

LANSING DEVELOPMENTAL DISABILITIES DIALOG

Lewis Cass Building

May 15, 2006

Summary of Session

- I. Judy Webb, of the Michigan Department of Community Health (MDCH), welcomed the 30 people who attended the Lansing DD Dialog. She introduced MDCH staff present: Patrick Barrie, Deputy Director for Mental Health and Substance Abuse Administration, Irene Kazieczko, Director of the Bureau of Community Mental Health Services, Deb Ziegler, who manages the Habilitation Supports Waiver, and Tom Renwick, manager of the Quality Assurance Section. She explained that the purpose of the meeting was to hear from individuals with developmental disabilities, and family members, about what is important to them for the future, and how services can be improved. John Beck, of Michigan State University, moderated the remainder of the session. After distributing the Meeting Guidelines, John began by asking the people present to list their expectations for the evening:
 - ❖ Vision for the long term
 - ❖ That we are not viewing people with a disability any differently than anyone else
 - ❖ Clarify policy and action steps to implement vision
 - ❖ Identify major concerns of consumer and report on the outcomes
 - ❖ Change visions that are going to policy now
 - ❖ Focus on only taking things down when we have something better to replace them
 - ❖ Multiple choices
 - ❖ Multiple options
 - ❖ Look at consequences linked to choices

- II. The participants were divided into several small working groups and asked: **“What principles and underlying needs and desires must be reflected in any outcome to make it a good outcome?”** Their responses were:
 - a. Group One: Outcomes need to be
 - Individualized
 - Community connections
 - Health and safety needs are met
 - Continue to nourish and build upon new trends (e.g., anti-stigma, inclusion, and self-determination)
 - Individual choices must support their needs for services
 - System is the facilitator not the dictator
 - Continue to change the system/improve
 - Dignity of risk
 - Flexibility
 - Acceptance of change with consumer and family input
 - Enlarge the scope for the continuum of services

b. Group Two:

- Service options are customized to the individual regardless of the nature of the severity of the disability (medical, behavioral, etc.)
- Assurance of physical and mental safety
- Real life – not practicing
 - Focus on what they can do
 - Have high expectations
 - Provide ongoing opportunities to learn
 - Work and growth opportunities
 - Increase knowledge and living skills
 - Help individual reach maximum potential
- Family comfort with decisions
- Attract, hire and retain staff through adequate pay, training to meet needs of folks they work with, support through ongoing training and quality control and oversight (monitoring and support)
- Confidence and trust
- Support families whose adult children continue to live with them (e.g., respite)

c. Group Three:

- Family involvement and authority – circle of support
- Community inclusion with appropriate supports
- Service choices
- No loss of individuality
- Consumer has authority and control over Medicaid funding/flexibility
- Customer service rating/satisfaction
- Market-driven quality services
- Choice and control over
 - Where and whom you live with
 - Daily activities i.e., work, volunteering, hobbies
 - Transportation
 - Support staff
 - Agency choice
 - Broker services
 - Clinical services (e.g., scheduling flexibility)

d. Group Four:

- Choices
 - Varied per individual and flexible
 - Right supports to make things happen
 - Appropriate transportation
- Protect what is working
 - Working situation
 - Living situation
 - School situation

- Funding
 - Follow the individual
 - Re-evaluate annually as needed
 - Continual follow-through, as needed

e. Additional comments:

- Feelings of security
- Honor/being valued
- Emphasis on thriving and quality of life
- Continuity and consistency of care
- Trust
- Live passion through actions

III. Patrick Barrie's Comments

Mr. Barrie began by discussing the history of ARCs, how they formed with the idea of collectively advancing the rights of a whole class of people: their children with mental retardation and related disabilities. This movement, from its inception, was, and remains, committed to "inclusion" and the further pursuit of full social participation in accord with the Americans with Disabilities Act.

Self-determination reflects the passing of control from state and local bureaucracy to families and consumers: this is not just something you do, not just a new "program," but rather a continuing process of facilitating people taking control of their lives and destinies. The opportunity to have an individual budget is one important piece of that. However, we need to develop a uniform methodology and ensure Medicaid fair hearing rights to it so there are not inequities in the system.

Mr. Barrie's concern for families who have opted for traditional programmatic approaches are that some providers may use this preference in the service of their own economic self-interest. MDCH is trying to engage families in a dialogue about these issues. Some families feel that some new, more innovative arrangements do not offer the long-term security they desire. Consumers and families have different risk tolerances and this impacts what they want available within their communities. MDCH is trying to reconcile the paradox and to look for new approaches to move the system in more individualized ways. The department knows that it will need to engage providers somewhere in this discussion, to help them change practice models and to innovate in support arrangements. Ultimately, increasing opportunity and inclusion is not just good for families and individuals with disabilities, but for our society as a whole.

While we develop new arrangements that allow greater flexibility in dollars following the person, there will always be new people who come into the system for whom we need to find new money. The questions that MDCH must grapple with are: "How do we make the new opportunities available to these individuals? How do we respect the concerns people have and ensure that these opportunities are available and sustainable? How can we link them back to a common interest?"

