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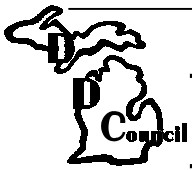

MondayUpdate

March, 2004

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Consumers, advocates concerned

Disability community joins forces, protests Home Help cuts

The Home Help Services program was in deep trouble last fall. Services were about to be cut for people with disabilities and seniors who rely on support services in their homes.

The response from consumers of these services and other advocates was unprecedented. It was the first time so many people raised their voices on behalf of people with disabilities!

It began last Sept. 26 when major reductions in Home Help Services were announced by the Michigan Department of Community Health (DCH)…$17 million worth of cuts in services that could drastically change people's lives and even send some to group homes. It was a time for people to step forward and raise a collective voice in protest of the impending losses.

Home Help Services is a Medicaid program that pays for home assistance to people and seniors in Michigan who cannot provide certain common elements of everyday life, such as bathing and shopping for groceries.

Because of the state's budget crunch, the state determined there was not enough money to continue funding Home Help at the same level. This would mean reductions to, among other things, salaries of the support personnel who provide in-home help.

The proposed changes were first scheduled to take effect Dec. 1.

But quick reaction by those who would suffer the losses resulted in meetings with state officials to voice opposition. The state's long-standing advocacy network, made up of people with disabilities, their family members, advocates, service organizations, rallied to the cause. A coalition was quickly formed from the network. Members wrote letters, made phone calls and knocked on doors, meetings with the Governor and other state Medicaid officials were arranged.

Network is effective

Marsha Moers, chairperson of the DD Council's Capital Area RICC (Regional Interagency Coordinating Committee), says the protest was formed in less than 10 days. "Someone said, 'We don't have much time,' and things took off from there." She says this was a good example of how effective a network can be.

Moers points out that the protest was a time for consumers to do the talking. "We have advocates who are very eloquent, but it was important we speak for ourselves."

Ellen Weaver, director of the Capital Area Center for Independent Living, said, "Finally, people spoke as one voice."

The protestors organized a rally at the Capitol Building that was loud and very well attended. Home Help consumers protested alongside support services workers. Advocates say they have never seen such a voice raised on behalf of people with disabilities and seniors. Moers estimates the crowd at 400 to 500. Weaver points out a major purpose of the rally was to "thank the Governor for listening."

The result of all this activity? After the meeting with the Governor and the protest at the Capitol, DCH agreed to meet with representatives of the movement and considered the input from all sides and issued a new set of changes in the Home Help Program in January. The protesting had an effect because the final, March 1 cuts are not the same as those proposed back in the fall.

The state had originally proposed fixing a flat salary rate for support workers -- $6 per hour – rather than letting individual counties set pay scales according their local economies. DCH has apparently dropped this idea.

Limited hours

Another proposal limited hours of monthly support a person could receive. For example, a person would be limited to seven hours of help with laundry, six hours for housework, and five hours for shopping. These limitations were kept in the new policy.

Also kept in effect from the proposals is a new provision that says for a person to get help with cleaning or cooking or shopping, he or she must also require help with personal care, such as bathing or eating.

Still, most advocates and consumers say they are pleased with their victory, especially keeping the pay scale policy intact.

However, say people with disabilities and advocates who were on the front lines during the period of protest, don't put away the placards just yet; the state budget is still in trouble and further budget cuts are on the way. The fight to retain basic, necessary services has just begun.

These recent cuts are, in part, a response to more need for fewer resources that begins at the federal level. There is just so much money to go around and today's federal government priorities place increasing emphasis on other items, such as military and security expenses.

Band of advocates

It was always clear last fall what advocates were protesting: people living independent lives being sent to nursing homes or being placed in harm's way.

Those advocates who met with the Governor included some familiar names: Elmer Cerano of Michigan Protection and Advocacy Services, RoAnne Chaney from the Michigan Disability Rights Coalition, Ellen Sugrue-Hyman of UCP Michigan and the Olmstead Coalition, and Ellen Weaver and Marsha Moers of the Capital Area Center for Independent Living.

Various legislators rallied to the cause with verbal support and even some hearings in Grand Rapids and Detroit. These featured a panel of lawmakers who heard testimony from consumers of the services to be cut. More than 100 advocates attended at each site.

Besides the meeting with the Governor and the rally in front of the Capitol, also key were the three meetings held with DCH Medicaid officials. Attending, besides Chaney, were Norm DeLisle from the Michigan Disability Rights Coalition, Dohn Hoyle of Association for Community

Advocates, the Howell Group and Arc Michigan, Mary Ablan of the Michigan Area Agencies on Aging, and Linda Potter and Ellen Sugrue Hyman of UCP Michigan.

