New Mexico
Developmental Disabilities
Supports Division

The Meaningful Day Idea Book

First Edition
Updated: 2/10/2009

The *Meaningful Day Idea Book: 2nd Edition*
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Introduction . . . . page 1

This selection provides an overview to the *Meaningful Day Idea Book*'s content, structure and purpose. It also acknowledges all of the people who helped create it.

- An overview of the Meaningful Day Idea Book
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Supporting *Individualized Access*

This selection contains idea papers about tailoring paid supports to meet an individual's preferences and needs. It also contains idea papers on supporting a person to get around and have the best possible access to his community.

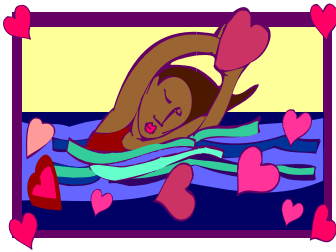## This Selection Includes Ideas and Information About:

Deep Connection with Ordinary *Community Life*

This selection provides practical tips for how to introduce a person to his local community and support him to become known as a respected, contributing citizen.

This Selection Includes Ideas and Information About:

Wellness and *Optimal Health*

This selection contains ideas for supporting a person to use community resources in order to stay as healthy as possible in all aspects of her life.

This Selection Includes Ideas and Information About:

Self Empowerment, Relationships, and **Respect**

The idea papers in this selection discuss how to support a person to be in charge of her own life and how to support a person in building meaningful relationships with other people.

This Selection Includes Ideas and Information About:

Champions Assure Progress is Linked to the *ISP*

This selection contains information on building supportive interdisciplinary teams for a person using services. It also contains information about DDSD's meaningful day definition and suggestions for documenting services related to a person's meaningful day.

This Selection Includes Ideas and Information About:
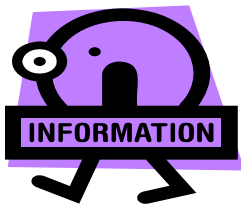
And Yet More: Handouts, Training Tools and Other Resources

This selection houses various documents that are referenced in the idea papers. It includes handouts, checklists, exercises and other tools that may be helpful in understanding how to support a person to have a meaningful day.

This Selection Includes Ideas and Information About:

And Yet More: Stories Worth Celebrating

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Introducing…

The Meaningful Day Idea Book
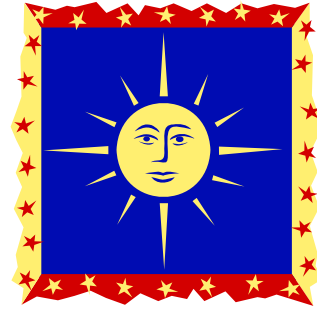
Not Just Another Manual…

Reviewers Rave about the *Meaningful Day Idea Book!*

"It doesn't weigh as much as the Standards!" Anonymous Reviewer

"*I didn't fall asleep when I read it!*" State Employee

What is the *Meaningful Day Idea Book*?

This *Idea Book* is more than a static manual. It is a growing collection of ideas and suggestions for supporting each person receiving DDSD services to lead the meaningful life (s)he desires. These ideas come to life through *Success Stories* that New Mexicans continue to contribute.

How is the *Idea Book* Built?

The *Idea Book* is simple on purpose. It is simple so that many people can easily understand it. The authors use simple words and short sentences. Each section is short. The letters are bigger so people can easily read them. Each chapter or "selection" name contains part of the "official" definition of meaningful day taken from the 2007 DD Waiver Standards. Each selection has "idea papers" related to that part of the definition.

Each idea paper includes *In a Nutshell* to briefly describe the paper's purpose; *Living It: a Story of Success* to tell a story about the paper's topic; *Bringing It To Life* to list proven and new ideas about the topic; *Check It Out* to give resources about the topic; and *Try It Out* to suggest ideas for hands-on exercises about the topic. In *Wanted: Your Success Story*, we tell you how to submit your story about that particular topic.

The idea papers are kept separate from each other, so readers can print and use only the papers most useful to them. The authors welcome ideas to make the *Meaningful Day Idea Book* even more simple and effective. Ideas, stories and resources will be added in order to provide the best and most useful information possible

What does the *Idea Book* Not Do?

The *Idea Book* does not offer a one- size-fits-all template to assure each person has a meaningful day. Each person's meaningful day is unique to the person's whole life. Effective supports are tailored to each person and his/her local community.

Who Can Use the *Idea Book*?

Everyone who is interested in creating, living and supporting meaningful days can use this book, for example:
- ✓ People receiving DDSD services,
- ✓ Families,
- ✓ Direct Support Staff,
- ✓ Community members who are part of a person's network,
- ✓ Community providers,
- ✓ Case managers,
- ✓ Therapists,
- ✓ DDSD staff, and
- ✓ Anyone else who is interested.

Who Wrote the *Idea Book*?

Tricia Farnham-Brownlee, Judith Stevens, Anne Mitchell, and Susan Shapero created the first edition of this book in July 2007.

Who Else Contributed to the *Idea Book*?

The authors would like to thank the following individuals and organizations for their contributions to the *Idea Book*:
- ❖ Our best mentors: people with diverse abilities (*currently called disabilities*);
- ❖ The chairs (Pam Lillibridge, Kay Lilley, Byron Bartley) and members of the User Friendly Effective Solutions Workgroup as well as the

Definition of a Meaningful Day from the 2007 DD Waiver Standards, Definitions

(Note: See *And Yet More* selection of the *Idea Book* for *It's Official: The Unabridged 3/1/06 Measurable Definition of a Meaningful Day* *)*

Meaningful Day means *individualized access* for individuals with developmental disabilities to support their participation in activities and functions of *community life* that are desired and chosen by the general population. The term "day" does not exclusively denote activities that happen between 9:00 a.m. to 5:00 p.m. on weekdays. This includes: purposeful and meaningful *work*; substantial and sustained opportunity for *optimal health, self empowerment* and personalized *relationships; skill development* and/or maintenance; and social, educational and community inclusion activities that are directly linked to the vision, goals and desired personal outcomes documented in the individual's Individual Service Plan. Successful Meaningful Day supports are measured by whether or not the individual achieves his/her desired outcomes as identified in the individual's Individual Service Plan, as documented in daily schedules and progress notes. Each Meaningful Day activity should help move the individual closer to a specified outcome identified in his/her *ISP.*

Help Us Make It Better – Please Give Us Your Feedback!

Supporting *individualized access*

IDEA 1: THE COMMUNITY SOLUTIONS COALITION: VISION, VALUES AND EFFORTS TO BUILD INCLUSIVE COMMUNITIES IN NEW MEXICO

Never doubt that a small group of citizens can change the world, indeed it is the only thing that ever has.

-Margaret Meade

IN A NUTSHELL:

We are a group of people with developmental disabilities, family members, professionals who serve them, advocates and state personnel who want full inclusion of people with developmental disabilities. We are from different New Mexican communities. We are the Community Solutions Coalition.

Our coalition started with a group coming together to envision the future New Mexicans with developmental disabilities and their allies desire.

Our vision is that individuals who use DDSD funded supports:

* Are the same as individuals who do not use these supports
* Have the same opportunities and choices as everyone else
* Learn through successes as well as mistakes
* Are in control of their own lives and are not managed by others
* Love and are loved
* Are heard with an open mind and honored for what they and their significant others have to say

Our Values:

  * Our vision (above) guides our actions.
  * Each individual has gifts and capabilities – we will learn what these are.
  * Individuals who use DDSD funded supports are full and equal citizens.
  * Each individual who uses DDSD funded supports, as well as people close to them, is listened to and really understood.
  * Employment is life-enriching.
  * Individuals of working age are employable.
  * Individuals who receive DDSD funded supports belong and make valued contributions to the community.
  * Individuals exercise meaningful choice.
  * Individuals who use DDSD funded supports are at the table for important decisions.
  * Communities are the first places we look to for supports and opportunities.
  * We always work to expand a person's life as he/she desires and to improve related supports.

  * Everyone's input is important to this process and we work hard to help each other to understand what we are doing and where we want to go. We have high expectations for ourselves, our supports and our communities.

The Community Solutions Summits

After creating this vision and values, we invited others to join us at two statewide meetings or "summits" to talk about them. At these meetings, we identified those topics most important to New Mexicans with developmental disabilities:

  * ensuring service systems support people enjoying a high quality of life;
  * developing inclusive services and communities;
  * supporting people with developmental disabilities to advocate for themselves;
  * taking a look at how guardianship affects people;
  * sharing good stories about people with developmental disabilities enjoying life.

Through the summits, Coalition participants created five Planning Alternative Tomorrows with Hope

(PATH) groups to figure out the steps it wanted to take around each topic.   These PATH groups have been working on solutions to these five issues since November 2006.

LIVING IT: A SUCCESS STORY
The Taos Awareness Project
For a story of one New Mexican's community's efforts to become more inclusive, take a look at the success story about the *Taos Awareness Project* on page 17 at the end of this idea paper!

on page 17

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS
The Community Solutions Coalition invites and welcomes new participants! Take a look at the information provided about each PATH workgroup and call toll free: **877-696-1472** if you're interested in joining any or all of them!

Information about Each PATH Workgroup

How the System Affects People with Developmental Disabilities PATH Workgroup

Many New Mexicans with developmental disabilities receive support services paid for by the State of New Mexico. The State establishes rules for these services and expectations about them. The *Systems* PATH workgroup wants to make sure that these rules and expectations make sense and result in New Mexicans with developmental disabilities having better quality lives.   The Systems PATH group has recently merged with the Advisory Council on Quality's Policy Subcommittee.

Promoting Full Integration PATH Workgroup
Many New Mexicans with developmental disabilities receive services that separate them from the larger community. They may work separately. They may eat lunch separately. They may not have the opportunity to build relationships with people in their communities who do not have disabilities.

The *Full Integration* PATH workgroup believes that *all* people deserve to be a valued part of their communities. This workgroup promotes community-based supports that enable people with developmental disabilities to be integrated and *included* in their

local communities. They are working to collect examples of how community-based supports are *better* for people and to find practical ways of encouraging families, service providers and communities to support facility-free services for New Mexicans with developmental disabilities.

Promoting the Self Advocacy of People with Developmental Disabilities **PATH Workgroup**

People deserve to be respected and in control of their lives. Yet, historically people with developmental disabilities have been controlled by others. Today, more and more people with developmental disabilities are claiming their right to make their own decisions. When people speak up for themselves, it's called *self advocacy*.

The *Self Advocacy* PATH workgroup supports New Mexicans with developmental disabilities to advocate for themselves. The group is working to make sure that New Mexicans with developmental disabilities have the advocacy skills and support:

1. To make decisions about their lives and services.
2. To serve in leadership positions and have their voices heard throughout the state.
3. To work with and be listened to by policy and rule-makers so they can advocate for what make sense for people with developmental disabilities.
4. To build a coordinated, statewide network of self advocates.

In order to meet their fourth goal, the *Self-Advocacy* PATH group has merged with the Southeastern Self-Advocacy Coalition and the New Mexico People First group to create one, coordinated, statewide network of self advocates.

Telling the Stories of Community and Personal Experience of People with Developmental Disabilities **PATH Workgroup**

Sometimes the best way to share information is through a good story. New Mexicans with developmental disabilities often have powerful stories about their lives that have never been told but can teach us all important things. The *Storytelling* PATH workgroup wants to support New Mexicans with developmental disabilities in sharing stories about their experiences, their jobs, their relationships and their services.

The workgroup believes telling stories is an effective way for New Mexicans to appreciate people with developmental disabilities as full and equal citizens.

Guardianship, Alternatives and the Impact on People with Developmental Disabilities
PATH Workgroup

Guardianship is the legal process that takes away a person's right to make his own decisions on certain things. Many New Mexicans with developmental disabilities have *guardians* who make decisions about where they live, how they spend their money and other fundamental life decisions.

The *Guardianship* PATH group supports people with disabilities in making their *own* decisions whenever possible. They hope to achieve these goals by supporting efforts that

1)   educate support teams, families, the service delivery system and the legal system about alternatives to guardianship;

2)   reexamine the guardianship status of New Mexicans with disabilities;

3)   support people with developmental disabilities in learning how to use their own voice in making decisions and advocating for themselves.

To learn more about the five PATH groups, go to the DDSD website at: http://www.health.state.nm.us/ddsd/PromisingPractes/PATH/TakingActionNM.htm

√ **CHECK IT OUT:**
GOOD RESOURCES

- http://www.health.state.nm.us/ddsd/PromisingPractes/PATH/PATHtoBetterLives.htm

- Asset Based Community Development: When People Care Enough to Act. Mike Green with Henry Moore and John O'Brien. Toronto: Inclusion Press, 2006.

- *Theory U: Leading from the Future as It Emerges.* C. Otto Scharmer   The Society for Organizational Learning www.solonline.org

- *Getting to Maybe*: *How the World Is Changed*. Frances Westley, Brenda Zimmerman and Michael Patton www.amazon.ca

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

- Join one of the PATH groups. Go to the DDSD website at: http://www.health.state.nm.us/ddsd/PromisingPractes/PATH/TakingActionNM.htm to learn how to join a PATH.

- Invite people to come together in your community to talk about issues that interest you. Make sure to invite a variety of people, get together in a comfortable space, have some food and ask compelling questions. Listen to the discussion and make action plans based on what people really want to do something about.

New Mexico Developmental Disabilities Supports Division - The Meaningful Day Idea Book - IDEA 1: The Community Solutions Coalition: Vision, Values And Efforts To Build Inclusive Communities In New Mexico

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LIVING IT: A SUCCESS STORY
GOING LOCAL TO PROMOTE FULL INCLUSION: THE TAOS AWARENESS PROJECT

As a result of the Summit's discussion around *inclusion* and the principles of *asset based community development*, a group of Taos citizens have begun meeting to think creatively about building a fully inclusive community that recognizes the individual gifts *each* citizen offers.

This group began when a Summit participant had coffee with a fellow Taos citizen who is equally committed to people with developmental disabilities. Together, they invited a small group of community members to come together and talk about their town and what *inclusion* means. These citizens brought various experiences and perspectives but share a love for their Taos community and know a lot of people *in* the community. The group met in a church rectory one evening and talked about what a fully inclusive Taos community would look like. The discussion was not about how to improve disability services but rather how to build a more inclusive community.

After meeting regularly for the last two months, the group has named itself the Taos Awareness Project and has identified those pieces of community life they feel are the most important for promoting full inclusion. These priorities are:
- expanding the physical accessibility of local buildings;
- working with local law enforcement and other "first responders" to build capacity when supporting a citizen who has developmental disabilities;
- creating more inclusive social opportunities for citizens with developmental disabilities, particularly children;
- working with local school systems to promote inclusive education.

As word gets out about the Project's efforts, others in the Taos community have asked or have been invited to join. The Project sees one if its primary functions as connecting citizens interested in a particular element of inclusion with other citizens who can help. While the Project is now shifting from its conceptual stage to taking action on its interests, one member observed, "There have been changes already just because of the conversations."

The *Taos Awareness Project* is not a formal service or program. It has no paid staff or formal funding. The Project is simply a group of citizens that wants its beloved community to be fully inclusive and to embrace the gifts each community member has to offer.

IDEA 2:   SMOOTHING THE WAY: COMMUNICATION AND PHYSICAL SUPPORTS
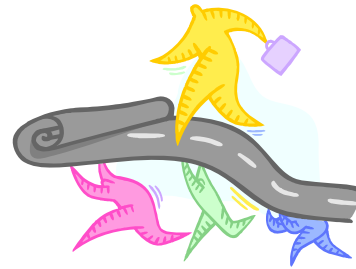
IN A NUTSHELL:

Many of us use some sort of device to assist us in doing the things we want to do in life. Some of us wear glasses to see better. Some of us wear hearing aids to hear better.   Some of us use a computer to talk. Some of us use a wheelchair to get around. It's hard to think about what our lives would be like if we didn't have the devices we needed. Would we be able to participate as well in the activities we love? Would we be able to do our work? Would we be confident in our abilities? Would we be able to make friends as easily?

This idea paper has thoughts and ideas about supporting people who use communication and other devices to have the support and tools they need to live their lives.

LIVING IT: A SUCCESS STORY
Cari's Story
"My name is Cari Carlston. I am a Navajo Indian. I have a medical diagnosis of cerebral palsy. I use my Liberator when I make cell phone calls. Writing poetry is a good release for me. I write it to express my feelings and get them out. When I write poetry, I feel better."
-Cari Lynn Carlston
from *Poems from My Heart*.

Cari says that because of her Liberator, she is able to do the things that are truly meaningful to her: to write poetry, to teach, to be an advocate and a friend.

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS

Create Space to Talk for Ourselves

- If you use a communication device, don't be shy about letting your direct support staff or others who assist you know that you want to talk for yourself when you choose. This includes when ordering a meal, talking on the phone, in a meeting, or checking out at the grocery store.

- If you assist a person who uses communication supports, encourage direct communication between the person and others she meets. If a community member asks *you* a question about the person, instead of answering, simply look at the person and wait for her to answer the question herself.

Sometimes the Only Communication Device Needed is Time

Sometimes people can communicate more than others assume if simply given the time and space to do so. Consider this, some people need up to *twenty*

seconds to process a question before they respond. When we talk with each other, are we giving people the time they need to participate in the conversation?

Reducing the Specialist Bubble

Can the person's communication device allow her to have conversations with another person *without* an interpreter or can others learn the communication technique easily?

Sometimes a person uses a communication technique that requires another person to interpret what he is communicating. For example, Gabe does not speak or use his hands. Using his eyegaze, he communicates by spelling out words on a board containing the alphabet and some short words. He uses his eyegaze to indicate which letter the board he is choosing. A second person must be able to understand Gabe's eyegaze and point accurately to the letter Gabe is choosing and then tell others what Gabe is communicating. It takes some training and a lot of practice to be Gabe's interpreter. While this system is effective, it limits Gabe's ability to have a conversation with

someone who isn't trained on his communication sheet.

If you support someone who uses a communication device or technique that requires an "interpreter," look for ways to make it simple for others to learn the communication style.

Simple is Sometimes Best
While there are lots of high tech gadgets out there, sometimes the basic ones are the most effective. For ideas of simple, inexpensive ways to meet a person's assistive technology needs, contact the DDSD Clinical Services Bureau. The Bureau's contact information is contained in *Check it Out* below.

Did You Know There's a way to Try out Some Devices Before Buying Them?
For information about New Mexico's *Augmentative and Alternative Communication Loan Bank* look in *Check it Out*.

√ CHECK IT OUT:
GOOD RESOURCES

- **For Information on *Assistive Technology* Resources in New Mexico,** contact the Office of the Clinical Services Bureau (CSB). The CSB is located at 5301 Central Avenue NE, Suite 1700, Albuquerque, NM 87108-1514. Call (505) 841-2948 or toll free 1-800-283-8415 or fax at (505) 841-2987 or email AT.Coord@state.nm.us.

- **For information about device loans,** contact the Augmentative and Alternative Communication (AAC) Loan Bank (800-283-8415 or 505-841-5254) located on 1000 Main Street NW, Los Lunas, NM 87031 or email us AT.Coord@state.nm.us.

- **For information about small grants for adaptive technology,** contact the Office of the Clinical Services Bureau (CSB) is located at 5301 Central Avenue NE, Suite 203, Albuquerque, NM 87108-1514. Call (505) 841-2948 or toll free 1-800-283-8415 or fax us at (505) 841-2987 or email AT.Coord@state.nm.us.

- **For Tips on Supporting a Person Who Uses a Communication Device to Speak for Himself,** consider reading, "On Being a Communication Ally" by Mayer Shevin. Available at http://suedweb.syr.edu/thefci/7-4she.htm

- For other exercises about supporting people to communicate for themselves, take a look at Mayer Shevin's paper, *On Being a Communication Ally* available at http://suedweb.syr.edu/thefci/7-4she.htm

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

- Pretend you are asking a question to a team. Now count to 20. Is this typically the amount of space people give each other to process a question before jumping in to "fill the space?"

- If someone you know uses a communication system, ask her to explain how it works. If it isn't clear to you, talk to the person and those who support her about how to make the instructions simpler so that other can talk to her more easily. Help create this simpler method and ask the person to try it out.

Supporting *individualized access*

IDEA 3: FINDING GOOD FITS BETWEEN DIRECT SUPPORT STAFF AND THE PERSON SERVED

Today, Direct Support Professionals (DSPs) partner with people who utilize community human services to live self-directed lives with dignity and pride. DSPs support people receiving services to realize their dreams and enjoy the daily liberties and human rights that others take for granted. -National Alliance for Direct Support Professionals

IN A NUTSHELL:

The support a person receives can have a fundamental impact on his quality of life. As a result, we are always looking for new ways to recruit and hire the best direct support employees we can. Sometimes a direct support staff member enhances a life that is already full. However, for many New Mexicans with disabilities, staff serve as the person's primary link to the rest of the world.

The process of cultivating quality direct support staff cannot be reduced to a formula. And as we all know, hiring great staff requires organizations to both make broad, strategic decisions and to take simple, everyday actions toward building a workforce and organizational culture that encourages person-centered support.

LIVING IT: A SUCCESS STORY

Harry Now Hires His Own Staff!
Tobosa has begun supporting the people it serves to interview and hire their own staff members. One person, Harry, requested that he develop the interview questions and conduct the interview since the new staff person would be working directly with him. Harry wanted to assure that his new staff person would share some of his interests and would be able to provide the support Harry requires. Tobosa agreed and worked with Harry to assure he understood the legal parameters involved. Harry successfully hired a new staff member and is now working on developing assistance for other people to learn to hire their own staff members!

