

*Designing the Future ... the Best of What We Know* – Dennis Harkins

1<sup>st</sup> small group discussion: **What are your initial thoughts about what we are creating?**

- Still want structure and guidance on what would be best for son; don't want to search
- Concern there will be less service versus present service
- Like the possibility of no waiting list
- Public funding
- Who are the decision makers determining services for an individual?
- Education
- Dynamic process, flexible, risk, freedom, safety
- What is consensus on what is the best of what we know?
  
- So lucky to have others to learn from
- We're one of the later counties
- Would like to see change and progress
- Time (delay) is a blessing
- Can't possibly plan for everything but need to move ahead
- Flexibility is good (self direction)
- Waiting lists growing longer—frustrating
- State can't stay with two separate systems
- Stopping action on plan was frustrating but it's nice to have time to do things like this
  
- Exciting
- Lots of responsibility
- Opportunity to get community more involved
- Grassroots feel
- Collective learning
- Good thing that parents are being asked input
- Good approach
- Parents will need lots of support and learning in transition to SDS
- Current system is strong—so it is a good system to base the new one on
- Opportunity to no longer do things that don't work
- Learn from other MCOs that are successful
  
- Clash between reality and financial/political needs/wants/values
- Parent from Door County is happy with the way it's been going; always has had choices—hoping for more choices
- Brown County representative concerned about duplication of services. If done correctly will be good. Political whims will possibly challenge the integrity

- Unfortunately the financial aspect will dictate
- We need to start with education. Are the younger generations compassionate enough?
- Does the buck stop back at the county level—they won't have the infrastructure
- We still need to live in the real world
- Person from Brown County who is already doing self-directed care for personal care services and likes it; but she is intelligent—knows it may be difficult for others
  
- Anxiety from stories from other family care counties; change causes anxiety
- Change of social worker = stress
- Relationships will need to start all over; switch "from one that you know". Can be good—may see something new in a person; or may see potential
- Sometimes we do too much
- New routines
- Volunteer opportunities
- Opportunities to "try" new things
- People with disabilities caring for others
- Friends at work; would miss if not at workshop
- Training the trainer
- What is being proposed regarding changes to where we are at? What are the parameters? Are there more in sight?
- Choices—please define
- Balance is great
- Can only make a certain amount of money due to benefits—will this be the same in family care?
- Are there enough employees to hire?
- Clients are proud
- Friends—socialization, focus
- What is "bad" about the current system?
- Define the "problem"; what is the problem of the current system....what needs to be fixed? Be specific
  
- How will we reduce waiting lists without impacting current service?
- How will the structure be different?
- Team/Care
- How will counties come together where there is so much difference?
- Embrace change
- Embrace family care principles
- Change does not need to be negative
- Create what people want
- Outcomes based
- How does family care differ from current model?

- Use more outside sources, informal supports
  - Current system creates dependence
  - Stay focused on the individual
  - Make meaningful community connections
  - How do we support all of our partners (providers/individuals/community members)
  - How do we reduce fear of family care change?
  - Look at creative models
  - Use best practices
  - Concerns related to changes to sheltered workshops—less accessibility
  - Need to pay attention to the business model
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- Families want to know more—is what they hear rumor or fact?
  - Concerns on agencies not knowing what to do
  - What is the bottom dollar?
  - State sets the dollar amount paid to the group homes, whether they do the job or not; i.e.: recreation activities. Day services is not an option due to travel, transportation and distance
  - Family and friends to help is a good idea; however, that is not an option for all
  - Deficiency—families trying to do care giving on their own
  - Little help from people you can trust and rely on
  - Families need help with transportation and respite for adult children
  - What do families or clients do when they live in their own home but need 24/7 care? Cuts will need to be made but where? They want to stay home
  - Concerns about having to move from home/apartment back into a group home. We will be digressing
  - We are getting services that we fought for!! Now what? Will we lose this? We need advocates for us!
  - Families are concerned about how we are going to serve everyone who is getting served plus take everyone off of the waiting list with the same dollar amount in the pot
  - Concerned about services being cut
  - Need better explanation of what will and won't be paid
  - Scary
  - Transportation is a huge concern for individuals in outlying areas
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- Can do things more effectively than now
  - More creative than what the system is now
  - A lot of people who don't fit in mold/categories
  - Families deserve to be informed and involved than to leave on their own
  - Increase communications with players involved
  - Power deferential—given back to client about their own lives
  - Want client to drive what's important to them

- We have an opportunity to create the system which is positive!
- Currently complicated system due to current family constraints. Desire flexibility to build into the system
- We have identified creative ways without funding to meet the needs
- Share the learning/support during other parent/family meetings
- Entitlement versus real needs for service—just want item because they are entitled
- Information/assistance/options
- Get businesses involved in hiring disabled individuals—educate them on hiring, recruiting
  