According to Potter, advocates "reviewed each issue one by one. The department then came up with a summary of the issues, which was mailed to each advocate. Advocates then reviewed and returned the summary with comments."

Potter says the advocate groups' comments ranged from complete dissent to complete agreement with the issues as provided in the department's summary. Also provided were alternatives. "You also have to provide solutions," notes Ellen Weaver. "You can't just say, 'no cuts," and let it go at that."

Who recertifies?

Other issues on the table included a requirement by the state that FIA (Family Independence Agency…responsible for managing Home Help Services; Medicaid money to finance the program is managed by DCH) receive an annual recertification by a physician (agreed, as long as there were some additional providers such as nurse practitioners); limiting help to those who also need other assistance (agreed, as long as there was an acceptable exceptions process begun by the client); one hour allowed for meal preparation (disagreed).

"I was very worried that the Home Help system would deteriorate badly and people would end up in nursing homes," Potter states. "It was one of the most significant challenges to the state's declared goals of independence and self-determination that I've seen in awhile."

RoAnne Chaney says she was optimistic the final result would be less drastic cuts based partly on the reception by the Governor to the issues. "She was very receptive to our concerns," says Cheney, "and has, I believe, issued a directive that consumers and advocates be consulted before such policy changes are announced in the future. I think she wants input from all stakeholders."

Cuts dangerous

Had the complete reductions gone through, she adds, "A number of people would be placed in a dangerous situation. At risk would be people's health and safety." Cheney estimates that about half of support workers are not family members or others who have more than a financial commitment to the services consumer. Lower wages for these already-unpaid workers, she figures, would mean many of them would just walk away.

Another effect that is not often discussed, says Weaver, is that cuts in funding will mean even more physicians in Michigan leaving Medicaid completely. "We've lost enough as it is."

Chaney also disagrees with these cuts. "Many of the people who receive these supports are, I think, really living on the edge. They're barely making it. Adding these cuts to that kind of lifestyle is beyond understanding."

Need the experience

Norm DeLisle says, "Some of the cuts are going to happen regardless. That's for certain." He says consumers and advocates must prepare a strategy immediately. "Most of the coming budget cuts that will affect seniors and people with disabilities are the result of an abstract notion - the people who proposed those cuts have no idea how folks with disabilities and senior citizens must approach living and, for instance, the need to pay for Home Help, when they are actually very poor."

Advocates believe that if a person has few resources, they constantly must to make decisions in crisis.

Rather than dwell on the cumulative benefits of a particular program, a person who relies on Medicaid services must be concerned with just getting through the next week. Cutting a service like Home Help doesn't make the week any easier.

Less costs more

The irony is that cutting funds for these supports may cost more in the long run. If a person with disabilities no longer receives this help at home, he or she may have to move to a group home. Living in a group home – which is also paid for by Medicaid – is much more expensive that the present cost of providing Home Help.

In fact, keeping people out of group homes is a main objective of Home Help Services. In FIA's description of programs, Home Help Services' goal "is to prevent and reduce inappropriate institutional care by maintaining or restoring independent living for aged, blind, and disabled individuals who have functional limitations."

Council speaks out

The DD Council also officially protested the cuts and sent a letter to DCH expressing the Council's extreme concern about the proposed cuts. Council member Andre Robinson, also chair of the Public Policy Committee, signed the letter.

In the letter to DCH, Robinson said about the possible pay cuts for service providers: "Home Help recipients already face difficulty attracting and retraining honest, responsible, competent providers at the current pay rate.

"In many counties, the proposed rate will be less than the current rate, so entry-level fast food jobs will be even more attractive."

In the letter, Robinson focuses on the "critical factor" that may be reduced in the cuts. They are "IADL supports" and Robinson says these may be the element that keeps people with disabilities staying at home.

"IADL" stands for Instrumental Activity of Daily Living. These are the supported activities might include nearly any routine required to keep a household running: doing the laundry; getting a meal on the stove; and going to the store for groceries.

It is easy to see what sort of life a person might have if IADL services are stopped. Robinson also expressed concern for people with disabilities who have children and what might happen to these children should IADL support cease.

Pay rate to be cut

In the Council's letter, Robinson took issue with the requirements of the proposed cuts, including requests for exceptions to the cuts; procedures for requesting exceptions; and proposed $17 million savings nullified by the cost of sending recipients who have been deprived of services to institutions.

Robinson says "This proposal should not be implemented because it will place many people at risk, and the state may actually spend more, not less, on their supports."

Advocates agree this is just a beginning. Tony Wong of the Michigan Association of Centers for Independent Living (MACIL) observed that the many voices raised in protest to the cuts "were a clear demonstration of the impact that organized consumers can have. But we must see it as practice for the tougher battles ahead."