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS

The Impact of Organizational Values on Direct Support Staff

- The qualities of direct support staff employees often mirror the culture and workplace in which they work. If the organization emphasizes protocols and formality, the direct support staff will likely prioritize these things as well.

- Consider the words we in human services often use to describe a person who uses services: client, consumer, patient. These words suggest *taking* or *needing* something from another person. These words don't reflect the contribution a person makes to others in her community. While these words apply to *all* of us from time to time (we may be our barber's client), these identifiers are rarely our primary identity. Yet, these words are often used to describe the entire identity of a person with a developmental disability. When described this way, a person is seen as more likely to see himself as part of the organization instead of part of his community.

For some suggestions on changing the language an organization uses to describe people with developmental disabilities, take a look at *Language Matters* on page 131 in *And Yet More*.

- An organization's values must be lived, discussed and reflected in the organization's budget for the framed "Vision Statement" on the wall to really matter.

Ideas for Direct Support Staff Job Descriptions

- Think about the qualities that direct support staff need in order to cultivate relationships for people: creative, reliable, positive, comfortable meeting people, respectful of the person served. After thinking about the qualities you hope to attract in direct support staff, take a look at your organization's job description for direct support staff. Does it match?

- Take a look at the job title, does it sound technical? If the title is something like *residential tech* consider a less formal, more people-oriented description like *John's companion.*

- If you don't already, consider making individual job descriptions around each person served. This provides potential direct support staff with a more accurate sense of what the position will include and what the person's interests and desired outcomes are.

Examine the Direct Support Staff Skill Requirements: Do They Prioritize Community Building as Much as Personal Care?

For people with significant support needs, it's critical to have staff who are competent at providing personal care. However, sometimes job requirements focus so much on personal care that they exclude creative, community-oriented applicants who have never provided personal care to anyone before. While some staff who are highly experienced in doing personal care are also great community builders, some of the best community builders have never done "this work" before. They may be artists, farmers, waiters, college students, teachers, lifeguards, horticulturalists, receptionists, lawyers.

Personal care skills can be learned. But it's harder to teach creativity and community-building. We need to make sure that as we increase our emphasis on supporting people to build relationships in their communities, our job requirements encourage people from all walks of life to become a committed staff person to a person using services.

Recruiting Ideas:
- Many people think word-of-mouth is the most effective way to recruit. For some suggestions on potentially new ways of recruiting, go to *Try it Out* on page 25.

- For some potentially new twists on the standard newspaper recruitment ideas, go to *Try it Out* on page 25.

√ CHECK IT OUT:
GOOD RESOURCES

- National Alliance for Direct Support Professionals at www.nadsp.org

- National Alliance for Direct Support Professional's *Code of Ethics* at http://www.nadsp.org/library/code.asp

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

Word-of-Mouth Recruiting Ideas:

- Invite people you serve, their families, friends, guardians, case-managers to identify potential employees.

- Network and present with people with disabilities at groups within community: civic clubs, churches, sororities, fraternities, softball games, job fairs, etc.

- Recruit people at places the person likes to go: the coffee shop, the YMCA, the library.

Newspaper and Web-Based Recruitment Ideas:

- With the person's permission, consider writing person-specific ads: "Cool 26 year old guy with autism seeks companion to support him at his job, take him to concerts and make new friends. Must be energetic, creative, and dependable. Knowledge of autism helpful but not required."

- In addition to the mainstream local newspaper, consider advertising in culture-specific, university and alternative newspapers.

- Consider posting on Craig's List (www.craigslist.org) and other web-based classifieds.

IDEA 4: STAFF MANAGEMENT STRATEGIES TO SUPPORT INDIVIDUAL OUTCOMES

IN A NUTSHELL:

Anyone who has worked in an organization understands that middle managers - those managers between the executive director and the "frontline" staff - are interpreters. They help interpret the organizational vision to those they manage and they interpret the perspective of "frontline" staff to the organizational leaders. While some organizations are shifting away from traditional "hierarchical" management models, in most organizations the middle manager remains a critical position in ensuring that both the direct support staff and organizational practices facilitate meaningful days for the people they serve to support individual outcomes. This section outlines some of the skills effective middle managers of community-based support organizations possess and some of the strategies they have used to facilitate meaningful, community-based, outcomes for the people they serve.

LIVING IT: A SUCCESS STORY
Middle Managers Customize Staffing Schedules to Meet Need of People!

The manager at one day service in the Metro area is encouraging staffing flexibility to meet the needs of people. When Stan wanted to go to see *Mama Mia* on a Friday night, one of his staff offered to go with him, though doing so was outside her typical schedule. Her manager then allowed her to shift her schedule the following week to accommodate the change.

At an organization in the Northwest region, staffing schedules are customized to each person and even adjusted *again* in the summer to accommodate people's desire to be out later.

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS

Some Qualities of An Effective Middle Manager

- She commits to always deepening her understanding of person-centered values.
- He knows the people served and their families well and in various capacities - both professionally and personally.
- She sees people's gifts and possibilities before their "deficits."
- She matches people and staff based on interests and personalities.
- He finds ways to identify and support success – and "catches people doing it right".
- She knows the staff she manages well.
- He is comfortable in his community, has a good reputation and knows people throughout the community.
- He enjoys understanding people: both appreciating the positive qualities people have and analyzing the challenges people often present.
- She can get things done through her positive outlook, creativity and by inspiring others to do their best work.
- He has a brain for logistics and the ability to synchronize and

manage multiple and potentially conflicting staff, transportation, meeting and activity schedules.
- She is persistent in getting what she needs from other departments in the organization to do her job well.
- He has access to and influence on the part of the organizational budget related to his scope of work and influence.
- She has access to and advises the organizational leadership.

A Proposed Framework for Managing Person-Centered Supports:

- **Begin by knowing the people you support really, really well, including how each person chooses to spend her time.** This information may be captured in the person's meaningful day definition and ISP but may also include subtle things that aren't formally documented anywhere. A person's family is often a wonderful source of history and information.

- Based on that knowledge, **work to find a direct support staff member who is a "good fit" with the person she serves.**

- **Support the person to interview (or help interview) applicants who potentially will serve her.** Create ways of folding the person's feedback into your own evaluation of the staff person's performance. Work in collaboration with the person to make termination decisions.

- **Match a person's interests with the appropriate staff person based on interests, personality, communication style, cultural and scheduling preferences.** Consider using scrapbooks and home movies to support the staff member in getting to know the person he now serves. If Sharon loves horses, is there anyone on staff who knows local ranchers? If Brad loves to talk about the same subjects over and over, a direct support staff who is a patient and a good listener may be a great fit.

- **Develop a support schedule that accommodates the person's needs and interests.** If Brent really enjoys playing pool at the local bar on Tuesday and Thursday nights, his direct support

staffing schedule needs to accommodate this.

- **Link staff's performance to the outcomes the person supported wants to have in life.** At the end of the day, staff are paid to support a person to live the life he designs for himself. Tying a direct support staff's *own* performance reinforces to this primary responsibility and creates clear opportunities to celebrate both the person's accomplishments and the staff's role in making them happen.

Cultivating A Culture of Conversation Among Staff

Work to create a workplace where people feel comfortable sharing both good stuff and hard stuff. Creating this culture will allow good ideas about supporting people to have meaningful days to be shared and challenges to be openly discussed and resolved. Some practical ways middle managers can cultivate this culture:
- **Meet regularly. Meet informally. Meet individually. Meet as a group.** A sense of staff isolation is one of the most challenging by-products of community-based services.

o While most middle managers have regular staff meetings (sometimes weekly, sometimes monthly), consider "touching base" each day, either through short group briefings or individual phone calls to communicate logistics and hear how things are going.

o Consider regularly going out to lunch, to a movie, to a ballgame with a person who uses services and his direct support staff member. Doing so creates relaxed ways to get to know people, model effective support, learn what's going well and learn what isn't.

- **Shamelessly Find and Celebrate the Good Stuff**
  o Celebrate what you value. As people are supported to live the life they choose, celebrate the significance of this. It doesn't have to be a big accomplishment: even just celebrating that Jo now begins every day with a trip to the coffee house is meaningful to Jo and celebration-worthy.

o Consider randomly asking staff and the people they serve at regular intervals questions like:
  ▪ "Tell me a good story;"
  ▪ "What's been the highlight of your week?"
  ▪ "What are you doing when you enjoy your work the most?"
  ▪ Capture and share what you hear.

- **"Catch people doing it right."**
  o If you see a direct support employee doing good stuff, thank them.
  o Invite other direct support staff to brag on their coworkers during group conversations and meetings.
  o Make it a point to pass on compliments you hear about a person.
  o Consider submitting a person's success story and the staff's contribution to it for an award to DDSD!

- **Push Out the Bad Stuff**
  o Do not, under any circumstances, engage in organizational gossip.
  o Do not, under any circumstances, gripe about

other managers or organizational leaders.

o Use mistakes people make (including your own) as an opportunity for staff and organizational learning.

Model the Joy of "the Work"

Supporting people with disabilities to lead full lives should be profoundly positive work. That doesn't mean it's easy or always fun (do any of us enjoy late night trips to the emergency room?). But this work *matters* and is about *building* positive things. Middle managers can set a wonderfully positive example for others by having fun and appreciating the cool things going on in people's lives. By highlighting the wonderful dimensions of supporting people, we potentially inspire staff to think in a positive and creative ways. For a few ideas for doing this, go to *Try it Out* .

Promoting Effective Problem Solving: Never Be Totally Hands Off.

When people come to you with challenges, be supportive. Supporting people with significant needs in a community-based setting is not always easy. "Just handle it" is not a very helpful to tell an employee; it shuts down essential communication between the manager and the direct support staff. Consider your role as facilitator, by creating space for direct support staff to develop their own solutions.

Work to be Solution-Focused

While creating space for venting is initially helpful, after people "get it out of their system," ask questions that direct them to finding solutions. Like "So, what do you see as the next step?" "How could we better ensure this doesn't happen again?" "How can we ensure this problem doesn't distract us from our work?"

Think People, Not Programs: Building Supports Around a Person and Across Service Programs

It seems to be a tension that's been present since the development of human services: "residential program staff" versus "day program staff." The tension is understandable: two managers, often two completely different organizations, two different sets of responsibilities and

usually no real sense of team between the two groups of staff.   We create organizations based on this model and then continuously struggle with the resulting tension.

What if we could get rid of that tension? The classic relationship-building ideas apply here:

o Get to know people.
o Thank and acknowledge people when they do right by the person, regardless of the organization.
o Bond together, both formally and informally.
o Start from a positive, optimistic perspective.

See some probing questions for people's teams to ask about any tension between different groups of staff in *Try it Out* .

Know the Organization's Money…or at Least How the Budget Impacts the Services You Manage

Providing person-centered support often requires a fundamental restructuring of services and budget priorities. In order to assist their organization in restructuring services, managers need to have access to the budget.

Having authority over a portion of the budget also streamlines procurement practices, provides managers with a stronger sense of expenses and provides interdependence so that responsibilities are covered by more than one person.

Reinforcing and Modeling "Community" for Direct Support Staff

- When looking for community-based activities that reflect a person's interests and ISP outcomes, begin the conversation by asking the person and her staff, **"WHO DO WE KNOW?"** Developing activities and community-based opportunities for people through the network of people we already have better ensures success.

- **Some direct support staff are fearless and natural connectors.** For someone like this, introducing a person she serves into a community activity is fun and easy. However, for some direct support staff, this process is more difficult. Consider spending time with this staff member and the person she serves with the sole purpose of modeling how to interact with

the public as the person's ambassador.

- **Model community-building skills with "the hard people."** Everyone knows who they are: the people an organization serves that for whatever reason, staff often struggle to support. Ask the staff who to identify a person for whom they struggle to build community. Focus your attention and modeling on that person. Assume some of the personal responsibility for cultivating a community network for this person. Doing so both expands the person's community and provides managers with a "real life" sense of the direct support staff's responsibilities and the community's circumstances.

- **Ask "favors" of staff that encourage them to think about their communities.** For example asking a staff person, "We know that Susan wants to learn to read. Do we know of any local efforts that offer literacy classes? Could you find out for us?"

Lead Staff to Apply What They've Learned and What They Know

- Middle managers can be the most effective ones in making sure that trainings, conferences and other continuing education opportunities for direct support staff are applied.

- Debrief together after a training to discuss what pieces could be used to improve the organization's service.

- Try to implement new strategies within two weeks of learning them. They're more likely to stick.

Language Matters

Direct support will take cues from the language you use. If you don't already, consider using language that supports the idea that people who use services are individuals and equal to the rest of the population. Words and phrases like:
- "clients,"
- "functions at a 3 year old level"
- "consumers"
- referring to other people with disabilities as an individual's "peers"

all reinforce the idea that people with disabilities are separate (and not equal to) "the rest of us."

This kind of thinking also makes it harder to use our intuition about how to respect a person and facilitate community for them.

Make Documentation as Relevant and Rewarding as Possible

When an organization receives public funding (like Medicaid Waivers) to provide services, documentation is almost always required. Middle managers can influence direct support employees' attitudes about "the paperwork." The following are some ideas for keeping documentation as meaningful as possible.

- **Value over Compliance:** Instead of discussing documentation in terms of "something we have to do," invite staff to identify why documentation can be valuable to the person's life and to the organization. Some reasons may include:
  - o It captures history: Sometimes, when we've known the person for a long time and see him every day, it's hard to appreciate how many good things have happened in his life. Invite staff to see daily documentation as an opportunity to tell a person's story. Every so often, take time as a group (and include the person) to re-read the daily notes and reflect on the person's year.
  - o Ask direct support staff to participate in the development of the documentation. Doing so will better ensure they have "buy in" into the process.

- **Involve the Person:** Documentation becomes a much richer and more respectful process when the person who the documentation is *about* is actually part of the process.

  Amazingly, people who use the services rarely look at the documentation written about them. Sometimes they're not interested, but oftentimes they don't think they're allowed to look at their "book." People have a right to look at information written about them and staff have a responsibility to include a person in the documentation process if the person wishes to be involved. For some suggestions about how to do this, see *Try it Out* on page 37.

- **Know What's Required and What Isn't:**
  Oftentimes, staff don't know *why* a particular part of the paperwork is required and as a result, don't see it as important. As a middle manager, it's important for you to understand the requirements and why documentation has to be structured in a certain way. If you're not sure, ask others in the organization and within DDSD. Oftentimes, organizations use forms to track unnecessary information. When this happens, it creates additional work for everyone. Make sure that the forms used in your organization are up to date.

- **Supporting Good Staff Who Have Trouble Writing Good Notes**
  Sometimes a great direct support employee has a hard time writing "good" notes. A few suggestions for supporting this employee with the documentation:
  o Model what you want. Invite another employee who writes good notes to lead a training or tutor other staff who may need help.

o Take a look on page 134 at *Documenting Community Building: Tips for Staff* contained in the *And Yet More* section of this Idea Book to give staff examples of how to put more useful information into the daily notes they write.

"Seek first to understand..."
Managers are often energetic, talkative and full of great ideas to share. Sometimes it's hard for many of us to do the one thing that will give us the most valuable insight into the quality of supports we provide: listen.

While listening is always important, it becomes even *more* important when there is a power difference. Direct support staff and the people they support are often intimidated by managers. For many, it's safer to simply say nothing and allow the manager to do all of the talking.

When managers stop, sit down, take the time to ask open ended questions to others and remain quiet until people answer (even if it takes some time) we have increased access to the best source of information for improving the supports we provide.

Embrace Capacity Thinking

- **Model the practice of "seeing people in their best light."** Celebrate the accomplishments of people you support. Reframe "negative" traits. For example, if staff complain that Jake laughs too loudly in the library, help brainstorm on roles and places where his laughter would be accepted or even embraced: workplaces with loud machinery, or places where he can be outside, farms, football games, fairs, etc.

- **Play to staff's strengths.** Celebrate that each of us has gifts and a contribution to make. Invite people to share their gifts: if you have a direct support staff who is well-connected in her community, invite her to mentor others who may not know the community as well. If a staff member is an artist, ask him to advise on how to best promote the artwork of someone served. If someone is really good with documentation, ask her if she'd be willing to mentor others.

The Value of Being *Hands On*

- **Know every person you are "responsible" for really, really well.** Spend time with

them outside typical services: over meals, through going to the movies, spending time with their families, etc.

- **Spend lots of "community-based" time with new staff as they are supporting a person.** Do not come with an agenda or an eye for "monitoring" but rather as a team member supporting a person to learn her job.

Work with Others in the Organization to Ensure the Various Components of the Organization Promote a Person-Centered Culture and Values

- Do job descriptions and hiring practices support person-centered approaches?
- Do staff training practices allow direct support staff to get to know a person, and his interests and support needs *before* services begin?
- Sometimes leaders need to be inspired too: share positive stories and outcomes with your leadership, even if you haven't been invited to do so.
- Advocate for what is needed for direct support staff to do their work well. Come with solutions. Follow up.

Tips for Managing Staff "Out in the Community"

Whenever support services become community-based, management and oversight approaches must be more "virtual." Mutual trust and open communication between the middle manager and the direct support staff become increasingly important when there is not an immediate way to provide "eyes on" supervision.   Having a management relationship that encourages these qualities is critical when supervising community-based services. Below, are some of the ways managers of community-based services can manage effectively even when you don't see anyone!

- **Daily briefings**: Touch base with a person's staff regularly (ideally, daily) just to check in, see how things are going, what the plans for the day are, and make any last-minute adjustments.

- **All weekly schedules mapped out on dry erase board**: Consider mapping out everyone's schedule on one large board. This ensures a manager can know at a glance where everyone is.

- **Use of cell phones:** Cell phones may be the best bit of technology to influence community-based services! Through using cell phones, managers can have immediate access to staff regardless where a staff member is. Some organizations provide additional oversight by requiring staff to call if the person's schedule changes unexpectedly.

- **Spot visits/checks**: Some middle managers have found it useful to do unannounced visits to the person and her staff according to the person's schedule. This provides managers an opportunity to observe staff's interaction with the person during an activity and also ensures that a staff is following the person's desired schedules.

- **Listening to others in the community**: Communities can be very effective at keeping people safe.   Many towns in New

Mexico are small with tight community networks. Occasionally, community-based managers will learn of a problem with staffing through another community member. Sometimes, the observation reveals a genuine problem that the managers then work to address. And sometimes, the "problem" is simply a skewed or uninformed perception. When this is the case, the manager has an opportunity to clarify the concern and potentially build new bridges with members of the community.

√ CHECK IT OUT:
GOOD RESOURCES

- Make a Difference: A Guidebook for Person-Centered Direct Support by John O'Brien and Beth Mount, Inclusion Press at www.inclusion.com

- The Minnesota Frontline Supervisor Competencies and Performance Indicators: A Tool for Agencies Providing Community Services, Available for downloading through the National Association of Direct Support Professionals at

http://www.nadsp.org/training/competencies.asp

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

A Few Ideas for Celebrating the Joy of the Work:

- **Occasionally invite staff to share how their life has been enhanced by supporting people with disabilities.** What "life lessons" have the people they serve taught them? Consider capturing these lessons on big paper in colorful markers that can be posted in the organization's office.

- **Celebrate anniversaries between a person and her direct support staff.** Sometimes people have had wonderful and committed working relationships for years and it's not celebrated.

- **We should take our work seriously but not ourselves.** Laugh. Play music. Create opportunities to be silly from time to time. Inject humor into traditionally boring trainings and meetings.

A Few Probing Questions About Tension Among Staff

- How would our perspective change if people hired their own staff, lived in their own homes, and decided their own schedules?

- How would the staffing dynamics change if a person's staff and services were coordinated by one manager?

- What would change if we built supports around the person's scheduling preferences instead of an organization's or home's operating hours?

- What would change if organizations saw themselves as resources to each other instead of competition, or objects of suspicion or blame?

Ways to Have a Person Participate in his Own Documentation Process

- Invite the person to sit with you as you are writing the notes and ask him questions about how you all spent the day like "So, Ryan, what did we do today?" "What was the best part of the day?" "Who did we meet?" Even if the person doesn't respond and you're responding for him, the person may be listening and enjoying being included in the process.

- Invite the person to sign his daily note.

- Read your notes back to the person. Ask him if you have forgotten anything or if there is anything else he wants to add.

IDEA 5: GETTING AROUND: TRANSPORTATION IDEAS AND OPTIONS

IN A NUTSHELL:

To become a contributing member of a community, a person must first be able to get around *in* her community. We all know that finding reliable, affordable, flexible and *accessible* transportation remains a large challenge for many New Mexicans both with and *without* disabilities.

We hope this paper will serve as a starting point for thinking in potentially new ways about supporting people with disabilities to get around in their communities.

LIVING IT: A SUCCESS STORY
Using Public Transit

When an organization in rural New Mexico decided to close its day centers, the staff looked to community resources to help solve the organization's transportation problem. While the local public transit in the area was limited, staff and the people they support are now using it to make some specific, pre-scheduled trips.

Using public transit increases people's comfort level and presence in the community, reduces people's dependence on the organization and provides additional flexibility as people pursue activities that are meaningful to them.