- Concerned about the corporate guardians—will work in the family care system
- Happy to be invited to the table and be a part of creating the system. That is a different experience for many people who are already working with other MCOs
- MCOs would like some more direction and structure/leadership from the state
- Where is my place in this new model?
- There is an opportunity to create something different
  
- Concern about having so many counties together
- Excited about possibility of self determination but concerned about economic reality of providing support
- Employment—one size does not fit all
- Go to the individual for determining needs
- Different mindset in partnering with families
- Using schools/university to provide opportunities—clubs, training, organizations—then expand to non-consumers
  
- Long term care system based on strengths that currently exist
- Are we saying we don't have a system that works?
- Feels like it is being said that we don't listen
- Feel tied by restrictions of community—not in my neighborhood (Green Bay) exceptional use permit
- Cost impacts ability to be innovative
- Everybody has a need—cost constraints
- One size fits all—often results from government involvement
- Identify what regulations that get in the way—use legislature to eliminate regulations
- Not everyone needs an RN/CM
- How many times do we make choices for program participants because we feel their choice is not in their best interest?
- Guardians are afraid of risk; limited choice
- Setting of outcome required by family care—question whether this limits choice

- There will always be a system or center—how do you build level of trust between consumer; circle of support?
- Providers already exist—build on those
- “I know family care is directed to adults, but I can’t help but think about the needs of children and the fact that’s where the system all starts”. Education starts early and system involvement should be introduced early
- The system promoted integration at school, residential. I believe there is a need for the option of segregated living and contained classrooms
- There is going to be a need for some real system change to help reshape our education system
- Let’s face it—Medicaid is the funding of last resource?! We need to empower the families and consumers to share existing supports and build from that
- Don’t look for entitlement. I feel services have been “pushed on me”
- Case managers need to unlearn the process of plugging in services; getting families everything you think they need/want/desire
- Let the services be the bridge
- Get your interdisciplinary teams out of the legacy world—train them to be of the mindset of planning with families on starting with skills, talents and resources of the circle of natural supports
- Training the providers. They are not used to tight contracts. If you want supported living, you get supported living
- Something that everyone fits in
- Appropriateness of services
- How to help people on waiting list
- Different people/different needs
- Options
- Communities need to open doors
- Family care—embrace the community and work with it
- Intent of law to not cluster; now limits
- Behavior challenges—no informal supports; what to do?
- Technology

*Hopes, Fears and Personal Experiences with Family Care and IRIS from One Parent's Perspective* – Deanna Yost

*2<sup>nd</sup> small group discussion:* **How might Northeast Wisconsin Family Care most thoughtfully, respectfully and creatively engage the strengths, assets, and resources of individuals and families?**

- Kids are individuals
  - Finding out what is available for services
  - Eliminate waiting list
  - Challenge of self direction
  - Change in case managers—good but slow process
  - Parents connect to workshops—connect parents to resources
  - Laws of confidentiality hinder connections in neighborhoods
  - ADRC goes into community
  - Right now limits too low to pay family
  - Listen what family needs
  - Transition from child to adult services is poor
  - What can your daughter help or do in community versus looking at deficits
  - See a lady who walks all the time—could she walk dogs?
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- Don't assume assets or liabilities
  - Sometimes liabilities are assets
  - Don't peg enemies—can become assets
  - Be open to everyone
  - Build partnership with counties and managed care
  - Engage churches to reach out
  - Be willing to ask
  - Start small, one person at a time
  - Staff bridged gap—had people bake cookies and take to neighbors
  - Included person with disability as volunteer—accepted
  - Break the walls between laws and community
  - Give people a chance to develop themselves
  - RAD a good method
  - Get the person out in the community
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- Support from family and extended family—natural supports
  - Pay for “camp”—special events for persons
  - If camp—“respite for family” not for person in group home, etc.
  - Engage DVR
  - Small communities have limited options
  - Look at all of the options for care of members
  - Use of natural supports

- It's Ok to talk about money with people
- Is what we have that bad?
- Rules and regulations; i.e. spend down versus paying for part of your service
- Decrease Federal and State mandates
- Keeping busy is important
- Family Care has evolved over the past three years
- Good to have regular forums—is really important
- Retirement “home”
- Open up businesses within the workshop
  
- By providing opportunities for engagement and by following up with continued engagement of those involved
- By developing ownership in the development of the system
- By developing an organizational culture that supports the concept
- By providing support needed to be successful
- By providing information about what family care is and how it can work
- By assisting families in crisis—developing relationships with families
- By pointing out that things are good and could even be better!
- Start with person centered approach
- People need to know what the value is in family care
- Develop consistency in the development of skills of interdisciplinary care management teams in MCOs in terms of their ability to engage families in understanding the opportunities that lie in family care
  
- Seek to understand the person and their needs rather than “dictating” what will be allowed
- Need to figure out a way to engage the communities (i.e. volunteers) or services that are offered to others for free
- Local stakeholder committees should continue (don't let it go by the wayside after MCO is established)
- People need to understand that their roles are changing
- Need to provide new innovative caregivers before family care starts
- Michigan has successfully switched from “facilities” to more independent supported living
- Challenge is to build a community of volunteers around person
  
