

## What We Hold Dear

The long-term care environment is changing in the United States and in Wisconsin. Experiments with managed cost control are happening across the country, Dane is one of a shrinking numbers of Wisconsin counties not covered by Family Care and IRIS and the Governor's budget proposals could result in more pervasive changes, sooner than anticipated. These changes will inevitably affect the way Wisconsin's Medicaid funded long-term support system responds to the demands of people with developmental disabilities and their families in Dane County.

Reports from the current expansion of Family Care say that the counties involved have had a very limited role in shaping the transition or the form that managed care takes for the people they have served. It is essential that people who want to preserve what has been achieved over two generations organize to influence the way Family Care and IRIS or their threatened successor function in Dane County. Families, people with disabilities, providers and county government each have an important role to play, but a shared sense of what we value will provide a firm foundation for action to shape the change.

Monica Bear hosted three meetings\* to ask people with developmental disabilities, their families and service providers to reflect on what we in Dane County hold dear: the accomplishments, values, qualities and capacities that have served our purposes well until now and are worth struggling to conserve as we meet the changes that come with managed care. These are the elements of our collective identity that we want to preserve and build on.

### Accomplishments

Dane County's DD System has created significant opportunities for people with developmental disabilities and their families. These accomplishments are the co-creation of people with developmental disabilities, active families, committed providers and county managers working together for 40 years. The system of support created by the interaction of these capacities offers Dane County citizens opportunities for community life on a scale that is hard to match in other places.

- There has been more local investment in supports for people with developmental disabilities than in any other Wisconsin County.
- Flexible, and when necessary intensive, support assists families through childhood and adolescence.

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\* Service providers met on 2 November 2014. People with developmental disabilities met on 2 February 2015. Families met on 3 February 2015. John O'Brien listened and made written summaries, which are compiled in this document. The purpose of the meeting was to gather as many different perspectives on what those involved value in the current system as possible. There was no effort to establish group positions on any point, so the summaries do not reflect a consensus. Many other voices could have been heard and will be heard as conditions continue to change. Quotes are paraphrases based on notes, not transcriptions. These notes represent my understanding of what I heard and not everyone present will see the way I have combined similar contributions or expressed ideas in the same way that I have.

