

REPORT

from the

**JOINT INTERIM STUDY COMMITTEE ON DEVELOPMENTAL
DISABILITIES SERVICES DELIVERY SYSTEM**

December, 1996

**Representative Knaperek
Cochair**

**Senator Petersen
Cochair**

The Joint Interim Study Committee on Developmental Disabilities Services Delivery System was created in session law during the second regular session of the 42nd legislature, 1996. The committee completed its duties which were to:

- ▶ research the technical means to allow families to purchase services directly from certified care givers by means of a voucher system;
- ▶ assess the availability and accessibility of community resources, including informal care givers;
- ▶ investigate the potential for the integration of an electronic fund transfer system within DES, or contracted for by a financial institution to establish accounts of preapproved service allocations for family consumers.

A list of committee members and copies of minutes are attached. The committee terminated December 31, 1996.

The committee held two meetings in December. Due to lack of a quorum at the first meeting, all the topics for discussion were repeated at the second meeting and recommendations were adopted.

RECOMMENDATIONS:

It is recommended that:

1. The joint leadership create a committee to provide ongoing oversight of the DD services delivery system and examine the feasibility of creating a new department of developmental disabilities.
2. The DD Division review their rules carefully in the interest of client safety in their recruiting of new providers.
3. The DD Division and related agencies streamline their paper flow in an effort to become more user friendly.
4. The Office of Risk Management submit its findings regarding liability issues in writing to the DD Division as soon as possible.
5. The DD Division develop an aggressive marketing strategy.
6. The legislature draft legislation requiring the DD Division to begin an electronic transfer pilot program in at least one urban and one rural county.
7. The legislature and DD Division continue to work with the Congressional delegation to get clarification from the IRS regarding employer/employee relationship issues for those who participate in the voucher system.
8. The legislature direct more dollars into the family support line item for expansion of the voucher system.

JOINT INTERIM STUDY COMMITTEE ON DEVELOPMENTAL DISABILITIES
SERVICES DELIVERY SYSTEM

Requested by Representative Knaperek

Strike-Everything Amendment to HB 2030 made in the House Human Services Committee on February 15, 1996:

Section 1. Developmental disabilities services delivery system study committee; membership; duties

A. The developmental disabilities services delivery system study committee is established consisting of the following members:

1. Two members of the senate appointed by the president of the senate from different political parties. The president shall designate one member as cochairperson.

2. Two members of the house of representatives appointed by the speaker of the house of representatives from different political parties. The speaker shall designate one member as cochairperson.

3. Two parents of developmentally disabled children or adults appointed by the speaker of the house of representatives.

4. Two parents of developmentally disabled children or adults appointed by the president of the senate.

5. One representative of the governor's council on developmental disabilities appointed by the governor.

6. The assistant director of the division of developmental disabilities in the department of economic security.

7. One representative of an advocacy organization that serves chronically ill children with developmental disabilities appointed by the speaker of the house of representatives.

8. One representative of an advocacy organization that serves parents of disabled children and adults appointed by the governor.

9. One representative of a firm that provides services to disabled children or adults in their homes appointed by the president of the senate.

10. One representative of a financial institution that provides statewide electronic fund transfer services appointed by the governor.

11. The director of the department of administration or his designee.

B. The committee shall:

1. Research the technical means to allow families to purchase services directly from certified caregivers by means of a voucher system.

2. Assess the availability and accessibility of community resources, including informal care givers.

3. Investigate the potential for the integration of an electronic fund transfer system within the department of economic security or contracted for by a financial institution to establish accounts of preapproved service allocations for family consumers.

4. Conduct its first meeting on or before September 1, 1996.

5. On or before December 15, 1996, submit a report of its findings to the governor, the president of the senate, the speaker of the house of representatives, the director of the department of economic security, the chairman of the house of representatives' human services committee, the chairman of the senate family services committee, the secretary of state and the director of the department of library, archives and public records.