MDCH needs to do things that will garner community support.

IV. Questions from participants, and answers from Mr. Barrie:

1. We have a grossly under-funded system. Certain numbers of families are getting something and many others getting nothing. There is inequality in access to services. The system works in crisis mode and people get things when they're in crisis.
 - A. Savings available in bricks and mortar probably aren't sufficient. We've lost some of the ability to convince our fellow citizens that using the "commonwealth" – taxes – for this purpose is something in the public interest and contributes to the common good.
2. Comment about changing nature of society. Want to develop more natural supports so that state services are only a supplement across the state.
 - A. Some people may not have those resources. Possibilities are variable across the state. What about people who live in communities where such supports aren't yet available?
3. If a community has something they feel is working, would you keep that going or would you drop it because it's not in your vision?
 - A. I would want to ensure that people had other opportunities as well. The skill is in negotiating the continuation of one type of arrangement while pursuing new options. There are more fiscal constraints now than in the 80s. Then we had an ability to financially support multiple options. Increasingly it is more and more a zero sum game. We need to recognize inefficiencies within the system. We may not need to make so many trade-offs if there are other areas where that money can be found.
4. Discussion about Washtenaw plan grant to eliminate day programs. This hasn't advanced towards the goal of increasing community integration and involvement.
 - A. We find that the state is often called in after some impasse or failure in dialog between a local community mental health services program and the consumers and families in their communities.
5. Opinion that there is a sense of misdirection on the part of MDCH communicating with the CMHSPs. There is a communication void between the consumers and stakeholders and the CMHSPs. It would do a great service if the state could be more direct in how CMHSPs implement state policies, i.e., CMHSPs must close day programs and group homes of a certain size. The families are the ones caught in the headlights. How do we propose to address the scarcity of finances in an era where we are encouraging unlimited wants and desires?

A. The power and the dollars are in the community. We as a state can do some things, we can promote dialogue and push for new options and opportunities. However, we don't want to, and shouldn't, accept the notion that the social compact, the responsibility to support services is over. In the policy area we know where we want to go. You're seeing different communities' interpretation of the policies. We need to have regional family-to-family dialogs to hear how this is happening.

V. Evaluation of the Evening

Positives

Small group, intimate discussion
Ground rules
Facilitator
Diversity of groups
Parents and advocates hear from each other
Common differences

What could be improved

Vary the times of the meeting
Hear from Judy & Pat first
These meetings should be the norm
Open to others
Questions in advance
Include people with disabilities

VI. Meeting adjourned at 8:30 p.m.

FLINT DEVELOPMENTAL DISABILITIES DIALOG
Genesee County CMH Cafeteria
September 27, 2006
Summary of Session

I. Judy Webb of the Michigan Department of Community Health (MDCH) welcomed the 25 people who attended the Flint DD Dialog. She introduced MDCH staff present: Patrick Barrie, Deputy Director for the Mental Health and Substance Abuse Administration, Irene Kazieczko, Director of the Bureau of Community Mental Health Services, and Lori Irish, who works on services for children with developmental disabilities. Judy also thanked Genesee CMH for providing the accommodations, including the pizzas, salads, fruit, cookies, and drinks. She explained that the purpose of the meeting was to hear from individuals with developmental disabilities and family members about what is important to them for the future, and how services can be improved. John Beck of Michigan State University moderated the remainder of the session. After distributing the Meeting Guidelines, John began by asking the people present to list their expectations for the evening:

- ❖ Better understanding of what is going on
- ❖ Truly listen to the needs of those who need services
- ❖ How do we go about getting our own places?
- ❖ Clarification on the difficulties between agencies
- ❖ What is going to happen with this information?
- ❖ Clearer direction on services (and outsourcing)
- ❖ The issue of transportation should be discussed
- ❖ Assurance of support services to allow people to live independently
- ❖ Continued funding to do that
- ❖ Self-determination – how do we achieve this?
- ❖ Caseloads and coverage
- ❖ Training for support personnel

II. The people in attendance were divided into three groups to address the question: **“What principles and underlying needs and desires must be reflected in any outcomes to make it a good outcome?”** After 45 minutes of discussion, each group reported back as follows:

a. Group One:

- All CMHs should be on the same page
- There should be consistency with all CMHs throughout the state
- There should be improved consistency with CMH and other governmental agencies
- They are not happy with outsourced respite provider and the fact that they have no choice of providers
- There needs to be equal Medicaid funding across the state; Saginaw only gets 63 cents on the dollar

- Transportation: problems with how it is funded, need in rural areas; cost to the individual
- Need support person to come in and clean and organize when people live alone. DHS provides funding for this service.
- There needs to be creative ways for writing grants to get funding for housing for people with DD
- Need more job coaching for people with autism

b. Group Two:

- They want supports for living independently (not in a group home)
- They want support coordinators who listen and then follow up on concerns; who are adequately trained; and have reasonable caseloads
- There needs to be quality staff and wages to support those staff
- There should be acceptance of training program that staff has participated in at another CMH or provider
- Need more funding for recreation and outings
- DHS and CMH need to have better communication, and changes in the laws to support the self-determination goals
- Personal health and sexual safety
- Real jobs with fair wages
- Community outings, but also retain centers for structured activities as some individuals cannot always do some outings
- Transportation: availability for any purpose
- Clearer guidelines for parents regarding education, work, and program availability for loved one. Also, funding, amounts, and access to information.
- Education: policymakers need to be in the classrooms and group homes to see what is happening
- There is disparity on the amount of counties to help micro-enterprises getting started
- i. Legal issues: how to handle people with DD versus a criminal; educating law enforcement

c. Group Three:

- Concerned about the cost of medication. CMH caseworker needs to be more informed and provide help to families so that they are not financially responsible.
- Housing: caregivers should be trained better and they need to be followed up on. People need to have more control over their lives.
- Vocational training: more jobs, more training, and more staffing.

III. Patrick Barrie gave his reaction to the group reports: He observed that what he heard in Flint is similar to what he heard at the first dialog in Lansing - there is a desire for more individual choice and personal control. Families want the comfort

of knowing that their loved one will have a consistent source for support and assistance. He expressed concern about the misinformation that participants reported receiving about cuts to services due to alleged state cuts in funding. In the aggregate, this is simply not true. In fact, the Legislature approved a 2% increase in funding. He noted that MDCH intends to do a better job of posting financial information about each PIHP AND CMHSP on its web site so that consumers and families can gain access to information. He noted that while MDCH has developed many standards that the PIHPS AND CMHSPs must meet – like the new customer services standards – but that MDCH currently has limited enforcement power.

IV. Feedback:

- a. Participants again raised the issue of lack of choice and control of providers, which affects quality of care. In addition, there is lack of access to transportation in rural areas, and excessive costs of transportation in urban areas. There needs to be education, resources and information for consumers and their parents.
- b. We heard about the St. Clair community collaborative that maintains a database of workers who are people with disabilities. At the regular business breakfasts, employers are trained about the benefits (such as tax breaks) of hiring people with disabilities.
- c. In Midland, the Arc works with the various police jurisdictions to help them understand how to distinguish a person with mental retardation who is not a criminal.
- d. The amount paid to care workers is very low. When there is low pay, there is low quality care. Pat told the group that the Legislature recently enacted a small wage increase for workers who provide certain types of personal care that is over and above the minimum wage increase.
- e. The increased cost of gas limits the outings that caregivers can take consumers on.
- f. There needs to be the same training for care workers and continuing education across the state. Judy indicated that MDCH has a standard training curriculum for home care workers that must be used, and an approved alternative to it.
- g. John observed the importance of partnerships and how work needs to occur across all levels, agencies and groups.

V. Next steps: John told the participants that they would receive a summary of the meeting and reiterated that if MDCH has a larger meeting of all the DD Dialog participants after the first of the new year, they will be invited.

VI. Evaluation:

- a. The group listed the positives for the evening:
 - Collaboration
 - Dialog
 - Having the meeting at all

- We were heard
- Inclusive group
- Diversity of needs
- Sense of humor

b. There were no negatives

VII. The meeting adjourned at 8:30 p.m.

MARQUETTE DEVELOPMENTAL DISABILITIES DIALOG

Pathways

October 9, 2006

Summary of Session

- I. Judy Webb of the Michigan Department of Community Health (MDCH) welcomed the 16 people who attended the Marquette DD Dialog. She introduced Patrick Barrie, Deputy Director for the Mental Health and Substance Abuse Administration. Judy also thanked Pathways CMH for providing the accommodations, including the pizzas, salads, cookies, and drinks. She explained that the purpose of the meeting was to hear from individuals with developmental disabilities and family members about what is important to them for the future, and how services can be improved. John Beck of Michigan State University moderated the remainder of the session. After distributing the Meeting Guidelines, John began by asking the people present to list their expectations for the evening:
 - ❖ To be clear on where things are going from here
 - ❖ Gain some knowledge on what is available
 - ❖ What will happen to our kids once we pass on?
 - ❖ What more is there that is being offered?
 - ❖ How can we ensure safe, secure, and stable homes?
 - ❖ Ways to ensure that helpers are consistent well paid
 - ❖ Get more information about programs going on
 - ❖ Will programs get cut? Are cuts going on?

- II. The people in attendance were divided into three groups to address the question: **“What principles and underlying needs and desires must be reflected in any outcomes to make it a good outcome?”** After 45 minutes of discussion the groups reported back as follows:
 - Medicaid –will it still be here in years to come? Concerns about frequent changes in approved medications; access to doctors; access to appropriate dental care in the UP (especially dental care needed under anesthesia)
 - Access to long-term services for the most vulnerable members of society
 - Stability in services – long term; families should not have to worry
 - Concerned if Medicare, Social Security and SSI will still be around
 - Secure group homes, whether group homes or family homes, and they need monitoring
 - Turnover in staff is a big concern for both group homes and semi-independent living; consistency of care
 - Bond and knowledge of long-term staff is really important. Need for administration to listen to long-term support staff.

