University of Nevada, Reno

Chair Leslie:
[Meeting called to order. Roll called.] We will work on Assembly Bill 525.

Sarah J. Lutter, Committee Policy Analyst:
These are proposed conceptual amendments. [Read from prepared text (Exhibit C).]

Assembly Bill 525: Revises provisions relating to autism. (BDR 40-1374)

Chair Leslie:
The only other amendments suggested during the hearing were in the discussion of the Senate bill. I felt uncomfortable in accepting those amendments since we did not hear any testimony, and there is a Senate bill pending. I discussed this issue with the major proponents of the bill, and they were fine with not going forward with those amendments at this time.

Assemblyman Hardy:
Page 6, line 25, Section 3, should the word "the" foundation be changed? Changing this word would put it in context with the amendment.

Chair Leslie:
Would you agree it should be "the" foundation?

Sarah J. Lutter:
Yes, that would be correct.

Chair Leslie:
We will make that correction. Are there any other comments or concerns?

Assemblywoman Parnell:
Regarding amendment five, the safe bet would be to go with "B". This would give them the leeway they need.

Chair Leslie:
I understand your intent. If they did not spend the full amount the first year, they lose the money.

Assemblywoman Parnell:
I am still haunted by the testimony on the lack of training of many pediatricians and caregivers. We cannot underestimate the importance of making sure people are utilizing their continuing credit and education in order to identify these cases at an earlier age.

Chair Leslie:
I think this bill has helped raise public awareness. Mr. Beers, are you including page 2, number 5(a), as your choice? Are you suggesting the first option which splits the money so there is less the first year, and more money in the second year, or are you suggesting (b), which is letting an equal amount of money to be used each year?

> ASSEMBLYMAN BEERS MOVED TO AMEND AND DO PASS AS AMENDED ASSEMBLY BILL 525.
>
> ASSEMBLYWOMAN PIERCE SECONDED THE MOTION.
>
> THE MOTION PASSED UNANIMOUSLY.

Chair Leslie:
Let us skip the first bill for now. We will go to Assembly Bill 394.

Assembly Bill 394: **Makes an appropriation to the Department of Health and Human Services to establish a pilot program to provide respite care for families of persons with mental disabilities. (BDR S-1006)**

Assemblyman Moises Denis, Clark County Assembly District No. 28:
For those who are unfamiliar with the definition of respite care, it is time off for the family members who are caring for someone who is ill, injured, or frail. There is no respite care for those who are mentally ill. I spoke with Dr. Brandenburg about instituting a pilot program which would allow $50,000 for the first year of the program, and $100,000 in the second year. On page 2, lines 20 and 21, we would suggest a change of terms. We would change "mentally disabled" to "severely mentally ill".

Chair Leslie:
Are there any questions from the Committee?

Assemblywoman Womack:
When you say respite care, is that only for the caregiver, or can it used for bathing, or other personal care of the disabled?

Assemblyman Denis:
It can be used for whatever type of care the family or the patient requires.

Assemblywoman Womack:
Will each family be helped only once within the year, or can they reapply as many times as needed?

Assemblyman Denis:
Currently, the family would apply for an amount of money, and would use it until the money is gone.

Assemblywoman Womack:
It would be a one-time appropriation per year?

Assemblyman Denis:
Correct.

Carlos Brandenburg, Administrator, Division of Mental Health and Developmental Services, Department of Health and Human Services, Carson City:
The purpose of respite care is to assist families who have family members with disabilities. The crux of the program is to assist the family members to remain intact. These family members are experiencing stress, anxiety, depression, and anger. A family can apply as often as they wish and the application could last as long as 12 months. This would be an augmentation to current programs. I would respectfully request appropriating the money to the agency providing the service.

Chair Leslie:
How would you split the money? Would it not be better to put it in the Division's budget?

Carlos Brandenburg:
As a pilot program, it might not be a bad idea to leave it in the Division's budget where it could be monitored and evaluated.

Chair Leslie:
We would add "The Division of Mental Health and Developmental Services" to "The Department of Health and Human Services", on page two?

Assemblywoman Parnell:
In Section 1, subsection 1, we might need to change the definition to conform to the change on page two.

Chair Leslie:
Everywhere it says "mentally disabled," your preference would be "severely mentally ill"?

Assemblyman Denis:
Correct.

Assemblyman Hardy:
Is this limited to adults?

Assemblyman Denis:
There is no limitation.