Ellen was one of the first people in the organization to use the public transit during the day. Ellen has severe cognitive disabilities and is often uncomfortable with transitions and trying new things. However, with staff support and preparation, Ellen comfortably took a bus to the local bookstore that she visits weekly!

BRINGING IT TO LIFE: THOUGHTS AND IDEAS

Using and Expanding Your Community's Transportation Resources

As we well know, reliable transportation is often a challenge for people with and *without* disabilities. By working with other community entities to improve transportation, people and organizations get access to more ideas, solutions and funding sources.

- **Consider carpooling.** Did you know that there are organized carpooling and rideshare programs in bigger New Mexican cities? For more information go to the New Mexico Department of Transportation's Transit and Rail Bureau website for car and vanpooling opportunities: http://nmshtd.state.nm.us/main.asp?secid=11201

- **Consider carsharing.** In many cities, a person can use a car for a few hours without owning it, by becoming part of a "carsharing" network. Consider working with other organizations in the area to start a "carshare" system in your community. For more information about *carsharing,* see the link in *Check it Out*

- **Consider taking the bus.** Do you know about the public transit options in your community? For a link to public transit options in your area, go to the American Public Transit Association's New Mexico page at: http://www.apta.com/links/state_local/nm.cfm#A6

- **Get to know your local government.** Do you have a working relationship with your local government? Can you work to improve the transportation options for people with disabilities in the area? For contact information on your area's city council, check out: the State of New Mexico's city and county directory at: http://www.newmexico.gov/government.php#city

Look into FTA § 5310 Grants for Purchasing Vehicles

Did you know the New Mexico Department of Transportation will help buy vehicles to assist people with disabilities to get around in their communities? For additional information, contact the Transit and Rail Bureau in the New Mexico Department of Transportation at 505-827-0410 and check out organizations that provide these services in your area at http://nmshtd.state.nm.us/main.asp?secid=11218

Developing Individualized, Person-Centered Transportation Solutions

- **Invite the person's family and friends to help with transportation.** Are we using the person's own networks to figure out transportation? For example, if Natalie goes to church every Sunday, have we asked her church if there is a way another member of the church could pick up Natalie (and her direct support staff) before the service?

- **Start small.** Sometimes tackling transportation issues for a large group can be overwhelming. Can you look to address the challenge one person at a time? For person-specific brainstorming, consider contacting the DDSD regional coordinator in your area. The coordinator's role is to facilitate quality outcomes in people's lives by providing technical support to organizations. For a list of the DDSD regions, see www.nmhealth.org/ddsd.

Designing Transportation Options within an Organization

- **Establish a clear organizational purpose about transportation.** Sometimes conflicts result when people have differing expectations around transportation. Decide as an organization if your role is to support people to build their own capacity to use the community's transportation resources or to provide transportation to them. Make this position clear to people, families

and others on a person's team before services begin.

- **Have a central location.** If your organization has a drop off site or facility, is it centrally located in the town? Can people walk to at least some activities?

Some Thoughts about Staff Using their Own Cars

- **Do provider agency staff know how to use any of the public transportation options?** Sometimes staff are uncomfortable using public transportation. See *Check it Out* for a curriculum to train staff about using public transportation options.

- **Give staff the option.** Oftentimes, we assume staff don't want to use their own cars. However, a staff person may prefer to use her own car when supporting a person.

- **Worried about the quality of staff cars?** Consider partnering with a local mechanic or auto repair shop to conduct regular spot checks on

staff's vehicles. If your organization is a not-for-profit, the mechanic may donate the service.

- **Increase mileage reimbursement.** Consider increasing your mileage reimbursement in exchange for the expectation of staff assuming appropriate insurance coverage.

- **Consider a mileage cap.** If you don't already, consider putting a mileage cap on staff mileage reimbursement. This will better ensure budget predictability and help prevent "van therapy."

- **Be quick with reimbursements.** Ensure your organization's mileage reimbursement is timely. Sluggish turnaround times often make staff distrustful of the organization and more reluctant to use their own vehicles.

√ CHECK IT OUT: GOOD RESOURCES

- New Mexico Department of Transportation, Transit and Rail Bureau http://nmshtd.state.nm.us/main.asp?secid=11201

- For information about *carsharing*, check out http://www.carsharing.net/

- "Curriculum to Introduce Travel Training to Staff Who Work with People with Disabilities" available at: http://www.arcofkingcounty.org/guide/downloads/traveltrain.doc

- For your local regional coordinator's contact information, see the *And Yet More* part of the *Idea Book*.

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

- If a person works, goes to church, plays on a softball team or participates in another organized activity on a regular basis, talk to the leader of the group (the boss, the minister, the coach) about figuring out how someone in the group could assist the person in getting to and from the activity.

- If you work for an organization, consider setting up a training session for direct support staff on using the local public transit options. Make sure this training provides a staff person "hands on experience" in finding a route, identifying schedules and pick up locations, and learning how to get to a specific site (like a person's workplace) related to the person she serves.

IDEA 1: CONNECTING TO THE *COMMUNITY*

IN A NUTSHELL:

Some people are born *connectors*: people who know lots of people and enjoy introducing people to other people.   As we support people with disabilities to become a part of their communities, we need to identify and enroll people who are already connected to our community, including direct support staff and people with disabilities themselves. We begin this process by understanding <u>what</u> a person receiving supports is passionate about. Then we <u>i</u>nvite connectors to introduce the person to others who share that passion.

Many community members choose to create or join organizations, associations and groups within their community: churches, softball leagues, civic groups and lots of others.

When supporting a person to build community, we can all help by brainstorming or *mapping* what organizations, associations and resources may interest the person and are available to *all* community members. We can then introduce a person to members of these groups and support the person to become an active, contributing member of the group.

Long-term relationships don't happen automatically. People must first be *connected* to other people for them to happen at all.

LIVING IT: A SUCCESS STORY
John's Story

Because he is so friendly and loves to meet new people, Jon has a lot of friends. Through his connections and relationships, Jon has accomplished a lot: he is a political advocate, a paid consultant and the President of the Arc of New Mexico. In addition to all of the things Jon has accomplished, Jon is passionate about the idea of one day living in his own home.

Jon called on his *Designing Dreams* circle of friends to help him think through how to best accomplish his dream of living on his own. With the help of his circle, Jon sampled different living situations by staying with different friends in different parts of the state. Through these weekend visits, Jon *further* expanded his network by meeting friends of his friends. His friends are now supporting Jon to apply for housing resources and to figure out what kind of supports he'll need when living on his own.

Thanks to Jon's connections and relationships with others, Jon's dream of living in his own home will soon be a reality!

BRINGING IT TO LIFE: THOUGHTS AND IDEAS

The Path from Isolation to Inclusion is Gifts
-John McKnight

Discovering Someone's Passion

- Mike Green describes a passion as something that when a person describes it or does it, time stops. The person is fascinated by the topic and becomes excited when talking about it. An example of a passion a person might have is collecting *Dallas Cowboys* football team memorabilia.

- Usually, if one person has a passion, others share it too.

- *Try it Out* on page 48, includes ideas for finding out what a person's passions are.

Finding Organizations, Associations and Groups in Your Community

- People who receive services can make a contribution to their communities by joining formal organizations. For example, someone who likes the outdoors might join the *Sierra Club*.

- Formal organizations are often listed in places like the telephone book *Yellow Pages* or *Chamber of Commerce* listings.

- There are also less formal associations and relationships that people build around a shared interest or passion. For example, a group of people may start a book club, a supper club, or regularly listen to music together.

  John McKnight describes associations as having "varied interests, many friendship opportunities" and being "flexible and welcoming." He says that an average person belongs to five associations.

- Usually, we can find community associations by asking people who really know the community what is happening.

- You can also go to the internet on your computer, enter an interest and your community in the *search* box and see what comes up.

- One effective strategy is to make a list, identify on a map, or draw a neighborhood map of organizations and associations in your community with a plan to update it as the community grows and changes.

Using a *Connector* to Introduce a Person to Other Community Members.

- John McKnight says that certain people are connectors to community and those great connectors are born, not made. He describes connectors as people who:
  o see all people as having gifts;
  o know lots of people and community associations;
  o are trusted in the community because of their contributions to the community;
  o believe that community is welcoming.

- Mike Green adds that what he calls "connector-organizers" are also persuasive, determined,

thoughtful, and creative problem solvers.

- Sometimes, we don't have to look very far for a *community connector*. Direct support workers, a person's family member or the person himself may all know lots of people in a community. By encouraging conversation about "who knows who" we can tap into the community connections that are often right in front of us.

- After learning what the person's passions are, these connectors can introduce a person to others in associations who share this passion. Because the connector is trusted, association members are likely to accept the person more quickly.

- This way, instead of staff members always having to make "cold calls" to try to connect people with disabilities with community associations, connectors can make what Mike Green calls "hot calls."

- The result is what John O'Brien calls the dimensions of human flourishing:
  o belonging,
  o being respected,
  o contributing,
  o sharing ordinary places, and
  o choice.

- Through connectors, John McKnight sees individuals moving from being "clients" who receive services to being "citizens" who share their gifts with other community members.

- *Try it Out* on page 48 contains ideas for identifying and recruiting connectors, through people who know the person: family, friends, direct support staff.

√ CHECK IT OUT: GOOD RESOURCES

- *The Inclusion Press* has good resources on MAPs, PATHs, and other strategies for identifying what's in the community as well as connecting to it through person-centered planning, http://inclusion.com/

- John McKnight and Mike Greene both presented at Toronto Summer Institute in 2007. Some of their comments can be found at the Institute's website: http://inclusion.stikipad.com

- *Asset Based Community Development: When People Care Enough to Act.* Mike Green with Henry Moore and John O'Brien. Toronto: Inclusion Press, 2006.

- For more information about *Designing Dreams*, go to: http://www.arcnm.org/index.php/personal_stories/article/174/

- The Center for Development and Disabilities (CDD), Library and Information Network for the Community (LINC) has a good collection of resources on mapping and other topics. For information, go on-line to http://cdd.unm.edu/linc/

- CDD also has a toll-free line (1-800-552-8195) called the Information Center for New Mexicans with Disabilities. Find more information on-line at: http://cdd.unm.edu/linc/babynet/index.htm

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

Ideas for Discovering a Person's Passions

- Observe how the person reacts to new opportunities, using the person's *Communication Dictionary*, if needed,
- Ask for the stories about what the person surrounds himself with in his home (for example: objects he collects, pets, photos),
- Listen to what friends and families say she loves to do and ask how they know it,
- See what the movies and television shows the person likes to watch are about,
- Notice what the person chooses to wear and find out why he likes those items,
- See what the person wants to do on vacation and why,
- What work interests the person has and why.

How to Tell if a Person is a _Connector_ to the Community:

If a person answers "yes" to the following questions, then that person is a connector:

- Do you love to meet new people?
- Do you start conversations with strangers that end up being interesting to you?
- Do you like to help others find what they need?
- Do you see people's gifts rather than what they can't do?
- Do you get a kick out of introducing people to each other who like the same things or you think would like each other?
- Are you curious about other people?
- Would you walk across a restaurant to say hi to someone you met once?
- Do you run into people you know wherever you go?
- Do you know a lot of people in your community?
- Do you help someone out if you see they're in trouble?
- Do you volunteer for community projects?
- Do you agree with Yeats that: _There are no strangers here, just friends we haven't met_?

Who Knows Who? Discovering the Passions, Gifts, and Associations of the People You Know:

- Invite a group of people you know to get together at a place you all like.

- Try to make the group as diverse as possible: a person who uses services, someone you know through work, someone you know personally, someone you don't know very well, someone who knows a lot of people and anyone else you'd like to invite!

- Have food and drinks!

- Begin by asking "What's good in your life now?" and inviting people to talk about what they do for work and for personal enjoyment.

- Notice when the person becomes passionate.

- See what connections there are between people.

- Ask each person in the group if she is willing to introduce a person to her associations.

- Remember: a person with a disability may also be a strong connector.

- Make a list or draw a map of the associations you have discovered and where they are taking place in your community. Distribute this list to people using services, direct support staff, family members and others who assist a person with disabilities to build community.

- Serve as "matchmaker" between person using services and those who have ties to community

associations and groups that share a person's passion. Get them together for a meal to meet and to arrange the first visit with the association.

- Follow up! Check in with the person how his first visit with an association went. Work with the *connector* and others to troubleshoot and celebrate the new connection!

Deep Connection with Ordinary *"Community Life"*

IDEA 2: TRANSFORMING FACILITY-BASED SERVICES INTO COMMUNITY-BASED SUPPORTS

"We did it because it was the right thing to do for the people we support."

THANK YOU...

Thanks to the following organizations that provided the insight and wisdom that served as the foundation for this paper!

- Tobosa Development Services
- DSI
- Los Lunas Community Program

- Katahdin Friends, Inc.
- Onondaga Community Living
- Common Ground, Inc.

- Arc of Iroquois

IN A NUTSHELL:

In an effort to support people in more typical, person-centered ways, organizations both in New Mexico and across the country are transitioning from facility-based services to community-based supports. Through thoughtful examination of its values and meaningful conversation about what community-based supports can look like, organizations are transforming both their structures and the lives of the individuals they serve. While each organization's transition process is unique and cannot be easily reduced to a list of "how tos," this paper was developed to provide organizations considering the

> **SUCCESS STORY**
>
> For the story of how Tobosa Development Services in Roswell transitioned its day services, take a look at "Transitioning from Facility-Based Services to Community-Based Supports: Tobosa Tells Its Story" included in the *And Yet More* section of the *Meaningful Day Idea Book*.

transition process some ideas and tips that may inspire, guide and support the transformational process.

A SUMMARY OF IDEAS AND TIPS INCLUDED IN THIS PAPER

**Theme One: A Commitment to Person-Centered Support
                 Usually Triggers Organizational Change**
- Ways Organizations Saw the Need to Change
- Undergo Organizational Change "One Person at a Time"
- Think about People First and Finances Second
- Look at the Person's Whole Life: Recognizing that a Person Lives and How She Spends Her Day are Linked

**Theme Two: Involving Stakeholders from the Beginning and
                 Getting Consensus on the Transition Process**
- Create Lots of Learning Opportunities
- Invite People to Be Involved in Developing the Game Plan
- Show 'Em
- Create Lots and Lots of and Lots of Opportunities for Discussion
- Identify Champions
- Show How the Service is a "Win/Win"
- Highlight Success Often
- Take the Concerns Seriously
- Know that Some People Will Leave

Theme Three: Making the Move: The Physical Transition Process
- Develop a Timeline, Making Sure it's Long Enough…But Not Too Long!
- Phase Out the Old Way of Doing Business
- Start the Transition with Those People Who Want Something Different or Clearly Aren't Happy with Their Current Services
- Consider an Incremental Transition Process to a Drop Off Site.
- Ideas for Working with Other Services
- While Having a Transition Strategy is Important, Some Things You'll Have to "Figure out as you go."

Theme Four: The Importance of Creating a Person-Centered Culture
- Make the "Conceptual Leap" from Providing Programs to Supporting People
- Celebrate the Transition's Milestones with Stories, Pictures and Parties
- Do Lots of Training
- Redesign Organizational Systems to Reflect and Reinforce Person-Centered Values
- Acknowledge the Cultural Shift May Take Awhile

Theme Five: The Money CAN Work
- Cost Shift
- Maintain a Lean Infrastructure
- Remember the Hidden Inefficiencies in Providing Services that Don't Work for People
- Acknowledge that the Transition Phase, with a Financial "Foot" in Both the Old Model and New Approach Can be Awkward
- Know Where Your Money is Going: Person-Centered Budgeting
- Consider Quality over Quantity
- Secure Funding Flexibility
- Rework Documentation to Ensure All Available Dollars Can be Captured under Community-Based Service Structure

And now, without further adieu...

IDEAS AND TIPS FOR TRANSFORMING ORGANIZATIONS

THEME ONE:
A COMMITMENT TO PERSON-CENTERED SUPPORT USUALLY TRIGGERS ORGANIZATIONAL CHANGE.

Ways Organizations Saw the Need for Change:

- As more people were introduced to "person-centered" philosophies through trainings and conferences, people and their staff became frustrated with the facility-based status quo.

- New leadership wanted to build community-based supports.

- "We acknowledged to ourselves that people were just clocking time in our day facilities." One organization recognized that having a physical space had become a "crutch" for staff and had reduced creativity and creative problem solving about community-based challenges.

- One organization experienced evolution instead of revolution. With an increased emphasis on community-based supports, the organization's day facility was being used less and less. This decreased use led to the organization's official decision to transition to community-based supports and close the day facility.

The Value of One Person at a Time

While transforming services affects everyone in the organization, most organizations believe the transition process must happen through thoughtful planning and developing support arrangements for *each* person served.

Below, are some of the ways organizations have planned transitioned efforts one-person-at-a-time:

- Organizing person-centered planning sessions, with independent facilitators, using PATH, MAPS or another futures planning tool.
- Having lots of thoughtful, relaxed conversations with a person, his family and his staff and working together to develop a support structure that feels right for that person.
- Inviting groups to come together around the most "difficult" people the organization serves to brainstorm on possible solutions to possible problems. (Note: these conversations are *solution* focused and are not intended to change the organization's decision to close its facility).

People First, Finances Second

Transitioned organizations tend to think about how to best meet the community-based needs of people and *then* develop a financial strategy that supports its goal.

Look at the Whole Life: Where a Person Lives and How She Spends Her Day are Linked

During the transition to community-based supports, many organizations noted they could not effectively accomplish their community-based goals without looking at the person's *entire life.*

This "whole life" approach means thoughtfully assessing a person's "day" and "residential" services and often merging, combining, or restructuring them so people live in their own homes or at least have a more flexible, "fluid" support services to accommodate the person's specific interests or scheduling needs.

THEME TWO:
INVOLVING STAKEHOLDERS FROM THE BEGINNING and GETTING CONSENSUS ON the TRANSITION PROCESS

<u>Create Lots of Learning Opportunities</u>

Organizations that transitioned typically immersed their staff, board and families in values-based trainings throughout the process.

Below are a few ways to provide values-based learning to stakeholders in values and transition process:
- Send direct support staff, managers and families to conferences together.
- Organize visits to other organizations that have transitioned services.
- Organize monthly facilitated conversations on different themes and opportunities in community-based supports at a time that is convenient for stakeholders.
- Invite current staff and family members to help lead trainings within the organization about the values of community-based supports.
- Develop learning opportunities for a person's team (including people who do not work for the organization, like the person's case manager). These team-oriented learning opportunities can be about general community-based supports or about topics specific to a person.

<u>Invite Them to Help in Developing the Transition Game Plan</u>

While an organization's leader usually makes the decision to transition to community-based services, listening to the feedback of others makes the process smoother and strengthens the community-based services that result.

Here are a few ways organizations have invited the feedback of stakeholders:
- individual conversations over meals and in people's homes;
- town hall meetings;
- meeting with each group that will be affected by the transition: people who use services, families, staff and community members;
- Email listserves/discussion forums;

- Asking people who use services and their families to sit on any workgroups or committees created to assist with the transition process.

Show Them What is Possible

Create opportunities for people who use services, families, staff and others to visit with people who currently receive community-based services and the organizations that support them. While some organizations may request a small fee for their staff's time, most organizations are happy to share their experience of transforming services with others.

Create Lots and Lots and Lots of Opportunities for Discussion

Most organizations recognize the value of people simply *talking* with each other during times of organizational change. Many of the organizations interviewed talked about how the long-term, trusting relationships they have with people, families and staff was a key reason the organization's transition was successful.

Below are some suggestions for maintaining a "culture of constant conversation" with people affected by the transition:
- Make sure people affected by the transition have "easy access" to the organization's leaders.
- Eat together!
- Meet one-on-one as needed with individual families.
- Let everyone know how the transition process is going through regular meetings and updates.
- Develop a family advisory committee to hold "family lunches" so families can discuss the transition and learn what they can do to make sure the effort is successful.

Identify Champions

When an organization decides to transition to community-based services, it does so to better meet the needs of at least some of the people it serves. When going through the transition process, get those people who will immediately benefit from the effort to help
"sell" the effort to others in the organization. As people who use services, family members and staff who support the transformation emerge, create

opportunities for them to have conversations about the transition with others.

Show How the Service Transition is a "Win/Win"

While the main reason for transforming services is to provide better supports to people with disabilities, the transition can also produce "perks" for others in the organization as well. Many organizations that transformed their services worked hard to make sure that the transition benefited everyone involved, not just the people who used services.

Below are some examples of how organizations made the transition a "win/win" for everyone include:

- Instead of requiring a family member to drop off a person using services at the organization's office or other site, one organization began picking people up at their homes. This saved families time and transportation costs.

- Several organizations used the transition process as an opportunity to increase a person's and/or a person's family's involvement in the staff hiring process.

- One organization developed individualized, flexible staff scheduling for each person that also incorporated the person's family's scheduling needs.

- Several organizations used the transition process as an opportunity to create better matches between each person's interests and the staff person who supported him.

Talk About Successes Often

During times of change, when there is a greater chance of confusion and concern, people need to feel that everything is going to be okay. Sharing success stories about the transition process can build morale and strengthen everyone's commitment to the transition process.

Importantly, even "small" successes --a person introducing herself to a waiter for the first time or a person interviewing possible staff for the first time-- should be celebrated.