- Stigma about being a "natural support" for a person with DD. Natural supports that are being encouraged are a major challenge in some UP communities where stigma is strong.
- Creative activities or jobs in communities, volunteer or paid, that are beyond old thinking; creative thinking outside the old box. Need for people with DD to feel a part of community, as a contributing member.
- Would like information on all current and future programs for people with DD
- SSI concern, should be able to work and not lose part of SSI because of pay
- Qualifications of those who serve
- Benefits to be received over the life span
- Help or support from the state and locally
- Does financial make a difference in what help we receive?
- Keep community programs, community inclusion
- Pay should be comparable to service, keep the turnover down
- Qualifications of group home staff – need for their personalities to fit
- Funding for rural transportation
- Attrition, consistency of care. If people like their jobs they will stay.
- Commitment to DD
- Community for DD: a place to belong
- RICC inclusion group supplies transportation to group activities
- Community of peers; activities that include all
- Keep vocational programs; more funding for community inclusion, which leads to self-worth
- Age limits on schooling based on functional level
- Equal supports across the state
- No more cutting for DD/elderly for assisted living and vocational programs
- DD dental specific to their needs
- What about assistance for the burial of people with DD for those survivors who cannot afford it?
- Hospital stays for lower functioning - who watches over, and advocates for, them?
- Transportation programs; need more access for those who need community inclusion
- Funding for outings; more recruitment and volunteerism

III. Patrick Barrie indicated that the concerns expressed by the groups reminded him of a box being squeezed from all sides. On one side there is the desire of families for security and continuity, on the other side is growing individual choice and personal control. On the top are federal pressures and legal changes, and on the bottom is a shaky fiscal situation, including the future of Medicaid.

- IV. Next steps: John told the participants that they would receive a summary of the meeting and reiterated that if MDCH has a larger meeting of all the DD Dialog participants after the first of the new year, they will be invited.
- V. Evaluation:
- a. The group listed the positives for the evening:
 - Liked small group activity
 - We see the similarities
 - People with developmental disabilities are able to speak
 - We worked together
 - b. The group listed how the meeting could have been improved:
 - More advance notice of meeting and its purpose
 - Put out agenda in advance
 - Link up issues to future actions
- VI. The meeting adjourned at 8:30 p.m.

GAYLORD DEVELOPMENTAL DISABILITIES DIALOG
Best Western Alpine Lodge
October 10, 2006
Summary of Session

I. Judy Webb of the Michigan Department of Community Health (MDCH) welcomed the 27 people who attended the Gaylord DD Dialog. She introduced MDCH staff present: Patrick Barrie, Deputy Director for the Mental Health and Substance Abuse Administration, and Mary Rehberg, who works with the Preadmission Screening for Nursing Facilities Program for people with developmental disabilities. Judy also thanked North Country CMH Services for arranging the accommodations, including the pizzas, salads, fruit, cookies, and drinks. She explained that the purpose of the meeting was to hear from individuals with developmental disabilities and family members about what is important to them for the future, and how services can be improved. John Beck, of Michigan State University, moderated the remainder of the session. After distributing the Meeting Guidelines, John began by asking the people present to list their expectations for the evening:

- ❖ What about Medicaid dentists?
- ❖ Coverage for substance abuse and schizophrenia
- ❖ Disability rights/jobs
- ❖ Food stamp amount is too low
- ❖ Success/getting on our own
- ❖ More programs
- ❖ Better transportation
- ❖ Easier judgments on disabilities
- ❖ Why does it take so long to receive services?
- ❖ More communication

II. The people in attendance were divided into three groups to address the question: **“What principles and underlying needs and desires must be reflected in any outcomes to make it a good outcome?”** After 45 minutes of discussion each group reported back as follows:

a. Group One:

- Staff ratio to consumers because of safety
- Food stamps amount is too low (\$10/month)
- Job support/training to make people aware of services
- Case managers are not responsive
- Continuing services - we are not receiving notice that this is possible
- Self-determination
- Slow services/or non-existence as staff, less amount of support; more self-determination
- Consumers should be treated with respect and as adults
- Lack of communication

- Transportation – not good schedules
- Dental assistance is needed close to home
- Public awareness and education so that the public can accommodate people's needs
- Technical education and social recreation classes are needed closer to home

b. Group Two:

