

Notes on Supporting People with Developmental Disabilities in Dane County Who Acquire Additional Disabilities as They Age

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The DD system faces two growing demands.†

These demands come at a time when it is increasingly difficult to generate the resources to meet them.

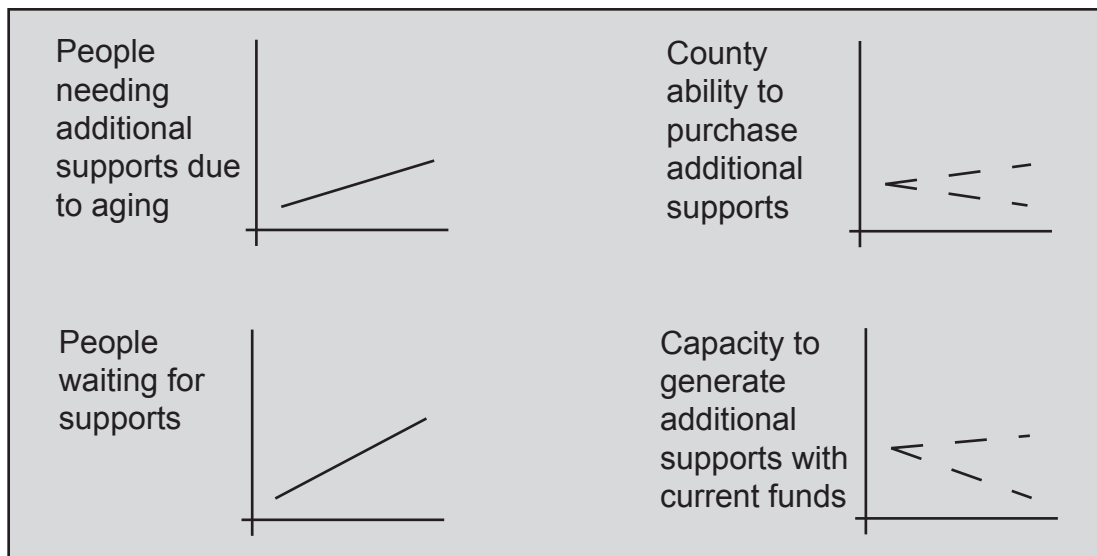
The system has the desire, the values, and the competencies necessary to respond to the changing needs of people who are aging. Providers have dealt capably with similar needs in younger people and with a growing number of older people.

However, managing the difficulties generated by the interactions among these four trends challenges the whole system. Much is at stake and there are no easy answers. Three principles will guide responsible people to act with integrity.

Sustain good relationships

Think in decades

Think of everyone



*These notes are based on four focus group meetings held on 15 July 2004 and a debriefing with Dane County DD managers held on 16 July 2004. The focus groups included 1) service providers and brokers; 2) representatives of families with a member currently receiving additional supports because of dementia; 3) representatives of families with an aging member who has died while receiving DD services; and 4) a group of people with disabilities who are themselves growing older and are concerned with the extra supports they and their friends need. We have done our best to be faithful to what people told us, but these notes summarize our impressions as an aid to the County's planning. Not everyone we listened to would agree with all of the points we have made here. Contact us at rsa770@earthlink.net

†All curves are simple illustrations and do not reflect definite numbers. The dotted curves on the diagrams suggest a range of possible future capacities.

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Many of these challenges arise from Dane County's history of success in personalizing supports, raising expectations, attracting County tax dollars, and maximizing income from Medicaid.

Sustain good relationships. Remember that acquired disability and our responses to it affect a whole web of relationships: not only the person but family members, friends and housemates with disabilities, and staff have a stake in what happens..

Positive relationships based on trust are a central accomplishment of our services. These relationships, and the individualized services that follow from them, are based on clear values, which are an important resource especially when we are in uncertain situations. We should not sacrifice our values and relationships to a narrow focus on treatment. We know that people are poorly served when their lives are medicalized. We need to join with that part of the elder services sector that is committed to assuring that people get appropriate medical services without over-medicalizing the life conditions that come with aging.

Sustaining good relationships means holding a strong, positive bias in favor of people and those who care about them having the opportunity to maintain continuity of living arrangements and important support relationships. Collectively, we know how to support almost anyone to age in place if the sufficient funds and creative energy are available.