Here a few ideas for how to share good news:

- At every kind of meeting, invite people to share successes.
- Write down the success stories—even if just a few sentences. Keep them and distribute them (changing the name to protect confidentiality if needed) through newsletters, meetings, the organizational website, whatever makes sense.
- Share the stories throughout the organizational community, through websites, newsletters, town hall meetings, dinners, etc..

Take the Concerns Seriously

When people who are going to be affected by the transition ask thoughtful questions about the process, the questions can really make the entire effort stronger.

Inviting feedback both encourages conversation and creates a chance to identify problems and possible solutions that the organization's staff may not have considered.

Taking people's concerns seriously also shows respect for them. This, in turn, builds trust—an element critical in a successful transition.

Some People WILL Leave

Some individuals will not agree with an organization's decision to transition to community-based supports. Many of these folks, with enough information and encouragement, will usually stay with the organization, at least long enough to see how the transition will impact them.

However, some people will never be comfortable with organization's decision to transition to community-based supports and may leave.   Nearly every organization interviewed lost people, staff or board members because of the organization's community-based direction.

Organizations making the transition to community-based supports should anticipate losing some people as a result of the decision.

THEME THREE:
MAKING THE MOVE: THE PHYSICAL TRANSITION PROCESS

Develop a Timeline, Make Sure the Transition Timeline is Long Enough, But Not Too Long!

Because each organization is different in size, composition and circumstance, the time between deciding to close a facility and actually closing it varies among organizations.

While the transition timeline depends on the organization, many organizations took roughly one year to change to community-based supports.

One executive director who led an organization through a two-year transition process reflected that the timeline was too long and in hindsight, wished the organization would have transitioned more quickly.

Consider Starting by Phasing Out the Old Way of Doing Business

Many organizations began the transition process by simply not accepting new people into the *old* facility-based services. For example, one organization decided to not accept any more in-house contracts. Any new person served after the organization's decision to transition received only person-centered, community-based supports.

Consider Starting the Transition With Those People Who Want Something Different or Who Clearly Are Unhappy with Their Current Services

Some people clearly want to receive services outside a facility. Some of these people use words to convey their preferences and others use their actions. Some people may not ask for community-based supports but have clear ways of communicating the status quo is not working for them. We know this through their behavior. When at the facility, they are more likely to hit people, become sullen, or go to sleep.

If your organization decides to transition to community-based services one individual at a time, consider starting with the folks who are clearly asking—either through their words or their actions—for something different than what they currently receive.

Consider Transitioning to a Drop-In Site

When transitioning out of facility–based services and into community-based supports, some organizations found it to helpful to establish a "drop-in" site where people with accessibility needs could use the restroom and people with medical complexities could rest.

The primary challenge is to ensure the drop-off site does not become "facility lite." Some organizations have worked to prevent this by using a space that is not big enough for people to stay in.

Organizations have also prevented this by ensuring the drop off site serves primarily as an administrative office, with only a small room for a person be changed or to get off his pressure points. One organization also viewed the drop-off site as an explicitly temporary solution and rented the space instead of purchasing it. Another organization reduced the appeal of the drop-off site by removing the soda machine!

Working with Other Services During the Transition

Bridging "Day" and "Residential" Services

When a person's services are divided into "day" and "residential" with different staff, managers, and sometimes even providers, it is difficult for organizations to build the individualized fluid, flexible support schedules usually needed for a person to have a "typical life experience."

Many organizations believe their transition to community-based supports was easier when they provided both "day" and "residential" services to people and could more effectively create a seamless support structure or at least require "day" and "residential" members of a person's team to work together.

One organization fundamentally restructured itself so staffing teams were configured around each individual person instead of service type. So, instead of the "Day Hab" staff meeting together and the "Residential" staff meeting together, those who supported John from "day" services and those who supported him in "residential" services would meet as "John's staff."

Shortly after transitioning its traditional day services into community-based day supports, one organization that did not traditionally provide "residential" supports, began supporting people to live in their own homes. The organization did so in an effort to provide more fluid, flexible supports to the people it served.

Working with Clinicians
Organizational transformation requires *all* people to change the way they work, including people not directly affiliated with the organization. This includes case managers, therapists and other clinicians.

Organizations report they often had to support clinicians to rethink how they provided clinical services. Instead of visiting a person at the facility at a time convenient for the clinician, clinicians had to think of community-based ways of providing therapies. This may mean doing physical therapy in a community gym or doing occupational therapy through "real life" activities like going out to eat or getting coffee.

While Having a Transition Strategy is Important, Some Things You Have to "Figure out as you go."
Thoughtful, creative planning about how the transition will happen is extremely important. However, even with the best planning, unexpected issues and challenges will surface during and after the transition.

Below, are some things that may help an organization unplanned situations:
- A strong, clear community-oriented mission and vision can guide organizations through difficult decisions.

- Listen to the person and continue making decisions "one person at a time." When faced with a decision that affects a person, ask yourself,

"what decision will lead to the best possible outcome for this person?"

- If you are a manager or a family member, have you asked for input and suggestions from direct support staff?
- Contact other organizations that have transitioned or regional coordinators to get support in thinking through decisions.

THEME 4:
THE IMPORTANCE OF CREATING A PERSON-CENTERED CULTURE

Making the Mental Leap from Providing Programs to Supporting People

Building person-centered supports often goes hand-in-hand with transitioning services into the community. This makes sense; the main reason for transitioning to community-based supports is for people to be included in community life. However, if people are grouped together, it is hard for people to become truly known and included as individuals.

Most organizations that transition away from facility-based services also restructure their services to be more person-entered. Redesigning services around each person served means building more individualized supports based on the person's interests and needs.

Here are few examples of how organizations have made their services more person-centered:
- Hiring staff specifically for an individual instead of for the organization.
- Developing a flexible staffing schedule for each person instead of a preset schedule that applies to everyone.
- Having staff identify themselves as "John's support" instead of working for "ACME Support Services."

Several organizations interviewed talked about how difficult it was for some staff to begin identifying themselves as a person's support instead of a member of a "residential" or "day service" team.

The following list outlines some of the feelings staff may have as an organization redefines how it provides services:

- "I am uncomfortable being seen as person's staff when I thought my role was to supervise the person."
- "If I am a person's staff but the organization pays me. Does that mean I have two bosses? Who do I answer to?"
- "Why does one person receive six hours of service and another person receives ten hours a day of service? That seems unfair."
- "I do not understand why it is important for her to volunteer. Her disabilities are so severe, I don't think she even notices."

As with most challenges, supporting staff need to think about their role in person-centered ways that may not have an easy solution.

Here are some approaches that organizations believe helped:

- Have a strong, living, person-centered mission and vision that can guide conversations about the organization's direction.
- Hold lots of conversation about people's interests and needs (not necessarily about organizational policy).
- Invite direct support staff to serve as a key advocate for the person's interest and the organization's vision.
- Involve direct support staff (and the person!) in the redesigning of services.
- Support staff to participate and attend conferences, trainings and consultations about person-centered support.
- Support positive staff to become organizational leaders on PATH, MAPS or other person-centered planning tools.
- Assist staff who are not comfortable with the organization's transition to find new employment. This is not a euphemism for termination or a forced exit, but rather an opportunity to support staff with job leads, networking and other efforts that lead to employment.

<u>Celebrate the Transition's Milestones with Stories, Pictures and Parties</u>

Transforming services is hard work and it is important to always recognize and celebrate the success stories the transition creates. Celebrations remind people why they are working so hard and also motivates others to try new, creative things.

Below are some suggestions of successes to celebrate:
- If a person is living in his own home for the first time, how can the organization help organize a house warming party for him?
- If a person has just hired his own staff for the first time, celebrate this with photos of the two of them together or hold a party or celebrate in a way that makes sense to the person.
- If staff are going to a conference out-of-state for the first time, take pictures.

Support Lots of Training
All of the organizations that have transitioned services note the critical role values-based conversations and training played during the transition process.

Invite people using services and staff to help lead the training and share stories. This reinforces the "people first" culture the organization is trying to create.

Organizational Systems Reflect and Reinforce Values
In transitioning services to providing more individualized, community-based supports, organizations often revise their internal systems (like human resources, finance, and administrative structures) to better reflect their more person-centered supports. For example, one organization reexamined what qualities it wanted in its staff and redeveloped its staffing job description and interview questions to reflect the increased emphasis on community-building.

Know the Cultural Shift May Take a While

As staff and families begin seeing the benefits of community-based supports (staff often say they enjoy their work much more after the center closed), the culture will begin taking hold.

However, it sometimes takes **several years** for an organization's culture to truly shift from facility-oriented thinking to individualized, community-based thinking.

THEME 5:
THE MONEY*CAN* WORK: THE FINANCES OF PERSON-CENTERED, COMMUNITY-BASED SUPPORTS

An organization's decision to offer more person-centered services is not usually motivated by money. Person-centered services do not usually result in a huge profit. However, providing person-centered supports can be financially viable. This section outlines key fiscal strategies used by organizations that have transitioned to community-based supports.

Cost Shifting

When an organization transitions to community-based, person-centered supports, *cost-shifting* is important. Some people will require more support than the individual's funding provides and organizations may serve them at a loss. It becomes critical for organizations to have alternative income sources to offset the loss of supporting some people.

Maintaining a Lean Infrastructure

Providing person-centered services usually increases direct support staffing, transportation, and other expenses that directly support the person. To make sure people get the level of service they need while keeping the organization financially stable, organizations often need to find ways to create a leaner, less expensive infrastructure.

Here are some ways organizations have saved money by reducing their infrastructure:
- Closing facilities resulted in a reduction of both fixed costs (rent, mortgage, etc.) and variable costs (utilities, insurance, etc.).

- Outsourcing human resource functions to contracted entities.
- Relying on volunteers to assist with office management and staff training functions.
- Using technology in effective ways.

Remember the Hidden Costs in Providing Services that Do Not Work for People

People providing traditional, facility-based services often question the cost-effectiveness of providing person-centered support. However, people often overlook the hidden costs of serving people in ways that do not make sense.

Below are a few of the hidden costs of providing services that do not work for people:
- Turnover costs related to staff leaving because of a person's "challenging behavior."
- Staff turnover potentially higher because of the stress of supporting several people at one time.
- Workers compensation claims resulting from injuries related to people's "challenging behavior" which often increases when a person is in settings he doesn't choose.

Transitioning Service Models Can Be Financially Challenging

The most difficult part of a transition occurs when an organization has both the "fixed" costs of the facilities that have not closed yet and the costs of providing individualized services to people. For example, one organization decided to close a group home and begin serving the residents in homes of their own. At one point, the organization was supporting two residents in their own apartments with individualized staffing while maintaining the fixed costs of the group home to ensure stability for the other two residents until they also moved into homes of their own. The organization noted this was financially awkward.

Know Where Your Money is Going: Person-Centered Budgeting

Often, the facility serves as a "cost center" in a facility-based organization's budget. The organization analyzes its spending trends from a facility or

"program" perspective. This approach makes it difficult to figure out how much support should go to each individual's costs.

When organizations use person-specific budgets as the centerpiece for their organization's budget, they have a better understanding of the specific support needs of each individual and are better able to provide the service and advocacy needed for a person to enjoy a high quality of service.

Developing a person-centered budgeting structure both reinforces a person-centered organizational culture and also provides an effective management tool. By building the organizational budget from the person out, it ensures the organization is prioritizing the support needs of the people it serves, and can more effectively determine where additional resources may be needed.

Consider Quality over Quantity

To manage costs of community-based, individualized services, one organization interviewed reduced the number of hours it served people in order to provide more individualized and flexible staffing options. So instead of a person being served from 9:00 am-3:00 pm without exception, the organization worked with people and their families to develop a four-hour-a-day support schedule with a lower staffing ratio. The person could choose the support companion who could shift from week to week to accommodate the person's and the families' specific scheduling needs.

Full Time Staff May Actually Cost LESS in the Longrun

One organization that transitioned services initially tried to trim costs by making its employees part-time. However, over time, the organization determined that this approach resulted in increased turnover and ultimately was *more* expensive to the organization. The organization now invests in full-time positions that provide greater continuity and are more economical in the long-term.

Rework Documentation to Get as Much Money as Possible

Traditional documentation requirements do not always support more flexible, community-based services. Often, traditional documentation is

divided by service type instead of by a person's "whole life" schedule. When people begin receiving community-based services, this traditional documentation becomes increasingly difficult to complete. As a result, organizations may not capture all of the funding available to them.

√ CHECK IT OUT:
GOOD RESOURCES

- For a summary of important lessons learned from transitioning a workshop services into individualized, community-based supports, check out: "Working Together to Convert the Last Sheltered Workshop in Vermont to Individualized Supports" by Jennifer Sullivan Sulewski. Available at: http://www.communityinclusion.org/article.php?article_id=201

- For an analysis of the process of transitioning a "residential service," check out: "Deliberate—Fire; An Account of Organizational Transformation in Onondaga Community Living, Syracuse, New York" by John O'Brien and Connie Lyle O'Brien Available at: http://thechp.syr.edu/OCL.pdf

- For case studies of various organizations that transitioned to community-based supports, visit Syracuse University's Center on Human Policy's website at http://thechp.syr.edu/. Select *Publications and Resources*, then *Resources and Reports on Community Inclusion* and finally, *Alternative Day Activities.*

- For a book on developing person-centered "day services," that includes a chapter on transitioning facility-based day services, read: *Make the Day Matter: Promoting Typical Lifestyles for Adults with Significant Disabilities*. Available at: http://www.brookespublishing.com/store/books/walker-67137/index.htm

- For a discussion of people with disabilities living in their own homes, take a look at: "A Reflection on Group Homes and Supported Living" by David Wetherow Available at: http://www.communityworks.info/articles/group_homes.htm

- For thoughts about facility-based services from a parent's perspective, check out: "Why a Facility?" by David Wetherow Available at: http://www.communityworks.info/articles/facility.htm

- For an analysis of closing facility-based employment services, take a look at: "The Successes and Struggles of Closing a Facility-Based Employment Service" by John Butterworth. Available at: http://www.communityinclusion.org/article.php?article_id=36&staff_id=2

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

If your organization is exploring how to provide community-based supports, pull together a group of trusted advisors (people served, staff, families, etc.) and collectively ask:
- What does our organization's mission call us to do?
- What would successful, community-based services without a facility look like to us?
- Do the leaders of this organization know each person well?
- Does any organizational reluctance to transition come from a need to put the organization's interests above the person's (examples include: fear of staff loss, fear of liability, fear of reducing a profit margin, fear that the process is just too hard)?
- Does our current way of doing things create opportunities for people to have typical experiences that most people without disabilities value: a job, living in one's own home, going on a date, getting to know others in the community on a first-name basis?
- Is each person we support *happy* with his/her services or simply not complaining?
- Have we shown people we support and their families alternatives to facility-based supports?
- Do we ask ourselves, with every facility-based activity, *HOW* could this be done in a community setting?
- Have we effectively used the staff's, families', and board members' community connections and resources to build meaningful opportunities for people in their communities?

Deep Connection with Ordinary *"Community Life"*

IDEA 3:   EMBRACING EXPERIENCE AND SUPPORTING THE DIGNITY OF RISK

Life is a succession of lessons, which must be lived to be understood.
-Ralph Waldo Emerson

IN A NUTSHELL:

We often talk about people with developmental disabilities having the same opportunities and choices as everyone else. And as people lead fuller lives in their communities, those experiences often come with risk. As a result, the conversation about "dignity of risk" becomes increasingly relevant.

As we all know, conversations about people with disabilities experiencing "risk" can be uncomfortable. These conversations often reveal two things: 1) we all have individual ideas about and comfort levels with *risk*; 2) when a person uses services, the circumstances and the approaches to decision-making *do* change--there are more people involved who all share some level of responsibility for the person's welfare. This creates an awkward but potentially inevitable struggle in our heads that probably goes a little like this:

"I really want [insert name of person using services here] to have a full life and do the things she wants to do. I totally get that there is risk involved sometimes and that we all learn from mistakes. But I just don't want anything bad to happen to her…especially (gulp) not on *my* watch."

> ### SUCCESS STORY
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> "C. met a friend online in a chat room. After talking for few weeks, our client decided she was going to on the bus to meet her in California. We had a team meeting with C. and talked about the dangers of going. We had the police talk to C. We gave C. our phone numbers. We called and talked to the friend in California before C. went. We knew the address and phone to where she going. C. went on the trip against everyone's better judgment. She stayed 3 days and called staff and was unhappy. Staff sent her a ticket and she returned home."

Ironically, protecting people from experiences may actually make them MORE vulnerable and potentially put them at GREATER risk of being in dangerous situations. Given that human beings *learn* through experience, we may best address people's safety by thoughtfully supporting them to have the experience of living a full, engaged life.

Despite the fears about supporting people to have typical life experiences, many New Mexicans with disabilities *are* leading full lives and receive the thoughtful, respectful support they need to do so.

Supporting people to have typical experiences and navigate potential risks is never easy and each situation poses a unique set of questions and considerations. There are no "quick and easy" answers for how to support people to live a full life. Therefore, the most important thing we can do is encourage thoughtful dialogue between the person and those who know the person best. In an effort to encourage conversation, this paper has been written as a series of questions to help people, teams and other entities have thoughtful conversation about typical experiences and the dignity of risk.

BRINGING IT TO LIFE
THOUGHTS AND IDEAS

THOUGHTS FOR EVERYONE

Aren't We Talking About Dignity of *Experience*?
"Risk" is defined as "a situation involving exposure to danger." Yet the everyday dreams and wishes of most people are not usually described as "dangerous"— the desire to own a home, to have friends and a social life, to go on a date and have a relationship, to participate in worship services, to try a new job, and to travel.

Certainly any activity has potential risk (or even danger) in it, but most people are not prevented from having the experience because of these potential risks. However, often the discussion about the wishes, dreams

and desires of an individual with disabilities focuses on the "risks" involved without first valuing the importance of the larger experience. As we support people with developmental disabilities to navigate risk, we must first commit to supporting people to have rich, full lives, filled with typical experiences.

What if We Committed to Using our Common Sense and the Typical Public Standard of Experience to Guide our Decisions and Supports?

If a person wants to try something, here are some questions to consider…

- Is this something that other people do?

- If my friend/my sister/my mother/my wife said she wanted to do this, what would my advice be?

- How can I both support this idea and give this person the information he needs to make an informed decision?

- Are there any special safety considerations we need to think about, given this person has a developmental disability and may be more vulnerable in some ways?

How Can We Keep Talking? The Importance of Conversation

Ongoing conversation about the concepts of *typical experiences* and *dignity of risk* is essential to individuals having fuller, richer lives.

Some ways to keep conversation going….

- Widely share stories about successful experiences.

- Create an organizational and team culture where people are encouraged to talk about challenges they are facing in supporting people to have typical experiences.

- When an experience doesn't go well, invite people to talk about lessons learned and if anything could have been done differently, instead of looking to assign blame.

- Facilitate opportunities for providers to talk to providers, family members to talk to family members, case managers talk to case managers, etc.

THOUGHTS FOR FAMILIES, GUARDIANS and TEAMS

Do we understand that our function is to <u>support</u> adults to have typical experiences?
Some ways to ensure team's support for a person's right to have a typical experience:
- When staff pose new ideas or ways of supporting typical experiences, acknowledge and celebrate the initiative and creativity BEFORE editing or critiquing the idea. Consider asking questions like:

    o "HOW can we make this happen?"

    o "What can we do to help?"

    o "How can the organization do more of this?"

- Teams should assume a permissive approach to supporting the person and her staff to try new things and enjoy typical experiences. Support people to "just go do" within the framework of 1) the activity being guided by the person's interests and 2) the person and his/her staff being thoughtful about mitigating the risks involved in the activity.

- When the person we support wants to try something new, do we talk about the "pros and cons?" Do we come up with a plan for what happens if the experience doesn't go well?

- If we are struggling with a person's desire to have a particular experience, have we asked for help to figure it out rather than simply saying "no"?

When an accident occurs in the course of doing a typical activity, can we work to ask "What can we learn?" instead of "Who's at fault?"

Sometimes accidents happen. Sometimes the accident is a result of poor planning, a flawed organizational practice, a lack of training, or an error in judgment. And sometimes, despite the best preparation, mishaps still happen. Formal investigations, while sometimes necessary, create anxiety among staff and foster a "fault finding" organizational culture. As teams and organizations respond to accidents, consider asking the following questions and incorporating the following approaches:

- Are we ethically or legally required to conduct a formal investigation? Can we learn about what happened through less formal channels?

- Do we ask the person directly if s/he thinks the incident could have been avoided? Are any future prevention measures acceptable to the people using services?

- Whenever possible, informalize the debriefing. Think through what happened with both the staff and the person directly involved in ways that everyone is comfortable being open and honest. Have the conversation over food, or in an informal space—like a living room.

- If staff were directly involved in the incident, consider inviting a group of fellow direct support staff to participate in the conversation and offer input and feedback about the incident and whether it could have been avoided.

- Are we at peace with the idea that sometimes NOTHING could have been done differently to avoid an accident? That sometimes, in the course of living a full life, unfortunate events that are beyond our control happen?

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Does a person's Individual Service Plan ("ISP") reveal a robust, passionate vision for a person's life?

In New Mexico, a person's ISP is considered the foundation on which services are built. By this logic, the ISP needs to be full of information about who a person is, what s/he enjoys doing, and ideas for new experiences.