- There are not always available adequate and appropriate services in rural areas nor opportunities for independent living. There are limited services, including supports coordination in Cadillac.
- We want skilled and caring staff. They start out good but lose interest. They lack training and they burn out early. Need a diversity of staff ages.
- There is poor nutrition in AFC. There should be more accountability, such as oversight of nutrition and a record of meals provided
- Affordable medication, good health care. Health care professionals do not want to serve Medicare and Medicaid.
- In AFC, residents should be allowed to move about home, and use their bedrooms and the phone freely
- Transportation - there is limited availability. For example, evening and weekend hours are not available. In addition, sometimes transportation makes us late for appointments.
- There is no one to help businesses be compliant with A.D.A. laws
- There is concern about people with DD being lumped into the goals for people with MI and that similar outcomes (i.e., recovery) are expected. There are very different goals for DD, thus, there needs to be more focus on DD.
- We need happy, reliable staffing

c. Group Three:

- Housing – in Mt. Pleasant – live on their own with support services. Consumers live at home – work at Quality Inn
- Job – has bus transportation
- Listening Ear – for social activity about every two weeks – Mt. Pleasant area
- Special Olympics is available for social activities
- Cadillac – Hope Network – S.I. son (privatized service)
- Housing – what will happen to impaired consumers – what plan does CMH have for future of persons as they get older and parents also grow older?
- More staff to assist consumers in extra activities – to be able to give consumers what they would like for trips

- RIC – grant-funded program for DD to become self-advocates – RIC is CMH community supports staff
- ROCC wants to provide services for consumers who wish to work in the community or those to stay at training center
- Mt. Pleasant – consumers cannot find jobs as easily because college people take jobs first
- Kalkaska County – CMH – has job coach – Mt. Pleasant needs staff to train consumers for jobs in the community
- Ogemaw has one group home most consumers go to but many have I.L.
- Cadillac – Hope Network – (Bridgeway) Son was fired because he had problems that could not be addressed
- Discussion: We fear the closing of training centers. We don't want group homes forever, but there are some people who could never live independently. There are not enough units of independent living for all consumers. They want the security of their "own friends" and not be pushed out into the community away from those friends. They would like to see information shared with families and consumers about best practices and good ideas. Police don't believe someone with developmental disabilities.

III. Patrick Barrie thanked the participants for coming to the session and indicated that his first and primary interest is to gain understanding of the needs, desires and preferences of consumers with developmental disabilities and their families. He noted that one of the common themes he has heard across the state is: individuals want state government to provide some consistency, stability and reliability for services and supports. Many have also noted the lack of stability in the direct care workforce, due to low pay and limited benefits. In many communities, the lack of transportation results in difficulties accessing community activities, including employment. There is also a lack of housing that is affordable to people with disabilities.

Mr. Barrie noted the importance of legislative advocacy for persons with developmental disabilities, since many of the decisions that impact people with disabilities are made by state and federal legislators. Funding is a concern because many of the services for people with developmental disabilities are funded by Medicaid, and Medicaid has become a target for federal budget reduction efforts. Unlike some other state funding priorities (for example, the school aid fund that earmarks dollars for education) there is no separate earmarked fund for mental health and developmental disability services. Moreover, when there are changes in regulation or funding at the federal level, it impacts state and local services.

He indicated that MDCH needs the help of all system stakeholders and particularly this session's participants' assistance to set an agenda for the

future. Visibility to the legislature and other decision-makers is always important during times of change. MDCH will try to bring all DD dialog participants together in the future to help plan a course of action.

In response to particular questions, Mr. Barrie answered:

1. If they have questions regarding a cap on earnings (SSI and SSDI), individuals should seek assistance from supports coordinators and from the local Social Security Administration office.
 2. MDCH does not intend, or have any plans to, privatize mental health services. We do need to ensure that services and supports are done right, maximizing flexibility so that people get what they need: dignity, access, and opportunity.
 3. People were randomly selected for this session from lists compiled by the area CMHSPs, advocates, and Regional Interagency Coordinating Agencies.
- IV. Next steps: John told the participants that they would receive a summary of the meeting and reiterated that if MDCH has a larger meeting of all the DD Dialog participants after the first of the new year, they will be invited.
- V. Evaluation:
- a. The group listed the positives for the evening:
 - Food
 - Diverse small groups
 - Positive outlook
 - Informative
 - Help the developmentally disabled to succeed
 - Discuss goals
 - Definition of MD vs. DD
 - Programs
 - Patrick Barrie's Spin
 - b. Ways to improve the meeting: revise the agenda
- VI. The meeting adjourned at 8:30 p.m.

GRAND RAPIDS DEVELOPMENTAL DISABILITIES DIALOG
Network 180 Building
November 1, 2006
Summary of Session

- I. Judy Webb of the Michigan Department of Community Health (MDCH) welcomed the 38 people who attended the Grand Rapids DD Dialog. She introduced MDCH staff present: Patrick Barrie, Deputy Director for the Mental Health and Substance Abuse Administration, and Audrey Craft, who works with the services for Children and Families. Judy also thanked network180 for arranging the accommodations, including the sub-sandwiches, salads, fruit, cookies, and drinks. She explained that the purpose of the meeting was to hear from individuals with developmental disabilities and family members about what is important to them for the future, and how services can be improved.