Chair Leslie:
Dr. Brandenburg, what do you suggest?

Carlos Brandenburg:
The Division of Child and Family Services would serve children in Washoe and Clark Counties.

Assemblyman Denis:
This is a pilot program with limited participation to start.

Chair Leslie:
Do you want to include children? What is the language you would like put in the bill?

Carlos Brandenburg:
The language could read "severely mentally ill adult or severely emotionally disturbed children".

Chair Leslie:
That would only be for children in rural Nevada?

Assemblywoman Womack:
Could we define "severely mentally ill"?

Chair Leslie:
The definition already exists in statute. Is there anyone else who would like to testify in favor of A.B. 394? Is there anyone who would like to testify against A.B. 394? The hearing is closed on this bill. We will bring it back to Committee. The first amendment suggested is to put the money in the Division of Mental Health and Developmental Services budget. The second amendment is clarification of this bill to serve severely mentally ill adults and severely emotionally disturbed children.

Assemblyman Hardy:
Is there a way to include Washoe County and Clark County?

Chair Leslie:
We would have to decide how much money to put into someone else's budget, because those children are served through the Division of Child and Family Services (DCFS).

> ASSEMBLYWOMAN PARNELL MOVED TO AMEND AND DO PASS AS AMENDED ASSEMBLY BILL 394.
>
> ASSEMBLYWOMAN GERHARDT SECONDED THE MOTION.
>
> THE MOTION PASSED UNANIMOUSLY.

Chair Leslie:
We will address Assembly Bill 575.

Assembly Bill 575: **Repeals an obsolete statute relating to county workhouses for indigent persons and homes for the aged. (BDR 38-1432)**

Donald O. Williams, Research Director, LCB, Carson City:
I am appearing here on behalf of the Legislative Commission, and under the provisions of *Nevada Revised Statutes* (NRS) 218.2473, to provide you with background information on A.B. 575. [Read from prepared text (Exhibit D).]

Chair Leslie:
This is a bill that would get rid of an obsolete law.

Assemblywoman Pierce:
When was the last time any county had a work house?

Donald Williams:
It was in 1972, in Elko County. I have asked the Nevada Association of Counties (NACO) to survey their members, and based on that survey, there are no plans to reestablish either a county workhouse or a home for the aged.

Chair Leslie:
Is there anyone else wishing to testify for or against A.B. 575? Hearing is closed on A.B. 575. We will bring this back to the Committee.

> ASSEMBLYWOMAN GERHARDT MOVED TO DO PASS ASSEMBLY BILL 575.
>
> ASSEMBLYMAN STEWART SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

Chair Leslie:
We will go to Assembly Bill 410. I will pass the gavel to Vice Chair Gerhardt.

Vice Chair Gerhardt:
Hearing is opened on A.B. 410.

Assembly Bill 410: Makes certain changes relating to the immunization of children. (BDR 40-877)

Assemblywoman Sheila Leslie, Washoe County Assembly District No. 27:
This is my effort to bring people together to get Nevada out of last place in terms of immunizations for children. I convened a few meetings with various stakeholders and this is the result. Basically, this bill does two things. It creates a central registry of immunizations with an opt-out clause. This clause allows people a choice. The second part of the bill, in Section 3, asks the Department of Health and Human Services to conduct a feasibility study of group purchasing plans. Anytime you get into the issue of how immunizations are purchased and how to make them available for less money, it becomes very complicated, very quickly. We need more study, and to submit regular reports back to the Legislative Committee on Health Care, which meets monthly in the interim. This would give us an opportunity to work on this during the interim. My daughter was to attend a class in Argentina, and needed her immunization records. I called the Washoe County Health Department and obtained those records. If they had not had those records, I do not know how we would have been able to recreate her immunization history. As a parent, the registry at the Washoe County Health Division was extremely helpful. The concern is the mobility of children and the possibility of double immunizations. This is wasteful, and we may find out that Nevada is not last in immunizing our young children. It may be that we are not tracking them effectively.

Vice Chair Gerhardt:
Identify yourselves for the record, please.

Cari Rovig, Executive Director, Nevada Immunization Coalitions, Reno:
More importantly, I am the mother of Emma and Katie. [Read from prepared text (Exhibit E).]