While a document can never truly capture a person's life experience (the fuller a person's life, the more difficult to reduce it to paper!), a thoughtfully developed, "possibility-oriented" ISP can provide a formal endorsement for supporting a person to try new things and have typical experiences.

When developing an ISP, consider asking…

- Have we encouraged the person and his/her direct support staff to "take the lead" on developing the ISP?

- Does this ISP work to expand a person's life by including new ideas for experiences based on what we know about this person?

- Have we included language in the ISP that supports a person to "try new things?"

THOUGHTS FOR PROVIDERS

Do we know this person well and are we doing our best work in our efforts to support typical experiences?

The better we know a person, the more thoughtfully we can prepare the person for a new experience. When we know a person well, we have a good understanding of things like:
- How a person best receives information (verbally, with pictures, etc.);
- Specific personality traits that may influence the outcome of the experience;
- Unique safety and support considerations that need to be considered when organizing the experience.

While we are always working to deepen our understanding of who a person is, it is really important to have a trusting, informed relationship already established with a person when supporting him or her to have new experiences. Some basic ways to get to know the person:

- Prioritize opportunities for getting to know the person, BEFORE services begin.
- Ensure that support staff knows the person well, has good judgment and can give the person his/her undivided attention.
- Create informal opportunities for a person, her staff and family to tell stories about the person and debrief on activities and experiences.

How can the organization's mission and vision be used to support typical experiences?

Most organizations that serve people with disabilities have value-rich language in their mission, values statements and vision. Organizations often are publicly committed to supporting people with disabilities "to achieve their dreams" or "to achieve their goals."   These articulated values are intended to guide the supports the organization provides and can be used to leverage additional support within the organization, on teams and within the communities.

Some questions that explore how organizational values can facilitate typical experiences…

- Are the lives of the people served by the organization consistent with the organization's values?

- When unsure how to best support a person who wants to try something, what does the organization's values call staff to do?

- What if an organizational donor or board member was invited to share her social network and time with a person using services in lieu of a financial donation?

- Are the organizational values widely distributed and discussed with families, community members, regulators, teams and staff?

Do we talk about our organizational values regarding typical experiences with people and their families/guardians BEFORE services begin?

As we all know, families and staff often have different ideas of what is possible for a person with disabilities. By engaging in conversation about the typical life experiences *before* services begin, people, families and organizations are able to create a foundation of common values on which to build future supports, decisions and experiences.

Some language that may be useful…

- "We all agree to work together to thoughtfully explore how this person can enjoy a rich life full of typical experiences."

- "We know that there may be times when we're nervous about supporting a person to have a particular experience. When these situations arise, we all agree to talk about how to ensure the person has the best experience possible."

- "We all understand that because of disability or circumstance, this person may require additional preparation or support when having a particular experience."

- "We agree to not limit the person or our thinking with concepts like "mental age" but will work to respect the person's adulthood and to acknowledge that people grow and mature through life experience."

Do we prioritize hiring staff with good judgment (even over experience in the field or certifications)?

Some ideas for how to hire quality staff…

- Invite talented direct support staff and people who use services to help identify staff candidates, both through recruitment and interviewing.

- Ensure the recruitment and interview process highlights and reflects an organization's commitment to typical experiences.

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- Include a number of "what if" scenarios about a person and a typical experience in order to assess the candidate's judgment and other important skills.

- For more ideas on hiring staff, check out the paper "Finding Good Fits between Direct Support Staff and the Person Served," located in the *Supporting Individualized Access* section of the *Meaningful Day Idea Book*

Do we create an "open door" organizational culture, so that staff feel comfortable asking for help?

Thoughts about how to create this culture…

- Do organizational leaders ask direct support staff for their guidance and thoughts on how to improve the supports to people?

- Do organizational leaders emphasize the importance of constant learning and asking questions, including questions that respectfully challenge the status quo or poor outcomes?

- Do we prioritize a staff person's critical thinking skills (fundamental for problem solving) over her expertise?

- Do we acknowledge that when engaged in the tricky, nuanced work of supporting people to have typical life experiences, "I don't know" is often the most honest response to a question and usually reveals an opportunity for critical thinking and conversation?

- When staff ask for help, is the organization responsive?

Have we scrutinized any internal policies that summarily restrict experiences that the general public would deem "typical?"

Some thoughts about policy development…

- Develop policies in partnership with the people who use services and their staff.

- Before developing policies, explore the questions:

  - o Does this proposed policy help or impede people's ability to have typical experiences?

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- o Is this policy consistent with common sense?

- o Is this policy easy to remember?

- o If you were receiving supports under this policy, would you be ok with it?

- Avoid drafting reactive policies—policies that result from an unfortunate outcome of a typical experience. Use unfortunate outcomes as an opportunity to think about how the outcome could have been prevented and whether the outcome reflects a systemic issue or an isolated incident.

- Acknowledge that all policies will have unintended effects once they are executed. Be open to revising policies quickly and as needed.

How do we ensure any concern about liability doesn't get in the way of supporting people to have typical experiences?

Just as thoughtful risk-taking is an essential element of having a full life, perhaps an organization's fullest potential is realized when it is not driven by fear of liability but rather by an openness to possibility by thoughtfully and respectfully supporting typical experiences in the lives of the people it serves.

When bad things happen, do we always respond in a way that:

1) encourages dialogue about what happened;

2) nurtures typical experiences; and

3) doesn't discourage trying new things in the future?

THOUGHTS FOR EXTERNAL ENTITIES

Do we recognize that the more people have typical, community experiences, the greater chance of real life happening—trips, falls and all?

√CHECK IT OUT:
GOOD RESOURCES

- For a collection of articles about experience, self-determination and dignity of risk, look at "A Few Words About Dignity of Risk" in the *And Yet More Section* on page 81. Special thanks to Lorie Ellison for compiling this information.

- Dignity of Experience Workgroup's Report to the ACQ, go to the *And Yet More* section.

- Consent Handbook for Self-Advocates and Support Staff. AAIDD, available through Quality Mall at http://www.qualitymall.org/products/prod1.asp?prodid=3659

- For discussion of liability, take a look at "Risks in Providing the Least Restrictive Environment in a Litigious World, Question and Answer Session with Chris Lyons, defense attorney." Available at: www.dhs.state.mn.us/main/dhs_id_057572.doc

Wellness and *Optimal Health*
IDEA 1: HEALTH AND WELL-BEING

IN A NUTSHELL:
Health and well-being are basic to people's lives. Feeling (being) healthy allows people to think about and work on other things that are important to them. Health and well-being cannot be guaranteed, but there are a number of things that we all can do to support good health to the greatest extent possible.

LIVING IT: A SUCCESS STORY
LYN'S EXCERCISES
Lyn needs regular physical therapy and did regular exercises at her day program's facility. When the day program decided to close its center, the program manager and Lyn's therapist wanted to design a program Lyn and her staff could do in a community-based setting. A staff member assisted Lyn to begin going to the aerobics center at the local community center and the physical therapist helped to redesign the exercises for the equipment that was available at the gym. Now Lyn has a place to do her exercises and an opportunity to meet other people in the community with whom she may become friends**.**

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS
Appreciate the fact that all of us think about our health and well-being differently. We have our own definitions of what is "healthy" or "unhealthy" and what makes us feel best. Many people with and without disability make decisions to continue to avoid exercise or eat more than we should. People should have the freedom to make fully informed decisions regardless of their disability.

We can support people to learn about healthy lifestyles and to introduce people to other people who engage in healthy lifestyles. It is much easier to exercise, eat right and quit smoking with the help of friends.

Help people to get the best medical care whenever they need it. Make sure that people use the same medical resources as others in the community. If the quality of medical care is not very good or there are missing types of care, work to improve it for

everyone, rather than creating a different system for people with disability.

Consider creative ways to assure that people can meet their medical needs (See the success story above).

Consider the person's emotional, as well as physical, health. Be aware that many people have been traumatized at some point in their lives and many of their behavioral responses may be due to past trauma. Research community resources to assist people in dealing with trauma and support the person to access needed support.

Remember that there are many health-related community organizations, groups, and resources, including alternative medicine, which may be helpful to specific individuals or at specific times.

Understand that medical powers of attorney, family consent statutes or policies, and circles of support can all provide decision making assistance in health care issues. It is best to think about the need for assistance in making decisions before a decision needs to be made.

√ CHECK IT OUT:
GOOD RESOURCES

- See the *Continuum of Care Health Primer for People with Disabilities and Their Direct Support Staff.* http://www.unmcoc.org/manual/index.htm

- America Trauma Society http://www.amtrauma.org/

- *A Good Life* by Al Etmanksi www.agoodlife.org

- DDSD Clinical Services Bureau The CSB is located at 5301 Central Avenue NE, Suite 203, Albuquerque, NM 87108-1514. Call (505) 841-2948 or toll free 1-800-283-8415 or fax at (505) 841-2987 or email AT.Coord@state.nm.us

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

- Get together with a few other people and make a list of all of your own behaviors that impact your health. What decisions do you make that might be considered healthy or unhealthy? Why do you continue to engage in any unhealthy behavior? How would you feel if someone expected you not to do it anymore? Listen carefully to the

other people in your group talk about these issues. Think about what you learn. Invite people whose decisions influence the life of a person using services.

- Join with others in your community who are concerned about the lack of affordable, accessible health care options for all community members and think about what your community needs and how you might make that happen. Remember that health is a universal issue and many other people are concerned too.

- Consider having people access medical specialists, (PT, OT, Speech, Nursing…) in the places and ways that other people access these services. Most people, unless seriously ill, go to clinics or offices to meet with these professionals rather than having the professional come to them. Very few medical professionals perform their services in other people's workplaces.

Self empowerment, Relationships **and Respect**

IDEA 1: BECOMING A PART OF THE COMMUNITY: CULTIVATING AND NURTURING RELATIONSHIPS

We can spend a lifetime going from one 'activity' to another and still be alone the next day (and for the rest of our lives), or we can try another tack. **-David and Faye Wetherow**

IN A NUTSHELL:

As people, we know other people. Usually, we have connections and relationships all over the place and don't think much about it. We've got connections through our family, our school, our neighborhood, our job, and through others we meet during our life. We don't really think about how the connections developed, they just kind of did. Not all connections become deep, long-lasting friendships but connections of all kinds seem to be important to us as human beings: whether it's discovering a best friend or just having the ritual of saying good morning to the McDonald's employee who takes your order every morning on your way to work.

Facilitating community for others is not much different from how community is built for anyone else: we participate in our community's life and connections result. So if the idea of cultivating relationships for others seems intimidating, be reassured that your own personal experience has prepared you well for the job.

The only real difference when facilitating relationships for others is embracing our responsibility to always have our eyes, ears, and minds open for possible connections and then act on what we notice.

Michelle and Carol's Story
Michelle has been a working woman for years, having held down two jobs at the same time. As luck would have it, Carol, who supports her as a host family provider is active in the *American Business Women's Association*. Several years ago, Carol began inviting Michelle to join her at ABWA's meetings and Michelle began attending the local chapter's dinner meetings on a regular basis. While it took the other members a little time to get to know Michelle, over time they bonded over the dinner part of the group's meetings. Michelle also gained the group's respect when it learned that she held two jobs. Michelle liked the group so much that she joined as a member. She is now invited by other members to assist in various projects and has met members from all over the country!

BRINGING IT TO LIFE: THOUGHTS AND IDEAS

Focus less on the activity and more on the relationships that can be created through it.
-David and Faye Wetherow

Over the years, we seem to be doing a better job of getting people with disabilities *into* their communities: going to the library, to the recreation center, to the park. But how would our support change if the measure of "success" became meeting people and not simply being around people? There are some very concrete ways that may be useful in facilitating relationships for people, like becoming a regular and tipping big in restaurants. For additional ideas, take a look at "Some Easy Ways to Be an Ambassador" paper, in the *And Yet More* part of the *Idea Book*.

It's Not What You Know, it's Who You Know: Tapping Into the Relationships of Likely and Unlikely Sources

We know that relationships are built through people getting to know other people. And often when thinking about how to expand a person's relationship network, we ask ourselves, "who do we know?"

Consider expanding the circle of people we ask to help us move a person's life forward.

People Who are Often Asked:

members of a person's service team: a family member, middle managers, therapists and case managers.

Some Other People We May Not Think to Ask:

- A person's direct support staff and *their* families and friends.
- Other staff within the organization: the receptionist, the financial manager, cleaning crew.
- The family members of *other* people served by an organization.
- People who the person sees casually on a regular basis: a coffee shop employee; a waitress, the minister of a person's church.
- Others who share a person's passion.
- A person's employer.
- DDSD regional coordinators and other staff.

Give up on Uniformity and *Dare to think small*

-Mike Green

In large organizations, we get used to thinking in terms of systems: programmatic, human resources, IT, etc. We often think in terms of "administrative efficiency" and "cost effectiveness." We initiate organization-wide efforts and programs to improve the lives of the people who use our services. And while there may be value to thinking in systems, a person's life is often transformed by ideas, relationships and connections specific to that person.

So, as organizations work to facilitate the community for the individuals they serve, let's take some of the pressure off. Instead of thinking of programs that can transform the lives or employ "60 people with developmental disabilities," consider focusing on changing John's life…then Anna's….then Roberto's. By concentrating on *one* person's life, the conversation, ideas and commitment are likely to be more thoughtful and creative.

Slow Down

While our need to have more relationships in our lives may be urgent, in our efforts to facilitate community for each other, we may need to slow down. As we all know, *real* relationships don't usually happen instantly and can't be dictated by imposed artificial timelines.

As we all know, many relationships start as acquaintances: someone we meet randomly at a party or someone who sits on the same pew as we do at church every Sunday. To assume or expect these folks to immediately become a friend-for-life would be (let's face it) a little creepy. Most of us need the time to build rapport and a sense of safety with new people.

As we work to nurture new relationships between a person with disabilities and other community members, slow down and take the time to notice what's going on around you. And then simply try to create the space for potential and relationships to develop. Is there a particularly friendly waitress at restaurant you frequent? Try to always sit in her section. Does your mom's best friend run a local hair salon? Maybe the person you know would like to get her hair done there if she doesn't have a regular stylist.

Always consider what the person is passionate about or seems to make her happiest. Seek others who share this. Go to places that are comfortable for the person you are supporting and don't cause anxiety. Make sure the person is told what's going on and what to expect. Listen and appreciate the cues the person you are supporting is giving you. You may introduce people, it's the person's choice about who he welcomes into his life.

Invite Organizational Leaders into the Relationship-Building Process from Time to Time

Many times, organizational leaders are extremely well-connected to people in the community and not as well connected to the people they serve (though most really want to be!)

When having an organized conversation about supporting

a particular person in facilitating community, consider inviting the organization's Executive Director, a Board member, the Parent Advisory Group, and other "higher ups" to participate in some of the person-specific planning. Doing so will accomplish two important things:

1) it will give a person personal access to additional community connections and contacts and

2) with all of the busy-ness that organizational leaders experience, it will provide them an opportunity to slow down, and reconnect with the people to whom they are committed.

Get to Know People Outside the Services They Receive

Sometimes, even with good intentions, we box ourselves in to limited thinking by getting to know people only through service-delivery channels: through reimbursable services, through ISP meetings, through reading a person's assessments and writing quarterly reports.

Consider creating opportunities to get to know a person in

ways that we usually get to know each other: through informal channels involving others (both paid and unpaid) who love and care about this person. For some specific ideas, go to *Try it Out*

When we "bond" it relieves the pressure to ensure that our interaction meets every requirement for billable services and creates a more relaxed, human way of relating to people. We learn about people in new and important ways and also build a stronger sense of community for everyone involved.

Avoid the Service Bubble

Oftentimes, when people receive services, there is an assumption that the provider will now meet all the needs of the person, even all of a person's needs can never truly be met through services alone. If organizations attempt to be all things to all people, it will likely result in people's identity, network and community being largely defined by the organization. The organization's role is to *facilitate* (not become) a rich community network for each

person it serves. How do we let others in the person's life know this? When beginning services, do we look to family, friends and the community first to provide supports?

√ CHECK IT OUT: GOOD RESOURCES

- See *Articles* section at Community Works! http://www.communityworks.info/

- *Importance of Belonging* by David Pitonyak, available at www.dimagine.com

- Make a Difference, A Guidebook for Person-Centered Direct Support, John O'Brien and Beth Mount, available through Inclusion Press at www.inclusion.com

- Asset Based Community Development Institute, includes free articles on community-building by John McKnight http://www.northwestern.ed

u/ipr/abcd/abcdrelatedpubs.html

- For tips for support staff on becoming a bridge builder See *How to Become an Ambassador* on page 126 in the *And Yet More* part of the *Idea Book*.

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

Ideas for Getting to Know People Outside the Services they Receive

- If you're an executive director, consider inviting a person who uses services to go with you to your next Chamber of Commerce social meeting. Simply introduce the person by his name or invite a person to your home for your next dinner party.

- If you're a parent of someone using services, consider inviting the person's direct support staff over to your home for a cookout.

Self Empowerment, Relationships and Respect

IDEA 2: LEADING YOUR OWN LIFE: SELF DETERMINATION AND ADVOCACY

"Nothing about us without us."
-People First

 ## How this paper was written:

Although we **all** can make a valuable contribution to the conversation about self-direction, people with developmental disabilities are the most important teachers on this topic.

For this idea paper, we asked others, more competent than we are, to provide the content of this paper. The answers and ideas contained in this paper come directly from self-advocates. Our thanks to Matthew Heady, Marilyn Martinez, Cynthia Berkheimer and Susan Weiss for being the real voices in this paper.

Not every idea in this paper will apply to everyone. At the same time, the thoughts and ideas contained in this paper apply to people with *and* without disabilities. We hope that the ideas empower more people with disabilities and help remind all of us how important it is to direct our own lives.

BRINGING IT TO LIFE: THOUGHTS AND IDEAS

How can people advocate for themselves?

- **Go with your instinct**. Don't second guess yourself. If you feel you're being treated unfairly or disrespectfully, you probably are.

- **Don't doubt your own ideas.** If you start doubting yourself, it makes you feel uncomfortable and less confident, making it

harder to advocate for yourself.

- **Get training.** "Training like public speaking, conflict mediation, leadership skills, self-advocacy, team building made me more confident in myself and more confident in what I'm putting out there. I now have the skills to be a more effective advocate for others." –Matt Heady

- **If you can't speak in front of people, it's hard to speak up for yourself.**

- **Create your own opportunities to speak up. Don't wait to be asked.** Whether it's being on the provider meeting agenda or simply calling your own team meeting, it's important to feel comfortable telling others that you need to talk with them.

- **Write down your thoughts and ideas on paper.** It helps you prepare for conversations

and think through your advocacy strategy.

What are the biggest barriers people with developmental disabilities face when they try to advocate for themselves?

- **Not being taken seriously.** People often assume a person with a developmental disability doesn't know what he or she is talking about.

- **Being pushed off to the side or ignored.** Sometimes it's intentional or sometimes it isn't. People assume that a person doesn't have the skills to do the task.

- **Not being asked for their opinion about their own lives.** A person knows naturally how to live their life. People are most familiar with their own strengths and needs but are not asked for input on their own lives.

- **System and agency policies and practices often work against a person running and living his own life.**

If I could tell regulators a few things about self-determination, they would be….

- **You can't run a person's life.** We need to use more common sense and support people in natural, more human, ways.

- **Nobody has the right to dictate what goes on in another person's life.**

What can a provider can do to support people with developmental disabilities to lead their own lives and services?

- **Be open minded.** If the provider comes in and says "it's going to be like this," the provider won't end up supporting the person in a meaningful way.

- **Know a person's personal story,** not just her case record.

- **Ask for input and provide opportunities to give input.** How can a person live her life if she is not asked what she needs to *live* her life? Who better to know how to live your life than you?

- **"When a provider gives me both support and space, I am happier with my services."** I need some space to make my own mistakes. This space makes me more appreciative of my services.

- **Let people hire their own staff.** If a person chooses her own staff, she is more likely to have the schedule and do the activities she wants to do.

- **Open *People First* opportunities to those not served by provider agencies.** Some providers host People First meetings. It would

be helpful if these meetings could be open to all people with disabilities and the provider offers the support needed for people not served by the agency to attend and to participate.

- **Support people served to attend self- advocacy conferences and trainings.** By providing the staff and the transportation for people who use services to participate in self-advocacy activities, providers can show they are committed to people becoming empowered.

- **Use "people first" language.** "I don't want to be called a 'case,' I want to be called a person."- Marilyn Martinez

What are some ideas for parents about self-determination?

- **Acknowledge what most parents want for their children is for them to be happy, healthy, safe, successful.**

- **Learn to let go.** "No matter how much protection you give, the world is coming anyway. When parents are first told that their child is going to have a disability, they are told they are going to need to take care of that child and protect them from the world. But the world is going to come anyway and you can fight it off as long as you can but when it comes, it's going to be a shock to a child who has been sheltered his entire life.

  - When I first started middle school, I had been sheltered all my life and the teacher I had wasn't a nice person and I had been told all my life that because of my disability, people would be nice to

me and he wasn't because I didn't fit the norm.

I went deeper into depression and started cutting myself off from the world. I figured if I didn't have any contact with the world, I'd be happier. It worked for a while but then I became lonely and felt like I wasn't getting support."
-Matt Heady

- **"I'm afraid to say certain things when my mom is around." -self advocate** Be aware that sometimes people are uncomfortable talking about certain parts of their lives in front of their parents. Parents can respect their son's or daughter's wishes to talk privately with others he or she trusts.