Ellen Weaver wants to consumers and other advocates to plan to attend the upcoming budget hearings. "People are going to have to react, contact their legislators and give them their stories." She recommends joining a local organization

that shares concerns, such as a RICC or "Capital Area CIL's new advocacy group."

Marsha Moers points out "we've had at least the last 10 years to get ready" for strong advocacy occasions such as the proposed Home Help cuts. She traces the foundations of this protest back 14 years to the first Event, a gathering of consumers and advocates in Lansing funded by the DD Council. The Event featured a march on the Capitol of some 800 people. "This gave us practice in creating a common agenda and responding to short notice.

"We also have established the practice of being a constituency. I felt that if these supports went away entirely, everything else would go, too. We're talking about independent living. It's the theory of the three-legged stool: you need a place to live, you need transportation, and you need personal assistance. Take one away and you fall right over."

But Moers admits, even with the cuts, times have changed for the better. "Fifteen years ago, nobody would have paid any attention to us, and would have told us to go away."

For more on upcoming hearings, joining RICCs, the new cuts and the state budget, contact the DD Council office at 517-334-6123.

People 'Speak Out' in Berrien RICC mini-grant

Speak Out is a Berrien RICC (Regional Interagency Coordinating Committee) mini-grant that has shown great success this year.

The grant is titled Nothing About Us Without Us. Participants shortened the name to Speak Out.

This project in southwest Michigan has been helping people with disabilities learn to speak out and tell their own stories. The main goal has been to improve their ability to make presentations to the general public, and to get their point across to legislators and other policy makers.

In the process, the project has dramatically changed people with disabilities. People with disabilities are getting braver and have more courage to express themselves. Involvement with others brings higher levels of satisfaction and self-esteem.

Making a difference

The project has made a difference in the lives of the participants and created systems change. The benefits went beyond the expected effects of the project. The opportunity to have others listen to their stories, and to hear similar stories from others, has created strong bonds between people in the project. It has given them more confidence, and overcome feelings of isolation. One person spoke at a court hearing and succeeded in having her guardianship terminated.

Mentors such as pastors, Toastmasters Club members, and media personalities worked with the group and gave them speaking tips and pointers.

Successes are numerous

Individual project successes include: Bob spoke out at the Local Advisory Committee (LAC). Sharon and Jane presented several times at the Regional level of Ventures Behavioral Health Committee. Mark and Carrie facilitated and presented their ideas at their person-centered planning meetings.

Connie joined the Kid to Kid Art program committee and spoke on behalf of children with disabilities. Hank, Rob and Sal attend monthly Community Mental Health board meetings and at each meeting present challenges that need to be addressed. All of

the self-advocates wrote letters to support their perspectives on recent actions reducing services by the governor.

Susie actively spoke up on her behalf and closed her case at the Michigan Department of Community Health. She wrote her story and continues to update others on her progress. James prepared his presentation for a local conference and had it delivered via tape (since he is non-verbal). Donna prepared her own person-centered planning notes and wrote her own personal story, in hopes that other will get to know her better and treat her with more dignity. She has given her presentation at least four times.

The project was instrumental in getting the needs and contributions of people with disabilities on the agenda of the Council for World Class Community, which is working for the betterment of Benton Harbor and Berrien County.

Of the 46 participants, 41 percent are from minority groups, including 16 African American, two Latino, and one Native American. One self-advocate is paid by project.

The people who spoke at the Michigan Rehabilitation Conference in November and October's Connecting to Your Community Conference showed the impact of the training. They were articulate in sharing their stories. In most cases they had a clear message or point to the stories. Although their skill levels varied widely, all showed progress in being able to speak up for themselves. One excellent use of technology was the use of a tape recording of the written words of someone who speak in ways other than vocally

For more on this successful project, contact Kathy Ellis, 269-925-6422, Community Connections, 133 East Napier, Benton Harbor, MI 49022.

Council committee and work group meeting minutes

Here are minutes from recent meetings of the Council's committee and work groups.

Multicultural Committee

Oct. 13, 2003.

Attending: Terry Lerma, Chair, Larry Betz, Angie Zamora, Theresa Arini, Pam Hall, Mitzi Allen and Rick Van Horn.

Lerma called the meeting to order.

Lerma added another item to New Business…the multicultural presentations to the council.

Introductions not necessary!

Old Business. Discussion continued regarding possible outreach collaboration with the Genesee RICC. Hall reported talking with Kathy Flowers, RICC chair. The latter said the RICC was interested in a partnership for outreach and that she forwarded the Committee's collaboration to coworker Linda Garrett who works with Flowers.