- Have to have annualized budgets to allow for flexibility when supports are needed versus structured budget/constraints
- What happens when we ask and encourage involvement and are met with resistance?
- Making people feel comfortable is an essential ingredient in the success of family care. Dismantling the fears

- Grassroots connections need to take place at all levels—get the word out
- Culture within the organization that takes the time to really get to know the person—no cookie cutter approach
- Having “the right person” as providers who are supported by agencies
- How do we keep the good providers: having a purpose, having a relationship, obtaining a balance of good pay and benefits, and making sure the match is something that works
- We have to respond to the needs of parents—maybe reestablishing trust that was lost along the way. Not being afraid to ask again if they are not ready
- Case workers are over worked—increase funding to assure services are adequately funded
- The question posed: does our system have the capacity to reward the good and hold on to providers who are exceptional at their word? A capitated rate does not promote flexibility
  
- Essential life style planning, circles of support, person centered planning—should be **person directed**
- Professionals, providers, guardian have say; but a lot of deviation from member—often tug of war between professionals and families as to who knows more—oftentimes person gets last
- Important to get voice of elderly requiring support particularly those “sick” elderly
- Issue—some elderly who no longer want to live in own home go to assisted living or CBRF—MCO/IRIS will not continue to pay for day services or older American program that senior may still want to attend to be with friends
- Policy decisions that impact choices—licensing requirement, nutritional supplements not being noted, personal care requirements for billing
- Focus on idea not policies; set aside personal agenda
- Formulate plan based on wants then look at barriers and how to meet wants
- DD—school transition to adult services
- Focus on younger persons currently in good health in order to encourage planning for future purchase of LTC insurance, burial trusts, investigating alternatives when able
- Focus on more decision making for kids with DD in schools; they are used to others (IEP team) making decisions
- Slippery slide into already existing services
- Increase flexibility or part of funding sources
- Maybe instead of CM or Case Coordinators need to be advocate instead
  
- Families and individuals must be heard
- Anxious (a lot) about how system works
- We need honesty from workers—don’t tell us what we can do and not deliver
- Include us in the conversations

- Be open and honest about what is possible
- Make a "wish" list and compromise on how to get there
  
- Avoid the all or none thinking—discourage taking more than needed because if you need it later it might not be available then. Flexibility! Families will use what they need but they system sometimes forces them to use more
- Many people have families that aren't involved or corporate guardians; it's hard to connect then
- Need to understand that natural supports are OK and need to eliminate the red tape involved; i.e. 12 people need to sign off on everything
- Make volunteering easier—we've become a society that fears liability
- Identify community resources
- Ask the individuals who their community is. Engage these people
- Understand reciprocal relationships. Utilize parents to help each other
- FLEXIBILITY!
- If it makes sense...let us do it!
- Realize that needs change regularly
- Empower parents more. Listen to them
  
- Recognize families do have values. How have you done this so far? Can teach a lot of things
- Teach families new options—families may "buck" change—address and teach want versus needs; address the "what ifs" with families
- What to do when families don't agree—different thought away from family workers. Help them see where we are going to go. "Asking them"....what would you do?
- Families forget what the "person wants" and have their own ideas or may have higher standards on how to care for loved ones
- Have a forum for families to network which allows building on individual resources which increases creativity
- Overall, make sure families are involved and part of the process
- Take small steps and add some risks. Families need to learn to let go...or what if when the parent is gone
- Families need the son/daughter SSI check--don't talk about rights or moves; families don't love them anymore if they move out
- Concerns with getting rid of day services? S.E?
- Work is what capabilities are....so there is something else different than traditional residential day/work programs
- Involve the community relative to residential/employment options
  
- Positive thing—there is a social worker and a nurse
- There is an assessment

- Get to know the client
- What are the strengths of the client?
- What needs do they have?
- Nurses on board to assist with medical issues
- Keep the same case manager. They need to get to know the client
- Family Care is striving to have self directed care
- Clients are afraid that they will be forced into doing things they may not want to do to cut costs
- Sharon Ryan explained to the table about what the job of the MCO is and how the funding source money is now in one pot which allows for more flexibility
- Family likes having the supports in the present situation from the social worker because the social worker can help/assist/give suggestions
- Wants to be able to change things such as choosing water therapy over something else. Willing to give things up to get something else
- Access to more resources for families
- IRIS is not the option for all
- Biggest challenge is finding the providers to provide the service for a reasonable rate
- Resources need to be available and affordable
- Individualized approach—not a cookie cutter approach; those are the two best things about family care
- Flexibility
  