C. Legislative staff shall provide the committee with administrative support and meeting room space.

The Committee shall report to the Speaker and the President on or before December 15, 1996.

The Committee Terminates: December 31, 1996.

Members:

1. (R) Knaperek Representative, Cochair
2. (D) Horton Representative
3. (R) Petersen Senator, Cochair
4. (D) Soltero Senator

Two parents of developmentally disabled children or adults
APPOINTED BY THE SPEAKER:

Two parents of developmentally disabled children or adults
APPOINTED BY THE SPEAKER:

3. Dorothy Sue Alig

4. Diane Hough

Two parents of developmentally disabled children or adults
appointed by the President:

5. Laura Areva

6. Judie Walker

7. Peg Kepner One representative of the Governor's
Council on Developmental Disabilities,
Appointed by the Governor

8. Roger Deshaies Assistant Director of the Division of
Developmental Disabilities in DES

9. William J. Timmons Representative of an advocacy organization
that serves chronically ill children with
developmental disabilities **APPOINTED BY THE
SPEAKER**

10. Cat Parenti Representative of an advocacy organization
that serves parents of disabled children
and adults appointed by the Governor

11. Jim Musick Representative of a firm that provides
services to disabled children or adults in
their homes appointed by the President

12. Barbara Sadler Representative of a financial institution
that provides statewide electronic fund
transfer services appointed by the Governor

13. Rudy Serino Director of the Department of
Administration, or his designee

STAFF: Chumbley

ARIZONA STATE LEGISLATURE
Forty-second Legislature - Second Regular Session

**Joint Interim Study Committee on
Developmental Disabilities Services Delivery System**

Minutes of Interim Meeting
Tuesday, December 10, 1996
House Hearing Room 4 - 1:00 p.m.

(Tape 1, Side A)

Cochair Knaperek called the meeting to order without a quorum at 1:27 p.m. Attendance was noted by the secretary.

Members Present

Senator Soltero
William J. Timmons
Peg Kepner
Frank Hinds (for Rudy Serino)
Roger Deshaies
Senator Petersen, Cochair
Representative Knaperek, Cochair

Members Absent

Representative Horton (excused)
Dorothy Sue Alig (excused)
Laura Arena (excused)
Diane Hough
Cat Parenti
Jim Musick
Barbara Sadler
Judie Walker

Speakers Present

Pat Chumbley, Research Analyst, House of Representatives
Margaret White, Planner, Governor's Council on Developmental Disabilities (GCDD)
Bev Hermon, Executive Director, Arizona Consortium for Children with Chronic Illness

Guest List (none)

Statement of the Mandate of the Committee

Pat Chumbley, Research Analyst, House of Representatives, reviewed the mandate of the Committee, as follows:

1. Research the technical means to allow families to purchase services directly from certified caregivers by means of a voucher system.
2. Assess the availability and accessibility of community resources, including informal caregivers.
3. Investigate the potential for the integration of an electronic fund transfer system within the Department of Economic Security or contracted for by a financial institution to establish accounts of preapproved service allocations for family consumers.
4. Submit a report of findings on or before December 15, 1996.

(For more details, see Attachment 1.)

Discussion of a Voucher System for Families: Barriers to Current System

Margaret White, Planner, Governor's Council on Developmental Disabilities (GCDD), said the voucher system is one of the most comprehensive family support legislative measures in the country. She noted that the measure contains no restrictions on age and is virtually "wide open."

Ms. White said the three different funding mechanisms are a voucher utilizing title XIX federal dollars, a voucher for individuals that uses state-only money without additional restrictions, and an actual cash subsidy. She noted that an evaluation piece provides that an IPP team will meet on an annual basis to review goals, objectives and the service plans.

Mr. Deshaies reported that even though the voucher program was expanded to a statewide option six months earlier, only 200 families are enrolled in the program. He mentioned DDD's surprise at the low enrollment and noted that DDD makes a point of mentioning the voucher option at public meetings.