Alex Haartz, Administrator, Department of Health and Human Services, Health Division, Carson City:
I serve as secretary to the State Board of Health. This bill would require the State Board of Health to adopt some regulations. We are going to open up in

the training environment, the current immunization system, and we will walk you through it. You can go on-line in Internet Explorer and see what a health-care provider would see. This requires a registry. We do not want to require only one registry statewide, or one registry universally, or have someone abandon their internal registries. What we look for is up-loadability and compatibility. If a healthcare organization has a functioning registry, we would like to ensure they could up-load the data routinely, and thus populate a larger registry. Within the Governor's recommended budget, there is a proposed enhancement unit for the Health Division, Washoe County, and Clark County. This proposal would provide additional staffing and resources to strengthen immunization registries. Currently, this bill, as written, does not create a fiscal note.

Assemblyman Hardy:
Who can get the record off this website?

Assemblywoman Leslie:
It would be convenient for a parent to be able to access a child's records.

Cari Rovig:
This would be a roll-out process. We would like to see schools have certain access. Records could be pulled up for entry, and parents to have some access.

Amanda Harris, WebIZ HelpDesk Coordinator, Immunization Program, Bureau of Community Health, Health Division, Department of Health and Human Services, Carson City:
You have been provided with a blue folder, inside which you will find a packet, specific to you. There is a user name for each of you in order to log into our test version of the immunization registry. [Walked the Committee through the use of website (Exhibit F).]

Vice Chair Gerhardt:
Do we have any questions? Chair Leslie.

Assemblywoman Leslie:
I would like to refer to Assemblyman Hardy's question on parental access. Would it be the Health Division or the Board of Health who would have to decide the regulations on how a parent could access their own data?

Alex Haartz:
This pertains to Section 1, subsection 5, regarding immunization information systems. To create a functionality by which a parent could access information, by having data exported from the registry, it would be best if that language

could be spelled out in the bill. The goal is to be able to provide identification, and have the requesting agency access the website. The ideal way would be to have the young adult go back to the medical facility to obtain an updated immunization record.

Assemblywoman Leslie:
We do not want to get too far afield. Perhaps the Board of Health can resolve these issues.

Alex Haartz:
There are other entities and systems that have working registries. This will not take over these registries.

Bobette Bond, Culinary Health Fund, Las Vegas:
I want to make sure you understand the Culinary Health Fund as well as the Health Services Coalition are supportive of the entire bill.

Vice Chair Gerhardt:
We have representatives from the Eagle Forum. I believe you are opposed to this bill?

Lynn Chapman, Nevada Eagle Forum, Sparks:
We are opposed to the bill. The Texas Department of Health built an electronic data base of over 3,000,000 Texas children. This data was based on birth certificates, and social security numbers, while ignoring the law that has parental consent. It is important for parents to have an opt-out to protect their children against unwanted immunizations (Exhibit G).

Lisa Foster, Saint Mary's Hospital, Reno:
I would like to echo comments in support of this bill. It would be helpful in improving the accuracy of the immunization program.

Angela Berg, RN Manager, Southwest Medical Associates, Las Vegas:
[Read from prepared text (Exhibit H).]

Vice Chair Gerhardt:
Do we have anyone else who is neutral or opposed? We will close the hearing on A.B. 410.

[Chair Leslie resumes Chair.]

Chair Leslie:
Thank you Madam Vice Chair. We will hold this bill until Monday's work session in order to give people who heard the testimony time to think about it since there was some opposition. Let us go back to the top of the agenda and open the hearing on Assembly Bill 293.

Assembly Bill 293: **Makes an appropriation to the Legislative Fund for the Legislative Auditor to enter into a contract with a consultant to conduct a performance audit of agencies which provide child welfare services. (BDR S-706)**