- How do you address the variety of needs?
- Include more parents at stakeholder meetings
- Address accessibility area in rural areas
- How do you engage families that are not currently engaged?
- Remove “silo” attitude
- Still be fiscally responsible
- How do agencies interact?
- Utilize ADRCs more
- Speak the same language with parents—stay away from acronyms
- Would like “how to get your child support with available resources”
- What does my child “need” stay away from the “take it all now” scarcity of resource mentality
- More opportunities for meaningful employment
- Creative mindset
- Take away barriers from service
- Partner with local businesses
- Find business mentors
- Focus on what they can do
- Showcase your talents

- Involve politicians
- Stop over compensating for employers
- Consistency
- Tell those positive stories
- Don't pity my son/daughter
- Think beyond benevolence
- Teach professionals going into the field to change their thinking
- Reduce regulations
  
- Sometimes providers jump too quickly to get paid services
- Identify assets in community (optimists: people volunteer and as a result make friendships)
- Reframe conversation about "boundaries"
- Need to identify community assets
- Until you give people a chance and allow them to participate you don't know what they can do
- Maybe ask high schools to give extra credit for providing help
- Think outside the box
  
- Need to understand one size does not fit all
- Shouldn't dictate the outcomes
- Need to individualize service plan
- Timing issues
- No duplicate services
- Benefit to people being able to relocate
- Current programs shouldn't be compromised—they are working; i.e. day programs
- Period of transition
- More advocacy needed
  
- Not good; lack of advocacy
- Create ownership
- Provide examples of what can be done
- Engage people in the process
- How do we get to the people who have the money?
- Older parents—what happens when we are no longer there? No extended care
- Parents being pushed into it and agencies are being pushed out
- Advisory group of parents, family members
- Education, education, education!
- Support networks

*Engaging the Strengths of Our Communities* – Kate Norby/Julie Strenn

*3<sup>rd</sup> small group discussion:* **What might we do where we live and work to engage the strengths and assets of our communities?**

- Hosting listening sessions, open forums
- Unless people are directly connected to “the system” it is really hard to engage them around what is happening
- The community needs to see a face in order to dismantle the myths out there
- Concerned about the cost of things, particularly when there are limited options/resources out there
- Person by person learning to help provide the education to the community about family care
- Enthusiasm and trust was lost as the result of the start of conversations with families about the evolution and planning of family care and then stop as we wait for the state to give us the green light—need to rebuild
  
- After work program at ASPIRO—bowling—parents, clients, staff, and volunteers
- Community recreation programs; i.e. Green Bay park and recreation, neighborhood recreation programs for all abilities
- Special Olympics, cheerleading squad
- Staying connected to others
- Open meetings—more often
- High schools being on a list for volunteering and developing programs
- Educating work places, businesses—work versus giving a donation
- Big Brothers and Big Sisters match
- Getting high school friends together
  
- By providing information to our communities about what we are creating
- Ongoing discussions
- Time banks
- Ask the question “why aren’t people at the table”?
- Educating our community
- Debunk myths regarding people with disabilities
- Better questioning of the people we support will lead to better community connections
- Use of social media
  
- Find a guy friend or mentor
- Sports league
- Use of ADRC and senior center
- Colleges and technical schools—PT, OT, etc.
- Transportation

- Volunteer center
  - Need to strengthen rural services
  - Buddy system with college students
  - Expansion of citizen advisory
  - Educate the community—educate young!
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- Help the community recognize there is a need; not authority/government stated need
  - Finding a passion that someone wants to share; person starting sailing program for persons with disabilities because of passion for sailing
  - People with passions are more likely to view those with disabilities as people rather than disabled
  - How do you connect?
  - In the past, church was strong source of connection in some cases, less now
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- Confidentiality issues get in the way
  - Education of the community about needs in the community
  - Shift “special needs” events
  - One small “brick” at a time—each event or new thing as a teaching opportunity
  - Find the “sweet spots” in the city where individuals are more accepted
  - Don’t saturate one agency/group with individuals with a disability
  - Create main street integration after high school
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- Talk to individuals—how do you live your life now? Use connections they already have
  - Have people/members out there—giver of services, not just receiver
  - Simple things like grocery items
  - Educate the community on their gifts and strengths; focus on can—not on can not
  - Go into a place looking for opportunities
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- Listen to what people have to say and respond and follow up
  - Start younger—open up opportunities for people to have relationships with people with disabilities
  - Don’t always rely on paid staff—look for opportunities to connect with others
  - Honor all choices that people make not just the choices that we prefer or value; i.e. sheltered workshop versus supported employment. People should have the opportunity to choose what is best for them!
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- Get ourselves out and educate the community; inform them they are needed—ask right out
  - Time Bank – people don’t think about what they can do/or their talents that they can share. Expand on this

- “We”—parent, provider, person served. Careful not to speak on citizens behalf
- Natural supports; i.e. IRIS, Iris consultant are encouraged to talk about “natural supports” use different “verbiage”—use every day language when expanding on this
- Tendency to think natural supports aren’t needed any more; going to be returned/restored
- Think about “social capital” everyone has something to offer. Barter exchange of social capital
- Structural thing “curb cuts” benefits everyone
- Accessibility and structural changes are helpful to all
- Visibility—billboards become the model. Are we ourselves hiring the disabled individual in MCO? Set an example
- Person served currently on CIP/COP need to volunteer. Give back to community. Being needed increases their value—volunteer i.e.: could wash fire trucks
- Create membership opportunities
- Be a good citizen
  