- II. John Beck, of Michigan State University, moderated the remainder of the session. After distributing the Meeting Guidelines, John began by asking the people present to list their expectations for the evening:
 - ❖ Learn and listen in order to understand
 - ❖ Make sure that DD are not forgotten in the planning
 - ❖ Make residential homes a better place to live
 - ❖ Want more programming for in-home
 - ❖ Make sure special needs are considered
 - ❖ Quality of services should improve
 - ❖ Housing and services
 - ❖ Feedback on how I can help people with DD
 - ❖ Handicapped people have feelings
 - ❖ Money to help me and other people with disabilities
 - ❖ Concerned about quality and scope of services at CMH: wants choice of services
 - ❖ Services for people with DD as they grow older
 - ❖ Quality and continuation of services planned for next generation to come
 - ❖ Preserve choice of settings
 - ❖ Listen, advocate for population who gets there via a different route
 - ❖ How to get information to families
 - ❖ Continuation of a wide variety of services
 - ❖ Services that support families
 - ❖ Advocating choice of services (MH, employment, transportation, home help, school) for consumers and access and eligibility requirements
 - ❖ Advocate for self-advocacy
 - ❖ A lot of work to do to keep people from falling through the cracks (e.g. insurance coverage issues)

- III. The people in attendance were divided into three groups to address the question:
“What principles and underlying needs and desires must be reflected in

any outcomes to make it a good outcome?” After 45 minutes of discussion each group reported back as follows:

a. Group One:

- Self-determination is a good thing
- Choices
- Residential options
- Long-term security in existing housing and assuming personal risk when lease runs out
- Increase in existing provision of services to change in staffing and provision of care
- Communication about existing services; need a road map to navigate the MDCH web site
- Equality of provision of services regardless of living situation
- Continuity of care associated with consistency of staff
- Safety of transportation
- Services need to interface seamlessly within the state, and across counties
- Person-centered planning brokered to needs of each individual
- Work to get into group home, access of services
- Quality of life which meets needs of individual; needs to be realistic and appropriate
- Wear same jersey/uniform but not on the same team
- Accountability of ineffective and uncaring staff
- Choices – choices – choices; key to individualized care and appropriate to the needs of the individual
- Safety is very important; the system pushes ideological way of life that is not appropriate to the level of functioning
- Transportation
- Need standardized daily support for families who continue to provide for the daily care of their child
- Choice of services
- Broaden the scope of developmentally disabled eligibility and then access to services
- Choices are the common denominator
- Dissemination of existing services
- Condense information to a manageable resource
- Ability to provide evaluation of services

b. Group Two:

- Protection from harm
- Specialized services specific to individual needs:
 1. Medical

2. Mental
3. Emotional

- Proximity to family
- Choice of day program activities
- Self-determination/family-centered services
- Continuity of care for the lifespan
- Security of current services while there is the opportunity for changing services
- Programs adapted to individuals
- Inclusion into the community
- Services that will provide a depth of services (e.g., medical)
- One model does not fit all – there needs to be options that suit a variety of preferences
- Quality of services
- Choice driven by what is appropriate to the individual
- Relieve tension between MI and DD consumers for funding
- Quality of life – emotional security and health issues
- Quality service in cost effective way sometimes may mean a congregate setting
- Openness and transparency; access to core services and clear information about how the system works
- Respect for individual's dignity leads to opportunities for jobs, education, and ownership
- Opportunity specific to the individual: safety, care, dignity and fun
- Continuity of staff and home
- Access should be streamlined
- Supports based on services; habilitative model and rehabilitative model

c. Group Three:

- Environment should be conducive to their needs:
 1. Comfortable
 2. Safe
 3. Respectful
 4. Dignity
 5. Love/care
- Align skills and talents appropriate to resources available. If not, create solutions. One size does not fit all.
- Educate the public
- Educate the providers
- Educate the schools, and community-based instruction facilities
- Educate the families about seamless transition from school to adult life, different gateways for information

- Appropriate legislation
- Appropriate support for individual needs which may be different
 1. Non-home
 2. Private home
 3. Home with mom and dad
- Prioritize the individual needs within the economic structure
- CMH needs to be visible and accessible
- There should be no penalty for an individual making progress, but rather a flexible array of supports to meet their needs as they change

d. Group Four:

- Choice: consumer and/or parent/guardian should be able to choose
 1. Type of living situation (e.g., small home, large home, own home, faith-based home)
 2. Day program (i.e., independent work, sheltered workshops, activity programs)
 3. One size does not fit all
- Safety: DD is a vulnerable population. Their safety should be a top priority:
 1. Physical safety
 2. Financial safety
 3. Sexual safety
 4. Medical safety
- Quality
- Evidence-based practices – continually strive to improve
- Access to the system:
 1. Should be universal
 2. Should be easier

IV. Patrick Barrie thanked the participants for coming to the session and indicated that his primary interest is to gain understanding of the wishes of consumers with developmental disabilities and their families. He noted that the public system is an extremely complicated system, one that is trying to provide both security and opportunities for personal choice and control. He acknowledged that the degrees of risk and amount of choice are an individual preference and decision. He noted that the common themes he has heard across the state are: people want from state government both security (consistent provision of services) and opportunity, and a work force that is reliable, stable, consistent and available. The problems with limited transportation (and the effect this has on constraining opportunities) have been a constant theme, as has the lack of affordable independent housing.