Shared responsibility is a key to sustaining good relationships. Under stress, it is easy to slip into a mindset that denies the complexity of the situation or blames a person for needing additional resources. We must avoid this kind of thinking and recognize instead that we may sometimes fail to live up to our aspirations. When we can't deliver an alternative to nursing home placement that satisfies guardian's concerns about stability or adequate care, we need to acknowledge our shortfall without being demoralized by our failure or tempted to rationalize.

Think in decades. Remember that we are at the front edge of a trend that will continue from now on. The choices we make now should not only respond to immediate need and immediate scarcity but also build the capacities our system needs for the long term.

One crucial long term concern involves encouraging families of young people with developmental disabilities to plan far ahead and take account of the likelihood of additional acquired disability.

Another long term investment involves learning how to meet the expectation that implementing self-directed services and brokerage will lead to steady and substantial growth in the resources available to people outside the DD and Medicaid systems. Mindful person-centered planning that involves a growing circle of support will be as critical to expanding available resources as it will be to making wise decisions about responding to additional disabilities.

Thinking in decades means remembering that the system we have today has been created by embracing a bold vision and then learning from what works for people. There are many lessons from our growing experience with supporting people through their last years, months and days. We need to continue to collect, share, and build on that experience by creating and communicating a positive, public vision of what is possible and desirable for older people with DD.

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This is especially important because of the difficulty of many of the decisions that people must make. Though it contradicts our system's explicit values, long term institutionalization in a nursing home seems to many people --including some guardians and deeply committed service providers-- as a normative, if difficult choice.

Some good people understand our system's purpose as assisting people to have the same life experiences as anyone else, it is reasonable to conclude that if many elders who did not use disability services before acquiring dementia or other impairments find their way into nursing homes then this is an acceptable outcome for elders with DD. Others point out that most elders and their families value "aging in place" and believe that it would be cruel to re-institutionalize people whose lives have been constrained by a past history of institutionalization. There are no easy answers, but the process of articulating a positive vision would provide an important opportunity to discuss these issues and, perhaps, to strengthen alliances with advocates and practitioners of "aging in place" as a core value in services to elders.

Think in Decades

Think of everyone. A growing number of people wait for services, A growing number of people require additional services as their needs change. It is easy to compartmentalize our thinking, focusing on one group and ignoring the other. Maybe sometimes it is necessary to compartmentalize in order to deal with individual circumstances. But we can't create a sustainable system unless we can see and think about the whole system by acknowledging all of the legitimate claims on its resources.

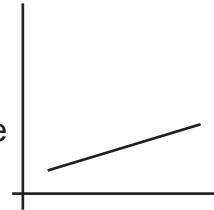
There is another sense in which it is important to think of everyone. Everyone involved has a contribution to make to dealing with these issues. One resource we may have overlooked is the capacity that people with disabilities themselves have to support one another.

The experience of increasing demand

Several people with developmental disabilities who are living with additional disabilities which they have acquired with age shared their perspective on the changes they are experiencing.*

* We have edited and clustered people's statements into paragraphs. The key phrases are people's own and this section was summarized for and approved as accurate by the group members.

People
needing
additional
supports due
to aging



The body changes.

There are more trips to the doctor.

There are more, different doctors.

There are more tests. There is more time in the hospital. Nurses and doctors in the hospital can have trouble understanding you or knowing that

you can speak for yourself. Nurses and doctors can make mistakes if they don't understand you. There is more and different equipment. You may need changes to your home. All this is scary and confusing, even if it is supposed to help you. This is really a problem if you have more trouble remembering things. The staff people you trust are very important to help you understand what is happening to you and to make sure things get done the right way.

There are things you can't do the same way and more things you just

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can't do any more: housework, walking on your own, taking care of your own money. You need more help with things where you used to be independent. It feels bad to lose your independence.

You see other people get sick and die: your parents, family members, your friends.† You miss people badly. You see people you care about go down hill: they can't remember things, sometimes they can't even remember you. They sometimes make a lot of noise. They sometimes have pain. You really need the people you care about to get through all this. It's hard, but we want to be there to comfort, and encourage, and cry with and for our friends.

When you begin to forget things or get sick, you wonder and worry if you will be like the other people you know who have lost their memories or died. You get afraid: Will it hurt? What will it be like to die?

The people you love and care about get more important. They make your

life worth living, even if your body and your mind are getting weaker.

The older people with disabilities who spoke with us talked of many fears and worries. However, each trusts that the organizations and some of the people who support them now will continue to be there for them. Many staff may come and go in their lives, but some staff people are among those the person is counting on to deal with the changes that aging brings. These people do not question that Dane County's DD system will continue to be there for them.