Mr. Deshaies reviewed several issues which are barriers to participation in the voucher program:

1. From the perspective of the Internal Revenue Service (IRS), if a family purchases services with a voucher, does the family become an employer responsible for tax-related work?
2. From an IRS perspective, will vouchers be considered taxable income?

3. If an individual hired by a family is injured on the job, who will be responsible for damages?
4. The federal title XIX program prohibits factoring.

In response to Mr. Timmons, Mr. Deshaies said DDD assumes the risk for families and is attempting to set up a contract so that DDD will be viewed as the employer.

In answer to Ms. Kepner, Mr. Deshaies explained that case managers and a DDD mailer made families aware of the voucher program. In addition, he noted that the program was mentioned at a series of 28 family meetings held throughout the state during the summer.

Ms. Kepner asked whether families must be under a certain income level to participate in the voucher program. Mr. Deshaies replied in the negative.

Ms. Kepner asked if an independent developmentally disabled adult living alone would be eligible for the program. Mr. Deshaies replied affirmatively.

With regard to the independent contractor liability issue, Mr. Hinds said that in order to address the coverage issue, Risk Management would need to know the precise employer/employee relationship. Mr. Deshaies offered to send a copy of the contract to Mr. Hinds.

Cochair Knaperek noted her intention to contact Congressman Salmon's office for suggestions on the issues before the Committee. She requested recommendations on overcoming the program barriers.

Mr. Deshaies mentioned that the use of electronic benefit transfers may help expand voucher program enrollment, and result in savings by eliminating some costs associated with contract compliance. He mentioned that DDD will be piloting a technical assistance center to help guide families in the recruitment of assistants, etc.

Still lacking a quorum, Cochair Knaperek sought input regarding the Committee's options. Ms. Kepner noted that the Committee cannot possibly meet the December 15 reporting deadline. It was decided the Committee would accept public testimony.

Bev Hermon, Executive Director, Arizona Consortium for Children with Chronic Illness, said that in days past, there was much more support at the local community level. As an example, she recalled that the school districts and cities jointly sponsored summer projects which accommodated the handicapped. She said the Tempe ARC currently has its own thrift shop and usually offers a free program every night of the week in addition to weekend dances and activities designed to normalize the lives of developmentally disabled individuals. She suggested that Arizona State University is tremendously underutilized, considering the number of students who require experience with the developmentally disabled and could participate in internships.

Ms. Hermon stated her belief that the combination of localized case managers and empowered parents would make it possible to keep developmentally disabled children within their respective communities.

Cochair Knaperek requested a report of DES's progress in working with electronic benefit transfers.

Bob Gilligan, Legislative Liaison, Department of Economic Security (DES), advised the Committee that electronic benefit transfers (EBT) have been utilized across the country for years in the form of pilot projects for the food stamp program. He reported that such programs were not more widely implemented because technology such as card readers in grocery stores has only recently become common. He said a second deterrent to EBT technology was a regulation which would have held the state liable for fraud exceeding \$50 on such a card. He reported that the welfare reform bill signed by President Clinton eliminated the problem of states being held liable for this type of card fraud.

Mr. Gilligan noted that if an EBT program proves successful in the state of Washington, the technology could hopefully be made available to other states by the same vendor which would reduce start-up costs. He stated DES's hope that the legislature will appropriate a couple hundred thousand dollars for planning.

Mr. Gilligan expressed hope that EBT technology will address the perceived problem of fraud, particularly with regard to the buying and selling of food stamps.

Mr. Deshaies said EBT cards would limit the consumer to using certified providers of services which DDD is authorized to reimburse. He noted that the mechanics of the program have yet to be determined.

Mr. Timmons mentioned that an article he wrote eleven years earlier regarding EBT technology addressed the food stamp system and day care payments. He said that although the program was approved and funding was made available, matching funds were unfortunately interrupted as a result of internal DES politics.

Mr. Timmons commented that a magazine entitled EBT Today is published on a monthly basis.

