PRESENTED BY

THE GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

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MINNESOTANS

SPEAK-Out!

1997 EDITION

A
SUMMARY
OF
INTERVIEWS
WITH
MINNESOTANS
ABOUT
DEVELOPMENTAL
DISABILITIES
ISSUES

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INTRODUCTION AND OVERVIEW

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In 1992, the Deputy Commissioner of the Department of Human Services appointed a study group to review the current structure under which developmental disabilities services are provided, and to review costs.

The study group decided to hear what Minnesotans thought. Town meetings were held throughout the state. A toll free, call-in day was held. Letters were received. What Minnesotans had to say was summarized in *Minnesotans Speak Out!*

Five years later, in 1997, a new *Speak Out* process was developed. Twenty-seven facilitators asked families of people with developmental disabilities and self advocates from 29 counties to speak up.

In most cases, focus groups of family members and self advocates were held. In some cases, individual interviews were done. Generally, each facilitator involved about twenty people in the process.

The 1992 Speak Out identified six themes or topics that had to do with the strengths and issues in Minnesota's system of services for people with developmental disabilities (listed on the left).

The 1997 Speak Out asked people if these themes are still relevant today, what has changed, and what they think about specific issues related to each of the themes.

From the focus Group

These comments from family members summarize the views of focus group participants on the ongoing relevance of the 1992 themes:

These themes are still relevant, but ***the shifts are too few and too slow*** *in occurring.*

These themes are still relevant, and will continue to be relevant with the changes in society and a greater number of individuals who will be involved.

I see that there have been improvements in the past five years, but there will always be more to do. ***The system needs to be refined*** *(overhauled) with more services provided and easier access to the system.*

Yes, I believe these are relevant. We need to continue the holistic approach to this system including all players on the team (individuals and family, service organizations, and educational components). Current trends tend to pit the ***components as opponents.***

The main themes that emerged are:

The lack of services in rural Minnesota.

The need to focus on the individual rather than a program.

The need to increase the salaries of the people who deal directly with the individual.

The system seems to be top heavy with not enough of the resources getting to the individuals who need the help.

Most of the participants thought that the family should be taken more into consideration when decisions are made concerning the person with the disability.

In response to these themes, the participants in the focus groups want to see the following issues addressed at the state level:

waiver slot system

voucher system for families

parents as case managers

properly funding the state mandates.

The summary of the focus groups and interviews for one Southern Minnesota county speaks specifically about the job to be done:

The general opinion was that we have come a long way in the past five years, and look forward to positive changes in the next five years. However, in addition to this optimism there was concern expressed about the future.

There have been good changes for some people. For example, by the end of 1997, our county will have no one living at any of the RTCs. This has happened because of the Medical Assistance Waiver that provides community services. Many resources have been and will continue to be utilized in Minnesota's "deinstitutionalization" effort.

While these efforts are supported, the number of people receiving these resources are few in comparison to all individuals in the State of Minnesota.

Somehow, and in some way, our State needs to address the needs of individuals who have never resided in an RTC or an ICF/MR. These individuals are children living with their families, and adults living with aging parents or in unsupported living arrangements.

There is a great need for people in our State to support and encourage self advocacy. People with disabilities are in the best position to SPEAK OUT.

The Response in a Nutshell

The hundreds of people who participated in the process had a lot to say. They explored many issues in great detail. It is important to read what they had to say. There are important messages that must be heard.

The over-riding message, a message of concern, sounds like this –

The 1992 themes are still relevant,
BUT the shifts are too few and slow in coming.

For those of us who get support, what we have is good, BUT, not good enough, and not enough. We need and deserve better.
AND… we certainly do not need a system that makes it harder.

For those of us who do not get support, we need support right now, or in the assurance that it will be available when we need it in the future. We worry that it is not there for us now, and might not be there in the future.
AND… we certainly do not need a system that is, in itself, unsupportive.

For all of us, the constant threat of cutbacks and program cancellations makes it even harder.

There are many initiatives and directions in Minnesota that make sense. The problem is that they have become so cumbersome they don't work very well. And for some people, they do not work at all.

THEME ONE:

We have a lot to be proud of and much remains to be done!

In 1992, people looked back over a decade of change. They saw the advances that had been made. They spoke of a new vision of how life should be for people with developmental disabilities.

In 1997, the celebration of progress continues.

As does the need to make sure the job gets done for those who have not benefitted from "the better life" in Minnesota.

From self advocates and family members we also get a down to earth vision of what a quality future should look like.

We have a lot to be proud of...

In county after county, families and self advocates spoke to the advances that have occurred generally, and specifically in terms of more acceptance and inclusion in society, school inclusion, support to families, the closure of Regional Treatment Centers (RTCs), and the development of options in the community. To a far lesser extent, they spoke of advances in self determination, the responsiveness of the system, accessibility and employment.

As in 1992, when people spoke of improvements, they also identified challenges we still face.

Generally, things are better.

Since 1992, the Individual Family Service Plan (IFSP) services have grown and extended from birth to age 5. The main area of growth is coordination of services among the agencies, such as public health, human services, education, in home and private providers. I have seen growth in collaboration, but there is still a need to improve these services. IFSP should be extended to age 21 if needed.

All of the parents I interviewed felt there had been improvements, or at least no reduction, in services and support over the last five years.

Everyone I talked to said it isn't as bad as it has been, but it's not as good as it should be. The almighty dollar still rules, and families with their needs are irrelevant.

All the people I interviewed said the themes are still relevant. Self advocates think, for the most part, that nothing has changed in the last five years, and nothing will change in the next five. Parents seemed a little more optimistic, and thought there would be more control and choice offered to individuals and families in an effort to reduce costs and allow people to have the services they need.

Most of the adults with disabilities in the focus group were satisfied with the services and supports they receive. Parents were somewhat satisfied with the exception of the fights, slights and disagreements with social services, schools and funding issues.

Despite the negativity, most of those interviewed, despite frustrations, were happy to live in an area where services were available and accessible, and were glad they were in a more "progressive" state.

There is more acceptance and inclusion generally.

Society as a whole is becoming more aware and accepting of people with disabilities. They are making things more accessible, so we can take our son to more events.

More children with disabilities are included in their neighborhoods, schools, churches and communities. There is much more inclusion in schools.

Education and transition have improved.

Considering the fact that the first child with special needs to be served by our public school system is now 25 years old – we have indeed made great strides.

Special education services have improved, and not so many people drop out of school.

Elementary school was a breeze for my daughter. The staff and teachers seemed truly interested in what was best for my child. Since moving to 6th grade there has been a different building, all new staff and teachers, and all supports have dropped. I'm not looking forward to transition at all.

Schools have become more aware of including kids in the regular setting, and including parents in the decision process. This is different than just a few years ago.

School inclusion is an improvement since 1992.

We have seen a lot of changes in our schools in the rural areas. Things such as elevators, busing, team meetings for IEP planning. But one thing still remains the same – a lack of understanding and a loss of identity. People are still lost in all the miles of paper work!

Since 1992, we have seen real improvement in transition services.

There are more supports to families.

I am grateful for the in-home support, respite and education. There are needs for improvement in all these services, but I really couldn't get by without any of these... I am grateful for the money I get through Human Services, but they make me feel like I abuse it when I try to get it. Every time I call they make me feel like I'm doing something wrong.

There is more support for families with children to keep them at home and in school within their community.

Putting your child in a treatment center was the way to go in the 60s. When my daughter left Cambridge, it was a hard adjustment for both of us. But we have both adjusted to the group home. I wish the supports families have now would have been there when my daughter was younger.

There is more concrete information on PCA (Personal Care Attendant) services now, and an increased understanding of autism.

Improvements include earlier diagnosis of disabilities with the help of preschool screening or Head Start. Services are then recommended and parents are referred to the correct agencies. More workshops and informational meetings have sprung up to answer parents' questions. Now there is a state run insurance program for low income families.

There is more support now and more respite care compared to 1992.

There are more places for parents to go to get help and support for their families.

I really like the Family Support Grant available now at the county level to help families through the local IEICs.

I think family support to the local IEIC is excellent. When you have an active group of parents and professionals, it's nice to have the funds to make programs for the local area work. My county has been able to do a lot of neat stuff.

The closure of RTCs and the development of options have proceeded.

We have made major strides in the last five years. RTCs are closing, ICFs/MR are closing or downsizing, and more people are getting waivered services as a result. One still relevant theme is waiting lists. Families should put their children on a list for adult services when they start kindergarten. Kids leaving high school have limited services available to them. Both the SILS program and the Waivered Services program have waiting lists. Residential options are extremely limited.

Everyone agreed that people should be served in communities in their families (when age appropriate), or in small or moderate sized group homes, or in a facility like Vasa Children's Home. They agree that RTCs should be closed.

I think things have really improved since 1992. Residents have been moved from the RTCs and into the communities. They are using the dollars from this to make it work for them.

Employment and accessibility are better.

Things are definitely better – I'm getting a raise at my job [at a fast food restaurant].

There is more support in job fields for people with disabilities than years ago.

There are more ramps in public places. There are also more people with disabilities in homes, rather than nursing homes.

Responsiveness/coordination in the system have improved somewhat.

There have been improvements in the area of waivers. They are available for children now. But, there is no one in our county to do the services because of licensing restrictions. The waiver in our county is only for SLS. We are supposed to get many others, but they are not available here.

Self determination/control is on the rise.

The ADA (Americans with Disabilities Act) allows us to have the power of the law behind our needs for accessibility and services. It's that power that forces action.

The account management system in Dakota County is a definite improvement.

Some agencies are starting to listen to families and go with their recommendations.

There is more talk and a greater focus on self-determination, but I am discouraged by the lack of commitment from providers, as well as some family members, to self-determination.

I've found that Partners in Policymaking™ is a great way to support families and individuals.

More kids are being identified, and parents are getting more support from other parents. There is a better parent network, and parents are getting trained and becoming better informed through their own efforts.