Mr. Barrie indicated the importance of advocacy and of visibility in a time of limited resources. The system is heavily dependent on Medicaid, and Medicaid

has been targeted for reduction at the federal level. While the CMHSPs received a 2% increase as of October 1, future funding could be impacted by the loss of revenues from the elimination of the single business tax.

Mr. Barrie reiterated an invitation that he has made at other sessions: For session participants to assist MDCH in setting the agenda for the future. MDCH is interested in bringing all DD Dialog participants together to help plan a course of action.

In response to particular questions, Mr. Barrie answered: MDCH will try to keep individuals and families informed about potential legislative issues through subsequent regional meetings, and through a possible "list serv."

V. Next steps: John told the participants that they would receive a summary of the meeting and reiterated that when MDCH has a larger meeting of all the DD Dialog participants after the first of the new year, they will be invited.

VI. Evaluation:

- a. The group listed the positives for the evening:
 - Encourage by the direction MDCH is taking
 - Keep everything going
 - Face-to-face small groups
 - We learned we're not alone
 - Dialog exists
- b. Ways to improve the meeting:
 - Agenda: questions and tasks are confusing
 - Meeting needs to be longer and later
 - Advise people that food will be served
 - Emphasize brainstorming on quality and accountability
 - Add more diversity to the participation
 - Staff involvement
 - Regional community-based (larger groups)

VII. The meeting adjourned at 8:45 p.m.

DETROIT WAYNE DEVELOPMENTAL DISABILITIES DIALOG
Guidance Center
November 15, 2006
Summary of Session

- I. Judy Webb of the Michigan Department of Community Health (MDCH) welcomed the 34 people who attended the Detroit-Wayne DD Dialog. She introduced MDCH staff present: Patrick Barrie, Deputy Director for the Mental Health and Substance Abuse Administration, Irene Kazieczko, Director of the Bureau of Community Mental Health Services, and Deb Ziegler, who manages the Habilitation Supports Waiver program. Judy also thanked Detroit-Wayne CMH and Guidance Center staff for arranging the accommodations, including the chicken, vegetables, cookies, and drinks. She explained that the purpose of the meeting was to hear from individuals with developmental disabilities and family members about what is important to them for the future, and how services can be improved. John Beck, of Michigan State University, moderated the remainder of the session.

- II. After reviewing the agenda and the meeting guidelines, the people in attendance were divided into three groups to address the question: **“In any decisions made concerning persons with developmental disabilities (small, large, personal or governmental), what principles and interests must be reflected in the outcomes to make it a good one?”** After 45 minutes of discussion each group reported back as follows:
 - a. Group One:
 - Safety at every level – personal; need to know that loved one is well taken care of
 - Recreational opportunities should be a general part of the community
 - Meaningful employment – life skills for volunteering or gainful employment
 - The desire to live with dignity and respect in an atmosphere that allows a person to make decisions about their own life
 - The desire to have the CMH case worker better explain/educate their consumers in person-centered planning and to know that they can use self-determination as an option
 - Respite care available outside the home on an unlimited basis
 - Transportation that will cross city boundaries and is readily available
 - Qualified direct care staff, better pay
 - Lack of funds forces people to be place in unsafe situations and people do not get to pick where they live

- Agencies get their cut. Self-determination assures that staff get all the money.

b. Group Two:

- I want the freedom of movement, including the flexibility to choose where to go, when to go, and how to travel
- Drivers on time and reliable
- Money for transportation
- Transportation to accommodate ADLs
- I want the freedom from having paid advocates who force their own choices on me. I want to choose my own advocate as case manager who is more accountable to me.
- Money to pay a private advocate
- More attention directly to the consumer
- I want to know how much is being spent, how it is being spent, and that I have some security in knowing the funds will be there
- I want to know that my medical and daily care needs are provided by competent and qualified people
- Have good health care from trusted providers with knowledge of my disabilities and needs (balance of physical and mental health)
- I want a clear understanding of the rules of the system and to know that others have the same understanding and accountability
 1. Freedom
 2. Accountability
 3. Quality of services
 4. Choices
 5. Clarity of understanding
 6. Consistency
 7. Security
 8. Peace of mind
 9. Personalization
 10. Privacy
 11. Dignity
 12. Control

c. Group Three:

- Citizens with disabilities are contributing members of the community. Supports should be targeted with this principle.
- Agencies that deliver community supports need to be more involved in training; increase the supervision of direct care workers and personal assistants
- Direct hire direct care workers and personal assistants, supports coordinators of all the supports for the individual.