Ms. Kepner asked if only families currently enrolled in the voucher program would be eligible for EBT technology. Mr. Deshaies replied affirmatively.

In the wake of the welfare reform bill, Mr. Hinds inquired as to which entity will be held responsible for fraudulent use of EBT cards. Mr. Gilligan shared his belief that the card holder will be held liable for fraud.

Mr. Timmons remarked that a national research institute on EBT has shown that technology is capable of providing acceptable safeguards. However, he stated his opinion that abuse of an EBT system would be most likely to occur at the white collar level.

Cochair Knaperek requested that copies of Mr. Timmons' article be distributed to Committee members.

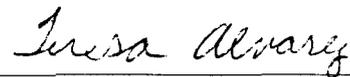
Cochair Knaperek assigned a variety of homework projects to Committee and staff members.

With regard to the voucher program barriers mentioned by Mr. Deshaies, Ms. White said she has heard complaints that the implementation process is very slow due to the amount of hoops families must jump through. She suggested the Committee do an in depth study of the program barriers.

Mr. Deshaies speculated that the voucher program is not popular simply because of the barriers and the probability that some families are satisfied with their current situation. Further, he reported his belief that the program has not expanded options in rural areas.

After some discussion, the Committee decided to schedule the next meeting for December 18 at 10:00 a.m.

Without objection, the meeting (which never had a quorum) ended at 2:21 p.m.



Teresa Alvarez, Secretary

(Original minutes with attachments and tape on file in the Office of the Chief Clerk. Copy of minutes with attachments on file with Cochair Knaperek and Cochair Petersen. A document present during the meeting but not specifically referred to is included as Attachment 2.)

ARIZONA STATE LEGISLATURE
Forty-second Legislature - Second Regular Session

**Joint Interim Study Committee on
Developmental Disabilities Services Delivery System**

Minutes of Interim Meeting
Wednesday, December 18, 1996
House Hearing Room 1 - 10:00 a.m.

(Tape 1, Side A)

Cochair Knaperek called the meeting to order at 10:10 a.m. and attendance was noted by the secretary.

Members Present

Senator Victor Soltero
Representative Herschella Horton
Roger Deshaies
Frank Hinds (for Rudy Serino)
Jim Musick
William J. Timmons
Judie Walker
Representative Laura Knaperek, Cochair
Senator David Petersen, Cochair

Members Absent

Dorothy Sue Alig
Laura Arena
Diane Hough
Peg Kepner
Cat Parenti
Barbara Sadler

Speakers Present

Bev Hermon. Executive Director. Arizona Consortium for Children With Chronic Illness
Marta Urbina. Parent of a 15-year-old daughter with developmental disabilities; Staff Person, Pilot
Parent Partnerships
Margaret White. Planner. Governor's Council on Developmental Disabilities (GCDD)

Guest List (Attachment 1)

* * *

Introduction of Members

At the request of Cochair Knaperek, Committee members briefly introduced themselves.

Statement of the Mandate of the Committee

Pat Chumbley, Research Analyst, House of Representatives, reviewed the mandate of the Committee, as follows:

1. Research the technical means to allow families to purchase services directly from certified caregivers by means of a voucher system.
2. Assess the availability and accessibility of community resources, including informal caregivers.
3. Investigate the potential for the integration of an electronic fund transfer system within the Department of Economic Security or contracted for by a financial institution to establish accounts of preapproved service allocations for family consumers.
4. Submit a report of findings on or before December 15, 1996.

Discussion of a Voucher System for Families; Barriers to Current System

Mr. Deshaies noted that approximately 200 families are currently enrolled in the voucher program operated by the Division of Developmental Disabilities (DDD). He added that the voucher program began as a pilot project and has since been expanded on a statewide basis.