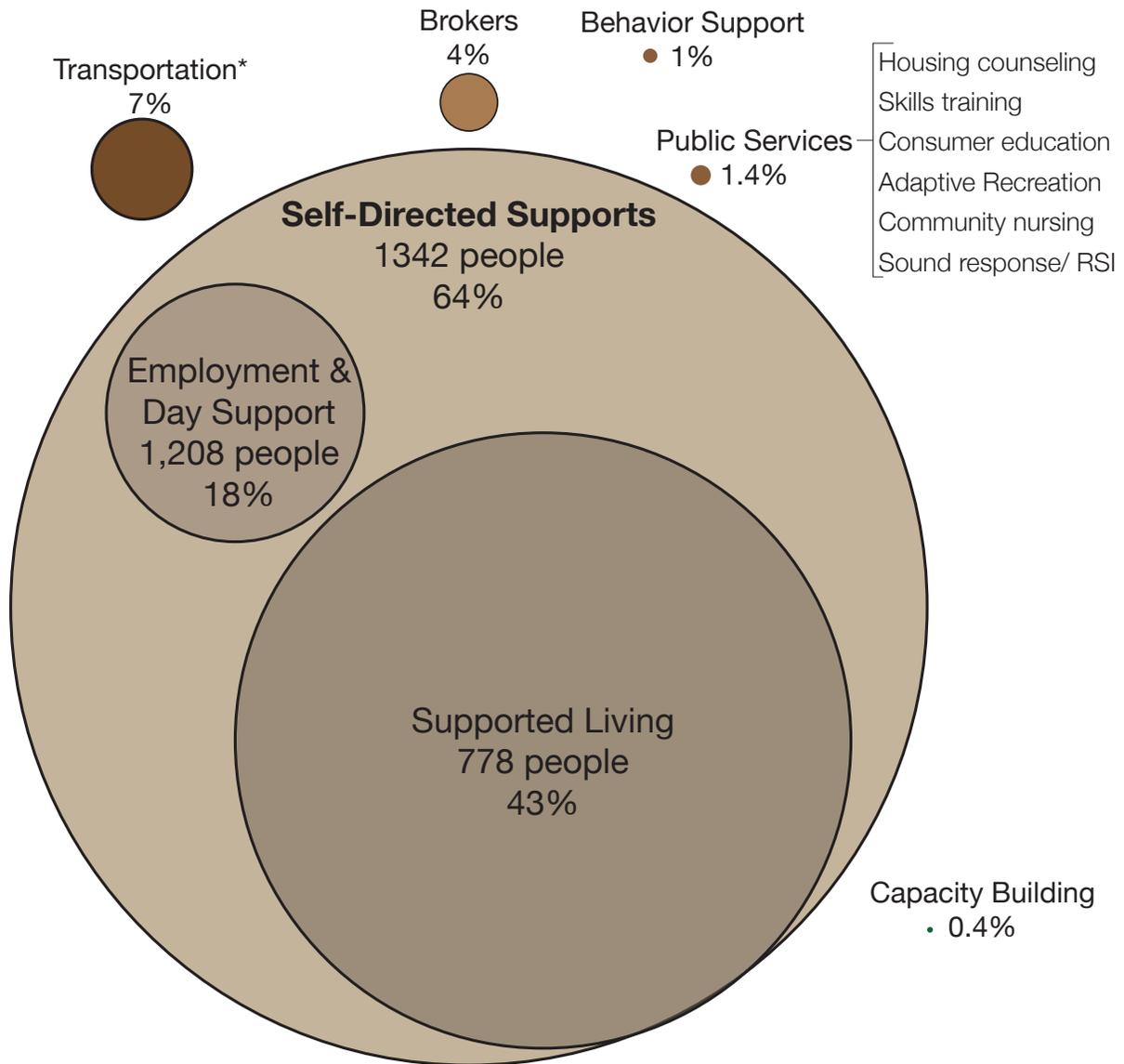
- Employment supports have assisted businesses in many areas of the county to respond to most people's desire and capacity for employment. According to one source, only one jurisdiction in the US reports a higher rate of integrated employment for people with developmental disabilities.\*
- More people benefit from individualized supported living in Dane County than in any other part of Wisconsin. A significant number of people own their homes. It has been possible to respond when family ability to support a person at home breaks down. Though the capacity has hit a limit in assisting people who want to move from their family homes for positive reasons in recent years, it has been possible to offer residential support to a substantially higher proportion of adults here than in other places (in 2011 Dane County had half the percentage of adults with developmental disabilities living with their families as Wisconsin as a whole did and about a third the percentage of people in the US as a whole).
- Dane County has eliminated long term institutional residence and minimized short term placement.
- Achieving permanency for every child has been an objective for more than 25 years.
- A Treatment Foster Care option has developed for a few young people who are better assisted by a supported living arrangement than in a family or foster family setting.
- A few people's needs have taxed local providers and crisis resources to the point that short term placements in IMDs or DD institutions are necessary. The people who challenge the system in this way have been the focus of intensive effort to develop or redesign supports.
- There is continuing attention to support people whose needs for assistance increase in consequence of age related disability or illness to remain in their homes rather than undergo long term nursing home placement. It is a victory when those who have supported a person can maintain a vigil with them when they are dying.
- Dane County is one of very few places in the US that provides each person a broker and an individual budget as well as access to a set of county funded public services (such as crisis response and technology consultation).
- Most young people graduating from high school have moved into supports that include necessary assistance to maintain employment, in home support and the services of a broker. This accomplishment builds on, and has influenced, most of the county's school districts to assure that young people graduate with paid jobs.
- There is a history of DD system support for family-led innovation that has increased capacity: Movin' Out, LoV Dane, Community Building Initiatives, family-led jobs.

These distinctive accomplishments result from wide agreement on values, investment in diverse ways to give form to these values in people's lives (shown on the facing page), and a