And Much Remains To Be Done

Many of the self advocates and families who participated in this *Speak Out* were receiving support. They talked about their concerns for the future and what was missing from the support they receive.

Some looked at the entire system and commented on needed improvements. Others despaired about the possibility of losing the gains we as a state have made over the last decade and a half.

Many fear cuts in funding and reductions in service.

There has been a negative shift over the last five years – there are fewer hours for PCA and respite, and it is hard to find competent staff.

I really think things are getting worse. Every year Developmental Disabilities funding is put on the chopping block. This is very stressful for families. They are insecure about whether they'll be able to care for their children the next year. This creates a strain on the family, marriages and siblings. Once you get a service or program, it's either taken away or services are cut.

There are less services now, and programs are being cut back.

Services and supports are harder to come by.

One parent wants current services to be continued and not dropped. Another worries that services for her five year old may be getting more difficult to obtain, especially if money is involved. She thinks that the climate is one of "tightening the belt" and needs are being scrutinized much more.

Supported employment is an ongoing challenge.

Supported employment is happening much too slowly. If all the funds that support sheltered workshops were given to supported employment services, we would be eliminating the last form of slavery in our country.

Our supported employment program is good. They really try to get people out into supportive positions. They are very aggressive. They have done a good job within the perimeter of a very depressed economic area and try to get people out in the community, rather than the DAC (Developmental Achievement Center). There is, however, big staff turnover and the achievements of the program depend on who works there.

Here, and under each of the other themes, family support continues to be an area for ongoing attention.

Parents of young children with severe disabilities all stated that there are not adequate supports given to parents to maintain their children at home. One parent said, "There are many families that are barely able to function. Underserving families puts children, families, and marriages at risk." One parents sees a need for more small group homes for children with disabilities who are too difficult to care for in the home. "Parents should not be condemned for placing their children."

We went through TEFRA – what a fiasco! We ended up getting bills for a year and were never able to use the service.

The promise of an inclusive education is not the reality for many.

Early intervention for infants and pre-schoolers make a big difference; however, inclusion needs to start happening at this age, too. These services should be provided with kids who do not have disabilities. Kids learn a lot from other kids.

Educators have given some recognition to the need for family support from birth to six years, but it should be from birth on up. Money is being provided to IEICs for parents to develop and drive family support projects, but they still have a long way to go.

Upon entering the school system, parents need to have access to an “introduction to the system” training funded by the state.

Making the education system the “lead agency” in meeting special needs has limited available services, options and alternatives.

I would love to see my daughter in the regular classes for everything, with proper support for her, but budget restraints and closed minds keep her from participating as a whole human being in the educational setting.

Teachers need to have more training in the areas of developmental disabilities. There is very little support for parents. They do not know who or where to turn to when they have problems in our school systems.

We have been told that a regular and a special ed teacher team-teach the regular education kindergarten classroom so that children with special needs can be included. The district is able to provide better services if these inclusive classrooms are clustered in certain schools through the elementary years.

Schools are slow in improving. Few teachers and principals advocate positively for kids with disabilities. Even with the service plans, parents don’t get needed support. Parents don’t get information. Schools should tell parents about options available. The move from early childhood and kindergarten to elementary school is very unsupported.

The available residential options do not always meet needs.

I’ve lived in a few group homes. They are not good places. I don’t like living in large groups.

The SLS facility my daughter lives in is very old and out of date. My daughter is not always happy with services (jobs, staff, entertainment), but has learned just to be quiet and not speak up anymore. She just gets told that is how it should be or that she shouldn’t feel that way. I would love my daughter to live around non-disabled people. They would give her more choices and options in her life, and challenge her.

Nursing homes should be viewed as a “normal” option for people with mental retardation if they are elderly and want to move into one. It is the final inclusion if you will. You shouldn’t have to prove you don’t need “active treatment” and a do a bunch of extra paperwork so a person with mental retardation can move into a nursing home.

Some parents are worried about the kinds of support people who leave institutions will receive.

There is an overall concern about having community support for folks coming out of the institutions. For instance, “my concern is that they will decide to put them back in the institutions because of funding or convenience.”

I’m worried that they are not lost between the cracks and put out on the streets.

There are not enough places to go, no community supports, and they are pushing too quickly.

Lack of housing, insufficient community based programs and trained personnel. Are there enough community support programs in place? Will the funding be used to support the RTC to follow the person or be funneled to local services to develop necessary programs? In other words, can all these people be adequately cared for in the community?

We need to organize a better system, care plans and follow ups to ensure a better quality of life for people who can no longer remain in RTCs.

But once they leave the RTC, are they going to be in any better position? So we take them all out and put them in group homes. They are still going to have the same needs they had when they were in the RTC, so let’s improve the RTC and not move everyone around. Making a transition can be very traumatic for the person and their families.

In our area, should your child need dental care, be on MA (Medical Assistance), and the possibility of a need for anesthesia is there, the only facility willing to do the treatment is Fergus Falls RTC. Two parents have this issue and they have done a lot to try to get other dentists involved. One got a local dentist to agree to do the care, if he could do it at the local hospital. He opened communication with the hospital, checked into reimbursement, insurance costs, and thoroughly followed through, ending up with the decision that even if he was willing to donate his time, there was not way he could take this on as it cost too much for the small amount he would get back.

Many are clear that RTCs should close and people should be supported in the community.

Most of the parents had no opinion about RTC closures – they felt very removed from them because they are not an acceptable option for their families.

The RTCs should close. They are not helping people anyway. They are getting worse, instead of better. People should be in the community.

Until they are closed, they are a THREAT to anyone with a disability.

When the families of the adults were asked if an RTC would ever be a possibility for their family member, I was met with a resounding “absolutely NOT!!!” from everyone there. One parent said that they are to stay in the community. This was also expressed as the main concern for the moms of the younger children.

People in RTCs are still living in substandard situations. Let’s move them all out into nice, four person homes.

I’ve visited two RTCs and have only one thing to say – close them down.

I was happy with the closing of the RTCs. I would have never let my daughter live there. The funding is much better put towards letting my daughter live in the community where she grew up.

People with disabilities who lived in RTCs are quite clear about the future.

Close them [the RTCs] all down. They didn’t help me. They tied me down and drugged me. They had seclusion and lock-up for misbehaving. They gave the wrong kind of treatment. They treated me inhumanely.

The closure of the RTCs is long overdue. I wish they had been closed sooner. I lived in one. Staff always told you what to do, the doors were locked, and you never got to do anything. Now it’s nice to be able to live closer to my family.

I spent three days at an RTC. The group home is much better. At least you get food.

Few want RTCs to remain open.

RTCs need to be available and closer to home. They act as a go-between and as advocates for people.

One parent’s son was moved through several group homes and then moved, at her request, to an RTC because of concerns about his behaviour and continuity. She feels that RTCs still have a place in dealing with challenging “clients”. No other adult or parent in the focus group had any dealings with RTCs.

Securing the future requires advocacy by and information to families.

Assertiveness training is not the only thing parents need. Skills in negotiation and conflict management would be helpful.

One of the comments that popped up most often was relating to the need for social services to be more effective in communicating to people what services are available, and then making sure that the appropriate services are provided. There is still a great need for education regarding people with disabilities, their assets, and their needs.

Everyone says, “have a vision,” but nobody told us how to get one.

Changing the structure.

I think the biggest thing that needs to be changed is the system structure. By that I mean people that have disabilities, pre-existing or not, should be able to get a job without penalty so as to have an equal opportunity. I personally feel that you could actually reduce the amount of spending in the social programs by continuing to grant funding for insurance and attendants. We need to allow people to have access to the necessary things like a van or a computer that will allow them to become a completely functional part of society.

Self Advocates and Families Have a Down to Earth Vision of a Good Life and A Responsive System

Self advocates have very clear ideas about their hopes for the future and what quality supports would mean to their lives:

Friends and relationships
Family close by
A job that fits my needs
Have/earn enough money to live on
A place of my own
Help to stay in my home as I get older
To get out and about and involved in the community
To have more control of their lives, and choices and support in their lives, so they can do what they want to do
To be treated with dignity and respect

Self advocates speak out.

“I have a job at the County, my own office, my name on the wall, and a phone on my desk. I make good money. I’d like to get my own house and live alone with one roommate.

I would like to hire my own person to clean and my own person to help me get ready for work. They [the agency] hires people for me that don’t meet my needs. I like in-home support better than the SILS program, but would like the money they use for me to disburse myself.

My friends and I are more accepted at the pizza place, pool hall, and in the community. I like that.

I like to go to the library and check out books, meet people at church, watch TV, and walk on the treadmill for exercise. I would like to meet more people in the community and have more chances to get out. The whole house goes if they go anywhere, so there are no individual trips.

I would like to get married and live somewhere with my wife. I would like a different job. I’m not sure what kind though.

I would like more choices and support in doing new things, but there are not enough staff.

I want less government “busy-body” requirements. It’s an invasion of privacy some times. The booklets you have to fill out for MA are ridiculous.

Sheltered workshops should pay workers more.

I want to live by myself with no need of PCAs and to earn enough to live on.

I want to bathe myself and be married.

The group home has more rules, and adult foster care allows me to be more independent and responsible.

I would like to be able to get in and out of bed myself, without help.

When asked what she wants when she graduates from school, one woman answered, “a new friend and my own home.”

One woman is very content with her supports and services. She would like more time with her attendant to be able to be “out and about.”

Parents of people with disabilities painted a similar picture. From their perspective, quality support means:

- Supported living, tailored to his needs (to live independently, with live-in support or PCA services)
- Job training and employment, meaningful work
- Recreation
- More choices, flexibility to choose
- Opportunities to make friends
- Opportunities to improve living skills
- Staff who are dedicated and well enough paid to prevent high turnover; who truly care about the well-being of the child and see them as people, first and foremost; service providers that care and are well trained
- An independent life without fear of being taken advantage of
- Continuity in staff and environment
- Finances to allow independence
- Being active in the community, being involved in things
- Maintaining healthy lifestyles
- Medical and therapy services available

Such support would come from a responsive and stable system:

- Support that is not totally controlled by the money available
- A case worker who is on the ball and can help to guide you through government programs, and get what is needed
- Supports that are funded and stable, not always in threat of being taken away

The Recipe for Responsive Services

Plan for individuals
Respect families
Listen to consumers
Advocate for change
Make choices available
Give people the power to act on their choices
Ensure accountability and coordination
Get rid of the paperwork.