Allen reported that Garrett is a good resource for outreach in the Flint community. Garrett said to get the project up and running, send out letters, etc., and then Garrett would contact her sources to invite them to join in. However, Allen pointed out, it was the Committee that extended an invitation to the RICC to collaborate and the Committee expected the RICC to take the lead, it being located in the community. The partnership function/event has been viewed

as a direct benefit to the RICC as well as the council.

As for funding the function, the Committee has $1,500 to spend on such things. Regarding the outreach project, Allen asked, "What are we trying to do?" Betz voiced concern over division of labor – Committee and RICC – involved in the project. The project requires that organization efforts be local – in Genesee County, from Flint. Easier than trying to run the project from Lansing where most Committee members are from.

Lerma recalled the initial project idea said that each community has key organizations to help the Committee reach out through an organized event to diverse communities. Using a theme or topic, provide refreshments to attendees gathered there through the efforts of local community groups and leaders, reach out, hook a few people into becoming involved in community disability interests. The suggested theme actually seemed to be more about recruitment than dispensing information. For this initial outreach effort, and since funds are limited, the Committee may wish to keep the event simple.

Betz emphasized that the outreach effort must rely on the local RICC to carry the weight, since the committee and many of its members are some distance away and would not be as effective.

Could the very successful Family Outreach Program that the council collaborated on be used as a reference for the Committee's effort? Allen said there was no follow-up with participants, no idea if they finally got into the disability network. But there may be access to the collaborators' database. There was also Outreach Program support from local Arcs and RICCs. People signed in during the event and signed up for transportation if needed.

Betz restated the goals of the proposed Committee outreach program: Awareness, education and recruitment. He underlined the need for community residents to have a part in organizing the outreach. Lerma asked, with education and awareness as objectives, what intersection between cultural and disability is really going to appeal to the local organizations that need to be involved who haven't been before?

Betz responded by also asking: How do we help people to see that it is to their advantage to become involved in the local RICC as a means toward shaping the policies, locally and statewide, that influence the services that they and their families require? He also pointed out that the Genesee RICC is outside the City of Flint in an area not very diverse.

In light of that, Allen pointed out, should the Committee outreach project contact leaders within communities to see if they were interested in collaborating? If these leaders get involved and invested, they will make certain their groups and organizations get the word about the event. For example, Allen noted, there are probably many black ministers around the state who preach each Sunday who are not at all aware of disability advocacy, or how to get services for same. Hall noted that in some cultures, the church is not the place to get support for disability outreach.

Lerma referred to the list Linda Garrett is to provide. Who on the list might be the most willing to join the outreach effort? With cuts in service promised and voting not an effective way to voice concerns, people may be looking for other avenues of protest over the approaching service cuts.

Betz said the next step, in order to move forward, is to get input for local people. First, in terms of this project, there needs to be ownership on the part of the RICC in that area. They know the territory and can gather the names needed for contact. But first, the vision of the outreach project must be explained to the RICC people, so there is a common vision. Hall believes there is already a common vision. What is needed now is a buy-in, one larger than the disability community.

Hall said the Committee should not be so focused on the RICC's involvement that the Committee overlooks other potential, suitable partners. The community's Urban League, The Family (John Sanford-led organization), seniors' groups and aging agencies are examples…common agenda items. Such groups have hands-on ties to their communities. Zamora told of a church in the Flint community that has very strong outreach. The Committee just needs more partners than the local RICC to pull this outreach project off. Look outside the box for additional partners. Ask Linda Garrett for faith-based contacts inside the Flint communities.

Hall proposed writing a form letter as an invitation to community individuals to come to the December Committee meeting. This is where the buy-in must start. Lerma will write the letter, Allen will mail to a specific list of possibilities. Personal calls should precede the letter where possible. Betz says the Committee may wish to do a little mining (research) to come up with names for the letter. Allen said the Committee must make certain it is well prepared for this meeting.

He asked what does the Committee wish to accomplish at the Dec. 8th meeting? Why do community people wish to be involved with the RICC? Names of possible invitees were discussed. Where should the meeting be held? Betz may secure a room in the state office building in Flint for the meeting. Suggested times for the meeting are being considered. Lunch should be provided.

V (b) - Allen suggested looking for ways to involve the people who have been to past Committee meetings in Committee activities. This is perhaps a method for improving meeting attendance and getting projects' support at the same time. Lerma suggested asking those former meeting attendees if they are still interested in the Committee. Allen said other council committees are also experience drops in meeting attendance. A letter from Lerma will be sent to missing Committee members ("Are you still interested"?). Possible details of the letter's message were discussed. Lerma postulated that as state services are cut, there might be an increase in advocacy, membership in advocacy groups. (VI-c) The Committee reviewed and discussed former meeting attendees, in addition to possible new members.