However, [consumer] employer of record is not the only way of hiring.

- Individual rights are very important
- Make sure we listen to what people say
- Let the person be involved in the decision-making process
- Be aware of the person's feelings; look at the whole person
- People need to know that they have rights
- Freedom to speak their minds
- Make sure people with DD are at the table when decisions are being made at the state and local levels
- Honesty from the government
- Increase the hours for personal care workers to assist in personal care and independent living
- Respect my independence
- Person-centered
- More control over the future:
 1. Be able to save money
 2. Plan for the future
 3. Modify your life
- Using supports should not mean you must live in poverty
- Ensure that people with disabilities have quality staff supports. Direct care workers and personal assistants need to be respected as professionals.
- Hire own supports coordinator
- Control my budget including my direct support hours
- Do not discriminate against people
- People have their own places, choose where to live, who to live with
- People need to take jobs seriously
- Choose staff to work for you
- Freedom to make decisions with the person with disabilities leading the decision-making
- Do not assume you know what I want or need, and an active decision-maker
- Value life
- Jail diversion programs that understand the variety of disabilities and how that contributes to the situation
- Nurses need to receive training in understanding challenging behaviors
- Create advocates to assist in legal affairs
- Better assessments when the living arrangements need to be changed
- Know how resources are spent
- Strengths-based approach
- Full participation

- Meaningful life is the ultimate goal
- Fully accessible communities
- Community membership
- Independence without support

III. Patrick Barrie thanked the participants for coming to the session and indicated that his first and primary interest is to gain understanding of the wishes of, and directly from, consumers with developmental disabilities and their families. He reiterated his message from other sessions that our system is an extremely complicated one, attempting to provide both security and opportunity. He called attention to the common themes he has heard across the state: people want a system that is accessible, offers security and opportunity, provides reliable supports and readily available information. Included under the concept of opportunities are housing, employment, and transportation to enable access to community activities and work. For many consumers, self-determination offers opportunity, choice and control. Individuality and freedom are important, but so are solidarity and the common good. We should not leave anyone behind in the pursuit of a better, more inclusive, system.

Mr. Barrie commented on the importance of advocacy (including self advocacy), visibility and participation, as state and federal legislators make important decisions (including decisions regarding Medicaid) that impact people with disabilities.

Mr. Barrie, consistent with his remarks in the other sessions, invited participants to help MDCH set an agenda for the future. MDCH wants to bring all DD Dialog participants together to help plan a course of action.

In response to particular questions, Mr. Barrie answered:

1. How does the state address transportation where it doesn't exist?
 - A. I am not an expert on transportation, but there are mechanisms to partner with local and state transportation authorities.
2. There seems to be no consistency across the state in how people access the system or the services. We have to fight the local access center on what is the definition of DD.
 - A. In the 1990s, the mental health system was decentralized, limiting the department's ability to set, enforce and monitor consistent standards. We recognize the lack of uniformity across the state, and have begun initiatives to establish access and eligibility standards.
3. Does the state have no control over local decision-making?

A. We have some control, but it is limited. The PIHPs have substantial authority and are attempting to ensure more consistent decisions and standards. The limitations of the department's scope of action is one of the unintended consequences of decentralization, managed care, and the creation of local mental health authorities.

4. Shouldn't we have just one CMH for the state?

A: There is value in having local and regional CMHs that reflect the local culture and practices. Several changes to the state Mental Health Code would be required for reducing the number of CMHs.

5. When I die I want to be comfortable knowing that everything will be okay with my child. It's a matter of trust.

A. You want to know that we all will be responsible for addressing the service and support needs of your loved one.

6. Is there anything we can do about the \$2,000 personal asset cap for Medicaid eligibility?

A. Most of the Medicaid regulations are set at the federal level.

7. Managed care has choked off the lifeblood of services to our child.

A. Medicaid managed care has a powerful tool for beneficiaries to redress negative actions: the state Medicaid fair hearing process. If your child is not receiving the services that are medically necessary, it is important to appeal.

8. Rules (e.g., level of care) seem to apply to some people, but not others in counties across the state.

A. Through these dialogs we have heard that people across the state receive different information about access, eligibility, and services. In fact, each PIHP should have the same "rules." We will publish information on our web site about access, eligibility and services, but will also facilitate individuals and parents reaching out to each other across the state.

IV. Next steps: John told the participants that they would receive a summary of the meeting and reiterated that when MDCH has a larger meeting of all the DD Dialog participants after the first of the new year, they will be invited.

V. Evaluation:

a. The group listed the positives for the evening:

- We got our voices out
- Chicken
- Facilitator
- Encouraging

b. Ways to improve the meeting:

- Make available an on-line list serv
- Make sure voices are heard across all disabilities
- Feedback
- Make questions easier to understand
- Make the staff aware of changes
- Staff involvement
- Regional community-based (larger groups)

VI. The meeting adjourned at 8:30 p.m.