Plans must reflect individual needs, not labels, or budgets.

Plans must reflect consumer values, world view, purpose and the worth of the individual.

I believe that there needs to be a wholehearted effort into understanding the context of a person's situation, so that you are helping the individual, not putting up roadblocks.

Service plans should be driven by consumer needs, rather than by labels or budget.

It has to be based on my son's individual needs. Quality will be defined by my son and family.

PCA services have been improved by an emphasis on health care, but training provided for PCAs and regulation of companies needs to be driven by client needs.

Presently, in order to be eligible for services you have to meet certain guidelines whether it is disability status, income criteria, etc.. This creates the possibility of someone falling through the cracks. Services should be based on functional needs, not the type of disability.

A medication felt necessary for her child's well being was disallowed by Medicaid. Trials with three similar medications that were covered proved that the one originally ordered was the only one that would ensure the effect needed for her child's health. The concern is that the system is more concerned with "across the board" funding of populations, rather than individualized care.

Parents must be involved, respected and informed.

Ask the parent or provider. Ask the families. What MA will fund isn't always what you need, and what you do need, MA doesn't fund.

Parents are not really "equal partners" at the planning table.

THEME TWO:

Individualization

In 1992, the town meetings underscored the importance of a major change in thinking – the development of principles and concepts which call for a focus on the individual. Such a focus means that services and supports are designed and delivered for the individual, and in ways that make sense for the individual with developmental disabilities.

The concept of individualization continues to be a cornerstone of federal and state laws, especially those dealing with education, case management, and service planning. Being true to the concept requires systems and supports that listen to the individual and family, empower them to make and act on choices, and create opportunities so that people have choices upon which to act.

In 1997, self advocates and families had a lot to say about –

how we can ensure that funded services are, in fact, needed services;

how the promise of case management remains unkept in many cases; and

how the system can enable self advocates and families to have more choice and control.

All seemed to agree that more sharing and communication is needed between agencies and families in order for families to feel they have any control at all. One comment that came up several times in both groups was that school, DHS (Department of Human Services) personnel, DAC, SILS (Semi Independent Living Services) employees, and others seem to have a problem acknowledging or giving credence to the role the families play. By doing this, they not only distort the picture, but do all of us, including themselves, and their job, a great disservice.

Parents need to be listened to and respected more. Our child's teachers, case managers, and service providers will come and go, as will their fads, but the parent and family will always be there.

Talk to parents – and listen!

Listen to those who live in rural Minnesota, not only the ones who live in the bigger cities.

Some workers think if their client is less informed, the worker's task will be easier. That is a fallacy! The more informed the consumer and the family, the more efficient the worker can be and the more helpful they are – if the worker is open.

One parent: My greatest need has been for information. Another: I can ditto that! Another: Agencies should be mandated by law to invite and include parents in professional and paraprofessional training. Another: There should be collaboration in training.

State information comes from too many sources and we are overwhelmed with paperwork and materials to read.

Consumer input and advocacy by everyone involved are required.

Talk to the recipients and see what they have to say!

Help develop Consumer Advisory Committees so people (families) who receive services can provide input and direction into service delivery.

To make sure funded services are needed services, we need advocates and lobbyists, and reliable, experienced workers.

There must be consumer input when they are designing the program.

Policymakers need to be aware of what people with disabilities need.

According to one mother, the only way to make sure that funded services are needed services, and that they are flexible enough to meet the needs, is for those that have control of the money to act as advocates for the families and the children – not just as employees of an agency. This statement seems to meet with the approval of all.

Choice requires the power to act.

Mainly we want there to be choices available so when our children are no longer in our care, they can have options as to what they want to do with their lives, where to live, and how to earn a living. Given appropriate transitioning, this may be possible.

Money should follow the individual not the program.

A voucher system where individuals identify what they need and are able to purchase non-traditional support services.

I don’t feel I have any control over the services. I’m told – “This is what there is, this is what you get.” There is no individualization. Funding only pays for certain things.

Waivers fail because of lack of money or no one provides the service allocated in the waiver. Money affects the services, and the licensure affects who will do the service, leading to non-existent services.

Give us accountability and coordination, not paperwork.

One parent said: “There needs to be better dialogue between schools when a child moves from elementary to middle school, from middle school to high school, and also from school to school within or between districts.” Another added: “The new case manager should be specified and included in the child’s review before the move.”

We had 5 plans running at the same time during the transition from school to work! There should be an IFSP (ages 5-22) that all agencies can use in place of the IEP, ISP, IHP, IWRP, and career plan!

There needs to be a better system of accountability and audits [linked to the consumer].

Accountability increases when money follows the person.

I would like to see those in government positions held responsible if services are not given or are cut.

We need coordination of agencies. Scale down the bureaucracy. Start over and create a system for PEOPLE!!!

When asked “What is required to make sure that funded services are needed services, flexible enough to meet individual needs and ensure quality outcomes?” three self advocates said, “Good case managers and team members who work together. And surveys to see what is needed and what is not helping or being met.”

The system creates too much paperwork and makes us numbers instead of people.

They should simplify the paperwork and have only one form for those who have no changes in income.

Have the workers use the phone to do interviews/reviews and use computers to cut back on cost and time.

Have the different service providers be in contact with each other to avoid us having to spend time doing the same forms over again.

Case Management

Families and self advocates had a lot to say about Case Management. As an idea, case management is seen as very important. People see its promise, and occasionally experience its usefulness. As a reality, case management is often either irrelevant or a burden in itself. People want to see effective case management. Many are not sure what the alternatives are to the current approach, but some think enabling parents to be case managers is, and could be, quite useful.

Case management can be useful.

I think a well trained case manager who is willing to be creative, has access to resources, is always working on the person centered outcomes, is key to a successful quality of life for people with disabilities and their families.

I don't have a case manager. They just assigned me a financial worker. I think a case manager would be very helpful in informing me of services available.

Another mother sees a case manager as one who sees that the individual is receiving services needed. The case manager should be an advocate who works to see that services fit the individual. Her daughter's case manager does not provide these types of services.

General consensus of both groups was that there seems to be a lot of "juggling" of moneys and services available that no one seems quite capable of keeping track of. Parents that are very involved may hear about funding sources, grants that may be tapped into, etc., but if you should happen to hold a job or be otherwise occupied (taking care of children), it seems that the likelihood of hearing about these is limited. It also depends greatly on how informed your case manager is.

Some families have case managers that provide services and supports that families find very useful. Given what other families experience, they feel fortunate.

All the parents I interviewed have a case manager, but most know them as their social worker, rather than case manager. The social workers should be the one who tells about services, reviews and updates files, observes at school. All agreed their case workers are busy, but never had difficulty getting their needs met.

I have been very happy with my case manager, but she recently changed jobs. It's been 2 months and the county is still in the process of finding a replacement with her type of experience. She was exceptionally helpful for us at meetings at school, to help figure out what was best for our son.

My case manager acquired a waiver slot and walked us through a variety of services provided – housing choices and the whole gamut.

Our case manager refers us to other services, coordinates providers, and advocates for clients.

My case manager is very involved in meetings and goes out of her way to make sure things are going well. She has a large case load, but puts a lot of effort into our case. She is always there when I need her, or when I have a question.

My daughter's case manager is from the co-op. She's great. She coordinates physical therapies, occupational therapies, TEFRA, and special education services. She hasn't missed a meeting. Before her, services were fragmented.

Our case manager is very busy, but he does return calls quickly and answers questions. He seems to have empathy for parents and will tell us about services that are available.

[A Southern Minnesota county] has good case managers. They work well with the parents we interviewed. People with disabilities really liked the case managers who listened to them, did not try to push them into something they might not be ready for, and supported them in their choices.

I'm very happy with my case manager. She has tried very hard to inform us of the different services and programs available.

One mother feels her child has a good case manager who advocates well for her. The teacher at school who is responsible for her educational program and transition is also a very good advocate.

I've heard horror stories about case management from other parents, but we have had only three different social workers in 29 years, and all of them have been wonderful. I thank the good lord that we have been as fortunate as we have been.

Many see case managers as over-worked, under-trained, ill-informed, not caring, disrespectful, always being replaced… but mainly as absent from their lives. Some families doubt their existence.

There is no such thing as case managers. You are lucky to talk to a human being when you call the county. All you get is voice mail.

When asked about case management, one mother replied quite sarcastically, "What's a case manager?" She sees or hears very little from the person assigned as her child's case manager. She has also been treated very poorly by the county financial worker assigned to her case.

I don't know if we have it [case management] or not. My son had three different social workers in a short period of time, but no one has contacted us for awhile.

Many people with and without case managers were very confused about what an "actual" case manager is.

My daughter has had many case managers, but the turnover is high. The case managers have never met me or my daughter. It would be an advantage if they knew who they are working with.

I see my case manager once or twice a year. They don't provide much information, just what's needed for the ISP. They help the staff come up with programs to help me out. I'm working on a measuring program with cups and spoons.

Case managers need to spend more time getting to know families and what their needs are. In the case of children, parents should have more say in what happens because they have known that child since birth. Case managers generally see them only once a year.

Our case manager provides assistance with paperwork. Our case manager is not aggressive in learning anything other than the "main road." If it hasn't been done before, it can't be done.

Another mom sees case managers as not having enough "vision" for their clients. They need to be willing to try different things in order to meet needs.

I've seen some of my paperwork where my county got MA reimbursement for case management and I hadn't even seen my social worker.

Our case manager came for her yearly visit. My husband went upstairs to put something away, and when he came down, less than five minutes later, the case manager was done. So, he didn't get a chance to talk to her. She only had me sign a paper without even explaining what the paper was. Then she left. The social workers use to stop in for visits, but now they don't.