Assemblywoman Susan Gerhardt, Clark County Assembly District No. 29:
I gave an extensive presentation to this Committee on March 12th, 2007, concerning the work of the State Blue Ribbon Panel-Child Death Review. Assembly Bill 293 is one of the recommendations from that work. Reports of the tragic deaths of children who were either in the child welfare system or who had contact with the system led to the formation of the State Blue Ribbon Panel-Child Death Review. This panel was chaired by former Supreme Court Justice Deborah A. Agosti, and composed of concerned citizens with diverse backgrounds in areas such as law enforcement, mental health, child advocacy, and education. During the course of this study, the panel found wide-spread systemic problems with a child welfare agency. The report included a number of recommendations, one of which is before you in A.B. 293. This bill relates to the panel's recommendation for close monitoring of each county's child welfare agency, to ensure action plans for improvement are being implemented. Monitoring helps ensure that not one more child falls through the cracks. The measure appropriates $200,000 from the State General Fund for the Legislative Auditor to contract with a qualified independent consultant to conduct a performance audit of each of these agencies. The bill requires the consultant to perform random, unannounced visits to the agencies. During these visits, the consultant must review the files of open and closed cases concerning children who have been abused or neglected. The consultant must also review the manner in which agencies respond to cases of abuse and neglect, review agency procedures used to determine whether to close a case, determine whether the agencies are complying with state and federal laws, evaluate the effectiveness of intervention services, determine the frequency of contacts placed in foster homes or emergency services, determine whether the agency has successfully implemented the panel's recommendations, and to evaluate the progress and efforts made towards meeting the requirements set forth in the federally approved performance improvement plan and corrective action plan. The bill includes language requiring cooperation from the agencies. I am proposing an amendment to this measure relating to the activities of the consultant. [Read from prepared text (Exhibit I).] Assembly Bill 293 provides a

critical audit for a child welfare system with the purpose of insuring the agencies have the necessary procedures in place to protect our children. The bill does not propose to create another office or another bureaucracy. It is a cost-effective method of providing an independent review through the legislative auditor who already performs similar functions for the State.

Deborah A. Agosti, Senior Justice, Supreme Court of Nevada, Carson City:
I urge the passage of A.B. 293, and I concur with the amendments that have been mentioned. There are many reasons why Nevada is in the situation it is with respect to both the crises facing children who are in need of protection, and the child fatality crises. One of the cures is over-sight. One of the reasons we ended up where we are is that no one was looking over our shoulder. The bill, in conjunction with other legislation which permits Michael Willden's shop to directly intervene with the Clark County and Washoe County entities, will provide an enforcement mechanism when problems are identified. Identifying the problems is what this bill is designed to do, and to identify them by someone who does not have a vested interest in the outcome. There is one additional look-see that I would hope the Committee would entertain, and that is with respect to page 2, line 15, Section 2, subsection (e). We add a judgment to this section to determine the appropriateness of the frequency with which the agencies have direct contact because there may be cases that require more than one contact monthly.

Chair Leslie:
Assemblywoman Gerhardt, are you in agreement with the Justice's recommendation for an additional amendment?

Assemblywoman Gerhardt:
Absolutely.

Chair Leslie:
We will add that to the list to be considered when we process the bill.

Assemblywoman Weber:
Will the qualified independent consultant be chosen through the Request for Proposal (RFP) process? How does that happen?

Assemblywoman Gerhardt:
In this case it will happen through the Legislative Auditor, and there will be an RFP.

Chair Leslie:
Would anyone else like to come forward to testify on A.B. 293?

Assemblywoman Gerhardt:
I was hoping we would entertain a motion today.

Chair Leslie:
I hesitate to do that because we have amendments. I would rather hold this until Monday to give the Committee an opportunity to look at the amendments, and to allow the public time to let us know if it has any concerns. We will close the hearing on A.B. 293. We will open the hearing on Assembly Bill 578. This bill was assigned to our committee on behalf of the Nevada System of Higher Education.

Assembly Bill 578: **Prescribes the requirements for surrogate decision makers to give informed consent for certain human subject research. (BDR 40-275)**

Daniel J. Klaich, Executive Vice Chancellor, Nevada System of Higher Education, Reno:
I am here merely to introduce the professional staff. I would like to introduce Dr. Mark Brenner and Dr. Susan Publicover.

Mark I. Brenner, Vice President for Research and Dean of the Graduate School, University of Nevada, Reno:
We are requesting the revisions of the statute. [Read from prepared text (Exhibit J).]

Chair Leslie:
Let us make sure we have your scripted presentation in front of us.

Susan Ford Publicover, Director, Office of Human Research Protection, University of Nevada, Reno:
I am testifying in favor of the revisions to A.B. 578. [Read from prepared text (Exhibit K).]

Chair Leslie:
Was it your plan to read the entire four pages?

Susan Publicover:
That was my hope.

Chair Leslie:
We have the four pages of testimony. It would be better for you if you would only highlight the main points. All of this will go on the record. Why does this have to be changed from the way it is with the court order?

Susan Publicover:
We want to allow International Review Boards (IRBs), pursuant to 45 Code of Federal Regulations (CFR) 46, to work with surrogate decision makers and researchers as a group to decide on the inclusion of these clients in research, in lieu of the judge. [Continued reading excerpts from prepared text (Exhibit K).]