- Involve agencies we volunteer for such as churches, food pantries, etc.
- May be more difficult for individuals who are not involved in their community or for individuals who do not have the family to help
- Search for interests in the community
- Google volunteering and that may give you ideas
- Make sure that during the assessment process we find out what is important to each individual
- Transportation could be an issue—expensive
- Networking between agencies to have collaboration—maybe agencies need to coordinate together
- Work together as providers in a network; look at having discussion groups among the providers so we are all on the same page
- Housing is an issue; accessibility. Landlords being reluctant to rent to people with disabilities
- CSLA model—look at Winnebago county
- Balance between regulation and risk
- Shared resources; learn to be responsible
  
- Educating the community and the “general public” on disabilities
- How do we educate everyone?
- Lack of awareness. Interpretation is persons with disabilities gets everything for free
- Grass roots effort—churches good place to start
- General public is afraid
- We need to learn how to ask

- Just do it—don't ask
- Get over pride
- A neighborhood watch-type program
- Privacy/confidentiality issues
  
- Awareness of the gift of "disability"
- Promote self sufficiency
- Invite them to participate in "our world"
- Involve citizen advocacy programs to build community
- Fox Valley Sibling Support—grow program like these
- Circle of Supports-ignite community passion
- Develop strong rural community assets
- Question idea of school integration—Sybil Hoppe a wonderful example of a school that gets it right
- Each one reach one
- Change perceptions
- More events like "The Big Learning Event" for the community at large
- Keep parents informed of options
- Reduce duplication of services
- Utilize volunteer centers more
- Focus on what makes them happy, how can they have a full life
- College for people with DD

*Designing and Sustaining Individualized Services* – John Agosta

*4<sup>th</sup> small group discussion:* **How, specifically, will we learn together in the coming year to offer more individualized services within Northeast Wisconsin?**

- Sometimes you need someone other than family to help you
- Expand the learning that took place here today to have more listening sessions
- We need to continue to hear from other counties who have been involved in family care and learn from them about what works
- The richness of what came from this event today is that it's a start of conversation but don't stop
- How do we promote a system that allows for flexibility where it is built on need, not "if you don't take this you will never get more"
- Helping the case managers learn the new system and abandon the mindset that is out there that promotes "take as much as you can"
- Conversation of technical schools about integrated learning or group learning for skill development
- One person at a time with intentional support

- Flyers, newspaper, offering resources the state offers like SDS website
- The learning can be “passive” in that it happens by way of the message NEW FC sends..the “brand” it champions. It could be “active” tied to actions taken or learning may occur in the doing. Message—Actions—Doing
- Maintain a clear vision and purpose
- Encourage positive attitude
- Be open minded to new ideas
- Be willing to change
- Build on passion
- Never say “can’t”
- Don’t be afraid
- Implement a communication plan to disseminate information and gather in feedback/opinion
- Offer training to help people listen
- Dialog between family care and families/individuals
- Continued dialog (not single events)
- Involve all stakeholders in conversations
- Use easy to understand language
- Education works so that they can implement change
- Better distribution of information
- Encourage questions
- Be honest—transparent—no secrets
- Information giving—information receiving—dialog; all two way streets
- Promote mutual learning; MCO to MCO, within provider networks
- Promote positive relationships among stakeholders
- Get the mechanics right: flexibility, choices, have options, be responsive to needs, get rid of all or nothing options, uniform rates, transparency in rates and allocations
- Listen to parents and clients more
- Develop other ways to do things
- Call 211
- Parent organizations
- Many people would volunteer if they knew there was a need—no one has ever asked
- Continue conferences like this
- Learn from other MCOs
- Good alignment of provider networks so members have different options
- Train teams on facilitating and listening
- Can’t train too much or hire too early

- Get to know people
  - Family care continuum of SDS
  - Ask deeper question—you want to socialize but won't go to the senior center?
  - How will the person without self advocates be heard?
  - RAD has to have person involved
  - NEW board needs to know what clients are facing
  - No waiting lists so if person works and goes off program can they get back on and not have to worry
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- Come up with assets we already have
  - Need to spend time to decide how to make the system fair (over/under served)
  - Try to look at how we can do more with less—are there other ways to support?
  - Look at present system to see what is causing it to fail (look at policies)
  - Look at community organization campaign to build community support
  - Work with present providers and individuals to not make them feel they have not been doing a bad job all the past years
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- Increase communication between family care and families
  - Being honest, follow up, over sell
  - Being transparent
  - Explain in understandable terms
  - Better way to distribute information
  - The language of social services is beyond most persons served
  - Family aging—set up parameters
  - We need to do a better job of talking to the people we serve
  - More open ended contracts with providers
  - Let's talk about issues
  - Confidentiality can hinder agreements
  - Need to get rid of "all or nothing"
  - Flexibility with living situations and social situations
  - Real choices
  - Truly respect self determination
  - Have a lot of options
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- District gradual approach—past history of these counties not working together well
  - Park pre-conceived concepts/ideas at door—be open to change
  - Providers need to have open mind as to how they provide services, not business as usual; increase flexibility
  - Individual approach to establish services helps keep budget in control
  - Constant communication/education of consumers, families, providers