They never seem to come to the parent to let them know about services. Unless a parent knows enough to ask about something, you'll never hear of it. That isn't right, that is their job. Our case manager's approach has been very hands-off. She's been to only one school meeting.

Local county welfare is not user friendly. We only use a financial worker because we are on the TEFRA program. Funding for the program is always in danger of being terminated. We've tried to get a case manager, but keep getting passed around. We get the feeling that nobody wants to deal with us.

The ratio of cases per case manager is too high.

They are very overburdened.

They are not adequately trained. They need to be educated not only in the social service field but on how to deal with families with special needs children and to be aware of the services they can provide to them.

Some county case managers seem to be calloused, harsh, as if they have lost a sense of heart. Case managers need to take an introspective look at themselves, and not be so pushy in dealing with clients.

It was mentioned more than once that when you are from a rural area, there are few case managers, and they could be neighbors or friends, which can make it very uncomfortable for the family.

Comments from a focus group – Some case managers appear trained, but some are not at all. They need to learn "people" skills. They are very rude. They are given too much power, so maybe that drives them to act a little less humane.

My case manager does not have the time or ability to keep abreast of changes in the law. She does not volunteer anything. Unless you call and beg for help, you don't get anything.

Sometimes the consequences are quite serious.

My case manager has so many people on her caseload that she does not have time to go and check on her other clients that are in a day program where I saw abuse.

The case managers in our county need improvement. They need training and also need to know where to get information from. They never let you know what you might be eligible for. I don't know if they don't know, or just won't offer the information unless you come right out and ask. I lost out on $3,000 because of my case manager telling me the wrong deadline, though I told her what I thought it was, but she said it wasn't. It turned out I was right and she was wrong. I lost out on the money I could have used for modifications to my home.

Most parents felt that county case management had fallen short of its objectives. In several cases, parents believed that their case manager intentionally blocked services that their children needed and qualified for to save the county money.

Often the reviews (and the experiences) are mixed.

Some are good and care about the job they are doing, and strive to do the best for the person with developmental disabilities and others. I swear others only put in their time and could really not care if they are really making the client's life better.

Is she adequately trained – yes. Is she a creative and possibility thinker – no.

Our case manager attends IEP meetings, has helped me get respite care, has notified me about different meetings or workshops. At times I'm afraid to tell the social worker about things I do or don't do because of the threat it may be misconstrued and work against me. I feel our case manager is adequately trained. Our previous one wasn't.

Our case manager does alright. I see her at annual and semi-annual meetings. Some case managers only do the minimum, but some will go beyond the call of duty.

Our first case manager who works totally with families with children who have disabilities was not a good advocate for my child, so we requested a different case manager. Our case manager now had worked mainly with adults, but we share the same philosophy regarding transition and other things. He gets programs going to work for our child. He returns calls. He also advocated to the county for a family support grant for us to hire someone to work with our child during the summer on safety and appropriateness in the community.

In terms of the work of case managers, the feelings of the focus groups were all over the place: "I don't know what they do." "They changed his case manager three times in three months." "I have to investigate and educate my case manager." "My case manager keeps me informed of changes and cuts through bureaucracy."

Having a case manager can take a lot of time and energy, or just be irrelevant.

Families need to be trained how to manage the case manager! Informing the payee regularly by leaving information on voice mail and reporting incidents helps to keep him/her involved. Training should include how to work with social services and what are the best techniques of involving the case manager to get what you need and want.

Another parent said they get little in the way of case management because their social worker has too large a case load. "Everything we got in the way of support we found on our own."

Dealing with our daughter's case manager was more stressful than caring for her ourselves, and that is saying a lot."

We have a case manager, but we still have to do the majority of the work in terms of finding services and coordinating care. We use up a lot of energy trying to coordinate all the services. Sometimes fighting with the doctors and the schools to get the care we need makes you understand why some parents just give up.

Parents as case managers is an alternative.

In county after county, many families were not aware of alternatives to case management. A very few mentioned parents as case managers, a child advocate, the use of transition coordinators, and the voucher system. Those who knew of the alternatives spoke to the advantages and disadvantages of parents as case managers.

No one had any experience with parents being their own case managers. Most of us didn't know that you could if your county agreed to it.

There should be parent training made available so one has the knowledge of what services are out there.

Three of the five mothers of younger children are their own case managers and feel very comfortable with this. The biggest advantage in being their own case manager was not having to deal with DHS. A disadvantage is that you may not hear about a service quite as soon as you could have.

Case management training should be replaced by or added to person centered training. Parents in all parts of the state should know about and be given opportunities for "Parents as Case Managers" training. Some of this has happened in the last five years but there needs to be more. It makes a difference. Most of all, we need to support self advocates to speak for themselves. There needs to be more interest and support for self advocacy organizations. The time has come where people with disabilities must be given the right to speak for themselves and the rest of us to listen.

Train more parents to be case managers. We are anyway! But this could be confusing and intimidating for the majority to feel comfortable.

The advantages of parents as case managers – they best know the needs, strengths, and weaknesses of the child and family. The disadvantages – the lack of knowledge of resources, programs, and how and whom to contact.

More training is needed for parents and self advocates to be their own case managers. A network of other people who are in the same boat would be helpful. The problem is that self advocates and parent case managers do not always get respect. Questions often come out such as "what do you know" or "who do you think you are?"

I know some parents who are their own case managers. It think it is better and cheaper. They need training and information, just like case managers get, and some kind of reimbursement. All they do takes away from another job. Does the government realize that all the advocacy I do is like a full-time job and takes away from my ability to earn money for my family?

In order for parents to be case managers, the number one change has to be in attitudes toward them. Parents need to be respected as the authorities on their kids, and trained and given the same resources any other professional would receive.

How to increase choice and control

Families and self advocates identified three areas for change in terms of their gaining more control and having more choice –

Parents and self advocates need to speak up and be their own case managers.
The system should loosen the control and allow flexibility.
Money should go to people, not to programs.

Parents and self advocates should speak up and be their own case manager.

As parents, we need to speak up in IEPs, training courses for parents, and to have some power and control.

Train parents and adults to be case managers. Involve them with scheduling of services. See that they are set up according to the individual or family's needs.

Loosen controls/allow flexibility.

Cut back on and loosen the regulations and be more open and flexible. If there are extended family members who can help provide services, let them and pay them.

There is a real need for flexibility in funded services so that they can "bend" to fit each individual. Funding streams often contribute to the mountain of paperwork, therefore affecting the availability of the right services.

This is where family vouchers would be much more effective. With adequate information and updates, I could be my child's case manager. I already do a lot of the "hunting" for needed services. When I've found them, I ask Family Service to access them.

Money to people, not programs.

One way to have more control over services would be a cafeteria plan – you get to pick and choose what you want. PCA hours would be more flexible.

I would like to see more money going to the person, rather than to the system for salaries for people to do paper work. Maybe they should just give the money to parents and let them purchase the services the family needs.

Money still goes to programs, not people. The government needs to trust people who need the services. They can be trusted just as much as some of the providers. If funds went directly to families and consumers of services, the funds would stretch further, provide more, and probably mean better services. There need to be more choices for individuals.

A Family Voucher System would eliminate piles of paperwork for case managers and allow the family the flexibility in decisionmaking to put together services that are truly individualized. The counties need to look long and hard at the benefits of a voucher system. The providers need to look at their hiring practices. After all, who's working for whom?

We absolutely couldn't get along without Medical Assistance, but we get tired of fighting the system. How about vouchers directly to the parents to secure their own services? No middle man. The case managers in our area have a pretty heavy case load. [Too heavy, other parents commented].

Staffing

In the 1992 Speak Out, there were many concerns about staffing. In every town meeting, there were repeated comments about the quality of staff in community programs, the impact that lower pay levels in the community have on staff turnover, and the need for training.

The specific issues center on pay scales, staff turnover, and staff training in community programs. High turnover results in increased training and staffing costs. The fundamental issue, however, is the impact of all of these conditions on the lives and futures of people with developmental disabilities who are supported by staff.

The issues for people with developmental disabilities are quality of support, continuity of relationships with staff, and fundamental issues of safety.

In 1997, this summary can stand unchanged. Focus groups had more to say about specific issues in terms of rural/urban differences, in-home support, residential staff, supports at school, and what would make it better.

In a Northwest Minnesota county, focus groups commented about different attitudes among family members and self advocates. These differences were frequent, though not universal.

There was a different atmosphere between the two groups. Parents felt as if Social Services don't respect them, and doctors don't believe them. Those who have disabilities felt they had respect from staff. They had more positive attitudes towards staff.

The general issues are the same – turnover, competence, wages, training...

Three parents in a Northeast Minnesota county summarized the feelings of people across the state when they listed the things they think hamper the effectiveness of staff – high turnover, incompetency, low reliability, low wages, unavailability, inconsistency in problem solving due to high turnover, not enough caring and training, and lack of backup and support from employers.

When asked if staffing meets their needs, NO!!! was the unanimous response at the table of adults who receive services and the majority of the mothers of younger children. Staff do not have enough time. They don't have time to share information or coordinate services for your child. One mother said that even though the ratio at the DAC is 1:4 she feels they are under so many unrealistic mandates, and given so little control at "base level," it is difficult for anybody to accomplish any thing.

One focus group identified a number of problems that hamper staff effectiveness –

government regulations
they don't pay people enough
staff turnover is a big problem
administrators don't listen to their consultants

Everyone surveyed was concerned about turnover. "You just get to know them and they leave." Some staff use the work as a stop gap in education, or a point on a resume. There is burnout. "Some can really screw up and get fired with the knowledge that they can probably walk down the street and get hired in another position due to privacy laws."

Some staff are holding down two or three jobs. By the time they come to my house to provide services they lack energy and commitment.

A lot of staff are doing this job until something better comes along.

There is too much turnover in the social service field. The pay scale is too low. Who can be committed at a wage of $7 per hour?