- **Mistakes happen.** Good intentions are good intentions but oftentimes what parents intend as protection results in control over their son or daughter.

You need to be willing to let the child go into the world, make their own mistakes, and learn from them.

- **Doctors and service providers don't have all the answers. It's important for parents to educate themselves about the options.** "When I was first diagnosed with a disability, my mother was told I would never be able to function on my own. The doctor told her I had one of two choices for when I got older: live with her or go into a group home. And this hasn't changed much. Parents still get told that and aren't given many options.

Parents end up seeing the system and local providers as the 'be all end all' because they don't know what other options are available."
–Matt Heady

- **Parents don't have to do it alone.** Talk to your pastor. Talk to a

school guidance counselor. Talk to other parents. Talk to anyone you would trust who you believe would support that person to be happy, healthy and support that person to grow and learn through their mistakes.

- **Relationships keep people safer.** By talking and building relationships in the community, you end up developing a community network and safety net for their child.

- **Talk with your child.** Parents need to ask their child what he needs to survive and what he wants in life.

- **Start early.** The sooner parents begin empowering their child with decision-making opportunities and chances to advocate for herself, the safer and more independent a person will be.

What are some ideas for supporting a person who doesn't use words to advocate for herself?

- **Even without using words, people still communicate.** People need to be aware of a person's body language and facial expressions. A machine can be programmed to say what a person needs to say, but it doesn't substitute for a person's body language.

- **Learn how a person communicates even if doing so requires stepping outside of your comfort zone.** It takes time and effort to pay attention to someone who doesn't use words or speaks slowly.

- **Don't assume you have all the answers or know what a person is thinking.** Sometimes you have to put your ego aside.

- **Reassure people that their input is valued.**

- **Personalized communication devices are a person's link to the world.** Communication supports need to be developed by people who know the person well. Communication devices need to contain phrases that support self-advocacy like "please talk to me directly" or "I deserve to be treated with respect."

- **Give people time to think about what they want to communicate.** Sometimes people need a little extra time to put their thoughts together. Be patient.

What are some ways to encourage a person's safety while leading a full life?

- **Let a person make her own mistakes.** Be willing to intervene when necessary and DO NOT intervene when it's NOT necessary.

- **Don't think about getting in trouble for supporting a person.** Before you can support somebody, get the notion out of your head that you're going to get in trouble if the person takes a risk. It's not the end of the world. "If we can get the state to relax, the provider can relax." —Matt Heady

  The more an agency gives you the room to make mistakes the more comfortable the person is with the agency. If a person is comfortable with an agency, it's less likely there is ever going to be a lawsuit if something bad happens.

- **Always look for opportunities to promote freedom and independence.** Put these opportunities into

the Individual Service Plan.

Other Words of Wisdom

- **Talking "person to person."** People are often more relaxed when talking one-on-one with another person where both people are treated as equals.

- **People sometimes respond like a child when staff are present.**

- **"Never hinder a person's will to try something new."**

√ CHECK IT OUT: GOOD RESOURCES

- People First of New Mexico and the Self Advocacy Project, 505-688-4225 http://peoplefirstofnew mexico.blogspo.com/

- The New Mexico Center for Self Advocacy, (505) 341-0036, http://www.nmddpc.co m/csa

- Self-Advocates Becoming Empowered (SABE) www.sabeusa.org

- For thoughts about promoting self-determination in services, check out "The Meaning of Self Determined Lives in Publicly Funded Systems of Longterm Care" by Tom Nerney available at http://www.self-determination.com/article s/meaning.pdf

- "People First Language" by Kathie Snow. Available at: http://www.disabilityisnat ural.com/peoplefirstlangu age.htm

- "Developmental Age vs. Chronological Age" by Kathie Snow. Available at: http://ftp.disabilityisnatural .com/articles/documents/ DevAge.pdf

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

- **"People with disabilities are our**

best teachers."—Judy Stevens
To schedule conversations or trainings about self-advocacy, contact one of the resources listed in *Check it Out* .

Champions Assure Progress is Linked to the *ISP*

IDEA 1: HOW TO BE A CHAMPION: IDEAS FOR INTERDISCPLINARY TEAMS AND TEAM MEMBERS

What we believe can happen dramatically influences our drive and accomplishments. This is also true of our expectations of others. Teams need to continually elevate their expectations regarding individuals whom they support.

- **Angela Pacheco and Teresa Tomashot**

IN A NUTSHELL:

Team members are in a unique and privileged position of deeply influencing what a person's life looks like. They guide a person's decisions. They advise a person on how to use his service funding. They largely determine what the person's services (and even life) look like. It is a role that should be taken humbly and in the spirit of truly supporting a person.

The very best teams include *champions* for the person and become *champion* teams.

LIVING IT: A SUCCESS STORY
Dorothy and Her Supports

Through a personal profiling session, Dorothy said she wanted a job. Her team was surprised since she was 60 years old at the time and had no previous work history. As a result, Dorothy got a job at a restaurant that she loved and where the regulars knew her by name. With her team's support, Dorothy made a career change and now works at OK Travel Center. Dorothy saves most of her money in her own savings account.

Her staff and her team also encourage her to make friends and do things on her own. Her team fully supports her membership in the Knights of Columbus and she won a recent volunteer award for her various community contributions!

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS

Ideas for Outside the Meeting

People Are People: Connect First as Human Beings.

- Spend time with the person you support in your "off hours" sharing mutual interests: a movie, a ballgame, a horseback riding trip.

- Work from an assumption that the person you support is your equal. Period. End of story.

- Work to support each other in different ways—look for ways to contribute to positive energy.

Work To See the Person in His Most Positive Light

- Model the respect you hope others will give the person you support.

- *Flip 'negative' behavior.* Is laughing loudly or talking a lot really a "negative" behavior? Support a person to find places where her "negative" behavior isn't a big deal or is even appreciated.

Support Each Other's Learning of What Person-Centered Support Means.

- Invite everyone on the person's team to commit to stretching a little outside his or her comfort zone if doing so is right for the person. For example, if a person's mom is anxious about her son living in his own apartment, ask if she will consider going with her son to *meet* others living in their own homes.

- Share articles, websites, books and conference materials that may deepen each member's understanding of how to support a person.

- Challenge your *own* assumptions about the person and your motivation for being involved in his life. Share new lessons you've learned about your own assumptions with others. Doing so creates a safe space for others to acknowledge and explore their own biases.

- Help organize a personal futures planning session for the person, where the person invites anyone he wants and only the people he wants. The session is about dreaming and

not necessarily about paid services.

- Attend "best practice" conferences as a group and talk about what you learned.

Ideas for Team Meetings

Create a Relaxing Space for Conversation

- Get out of the conference room. Meet where people connect most comfortably: at their homes, in a meeting room at a favorite restaurant, at a park.

- Go where it's quiet. Natural light helps too.

- *Peace Begins with a Smile*
            -Mother Theresa
  Try to check any frustration you're having at the door. The person deserves positive, attentive support. Just smiling helps.

- Consider starting each meeting with a positive quote, reading or something else chosen by the person. Invite the group members to share what they're grateful for or share a success story about the person at the center of the meeting.

Fun Is Effective

- Consider partying at the meeting: bring fun food, celebrate accomplishments with music, balloons or whatever makes the person happy.

- Look for opportunities to laugh. Consider inviting everyone to come to the meeting and share their favorite joke, their favorite "Top Ten" list from David Letterman, or their favorite movie clip from a funny movie.

- Go party as a group afterwards. Go out to eat. To a ballgame. To a movie. To play pool. Bond as people.

It's All About Her

- Support a person to lead, facilitate or contribute to his meeting. If she's falling asleep, chances are there's a better way to involve her or structure the meeting. See the *Check It Out* section for resources about supporting a person to lead or participate in her own meeting.

- Listen *deeply* to the person as if you had all the time in the world…and ask follow-up questions.

A Proposed Order of Conversation: Person First, Team Second, ISP Form Third

- Try keeping the general ideas and the general questions from the ISP in your head and then frame the meeting as a conversation with the person. Don't write immediately. Listen. Ask follow up questions.

- Invite positive input from the team after the person has had an uninterrupted opportunity to talk about what he wants in his life and in his services.

- As a team, consider identifying an ISP "note taker" who is quietly completing the ISP form based on the conversation. Then work together as a team at the end of the meeting to make sure everything is captured.

- If you're responsible for preparing the ISP, come prepared with the simple parts of the form (a person's name, address, etc.) already completed. This leaves more time for creative, person-centered conversation.

Being Sensitive To the History: It takes a lot of guts to share your entire history with a bunch of people.
Before starting a meeting, consider asking the person for permission to discuss their story. Some people enjoy telling their story and will readily share it with others. If so, support them to tell it and ask questions that invite them to share new information.

Other people have grown weary of telling and retelling their story. If that's the case, here are a few suggestions:

- Build from what history you already have. Instead of expecting a person to retell his story every year, ask him to share what's happened since you last met.

- Minimize the negative history that is no longer applicable. People make mistakes. People grow. People change. Support the person you serve to release the part of his identity that no longer applies to him. If he hasn't started fires in 15 years, it may not be necessary for new people in his life to have a conversation about this history; it's in his file if, for some reason, they must know it.

Model Optimism and Enthusiasm for Others

- Ask yourself with every decision, what is the most positive outcome for the person I serve?

- Celebrate successes…even the tiny ones. Has the team arranged for Anne, a coffee lover, to go out for coffee every morning before she goes to work? That's probably a big deal to Anne. Support the team to celebrate these accomplishments.

- While staffing issues affect a person, try handling these issues at a staff meeting instead of during the person's ISP meeting. When you *do* handle them, involve the person in the management decision and proposed solutions.

Being The Person's Ally

- Before meetings or conversations, consider taking a minute to remind yourself of all of the person's positive attributes and why you choose to remain a part of her team.

- Model good listening when the person is talking. Make eye contact if culturally appropriate,

don't interrupt, put down your pen, ask follow up questions, and summarize what you heard.

- Understand that the person's preferences may be unexpected: sometimes a person actually wants to meet in a conference room because the meeting goes faster!

- If the team wants to meet without the person, consider what that preference suggests. It often means that the team wants to "strategize" about how to have a "unified front against" the person. It's difficult to believe that team members are true allies of the person when this occurs. Have the courage to thoughtfully tell others why meeting without the person makes you uncomfortable. For suggestions on how to voice your concerns, see *Try it Out* .

- Invite the opinions of others. Listen to those who may not always be encouraged to share their perspective: the person (of course), but also their direct support staff.

- Guardianships are often much more limited than we assume.

Under law, guardians are still required to support a person to make her own decisions to the extent possible. If a person has a guardian, make sure you know what kind of guardianship it is and exactly what rights the person has had taken away. Help the person share his wishes with his guardian.

Inspiring Others to be Allies: *Voting for Opportunity*

- Be the one who shifts the conversation from *if* a person can do something to *how* a team can support a person to do it. Sometimes, just changing the words used can make a huge difference. Be the one in the group that asks "So, *how* can Sara live in her own home?" instead of "Can (or should) Sara live in her own home?"

- Acknowledge and openly appreciate the gifts *everyone* on the team brings. Sincere compliments, playing to people's strengths and using the gifts we each have encourages others to embrace "capacity thinking."

- Consider suggesting to the team that the words "no" or "can't" be off limits, unless voiced by the person.

- Build personal relationships with each team member. If a team member always seems reluctant to try new things, get to know that member well. Oftentimes, people become reluctant to try new things because they are afraid. Relationships based on trust can help people overcome their fears.

Discussing Money

- Remember, each person paid through a person's waiver can have a potential conflict of interest: the team member's income level is often directly tied to the amount his service is authorized to provide. Trust your gut. If a team member is recommending services that you don't think a person needs, probe a little about 1) why the service is needed and 2) what other "non-service" ways a person could receive the same kind of support.

- Sometimes a person or his family renews the same level of the same services every year out of habit. And sometimes, a person may not know they have the option of adjusting his services or how his funding is used. A champion reminds the person/his family of these

choices and supports them purchase the services that best meet their needs. See *Try it Out on page 108* for ideas on explaining the ARA budget and the option to adjust services.

The Space between the Reality and The Vision Is Where the Creativity Lies...Cultivating Creativity

• "I want to be president." Champions encourage big dreams. Dreams don't always come true but they inspire us to stretch and try new things as we work towards them.

• *Don't think outside the box, throw the box away.*
    —Judy Stevens

What would a person want in his life if:

• Money weren't an issue
• He couldn't "fail"
• There were no safety concerns

When supporting a person to dream start with the answers to these questions.

When We Disagree Or Are Stuck...

• Listen to the person first. Let the opinion of the person using services guide the conversation.

• If the conversation is heated, strive to be the calm one in the group.

• Take even more time than usual to collect your own thoughts before speaking. When people disagree, the words, tone and style they use when talking can determine the productivity of the conversation.

• *You cannot solve a problem by using the same type of thinking that created it.*
    —Albert Einstein

Consider inviting "new blood" into the thinking process. There are "good thinkers" both within the DDSD system and in the community that may bring a different perspective.

• Be careful about making absolute statements that tend to create an adversarial dynamic like "that's wrong." Articulate things from your perspective, using phrases like,

"The way I see it" or "I think that…" "As I understand it…."

- Come back to the things everyone *can* agree to and start there.

- Remember, complete consensus from the team isn't required for a person's decision about her life to be respected.

For additional ideas for working together when team members disagree, see *Try it Out* .

Doing The Right Thing Over Doing Things Right

- The team's first responsibility is to *support* a person. Sometimes, in urgent situations, like when a person's family member dies or there is another emergency, doing what's right for the person may not be consistent with what the rules require. This may mean that meetings and paperwork are temporarily set aside while team members support the person to cope with the emergency at hand.

  In urgent situations where you don't follow protocol, consider asking yourself three things: 1) am I doing what is most respectful and matters most to this person right now? 2) Who do I need to call and keep up-to-date on what's going on? 3) Would it be a good idea to write down a few notes about my approach to supporting a person?

√ CHECK IT OUT: GOOD RESOURCES

- For resources on team-building and conflict resolution, contact Christine Wester at 505-841-5529 or at Christine.wester@state.nm.us

- For ideas for involving people with disabilities in meetings, check out *The National Association of State Directors of Developmental Disability Services* handbook: *The Guide: The NASDDDS Handbook on Inclusive Meetings and Presentations* at http://www.nasddds.org/pdf/TheGuide.pdf

- For ideas for being a "communication ally," take a look at Mayer Shevin's article "On Being a Communication Ally." It's available at: http://suedweb.syr.edu/thefci/7-4she.htm

TRY IT OUT:
ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

Exercise: A Tale of Two Teams

Read the following scenarios and then as a group, discuss your answers to the following questions:

1. If you were Maya, which team dynamic would you want?
2. What practical things can we each do to build a team that supports a person to live a life she chooses?

Scenario One:

Maya has an IDT team consisting of a corporate guardian, case manager, day services manager, a group home manager and a behavior therapist. Maya rarely sees her guardian outside the ISP meeting. Each year, this team meets in the day service conference room to develop Maya's ISP. Maya says she really wants to live in her own apartment, but the team notes that if Maya moved into her own apartment it would result in lost revenue to the group home. The team decides to table the discussion about the apartment. The team spends the majority of the meeting discussing how Maya is manipulative. The team authorizes another year of behavior therapy on the ARA. Even though Maya says she doesn't want this therapy, the guardian overrules this decision without further discussion. The rest of the meeting is spent completing all parts of the ISP form, which frustrates the providers who have already submitted some of the information to the case manager to be included. After the signature page is circulated, everyone leaves and goes to other meetings.

Scenario Two:

Maya has a team consisting of her former guardian (who is now Maya's friend), her case manager, day services manager, a group home provider and behavior therapist. Maya used to have a corporate guardian but the team petitioned the court to reconsider the need for this after it became clear that with supports, Maya could make many of the decisions assumed by the guardian. All of Maya's team is committed to doing what they can to support Maya to thrive. Each of them has spent time with Maya informally: going to a movie, out to eat or sharing a "smoke break" with her. They all knew before the ISP

meeting began that Maya really wants to live in her own apartment and doesn't want as much behavioral therapy. Maya decides to hold her ISP meeting over lunch at her favorite restaurant and with the help of her direct support worker, reserves the meeting room there. During the lunch meeting, the case manager and Maya lead a conversation about what it would take Maya to live in her own place. Her group home provider offers to provide come-in support to Maya in Maya's apartment. Maya's direct support worker from her day services program has a friend who manages an apartment complex and has agreed to be an emergency contact for Maya if she decides to live in the complex.

During the meeting, the case manager takes notes as the team develops an action plan for Maya to live in her own apartment. Maya and her team think it's possible for Maya to move into her own apartment within six months and commit to doing so.

Exercise: Supporting People to Understand Where the Money Goes in the ARA.

Some ideas:

1. Talk to them: Sometimes simply sitting down with a person (and her family if appropriate) and explaining how the ARA works is enough. Ask a person to share what services are most important to her. Ask her if there are services she thinks she doesn't need anymore? Are these preferences reflected in the ARA? If not, make sure to point this out to the person (and if appropriate, her family).

2. Show them: For people who don't read or do math, a pie chart can be a really useful tool for showing how much of the budget or "pie" goes to each service. This enables a person to make a more informed decision about how to spend her ARA budget.

3. Brainstorm with them: Sometimes a person will continue services she doesn't really want because she likes the person providing them. If this is the case, consider brainstorming with the

person and her team for how the person can remain connected to the service provider without continuing the service.

Exercise: Some Ideas for How to Disagree Nicely

Finding a "right" way to disagree or raise concerns to others is never easy. And an approach that may work really well for one person, won't work at all for another. However, there are a few approaches that seem to work well in most situations.

Try to Keep People from Feeling Defensive

- Avoid using "you." Look for ways to use "we" or "the team." For example, instead of "You shouldn't have meetings without Tim" try "I don't think we should hold Tim's meetings without him."

- Frame your thoughts as your opinion rather than a fact. For example, consider saying "I am really uncomfortable about having a meeting about Tim without him" instead of "It's wrong to have a meeting about Tim without him."

- Even better, frame your opinion in the positive. For example, "I

think we could better serve our roles as team members if Tim were a part of the discussion."

Open Up the Conversation to the Group

- Ask team members to share their own thoughts. "I would really like to talk about why we want to have a meeting about Tim without him." Simply raising the issue is sometimes enough to get people to rethink the logic of the decision.

- Gently ask the question: "Do we have the Tim's permission to meet without him?" Sometimes team members simply assume its ok to meet without the person. Asking the question encourages people to think through this assumption and potentially develop a more person-centered alternative.

- Oftentimes, it's only one team member who truly wants the team to meet without the person and other team members silently go along with it. Sometimes, by gently raising another alternative (like including a person in his own meeting) other team members will have the confidence to voice their own opinions.

A Note About Personal Choice

- Sometimes the person actually *doesn't* mind when others talk about him without him and would prefer to not be a part of every meeting. The key is to ask the person what his preferences are *before* holding a meeting without him.

Champions assure progress linked to the *ISP*

IDEA 2: HOW TO WRITE A GOOD DEFINITION OF A MEANINGFUL DAY

IN A NUTSHELL:

A good personal definition of a meaningful day supports a person to flourish in a fulfilling life. It belongs to the person, is unique to the person, supports progress towards his/her vision, expands and grows with the person, is concrete enough to know when it is happening. In addition, with other parts of the ISP as well as spontaneous choices the person makes this definition, is an expression of how each person wants to guide the content of her/his daily experiences and the supports to make those experiences happen.

LIVING IT:
AN EXAMPLE OF A GOOD DEFINITION OF A MEANINGFUL DAY

See *ISP Instructions* that include examples of good personal definitions of a meaningful day on the DDSD website at:
http://www.health.state.nm.us/ddsd/PromisingPractes/documents/ISPInstructions7-5-06version.pdf

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS

Some Questions and Answers about *Meaningful Day*
What is the official purpose of the meaningful day definition?

- Each ISP must contain a definition of the individual's unique meaningful day so that the team will be able to support the individual in participating in ordinary community activities and functions of his/her choice that the general population desires and chooses.

What timeframe does the "day" in meaningful day cover?

- The term "day" does not exclusively denote activities that happen between 9:00 a.m. to 5:00 p.m. on weekdays.

What does the definition describe and support?

- Each person's definition of a meaningful day captures what the person desires to do, including community connections.
- The personal definition supports progress toward the vision, but can be broader than the vision and action plan.

What does a good definition include and have as a result?

- A good definition of a Meaningful Day contains concrete descriptors to answer the question: how will you know the person is doing activities related to his/her definition of a Meaningful Day when you see it?
- As a result of the implementation of the person's meaningful day definition at a specific time, the person should come away with more today than (s)he had yesterday and be closer to achieving his/her desired life and outcomes.

Who develops it?

- The person develops the definition, supported by friends, family, close staff members, other IDT members, and the case manager.
- Each member of the IDT takes an active role in supporting the person to develop a definition.

How does everyone prepare to develop a good personal definition of a meaningful day?

- Ask the person what makes him/her feel good in life.
- Think of fun ways that a person can own her/his own definition of a meaningful day. See examples of how to do this (including involving friends, family and staff members who are close to the person) in *TRY IT OUT* on page 116.
- Providers offering Adult Habilitation or Community Access services can help the person prepare by supporting him/her to experience increasingly varied and broad community inclusive options so that s(he) can make informed choices.

