Summary of Focus Group Meetings: Person-Directed Supports in Dakota County, Minnesota

Submitted to:
Dakota County Developmental Disabilities Management Team
On
August 10, 1999

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This report was supported by Cooperative Agreement H133B980047 from the National Institute on disability and Rehabilitation Research, U. S. Department of Education to the Center on Community Living, Institute on Community Integration (University Affiliated Program), College of Education and Human Development, and the University of Minnesota.

The Developmental Disabilities Section of the Community Services Division of Dakota County is committed to transforming the service delivery from a program-centered system in which government contracts with providers to serve its citizens to a person-centered system in which government provides people with disabilities and their allies control of resources to purchase the support they need and want from individuals and agencies they choose. The management team of Dakota County's developmental disabilities service system is interested in learning how responsive and effective this transformation is for people. To this end, staff from the University of Minnesota gathered and analyzed information for Dakota County's Developmental Disabilities Unit of the Community Services Division to monitor its effectiveness in achieving its desired outcomes. As a first step, staff from the University of Minnesota convened focus group meetings to gain an understanding of people's perceptions regarding what it really meant for an individual or family to "be in control" of supports. The county additionally was interested in learning more about what the issues were for their staff in assuring all of it's practices supported people with disabilities and their families being "in control" of their services.

Six focus group meetings were held with five different stakeholder groups. These groups included a) parents of young children with developmental disabilities, b) parents of adults with developmental disabilities, c) adults with developmental disabilities who were members of local self-advocacy groups (self-advocates), d) service providers, e) county case managers, and managers of the developmental disabilities section. Each focus group meeting was homogenous according to stakeholder group, and each group was asked to discuss the same set of focus group questions. These questions were the following:

1. What helps people feel in control and be in control of their supports?

2. What does control of and responsibility for your support mean to you?

3. What are the barriers for people with developmental disabilities and their allies to gain control of supports and resources?

4. Who are the major stakeholders?

5. What are the roles and responsibilities of the major stakeholders in moving the system to clients designing and directing supports?

6. What are your concerns related to shifts in roles and responsibilities of the major stakeholders?

7. Do you have any other comments?

Some questions were modified to make them more clear and understandable to self-advocates. The groups with self-advocates did not have enough time to respond to all questions.

The report is divided into five major sections: 1) feelings related to being in control of supports, 2) factors related to control and responsibility of support, 3) barriers to gain control of supports and resources, 4) roles and responsibilities in moving the system from program-centered to person centered services and supports, and 5) concerns related to the shift in roles and responsibilities of major stakeholders. The appendix includes most of the thoughts and ideas, and direct quotes from stakeholders who participated in the focus groups.

Feelings Related to Feeling in Control of Supports

At the beginning of each focus group meeting, participants were asked to identify feelings associated with being in control of supports and services. While the ideas presented by individual participants and groups varied, there was agreement that feeling in control meant that the person had the following: a) a sense of power, b) access to resources, c) relationships and roles associated with these relationships, d) access to training and accessible information, e) "real" options and f) a sense of safety and security.

Each group provided several examples demonstrating that feeling in control means having the opportunity to make real decisions regarding supports and to feel the results of those choices. The group of case managers suggested that having control in hiring and firing support staff, of who will attend support team meetings, and where such meetings will be held, are some important and valued decisions for families and persons with disabilities to be in control of. Parents of children said feeling in control meant that they were acknowledged as the "best expert" on the needs of their son or daughter, and knowing the decisions they made would not be second-guessed by others. Case managers who said parents shared this sentiment and persons with disabilities will feel in control as they are allowed last say in important team decisions.

One parent of a child equated a feeling of control with the ability to make spontaneous choices regarding purchases of special equipment rather than needing to have every purchase approved. Another parent indicated that control meant "no never-ending paperwork." Both parents of adults, and members of the county's management team discussed a feeling of control coming when service providers became accountable to persons with disabilities and families rather than some other entity. Self-advocates said they felt in-control when they made real choices, such as where to live or whether to have a pet. They felt in-control when they were contributors to their community (i.e. provide help to others, or serve as an officer in an organization like People First). Providers saw persons with disabilities and families feeling in control when each was able to make those decisions they value most highly, which are sometimes not available due to system rules.

Both groups of parents, as well as case managers, members of the management team, and providers discussed that feeling in control of supports necessitated that persons with disabilities and families know about the resources available to them. One member of the management team noted that people would feel in control of supports as they learned what it was they had control over. A case manager discussed the importance in knowing what the parameters were for using those resources. Parents reported they felt in control when they had adequate resources available to meet their son or daughters needs, and when they had access to the "right funding" or funding that could be used to purchase those supports their son or daughter was most in need of. Self-advocates did not mention the funds used to pay for their services as something they valued having greater control of.

All stakeholder groups cited the ways in which the relationships of persons with disabilities and their family members greatly affected the amount of control people felt they had in their lives. Self-advocates talked about feeling in-control, as they were able to speak clearly about what they wanted and when others met such requests with action. This notion that people felt in control when their requests were heard and taken seriously was shared by parents of adults, case managers, providers, and members of the management team. Both parents of adults and members of the management team noted that persons and family members feel in control as they are allowed to evaluate providers of support, rather than be evaluated by them. Parents of children added they felt in control as they saw others trusting their judgement in making decisions regarding support needs. A very significant "bottom-line" issue in the area of relationships is that people with disabilities and members of their families feel in control of supports as others treat them with respect.

A fourth area repeatedly cited as important to people feeling in control of supports was having access to training and technical assistance in arranging supports. Members of the management team discussed the need for very usable information systems on topics such as tax laws and labor laws, as well as information about actual support options. It was noted that right now there is a great deal of information that would be potentially very helpful and important to families in arranging supports, but it is scattered and hard to access. When parents talked of information needs they were most interested in having access to the right information, and especially being directed to the right person as they had questions or needed assistance in various service systems. Specifically parents of children wished they were more people at the county level available to answer questions that came up for them, and place a premium on county employees who "know how to communicate".

Many stakeholder groups discussed that people felt "in control" of supports as they had several viable options from which to choose. Parents of children requested there is greater flexibility within traditional service options, and both parents of children and members of the management team saw the need for greater flexibility in rules and regulations. Case managers and others noted that people having a real sense of control over supports is enhanced when they are not given a set of options from which to choose, but rather encouraged to think about what they really want, to "think outside the box" and create new service options. Other important components to people having real options was having access to qualified and competent support staff, having access to services simplified, and having an opportunity to actually receive and experience quality services.

Several comments by stakeholders point to the idea that having control over supports means that persons can "trust in the system", and not be fearful that they will be left with no support if they make a mistake, or if their situation changes. This category included the idea that people will feel in control as there are some provisions for safety nets, and having information about what is expected to happen in the future as well as current resource availability. Parents of children expressed some apprehension regarding what may happen to the funding priority of children with disabilities in light of other groups, such as aging baby boomers. Case managers noted that feeling in control of supports meant persons with disabilities and family members knowing that it is possible to change your mind if a certain type of support doesn't work as expected.

Meanings Associated with Control of, and Responsibility for Support

As stakeholders were asked to identify the meanings associated with being in-control, and responsible for supports, nearly all groups again discussed that being in control meant having the opportunity to make significant decisions regarding the support they would use. Parents of young persons specifically talked about the ability to make purchases of special equipment and toys related to their child's special needs, and not have to ask permission or wait for approval. Parents of adults mentioned that being in control of supports meant having the ability to make decisions regarding what to pay providers of support based on the quality of their work, and the type of work they did.

A case manager noted persons with disabilities and families are in control of supports when they are allowed to choose to move in any direction they desire. Another comment was made during the group meeting with case managers that having control meant persons with disabilities and families would have the chance to create new service options to meet their needs and preferences, rather than simply choosing from a menu of options currently available. Several stakeholder groups noted that being in control means that consumer and families are not inhibited by system rules, or a lack of flexibility on the part of the persons or agencies in choosing and arranging supports that will be most helpful to them. Members of the management team, and case mangers added comments illustrating how being in control of supports means not only choosing where you are going, but also the processes you use to get there. A self-advocate noted she wasn't bothered by working through systems in getting the supports she wanted, but simply asked that the "rules" of the system be made understandable to her.