You need to feel confident with the staff that works with your child. This means paying them well, and make it a career, not just a job.

Parents think that staff try to focus on individualized care needs but are held back because the agency says there are liability issues, so they refuse to let the staff provide the service.

Staffing does not meet people’s needs. We should be able to pick our own staff.

Case load burden could be reduced if professionals trained others and relinquished turf.

Incentives such as educational help, bonuses or a more realistic wage might be beneficial. Direct payments from parents to caregivers might work.

Staff schedules sometimes determine client services. It should be the other way around.

We need sensitivity training for medical staff at hospitals. They need to pay more attention to how they approach parents and their children with special needs.

Background checks are not always done prior to someone starting work. Some staff are right out of high school with no prior experience. They aren’t always mature. They aren’t always suited to provide services to people with disabilities. If this is the age group that provides services, then it would make sense to work with the high schools to develop a training program during the Junior and Senior years in school.

The challenges are greater in rural communities.

What makes it difficult for staff to be effective – Pay in rural areas, high turnover, not respected or valued by society, not trained or poorly trained, high case loads, unable to communicate with person with a disability, discouraged from being involved with person or family, don’t have choice of staff.

Rural community services still cannot find and keep good staff. The positive shift to more waivered services has created a need for more staff.

In rural areas, there are too few staff with too many demands on their time, and long distances to travel.

PCA hours should be allotted by the week, not by the day. This would help cut down on long drives for PCAs in the rural area, and maybe make it easier for the parent and the PCAs.

Here, as with other themes, paperwork is a major issue.

Three mothers talked about paperwork – “staff gets so caught up in the paperwork that they are sometimes unable to provide services;” “paperwork is such a stumbling block to staff meeting the needs of the individual;” and “the paperwork is so insurmountable at times, they cannot attend to immediate needs of the child because of deadlines.”

The staffing situations for in-home support may leave something to be desired.

Parents who receive PCA services complained that the responsibility for locating a worker has fallen on them.

The PCA job is poorly paid and the hours are often allotted for small time periods. Consequently, it is hard to find good, responsible people who are willing to work. It is even harder as a child ages and becomes difficult to lift, or when behavior problems become more severe.

The consensus was that some staff are good and some not so good. Some staff make decisions for you because they think they know best. Many staff do not take their jobs seriously and just don’t show up at scheduled times.

“Supervisors do not find anyone to fill the shifts either. Maybe they should pay the parents when they have to cancel work or plans.

Our son needs total care. We have adequate hours allotted but cannot find people to provide care through PCA services. We would rather use home health aids because they are reliable, but our case manager says they are more costly. She does not seem concerned that we are going without service as a result.

Hours can’t be met because frequently there aren’t enough staff to provide them.

Our needs are not always met. When I went home, they sent over very young and small therapists who were not strong enough to help me with my exercises. I’m a big guy and I really felt bad to see how hard it was on them.

Many times PCAs are not trained properly in terms of the individual’s needs. They are overworked and underpaid.

Two parents have been having problems with PCAs, to the point where they feel threatened by the PCA trying to tell them what is right for the child.

I want to interview possible support people.

The number of people to be supported residentially makes a difference.

Staff help a lot, even when I don’t want the help.

My daughter [who lives in a group home] never gets to go anywhere. There is only one staff, so if one goes, they all go. It usually requires more than one staff to take them anywhere so they don’t get out very often. I want my daughter to have more freedom to come and go when she pleases, with assistance.

I think staff are great. There are only two of us, and one of us can be left alone. We get plenty of individual time. [This woman’s mother is very pleased with the new arrangement. She insisted that only two people live together. Her daughter is so much happier.]

The staff who sat in on a focus group for self advocates said that it is hard working for large group homes of 15.

The residents are treated like an assembly line of people rather than as individuals. It requires a lot of staff all working at the same time, which is sometimes hard to deal with also.

Staff turnover is very high in the group home. My daughter has learned not to get close to staff because it hurts too much when they quit.

A self advocate said that staff can’t do things with just one of us. It always has to be something with four people. “I want more individual staff time.” Another wants more staff time to do community things, too. “They just keep doing goals over and over again so we don’t have time for fun things.”

Staffing doesn’t meet my needs. SILS doesn’t work the hours that I need them. They don’t start until 9 a.m. and I have to be to work by 8 a.m. I need help getting ready to go. They won’t come that early.”

There are staffing issues at school as well.

There needs to be more training for regular education teachers and special education teachers to deal with materials and services. But schools are not willing to let parents hold workshops and help staff.

One mothers finds that, especially in education, staff are often protective of their “Special Ed program” and reluctant to try new things or accept other ideas. She feels that egos and turf often get in the way of what is in the best interest of the child.

The staff at the school are very receptive to my ideas, but few are actually implemented. I constantly am checking to make sure they are following up on my child’s IEP.

Paraprofessionals are asked to act as teachers. Many are not trained and have limited access to very limited training opportunities. They are often left out of the team building process.

There are not enough special education staff in most schools and zero at others.

The therapists and case managers at the schools need more help. They are too overburdened at this time.

Aides are not trained in various types of disabilities. Parents should definitely be involved in training the aides that work with our children. Often the aides don’t know very much.

Creativity is another thing that could allow staff to meet individual needs much better. This mom had several instances where she suggested to her daughter’s manager at school a more creative way of getting “the job done.”

THEME FOUR:

Leadership and Bureaucracy

In 1992, the town meetings talked about the importance of leadership. Important ingredients of leadership are having a vision of the future, drawing others to that vision, and making it easier for people to take action consistent with the vision. Leadership means making sure that people have the resources and support to achieve the vision.

Minnesotans who rely on the service system look to it to be user friendly; helpful not hurtful; concerned with people and quality, not forms and paper.

In 1997, focus group partcipants said that this was not the system Minnesotans actually deal with.

There are three major areas of concern –

■

An unfair, overwhelming, paper-driven system.

■

The fact that people, not paper, should guarantee quality.

■

Concerns and fears about Medical Assistance.

Minnesotans, by and large, do not like the system that is supposed to help.

Their words do not describe a caring system.

In 16 of the county focus groups, participants were asked, “What are five words that you would use to describe the service delivery system in your area? In the state?” Most did not differentiate between state and local. There were many negative words, some of which (such as “slow”) were repeated often. Negative responses outnumbered positive responses five to one. Participants also had positive experiences.

The following are selected responses:

POSITIVE

- easy
- generous
- concerned and caring
- needed
- necessary
- fair
- average
- OK
- listeners
- good
- available, respectful
- caring
- secure
- service
- resource
- probing
- super
- support
- supplement
- decent
- client driven
- pretty good
- helpful
- conscientious
- good
- efficient
- accessible
- caring
- responsible
- fortunate
- a good example at the local level for our county
- quality when acquired
- well-intentioned but overburdened
- proactive
- improving in the state as a whole, slower in rural areas

NEGATIVE

- overburdened
- isolated
- non-informed
- inadequate
- not accessible
- not efficient
- lack of communication between service workers
- paperwork
- red-tape, slow
- paperwork
- impersonal
- inadequate
- cumbersome
- stringent
- vague
- slow
- poor
- fragmented
- self-serving
- exclusive but supposed to be inclusive
- ill-prepared
- unaware
- erratic,
- exhausting
- tenuous
- hit and miss
- discriminatory
- lacking
- oblivious
- slow
- dishonest
- deceptive
- unreachable
- disjointed
- no communication
- antiquated
- confusing
- burdensome
- astronomical
- book work
- distant
- reserved
- impersonal
- wasteful
- too much paperwork
- adversarial
- complicated
- no follow through
- massive
- paper work
- not user friendly
- guidelines not consistent
- not willing to offer services
- slow, slow, slow
- fragmented
- excessive
- poor
- bad
- overloaded
- hard to stomach
- slow and conservative
- sometimes very frustrating
- papered
- somewhat money hampered
- outdated
- slow
- inadequate
- paper bound
- no interagency communication
- slipshod
- nonexistent
- inefficient
- stuck in old ways
- undertrained staff
- over paper-worked
- case loads too heavy
- unavailable
- nonexistent
- count-bound
- inadequate
- ignorance
- unawareness
- poor communication
- inadequate service
- staff caseloads too large
- intimidating
- hard
- confining
- limited
- degrading
- embarrassing
- frustration
- overwhelming
- mediocre
- poor
- inadequate
- tiresome
- sightless
- ignorant
- enemy
- cold
- confusing
- preferential
- inadequate
- fragmented
- sucks
- cumbersome
- cost-ineffective
- non-person-centered
- redundant
- bureaucratic
- slow, slow, slow, slow, slow
- limited
- paperwork, paperwork
- sporadic
- geographic
- long distance
- limited
- fragmented
- slow
- not well informed
- not too creative
- need advocates everywhere
- can be cold and uncaring
- too much paperwork
- negative attitudes
- too controlling
- don’t really know what a person with disabilities really needs
- lack of cooperation, limited
- frustrating
- variable
- dishonest (at times)

In summary, the system is unfair, overwhelming, paperwork-driven.

The system is overwhelming to families... case managers at the school, case managers from the county, DRS (Division of Rehabilitation Services) counselors, waivered service providers... and all of them have their own pile of paperwork and regulations. On the other hand, many families do not know what is available to them. They have young children and have no idea what services they can receive to support them.

SSI is totally unfair with how they determine who gets what services. You try to save, live within lesser means, and end up hurting yourself. SSI needs to be determined by the child's resources, not the parents'.

Social services mean paperwork!!! You deal separately with SSI and MA, who have different rules and long duplicate forms.

We have TEFRA. It is a hardship to have to do all the things every year, over and over again for recertification, especially when you have a diagnosis that is not going to change. You just get done seeing all the doctors, psychologist or other professionals you need for recertification, and then pretty soon you have to start thinking about getting it together all over again. Our son is missing the 17th chromosome. He is not likely to get that piece of material back, so you would think in certain disabilities they would make exceptions and have you do it once every 2-3 years. You have so much to do already when you have a child with medical, physical and behavior problems.