Allen said the December 9th Council meeting's multicultural contribution will feature Thomas Gunnings, an African American psychologist. Discussion followed about the success of the two previous diversity speakers at council meetings. Further discussion on future council meeting topics/speakers supplied by the Committee. So far, topics have been of a general nature. Future speakers could address more specific issues. Family members are a good area to consider.

Lerma will send a letter to the council's executive committee suggesting a council introduction to, and collaboration with, the state HIV/AIDS council. She feels it would

make an excellent partnership because of the overlap in both advocacy and multicultural issues.

The order of the agenda was changed at this point.

On the subject of the Committee's work plan (VI-b), the previous day's presentation of a work plan by the Family Support Work Group was discussed. Little was said in the work group's plan about diversity matters. This is typical of all the council's work groups and committees. It was decided Lerma will send each committee and work group chair a letter reminding them to include diversity and multiculturalism in their work plans.

On topics for the next council retreat in 2004 were considered, among them: we are not all the same and that is good; the extended family is important; how to build competency, etc. Submit other topic possibilities as they occur.

Council RICCs will have a one-day retreat sometime before the end of fiscal 2004. Allen said this might be a good opportunity for some diversity training.

Discussion of demographic surveys… Lerma has a good one downloaded from AARP that she will share with the Committee. The state also has a survey of what languages are spoken in each county!

Lerma will send a letter to three RICCs – Midland, Bay, and Isabella - who are holding a diversity conference on April 28, 2004 in Midland, to learn how the Committee can participate.

Lerma announced that Wayne County once again has a CIL – based now at the Wayne State U. College of Education, and services are also being provided through some voc-rehab offices. Lerma will provide brochures of this CIL.

Allen announced the MARO Conference at Grand Traverse Resort on Nov. 3-5 will feature a number of Council members and staff giving presentations.

She said the Council is updating its display board at present. Council brochures are being rewritten and will then be translated into Spanish and Arabic.

Allen said the Committee received an thank you letter from member Angela Zamora for participation at the annual Cristo Rey health fair in Lansing. The council display booth was set up and staffed. Council water bottles and posters were distributed. Allen reported a number of people stopping by to ask about the Council.

Hall announced that Michigan Office of Services to the Aging is accepting applications for their state advisory council, which covers statewide seniors issues. Applications are available on the web at miseniors.net. Send the application to hallpamala@michigan.gov.

Zamora moved to adjourn the meeting. Hall seconded. Adjourned at 11:58.

Education Work Group

Sept. 16, 2003

Members Present: Lauri Stein, Bud Kraft, Jane Reagan, Andre Robinson, Tracy Vincent

Members Present by Phone: Lynne Tamor, Sherry Cormier-Kuhn, Marta Hampel, Karen Massaro-Mundt

Welcome and introductions were done.

Oakland ISD was discussed:
ISDs can vote for millages. Because of press, it is expected to be difficult to pass. Monitoring issue – having ISDs monitor themselves. The state has two or three state employee monitors.

Jane motioned to approve the August 6, 2003 meeting minutes and amend the meeting schedule. The December meeting has been cancelled. Sherry seconded and the motion was approved as amended for the meeting schedule.

A note will be added when the schedule is published: "call the office to confirm the date, time, and location" along with the DD Council's office number for people to call.

The group discussed meeting by teleconference instead of having to meet face- to-face for every meeting. The group would like to meet by videoconference as well. Bud will look into this.

It was discussed to get administrative persons involved in the Education Work Group meeting. Some people to invite include:

Pat McQuarrie, Macomb County
Jan Holliton, Farmington District
Barbara Mick, Grayling
Gloria McCullough, Native American
Senator Gilda Jacobs

It was discussed to send a letter to the above individuals and then follow-up with a phone call to them. Lynne will make the phone calls.

The Transition issue keeps coming up at the DD Council meetings. It seems to be the number one issue right now. The State has put a lot of money in this area, but there have been few good outcomes.

Early Childhood was discussed. Parents need to be talked to before their kids enter the school system as a way to implement the Universal Education Policy. Glenn Ashley will be invited to the next Education Work Group meeting to report on the progress of the Early Childhood grant that Esther Onaga is leading. The group will invite Esther to present at the November 18th meeting.

The 18 points from the vision responses were discussed. Following is a combination of categories generated during the meeting and those contained in the "How did we get to where we are?" document submitted to the group by Lynne Tamor in July, 2003:

General areas of concern (in no particular order):

1. Preservice/inservice training of teachers and other staff working with students or parents (teachers, paraprofessionals, therapists, social workers, administrators, school psychologists, etc.)

a. Changing credential requirements to insure competence in inclusive practices

b. Influencing course content in institutions of higher education

c. Influencing content and availability of professional development

d. Specific focus on local school leaders, usually principals

e. Other

2. Building school and classroom communities where students offer mutual support, school units (classrooms or other subgroups) constitute cohesive social groups, and all students have continuous opportunity to build self-advocacy skills.