Along with ultimate power to make important decisions, nearly all stakeholder groups specified that being in control of supports implied that persons with disabilities and families would feel an increased sense of responsibilities for decisions made, and would experience the consequences of both good and bad decisions. It is somewhat interesting and informative that only the group of case managers associated greater control over supports with feelings of safety and security. It seems clear to all stakeholder groups that having increased control in choosing and arranging supports is not meant to create an easier or more secure lifestyle for persons with disabilities and members of their families, but it does seem clear that having increased control will greatly decrease stress levels. A parent of a young person made the comment "I do need the help, but being told exactly what I am going to do and how I am going to do it, plus having all this paperwork, is stressful. If I had control over the situation I would experience a lot less stress." Self-advocates discussed that their feelings of control were enhanced when they were allowed the chance to provide support to others as they also received supports.

Case managers and members of the management team noted that with having increased control over supports, families and persons with disabilities will need to tolerate a greater level of risk and let go of the idea that safety nets will always be available when something unexpected happens. A case manager noted that beginning to view persons with disabilities and members of their families as responsible for arranging and managing the supports they receive as quite a large paradigm shift for some people, and may be quite frightening to some of these persons and families.

The focus group data demonstrates the importance of feeling respect from others is to persons with disabilities and members of their families in having control of their supports. Stakeholders further talked bout how being in control of their supports caused people to feel an increased sense of personal value and self worth. A parent of a child discussed the "put-downs" she experienced when others made decisions regarding her child's support while turning down the ideas she had. She contrasted this with the feeling of power she has when such decisions truly are hers. A case manager echoed this sentiment in saying that having control over supports meant the decisions of persons with disabilities and family members were not "second guessed" by others, a sentiment also reflected in responses to question 1.

Comments made across several of the focus groups further seemed to suggest ways that having a sense of control regarding supports will cause persons with disabilities and family members to interact with others in new ways. A case manager noted the being in control meant persons with disabilities and families could stop being very compliant or passive/aggressive when arranging supports, and instead speak clearly to what they want and need. A self-advocate suggested being in control meant others listened, and then let him/her "get the job done". Members of the management team characterized this shift as persons with disabilities and families taking on a greater sense of citizenship. This citizenship included obeying the law, being well informed, and taking responsibility to understand the needs of other community members as they take on increased responsibility for their own needs.

Barriers to Gain Control of Supports and Resources

The stakeholders who participated in the focus group meeting identified a wide variety of barriers that currently exist to persons with disabilities and members of their families having increased control over their supports. While many specific barriers were mentioned by only one or a few of the stakeholders, nearly all groups mentioned lack of access to information as a significant barrier to people controlling their supports. Different stakeholder groups characterized barriers to persons with disabilities and family members receiving important and necessary information in different ways. Parents of young persons talked about difficulties they experienced in getting to the right person and receiving accurate and useful information from county offices. A parent of an adult echoed this sentiment in saying s/he sometimes had to beg people in order to get necessary information. County managers discussed the need to create guides that families and individuals could use in selecting and managing services without needing to contact an intermediary. They saw barriers however in the sheer volume of information families may need to access, and the fact that currently much of it is written "in code" not understandable to anyone beyond county employees.

Another barrier noted across several focus groups was concern over the possible lack of resources for families and individual to access as they arrange and manage their own supports. A primary concern was a lack of people to provide supports as part of the general labor shortage. Throughout their focus group meeting providers seemed to warn that as persons with disabilities and families make alternative choices with their service dollars, traditional providers, and the service options and expertise they provide on an ongoing or sometimes emergency basis might not be available. One case manager also shared this concern.

Most of the other barriers identified across the stakeholder groups seemed to revolve the momentum of the status quo, or things not really changing very much. Case mangers feared that persons with disabilities and families wouldn't take the level of control available with new approaches due to feeling dependent on those who had traditionally been in control or lacking confidence, or that persons with more severe disabilities may be left-out. Parents of children worried current service providers would not be flexible in assisting to arrange new kinds of support, or may become defensive when asked to provide support in different ways. Many stakeholder groups including parents, case managers, and members of the management team worried that the rules that dictate use of state and federal service dollars would continue to be barriers to families controlling their supports even though Dakota County has freed up it's share of service dollars.

A final category of barriers discussed seemed to revolve around personal attitudes and relationships. Providers felt a barrier to persons with disabilities gaining control of supports may be the desire of their parents or other natural supports continuing to have control. A parent of an adult saw a potential being unwillingness on the part of some to allow persons with disabilities to take some risks and make some mistakes to engage in the learning that comes from that. Members of the management team had a related fear that gains people experience in the process of making decisions and controlling supports may not be noticed or discounted if the outcomes of that increased control are neutral, or occasionally negative.

Roles and Responsibilities: Moving from a Program-Centered to a Person-Centered System

Each of the groups who participated in a focus group meeting were asked to identify who they saw as an important stakeholder in allowing persons with disabilities and members of their families greater control over their supports. Groups were then asked to discuss how they saw the roles and responsibilities of each stakeholder group in assuring persons with disabilities and family members had success in gaining control over supports.

The groups identified eight stakeholder groups. There was agreement regarding the role of each stakeholder group. For example, the groups indicated that the general public has a role in recognizing the current and potential contributions of persons with disabilities to the larger community. Additionally, service providers and case managers need to view their roles, and communicate with persons with disabilities and family members in a new way. Moreover, county and state agencies need to become more flexible in judging the quality and appropriateness of particular services as they perform their function of monitoring supports. However, there are many other examples of each group had somewhat different ideas about the roles and responsibilities of particular stakeholder groups.

There was significant discussion within focus groups regarding roles and responsibilities. There were several discussions that occurred regarding whether the approach of people with developmental disabilities and families being the controllers of supports should become more widespread. Some case managers cautioned that having such control might place additional stress on some families who may already 'have their plates full. However, families who lobby at the legislature and who take other steps typically see having additional control as a stress reducer. Service providers added several cautions regarding issues they had traditionally shouldered that may fall on people with developmental disabilities and families as service providers cede control. These types of discussions highlight the challenges in realigning roles and responsibilities in a system where people with developmental disabilities and families truly control resources, and perhaps in defining a new role for traditional service providers given their special expertise and background in service delivery.

Finally, while all groups named people with developmental disabilities as an important stakeholder group, it was difficult to sort out what particular role they had that wasn't shared with their supporters, such as family members or friends. There were however role and responsibility shifts which seemed more exclusive to family members. For these reasons there is no category that specifically addresses the roles of individuals with disabilities. Instead, the first category discusses the shared roles and responsibilities suggested for persons with disabilities and members of their families, and the second category discusses specific recommendations for family members of persons with disabilities. The comments seem to represent a commitment by persons from Dakota County that persons with disabilities should not be the persons asked to "change" as the system changes. At the same time, the lack of specific recommendations regarding the roles of service consumers may represent the lack of expectation that persons with disabilities are able to make contributions to the process of changing the system. In the appendix to this report the eight stakeholder groups are listed, along with ideas about the roles and responsibilities of each in designing an approach in which persons with disabilities and families arrange and manage their own supports. Readers are encouraged to review this portion of the appendix since it contains several ideas.

Concerns Related to the Shift in Roles and Responsibilities of Major Stakeholders

The factors that people identified as their concerns related to the shift in roles and responsibilities of major stakeholders included: a) education and information, b) individualization, c) responsiveness, d) staff availability and e) supply and demand. Individualization was mentioned by providers, parents of children, managers, and self-advocates. The following represents the dichotomy of responses two comments: A parent of a young child said, "Give me the control and watch me go." On the other hand, a case manager said, "Families and clients that won't take on the responsibilities. They've been taught that and going the other way is a hard process."

The development of quality education programs, and systems to share the information necessary for persons with disabilities and family members to truly control supports was mentioned as a concern both by parents of children, and members of the management team. Both parents of children, and of adults expressed concern that persons who began to control their supports would not receive enough information about what options exist for them. Parents were interested in having information available that would be user-friendly, and would give persons with disabilities and their supporters some knowledge that would set them up to take full advantage of the control available to them. Both parents and members of the management team agreed that providing consumers of services clear information regarding all of their options was not traditionally known as a skill of government agencies.

There were several concerns that approaches allowing persons with disabilities and family members greater control over supports would be implemented in ways that may hinder their chances of success. A service provider observed that little control will be gained if persons with disabilities have the opportunity to control where resources are spent, but the regulations under which service providers operate are not relaxed correspondingly allowing them to provide services in different ways. A member of the management team expressed concern that as long as only a small number of persons with disabilities and families are controlling resources and arranging supports for themselves, rather than using such an approach system wide, it's chances of causing fundamental changes in services to persons with disabilities was limited. This concern can be countered by the comment of a case manager who wondered whether persons and families would have an option to return to receiving traditional services of the same type they had previously if they choose to purchase and manage their own supports, but it did not work well for them. Another case manager repeated a concern also shared by service providers that some service options that are needed by some persons may cease to be viable and will no longer be available when needed if persons with disabilities and families control their service dollars and purchase supports.