Mr. Deshaies explained that for program recipients not enrolled in the Arizona Long-Term Care System (ALTCS), DDD will offer families the opportunity to receive cash through contracts. In cases in which an individual is enrolled in ALTCS, he said a voucher will be provided which authorizes certain privileges. He explained that ALTCS enrollees cannot receive cash payments because federal requirements pertaining to third-party reimbursements prohibit the giving of actual cash.

Mr. Deshaies asserted that the greatest barrier to expansion of the voucher program is bureaucratic red tape. For instance, he explained that because of the Internal Revenue Service (IRS) definition of an employer/employee relationship, some families and the DDD are concerned that families will be viewed as an employer for purchasing services with a voucher and, as such, will be forced to fulfill tax reporting requirements, etc. He pointed out that in the foster care arena, reimbursement for services is considered hardship and is not taxable.

As a final barrier, Mr. Deshaies explained there is some question as to what party will be held liable should a provider injure himself while delivering services in a home. He said interpretations are varied, and that the inability to issue a clear answer further discourages participation in the voucher program.

In response to Senator Soltero, Mr. Deshaies indicated that the majority of insurance companies will not provide coverage for an individual who sustains an injury while caring for someone in the home because such a situation is viewed as an employee/employer matter. He added that in two such instances, DDD and Risk Management provided coverage for an injured person in order to avoid a court case.

With regard to barriers, Mr. Deshaies admitted that DDD has not done a good job of marketing the voucher program as an alternative. He said efforts are being made to identify resource people in each district office who can make themselves available to families and provide assistance with screening applicants, writing newspaper ads, etc.

Mr. Deshaies reported that in rural areas, the move toward individual funding and family control can result in management problems for small agencies. For instance, he said that if some small providers are not guaranteed a base amount of business, problems will arise with regard to staffing needs.

Mr. Deshaies said one requirement which does not make sense stipulates that a caregiver must take seven or eight core training classes (e.g., CPR, first aid) even if he or she is a trained health care professional.

In response to Ms. Horton, Mr. Deshaies said the core training requirements are prescribed in rules, and that it is within the ability of DDD and the Arizona Health Care Cost Containment System (AHCCCS) to modify or interpret such rules.

Ms. Horton said that as a registered nurse, she is required to take cardiopulmonary resuscitation (CPR) training each year. She said those who seldom use CPR have need of regular training, and she suggested it be carefully considered whether or not to eliminate training which may save a life.

In response to Cochair Knaperek, Mr. Deshaies estimated that any modification to the rules would take between ten and twelve months for adoption.

Mr. Timmons asked if Health Care Finance Administration (HCFA) approval will be required to modify AHCCCS-related regulations. Mr. Deshaies answered affirmatively, explaining that an amendment to the waiver must be submitted to HCFA for approval.

Cochair Knaperek asked if DDD has approached AHCCCS about changing the HCFA waiver. Mr. Deshaies reported that proposed changes to the HCFA waiver were submitted to AHCCCS for consideration several weeks earlier.

Ms. Chumbley referred to a memo from Terree Wasley (Attachment 2) of Congressman Salmon's office regarding federal employer tax issues for families coping with developmental disabilities. She reviewed item #1, as follows:

- 1) If families do not use a debit card to purchase services, payment for services should go directly to the provider.

Mr. Deshaies remarked that item #1 addresses factoring or, more specifically, situations in which the presence of a third party interferes with Medicaid payments.

Cochair Knaperek mentioned that in a telephone conversation which took place prior to the Committee meeting, Ms. Wasley indicated that HCFA was noncommittal about item #1 even though it liked the idea of a debit card for services.

Ms. Chumbley reviewed items #2 and #3 from Ms. Wasley's memo, as follow:

- 2) Regarding the independent contractor law, the Internal Revenue Service (IRS) would review each case separately or the state may request a waiver or a letter from the IRS stating that they would not prosecute for any violations of the independent contractor law.
- 3) Regarding the factoring issue, HCFA said it was uncertain whether Arizona has requested a waiver for this practice.