I have found that if they need something, it has to be RIGHT AWAY - NOW!
If I need something, it takes time, paperwork. It's PLEASE WAIT - PATIENCE!

Wanted – caring, compassionate, creative, communicative, and coordinated leadership.

Those in leadership and governmental positions should be resourceful and caring. They should be able to see through all the red tape and be able to provide for an individual's needs in the best way possible.

Parents in one focus group identified the following – people who put family first; accountability with compassion; creativity with power to change things; people who can redesign old systems. Streamline – get the dead wood out.

Courage to be independent of the bureaucracy, open-mindedness, creativity, trust families, know what they need. LISTEN, don't just hear.

Futuristic, guts to go for it and do the right thing, challenge our society as a whole for the responsibility of caring for those who need care.

When asked what leadership qualities they would like to see in the state departments with which they deal, one member of a self advocacy group said "that the state receptionists and operators be trained to deal with problems with sympathy. So far I have found many of them to be real abrasive when answering my questions."

Leadership qualities needed in the state department – positive vision, knowledge, compassion, family orientation, better communication and coordination.

And in touch with people and their lives.

Leaders and professionals who have first hand involvement with individuals with special needs make better decisions.

Law makers need to have personal contact with people with developmental disabilities. Our county commissioner used to baby sit our boy, see him in church, and pray for him.

I'd like to take our son into the Governor's office and leave him awhile. Someone told us "with just a little support, he will function in this setting."

I think that if state legislators made onsite visits to DACs and school systems, and visited with families, they might see how laws affect them. Then things might change for the better.

People in positions of decision either know first hand or have experience with families and their special needs child.

That the state starts to deal with the individuals and not only the agencies.

Legislators should live in the parents' world for two weeks.

A call for cooperation and an end to turf protection between departments.

Not only do agencies not bother to talk to each other, but deadlines are ignored. Isn't there a way for agencies to cooperate and share information? At this time, there is no cooperation between agencies. There should be wraparound and collaborative systems. Right now, agencies try to retain their turf.

Departments should remember that their work is to SERVE the people, not whatever else it is they do.

We especially need leaders who will advocate for people and not for more paper. The competition needs to stop and cooperation needs to begin. The turf war we parents see between the residence and the workplace is going on at the state level between the Department of Human Services and the Department of Health. We parents are tired of the battles. If the different areas can't work together, just give us the funds and we will do it ourselves.

There are communication problems everywhere because there are too many DHS departments responsible for services, and they do not talk to each other.

We need more communication, team development, and management skills.

Eliminate redundancy and turf protection.

Let's see some uniform applications and communication between departments so we as parents don't have to be redundant. What would it hurt if departments shared information?

And certainly an end to unnecessary paperwork.

Paper work is too long, too frequent and often it seems, not even looked at. If the condition doesn't change, quarterly and even some yearly reviews are just a waste of time and create more anguish for families. Kids can be reviewed for TEFRA, school, county, Medicaid, and more.

“Rules and regulations dictate too much of what needs to get done at the expense of provider services that are truly inclusive. Staff are tied down to logging everything, when they could be assisting people to participate in community life.

There is more paperwork than there was five years ago.

Agencies need to communicate more among themselves and not have as much overlapping paperwork. How about one universal application for all agencies.

I believe paperwork has become more important than people.

We no longer use services from the county. Respite was fine for a year, then it became more of a hassle than it was worth. We still only deal with social services two times a year, when we are fortunate enough [heavy sarcasm here] to fill out that 36 page report that doesn't change.

I recently went back to work full time. I no longer have the time to chase workers, school personnel and government agencies with questions and paper work. I am trying hard just to keep my family together. With our rise in income, we were overpaid by SSI. They want the money back, as if now we are rolling in the dough. They waste my time and my money by asking me the same stupid questions every 6 months, like our child's disability is going to disappear.”

People, Not Paper, Should Guarantee Quality.

Focus groups were asked “What in the system ensures quality outcomes. What would better ensure these outcomes?” In response, they identified three important parts to guaranteeing quality –

Families and advocates
Good professionals, working together
Good planning

What guarantees quality? Families and advocates.

That the parents be well informed of services available and that all the members of the child’s team work together and communicate to do what’s best for the child. This team includes case managers, teachers, doctors, therapists, Social Security, and parents.

There isn’t much in the system that ensures quality outcomes. Families have to do the monitoring.

The families.

One parent felt it would take a revolution of parents to ensure any kind of quality outcomes for their children. Quality of life not only includes the person with a disability but the entire family. Parents must persevere and not be afraid to challenge “experts.”

I have been asked by my school district to serve on several committees. I later found out that it’s only because they need to have representation from the community for persons with disabilities. It seems like such a lame attempt at putting a band-aid on things. Maybe they should actually have a majority of persons with disabilities so they would get a true picture of what we need, rather than what one person needs or what they think we need. It is just politics.

What guarantees quality? Good professionals, working together.

From a parent focus group – good case managers and service providers, working together and keeping everyone informed; parents and legal advocates; small caseloads and more advocacy from social workers and teachers.

The move to performance based outcomes is positive. We sure don’t need people coming down from the State to read reports. We don’t need QMRPs. We need people with common sense and permission to use it.

More caring people involved with people with disabilities who will notice and speak up for quality .

What guarantees quality? Good planning.

Good follow through by those doing the planning and a lighter load of cases.

Good planning and follow through with person centered planning.

My daughter's IEP seems to be nothing more than a funding source for the school. Every year when a new one is drafted, it looks just like the last one. After 10 years, I'm getting tired of the battle.

Parents felt IFSPs, IEPs, IHPs, IWPs, along with knowledgeable parents and professionals were the best ways to ensure quality outcomes. As one parent said, "I think the IFSP is just the best. It involves a coordinated effort among all the organizations involved but I wish it would continue for a longer period of time, possibly to the age of 7 or beyond."

There are Many Concerns about Medical Assistance.

When families and self advocates were asked about Medical Assistance, a number of concerns emerged, chiefly –

The reality and threat of cut-backs
The restrictions and barriers in the system
Concerns about the move to managed care
The need for constant recertification and paperwork

The reality and threat of cut backs.

The cuts are too severe and are going to hurt a lot of people. Helping them now will save money in the long run.

Its very existence is dependent on the whim of politicians.

My major fear is MA budget cuts.

Worried that it might not continue, or will eliminate certain populations.

All the people I interviewed are concerned about losing medical benefits.

The legislature is always threatening cuts to the TEFRA system. What other insurance is there for us as parents to assure that we'll be able to care for our children at home?

I know of circumstances where, rather than paying for an augmentative communication device, TEFRA only pays 80% to the vendor. Unless you private pay or have private insurance, many devices are unavailable to children. The vendors will no longer work with Medical Assistance because they won't get paid.

Most were concerned about cutbacks and not knowing what the long term future held for families. One rural woman was very concerned – as farmers, a rise in income will disqualify them.

It is devastating to families to hear that TEFRA may be cut.

It seems impossible to obtain.

Restrictions and barriers.

The base income needs to be raised. The $420 is good for the elderly but not for those of us who want to work.

MA keeps people poor.

I'm very concerned about the capitation for long term care and the capitation for medical care. How can you work in a system where the benefits are capitated when my son's needs are not capitated?

There are problems with "allowable" brands of wheelchairs, diapers and communication devices on the TEFRA waiver. I had to get a legal advocate to get the brand that we got when we paid for them ourselves. The quality of equipment should be the best, not the cheapest.

The school demanded I get either training pants, which MA doesn't cover, or Pull Up diapers, which MA doesn't cover. My daughter cannot control her bladder, and the school wants her to be able to pull on her pants and anything under it. My daughter cannot put her diaper on and off by herself, but she can assist in pulling up a Pull Up. I spoke with MA and they said they will only cover diapers, nothing else. I told them I had to have these but they said no.

Not being able to have a specific doctor you want.

There are no local dentists or optometrists.

Medical Assistance is too limited. It does not cover costs which the insurance company won't pay.

Medical Assistance should not be based on income. It should be based on the need of the child.

Should be available for everyone. Shouldn't be income based for kids with disabilities.

Reimbursement for travel expenses should be universal, not at the discretion of the county.

MA won't pay for things that are needed and prescribed by a doctor – wheelchair, blood pressure cuff and gauge, lifts for shoes.

In our case, physical therapy has a limit with MA and has to have prior authorization. Why have such unfair limits? The school district hires a PT to do physical evaluations and tells us PT is no longer educationally necessary, but physically necessary. Without PT, our daughter would not be in public school. These limits have caused delays in our daughter getting the services she needs so much.

Managed health care.

My concern is that it might go away. They are moving toward managed care. There is little evidence that managed care organizations have experience to meet the needs of people with disabilities in a managed care environment.

All participants seemed to fear the move to managed health care. The concerns were – nobody takes responsibility, you don't get what you need.

Managed Care – what is it? When will it impact us?

I don't like managed care. It is not appropriate for kids with disabilities.

Constant recertification and paperwork.

One mother applauds the availability of MA, especially through the TEFRA waiver. On the other hand, the need to recertify a child with a genetic developmental disorder every year seems to be a waste of time and money. The disability and the need for services are not going to change.

The problem is getting a waiver slot. Once you get hooked up, wonderful; but wading through the paperwork by yourself is horrible.

THEME FIVE:

Inequity of Resources–Inconsistency in the System

When is the State going to say to parents "We applaud your love and commitment, and want to support you in your efforts. Here are the services you are entitled to?"

From a Parent in a Southern Minnesota county

Many focus group participants think there are inequities in terms of funding and services across Minnesota.
Five issues stand out –

The availability of waiver slots

How families find out about and get services and funding

Geography – county to county and rural to urban differences

Race and culture

RTCs

In only one focus group did people think there was an equitable distribution. "Everyone I interviewed thinks that resources are fairly distributed."

When asked what should be done to make sure funding is directed to where it is needed, the focus was on three areas –

Create a voucher system

Listen to people

Close the RTCs and focus resources in the community

Inequities in Resources.