- Counties begin process now of reviewing services, appropriateness—what participants want/need
- Learn what other MCOs and counties are doing to create individual plans
- Day services are very important—socialization
- Meetings or education with case workers
- Meeting like this for families
- Providers in transitional counties did not see much change in how plans were put together after transition—county workers were already doing individualized plans
- By inviting those who can provide information and knowledge based on experience
- By learning about each other and our perspectives on SDS
- By talking with families and participants
- Provide written information
- Give people a voice!
- Keep conversations going. Ask questions, brainstorm, consider options
- Include all stakeholders in the conversations. Capitalize on collective wisdom!
- Remember not to get so hung up on the money, look at a persons' outcomes
- Transparency in rates and allocation decision making is very helpful
- Valuing and soliciting participation from community members and families
- Not what we want
- How do we create an environment where we integrate disabled and non-disabled individuals?
- Listen more to people we serve
- Continue to provide opportunity for stakeholders to express their concerns
- Change mentality and attitude
- Get the word out—as to what the needs are for individuals with disabilities
- Educate the community
- Establish our goals; have a vision
- Communicate with agencies in other parts of the state who are going through this
- Communicate
- Collaborate
- Volunteer transportation of people; collaborate transport
- Presently, people are forced to take the whole package
- FLEXIBILITY
- Start a system but realized that this system needs to change as the family or client's life changes
- Educate the clients, parents, guardians, providers

- As providers—more uniformity to rates
- Insure financial soundness/proper funding before moving forward
- How do we do more with less?
- Improve use of public transportation
- More conferences
- Advocacy
  
- Better way to support the 46% of those who stay home
- Awareness of funding inequities
- Do not isolate parents—great offense taken to “pouring money into individual homes”
- DME modifications
- Stick to AFH
- Use communication equipment
- Have a transition plan—pathway to moving out
- What about kids who are not able to communicate what they want?
- Change the educational system—we must encourage self-advocacy
- Respect parents knowledge of children
- Stop keeping “bad apples”
- Never say can’t

*What have we heard today? **Where We Go from Here** – Rolf*  
**Concerns and Suggestions**

- How will long term relationships between persons served and caregivers be maintained in a system where costs may be cut and the caregivers barely make an affordable wage?
- How can small providers compete with nation-wide providers who can spread administrative costs and even afford to lose money in some areas?
- When will we have answers on when the expansion will happen?
- Be careful to assure the elderly needs are not forgotten—they were/are a part of COP
- Remember to train your CM/RNs on how to implement family care prior to the roll over. They need to hit the ground running
- Many people with disabilities are not able to self advocate or are fearful of change. How will this system promote choices in their life?
- With so many people living at home with their parents, what is the balance between choice and family support? With so many parents making sacrifices to keep their children at home in a safe, loving environment—this program seems to discourage their involvement. For some people moving to an apartment is an

option, but for others you encourage CBRFs and adult family homes? What happens when the parents are no longer able to care for their child at home?

- Make sure that the support many of us need as parents is still there. We do not want to go from having lots of information from the providers as to what is “out there” to having to go to finding everything out ourselves just because we want to go to a self motivated or self oriented program
- Day service programs and sheltered workshops—what if clients still want to attend these? Will they be able to do so?
- Costs—pulling individuals off of the waiting list...where will all of the money come from? Will there be a waiting list like other parts of the state are now facing?
- Choices are important. Don't eliminate options like sheltered employment. Some people are happiest and most productive there
- The “state” will continue to evolve and listen
- Programs will be thought out before they're rolled out
- Parents given more information about family care/IRIS prior to having to make a choice
- That ideology will trump choice. That we must discontinue some programs and services that some people still want
- That family care will lead to low wages for direct care and support staff and not attract the best staff
- Programs/services such as sheltered workshops (please change that name) how are these going to be considered when present consumers express this is their work family and would otherwise be jobless?
- Their quality of life
- Concern that there is too much regulation and red tape that inhibits creativity and flexibility
- Concern that direct support worker wages are too low and we will be heading into an employment crisis
- There is a heavy bias towards the values that we think people should have. We need a system that truly opens up all choices—not only the ones we think people want
- There is not enough money in the system to adequately fund hundreds of people that are currently on the waiting list without seriously limiting the people that currently receive supports. The reality is people's choices are being limited not expanded in many MCOs
- In our process of developing a new system or approach, how can we be sure we “do no harm” for people in the current system?
- Principles of the culture—we are beginning to develop (values, etc.)
- Developing a mission statement
- Regular meetings—with all entities represented (administration, care managers, parents, providers, clients, staff, guardians, direct care staff, county board members)