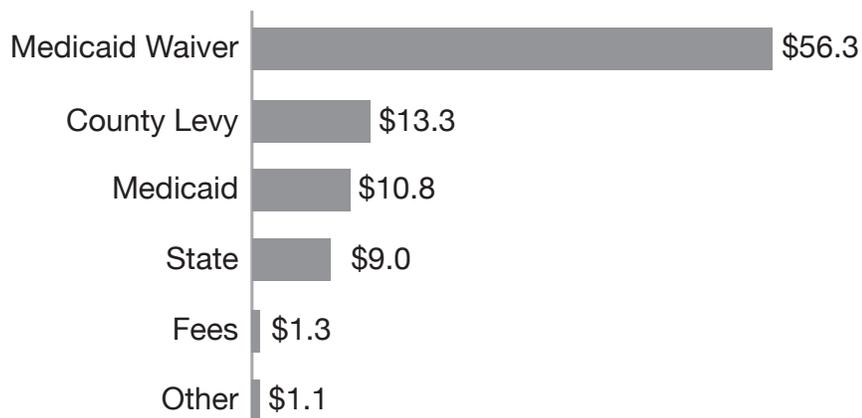
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\* *State Employment Leadership Network Accomplishments Report 2012-1013* <http://goo.gl/65IHcY>

# Dane County Human Services Investments in Supports to Adults With DD, 2015



Funds by Source (Millions)



\*Madison Metro pays local Medicaid match of \$2.1M for transportation.

desire to continually learn and improve collective capacity to realize them. The values that set direction for Dane County's accomplishments include these.

- Full participation in community life.
- Individualization, flexibility and nimbleness in assistance. Support that respects each person's identity and interests, recognizes what matters to each person and adapts to changing requirements for supports.
- Choice and self and family direction of publicly funded assistance. Keeping the person at the center of concern, especially at difficult times.

These values are commonly held across the US. While there is plenty of room for further progress, we want to conserve the capacity to accomplish them to the high degree Dane County has achieved so far and continue to improve and innovate.

### **What works for people with developmental disabilities**

These are the views of a small but diverse group of men. One participant has recently graduated from high school, another is about 60 years old. One person is an influential self-advocate whose voice makes a difference in many discussions; others were taking the first opportunity to make their views public. Two people are survivors of more than one institution, where both experienced abuse. Two people moved from their family homes. Everyone present had something important to contribute to the discussion.

### **Individual support for jobs**

All of the participants have at least one job and one person has three. Each has a different form of support for on-the-job success. Low-tech job aids and consulting support to his supervisor makes success on one job possible with no on-site job coaching. All agree that having their own job, with individualized support, makes a big positive difference in their life. Jobs provide income, a place to learn skills that improve their job performance and sometimes are helpful outside of work, a chance to be part of a group of workers, and offer a chance to contribute. Some people have had trouble at work and it has been very important that there has been support to either solve the problem or move on to another job.

### **Home with individualized supports**

Each person has individualized living arrangements that reflect their choice of what works for them. People feel like they usually get the help they need with matters ranging from managing money and taking medications to active support, including transportation, for success at work and in church and civic life. One person's complex health needs are capably managed through careful staff attention to a daily check list made and monitored by a health care team.

People feel they have a real say in who they live with and in the support they need. There have been roommate problems and people have had help in either resolving them or making a change. A live-in staff person works very well for one person; feeling like part of a team that

works together to make their household work is important to another's pride in his independence.

People's homes are located in ways that support their independence. One person can walk on his own to his job and to most of the places he likes to shop and spend time. Others live convenient to bus lines. Another person's support arrangements includes rides with live-in staff.

### **Friends and family**

People's families are important to them, even when there have been difficulties. Staff respect for and openness to family involvement is important even when there are disagreements or its a long time since family members have been actively involved. As parent guardians pass away, sisters and brothers are taking over guardianship, so keeping them actively involved is very important.

Friends are always important and never more so than when a person is grieving. One person has recently lost two close family members and says that it has been really important that so many people, including members of his church and former and present staff people, "care for me a lot and are there to visit me, talk to me, spend time with me and cover me with love and kindness."

Friends and family also make a big difference when people reach positive life milestones. Having friends, including staff friends, witness a person's baptism in a church that has become very important to him made the occasion especially powerful.

Some staff have become good friends. Some of these friendships have lasted more than ten years. Respect between people and staff is always important. Friendship that grows from that respect is a good thing.

If people need some assistance keeping in touch with friends –like people a person used to work with or live with– its good when staff can build that in to their schedules.

In conclusion. One person, who has lived in a full continuum of residential options, summarized what works for him like this.