They also have a number of practical ideas about what works, at least in the early stages of increasing impairment they are experiencing.

Keep your independence as much as you can and keep doing things.

Keep your job.

Stay active, even if you need help.

Don't be ashamed of needing more help.

Don't pull away from people who matter.

You need to help yourself and you need to help other people too (one person volunteers with an organization that advocates for people with Alzheimer's Disease.)

Learn more about the new disability. Get some information.

Ask questions. Get people to explain things.

Use your voice.

Be part of the decisions.

The **mothers and sister** who spoke with us also expected the Dane County system and the provider agencies they chose to continue to adjust to their relative's changing needs.

They support the idea of "aging in place" both for themselves and for their family members.

They spoke of hard decisions: When is it time to consent to a "Do Not Resuscitate (DNR)" order? If an agency has developed special living and daytime services for older people with DD and additional disabilities, when is it time to move the person into them and out of their familiar routine?

† Group participants with Down Syndrome have frequently been grouped with other people with Down Syndrome throughout their lives. This means that they have seen more of their friends develop dementia and die than most non-disabled people of their age have.

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They told of agency staff going the extra mile and of agencies responding well to changing needs. In general they appreciate the willingness of staff to involve them, honor their decisions, and collaborate with them for the benefit of their family member. They see continuity of core staff as a great benefit, especially in helping to remember who the person is and what has been important for them. They are pleased with staff commitment to keep the person active and continuing to look for new experiences. Being able to have and keep pets has been important for two people.

It is important to keep people out in the public doing things they've done before as well as trying new things. I don't know if she knew what was going on, but I still think it makes a difference. It keeps staff involved and interested in the person.

Somebody needs to remember who my daughter was and not just know her as she is now. Her history needs to stay alive.

One person, who had experienced Alzheimer's Disease with another family member, was able to offer practical help

and support to staff and she welcomed their willingness to learn from her.

While one mother said that she had to advocate continually and vigorously in order to assure that her daughter's growing needs were not overlooked by group home staff, she sees this as a local management problem rather than as a sign that the system could not support her daughter through to the end.

Support providers are generally confident of their ability to support people as their needs change. Their confidence is based on their experience with other people who had more substantial disabilities as younger people. They have relevant experience in solving most of the practical problems that come with additional acquired disabilities because they have solved similar problems in providing high levels of personal care or supporting people to cope with significant cognitive or behavioral impairments for other people.

The most important areas of increased demand include:

- Decision making around when changes in people's capacities call for major changes in supports and

routines. There is a balance to draw between prematurely reducing the experiences and independence a person has valued and assuring that a person is not stressed by situations that have become unmanageable.

- Making sense of medical advice and integrating it into ongoing supports. This is especially difficult when advice conflicts from different specialists in different aspects of the person's situation. It can be hard to get knowledgeable help in interpreting what physicians and other specialized personnel are advising.
- Making decisions and revising plans can include a substantial number of people: the person, guardian, family members, staff, brokers, county managers may all need to be involved. Often the changing situation calls for more involvement than people have been accustomed to having. As well, people have to work through their own feelings about the way the person is changing and about what will be most effective for the person. Because staff often have a relationship with the person, there can be conflicting understandings and judge-

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ments. These differences take time and energy to resolve and the changing course of a person's condition may bring differences and conflicts back repeatedly.

- Staff who already know a person may need to develop new knowledge and skills to deal with changing requirements to respond to confusion, increased communication impairments, behavioral difficulties, incontinence, daily medical treatments, strategies to manage memory loss, need for physical guidance or additional personal care. Additional staff may need to be incorporated into a household's routines.
- People need extra emotional support. The person, family members, and staff may experience anxiety, anger and depression, And everyone involved has to figure out how to cope with others' emotions as well as their own.
- Many staff need time and support to think through the philosophical or values issues at stake in a changing situation. For example, staff who are deeply committed to assuring that people make their own choices

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have to sort out the implications of a person's dementia for their right to choose.

- Hospice care generally provides effective support toward the end of life and respects the desire that the person stay in their own home. This makes supporting someone as their life is ending less demanding than dealing with "the beginning and middle stages" –times when there is more variability in the person's functioning, more uncertainty, and more adjustments to be made.
- None of these issues are confined to people who receive 24 hour support. Older people who acquire additional disabilities while still living with their parents can pose a particular challenge when their parents can no longer do the work necessary to support their increasing needs.