Cochair Knaperek reported that Ms. Wasley was unable to secure definite answers from HCFA or the IRS. Mr. Deshaies said that in his discussions with the IRS, it was made clear that an individual who directs the work of another is classified as an employer.

Mr. Hinds, attending on behalf of Rudy Serino, identified himself as a Property and Liability Claims Manager for Risk Management and said he researched A.R.S. 41-621 to determine whether Risk Management could cover on-the-job injuries suffered by providers. He reported that Risk Management has covered two such cases in the past, but pointed out that A.R.S. 41-621(B) was modified during the 1996 legislative session to clarify that medical coverage was never intended to become part of the Risk Management provider program. He read an excerpt from A.R.S. 41-621(B) (Attachment 3), as follows:

“... The insurable programs shall include foster care, programs for the developmentally disabled, an independent living program pursuant to section 8-521 and respite-sitter service programs. The department shall obtain insurance or provide for state self-insurance pursuant to this subsection to protect the clients participating in these programs and individual providers of these program services on behalf of the state and its departments, agencies, boards or commissions...”

Mr. Hinds concluded his remarks by stating that as long as providers are of the type covered in statute, liability coverage will be provided for them with the exception of medical and workmen's compensation.

Cochair Knaperek asked whether the Department of Administration (DOA) could send a letter to DDD stating that coverage will be provided. Mr. Hinds indicated no objection.

Discussion of the Availability and Accessibility of Community Resources

Bev Hermon, Executive Director, Arizona Consortium for Children With Chronic Illness, reported that the communities of Tempe, Mesa and Tucson have developed programs for community members experiencing certain problems. She recalled that when her developmentally disabled child was in school, programs were developed jointly between the city and school. Further, she said that Boy Scouts, Girl Scouts and churches were once much more involved with handicapped children and their families.

Ms. Hermon speculated that the advent of federal monies resulted in more institutionalization, and subsequent loss of community involvement.

Ms. Walker noted that some areas have seen a resurgence of community involvement. She said children with developmental disabilities are increasingly included in community activities. She lauded the advances which have allowed developmentally disabled children to remain in their homes and communities while receiving care.

Cochair Knaperek requested an example of how the voucher system can improve matters for families of the developmentally disabled. Ms. Walker said her family is not involved in the voucher system because participation would merely interfere with family life. She said that providers who enter the home deliver very personal services, and that caregivers made available through an agency may not meet a family's needs or values. As an example, she explained that her teenage son is not a morning person, and can have either a good or bad day based on whether or not his bath goes smoothly. In addition, she stated her preference that a provider be able to interact positively when out in the community with her son because children learn from such interaction.

Ms. Walker summarized that it is critical for families to have a say in selecting caregivers because there are bad eggs in every industry.

Discussion of Implementation of an Electronic Fund Transfer System for Families

Mr. Timmons referred to an article entitled Arizona EBT Project (Attachment 4) and recalled that several years earlier, the Department of Economic Security (DES) applied for federal grant monies to implement an electronic benefit transfer (EBT) system for programs such as Aid to Families with Dependent Children (AFDC), food stamps and day care. He reported that even though the grant was awarded, program implementation unfortunately never occurred as a result of political infighting.

Mr. Timmons summarized that the idea behind the EBT system was for an applicant to apply for benefits and, once eligible, have a benefit type and dollar amount programmed onto a debit card with a personal identification number (PIN). He said such a debit card could then be swiped through a card reader at a grocery store.

With regard to day care, Mr. Timmons explained that a card-swipe system must work differently because the day care industry is time oriented, as opposed to cash oriented. In such a scenario, he said a point-of-sale device installed in a day care center would have to have access to information on all individuals eligible for day care services, as well as their benefit type and subsidy amount.

He said that a parent would swipe the debit card upon dropping off and picking up the child, and that a check for services would be mailed to the day care center two days later.