3. Universal education available before kindergarten for students who would otherwise be enrolled in PPI, SXI/SMI, AI or other segregated programs.

a. Building an inclusive vision among parents of infants, toddlers, and preschoolers

b. Influencing local school boards planning to expand into free or tuition based

preschools to make sure such projects are inclusive

c. Outreach to childcare providers and private preschools

d. Other

4. Exploring and advocating for ways to make formal assessment (NCLB, MEAP, etc.) compatible with universal education

5. Exploring and advocating for monitoring and quality assurance that meet statutory requirements and at the same time support inclusive practices and universal education

6. Strengthening the capacity of students, families, schools, and the adult service system to improve transition planning, formulation of transition IEPs, and ultimate outcomes relating to adult employment and community involvement.

a. Helping all parties build a vision of community based adult opportunities across the entire disability spectrum

b. Involving community-based agencies and organizations like People First and CIL's in transition planning on a systematic basis

c. Educating parents and school staff on transition planning and its relationship to IEPs

for students 14 and older

d. Encourage RICCs to reach out to high school students with disabilities

e. Other

7. More fully articulating and expanding the Council's view of universal education to provide greater detail and to explicitly cover issues of concern such as those on this list.

a. Continue to work with all Council members and RICC members to build a shared

vision of universal education

b. White papers or other position statements/publications

8. Analysis of the economic value of universal education

9. Insure that assistive technology (low to high tech, depending on needs) is available to all students in all settings where it would enhance inclusion in school and community

10. Build broad public understanding and support for the basic concept of universal education

a. Model demonstration projects with associated publicity

b. Media coverage of existing inclusive practices

c. Media coverage of efforts to increase universal education

d. Other

11. Build explicit legislative and policy-level support for universal education and inclusive practices

a. State board of education

b. State legislature and administration (governor, MDE)

c. ISD's

d. Local school district

e. Public academies

f. Court system

g. Medical practices

h. Other

12. Direct support to parents seeking inclusive educations for their children

a. Individual advocacy

b. Parent networks

c. Other

13. Coordinate with other workgroups to build education aspects into projects

focusing on transportation, employment, housing, healthcare, and so forth

a. Coordinate closely with the Family Support Workgroup

Proposed next steps:

An attempt was made to stay away from defining specific projects or actions in the list of areas of concern. As EWG members review this list, it is hoped that they will think about a number of factors including:

1. Is this topic of high priority to the workgroup?

2. Are others presently addressing this issue, and if so, does the EWG see on-going activities as adequate?

3. Is this currently a "hot topic" or is there an open "window of opportunity" that may close if attention to the topic is delayed?

4. Are there projects or activities that the EWG could undertake or support financially that have a reasonable change of bringing about desired change?

In the end, we are trying to arrive at a shorter list of general goals, together with strategies for achieving those goals and specific plans for implementing those strategies.

Family Support Work Group

Sept. 17, 2003

Members Present: Randy Krause, Sharon Newcomb-Case, Laura Mahank, Aaron Sherbin, Bud Kraft

Welcome and introductions were done.

Aaron motioned to approve the August 27, 2003 minutes. Laura seconded. Motion approved.

Reports of the subcommittees were discussed. Common interest between the subcommittees include:

- Communication: through website and listservs and the parent-to-parent support group
- Influence Policy: Policy development and Family Support Network (provide toolkit to families and policymakers to understand need for funding)
- Parent Trainings: Parent Leadership, CAUSE, advocacy training program for parents, Children's Special Health Care Services Committee, RUDY, Project Perform

Parents and consumers need to be at every level of decision-making and policy making. The Family Support Network focuses on matching parents together through a database to provide parent-to-parent support.

Discussion took place on developing a website list that would be listed by category such as specific disability, medical equipment, etc. An alternative to a website list would be to list 800 numbers of different organizations/agencies in a booklet. Some individuals may not have computers.

How are we going to get the message out to the parents? Other agencies are not referring to each other so many parents do not know what is out there for them to use. At the local level, there has been a lot of competition on who has to pay for various services. A database needs to be compiled that cross-references agencies to get the right information. Agencies need to work together.

Some of the programs could share blended funding so families are not getting bounced between agencies. A problem is high turnover of employees plus retirements. A lot of information is lost with turnovers. Programs change so a lot of information is lost. It is hard to relay information to parents when employees are scrambling to keep up with information and program changes.

How to get the information out to the parents?
- through RICCs, PACs, LICCs, and IEPs,
- anywhere parents receive services.
- Multipurpose Collaborative Bodies
- create a webpage with links that describe what the link is. Could be broken down by category such as qualifications, stipulations, who is eligible, etc.