- More support, training, mentoring, and networking
- Work on building better relationships with communication
- Ways to engage providers/families/consumers: community board, internet, website, blog, formal newsletter (bi-monthly), group meetings, small meetings to give people opportunity to network with one another
- MCOs (Community Care) give the impression of “here is what you get. Make it work within our requirements”. It does not as a whole look at the person in the situation which is supposed to be the entire focus. The focus is “we are Community Care; we will tell you how much money you will get, you work with it”.
- The future needs to be built on what is now working—today in hearing many providers and parents, the feeling was here is what great things the MCOs are doing—many counties working within the waiver restraints are just as creative and thought provoking as the MCOs
- Providers have been doing a good job and need to be worked with
- I think the state needs to implement a positive campaign TV/Radio (pro sports figures) advocating people helping people in public service sector while preparing for changes to come into effect. Also for all agencies to look deeply into policies and regulations to see where the flaws are or may be and correct these errors. This is in reference to misuse of people using funds fairly
- My concern is that our son is very low functioning and his day program is very important to his social life. He’s unable to do a job, so if this is eliminated, all his friends and connections will also be eliminated. That makes his quality of life go down. We cannot be everything to him all of the time.
- Although the concept of individualize services is appealing, as a parent of a low functioning adult, I (we) feel it’s critically important to continue with day service program options
- It is difficult to remain positive as a group home provider or a sheltered workshop provider when these things are actually listed on Power Points and projected to the group as what needs to change. Slides that say “values need to change” suggest the speakers know the values of these providers. Who is to say we have not valued people over programs all along?
- Although the item above is a tough criticism, it is a simple fix—I don’t think for a second this was the message you intended to send. I know you mentioned valuing our past, but none of the presentations really suggested value! Have a provider review the Power Point—get their gut reaction before final presentation. I believe it was more semantics than intent, but I fear you may lose part of your audience
- How involved will guardians be in the individualized plan?
- Family care—we don’t know how family care will work if we don’t have a concrete idea how it differs from the system we have now
- People in attendance and their support for people with disabilities and the means/way to provide this support is more alike than it is different. People on both sides are well intentioned. Unfortunately, why do people think there are two sides?

- What appears ironic is that self direction/self determination is not supported when certain choices are made. The menu seems to be shrinking. As a result of some advocates who are under the impression they are speaking for all. Where is the individualization in that?
- Once family care become available in northeast Wisconsin, will it be set in stone or will there be flexibility should it become needed? Can changes be made if the need is there?
- What about the rural areas? Connecting with community may be even more of a challenge so much could be centered on Brown County/Green Bay
- Lack of flexibility, choice (but only within set parameters)
- MCOs policy sway self determination; i.e. policy that states no money for x, y, z
- Expectation that if person chooses ALF, that provider is to meet all needs—opportunity to “go out” i.e. senior center, day programming, work is taken away—won’t be funded or supported
- Advocacy doesn’t occur until situation reaches reduction or termination of service (appeal level)
- Need to keep the conversation going
- Give people real choices
- Some persons at the event felt they needed more information on the specifics of family care and what the specific changes would be
- You must speak the language of the “common” lay person
- You must be flexible—don’t offer what you feel is needed but know what your clients/families/communities need
- Allow for agreements between clients and providers that are more open-ended; i.e. if I need this service, don’t tell me when I can opt it, how often, etc. but let me tell you what I need and let me share providing it by letting family/friends do it sometimes without risk of losing it
- Things must be fluid, needs fluctuate
- Utilize my personal resources—ask me about these
- Don’t limit options—don’t judge group homes or other living arrangements; they probably are needed/desired by someone. That’s what makes it an individual self directed plan
- We will not stay focused on self direction, rather we will look at most cost effective options and forget about members’ preferences
- Choices/providers may be limited due to low reimbursement rates
- Community will not “buy in” to idea of supporting individuals, leaving a lack of supports for some members
- Advocacy doesn’t occur until it is too late—appeal/grievance level
- Need to be proactive when case manager sees a problem starting
- Communicate
- Family involvement (more)
- Flexibility