- In 2007, these providers are supporting each person to develop a draft definition of a meaningful day to bring to the IDT.
- After 2007, these providers and other IDT members will gather information from the individual and others who know the person well prior to the IDT to enrich the definition over time.
- The ISP reflects that input from the person as well as informed choice, regardless of his/her level of care, method of communication, or current services offered.

Where is the definition finalized?

- Each individual's definition of a meaningful day refined, expanded, and finalized at the annual (or special) ISP meeting.

How is the initial definition documented?

- The person may supplement written documentation with a scrapbook of photos or other ways shown in *Selection 7,*

Idea 3: Tracking the progress documentation *.*
- The case manager records the results of the IDT discussion in the ISP.
- Community Access and Adult Habilitation providers report the date of the ISP that the definition was developed for that individual in the Performance Contract Quarterly Report.
- The reporting is specific to each person's definition (example: Josephina went to the mall – why? What happened there specifically related to her definition?).
- For more information see: *Selection 7, Idea 3: Tracking the progress – documentation*

When will everyone have a meaningful day definition?

- Using the 10/1/06 ISP form, all individuals served by DDSD will have a meaningful day definition no later than 9/30/07.

How does the definition relate to Community Inclusion Services?

- The person's definition of a meaningful day should be reflected in the choices and activities (s)he is offered in Community Inclusion Services.
- The individual should have enough information and experience to make an informed choice about what (s)he wants to do on a daily basis to support progress towards his/her outcomes listed in the ISP.

What a *Meaningful Day* Isn't:

- The person's meaningful day definition is not the same definition as the definition every other person in a specific program has.
- The person's meaningful day definition is not just a time filling list of activities or a restatement of what the person is currently doing.
- A definition that lists what the person will not do or does not want to do.

√ CHECK IT OUT: GOOD RESOURCES

- See *Selection 8: And Yet More…*, *Resource 1: It's Official: The Unabridged 3/1/06 Measurable Definition of a Meaningful Day* on page 122.
- You can get technical assistance on how to develop a good personal definition of a meaningful day by submitting a Request for Intervention Form (RFI) to your DDSD Regional Office. See the map of DDSD Regional Office contact information on the DDSD website at: http://www.health.state.nm.us/preview/ltsd/providerlocationspagedevelopment/providerlocationspg06.htm
- See *ISP Instructions* that include examples of good personal definitions of a meaningful day on the DDSD website at: http://www.health.state.nm.us/ddsd/PromisingPractes/documents/ISPInstructions7-5-06version.pdf

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

Think of fun ways that a person can own her/his own definition of a meaningful day, for example:
- Ask the person to choose a team member (s)he trusts.
- Ask the questions that help the person think about what (s)he wants from life (for example: what don't you do now that you used to enjoy?)
- If the person does not use words, use his/her Communication Dictionary and observation to figure out what the person likes (for example: the person laughs when she is bored, and stares intently when she is interested – note what's happening when both occur).
- Ask friends, family and staff members who are close to the person what (s)he is doing when (s)he is happiest.
- Figure out how to build a picture of what the person wants in life (for example:

make a collage out of photos the person selects).
- Decide how both can present this to the team for inclusion in the meaningful day definition (for example: one person points to the photos while the other sings a song that describes it).

Write a meaningful day definition for yourself.
- Review the criteria for a good definition under *BRINGING IT TO LIFE* on page 112 to see if your definition meets the mark.
- What did you discover about yourself from writing this?
- How can having this down on paper help you grow in the directions you want?

Work backwards from the bottom line, a great life:
- Identify someone who is flourishing in a fulfilling life enjoying loving relationships, strong connections to the community, rewarding work, a home s(he) is proud of, wellness and lots of opportunities for

fun doing what s(he) is passionate about.

- Look at that person's definition of a meaningful day (if the person does not have a definition, try drafting one).
- Does the definition describe this good life?
- How can the definition expand to support this person to grow even more?
- What can you learn from how this person achieved this life?

Take a look at current ISPs and ask (*hint: the answers should be "yes"*):

- Is the ISP form implemented by DDSD in 10/1/06 used for ISPs developed since that date?
- Is a meaningful day definition in place for each person who has had an ISP since 10/1/06?
- How is the person achieving desired outcomes in a timely way?

Take a closer look at one person's definition and see:

- In what ways is this meaningful day definition unique to this person?
- How does the meaningful day definition support the person's vision?
- Is the meaningful day definition written concretely and specifically enough that results of it can be documented?
- Is the definition of the person's meaningful day changing over time as the person experiences more varied and broader community inclusive options from which to choose?
- How is informed choice being assured, regardless of level of care?

IDEA 3: TRACKING THE PROGRESS THROUGH DOCUMENTATION

IN A NUTSHELL:

How do we show that people are doing the things that are important to them and are getting out into their communities? Like everything we do, we need to start with how documentation can be owned by the person. A group of stakeholders thought about how to show that each person is asked what (s)he wants to do during the day and evening, spends most of his/her time doing the things that are in his/her individual plan and definition of a meaningful day and spends time in ordinary places in the community doing the things (s)he wants to do.

LIVING IT:
A Creative Way of Tracking Progress

A Community Practice Reviewer visited a person's home. The person receiving services, the Family Living provider, and the reviewer had a good talk about what the person had been doing that was meaningful in his life. He likes to be in plays. He likes to buy art at art flea markets. He likes to make art. They showed the reviewer a scrapbook of dated photos, a collage showing gatherings he was part of, as well as art he made and collected. The reviewer saw concrete evidence of outcomes of things the person likes to do that helped bring the written documentation alive.

BRINGING IT TO LIFE:
THOUGHTS AND IDEAS

Find out how a person likes to remember the good things that (s)he wants in life and use those ways to bring written documentation alive. See *TRY IT OUT* on page 120 for examples of how to do this.

Here is what the group of stakeholders says you should see if documentation is good and meaningful choices are being offered throughout each person's day:

- the ISP has lots of clear and specific ideas about what the person enjoys and where s/he likes to spend time.
- daily notes show that each person is given lots of choices for things to do each day that are meaningful the him/her in a way (s)he can understand (what choices are being offered, how they are being communicated, and how often),
- if you ask direct support staff, they can tell you what and how choices were offered to and made by each person supported,
- if you observe the person, you can see how choices are being offered throughout the

day that are personally meaningful and understandable, and, like many people,
- each person has his/her own date book or calendar that shows what (s)he did, and when and where (s)he did it.

Here are some additional elements that should be observable and documented:

- the expanding variety of experiences the person has had to be able to make informed choices,
- the communication supports that are in place and being used throughout the day to make choices (for example: how is a person's communication device programmed so that the person can make a variety of choices – including being able to say "no" and to show if (s)he doesn't like an activity)
- that the person's ability to answer and the staff's ability to understand that answer match (for example: the person has a unique method of signing and staff members can communicate using that method),

- evidence that the person is accomplishing desired outcomes.

√ CHECK IT OUT:
GOOD RESOURCES

- *See Selection 8: And Yet More…, Sample Daily Note, Documenting Community Building* on page 134
- You can get technical assistance on documentation by submitting a Request for Intervention Form to your DDSD Regional Office. See the map of DDSD Regional Office contact information on the DDSD website at: http://www.health.state.nm.us/ preview/ltsd/providerlocationsp agedevelopment/providerlocati onspg06.htm

TRY IT OUT: ACTIVITIES, EXERCISES AND COMPELLING QUESTIONS

Find out how a person likes to remember the good things that (s)he wants in life and use those ways to bring written documentation alive. This can also be useful for letting new people in the person's life

- For example, if a person likes music, (s)he can pick a song that reminds her/him of what happened, make up a song about what happened.
- If a person likes to cut out photos, (s)he could create a collage of photos from magazines that show what happened.
- If a person likes to draw, (s)he could draw a picture of what happened.
- If a person likes to take photos, (s)he could take photos of an event, put the photos in a scrape book, frame them, or make a collage.
- A person might like video. If so, video clips could be taken at important happenings.

Spend a few minutes with a group of people talking about how you document to show that each person is:
1) asked what (s)he wants to do during the day and evening in a way that is meaningful to and understandable by that person,

2) spends most of his/her time doing the things that are in his/her individual plan and definition of a meaningful day, and

3) spends time in ordinary places in the community doing the things (s)he wants to do.

- If someone asked if these three things were happening, what would you show them?
- Compare how you are currently documenting that these three things are happening with the samples in *LIVING IT: AN EXAMPLE OF* on page 118 and in *Selection 8: And Yet More...* see page 139, *Resource 2: Tracking the progress: how some providers are doing it* see page 118.
- Look at the ISP of a person you know. Does it include lots of ideas about what the person likes to do and where and when those things can happen? If it does not, what and how could you add to it? Share your ideas of how

to improve and expand the ISP with the person and his/her team as soon as possible.

- Look at the daily notes written by others who support the person. Do they show that choices were given and made in a way that is meaningful and understandable to each person? Draft a way to change the form to remind people to write information about choices.
- Does the person have a date book that shows that (s)he spends time in the community doing the things (s)he enjoys? If there is no date book or you have ideas to make it better, meet with the person to make it happen.
- Share your new documents with anyone who needs to know and use them.

And Yet More...

IT'S OFFICIAL: THE UNABRIDGED 3/1/06 MEASURABLE DEFINITION OF A MEANINGFUL DAY
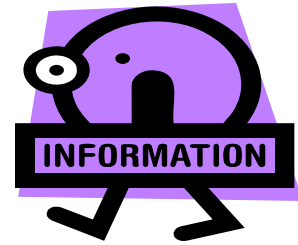
Measurable Definition of a Meaningful Day

Definition

Meaningful Day supports provide individualized access for individuals with developmental disabilities to support their participation in activities and functions of community life that are desired and chosen by the general population. The term "day" does not exclusively denote activities that happen between 9:00 a.m. to 5:00 p.m. on weekdays. This includes: purposeful and meaningful work; substantial and sustained opportunity for optimal health, self empowerment and personalized relationships; skill development and/or maintenance; and social, educational and community inclusion activities that are directly linked to the vision, goals and desired personal outcomes documented in the individual's Individual Service Plan. Successful Meaningful Day supports are measured by whether or not the individual achieves his/her desired outcomes as identified in the individual's Individual Service Plan.

Criteria

Meaningful Day supports are measured by each individual's achievement of his/her desired outcomes, as identified in the individual's Individual Service Plan and as documented in daily schedules and progress notes. Each Meaningful Day activity should help move the individual closer to a specified outcome identified in his/her ISP.

1. Does the ISP action plan contain activities that are linked to the individual's vision, goals, and desired outcomes and would lead to a meaningful day for the individual?
2. Are these activities being carried out in accordance with the plan and with the frequency specified in the plan, at least 75% of the time?
3. Are these activities resulting in self-empowerment, new relationships, work/volunteer experiences, memberships, valued roles, skill development and social, educational, and community inclusion, consistent with the individual's desired outcomes?

Meaningful Day
Considerations for Team Planning

What is a Meaningful Day

Meaningful Day activities support an individual to routinely explore, secure, maintain, and/or change memberships, valued roles, and/or personal relationships in the community. Meaningful Day supports are age appropriate and provide a wide variety of planned opportunities to facilitate and build relationships and natural supports in the community. Meaningful day includes substantial and sustained opportunity for optimal health, self empowerment and personalized relationships; skill development and/or maintenance; and social, educational and community inclusion activities that are directly linked to the vision, goals and desired personal outcomes documented n the individual's Individual Plan. Such planned activities may include opportunities to:

1. Explore, secure, maintain and/or change supported or competitive jobs;

2. Explore, secure, maintain and/or change post secondary educational activities;

3. Explore, secure, maintain, and/or change volunteer activities;

4. Experience and participate in community exploration, companionship with friends and peers;

5. Develop, maintain and regularly experience chosen hobbies;

6. Maintain family contacts;

7. Engage in community events, education experiences, and those activities and services where persons without disabilities are involved.

8. Learn and develop new skills to support purposeful participation and independence in the community.

All of these experiences would be planned, purposeful, and reflected in daily schedules. Experiences are not just "events" or time fillers.

Meaningful Day Activities – Examples

The following are examples of "meaningful day" activities, for use by IDTs in creating measurable ISP action plans related to the definition of meaningful day.

1. The individual is engaged in daily activities that lead toward his/her personal outcomes.

    a. The individual is trying new things, which are intended to result in the attainment of an identified outcome in his/her ISP.
    b. The individual is learning new and/or maintaining skills, which are intended to result in the attainment of an identified outcome in his/her ISP.

c. The individual is doing things on his/her own in an effort to gain more confidence and skills.
d. The individual is choosing what he/she wants to do and is doing things in the community.
e. The individual is engaged in preventative health care activities/interventions as needed.

2. Support provided to an individual while he/she is engaged in work that is compensated under the Fair Labor Standards Act.

3. Work exploration in the community in order to learn about jobs that might match the individual's interests and skills.

4. Volunteer time in the community, as long as the individual can be observed to have regular significant personal interactions with non-disabled peers or   recipients of the volunteer service.

5. Instruction, when it can be demonstrated that learning objectives or skill development are linked directly to the individual's vision goals, and desired outcomes. (Includes instruction by direct care staff that is conducted under a structured plan developed by a therapist or time when the therapist with the active engagement of the individual, is modeling/instructing or consulting with direct   care staff on therapeutic interventions.

6. Time that the individual is engaged in exploring new interests and/or relationships or establishing meaningful social roles consistent with the DDSD policy.

Examples of activities that would <u>not</u> support this definition are:
1. Activities that the general population would not engage in on a regular basis for extended periods of time.

2. Sustained or extensive time spent in skill building, or frequent use of leisure activities, that isolate the individual from non-disabled peers, such as:

a. Sheltered work for longer than needed for specific skill development.
b. Window-shopping or mall walking with program staff/housemates as a time-filling activity.
c. Volunteer work in isolated or congregate settings intended for persons with developmental disabilities.
d. Instruction not linked to an individual's vision for life or ISP.
e. Activities that are not individualized or age appropriate, e.g. coloring in children's coloring books every morning at the day habilitation program.
f. Watching television alone or with staff/housemates regularly, for extended periods of time.

<u>Additional Considerations for Retired Individuals</u>

Retirement Planning for individuals with developmental disabilities should include the same considerations used by the broader culture and will be consistent with the DDSD definition of meaningful day. Considerations should include adequacy of resources, implications of long term disabilities on the person, implications of the person's changing health status, identification of

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interests to pursue, implications for others who are significant in the person's life or impact on the person's self-esteem.

The individual and his/her IDT should incorporate the results of retirement planning into the ISP after exploring these, and any other, considerations that are important to the individual. The ISP should ensure support for an active and meaningful life in line with the individual's preferences and needs.

Service planning for retired persons should be individualized, and should take the following into consideration:

1. Services options will not be restricted based on the fact that an individual is retired. Retired individuals have access to all services and supports available to non-retired individuals.

2. Service planning will address the individual's need for continued growth and development and access to learning opportunities.

3. The individual will determine their daily schedule as part of ISP development and implementation. The pace and timing of a day's activities and events is consistent with the individual's wishes.

4. Daily activities will focus on preventing isolation and maintaining/increasing purposeful activity, including recreational opportunities, in the community.

5. Activities are sufficiently individualized to reflect the interests the individual wants to pursue.

6. Participation in groups, civic organizations and volunteer work reflects the interests the individual wants to pursue.

7. Exploration of new interests and opportunities to form new relationships are consistent with the individual's demonstrated or expressed desire to have new experiences.

8. Supports necessary for the individual to participate in and enjoy activities and events are available and use.

And Yet More…

INFORMATION
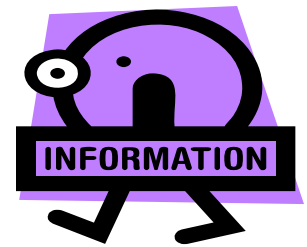
SOME EASY, PRACTICAL WAYS TO BE AN AMBASSADOR FOR A PERSON YOU SERVE

Always, Always, Always Be on the Lookout for Potential Connections and Resources.
We sometimes find potential friends and supports in unexpected places. As a person's staff member, we play an important role in supporting the person we serve to expand her circle of friends and community connections.

Some simple ways to do this:

- Support a person to "become a regular" at a place. Matt got a job at the YMCA because he swam there twice a week and his support worker helped him build a friendship with the lifeguard.

- Strike up conversations with a person in line at the store or at the bus stop in ways that the person you support can participate.

- Support the person to get to know people in the community by name (the bus driver, the waitress, the bartender, the librarian). Greet people using their names.

- Work with family members and others on a person's team to identify community contacts that could support a person's interest and become potential friends.

- Support a person to read the paper or surf the internet to learn about community opportunities and activities that interest her.

Model Interaction for Others
When *you* show respect for a person, recognize him as your equal, and support him to speak for himself, others in the community will follow.

For example, when the waitress asks *you* what the person wants

Created by Valued Customer

for lunch, gently encourage her to ask *him directly*.

If he needs support in answering, direct the comment to him first: "Jim, my guess is you'd like a hamburger with no mustard."

"Peace begins with a smile."
                              - Mother Teresa

When others in the community see you and the person you support, you can set the tone, no matter what the situation.

Be in the habit of smiling, making eye contact with others and being friendly whenever you're with the person.

Tip Big!

As you support a person to "become a regular" at his favorite coffee shop, restaurant or bar, support the person to tip big if the service was decent.

Servers often base their impressions of customers on the size of the tip they receive. So if the server is friendly and respectful, leave a big tip. Twenty percent of the total bill is considered a nice tip. The easiest way to determine 20% is to take 10% of the total bill by moving the decimal one place to the left and

then doubling that amount. So if the bill is $12.00, 10%=$1.20 x 2= $2.40 tip.

A special note about timing in restaurants: Servers say the best time to become a "regular" is before or after the busiest time at the restaurant. Servers are able to spend more time talking and getting to know the customers that eat at slower times of the day.

Support the Person to Practice Random Acts of Kindness

There isn't enough kindness in the world and as we support people with disabilities to become a part of their community, we have an opportunity to facilitate "random acts of kindness."

How people do this depends on the person's interests and style, but here are a few examples:

- A person can give a card to her mail carrier at the holidays;

- A person can hand deliver a thank you card to her favorite grocery store clerk or local fire department;

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- A person can bake cookies or run errands for a sick neighbor;

- A person can offer to pick up his neighbor's mail or water his neighbor's plants when the neighbor goes out of town;

- A person can make an annual donation to a charity of her choice.

Assume Everything is Possible and Ask for Assistance to Make it Happen.

Our job is to support a person in doing things that are important to him and in trying new things. Our job is not to ask *if* something can happen but *how* can it happen.

Always be open to think of as many ways as possible for something to *work.*

For example, what if the person you support wants to take a class at the local college, but doesn't know how to register? How would you support the person to find out? Some ideas:
- Call the college;
- Ask your daughter who goes there.

- Ask your manager for assistance in learning the process.

What if the person has a job but doesn't have a way to get to it? How would you support a person to find transportation?
- Talk to the people at the local transit service;

- Brainstorm with the person and his co-workers.

Bring a Positive Outlook to Awkward Situations

Sometimes we find ourselves in awkward or embarrassing situations: Jeff sits down in the parking lot and refuses to get up; Stan spills a drink…or two…while at the diner.

We've all been there and people (both the person you support and those around you) will take cues from you about how to handle the situation. Smile. Breathe. Be helpful, patient, positive and keep your sense of humor even if on the inside you feel embarrassed or uncomfortable.

Do WE Make a Person Look Different than Everyone Else?
Sometimes as paid staff, we do things when we're in public that make the person we support look different from the rest of the community. This makes it harder for other community members to identify with the person using supports and therefore can make it harder for the person to build relationships.

Sometimes, we can make simple changes that can make a difference in how a person is seen by other community members.

Below are some examples of questions to ask yourself when you're supporting someone in public:

- Do you bring the entire medication box into a restaurant when you go out to eat the person you support? What about just bringing the pills he needs instead?

- When you're out with the person you support, do you tell others in the community that you work for an organization that supports the person? Is this necessary?

- Do you wear a name badge or scrubs or something else that shows other community members that you are paid to support the person? Can you wear your regular clothes? Doing so will likely make you (and everyone around you) feel more comfortable!

- Is the organization using a van that has the organization's name on the side of it? Is there a way to get this lettering removed or use other cars?

Go Outside Your Comfort Zone.
Hopefully, you and the person you support are "a good match" and are interested in the same things. However, we're all different and sometimes the person's interests are different from your own. Your job is to support the interests of the person you serve.

It's okay to say "I've never done that before" or "I'm nervous about trying this" as long as your discomfort isn't stopping the

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person from pursuing *her* interests.

Here is an example:
What if the person you support prefers going to the Catholic church service, but you're not Catholic?

A few options:
- Do you and/or the person know others in the church who could attend the service with the person?

- Would the person agree to have another coworker (who is Catholic) go instead?

- Are you willing to try it, with maybe a little "tutorial" in Catholic traditions from the priest or someone else before the service?

Invite Others Into the Person's Life

While you may know a person really, really well and play an important role in her life, the person deserves to have has as many *unpaid* supports in her life as possible.

Our job is to create opportunities for connection between the person we support and other community members based on mutual interests, values or experiences.

Any effort you make that works toward this goal is good work!