*I go to work. People there like me and I do a good job. I come to my home on the bus. The garage door is open for me. There is somebody there to greet me. I come in. I close the garage door. I take a shower. I put on clean clothes.*

Listeners' headline summary of what works (OK'ed by participants)

**Real jobs and (for one person) church membership.**

**Respectful, individualized support from people who know you and treat you right.**

**Welcome for family (including brothers and sisters) and friends involvement in your life.**

**A say in where you live and who you live with.**

## What families hold dear\*

One participant sees the political challenge of navigating the shift to managed care this way.

*In Dane County we have many good things that most Family Care participants do not. We also have an unacceptable number of people waiting for support for a place to live outside their family. We need to hold on to what is good now and get the benefits that Family Care offers.*

Another participant describes the platform for discovering how this challenge can be met.

*Our system is not sustainable. Numbers continue to grow. People can't continue to rely primarily on their families for decades. A sustainable system can only evolve from collaboration with innovators: families, people with disabilities, others who genuinely care and are willing to try new ways. We will only find out how to get to a sustainable system by investing in innovation. Without personal knowledge and trust, collaboration can't happen.*

## Investment in support for family action

Being and feeling connected to what is developing and opportunities for action is in itself an important support for many families. There are important benefits in multiple opportunities for family-to-family connection from information sessions that bring families together to share experiences for an evening to ongoing capacity building projects that join a group of families for years.

Investment in LOV-Dane and other capacity building projects provides an infrastructure for families and people with developmental disabilities to join together, imagine and initiate actions that matter to their lives. This produces meaningful opportunities from new entries on a person's social calendar to configuring available resources into a successful move from the family home. It is truly empowering.

These initiatives also allow families to engage their deep concerns about how to form and sustain an intergenerational structure of caring that will survive a person's parents. Care can't be bought, though adequate public funds and prudent estate planning are necessary. Service buildings have never yet provided a lasting guarantee. Holding and pursuing the critical question, "Who is integrally involved with my son or daughter?" is better pursued in company than in isolation.

The final years of high school are often stressful, even for parents who have access to good information. Anxiety rises when parents come under the spell of a common story that portrays the experience of graduation as one of falling off a cliff into an abyss of isolation. The sense that there is no option but to wait for the system to deliver can be debilitating. Efforts to con-

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\* Participants described what they have experienced when Dane County's system is functioning well. There is no claim that any of these positive experiences always happen or happen for everyone. For the purposes of this discussion, what matters is description of capacities necessary to create positive experiences because that is what is worth fighting to preserve as the environment continues to change.

nect families on either side of graduation have positive effects, though there is more to do. Uncertainty about the changes that will come with Family Care and IRIS effects parents of special education students and makes it important to include them in influencing the transition.

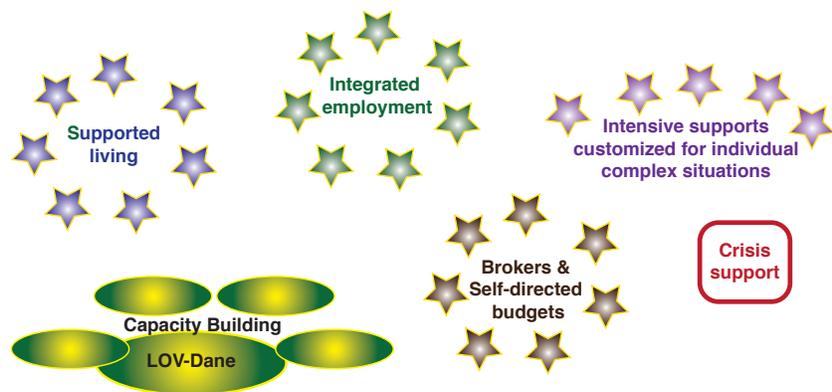
Families have great resilience and the capacity to accomplish remarkable things. Families are fragile and vulnerable. Both statements are true. It would be a serious mistake to assume that family investment and family creativity can be sufficient to take up all of the slack generated by public underinvestment in needed assistance. Supporting families in generous, flexible and family directed ways is necessary to sustain family resourcefulness. Families accomplish far more together than they can alone, so investments in organizing families multiply the possibilities for productive collaboration.

### A culture of community participation

There is a strong and consistent expectation that people with developmental disabilities will be active contributors in community life. This shows up in the exceptionally high number of people in integrated jobs and in the sustained policy of assuring that eligible graduates who have jobs receive ongoing support to maintain or improve them.

Over decades, this accomplishment has accumulated powerful indirect effects.