Ms. Horton mentioned that barriers to similar card-swipe programs have been hotly debated for at least six years. She recalled that in rural areas, small "Mom 'n Pop" grocers testified against such programs because only the larger grocery stores would be equipped with card readers. Mr. Timmons reported that a demonstration project was implemented in Mesa and that the willingness existed to install point-of-sale devices in Mom 'n Pop stores. He expressed doubt, however, that small grocers could be equipped on a statewide basis.

Cochair Knaperek diverted attention from food stamps to providers.

Mr. Deshaies explained that in the State of Maine, a program was instituted which allowed individuals, through a modem, to bill electronically. In rural areas, he said an electronic billing location was made available to people in return for a small fee. He said that within seven days of billing, an account was electronically credited for reimbursement.

Mr. Deshaies commented that a program is envisioned for the Lake Havasu City/Kingman area which would allow contracting with a provider to furnish point-of-sale technology.

Cochair Knaperek mentioned that Ms. Kepner could not attend the meeting but mailed in some suggestions. She recalled that Ms. Kepner's recommendations were to disseminate information through a newsletter and a mailing to prospective families. Mr. Deshaies remarked that mass mailings have not been attempted.

Marta Urbina, Parent of a 15-year-old daughter with developmental disabilities; Staff Person, Pilot Parent Partnerships, began explaining the mechanics of an individual service program plan (ISPP).

Senator Soltero requested insight into some of the services available to the developmentally disabled.

(Tape 1, Side B)

Ms. Urbina said her daughter has cerebral palsy and must use a wheelchair, in addition to having visual impairment and an inability to communicate verbally.

Ms. Urbina explained that an ISPP is a process by which a case manager sets dates with the family. She stated that her daughter is eligible for ALTCS, and that the ALTCS eligibility process is very cumbersome and intrusive for a family. She said the eligibility process focuses on medical needs, using "at risk of institutionalization" as a criteria, and financial status. She mentioned that it is very intrusive for an outsider to review your bank statements, bonds, employment status, income, and expenditures. Further, she indicated that financial eligibility must be redeemed on a yearly basis.

Ms. Urbina explained that she sustained a back injury two years earlier while moving her daughter. As a result, she said the family has made concessions and now has a "Mr. Mom" who functions as a full-time caregiver. In addition, she said her daughter receives respite services and attendant

services for personal care such as bathing. She emphasized that the family must trust and develop a good relationship with any caregiver who enters the home.

Ms. Urbina said that although a voucher looks marvelous on paper and seems to give the flexibility to hire or recruit individuals, the program requirements effectively form a barrier.

Ms. Urbina invited Senator Soltero to visit her home and observe the ISPP process firsthand. Cochair Knaperek suggested that Cochair Petersen may be interested in the offer.

Cochair Knaperek inquired how best to enhance programs for the developmentally disabled. Ms. Urbina shared her belief that efforts are focused in the right direction in terms of providing flexibility. She reported her biggest obstacle to be the amount of time expended on recruiting providers. She added that she, like many other families, manage to recruit providers only to lose them as a result of program delays and bureaucratic red tape.

Ms. Walker asserted that electronic reimbursement could play a critical role in eliminating the paperwork backlog which sometimes forces caregivers to leave the employ of families to seek work elsewhere.

In response to Cochair Knaperek, Ms. Urbina said that ISPP case managers advised her family of the pilot voucher program. She said she believed the program would give her more control in recruiting individuals, and the freedom to avoid utilizing agency providers.

Cochair Knaperek asked how families are made aware of the voucher program. Mr. Deshaies said case managers may advise a family of the program, or a family may place a call to a DDD district office.

Cochair Knaperek and Mr. Deshaies discussed the mechanics of participation in the voucher program.

Ms. Walker pointed out that, sometimes, a very small expense will allow her son to participate in an existing program. However, she said it is a very undesirable prospect to suffer through a lot of paperwork in return for enrollment in a six-week program. She asserted that rural areas do a better job of meeting community needs and added that families should not be forced to relocate to cities to access services for the developmentally disabled.