Chair Leslie:
Are you saying the current system is too unwieldy? What is the problem?

Susan Publicover:
It creates an access barrier, for optimal care, to ordinary people. The costs are high because they have to pay court costs. We believe the IRBs with their wealth of expertise, both scientific and ethical, have the ability to make those decisions in lieu of the judge. They approve the research through a thorough vetting of the documents and provide continuous monitoring. This includes the consent process.

Chair Leslie:
You want to substitute the judge being involved by mandating the IRBs take over that function?

Susan Publicover:
Yes, but only those IRBs that actually have filed an assurance of compliance with the federal government, so they follow the same rules which we do.

Chair Leslie:
If there is no IRB, it would default to the judge? Or would there always be an IRB involved?

Susan Publicover:
There would always be an IRB involved. We do not allow research to go forward without an IRB. The composition of the IRBs is such that it involves community membership and advocates for special populations. It is a mix of professional expertise. Any researcher who has gone through an IRB will tell you it is a rigorous vetting of the process.

Chair Leslie:
Are there any questions from the Committee on the intent of the bill? Who will explain the amendment?

Susan Publicover:
I can do that if you wish. In what way would you like me to go through it?

Chair Leslie:
If you would tell us what the intent is? What are you changing and why?

Susan Publicover:
[Continued reading from prepared text (Exhibit K).]

Chair Leslie:
We will have to process this independently of the Senate. If there is a conflict in the end, we will address it then. In Section 13, number 4 what does the word "additional" mean?

Susan Publicover:
That is an addition based on the other language which established the hierarchy of individuals who could give surrogate consent on behalf of the ward.

Chair Leslie:
Why is the word "capacity" struck?

Susan Publicover:
That must be a drafting error. That was not something we did.

Chair Leslie:
Are there any questions from the Committee on the amendment? There will be more testimony today, so we will hold this. Who else would like to testify in favor of the bill?

Charles Bernick, Director, Lou Ruvo Center for Alzheimer's Disease and Brain Aging, University of Nevada School of Medicine, Las Vegas:
This bill impacts me every day. We have an extensive network of Alzheimer's care in Nevada. Ten percent of our citizens over age 65 have Alzheimer's disease, and that number will increase by 100 percent in the next 20 years. It is the mission of the Ruvo Institute to develop better therapies, treatments and eventually a cure for Alzeimer's disease. The problem is we are severely limited by current law. Most patients who are moderately symptomatic with Alzheimer's disease, truly lack the ability to understand and remember the nuances of involved research. Many of these patients do not have guardians.

The current law requires a guardian go to court to allow participation in research projects. This, in effect, precludes these people from participating. The IRB is there to provide human subject protection. Does having the current law add any further protection than the bill suggests? Would passing this bill, allow opportunities that are not currently available? Besides denying patients the opportunity of participating in research, it hurts the State from participating in nationwide research. It is a cumbersome process to go to court and get authorization in order to enroll patients. This is a barrier to bringing researchers to Nevada.

Chair Leslie:
Is there evidence this has actually prevented research from moving forward?

Charles Bernick:
We have been involved in trials for mild to moderate Alzheimer's disease, and we cannot fill the moderate patient load because we cannot enroll people who do not have the capacity to understand the research. I have not had one patient that was willing to go to court to do this. The only people who go to court are those who have the resources.

Chair Leslie:
Do most states do it the IRB way?

Charles Bernick:
We are one of four states in the nation that have this type of restrictive law. All the other states have modified their laws to allow surrogates to give informed consent.

Debra Fredericks, Associate Director, Center for Cognitive Aging, University of Nevada School of Medicine, Reno:
Through our three clinics we have a caseload of 1,000 patients. These are patients with Alzheimer's disease and related dementias. A day does not go by that a patient does not ask us what is new or available. Often, we have to send them out of state. Only wealthier families will have the opportunity to engage in this research, and receive research medications and other procedures.

Jane Fisher, Executive Director, Nevada Caregiver Support Center, Reno:
We cover seven counties in northern Nevada. [Read from prepared text (Exhibit L).]

Chair Leslie:
Are there any questions for this panel of witnesses?

Assemblyman Beers:
Would this extend into the area of Multiple Sclerosis in the elderly?