Waiver slots are backlogged.

The waiver slot policy is ridiculous. It is terrible to have to wait years for a slot to come available to receive very badly needed services.

Everyone wants the waiver so there is the slot issue.

There is no improvement in the way waiver slots are dispersed; long waiting lists exist. We got our child on a waiver because we had an aggressive case manager. But another parent, whose child has multiple disabilities, has been told by her case manager that her child won't ever get on the waiver.

There are not enough waiver slots.

The waiver system seems to be backlogged to frozen in Greater Minnesota.

Differences in how families find out about and get services and funding.

No two situations are the same, just as no two people are the same. What may be support for one person may seem like interference to another; HOWEVER, information regarding rules, laws, grants, education and services must be equal and the ability to access these things must be equal. They are not! There are inequities everywhere. Funding must follow the individual and their needs (such as housing and respite care), not the needs following services.

The uninformed don't get services.

Whether or not you get services depends on where you live, and whether you have waivered services or are sitting on a waiting list. Some parents tell their counties they are going to place their child in an out of home placement, and then they get services... When is the State going to say to these parents "We applaud your love and commitment, and want to support you in your efforts. Here are the services you are entitled to"?

In our county, a few people have access to a lot of money, and a lot of people have no funding. The need for service is far greater than the money allotted to provide it.

County to county and rural to urban differences in the types and variety of services, who is available, and quality of life.

The services should be more uniform between the counties. Now, one county will provide a service and the next county won't.

Consistently, people pointed out the disadvantages of living in a rural area. There is a lack of resources for medical needs, behavioral needs, and social/recreational opportunities. On the other hand, no one wanted to move to a metropolitan area.

Many parents said services were much more available in the metro Twin Cities area, but they wouldn't want to live there. We are out of the information loop in many ways.

There are all kinds of services in the county seat area, such as group homes, supported employment and services. Those of us in the outer area live on another planet. Why do we have to suffer to get services?

Families think the metro Twin Cities area has the best variety of services. The southern part of the state comes in next. The northern part has little to offer. Some services are just not available in some parts of the state.

Funding for transportation in the rural areas is needed. For instance, a woman with a disability works at a restaurant, but uses most of the money she makes to get to and from work. She will never gain Social Security if this transportation cost continues. She will not be able to become independent and will always be in need of assistance.

I believe that services are different in various areas of the state because some counties have more providers, especially when it comes to respite and foster care.

I feel our county has been good to us. I've been talking to parents in other counties, and they don't seem to have services that are as good as we have. The case managers and public health nurses are always looking for ways to improve things. Although we're rural, we probably have better quality services because we all know each other.

There are a lot of differences from one county to another – dollar disbursements, case management work loads, and availability of specialists differ.

Especially the parents of the adults felt that if they lived in a different part of the state, services would be different.

Counties differ. I had to go to Grand Forks to get my driver's license, because my county refused to deal with it.

There are more options here. Back home, they only had group homes, no foster homes.

I would like to see more money in the smaller communities and programs like preschool education.

Most agreed that we who live in very rural areas receive less services than if we lived in the metro area. And if we lived closer to cities, the people that deliver the services would probably be better trained.

Metro schools have a ton more vocational, after school, and community activities compared to a rural school district.

Having moved from the cities to Greater Minnesota, there is no question in my mind how much more difficult it is to get services out here.

One mother has a big concern about inequity of services. The funds are not always allocated to best fit their needs. She could see her daughter having more peers and opportunities if they lived in a different location; a support group could be formed that could help her daughter make daily decisions.

Race and culture have an impact.

One parent said, “Services are definitely varied. It varies because of income, cultural differences, and race.” Another gave an example – Provider agencies can’t recruit people to work in certain neighborhoods because of the fear of working in a neighborhood made up of people of color. Therefore, people of color have a harder time getting services they need. Hence, it is harder for them to keep their families intact.

RTCs represent an inequity.

According to one parent, about two years ago six clients from a Northwest Minnesota county were in the RTC. The per person cost was between $300 and $600 per day, but the DAC has problems with their budget at $100 plus a day – where is the equity?

I don’t think the inequity is as bad now as in 1992, but I don’t know where the funds are going that were going to the RTCs. Those funds should be found and add more waivers with them.

The personnel at the RTCs are higher paid than the people at the local level. It should be a level playing field. You can’t expect people to stay in the local jobs if the compensation is not there.

How to Redirect Resources

Issue vouchers.

Two participants think issuing vouchers to individuals to be used as needed is a good way to redirect funds and allow the individual to receive the most effective help. Another thinks that the system should be reoriented toward the individual by letting him/her have a part in determining what services are needed and the best way to deliver them.

A parent said she could do a better job of managing the resources to meet her son's needs, and spend less money, if she could have more control over the funding.

Give families vouchers.

Listen to people.

Talk to the people receiving the services for their opinions.

Listen to folks with disabilities and their families, then direct funds toward those priorities.

Close the RTCs and target resources.

When a person leaves an RTC, the money should follow them, and not stay in the RTC budget. As long as RTCs are open, more money will be wasted.

Efforts to close RTCs are greatly supported. It appears that this has been the State's goal over the last five years. However, little, if anything, has been done for children living with their families. There has not been any new service or additional funding. Some families are struggling. Waivered services are mostly available to people in the RTCs or ICFs/MR. There just isn't equitable funding for children and their families.

In terms of redirecting funding – "help us to adapt to our disability and get us back to work so we can be independent."

Not enough money gets to the clients. It seems to be spent on wages and paperwork, not services.

A self advocate said he wants to live in an apartment with a friend, instead of the big group home. In the group home, he has to do what everyone else is doing instead of what he wants to do. He would like the Governor to give more money to people with disabilities so that they can live where they want.

Pay less for case management; $60 plus an hour – Ha! As a parent, I could do it cheaper and better.

Funding needs to be redesigned for services that pertain to cross-disability issues. There are too many single disability groups fighting against each other for limited funds. Probably the only way of doing this is going to be some type of voucher system that allows individual choices about which services to use.

One idea for redirecting funding – Take the cap off regulating how much a person with a disability can have for assets. They could then gain the financial security they need, without losing support.

The system didn't seem to work for me when my daughter lived at home. But as soon as she moved to the group home and I gave up some of my control in the decision making, the system liked me. Why did it take my daughter's leaving to make the system user friendly?

THEME SIX:

Community Programs and Support

In focus group after focus group, participants talked about what goes well and what does not go so well in community programs and supports. For some people, their current support arrangements are meeting their expectations. For other people, improvements are needed.

Families are concerned about the general design of services and their availability, now and in the future. At this point in time, some are paying more for services, especially in out-of-pocket expenses.

Expectations and Improvements

There are gaps in services.

Transitions, all through life, often mean a change in the quality of support.

Advocacy and constant vigilance are required.

Respite is not available in ways and amounts that meet the needs of families.

Employment opportunities are an ongoing need.

The support at home meets the expectations of some families and self advocates. Others want a change, the support to which they are entitled, and the assurance that alternatives will be available when needed.

The world is not just about services. People need friends. They need to be involved in the life of the community.

Except for legal aid and legal advocacy, families do not think much about the generic service system as something that is relevant to their lives.

Early education and the transition.

I'm very happy about early education services here. Efforts are made to include everyone, regardless of disability or income.

There is a need for day care programs to accept children with disabilities.

After early education, the school system starts to fail us. The teachers need training on how to deal with the kids with special needs.

While my son was in the early childhood program, the planning process was centered on the family and individual. When he entered elementary school, the process became fragmented and driven by the needs of the service providers.

School programs.

School is not meeting our expectations. Services should be provided in the classroom instead of having pull-out. My daughter loves music but is not allowed to play an instrument. Assistive technology information is not included on the IEP like it should be.

Within the last five years, more and more kids are included in school programs; however, if a child has multiple disabilities, behavioral needs, or is non-verbal, they are more likely to still be segregated in the school setting.

The school has fallen short on special education services – Not enough staff, poorly trained.

If you don't pay attention to everything the school is doing, your child will not get all the services they qualify for whether it is in the IEP or not. It is not the best interest of the child– It is only the bottom line.

I did not have very high expectations of the school, but they have exceeded them. The staff is well trained and they treat me like an equal partner.

The school situation is very good now that the Principal understands that I will advocate for my son. She knows that I will talk, organize the parents to make sure our children's needs are met, and go over her head if I have to. I went to the school board. I will do whatever it takes to make sure my child's needs are met.

School programs can work well, as long as you are a well informed parent. Parents need to be trained to ask the right questions. Parents of older children have dealt with the system, so they have learned what the system can and can not do. Parents of younger children are just beginning the struggle. They shouldn't have to struggle to get their children a good education that they deserve.

One parent said her daughter's school situation met or exceeded her expectations. Another said her deaf daughter was not being taught American Sign Language (ASL), but a combination of English and ASL. She thinks lack of training is the reason her child is not receiving the education she deserves.

The transition from school to work and adult life.

Kids need more rehabilitation services, and earlier. They need more exposure and career counseling. The DRS won't serve kids until one year after graduation; they should get involved earlier. Transition planning needs to start at 14, or the 9th grade, if not earlier. There needs to be an attitude change – that all people deserve employment opportunities. There needs to be better sharing of responsibilities about who's going to provide the service – school, county, employers.

Transition from school to adult living needs to start at a younger age.

There are very few school-to-work options in our area.

There are limited school-to-work options in our small communities.

Often, according to two different families, it is assumed by school personnel that all people with severe disabilities will go to the DAC for a job. Since we don't have a job developer in the area, it is up to the families to find an individualized job or go with the "norm."

Family support and respite.

The Family Support Grant is wonderful. There should be more funds available to provide social activities for parents. We don't need more meetings, just an activity that is free and allows us to get together to network. Partners in Policymaking and the Disability Law Center are also great.

I wish there were more people willing to provide my child with respite.