Concerns regarding the availability of qualified persons who are able to provide support in high quality ways was mentioned by providers, case managers, and parents of adults. Several stakeholder groups shared the sentiment that the quality of supports received was very dependent on the availability of persons who were capable and committed to providing the support. Providers were additionally concerned that persons with disabilities and families would be able to pay people a higher wage, and thus hire away staff members who have been recruited, trained, and gained work experience in traditional service agencies. This was of particular concern to agencies in light of current labor shortages. A member of the management team was also concerned there not was an adequate number of community members who saw it as their roles to be available and provide natural or unpaid supports to people, which are important to the success of this approach. The manager was concerned the idea of supporting one's neighbor had become less of societal value in recent years, and would be difficult if not impossible to bring back.

Concerns regarding increased competition were mentioned by providers, and by parents of adults. Service providers spoke about the possible increased costs of providing services that matched peoples interests on an individual basis, rather than sharing resources and splitting costs among a small group of individuals. Providers noted that while families and individuals could come together to problem solve and pool resources to make their service dollars go farther, the process sometime became quite complicated and has largely been coordinated for families and individuals by provider agencies. Some provider agency staff pointed out that an approach in which persons with disabilities and family members have greater say in purchasing services costs might go up. Service providers had some skepticism regarding the cost savings motives behind using this approach. One service provider expressed concern that increased competition among service providers may cause some to become "low-cost" providers and underbid what it costs to provide services in a quality way. There was a concern that this would cause individuals and families to receive less service than they had been promised, and in the long run will hurt all service providers. Parents of adults cited an example of a community person charging a significant price to provide leisure outings for persons with disabilities in Dakota County and were somewhat concerned about people in the community taking advantage of persons with disabilities and families.

Additional Concerns of Stakeholders

At the end of each focus group meeting, stakeholders were given an opportunity to make any additional comments they wanted. Due to time constraints, the group of parents of adults, and the two groups of persons with developmental disabilities did not have time to respond to the question. The group of parents of children used this time to ask the facilitators how the information they had shared would, or could be used to assure that person-centered services and supports come to be used with greater frequency.

Members of the section management team brought up several issues which need to resolved as more persons with disabilities and family members choose to take greater control in managing available resources and arranging supports. These include developing a just allocation system capable of deciding how much money individuals and families should receive to arrange services based on their needs, and a single funding stream for access by persons with developmental disabilities to arrange supports instead of the very fragmented system of service funding that currently exists. Members of the management team also discussed the need to develop a more individualized method of evaluating the quality of supports people were receiving.

Case managers were somewhat concerned that most individuals and families were much more concerned about receiving better quality supports from the traditional service providers rather than having greater control in arranging supports. One case manager questioned whether families would really take advantage of the control they were being offered and uses it to develop better and more individualized support options. Case managers also had concerns that allowing persons greater control was a passing fad that would come and go, or that it would simply become another system in which most individuals and families made largely the same choices regarding the supports they would use that they saw others having success with.

The remaining groups seemed to use this time to present cautions as Dakota County proceeds in giving greater numbers of people with developmental disabilities and family members greater degrees of control over their supports. It is interesting to note that the groups made up of service providers, and of county case managers seemed to caution against moving too quickly with the widespread use of such an approach, citing possible losses over the long term as individuals with developmental disabilities and families realize greater control. Members of the management team cautioned in a nearly opposite direction, suggesting the real threat to the success of the transformation of the service system would be not moving forward, and addressing remaining issues in a decisive manner. Managers were concerned this approach would be "squashed" by state or federal policymakers before it had a real chance at being successful.

Summary

This report is a summary of many comments made during focus group meetings with many stakeholders. It seems important at this point that members of the management team of the Dakota County Developmental Disabilities unit, along with members of the research team from the Institute on Community Integration review the themes illustrated in this summary, as well as in the attached appendix. There are several themes indicated that will support Dakota County in moving to a system in which persons with disabilities and family members truly control supports, as well as comments and themes that represent possible challenges to this transformation. In deciding next steps it seems important for members of the management team and of the research team from the University of Minnesota need to discuss the following questions:

1. Does the summary accurately reflect the comments made in the focus groups?
2. How should this information be utilized?
3. Which themes suggested require further investigation?
4. What other themes and concerns that did not come out in any focus group need to be investigated?
5. Who are the best informants in gathering further data, and what are the most effective methods for gathering it?

Appendix A: Comments by Focus Group Members

I. Feelings Related to Being in Control of Supports

A. Sense of Power

Realization of Results

"I feel in control as I "…have my own apartment." *(Self-advocate)*

"People can realize their choices, they can see that it happens." *(service provider)*

"… People can decide where they live, what kind of neighborhood and house, people they live with." *(service provider)*

"Ability to hire and fire, control of who makes decisions." *(case manager)*

"I know for a lot of my families it's being able to choose who comes to their house or not for meetings and things...." *(case manager)*

"… and a lot of them don't want to have meetings at their house, but they feel they have to." *(case manager)*

Opportunities to Select Services and Supports

"To have a voice in the programs." *(Parent of an adult)*

"…when I can be my son's best expert and determine what his needs are and how to get them for him without a school or an agency coming in and telling me, ' No, that is not what he needs." … I like the idea that I have the control to make those decisions and no one will take them away from me." *(Parent of an adult)*

"Some of my clients get their support somewhat dictated to them. You can get this or this. I'm thinking more folks that live in homes, SLS's, but even when people support in their own homes- it's kind of dictated to them. The clients aren't' treated like customers and that's a real different approach." *(Case manager)*

"The clients want to feel like they have last say, not someone else. Parents too, a lot of the kids say, mom and dad wants this but I want this." *(Case manager)*

"I think having support that they ask for rather than having support someone else thought they needed. And the way that they asked for it." *(Case manager)*

People are Accountable

"People are accountable to me, I am the consumer." *(parent of an adult)*

"I will take my money someplace else if I'm not satisfied." *(parent of an adult)*

Opportunities to Do Those Things Most Important to the Person

"I can think of one boy that I know who really would like to be able to shop for his own groceries. Because he has PCA services and other services, nobody can do that. ...This is not a goal for the boy. It would just be services that match what he wants to do." *(service provider)*

Opportunities to Make Choices

"...I pick the people to help me." (self-advocate)

"...give me the choice whether or not to go out." (self-advocate)

"...to stay in my room", "...to feed my cat." (self-advocate)

"Having the choice to help with decisions." *(parent of an adult)*

"To have options/choice." *(parent of an adult)*

"With the people that I have, they have more choices." *(service provider)*

Contributions to the Community

"... Other people want me to give help." (self-advocate)

"... I am president of People First." (self-advocate)

"... We help each other." (self-advocate)

"...I open my mouth and make my point." (self-advocate)

Spontaneous Choices

"To be able to pick up the telephone and say I need that. I need that in my living room and I am going to call there and order it now without worrying about your own family's budget paying for it and maybe being reimbursed at some point maybe." *(parent of child)*

Less Paperwork

"… When there is less paperwork that has to be filled out every time you need just a little piece of equipment for your daughter or son." *(parent of child)*

"That self-determination project allowed us to free up on the paperwork." *(parent of child)*

"It (paperwork) really is almost a barrier and it is never ending. As soon as you get through one cycle of it they make you redo it all again." *(parent of child)*

B. Access to Resources

A Set Budget

"Knowing what you have, and what you can spend." *(service provider)*

"If they know what it is they are in control over. In terms of the budget, they have X amount of dollars they'd get to use." (case manager)

Knowledge of Parameters for Using Resources

"To have the 'right' funding." *(parent of a child)*

"It's not just that they know how much resource that they have, they also need to know the parameters of what they can spend it on." (case manager)

"… Those (parameters) can change but some of it might be money, legal. You can have control of your support but if you have no money then you don't have support." (case manager)

Adequate Money to Meet Important Needs

"…. I wish we had enough finances so that we could do something but the government does not give you enough money to make those decisions." *(parent of a child)*

"I have to buy special laundry soap because she is allergic. That costs twice as much as going to the store. I cannot afford it so therefore she does not get it." *(parent of a child)*

C. Relationships and Roles

People are Heard and Supported

"I ask for help, and get it." *(self-advocate)*

"Social workers who listen, and respond to what is said." *(parent of an adult)*

"Maybe one of the important things about all of that is that you feel in control when there are people around us that support decisions that we make." *(service provider)*