Margaret White, Planner, Governor's Council on Developmental Disabilities (GCDD), shared her belief that the family support bill which was adopted several years earlier would answer the issues addressed by the Committee. She expressed sadness that the implementation process has been so slow.

Ms. White expressed her hope to see government place more trust in families because it is the family that will make the best choice for an individual with developmental disabilities. She recognized paperwork and a lack of trust in families as major program barriers.

Ms. Walker stated that some entity must pay for the army of people who fill out and shuffle pieces of paper. She emphasized that if government cannot do the right thing by placing its trust in families, it should at least do the right thing for the simple reason that it will remove layers of administration. She dispelled the idea that families lay awake at night wondering what new services they can "pack on" because each new service represents a major intrusion into a family's life.

Ms. White acknowledged the efforts of individuals and said Mr. Deshaies has been wonderful in his attempts to fix the system. As an example of program setbacks, Ms. White explained that a group of people met to discuss an implementation plan and to develop rules, and were discouraged to find that the final rules basically negated the concept of flexibility by requiring that families meet various requirements and jump through an assortment of hoops. She suggested that families simply be given a flat \$200 per month.

Mr. Deshaies admitted to encountering difficulty in finding a balance between flexibility and accountability which state agencies need for reporting purposes. He said the situation is further compounded by input from legal experts whose goal is to limit liability to the state.

Cochair Knaperek stated that rules are not supposed to supersede statute. Mr. Deshaies shared his opinion that legislative intent is clear and that DDD must do a better job of finding a balance.

Cochair Knaperek suggested the Committee could focus its attention on DDD if that entity were a stand-alone agency which was not shrouded by DES.

Recommendations

Ms. Horton suggested that rules be reviewed carefully so as not to sacrifice safety in an effort to attract more providers. She also suggested DDD and other agencies streamline their paper flow in an effort to become more user friendly to consumers. She further recommended that a committee be created to provide ongoing oversight of the developmental disabilities services delivery system.

Cochair Knaperek recommended the following:

- 1) Submit Risk Management's findings, in written form, to the Division of Developmental Disabilities as soon as possible.
- 2) Develop an aggressive marketing strategy.
- 3) Reduce paperwork and initiate an electronic benefit transfer system.
- 4) Draft legislation requiring the Division of Developmental Disabilities to begin an electronic benefit transfer pilot program in at least one urban and one rural county.
- 5) Separate the Division of Developmental Disabilities from the Department of Economic Security.

With regard to item five, Senator Soltero stated his desire to postpone a decision. Ms. Horton pointed out that item five would expand state government. She said the Committee should instead wait to study the findings of an ongoing oversight committee.

Cochair Knaperek countered that DDD currently pays administrative fees to DES. She voiced her belief that if broken out as a separate agency, DDD could continue contracting with DES for administrative services, thereby avoiding the creation of more bureaucracy.

(Tape 2, Side A)

Ms. Horton suggested an oversight committee examine the feasibility of creating a new department.

Mr. Musick said that as a provider, he would like to see DDD aggressively expand the voucher system into other areas.

Ms. Walker remarked that if the voucher system is to be expanded, families must be assured in writing that any conflict with the IRS has been resolved. Ms. Horton recommended written clarification be obtained from the IRS, but also cautioned that IRS clarifications are nonbinding and can be reversed at any time. Cochair Knaperek suggested the congressional delegation may be able to get clarification from the IRS.

Cochair Knaperek recommended DDD expand the voucher program and direct more monies into the family support line item. Ms. Horton mentioned that such action is available to legislators through the regular appropriations process.

Ms. Horton repeated her idea of working with Cochair Knaperek to develop a joint oversight committee comprised of legislators and others.

Without objection, the recommendations were adopted.

Without objection, the meeting was adjourned at 12:13 p.m.

Teresa Alvarez, Committee Secretary

(Original minutes with attachments and tapes on file in the Office of the Chief Clerk. Copy of minutes with attachments on file with Cochair Knaperek and Cochair Petersen.)