Charles Bernick:
Yes, it would apply to any condition, no matter what the cause, that results in impaired cognition, and impaired ability to understand the research protocol.

Assemblywoman Womack:
It is much easier to speak to the whole family if you do not have to go through a court procedure.

Assemblyman Hardy:
How does one determine which sibling has the authority to make decisions? The law says "attorney-in-fact." When we talk about research improving care, we all know research does not improve care; except for the half it works on. The control group could be better, or the research group could be better, but we do not know that until we do the study. To portray this as better care because we are doing research and not an experiment, does not give us the answer.

Chair Leslie:
Who is the best person to answer the technical question Dr. Hardy raised on Section 11(a)?

Daniel Klaich:
Madam Chair, could you take one other question? I will have a look at Dr. Hardy's question.

Chair Leslie:
Was your second question answered?

Assemblyman Hardy:
From a legislative intent, does the person from the sibling group who votes "no" supersede any positive action from another sibling?

Assemblywoman Pierce:
If some siblings are without comment, does that take them out of the decision-making process?

Daniel Klaich:
If someone has the attorney-in-fact granted, that person is clearly number one.

Assemblyman Hardy:
I am not familiar with the term "attorney-in-fact."

Daniel Klaich:
An attorney-in-fact is a legal term which indicates an individual has been given written authority to act for another. When you refer to a medical Power of Attorney, the person to whom the authority to act is given is referred to as an attorney-in-fact. It is the person who is named in that durable Power of Attorney. The "no" vote reigns. One "yes" and five abstentions is a "yes."

Debra Fredericks:
The type of research to which Dr. Fisher referred is behavioral research. Those are single subject designs. Over the course of those studies better treatments do come to bear, and are often placed in the care of the person within weeks.

Chair Leslie:
Thank you. We have to leave some time for those who oppose this bill.

Sally Crawford Ramm, Elder Rights Attorney, Division for Aging Services, Reno:
I have some real concerns about A.B. 578. Some of the law is getting a little bit confused here. If a person has a durable Power of Attorney, or an attorney-in-fact, for health care decisions, that person has chosen them before they become incapacitated. A person cannot sign a durable Power of Attorney once they have become incapacitated. Chapter 159 pertains only to guardianships. That means the incapacitated people referred to in Chapter 159 have already been deemed incapacitated by the court. If a family wants to have their incapacitated family member be part of a research project, they do not have to go to court. They can do it because they have the authority based on the paperwork that was signed by the person before they became incapacitated. In Chapter 159, the only people who have to go to court to get permission for research are the people who have already been deemed incompetent by the court, and the court has chosen their surrogate decision maker. Chapter 159 is the guardianship law.

Chair Leslie:
The original bill is in Chapter 439. You are suggesting it be changed to Chapter 159. I think you are suggesting that is not appropriate.

Sally Ramm:
The wording used in their bill and in their amendment is for Chapter 159.

Chair Leslie:
We need to make sure both parties understand which chapter and why, before we process anything on this bill.

Sally Ramm:
I am not that familiar with Chapter 439 as it applies to this. I would have to get someone who knows more about it.

Chair Leslie:
Let us hear any other concerns you have.

Sally Ramm:
[Read from prepared text (Exhibit M).]

Chair Leslie:
Are there any questions for Ms. Ramm? I think that chapter issue needs to be discussed.

Marietta Bobba, Director, Washoe County Senior Services, Reno:
Inclusive in Washoe County Senior Services are social workers, mental health therapists, and the Senior Law Project. The process and programming that are done in guardianship cases is much more comprehensive. I would recommend that rather than support this bill, and move it along, that some research be done into how other states view research and experimentation. Sometimes people have the best intentions, but sometimes the outcome does not reflect the intent. An article written in 2004, stated that data revealed about subjects with no known cognitive impairments often failed to give valid consent. We need to work harder in order to insure informed consent. Is this a bill about people who already have guardianship, or about people who have mild or moderate cognitive impairment? Those are distinct and separate categories. If the bill is addressing moderate or early impairments there is a need to be vigilant. This bill speaks to both behavioral and medical research. I am not sure what Section 11 means in terms of looking for a family member. I would urge that you not pass this bill, but ask for further research on how other states deal with this issue.

Janice R. Ayres, Executive Director and CEO, Nevada 15 Rural Counties' RSVP Program, Inc., Carson City:
We have a home companion program, and a respite care program. I gave you some amendments (Exhibit N), and I agree this bill needs a lot more consideration and caution. I have seen some well-intentioned people, but we are here to see that everything is in place. Sometimes we do too much to seniors, rather than for them. We are not against any research, or treatment which benefits people in that position.