- Please be aware that clients who are blind (there aren't very many who are totally blind) need services. They have a need, especially for social skills, computer skills, training in "jaws program"
- Focused on residential
- Continue with the line of thought that we are building and expanding...keeping what has worked
- I am amazed by the simple process of these listening sessions yet we forget to use it. We need to listen more, rather than speak
- I am challenged to think about what strategies we might use to better educate seven counties on family care. We need to think and be ever so mindful about conveying this information in a number of different ways. I worry we need to get to families and consumers sooner, than later. Rebuilding trust is important—and credibility about the timeline and evolution of family care here in Wisconsin
- Family care for elderly in our Brown County is being addressed (by a group) and they have had great attendance and passed on valuable information for those needing that!
- What can we do for students who have need for job and social skills help after getting out of the grade school (Sybil Hopp) and through high program? Are these program funded in state programs?
- Options "not one shoe fits all"
- There are more challenges afoot than our collective mindset. There needs to be more dialogue related to regulatory roadblocks, housing, transportation needs
- SDS and three functioning institutions in the same state is a ridiculous irony
- Getting thorough knowledge of the needs of people in the community is the best place to start
- Still unclear on what the future holds in care for our child. Still unclear about where we are going—seems like way too much too fast. We are interested in continuing with discussions
- Providers that are flexible and willing to collaborate with MCOs (and vice-versa) versus digging in the heels and wanting things to stay the way they've always been will succeed and continue as business/community partners into the future
- Who should take the lead on payment for the individuals who will work on building community connections that don't currently exist?
- Drastic "across the board" rate cuts rather than looking at each individual provider and services separately
- How are all the services promised going to be provided when funding obviously isn't going to get better?
- Not enough money to pay fair wage to providers
- How to support families with payment and monitoring so this isn't abused
- Funding issues are permanent. How will we get funding for a system that will lower costs per user but increase cost overall since there will be an increase in the number of users—no waiting list

- I worry about inappropriate placing of clients because of a lack of funding clients are being placed in homes/situations that are not apartments
- SDS is great but needs to be done for right reason—not to save money but to provide the life person wants to live—money savings benefit from doing it right
- Families need time in life when they are not caregivers—cannot base system on families taking responsibility for care and support of loved one
- Focus on changes needed in how system is operated—internal and external rules and regulations to increase flexibility of how money used and recognize fluctuations in needs occur routinely
- Concerns that adequate support mechanisms are in place to support decision making process—adequate awareness of potential resources, flexibility, consultant to decision makers

## **Comments**

- I am amazed at the number of people who remain committed toward positive change and wanting NEW FC to do it right. There are amazingly a large number of people not just committed, but unbelievably passionate. If we did anything through this process, we brought that passion out and allowed voice of commitment to these issues....our creation of something great!
- Kudos for bringing the experts to the table to share their knowledge, vision, and experiences
- Good seminar—well handled
- Still very confused, but I liked the idea of the group discussions
- Excellent presentations! There is always the question of how the ideals model translates to reality of operation
- Really liked the opportunity to discuss topics with the other people present
- Some time could be devoted to suggestions to parents who take care of their son/daughter at home because that individual is not physically able to live in a group home or independent living situation
- Today was too long—two ½ sessions would have been better
- Next meeting focus on actions that could be taken to forge a new pathway. Assign tasks, have a follow up meeting with tasks accomplished
- Public hearing for those individuals who are receiving the funding—many of them are still confused as to what family care is
- Thanks for having this conference! Great opportunity to share ideas and help shape the future of family care
- Engaging others and feedback ideas: local internet chat board, webcasts, future ongoing conferences
- I felt today was a valuable day and I liked the format

- Include perspective of a person(s) who are consumers of service. Parent perspective is good, but let consumers also speak
- Continue to bring to northeast Wisconsin: participants, MCOs, providers who have experienced success in both family care and SDS to further educate and have an understanding of this change
- This day was very informative and a major sharing of individual information and ideas. I appreciate the opportunity to learn
- Liked the time to discuss—felt the questions were broad and made it difficult to stay on task. Often the problems kept coming up and not focus on solutions or possible solutions
- Are we going to keep talking? How structured?
- Last speaker was more mental—take a look at yourself, etc.
- Should provide similar event for case managers from the counties. This would honor what we already know and help us learn as well as help their fears
- Format worked well. It would be interesting to hear John talk about how that transition has worked elsewhere
- The roundtable breakout sessions kept the day interesting and they were also very informative
- Overall, great session today. Glad I had the opportunity to participate
- Future meetings of specific groups such as providers, families, guardians, etc.
- Discussion group questions got “old” by the end. Too narrow in their focus—somewhat repetitive
- Next event could be to hear from consumers and families on how they perceive the current system. I think there is more opinion out there on a variety of needs that are not included in the “thanks for what you do but I don’t want it”
- A future event educating all on the actual money needed/being spent by other MCOs, etc.
- Explain/show the financial sustainability
- This was very good
- I liked the graph John Agosta had comparing need/money
- Case management staff needs a similar listening session
- Went well, no issues—THANKS!
- Perhaps asking a representative from each MCO to be present for a Q&A session. Some are well represented, others do not have a representative here
- A lot to soak in on one day—thank you
- Will there be more of these meetings as time progresses?
- I felt there was too much focus on the DD population in the examples, presentations, and even in the audience representation. Family care will affect even more elderly than any other group especially in the future

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*Northeast Wisconsin Family Care is a member driven organization passionate about delivering service options by supporting personal choices which promote the greatest opportunity for an independent quality of life, in a caring, respectful, and efficient manner.*