It was suggested to contact the Child Abuse & Neglect Council (CAN) around the state to see if they are producing a resource guide, and if not, to see if they would help create one. Also ask them to see if anyone else is producing a guide.

Resources Available
National
Webpages
State
Listservs
County
Databases
City
Schools (ISDs, PACs)
Diagnosis
CILs (13 around the state)

Information out to families
Databases
Schools
Hospitals
Agencies (Public & Private)
Social Workers
PIAM
Local Health Department
Arc, Cerebral Palsy, Autism, etc.
Therapists
Michigan Rehabilitation Services

Issues that need be addressed:
1. Put together resources guide whether it is a website, a book or folder.
2. Distribution of information to parents and families.

It was suggested to have both a website and resource guide. A consumers guide on agencies would give the FSWG the ability to write their own definitions and would allow people to give their opinions on the website.

<u>Costs to develop a resource guide:</u>
Resource Gathering
Organizing
Publishing

Distributing – Focus on first
Establish a network
Community Forums
Conference Agenda – get on one

How fast do we want to get things out to the families? There are a few choices on how to address this:

1. use the information that is already out there
2. create own information list
3. put together package of other people's material as well as create own information

Information can be taken from others but it needs to be distributed in a meaningful way. Whatever the group decides, it has to be put in writing for people who do not have computers.

For the next Family Support Work Group meeting, each group member will come up

with ideas for resource gathering. Look at how the material will be organized and target what kinds of resources to gather. Work plan forms will be e-mailed or mailed to each FSWG member to complete. When filling out the forms, please address the issues of 1) putting together a resource guide 2) distribution of information to parents and families. Those plans should be e-mailed to Tracy at vincenttr@michigan.gov or faxed (517) 334-7353 by September 29.

Public Policy Committee

Oct. 14, 2003

Members Present: Jane Spitzley, Tony Wong, Bud Kraft, Rick Van Horn, Tracy Vincent, Terry Hunt, Tandy Bidinger, Robyn Saylor, Tom Stegehuis Kathy Flowers, Deb Ziegler, Pam Hall

Agenda:
1. Introductions
2. Approval of September 9, 2003 Minutes
3. Work Group Strategic Plan
4. Public Policy Updates
5. Person Centered Planning/Self-Determination
6. Medicaid Changes
7. Home Help/DCH Changes
8. Other

Welcome and introductions were conducted.

Saylor moved to approve the September 9, 2003 minutes. Wong seconded. Motion approved.

Work Group Strategic Plan

A special meeting on Oct. 7 was held to discuss the work group strategic plan. The Public Policy Committee (PPC) is a bit different than other groups since it is not specifically tied to one certain issue. The emphasis is "global" so they could then take positions on certain issues.

The Council has never had a formal policy on institutionalization, however with the Olmstead Coalition discussion, who began to look at the development of some policies. The October 7th minutes will be ready for future meetings. The question was raised: What is the hierarchy of the DD Council and the PPC and the work groups? The PPC is more of an advisory group, but it is the Council that establishes policy.

Public Policy Updates

Possible revenue enhancements were discussed. The Coalition for Fairness in Health Policy (Street Gang) asked the DD Council to sign onto the document which the Council used the Rapid Response procedure for the first time to do so.

RICC certifications are now in. The DD Council has a total of 50 certified RICCs across the state.

Discussion took place on Olmstead issues. The waiver lawsuit is at the point of being settled soon. Advocacy groups sued the state over Olmstead violations. One problem with the proposed waiver settlement is that long-term care screening would not be administered by AAA or other agencies. It would still be administered by nursing homes. The positive side is that $25 million is going into the waiver and there will be a uniform screening tool.

Governor's Long Term Care Task Force is in the process of being created. Twenty-one people will serve on the task force: seven "Bureaucrats" (state employees), seven providers, and seven consumers. The Olmstead Coalition wants a list of names to

suggest to the Governor for each of those categories. When nominating a person for this task force, provide rationale, credentials, and personal experiences, etc. The Olmstead Coalition will send the list to the Governor's office. Names can be sent to Tracy Vincent at the DD Council office by e-mail vincenttr@michigan.gov, by fax, (517) 334-7353 or by phone, (517) 334-6123.

MDRC has a grant from DCH called Michigan's Money Balancing Initiative. There will be a Long Term Care Round Table to give more opportunities for families and advocates. They are seeking the names of advocates, long-term care, consumers (past or current) and provides for this group as well. Send names to Tracy Vincent. The staff will forward them to MDRC.