- Priority on integrated employment has aligned the focus of special education in most of the county’s school districts. The availability of continuing support for an integrated community



### Individualization • Flexibility



jobs empowers parents to assure the relevance and effectiveness of IEP's and encourages shared problem solving between parents and school personnel.

- One participant, parent of a young person still in school, has been struck by how welcoming the library, theaters and many other community places are for her son and how matter-of-fact the welcome is. She thinks that one key cause of this is that most of these settings have had employees with developmental disabilities who have broken down common stereotypes and made the presence of people with developmental disabilities no big deal.

The commitment to community participation shapes the system's focus on delivering supports that are sufficiently powerful to absorb the crises that people experience without resort to institutional placement. Last year the local combination of crisis resources and investment in the re-design of individualized supports worked for all but seven people (this is a very low rate of utilization of out of county placements). Reflection on their experience informs efforts to further strengthen the system's supports.

Leaving school and beginning adult life marks one life transition, but not the only one. Transitions happen through the lifespan. A growing number of adults who have had good lives as workers and even home owners face a transition impelled by acquiring substantial additional needs for assistance in consequence of a health crisis. Not only can this substantially increase the need for public funds, it also demands re-developing a person's support system.

One participating family, no doubt speaking for others not present, thinks that county manager's interpretation of community inclusion goes too far. They see their family member with autism, now in school, best served in the future by a living arrangement somewhat similar to an assisted living development for elders. Models of this arrangement are already established in other states: 30 or more people each have their own apartment in a development that includes common space for shared activities and meals, on-site support staff, and on-site organizers of activities both within the development and in the community. Given their understanding of the needs of the rising number of adults with autism that will come into the system in the next ten years, this kind of setting would offer long term security and tailored opportunities for social connection in a cost effective way. They see the county as arbitrarily limiting family choice by rejecting such developments, apparently in the name of community integration. Their judgment about the means to assure that people have secure homes and do not sink into inactivity and isolation were not shared by the other participants who commented on their idea, but everyone who spoke shared a desire for security that reaches past the time when parents can play an active role, good social connections, a sense of community, and meaningful activity.

### **Individualization, flexibility and innovation**

Dane County does not aspire to be a producer of cookie cutter services where people have to settle for a fixed menu of services and hope for a good enough fit. The focus is on people getting the assistance they need to have good lives as contributing citizens. Building fertile soil through local investment, leadership committed to common values, and purposeful strategies

for building a more inclusive culture has allowed flexible, individualized supports for family action, employment and community life to grow.

A sustainable system expects and assists people with developmental disabilities to be life-long learners. The idea that people stop developing when they graduate from high school is as mistaken and wasteful as the idea that some people are incapable of learning at all. Many people with disabilities have demonstrated that when they have the opportunity they learn skills that not only increase their independence but sometimes decrease the amount of assistance they need. Opportunity includes: a safe space, engagement in meaningful activities with typical people, access to assistance with learning, and technology.

It is essential to preserve the capacity for flexibility and individualization. This is not a service but a way of bringing people with developmental disabilities, and their families together with service providers to think, try things, and figure out what will work best for a person. This raises an important question for families, “Who else is becoming involved in planning with us?” County managed resources can be fluid: one person used some vocational support hours to assist in building the foundation for his art business.

Having a broker, and having a choice of brokers, supports individualization and changes in supports to keep up with changing interests and needs.

Openness to influence and willingness to hear are keys to flexibility. Capable managers and providers hear parent voices when things are not working for a person and work with them to find better ways. Sometimes this means letting go of usual professional models and rebuilding a person’s support system from the mindset that has shaped plans and practice to the smallest details of a person’s routine. One parent is sure that these capacities actually saved her son’s life and opened new opportunities for him.

Openness and respectful listening apply to people with developmental disabilities as well as family members and guardians. Different perspectives and priorities can lead to better support for richer lives when those involved work through their differences.

Recognizing the importance of a variety of responses motivates rethinking family support. Some families clearly benefit from more hands and trustworthy eyes so parental energy and attention can turn from the work of providing personal assistance to other pursuits. The options of skilled others who intentionally build community connections or support a person’s learning are also critical dimensions of supporting families.

There is a culture of learning and building knowledge that encourages innovation and resourcefulness. More and more people are making imaginative use of smartphones and other everyday technology. Some people are exploring different ways to understand people’s disabilities and support self-regulation and communication. There are networks that connect families and service providers and serve as channels to spread new ideas and practices.