"I think the ability to influence who is providing the support for them. To be listened to and understood." *(service provider)*

"Hopefully they (case managers and provider agency staff) would be tremendously good listeners. People who could help access resources, have knowledge of resources. ... I think people would gain a lot more control if the system ... actually viewed the people like themselves. ... Part of the power is in how people are viewed and the self-esteem that comes from that." *(case manager)*

"... A really good advocate, not just for the whim of the day but with frequency. Someone concrete." *(case manager)*

"I would say making the people feel comfortable to ask questions. ... giving people permission to say what they want." *(case manager)*

"I think a lot of it is that people are heard. What they're saying is not going into the wind somewhere." *(case manager)*

Dignity and Respect

"People who are friendly, nice, and who are not angry." *(self-advocate)*

"Helpers don't "act bossy", or "have an attitude." *(self-advocate)*

"(People) respect my rights and feelings." *(self-advocate)*

"People know I can do things for myself." *(self-advocate)*

"I value "mutual respect on both ends".... "Paid friends, not paid staff." *(parent of an adult)*

"Have someone understand abilities/individuality." *(parent of an adult)*

"That you receive support from county's formal providers rather than care taking." (case manager)

"The ability to make your own decisions rather than having somebody else make them for you." *(parent of a child)*

Evaluating the Quality of Services

"You as a family or individual get to evaluate the support, they don't get to evaluate you. Anytime I get support or a product I evaluate it, they don't evaluate my use of it." *(Case manager)*

"Being able to change your mind. Maybe you try something based on the information you have and you get more information and you want to make a new plan. The ability to change your mind." *(case manager)*

"Rules are flexible. They don't get in the way of how you want your support." *(case manager)*

"A lot of rules have been created with a lot of good motivation. To protect people from unscrupulous people or from being taken advantage of, but that are really restrictive when people want to get more flexible. When they want to do things that make sense to them in their situation." *(case manager)*

Needs are Recognized as Important

"Is there a chance that the needs of children and adults with disabilities be compromised in fervor to address the concerns of other groups, such as aging baby boomers? This was a disconcerting thought, and concern of parents who attended this meeting." *(parent of child)*

"I think it also depends on the level of the individual, too, because many of the people that I serve wouldn't really understand what self-determination really is. I don't think that's really been addressed." *(service provider)*

"It's all those things that happen behind the system, but for the individual it's just this is your money, and you can figure out how to use it. Like you said, it doesn't matter if I'm in this, this, or this if it's what I need and what I want to do." *(service provider)*

Simplify Access to Services

"I get my support and do my support like I do anything in life. Not out of some cockamamie system that doesn't look like anything else, with all kinds of rules, regulations, funding, sideways backwards comments, initial secret language, codes, no-just like buying any other kind of support, so simplicity." *(case manager)*

Receiving Quality Services

"When my child is happy, and is receiving quality services." *(parent of adult)*

"When issues are dealt with in a satisfactory way." *(parent of adult)*

Think Outside the Box.

"To define what support they want as opposed to what they are eligible for." *(case manager)*

"We've gotten so used to having things being one way that we forget to ask tough questions of ourselves and families asking them of themselves. Many of them know what they want they just don't feel like they can get it so they don't bother saying it." *(case manager)*

Short and Long Range Goals

"Short term and long term goals, knowing that you may have a shot at making them." *(case manager)*

F. Safety/Security

Knowing Safety Nets Exist

" Feeling in control means knowing I will get the support I need if I have a seizure." *(self-advocate)*

"They say they screen the people but they do not screen the people." *(parent of child)*

"A safety net, something that as a backup they can understand- if they're trying some things outside of a formal system that has backups to it – family and neighbors helping out, doing some care – that if that kind of support fails for some reason that there is some kind of a backup system they can access on an emergency basis." *(case manager)*

"For the safety concerns, as people get older, it seems like the concern that the son or daughter will be protected and safe over time.... If this system that I develop breaks down, then something will pick up quickly and adequately." *(case manager)*

Security

"I think trust is a huge factor, not just knowledge and actual money, but trust that this system isn't going to be changed on you. What you're setting up will be something different, and a few years from now this isn't going to work the same." *(case manager)*

II. Factors Related to Control and Responsibility of Support

A. Capacity

Learn from Experiences

"As we talk about control, there is responsibility that goes with that, keep a balance. Obviously there has to be a balance. Being able to learn from the consequences of decisions-if you are ever going to be able to grow in your responsibility." *(service provider)*

"Along with that you get to handle the consequences. I get to be responsible for my choices. I don't get to blame anybody. But if I choose to risk and I fall down, cool, at least I know I had the opportunity to risk." *(case manager)*

B. Power

Increased Self-Worth and Self-Esteem

"The more control you have got of your own choices the more self-worth you get for yourself. When you get caught up in other people making decisions and turning down what you want putting you down with your inability to do something." *(parent of child)*

"You are also making your PCAs that you have hired you make them feel that the work they are doing-that they are worth that." *(parent of child)*

"Part of it would be being respected for the choices you make and not always being second guessed." *(case manager)*

Sense of Openness

"Your doors are wide open to people that want to come in and see people that are just getting started so there is nothing hidden. No one is hiding anything people that work with these kids know where the money is going." *(parent of child)*

Increased Influence on Agencies

"I think the self-determination program is a threat to the agencies out there." *(parent of child)*

"These are organizational needs opposed to service needs. Increasingly, when you talk about lack of control and self-determination it's a response to hierarchies and organizations that are stuck. Hell, the customer is the county, as long as the county pays them. That's cynical, I think providers are best when they're hungry." *(case manager)*

Opportunities to Make Choices

"When people listen to me and I get the job done." *(self-advocate)*

"When I decide what I do." *(self-advocate)*

"I know I have control when I get to choose whatever direction I choose to go in. I have control over that choice and I know I have responsibilities when the consequences of that choice are mine-good, bad, or indifferent. Short of that I have neither control nor responsibility." *(case manager)*

"There's no magic set of rules that says everybody has to be all even-they can choose what they want to do." *(case manager)*
"The biggest control isn't over what you do but how you do it." *(case manager)*

"Being able to change your mind. Maybe you try something based on the information you have and you get more information and you want to make a new plan. The ability to change your mind." *(case manager)*

When you take control you always have a lot of flexibility in determining how the service is performed. Exactly when it happens- so I see no problems in terms of the risk, there are some." *(case manager)*

Increased Creativity

"A full-time job during the daytime, she works Saturdays and most Sundays. She was working two nights with my son, when do you have time to spend time with her family. What better way than to encourage her to do things with my son where her family can go along so at least she is spending quality time with her family and our son is getting quality family with her family." *(parent of adult)*

"Allowed to create more options." (case manager)

"Yeah, if they feel like they have the final decision then they really look at what are the options- maybe we want to do this. They can just be more creative. If they really feel like they have the control and the responsibility. ... But those who feel like they are more in control, they think of different things, instead of doing the survival, they look beyond that." (case manager)

C. Real Options

Identification of What is Important

Comment from the parent of a child: "You start putting value on what is important and what is not quite as important. Especially when you have a full schedule of appointments." *(parent of child)*

Comment from a case manager: "For me the bottom line is saying yes or no, I want it or I don't want it." (case manager)

D. Resources

Adequate Money to Meet Important Needs

"We were able to get a loan to pay off our debt and we were able to get it down to where we can make our bills again. When the bank saw the county stepping in saying we think this is a worthwhile effort and we are willing to support this child for the next two years the bank says we understand now we get it. So they were able to secure the financing." *(parent of child)*

"Our kids are into more programs that the toy cost alone. We are rotating toys with other families now." *(parent of child)*

"Getting approval, as long as I can do it within budget constraints, I do not have to wait. Do away with the hierarchy of command." *(parent of adult)*

"It is good and bad, and the bad ones give you the same old excuses- we cannot recruit staff, our budget is not big enough...that is why if I have control of my budget I can treat my staff with respect." *(parent of adult)*

E. Roles and Relationships

Learning New Set of Rules

"There are times when we have to compromise (If I know the rule not so much arguing). The rules were not explained in a way a person understands." *(self-advocate)*

"... Learning a new set of rules around the way we are faced with our community-the human beings I come in contact with. I think that, to me, really speaks to a great level of responsibility and a great level of risk and the need to be savvy about that." *(service provider)*

"I think it is scary to some people then too because that is an unknown quantity-what are the rules, what is going to happen." *(service provider)*

Reciprocity

"I get my support and provide support as well, get the two opportunities." *(service provider)*