Update on Legislation of Interest handout was discussed. It is a brief summary of major federal legislation of interest to people with developmental disabilities, their families, and remaining communities in this 1st session of the 108th Congress.
It was suggested to encourage people to write and call Senators Stabenow and Levin and Congress to support the MICASSA legislation to shift the Medicaid institutional bias from nursing homes to community based options.
Wong motioned to contact and educate senators Stabenow and Levin and other members of Congress regarding the MICASSA legislation. Saylor seconded. Motion approved.

Person Centered Planning/Self-Determination

The new Self-Determination Policy has been in effect since Oct. 1. Bidinger and Hunt attended the Person-Centered Planning Conference in September. Michael Smull was a presenter there. Many consumers attended as well.

The DD Council staff is working on materials regarding the Self-Determination Policy to make it user-friendly for consumers, and more understandable for people with cognitive disabilities.

Medicaid Changes

As of Oct. 1, dental, podiatry, eyeglasses, hearing aids and chiropractic Medicaid services were cut for adults. They will only receive extractions and some limited emergency dental services. Primary care physicians will have to pick up podiatry under general care.

Home Help/DCH Changes

Public comments are due on October 26, 2003. The draft document indicates two activities that Medicaid will pay for: 1) activities of daily activity (ADL) and 2) IADLs, which are supports – cleaning, shopping for food and medicine, food preparation, and taking medications.

To get assistance with an IADL, assistance with an activity of daily living is required. One possible consequence of the Home Help cuts is that if a parent cannot provide a clean home or food for a child, the state may remove the child from the home due to neglect.

The standardized pay rate being proposed for individuals is $6.00 per hour and $10.00 per hour for agencies. Pay rate in six counties would go up because they were so drastically low. The Governor indicated that Wayne County has so many individuals receiving Home Help that they are raising it 85 cents per hour. It will cost the state $200 million! However, this will lower the rate

dramatically in many other countries in Michigan.

Question raised: why should an individual family member be paid to take care of his or her own family member? Part of the problem may be that the public perceives this as paying people to do something they should do anyway! Public and legislative education is needed to explain costs and the realities involved. Relatives are often the only reliable persons who will provide the assistance at the low wage!

Agencies are being paid for two hours when the consumer may only receive 45 minutes of service. Flowers suggested that the consumers need to be educated on how to better negotiate for services.

There are a lot of overhead costs involved with agencies. One of the first questions agencies ask individuals who need services is if it is private pay, because the rate changes. There are not enough available workers to cover such a high demand. It needs to be made a more attractive field to go into because some workers are not getting raises or benefits.

The question was raised: Who is following up to find out if the Family Independence Agency(FIA) is actually informing people of reduction of hours and what they can do with the two hour time block? Is it being handled? It was felt that they need to spend time training workers that are interacting with the consumers.

Wong discussed the Axis Model, which has complete coordination of individual needs. It costs less money to get people out of nursing homes and there are fewer hospitalizations. It is a managed care system.

There are biases toward the medical model of care that is going to limit people's opportunity to live in the community. The Home Help Program is too limited. A lot of issues are overlooked.

A large rally to protest the proposed Home Help cuts was held in Lansing, on Oct. 9. Hundreds of people have sent in comments and contacted the Governor's office and legislators.

Other Updates

The U.S. Supreme Court has handled 48 new cases this year. The Federalist agenda is continuing. State rights issue came up.

The Michigan Senate Mental Health Care Joint Hearings were discussed. Koopmans provided testimony as well as the Council. An article titled "Mental Health Care Fails" was discussed. The Mental Health Task Force will come out of the Senate Joint Committee.

Health Issues Work Group

Sept. 23, 2003

Members present: Yvonne Fleener, chair, Theresa Arini, Kathy Reynolds, Ro Anne Chaney,
Staff present: Terry Hunt

Yvonne welcomed members and reviewed the agenda.

Motion (Reynolds/Chaney): approve August minutes as distributed. Unanimously approved.

Reynolds summarized the highlights of her paper which included: access to health care, quality of health care, and disparity of people in/not in the CMH and their access to

health care. Reynolds suggested a partnership between a hospital and CMH which provides an incentive to the health system to implement care coordination. The grant will track improvements (e.g. lack of ER visits, hospitalizations, etc.) Grantee would either be CMH or hospital. Data collection will be essential.

Chaney reviewed the highlights of her proposal. People with chronic conditions do have a comprehensive, coordinated system to assure their needs are met. Non-Medicaid services need to be built into a care coordinated system.

Considerable discussion regarding combining the two proposals.

Timeline for project: should be three years
year 1: get systems in place
year 2: begin to serve people
year 3: continue to serve and analyze data

Chaney and Reynolds will meet to combine their proposals.

Members reviewed the draft work plans and decided to postpone revision because Reynolds' and Chaney's concept paper is expected to address some of the issues to be listed in the work plan.