Service providers identify several important lessons from their experience so far.

The scariest part is fear of abandonment that comes from past experience. We need a basic belief that we will stick with you and, if we don't know how to do what you need, we'll

try to learn what we need to know. We'll "try another way."

Quickly bring in people who know about stroke or dementia.

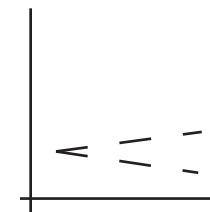
Add staff time as needed.

People often need to change doctors. It helps to find doctors who think there are things to try and things that might make things better.

A strong willingness to rally around people is essential.

Limited ability to purchase additional supports

County ability to purchase additional supports



At least in the intermediate term, it is unlikely that Dane County's ability to purchase additional supports will grow sufficiently rapidly to meet the growing demand for services.

This was not a central topic of discussion, but it did come up in every group. Participants made these points:

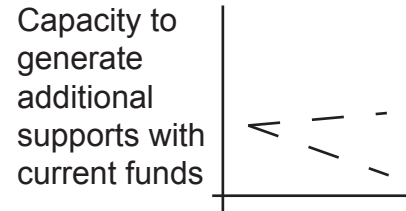
Think of Everyone

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- Wisconsin and Dane County have been highly effective in maximizing the use of Medicaid. There are no doubt some further opportunities (such as the option of developing a shared nursing service), but it seems more likely that the continuing shortfall in the state Medicaid budget will increase pressure on the county system than that substantial new Medicaid revenues will be available.
- Dane County invests substantial local tax money in the DD system. This money is matched with Medicaid, so a decrease in local investment would be multiplied. Some people think that concern about the whole County budget raises questions in some decision maker's minds about the sustainability of the personalized services that are the system's greatest achievement.
- Rapidly rising costs of health insurance and worker's compensation decreases the purchasing power of county funds.
- A competitive labor market –and a concern to pay fair wages– raises the cost of services.

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Uncertain capacity to do more within existing funds



Dane County's system has grown strong because of widely shared values, the County's ability to allocate funds to meet increased need, and willingness by many providers to create and flexibly maintain new responses to new circumstances families. These forces are interdependent. Trust that the County can provide adequate funds underwrites provider's willingness to assume greater risk. Provider capacity to deliver justifies trust by County leaders. Strong common values support going the extra mile.

The system has drawn substantially on its stock of resiliency.

- Budget cuts, though modest compared to what other systems face, have affected the quality of supports that some people experience.
- Rising insurance costs erode the benefits providers are able to of-

fer. Attempting to recover increased costs by passing them on to individual budgets could result in reducing or even withdrawing services. Though workers may not blame provider agencies or the County, the prospect of small if any increases in pay and reductions in benefits affects morale and turn-over.

- Reduced funds and increased costs have pushed many providers to compromise their own standards for quality. Many feel that there is little more room to compromise further without a significant departure from agency values. Because they have personal connections to the people affected, these compromises are hard to make.
- A number of providers are uncertain about how far beyond the DD Program the County's support for their values extends. Some have drawn strength from their belief that "we are doing what our community wants." This belief seems less warranted and this is discouraging to some.
- Implementing self-directed services has required substantial work on provider's part. Broker's roles and

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- contributions are still being clarified. As yet, self-directed services have not substantially decreased the amount of effort a provider needs to invest on behalf of people who have been in their agency for a long time.
- Some provider managers are aware of having assumed many risks over the past two or three years. Each decision was a considered one, but there is a sense that these risks are piling up in a way that makes the people who count on the agency and the agency itself more vulnerable.

- Many supports feel stretched thin and there is less confidence among some provider managers that there are reserves to draw on. It is harder to mobilize staff for necessary extra efforts.
- A number of experienced staff and managers have dealt with the stress of uncertainty, repeated demands for extra effort, and the need to try to influence the larger systems that people count on to the point where it can affect their health, their confidence in making good decisions, and their sense of adequacy in their work.

These potential limits on the systems resiliency affect the system's capacity to respond well to people's changing needs.

It is a nightmare scenario to imagine a provider's resiliency to continuing increases in demand crashing. The only reason to imagine the possibility is to underline the importance of the different stakeholders in the DD system working together to rebuild the capacity for fast, flexible, and effective responses to people's changing needs and opportunities.