Change in Roles and Relationships

"I think for a lot of people it would mean a change in roles, and relationships with the people who provide the support and have experience. The people that provide the support are family members as well." *(service provider)*

"I think it means I have to put work into what I do. ... it doesn't mean stuffing stuff on other people." *(case manager)*

"Here's what I think you have to give up if you're really going to really take responsibility. You have to give up the passive-aggressive role and the complaint role." *(case manager)*

"One piece that we don't talk about is society has to take some responsibility that they never have. ... There are a lot of consequences that society is not willing to give people with DD, as well as a lot of control. As long as you keep that dichotomy then you will always have a dichotomy of control and responsibility." *(case manager)*

"It feels scary to be in control. It feels good but when it isn't feeling good it's feeling scary-cause you're responsible." *(case manager)*

"I guess I never see the clients in control. No matter how much control you want to give them, they need support. It comes back to team decision. To me that's controlling responsibilities." *(case manager)*

Sense of Citizenship

"The responsibility to obey the laws, to become informed, I am responsible to be concerned about my fellow citizen, it was more than just control where I went." *(case manager)*

F. Safety and Security

Loss of Safety Nets

"Along with that you get to handle the consequences. I get to be responsible for my choices. I don't get to blame anybody. But if I choose to risk and I fall down, cool, at least I know I had the opportunity to risk." *(case manager)*

"The responsibility area is the one area in our brief experience with self-determination where people shy away from it. For them the responsibility is a real loss of safety." *(case manager)*

"If they lose staff how do they find more. How do you deal with tax and papers. The risk is overwhelming to people. I think the biggest thing is how do you find someone. That's the biggest fear, if this person leaves, that's my job support- if that person's done I can't keep my job." *(case manager)*

"I think too sometimes people say it's risky but they don't know everything. They are taking risks before they have all the information. Like the financial thing. It changes." *(case manager)*

G. Stress

Reduced Stress

"This is a little off the mark but for me it would mean less stress. I mean I am only two years into this and I am used to being in control of my own life and my children lives. Now all of a sudden I know what my son needs, but I am confined. I do not have the resources to help him because his needs greatly exceed anything I counted on when we had him. So I do need the help but being told exactly what I am going to do and how I am going to do it having all this paperwork it is stressful. If I had control over the situation I would experience a lot less stress." *(parent of child)*

"It is a big piece that is missing the stress. How in the heck am I going to deal with this for the next week. Stress is big." *(parent of child)*

"The more you are boxed into the tight regulations the more you are limited to who you can make contact with the harder it is to get things done. The more stress." *(parent of child)*

"The first thing was the sense of relief because we were making great progress. We went to bed and slept. We had a Christmas that we paid cash for." *(parent of child)*

Increased Stress

"The more you are boxed into tight regulations the more you are limited to who you can make contact with the harder it is to get things done. The more stress." *(parent of child)*

" ...sometimes I think we give people the illusion of control. They really don't have control." *(case manager)*

"We may set people up for disappointment." *(case manager)*

III. Barriers to Gaining Control of Supports and Resources

A. Personal Attitudes

Perceptions

"In my understanding when I first went to the meetings educating myself about what self-determination is about. It is supposed to be giving the parents control, it is supposed to be allowing us because we know best. I am still finding that my roadblock is the social worker questioning, and it is frustrating. I think it is a power thing, they are so used to the way things were. I can see that it is hard making the transition." *(parent of child)*

"As hard as we try, people with disabilities are labeled and treated differently by their community and I think that stands in the way, I know it stands in the way. It certainly, in trying to be a productive community member. I think that it then requires a different level of support." *(service provider)*

"Individuals living out of the home have different desires than the mother and father." *(service provider)*

"Other people's opinion about what they would be. That's a big barrier." *(case manager)*

"Well, if you don't believe you're worth anything you don't ask for what you need." *(case manager)*

"I think assertiveness can be a real barrier when you're dealing with the county or services. People that are more assertive get more services." *(case manager)*

"I think another barrier is the system, but the system holding the belief that they're responsible for what happens to people and that the outcome that happens to the person is their outcome rather than the person's outcome and so a lot of blocks get put up to people. We relate our adequacy to whether or not the people we support fail or succeed, not whether they tried or got what they wanted or got the help they wanted in the way they wanted it." *(county manager)*

Lack of Trust

"Defensiveness is a barrier. There is a lot of defensiveness on the part of B probably more so for professionals than parents because we have been level 3 early on. And that's good. You have to be depraved before you pull yourself together and recreate yourself and your family. But I hear them mention the word self-determination and a lot of defensiveness in professionals. I am not going down that road now. I am not saying a word, I am just saying, you know, think about it." *(parent of adult)*

"My biggest frustration is always having doors closed, and other people saying 'do you think he can handle that.' We will never know unless we try. We have tried to hook him up with the philosophy, try it and if you do not like it try something else. Everybody fails at some point in their life and there is nothing wrong with that. That is how we learn and grow." *(parent of adult)*

"The word trust. I think the people with disabilities- whether it be an advocate, or their families- I'm thinking of people and their providers. I sometimes get the impression there is an overtone of distrust. That maybe people are not always, or believe they are on the same page- when in essence they probably are." *(service provider)*

Fear

"Fear, they do not know what it means or what is going to happen, or they are going to be put out of business. If they are good they are not. They are being supportive. We are still banging on their door. If parents had money and they knew this was a great place they would be banging on the door." *(parent of adult)*

"I get so fearful, but that is how you grow. Sometimes you take a risk and its disastrous, but you see that in the regular world too. But our kids deserve to fall on their face too. How else do you experience it?" *(parent of adult)*

"I think fear is a barrier. Fear of failure." *(case manager)*

B. Poor Communication

Poor Communication

"I think communication is a barrier where the person may have DD and is not able to communicate their ways and nobody is doing what they can to make sure they can communicate. They aren't using all available means to let them communicate what their needs and wants are. People don't go far enough. Also, assuming that a person is not able to make a choice. Whether its school, parent, or social worker. Or the person themselves. It can be ruled by what a person's IQ is. It becomes ruled by numbers. So if a person has an IQ of whatever, they're not capable of making a choice or knowing what they want." *(case manager)*

C. Lack of Information

Lack of Information

"I think part of it too is the education. We have done it so long for everybody that it is a whole different concept that I can have the dollars and do it myself. What does that mean, if I have that authority and that responsibility, what does that mean?" *(service provider)*

"In some sense we are beginning consumers. Customers that don't know how much things costs or how much money you have to spend or what it would buy." *(service provider)*

"There should be a class called 101 for parents at the age of 18. I really do. I have the fortune of having all 23 year-olds, but the parents had not a clue, not a clue about anything. They weren't even thinking about placement and when they actually got into it. It is very important for the parents to know at least what is going on, because sometimes parents can be the biggest barrier." *(service provider)*

"The lack of support in planning a budget." *(service provider)*

Lack of Access to Information

"Getting a hold of the right person to get the right information about equipment or finances." *(parent of a child)*

"I did not know, because we are...we have had the same case worker and she has been extremely supportive and flexible with whatever seems to be the right thing to do. When this whole things came up she said it is fine, but I am not sure what you are going to gain from it." *(parent of a adult)*

"I knew about self-determination when it first started, it was not worth it then. But when I realized later that I did not have all the information, and I did not have the budget then. It is more work." *(parent of a adult))*

"You have to beg for information and some of the resource guides you know they have. Send me that, let me know, give me a map. My concept is that they should be offering that, you should not have to ask." *(parent of a adult)*

"I think it's dependence, period. They depend on other people for information, money, accessibility. Especially if they don't have a choice who they get that information from." *(case manager)*

"I think we have to do a better job with the knowledge we do have, putting it into tools that families can use." *(section manager)*

"I think another barrier is controlled access to information. Other people decide who gets what information when, if they get it at all." *(section manager*

"There's a lot of issues with information. Getting the right information, distribution, accuracy, is it in code, or being fabricated." (section manager)

Section managers noted current efforts to create resource guides for families, including a guide to service providers being prepared on services and supports throughout the metro area available to persons with developmental disabilities.