There are a number of issues that call for continuing innovation through collaboration among people with developmental disabilities, families, providers and the County:

- Create structures that involve families in planning for Family Care and IRIS or developing strategies for dealing with their successor.
- Reducing the number of people whose families do not play an active role in their lives and increasing the number of people who are personally committed to those whose families are not active.
- Reducing the extra work that families who are not on a Metro Transit route have to do, especially when they want to support social life outside the family home.
- Finding ways to make expanding social connections a priority for action rather than a “when we get time for it”.
- Assuring that support to families is as flexible, responsive and resourceful as possible and that brokers assist families to pull together the widest possible range of resources.
- Continuing to improve the knowledge that families of school aged people have of adult development and of adult service options.
- Continue to improve the timeliness and quality of responses to adult transitions caused by loss of family support or sudden increases in needs for assistance.
- Thinking a decade ahead to anticipate effective responses to the growing numbers of children and young people diagnosed on the autism spectrum.
- Continuing to multiply the options that offer people routes to establish their own households.
- Continuing to improve people’s job and career options and increase people’s income.

### **What providers hold dear**

Providers want to preserve a way of proceeding. The social creativity that characterizes Dane County’s response to citizens with developmental disabilities and their families is generated by a web of face-to-face relationships among people who share a way of proceeding and act on common principles. Over time, investing time in thinking, working and reflecting together has resulted in a shared history, a shared story and a culture that generates and sustains our accomplishments.

Many of the relationships that encourage accomplishment have developed over time. A substantial number of key people have long tenure, sometimes in changing roles, because of the personal meaning they find in the work. Relationships sustain hope and encourage finding another way when a situation gets stuck. In the search for better responses to difficult or changing circumstances, role and position matter less than willingness to engage others and search for the best available way forward. The responsibility to offer leadership belongs to everyone.

One important source of meaning is a sense that others share a commitment to discovering and doing the right thing for people and their families, even when a complex situation makes it hard to see what the right thing may be and uncertainty provokes anxiety, fear or anger. Humility enough not to assume certainty about the answer before shared inquiry is valuable in dis-

covering the right thing to do. Willingness to come together, face and move into difficult situations rather than take easy ways out by withdrawing and trying to fix blame has strengthened relationships and built resourcefulness. There is a belief that prudent use of public funds and effective response to risk demands understanding a particular person and their purpose and coming to a joint sense of what is right for them before figuring costs and working out ways to limit danger. There is an active search for better ways to understand and respond to people's disabilities and the effects of their impairments on their quality of life.

Another source of meaning comes in celebrating the ordinary life experiences that assistance makes possible for people with developmental disabilities: contributing through employment; pursuing personal interests and the simple pleasures of friendship and others welcome when you show up; living securely in a place that suits you with people you choose. People with developmental disabilities are likely to miss these familiar satisfactions without purposeful action to assist them. More often than big changes, better lives come through many small victories. Useful knowledge is likely to come from the kind of personal connection that includes just being together. Discovering, respecting and valuing people's and families' visions and working collaboratively with them to move toward those visions sustains people in the work and energizes relationships that can otherwise be overshadowed by cynicism or hopelessness or tiredness. The provision of good support is a matter living up to promises, not complying with the requirements of a transaction.

The people who develop and deliver effective supports have purposely cultivated collaboration and creativity. Those who are willing to join in partnership –whether as a member of a person's team or in an effort to increase the responsiveness of an organization or the system as a whole– have a sense of mutual support and accomplishment. They can say,

*I never have to feel alone. We have made a place for everyone who wants to be a partner. We can always reach across organizational boundaries, sit down, listen to one another and work things out.*

Partnership depends on people investing their trust. The most fruitful partnerships occur when passions and purposes resonate and people are willing to move beyond their egos into mutual respect and care for one another. When a person's desire for a full life that builds on strengths, a parent's concern for a good present and a secure future and a commitment to make a positive difference in other's lives coincide, the capacity to sense and act together beyond currently accepted limits opens up. Stubbornness about purpose and intention and great flexibility in trying different approaches to realize purpose are a regular feature in stories of real progress. Witnessing other's growth and learning from other's ways of navigating difficulties and discovering opportunities encourages and informs courageous action.