Respite has come a long way since my child was born five years ago. We had to prepare hours of data to back up my statements about what was working in other areas of the state. I went to many meetings, and met with county officials before they adopted a new respite plan to give parents the opportunity to hire, train and fire staff.

Respite is a concern for many parents, especially in terms of cuts and quality of staff. Respite for older children and those with attention deficit is much more difficult to secure. Many wondered how respite can vary so much from county to county.

We need more respite services here. Respite has been cut and parents need more breaks.

Respite is not an option. There is a lack of accessibility and funding, and people are just tired of having others in their homes so much. Of these ten families, only one is currently using respite.

We are receiving sporadic respite. We would like out-of-home respite, but it is not available.

We qualify for respite but aren't receiving it because it is so difficult to find a provider. Living in a rural area, we have difficulty finding PCAs and respite care providers.

We need more respite and closely supervised time. This will lessen the stress on the family.

Several families in the focus group receive respite, but not to the level they need it. They think an emergency fund would be helpful for illnesses and the like.

PCA services are being cut. Even though our child's needs aren't less, the services are less. Respite is provided by the county grant but no one is qualified or set up to care for our child.

Work/employment.

There need to be more job opportunities in this area.

It has been easy to find work, thanks to my parents.

Most focus group participants think jobs are a priority, and that the situation may become worse in the future with increasing numbers of cutbacks in companies and increasing numbers of those who need jobs.

I would like to see something in every small town for work programs, not the DAC, but a real job in the community. There are lots of them. Maybe someone from the government should spend their time exploring that rather than exploiting us.

My daughter enjoys her employment. She's also learned not to criticize her options because she gets a negative response.

For our children who are deaf and blind, there are no options at this time.

All the self advocates are happy in their work situations. Two of the men are very happy and proud of their paychecks. One woman works at Functional Industries, but doesn't like doing the same thing every day. They often run out of work so the workers just sit around with nothing to do.

Transportation.

My concern is with transportation. Many times I have been left waiting for scheduled bus service so I can get to programs in the community. The bus is late; one time it was 45 minutes late. That cuts into my program time, and people think I am a "tardy person" when I am late for scheduled appointments.

I'll need help with transportation if I'm ever to get an education or a job.

Transportation to and from work, and to and from activities in the community was crucial. The system remains unreliable and not easily accessed by those who need it.

Home and family life.

The self advocates I interviewed are in a home situation they are happy with, except one woman who would like to move to a different home where the others are more independent.

Four self advocates said they are enjoying their living situation. One, however, went from living on his own with support in Minneapolis to an ICF/MR and does not like it at all.

My son is in the best home situation right now. He will never leave here until the last RTC is shut down. He will never be in a place like that. I'm afraid the state will move people with disabilities back into the institutions.

A parent said her son's adult foster care situation is an excellent home for him. He lives in a rural setting and works at many different jobs in the community. She feels he is developing a good sense of self esteem, and is treated with respect and concern.

Group homes need to be monitored more effectively. One family's son was in a group home. They had to go and pull him out abruptly for safety reasons. The adults in the home were poorly monitored and there were some inappropriate sexual advances. Issues were brought up to the county but nothing happened. The family thinks it may be due to the shortage of group homes, and the county is reluctant to close bad ones without options to find other accommodations for people in the home. As a result of pulling their son out of the home, they lost the opportunity for waivered services. The policy stipulates you must give group homes three month's notice.

It was interesting how social services found funding, all of a sudden, when we started talking about putting my grandson in foster care.

I'm almost afraid to look into the SILS program. From what I hear, I better start now, even though my daughter is young. It may take that long on the waiting list.

A parent said that when it was necessary to place her child with severe disabilities in foster care, the county said that the goal of foster care was reunification. The parent said they were a unified family, but her daughter's needs exceeded what they could provide. She felt the county treated them as if abuse was the issue. Her daughter received more in-home support in foster care than she did in her family.

The support we get at home is not great. We have a waivered service contract for 30-40 hours a week for an in-home staff person. We only get 2 1/2 hours a week! Our school situation is much better. I love my son's work program. It is in the community. He gets paid an hourly wage and earned enough to buy himself a leather jacket.

Friendships/relationships.

One important factor in my son’s life is the lack of normal male friendships.

The real problem is not having friends who do not have disabilities.

My son needs real friends.

Recreation/community activities.

Appropriate recreation and leisure activities are as lacking.

Activities were important to all ages. There were good things said about Project Explore through community education, parks and recreation programs, Livewires, Special Olympics, churches, Girl Scouts, Boy Scouts, and 4-H. Bad experiences with some of these organizations were also discussed or noted. Charitable funding for some of these programs has decreased.

One mother suggested building a “state of the art” community center for kids and adults with disabilities, then invite non-disabled kids to use the facilities.

Generic services.

One family said that the legal advocate was a godsend a couple of times when they were at the end of their rope. She gave us the encouragement and knowledge to not give up, and start climbing back up.

Another family said that legal aid was not easily accessible. Funds were cut and the legal aid worker was hard to contact.

There is no direct service from any of these generic social service providers. We have neither asked for it nor expected it.

As more and more adults participate in and become members of our communities, there need to be more mental health professionals available to support people with disabilities around relationship issues and day-to-day stresses that are overwhelming. People are getting married and in some cases having children.

Staff at crisis centers need to be trained better on how to handle the calls they receive.

We have to leave town when there are crisis upsets around mental health issues.

General Design and Accessibility of Services

Families want to see expansion in the waiver system, a better chance to get into new services, ongoing support to families, the protection of the law, and a more certain future.

> There should be a waiver system for everyone. More slots are needed in our county.
>
> Often times, support programs are marketed to be available, but by the time you hear about them and sign up, you're told the program has been canceled due to the low number of participants. Programs should be able to run with low numbers for a while so active participants can get the word out in the community and allow time for a snowball effect.
>
> I am concerned about the lack of laws on future care for adults with disabilities.
>
> Most people think TEFRA fees are manageable; however, there is concern about TEFRA continuing and what impact managed care will have on families with children.
>
> Two respondents mentioned backlash, especially in the education system, regarding funding – pitting regular education against special education, parent against parent. There was an uncertainty about future federal and state cuts in programs and funding.
>
> Families are still the biggest support, resource and providers. Train them, use them, help them to function and make the best for everyone.

Parents may not be paying more to the State for services, but many are covering more out of pocket expenses and non-reimbursable items.

> More than half the families were spending more money on medical trips, kicking in $25 per month for respite, and so on.
>
> Parents are not paying more to the State, but many are paying for extras, or even things that are reimbursable.
>
> They just choose not to go through the struggle for reimbursement.
>
> Two parents said the guidelines for parental fees have gone down, and insurance costs have gone up, so they are paying more out of pocket. Another parent said she pays transportation costs, some medications, and now pays more for her share of housing and heat.
>
> In one county focus group, six families say they are paying some of the costs for services.
>
> None of the families in another focus group were paying out-of-pocket costs for services.
>
> In rural areas, people and parents are paying more out-of-pocket costs for needed services.

from the Focus Group

The focus groups and interviews provided a way for Minnesota families and citizens with developmental disabilities to speak out on issues that face them on a day to day basis. The participants are ordinary people who think about what needs to be done to help them with the realities of their lives. They have not met together to devise system strategies and policy initiatives. They have simply and clearly spoken from their own experiences, analysis and desires. They did not come up with a recommendation for every problem they identified, or effective programs they wanted to protect.

Throughout their analysis, some recurring recommendations emerged. They are direct and to the point. Others may have to develop the policies, time lines, resource plans, and interagency/intergovernmental agreements to carry the recommendations forward.

Direct Support

Support families. Support families. Support families.

Make the supports that are currently available to some families (in-home support, respite, and so on) available to all families.

Support families to develop advocacy skills.

Ensure that families get good information about what is available, and what approaches and options actually achieve quality outcomes.

Increase the availability of waivered services.

Encourage young (pre-school) children to spend time with other children without disabilities.

Provide systematic support to inclusive education.

Ensure and plan well in advance for a smooth transition from school to adult life.

Ensure that adults with developmental disabilities have a chance to have their own homes where they receive the necessary support to meet their needs, and how they spend their time is not defined by what a group of other people are doing.

Increase the resources available to support employment and job opportunities for adults with developmental disabilities.

Recognize and respond to the specific needs of individuals and families in rural areas.

A Supportive System

Reduce the paperwork. For instance, use a common form or source of information.

Don’t make us fill out forms every year unless there is a real change in circumstances.

Make the case management system work. This would include reasonable caseloads for well trained case managers supporting parents and adults to be their own case managers.

Implement a voucher system so that families and self advocates can have more control over the supports they receive, are better able to ensure quality, and less entangled by paperwork.

Make the Medical Assistance system work. Don’t cut TEFRA.

Close the Regional Treatment Centers and reallocate the resources to ensure quality supports in the community.

Create funding and service development mechanisms so that planning is actually determined by individual needs, rather than by labels, budgets, and waiting lists.

Commit the system to ensuring that when staff support people, they are equipped to do a good job. This means paying them well, training them, supporting them, and encouraging them to see their work as a career, not something to do until something better comes along.

Ensure that people who work in the system respect families, seek and value consumer input into planning, and advocate with people.

“The entire system needs to get some respect for families. Leaders should be people who are caring, compassionate, creative, communicative, willing to coordinate their efforts with other, and in touch with the realities with which families and people with developmental disabilities live.

Link accountability to what is happening in an individual’s life.

Agencies and departments should work together, not against each other or in spite of each other, but in support of people and not against them.

Be True to a Down to Earth Vision.

And in the final analysis, make sure that the “system” enables people with developmental disabilities in Minnesota to realize their down to earth vision of what a good future should be. Self advocates have very clear ideas about their hopes for the future and what quality supports would mean in their lives:

Friends and relationships
Family close by
A job that fits my needs
Have/earn enough money to live on
A place of my own
Help to stay in my home as I get older
To get out and about and involved in the community
To have more control of their lives, and choices and support in their lives, so they can do what they want to do
To be treated with dignity and respect.”

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