D. Resources

Fragmented Resources

"Everything is so parceled out- if you want these services you have to fit into this category, and residential is the one that is hardest for me. If you go to those where you have to convert to divert to make a bed good- I mean you're talking about a person's life here. As a family member if you go to any of those meetings where they are trying to determine that you come away thinking, is my significant person valued or not- is there a place for them." *(service provider)*

Lack of Resources

"Waiting lists are a barrier. That and program rigidity. Any program without a waiting list you can assume it is fairly rigid. The waivers got the big waiting list. I am not sure if that is more of a state issue." *(parent of child)*

"Well people you want your kids to spend the day with." *(parent of child)*

“It depends on where you live too. We went with one agency that they said they could find people easily who lived in this area. In between them. There was no PCAs at any place.” *(parent of child)*

“Lack of supports and resources. There isn’t enough to go around, waiting lists.” *(service provider)*

“Residential support.” *(service provider)*

“I think a big one is getting home health care, getting something available for individual-beginning with residential housing.” *(service provider)*

“Another related point, the client almost always has to make compromises in the choice of the care givers because of the lack of availability. People they would normally not consider wanting to help them. The choices are not as good as ten years ago.” *(case manager)*

“I wanted to say about that placement issue. If people really want to have a choice about where they want to live they don’t. The barrier of not having the choice to live where you want.” *(case manager)*

Rigidity

“Well the PCA program that we are in is a perfect example. I will have X number of hours and X wage or nothing. That is fairly rigid. ... It is kind of an exaggeration to make a point but why can I not have less hours and pay people more.” *(parent of child)*

“The current system being so rigid does tend to kind of criminalize parents and their PCAs just to try to do what is right for the child. Basically trying to make their rigid program work much the same way the waiver program does work.” *(parent of child)*

“It does not really work well because the agency is still getting half of that money and why not put the money right into the kids. Instead of into the agency.” *(parent of child)*

“There are other things too. I cannot have PCA’s overlap. So if I have a PCA that I want to work with the other PCA so they are consistent. They cannot bill for the same hour. Yeah we got in trouble for that too. I did not know we billed them for the same hour because they were there then at the same time.” *(parent of child)*

“We do a good deal of complaining that such and such a group will not accommodate a client, but I think the creativity goes both ways. Sometimes the special education providers cannot see a way out of it either. We just have to be more open and listen. It is a risk.” *(parent of adult)*

E. Lack of Responsiveness in the System

Not Returning Telephone Calls

"She calls someone and they do not call back for three days and we needed the answer two days ago. It holds up something that holds up something else." *(parent of child)*

"People not returning your calls. Are they so short staffed? Are they so short staffed at these county offices your human services offices." *(parent of child)*

Staff Not Repecting Individuals

"Staff don't let me use the phone." *(self-advocate)*

"I can't cook, but I want to cook....staff won't let me cook." *(self-advocate)*

"If someone says they are going to do something and they don't." *(self-advocate)*

"I can't get support when I need it. When I really need something and they are not there." *(self-advocate)*

F. Rules and Regulations

"There is not equitable allocation of resources. (there are the) "haves" and the "have-nots." *(section manager)*

"All the rules and regulations-you can just put up that rules and regulations don't facilitate this at all."*(section manager)*

"Laws and federal rules get in the way." *(case manager)*

"I'm thinking of waiver rules. You can only do things a certain way. You can't pay a certain person, like the sibling. There, constantly- we can't do that with the waiver. And every program is a little different. That's definitely a barrier." *(case manager)*

"Agencies are big barriers with their rules and regulations." *(parent of child)*

G. Safety and Liability Concerns

Liability

"Well it scares the crap out of everyone in the system if we ever allow a risk and something doesn't work. The public is supposed to be kept immune to something bad happening and if something bad does happen then the responsible party is the system. So the system builds up a bunch of rules and regulations to protect itself in the name of protecting the client." *(section manager)*

"Somebody could sue you! I talk to people about what we're doing and what we've been doing which is thoroughly denying basic programs. About the first or second question is how did your county attorney ever let you do this?" *(section manager)*

"First question I always get with supervisors throughout the state is what's the liability, how do you guys work that out? God I wish we could, but the county attorney would never let us touch this- huge issue, it's an absolutely large..." *(section manager)*

"It think that some of the families- the liability issue is in terms of if somebody I hire gets hurt, how's that gonna work out. It's not so much of a barrier as it is a concern. The systems are not well set up for people to do things on their own- whether it's insurance. All the things that get built into an agency or a formal entity. everything from workers comp to access to different coverages are just not there for people doing things on a relatively large scale on their own. So when you start getting into the dollars that we're talking about here, people are doing big-scale stuff. All of a sudden there are..." *(section manager)*

"Wage and tax laws and liability issues, so you're stuck." *(section manager)*

"You've got all that liability of being an employer. If the person I hired to take Johnny to the doctor hits somebody on their way...that kind of stuff." *(section manager)*

H. Lack of Transportation

General Comments

"Transportation." *(service provider) (self-advocate)*

"We don't have much to do when we get back from work. Like taking turns to cook. I want a say in my program. (Transportation, a trip on my own like everyone else)." *(self-advocate)*

IV. Moving from a Program-Centered to a Person-Centered System

Stakeholder Group: Individuals with Developmental Disabilities and Their Families

Increased Assertiveness

"Consumers and families need to stop asking permission all the time." (section manager)

"Consumers and families need to act rather than complain." (section manager)

"I don't that it necessarily is about us. I mean, we're part of it but ultimately it comes down to the consumer and how do they want to drive it? What do they want? How do I fit into that? With what's available, because there will always be a newness to what's available. I can sit here and say what my parents think or what my kids think but ultimately it has to come from them." *(section manager)*

Know What They Want

"Persons with disabilities and family members need to think about, and be aware of what they want." *(case manager)*

Gain Power

"I really think we (persons with disabilities and families, as well as all other stakeholder groups) need to take some of the power away from the system because the system won't give it up, so we have to take it." *(section manager)*

"Consumers and families need to help advocate for the rules, regulations and resource changes." *(case manager)*

"Persons with disabilities need to take on a role in checking up on staff, and make sure they are doing their jobs." *(self-advocate)*

Become Mentors

"Consumers and families need to share information, support, and mentoring with each other." *(section manager)*

Know Strengths and Limitations

Comment from Managers: "Consumers and families need to have strong self-awareness and self- knowledge."

Comment from Managers: "Consumers and families need toto now the bounds of their own confidence."

Comment from Managers: "Part of the issue is people's energy levels, in terms of feelings and taking things on. It's an issue for individuals as well as the families."

Comment from Managers: Persons with disabilities and families need to: "Know your limits. Know what you're willing to take on."

Comment from a manager: "We get families coming in, it's a battle to make a doctor's appointment. No way are they ready to take on any large chunks. They may want some pieces of it, they may want some of the decision making things. I mean they've got three kids at home and one is disabled and it just kind of mushrooms, the point is not everybody is in the position to do this stuff."

Let Go

"Obviously a family, as parent, my beliefs and values influence how I make a decision for my kids, but my kids might want to make some other decisions." *(section manager)*

Make a Long Term Commitment

"This is value based, so I get a little nervous saying this, I think families need to make a long-term commitment to their individual. That doesn't mean they keep them at home, it means they stay in their life some way. I think that's been negated by us, the system, but in some instances not. I think that needs to become an expectation." *(case manager)*

Stakeholder Group: Community Members, Taxpayers

Public Education

"They are just not a drain. There are a lot of people who are affected by this. They are drivers, and my daughter is hanging up the clothes at TJ Max. If they are not hung up they will not be out in time for the sale. There are a lot of people who are affected by us." *(parent of adult)*

"The stakeholder also is the employer because there are different jobs that these people enjoy that maybe the next person does not. Right now we need more employees. There is a shortage. They are now starting to look seriously at people with disabilities and their qualities and the fact that many of them are so happy to have a job. It seems like sometimes they accept the responsibility more seriously than someone coming out of a high school. They take their jobs seriously and they really contribute a lot. That is exciting and everybody wins there." *(parent of adult)*

"Well you know there is a whole community at large that has a stake in this. It is a cost, a responsibility. But there are a lot of people who did not know us before who know us now who have gotten a lot of joy from us too." *(parent of adult)*

Comment from Managers: Members of the community need to: "...see the person first."

Comment from Managers: Members of the community need to: "... give up the feeling that there has to be an answer for something....There is no resolution in some areas. Not even if you try hard."

Comment from Managers: "There's another- the idea that because you use a resource then you are beholden for something. To get rid of that notion that using this resource that – it's more than conforming, it's beholden."

"Members of public need to develop a sense of social responsibility." *(case manager)*

Comment from managers: "Members of the community need to let go of the notion that persons who receive public assistance ...don't have any rights.... They 'should be grateful.' ... (that) there is no societal obligation to provide (people) with what (they) need. The grovel approach."

Natural Supports

Comment by managers: "I think there has to be a willingness for extended family, neighbors, and community in providing support- even if that support is through a paid system. Willingness to engage for money or not for money in activities."