Chair Leslie:
We have your amendment, and note your concerns. Our deadline, to get it out of Committee, is next Friday.

Daniel Klaich:
Our amendment is incorrect, your staff is correct. It is Chapter 439, not Chapter 159. There is a cross-reference in Chapter 159, and there is a statute in Chapter 159 that needs to be amended. That is referred to in Section 13 of the Act. That was a necessary cross-reference because of the addition, but it did not require the shifting to Chapter 159. We believe our offering of that amendment caused the confusion referred to by Ms. Ramm.

Chair Leslie:
I thought that would be your conclusion. We will disregard that it is drafted properly. There have been some significant issues that caused me some concern. We all agree UNR does some great work, we want them to be able to do research, but we have to make sure if we were going to process something of this magnitude, we know what we are doing. If this bill is not ready to go, I am not inclined to process it. If you can return with an amendment that makes sense, within the next week, we will certainly take a look at it.

W. Larry Williams, Associate Professor, Department of Psychology, University of Nevada, Reno:
I am the Chair of the Social Behavioral Institutional Review Board. I am a clinician, and have worked for over 35 years with people with intellectual disabilities. I am also a researcher. In the 1960s and 1970s, people could do whatever they wanted in terms of research. That ended in the late 1970s. Research is now universally controlled by IRBs. It is so well controlled that the current statute was discovered, and is hindering everyone who is doing research with people with mental retardation, because they would have to go to court to get permission just for me to ask them if they would participate in my research. The research I do is not experimental. It is to try to find out which part of the therapy is most effective, so we can make the therapy more efficient. I have to relay it to my colleagues, so I publish it. Through the IRB process, if you want to publish that research, you cannot do it. I am not allowed to disseminate, I am not allowed to help people with mental retardation to obtain better treatment because they would have to go to court to get permission for me to use the very data I collected on them. I cannot accept any new students. We are the clinicians. We are the State's right-hand people for dealing with people with severe behavior disorders. If we are not going to be able to continue to do our work because we cannot publish any of it, then I am out of business. The people with mental retardation will be out of business. Notwithstanding the former discussions, these are issues that already exist, not because of our proposal. I am appealing to you that all of the work that has been going on in Nevada with people with mental retardation will likely come to an end. Because we cannot publish our work, we cannot share it. I cannot give a talk about it

anywhere without IRB permission. This shows you the level of protection already in place. We do not need the current statute we need a bill like A.B. 578 (Exhibit O).

[Hand-outs distributed, but not addressed (Exhibit P).]

Chair Leslie:
Are there any questions from the Committee? Is there anyone else who would like to testify for or against this bill? I do not see anyone. The hearing is closed. If we do not have a quorum, the bills in our work session will die. Please plan accordingly.

[Meeting adjourned at 2:49 p.m.]

RESPECTFULLY SUBMITTED:

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Patricia Evans
Committee Secretary

APPROVED BY:

____
Assemblywoman Sheila Leslie, Chair

DATE:______________________________________

EXHIBITS

Committee Name: Committee on Health and Human Services

Date: April 6, 2007 Time of Meeting: 12:06 p.m.

Bill	Exhibit	Witness / Agency	Description
	A	***************************	AGENDA
	B	***************************	ATTENDANCE ROSTER
AB 525	C	Health And Human Services	Relating To Autism
AB 575	D	Donald O. Williams	Background Information
AB 410	E	Cari Rovig	Improving Children's Immunizations
AB 410	F	Amanda Harris	Demonstration Guide
AB 410	G	Lynn Chapman	Follow The Money On Vaccines
AB 410	H	Angela Berg	Immunization Registry
AB 293	I	Susan Gerhardt	Proposed Amendment
AB 578	J	Mark Brenner	Testimony In Support Of Bill
AB 578	K	Susan Publicover	Testimony In Support Of Bill
AB 578	L	Jane Fisher	Testimony In Support Of Bill
AB 578	M	Sally Ramm	Testimony Opposition Of Bill
AB 578	N	Janice Ayres	Testimony Opposition Of Bill
AB 578	O	W. Larry Williams	Behavioral Research
AB 578	P	Leslie, Parks, Mcclain, Segerblom, Womack	In Support Of Bill