Comment by managers: "We don't get to just say oh gee that's too bad and then walk away. There are some social responsibilities. Whether you're the grandma or the neighbor. It's part of community living."

Comment by a manager: "If they are competent to deal with it doesn't take somebody special to support somebody, just someone who cares about them."

Believe in the Power of Relationships with People

Comment by a manager: "I don't see them doing a lot of legislation, natural supports just need to be there. To hang in there and be willing to take things on. Have a relationship."

Comment by a manager: "I know what I'd like them to do, but I don't know if it's possible. I'd like them to start believing in relationships rather than rules...and individual self worth rather than hierarchy. If that would happen we'd be in great shape."

Recruitment

Comment by a manager: "...maybe talk it up it their own area. One of the great things about having those natural supports is that they talk to people about it."

Comment by a manager "They expand people's minds."

Stakeholder Group: Advocacy Organizations

Lobby

"Arc is really involved I think. Advocates are keeping a watchful eye on the bills being presented to the Legislature and House of Representatives." *(parent with child)*

Moderate their Adversarial Approaches

Comment from Managers: "Advocates need to become supporters and facilitators rather than litigators and protectors."

Comment from Managers: "Advocates need to become more coalition builders rather than litigants and adversaries."

Comment from Managers: "I think they need to (become adversarial to assist persons with disabilities and families) on an individual basis. There's two levels."

Comment from Managers: "Yield power to individuals receiving services."

Stakeholder Group: Traditional Service Providers

Disabilities Awareness Training

"just because we have self-determination doesn't mean we're not going to be there to provide the supports that people need. We're not going to have to program for them 24 hours a day and make them do things they don't want to do if it's not a matter of health of safety." *(service provider)*

Comment from a manager: "I think all of us have to make sure whatever we do is in the best interest of the people receiving the support rather than the system we're in. So simplicity, accessibility, common language and all that kind of stuff goes, good information."

Comment from a manager "I think providers have to stop being controllers and move to being supporters of the individual."

Persons with disabilities are usually very aware of things they like to have help with from others, and things each person preferred to do for themselves. Self-advocates urged staff members to ask the persons they support about such preferences before jumping in to help. Self-advocates also felt strongly that staff members need to know what their job is." *(self-advocate)*

"I started the support group with a social worker and they asked my son to help facilitate. Being open to that is the most effective self-esteem booster. It gives them the power. My son is very sensitive and he said it makes him feel good because he helps people to understand and to feel better." *(parent of adult)*

Improve Communication

"Being honest with people about what can and cannot be done. The parameters. Not promising what you can't deliver."

"I get very frustrated when provider feels they can decide what services are best for a consumer, when services become clearly provider-directed." *(case manager)*

"Providers need to convene more regular team meetings, but only on the condition these are a forum in which consumers are truly heard." *(case manager)*

"Provides ways for consumers and families to offer feedback (in a manner that works for the client)." *(case manager)*

Advocacy

"Providers have a responsibility to pay attention to who is speaking for a consumer, and to assure the consumers true preference from their perspective are heard." *(case manager)*

Incentives and Training for Direct Service Workers

"The work of direct service staff needs to be valued more highly, and rewarded with higher wages." *(case manager)*

"I think it's a difference in helping the people providing the direct services as well to understand what their role is. A training, teaching and supporting a relationship kind of a role." *(service provider)*

Stakeholder Group: County Case Managers

Disability Awareness Training

Comment from the parent of a young person: "We have generally found too that the workers who come to our house and interact with our family are much more involved and effective than the people who sit on the telephone in the office all day long. It is really noticeable."

Comment from the parent of a young person: "Some of the decision making people see it opposite and they go by the regulations and the book but they are not working in reality. The people who come to my house and know intimately what is going on, those are the reality workers. They help push things through and get some of that stuff done easily"...."They make house calls. Really important."

Share Information

"The social worker should have told me some of these things". I went to the parent meetings, but "you need the information before you can utilize the tool. I do not know if other people have had that experience, but there must be a way somehow to motivate people to be involved. For us, it has just alleviated so much stress and just having that control and knowing we are doing what is best. I do not know if they are informing people enough." *(parent of adult)*

"Arc has said that they have facilitators who are willing to work with you if you want to sit down and make a formal plan. You should have been made aware of that at the time." (parent of adult)

"We need to tell consumers and families about all their options, not just those we think are best." (case manager)

"Case managers need to model the skills to use the system." (case manager)

Advocacy

Comment from a case manager on their role: "Listen and be aware of what consumers and families are asking for, as well as what resources exist."

A self-advocate made a similar comment: "My case manager needs to listen to me instead of making up (his/her) own idea about who I am."

Thought from a case manager: Case managers need to believe that possibilities still exist in the current system, and in the larger community. Case managers need to act as catalysts for persons with disabilities and families in generating new ideas for supports.

Suggestion from a self-advocate: It would help if case managers could help self-advocates get prepared before their annual, or other planning meetings. Such preparation would really help people to be in control at the meeting.

Comment from managers: Be advocates for families and consumers

Comment from a case manager: "We need to 'stand-up' for consumers and families with service providers and in other situations, and then we need to tolerate the discomfort that comes with that."

Comment from a manager: "I think all of us have to make sure whatever we do is in the best interest of the people receiving the support rather than the system we're in. So simplicity, accessibility, common language and all that kind of stuff goes- good information."

Stakeholder Group: County Agencies

Support Agencies

Comment from a service provider asking county social service departments to share the financial risks they face with this new approach: "One of the major responsibilities for all of us is the whole issue of risks. There is going to have to be some shared risks. Between the county and providers, we're talking about households where someone moves out. There are financial risks that need to be addressed for providers. I think that shared risk is a big issue."

Support Change in Roles

"Getting tougher on issues on the current system, and letting go of the other kind of decisions that consumers can make and don't have to have made for them." *(service provider)*

Comment from a manager: "I think all of us have to make sure whatever we do is in the best interest of the people receiving the support rather than the system we're in. So simplicity, accessibility, common language and all that kind of stuff goes- good information."

Comment from a manager: "My one shot deal for the county is we've got to stop being givers and caretakers and move into being helpers."

Create Support and Information Networks

Comment from the parent of an adult: "The input from other people could help. I know at one of meetings last week one of the things that one of the other parents said was that this is your budget, write it up. Even though you know your boundaries, it would have been helpful to talk to Don who has been in the program for a year and knows its ins and outs. Getting feedback would be helpful."

Comment from the parent of an adult: "Even a phone list. I know that the support group of the epilepsy foundation exchanges phone numbers."

Comment from the parent of an adult: "I personally as a parent would want to have a small group because many parents would not feel comfortable dialoging with professionals. A lot of parents would be intimidated by that, and they would not share. They need to get some structure and guidance."

Provide Other Supports

Thoughts from case managers: As persons with disabilities and their family members take increased control in designing their supports, they will need different types of supports than in the past.." *(case manager)*

Increase Opportunities for Dialogue Among Stakeholder Groups

Comment from the parent of an adult: "I also think from a county standpoint we really need to have some scheduled meetings where you have a collaboration of people involved, like providers and social workers. It would be very structured, you come in and have some key issues that you want to address, and you have professionals to mediate. I think it might do a lot for the tension."

Stakeholder Group: State and Federal Funding Agencies

Shift Power

Comment from a service provider asking the Minnesota Department of Human Services to cede greater control to counties: "It's going to come to more local control. The state is going to have to find a way to have whatever control they need to maintain but to loosen up on that and let the county be able to take a look at what it needs to do."

Comment from managers: "Just keep sending the money. Show us the money."

Comment from managers: "Give us waivers when we ask for them."

Comment from parents of adults: It is very important for systems to be in place to "educate those people who are coming into the field. Case workers or people working with people with developmental disabilities do not have that kind of creativity or flexibility or that kind of mission statement it is going to be hard to influence them."

Flexibility

Comment from parent of a young person "It should not cost more money at the state but they just need to make things more flexible. Then things will become more effective. It is almost too simple. It is frustrating."

Comment from managers: "All the rules, laws, procedures, that people operate under need to be written in a way, and practiced in a way to give support and control to the clients."

Comment from managers: "State needs to move from rulers and rule makers to expediters."

Stakeholder Group: Medical Professionals, and Therapists

"They should have some central place at the hospital that acts at a functional social worker level to help direct you." *(parent of child)*

"The doctors should tell the social workers and the social workers should help you. It is the branches of the tree system." *(parent of child)*

"The hospital helps put you up with another parent with experience with that disability for two or three years so that the newborn parents can have some guidance for a couple of years. We were looking to get somebody when our child was born." *(parent of child)*

Stakeholder group: Pre-service training programs for professionals, and all support providers

"Training programs need to "...educate those people who are coming into the field. If case workers or people working with people with developmental disabilities do not have that kind of creativity or flexibility or that kind of mission statement it is going to be hard to influence them." *(parent of adult)*

V. Concerns Related to the Shift in Roles and Responsibilities of Major Stakeholders

Adequate Education and Information on Services are Made Available

"I think there needs to be an effort in educating people in what their options are and how they can be effective. As you empower people you have to give them knowledge too as to what their options are." *(parent of child)*

"And even currently without any changes there has to be more of an effort on educating people on what their options are." *(parent of child)*

"They need a guide - a road map. A guide to tell you what is available like at state parks so at each particular camping spot you can tell whether there are trees and picnic tables or a firepit or a public restroom or a shower."

"You have to know about it to ask to get the information." *(parent of child)*

"That is something that the government cannot handle. Governments by nature have these services available but don't want people to know about it because they don't want to put more and more people on the roll. An advocate organization like ARC will do that." *(parent of child)*

"People need the guidelines to do whatever they want to do." *(section manager)*

Flexibility

"I think a lot of it depends on consumers having control of the resources and spending those resources on ways that drive the creation of the change of the service system to become something more responsive that it is. ... Consumers don't really having purchasing power that creates change that the regulations are still so restrictive that the services can't be flexible enough. I'm pretty sure that's where we'll be until we go through a transition." *(service provider)*

"Only that we're going to give people money and not support. I worry if a person wants to give up what they have now but then wants to go back, will they get the same level that they get now." *(case manager)*

Cost Containment

"Another concern I have is with individualized programs. People are wanting to purchase and know that their price is going to affect the value of what they are getting for the amount of service. That's a much more complex system, more complex for their providers. Doesn't that add cost to the system? If it does, is it worth it? In some sense, it's in the opposite direction, as in managed care where you pay the same premium in the end, but you get what you need when you need it. They take the list whether they can manage it or not." *(service provider)*

Quality of Services

"New providers, something that begins to look more like a market, which I think the theory is that the market generates more choices. I think what you're going to see is there enough money? ... I think that's going to raise prices. I may be wrong on that. There may be a lot of small providers, and maybe they'll be cheaper. But what happens to small providers is if they want to expand they start falling into that whole deal where we run into a lot of problems when you get to certain size or scale and it just kills you. It is an American empire- everything big gets bigger and bigger." *(service provider)*

"I think too that low cost providers or some of us make bids too low and that ends up hurting us." *(service provider)*

"I'd be concerned they (persons with disabilities and families) wouldn't get what they needed." *(service provider)*

Delay in Choosing An Approach

"In some regards wiping the slate clean then building again. Building maybe isn't so hard but reconstructing it, and we're running parallel approaches right now, so when you do that it's hard to let go of the old stuff." *(section ,amager)*

Little Control Over Supports and Resources

"Don't put us in 'slots' because of our disabilities. It may be issues with transportation (supports)." *(self-advocate)*

"Give me the control and watch me go." *(parent of child)*

Lack of Natural Supports

"I'm afraid there won't be enough people in the general public that will be natural support people. That we've gotten so far away from this as a societal value that even with money we can't bring it back. I'm afraid also that a couple of mistakes in the public will kill us." *(section manager)*

The Shortage of Direct Support Personnel

"And you sit around in meetings where they want to put together a home. They have social workers sitting around, case workers saying I want double coverage Wednesday nights and Friday nights, I want double Sunday mornings. Some will go, I want triple coverage at night. Do you think there's all of these staff running around and I can put a pen to paper and get them like that? That's a lot of money! If a client wanted to come and say the same thing, you could say, fine, but this is what it's going to cost." *(service provider)*

"The staffing issue is a crisis and that's a hard thing to separate out of this whole consumer-directed issue. You could end up real isolated- we gave you the money, go hire somebody! But they don't have anybody." *(case manager)*

"I heard a comment from a staff person that the quality of staff there- the quality had gone so dramatically down that she said it's amazing you can see signs on the street that McDonald's is hiring at $8-8.50 an hour. Here we're asking people to work in places where they might get hit, where they can be subjected to XYZ, for the same money they can go and walk away from their jobs. It's not working." *(case manager)*

"No matter how much money you have if something tragic occurs - and if you don't have quality staff, it's no longer self-determination. It's just survival mode." *(case manager)*

Competition

Comment from a provider: "In the last couple of years because primarily self-determination, the amount of services we provide is almost half because families have gone out and bought their own service, or they use their own resources. So what we're finding now is that the amount of service we're providing for families has gone down quite a bit even though we have to do the same kind of paperwork we've done in the past." *(service provider)*

"We're losing a lot of our staff that we hire and train through the families, and it's getting harder and harder to operate the program. With that option, we don't know what the future is going to be. It's good for families in one way, but for the families that want to use it and don't want to do all of their own work, we don't know what the futures going to be for us. We're moving fast, and hiring teaching staff." *(service provider)*

Manipulation of the System

"A concern that I have seen is that a lot of the teachers in my son's program are wanting to get involved in doing respite not as a weekend respite, but as a day respite. I will not pay that kind of money, but there are people who take advantage of people who are too intimidated to say anything. There is a man I know who is not even licensed who takes 6 to 8 guys out on a guys night out and charges the family $18 an hour. That is frustrating to me." *(parent of adult)*

The Role of Traditional Service Providers

"I guess I look at my organization as a service organization. I don't care who's buying services, the consumer, the county, the state. If we can sell the service, we'll sell the service. That's the way I look at it. To me it doesn't matter. If we're providing good services we'll stay in business. If we're not, we won't." *(service provider)*

"The more and more- it can be a good thing and a bad thing- more and more funding is directed through the consumer and more resources to read about or the less resources there could be. If certain things aren't utilized, then they go away. There might not be specialties or there might be more developed- it could go either way. Kind of like what happened with the state hospital. Now if you ever needed to use it, you can't. It may not have been the greatest place on the planet but if you needed that maximum of structure and service." *(case manager)*

VI. Additional Concerns of Stakeholders

Parent of Child

Monitoring

"Abuse or lack of the ability or will to carry it our could really cause problems and cause the whole thing to collapse. There has to be some sort of guidance or control."

Service Providers

Roles

One service provider expressed some concern over a perception that the movement toward allowing persons with disabilities and families greater control over resources was a reaction to the failure of provider agencies to deliver quality services. Providers noted that they did care a great deal about persons with developmental disabilities and their families, and that they continued to want a role in the system.

Case Managers

Time

Comment by a manager: I hope this approach doesn't "get squished by the public or the state."

Development of Allocation System

"We need one thing- we need good allocation methods which we don't have now.

One Funding Stream

Related but separate issue, creation of one funding stream: Managers also noted the importance of combining resources available to fund services be brought together into a single funding stream.

Monitoring

"Better ways to monitor, evaluate that are not based on the people getting supports, but rather how good the supports are."

"If you offered the families I work with quality or control they'd choose quality."

Conflict of Interest Between Parent and Child
"Her mom appears to like the project more than the daughter actually does. The mom gains through the project, but her daughter really could care less if it would have been a waiver, etc… I have seen some decisions that have been made that wouldn't have been her daughter's. I make sure mom knows what her daughter wants, but ultimately it's up to mom."

Flexibility
"I'm nervous about locking them in and not giving them options to go back."

"And people change. One minute they may have had all these abilities and then they have a stroke and then you've got someone that can't do anything. Their whole life changed, and their services change. And it's like what you gave before doesn't work anymore and now we don't have anymore funding. Well, circumstances change, and choices change."

Fear of Change

"There's a real desire that people have to try the system at times, including the people receiving the supports. We end up- one family comes upon a great idea then they think that's how everybody else should do it. We are all like that. This resisting the urge to create another system to replace another system that is as restrictive but called something else. And fear."

"I'm consumed with these ever growing movements. Ten years ago everything was ICF's, then SILS, SLS, before that it was more group homes that was the cure all to everything. What I'm concerned about is too much emphasis on movement. Ultimately we should give people with disabilities a number of different pools to emancipate themselves. And not be too hung up on one or the other. I see there's a certain woo factor in this whole thing. I don't mean to be (negative?) about self-determination, I think I've always- the first thing they tell you in social work is self-determination, but I hoping not to push either plan."

Comment from a county manager: "Families and clients that won't take on the responsibilities. They've been taught that and going the other way is a hard long process. There are a few that are really into it. But most people want things different but they still want their control. That scares me."