"Be part of the solution."
-Mary Kissel

Life is full of challenges and barriers for all of us, including people with disabilities. There will be times when you don't feel you can support a person very well because of barriers that may be out of your control ("The van is broken." "We don't have enough staff").
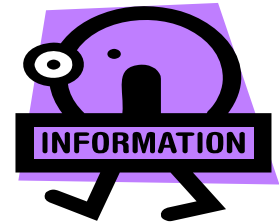
The world has enough people who identify the problem. It's the sign of a true leader who will be part of finding the solution!

When others give you reasons (or excuses) about why a person can't receive the services she deserves, offer to help find solutions.

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And Yet More…

## LANGUAGE MATTERS: REFRAMING HOW WE TALK ABOUT PEOPLE

As "professionals," we often use words to describe people with disabilities that are unintentionally disrespectful and perpetuate the idea that people with disabilities are not equal to community members without disabilities.

Sometimes we use these words to sound professional. Sometimes we use these terms because they are shorter. Sometimes others have taught us to use these words. Below are commonly used "professional" words and terms and some more respectful alternatives.

Instead of…	How about…	Reasons to Change
client or *consumer*	• A *person using services* or • a *person supported* or • a *person served* or • just *a person!*	By using terms that remind everyone that a person is a person, it reinforces the idea that this person is choosing the service instead of having an identity because of the service.
Adam went to a ballgame and socialized with his peers.	*Adam went to a ballgame and talked to Rick.*	The word *peer* means a *person who is the same age or has the same social status as you.* -Oxford Advanced Learner's Dictionary In traditional disability services, staff without disabilities typically use *peer* to describe the relationship between two people with developmental disabilities, even if the two people are different ages or otherwise have nothing in common with each other. Using the term *peer* in this way suggests that the person with a disability is equal only other people with disabilities and of a lower social status than the writer or people without disabilities.

|		
Jim is my client.	*I support Jim.* *I assist Jim.* *I work for Jim.*	A staff person doesn't own the person she serves.
This is Anne. She's a consumer of [Name the organization].	*This is Anne.*	It's rarely necessary for people in the community to know that Anne uses services. Additionally, telling people of a person's affiliation with an organization may break ethical codes and privacy laws.
Today I fed Amy.	*Today, I supported Amy in eating lunch.*	Try to avoid terms you would only use with babies or animals when describing your assistance to a person with disabilities. Think about describing your actions as supporting the person's *own* actions.
Karla is a 57 year-old female.	*Karla is a 57 year-old woman.*	Try to avoid terms that we wouldn't use in ordinary conversation or that have a "medical" tone to them.

And Yet More...
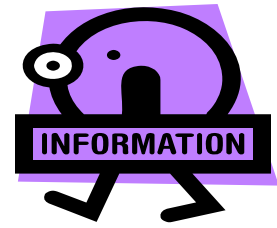
ADVISORY COUNCIL ON QUALITY'S DEFINITION OF SEGREGATION

The DDSD Advisory Council on Quality for Persons with Disabilities and Families (ACQ) Subcommittees on Policy and Quality (after merging with the Systems Change PATH group) spent a great deal of time defining the word "segregation". This definition and position statement was unanimously approved at the July 26, 2007 ACQ meeting:

Definition: "We see segregation as being the act, by perception, attitude, word and/or action of grouping people apart from the larger whole of society."

"It is the position of the ACQ that all of us, including people with developmental disabilities, have unique contributions to make to our local communities.

- We recognize that segregation deprives the community of the presence and gifts of people with developmental disabilities.
- We know from our collective history that segregation damages communities, and once people are segregated, it becomes harder for them to become a part of their communities again.
- Therefore, we re working to ensure New Mexicans with developmental disabilities are not separated from their communities and have full opportunity to become respected and valued citizens.
- We recognize there are multiple types of segregation: physical, social, economic and others.
- We choose to begin our work by defining physical segregation.
- We believe people's needs around activities, friendships, personal care, etc. can and should be met in places and environments typical to people without disability.
- We are committed to ending segregation of all types."
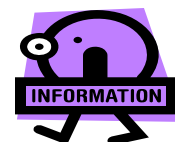
And Yet More... Documenting Community Building

INFORMATION

So... What IS "Community Building?"
It's supporting a person to build unpaid relationships and engage in activities that are meaningful to that person.
You may be doing it without even realizing it!

INSTEAD OF….	HOW ABOUT…	NEXT STEPS and NEW IDEAS
"Sam went to church."	"Sam sat next to Mrs. Ortega in church today. I supported Sam to talk with her before the service began about the snow we had last week. Sam really enjoys the music. We stayed after the service to say hello to the choirmaster and compliment him on the music. Sam and I enjoyed having coffee and donuts after the service. I supported Sam in talking to Mr. Jones about the Los Lobos basketball season."	How Could You Support Sam to Have More Unpaid People in his Life? *Could Sam sing in the choir? *Could Sam bring the donuts one Sunday a month? *Could Sam invite Ms. Ortega out for dinner? *Could Sam invite Mr. Jones to a UNM basket ball game?
"Sam went to McDonald's for breakfast."	"I supported Sam to have breakfast at McDonald's like he does every Tuesday. We said "hello" to Lisa, the cashier, who knows us because we come so often. Sam ordered a McGriddle without any support. I supported Sam to figure out how much money he owed. Sam gave the money to Lisa and then put the change in his wallet. Sam and I enjoyed our breakfast and told Lisa "goodbye" before we left."	How Could You Support Sam to Have More Unpaid People in his Life? *Could Sam get a job at the McDonald's? *This ritual is important to Sam. How do we make sure Sam gets to go to McDonald's every Tuesday even if a different staff person is supporting him?
"Sam went to Wal-Mart."	If Sam is going to Wal-Mart more than once a week, ask yourself: • Do we go to Wal-Mart because we don't have anything better to do? • Do we go to Wal-Mart because it's hard to try new things? • Do we go to Wal-Mart because I'm not sure what else Sam likes to do? If you answered "yes" to any of these questions, ask for help in figuring out new and creative ways for Sam to spend his time and build relationships. Strong employees ask questions!	

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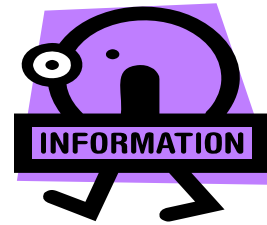
A FEW WORDS ABOUT DIGNITY OF RISK

The world in which we live is not always safe, secure and predictable… Every day that we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is. We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further cripple them for healthy living.

- Robert Perske

WHAT IF…

What if you never got to make a mistake?

What if your money was always kept in an envelope where you couldn't get it?

What if you were never given a chance to do well at something?

What if your only chance to be with people different from you was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was act out?

What if you couldn't go outside because the last time you went it rained?

What if you took the wrong bus once and now you can't take another one?

What if you got into trouble and were sent away and you couldn't come back because they always remember you're trouble?

What if you worked and got paid $0.46 an hour?

What if you had to wear your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of the grocery shopping but weren't allowed because you couldn't do all of the shopping?

What if you spent three hours every day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

> *-Linda Stengle, Laying Community Foundations for Your Child with a Disability*

Dignity of Risk

Overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hopes and expectations, and strip them of their dignity.

Overprotection can keep people from becoming all they could become.

Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try. Persons with special needs need these chances, too.

Of course, we are talking about prudent risks. People should not be expected to blindly face challenges that, without a doubt, will explode in their faces. Knowing which chances are prudent and which are not - this is a new skill that needs to be acquired.

On the other hand, a risk is really only when it is not known beforehand whether a person can succeed…

The real world is not always safe, secure, and predictable. It does not always say "please", "excuse me", or "I'm sorry". Every day we face the possibility of being thrown into situations where we will have to risk everything…

In the past, we found clever ways to build avoidance of risk into the lives or persons living with disabilities. Now we must work equally hard to help find the proper amount of risk these people have the right to take. We have learned that there can be healthy development in risk taking… and there can be crippling indignity in safety!

-Robert Perske, *Hope for the Families*

Some Considerations for Support Staff:

In working with young people and/or people with a disability there is a need, through planning, to minimise possible harm. It is not possible to eliminate risk, only to formulate strategies to minimise it. Allowing someone to undertake or engage in a risky activity does not make you negligent. Failing to take any steps to minimise foreseeable harm could be. This is called 'dignity of risk'.

The ideal for individuals with a disability is to live a life which is as typical as possible to their nondisabled peers. All people take risks. Duty of care can sometimes seem in conflict with allowing risk. Simply allowing a person to engage in an activity with inherent elements of danger or risk is not automatically negligent.
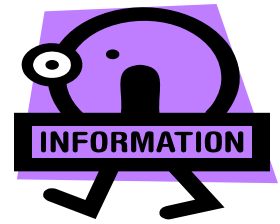
When a staff member is uncertain, they should discuss the situation with other staff, a supervisor or seek guidance from management.

From "Duty of Care, Critical Thinking and Ethics"
Facilitated by Dr Caroline Ellison
Email: Caroline.Ellison@flinders.edu.au

And Yet More...

SAMPLE MEANINGFUL DAY DEFINITION AND DAILY NOTE

Maria's Meaningful Day Definition
[consider including the person's definition at the top of the daily note]:
Maria enjoys helping children as a volunteer at the ABC Preschool two days a week. Some of her hobbies include listening to country music, gardening and baking. She loves to shop at thrift shops and craft fairs for jewelry and items for her home. She likes to keep in shape by going to CURVES a couple of times a week and swimming at the YWCA on weekends. A good morning for Maria starts with a cup of Starbucks coffee. On weekends she usually prefers to sleep late. Her favorite restaurants are Tia Juan's and Chow's. Her favorite TV shows are American Idol and The Closer. She rarely misses an episode. She has a DVD collection of favorite comedies and likes going to the movies to see new releases. She likes to visit her brother's family in Rio Rancho every few weeks and play with her niece and nephew. She also likes to spend time with her grandmother who lives here in town. Maria has attended St. Paul's Church for many years. She recently expressed interest in joining a Bible Study group there. Maria's best friend Barbara lives in East Albuquerque. The two friends enjoy visiting with each other, shopping, sharing recipes and cooking and talking on the phone. Maria likes to talk to her sister Sandra and her mom as often as she can.

SAMPLE DAILY NOTE BASED ON MARIA'S DEFINITION
Below is a sample daily note for Maria that shows how she engaged in some of these activities last Thursday:

Maria woke up at 7:00 am and selected her new blue dress and blue shoes to wear to volunteer at ABC Preschool today. At 8:30 I drove Maria to Starbucks for her morning latte. Then she and I drove to the preschool. The children arrived at 9:00 am and Maria helped Joshua work on unbuttoning his coat and tying his shoes. She sat with the children during morning show and tell and encouraged them to sing during the morning song. Today's activity was baking a chocolate cake and Maria brought her favorite recipe. She helped Anna use her communication board to show the children each step. She worked with the staff members to help the children ice the cake, serve and enjoy it. It was a hit. The teacher then asked them what dessert they'd like to make next week and they chose Pineapple Upside Down Cake. The

teacher asked everyone to look for a good recipe and Maria said she would ask her grandmother for hers.

At noon, after volunteering, I took Maria to her friend Barb's house where they had arranged to meet and make lunch. They made chicken burritos. They talked for awhile and then Maria wanted to go to CURVES. We arrived at 2:00 pm and Maria changed into her workout clothes and worked on 4 of the 6 machines. She told me she finds the step machine and the arm raising machine too hard. I encouraged her to ask a new CURVES participant, Tracy, how she used the step machine and Tracy volunteered to help her next time she comes. At 3:30 pm Maria showered and changed her clothes at CURVES. At 4:00 I drove her to Chow's Restaurant, we got a table and when her grandmother arrived at 4:15, the two had dinner together and I left. Her grandmother brought her home at 6:30. She told me she liked the Moo Goo Gai Pan and her grandmother is going to help her learn to make it.

Maria asked if we could go to Hastings to see if the new Kenny Chesney CD had come in. We talked about how much it would cost and she had the money in her budget, so at 7:00 pm I drove her over to Hastings, they had it, and she purchased it. She couldn't wait to get back and listen to it. When we returned at 8:30 she went straight to her room and listened. She said it was his best one yet. She especially liked the song about the island. At 9:30 she was watching CSI, when her mom called. They talked til about 10 pm and then she went to bed.

And Yet More…
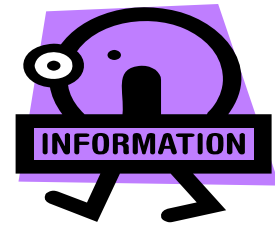
MAKING THE MOST OF IT…
IDEAS FOR GETTING THE MOST OUT OF SOME TYPICAL COMMUNITY PLACES.

As organizations move from providing services in facilities to providing services throughout local communities, people with disabilities are spending more time in typical community places, such as:

- The mall
- The bowling alley
- The local recreation center
- The park
- The local café and bookstore

These papers will help people with disabilities and direct support staff get the most out of these community places.

They include practical tips for full experiences and for building connections and friendships with other community members. Happy reading!

At the Mall

Before…

Does the person want to go to the mall?
- Set up groups that have interest in and a reason for going to the mall that day.
- Does his or her ISP/meaningful day include shopping?
- Ask the person. Make sure it is an informed choice from a rich selection of options.
- Keep groups small (3 or fewer).

Does each person have what they need?
- Be sure each person has a functioning communication system to ensure choice making and communication with people they meet.
- Do people have the money for the things they wish to purchase?
- Support the person to choose the shopping center and stores where s/he wants to go.
- Talk about what is available at each location, and what each person wants to do there.
- Has the person selected appropriate clothing for the day?
- Does his or her communication dictionary support the things s/he may want to communicate to others at the mall?
- Does the person have the supplies needed for positioning and medications?
- Does the person have other assistive technology devices s/he can use there?

Have we prepared to support each person?
- Find ways to support what each person wants to do at the mall that day. For example, if 3 individuals want to visit 3 different stores, discuss whether they will all go together and what each wants to do in each store, or consider the level of support needed to allow people to split up.

During…

Are we doing what we can to make sure people we support don't "stand out?"
- Try not to spend time with other groups of people with disabilities. Instead, help each person do what they want to do as independently as possible.
- Make sure the person is going to pursue an interest at the mall, not just to walk around (unless he is participating in something like a community mall walking group).

Are we always looking for ideas for new opportunities?
- Always be on the lookout for flyers and posters that might have information about other activities in the community or regular scheduled activities that occur there.
- Look for ways to meet new people.

Are we supporting people to be members of their communities?
- If a clerk talks to the staff member instead of the person, look at the person to answer.
- Encourage the person to introduce himself and to communicate his questions, desires and interests to others.

Are we using the person's interests to guide the trip?

Some examples:

Kendra Thinks about Pumpkins…

Kendra likes pumpkins and gardening. Staff can ask Kendra if she would like to go to Barnes and Noble to find information about the subject. Staff can help Kendra go to the information desk and ask for help finding the books on pumpkins and gardening. Staff can assist her with choices of books to look through, and then find a place to review them. If Kendra wants to buy a book, staff can assist her in doing so. Kendra also wants to buy a birthday present for her mom. Staff can help her brainstorm ideas and then check them out. They can help her decide how quickly she needs to buy the gift.

Dave Pursues His Love of Walking…

Dave wants to buy new walking shoes. Staff can take Dave to different shoe stores at the mall. Since he arrives early and knows several of the mall walkers he passes, staff can encourage him to say hi and converse about his week. Since Dave wears size 11 shoes, staff can help him look for # 11 on boxes when he finds a style he likes and can show him what the sale tags look like. If he cannot afford to buy the shoes he likes that day, staff can help him record the information so that he can return later. For example, staff can help him take a picture of the shoes he wants.

Susan Communicates What She is Looking For…

Susan wants to decorate her new bedroom. Staff can help her use her communication system to ask the store clerk about where she can find the items she is looking for (bedspread, picture frames, candles, lamp) and record prices for comparison or buy them on the spot.

After…

How can people pursue their interests outside the mall?

- So that people don't get bored going to the same places day after day, staff can follow up on the previous day's interests.
    - Kendra might want to go to the library or do more Internet research on growing pumpkins, or she might want to visit a pumpkin patch or gardening store. If she needs to make a decision about her mother's gift, staff can ask her if she wants to get something she has already seen or make some suggestions of other places to look for a gift.
    - Dave might want to go to other shoe stores that are not in the mall or buy the shoes he found the next day.
    - Susan might want to go online and check the prices for the items she liked from other sellers, or she might want to go to another home store not in the mall.
    - Help them plan transportation so they can pursue these new interests.

At the Bowling Alley

Before…

Are we taking the right person?
- Does this person want to bowl?
- Does his or her ISP/meaningful day include bowling?
- Ask the person. Make sure it is an informed choice from a rich selection of options.
- Try to support no more than 3 people and be sure the staff likes to bowl, too.

Is the person prepared for the trip?
- Support the person to choose the bowling alley where s/he wants to bowl.
- Talk about what is available at each location, such as video games and snack bars.
- Does the person have money for bowling, snacks?
- Has the person selected appropriate clothing for bowling?
- Does his or her communication dictionary support the things s/he may want to communicate there?
- Does the person have the supplies needed for positioning and medications?
- Does the person have other assistive technology devices s/he can use there?

During…

Are we supporting the person to fully participate in the activity?
- Find ways for the person to ask for his/her own supplies (ball, shoes, a ball ramp if needed).
- Find ways to explain HOW teams bowl (how to keep score, what a "strike" and a "spare" are, etc).
- Ask a clerk to give a tutorial.
- Encourage a visit to the snack bar to give a person the opportunity to order for himself, even if it is only a cup of water.
- Help the person ask for the correct size of shoe, quarters/tokens for the video games.

Are we making it as easy as possible for people to meet new people?
- Choose a time when the bowling alley is open to the public. Don't go at a "special", segregated time.
- When choosing a lane, ask to join or be next to other bowlers instead of being in a lane away from others.
- Individuals should also be encouraged to introduce themselves and ask employees for their name. Staff can model techniques for remembering a name.
- Check for information regarding leagues or scheduled events that might be of interest. Encourage individuals to ask for information.

> **3 Tips for Remembering New Names:**
>
> **Say it a lot**: "Thank you, George. It was nice to meet you, George. See you later, George."
>
> **Write it Down:** When you have a chance, write down the person's name in a notebook, daily log or somewhere else that you and the person you support can look at it.
> " Clerk at bowling alley with goatee—George."
>
> **Take Photos:** Label them.

- Model conversations with others in all areas of the bowling alley, such as, "How are you today? Great weather we're having! Do you bowl often? Wow, you're a great bowler. Can you show me how you did that?" Bring the individual into the conversations.
- Identify friendly players who have high scores and ask them if your group or just one of the individuals from your group may observe them to learn more about the game.

An Example

Tom Learns to Bowl!
Tom has always enjoyed going to the bowling alley—he enjoys the people watching and trying to hit the pins. But no one ever really taught him how to bowl, so he never really became a "bowler." However, his new staff person, Nick, is an energetic guy who also wants to learn to bowl! Nick suggested to Tom that they look into whether the bowling alley offered tutorial sessions. Nick saw this is a way for them both to learn the game and ALSO create an opportunity for Tom to meet someone new (and for someone new to meet Tom!). So before the two of them went to the bowling alley for the Thursday "All You Can Bowl" night, Nick coached Tom how to ask for a tutorial. They arrived early, and just like they had practiced, Tom approached the clerk and said "My name is Tom. Nick and I want to learn to bowl. Is there somebody who can teach us?" Charlie, the clerk, offered to do it himself and spent the next 20 minutes teaching them the basics. Nick then asked if there were two other people at the lanes that night who were also beginners and may want another pair of people to play with. Charlie didn't know anyone but did know a really friendly group that would love to coach Tom and Nick. Charlie introduced everyone; they hit it off and Tom and Nick now have a group of people they bowl with regularly!

After…

Ask the person's thoughts about the trip.
- Document what, if anything, they liked and build on it. If they did not like it, talk about what to try next.

Have we talked to others about the experience?
- If the person enjoyed the experiences, encourage him or her to tell others like other direct support staff and "residential" staff.
- Add new interests to communication dictionaries.

- Brainstorm with other staff how everyone could support the person to pursue the interest. For example, if a person wanted to join a league that bowled in the evening, how could the staff support the person to do this?

How can we get ready for next time?
- Help the person keep a log for scores to use for the next time.
- Search the Internet for other bowling opportunities.
- If the person is interested, help to sign up for a league and arrange for supports as needed.
- Identify interests in other special activities, such as twilight bowling and make arrangements to attend.
- Plan transportation so the person can pursue these new interests.
- Identify any needed therapy supports and schedule them for upcoming bowling days or nights.

At the Local Recreational Center

Before…

Do we think Billy is interested in going to the recreation center?
- Ask Billy! Have a conversation with Billy about types of activities that are offered there and if he would like a tour.
- Review Billy's ISP, looking at his Meaningful Day, Visions, and Desired Outcomes.
- Try to support no more than 3 people who are really interested in going to the recreation center.

Do we know what's available at the recreation center?
- Visit or call the center and ask for a list of activities it offers.
- Ask for times and fees. See if the center offers a one-day trial.

Have we prepared Billy for the experience?
- Before visiting the recreational center, talk to Billy about the environment and what he might want to do there today.
- Make sure Billy is dressed for the things he wants to do. See if he wants to take bottled water and maybe a towel.
- If Billy uses a communication system, support him in using his device and to prepare phrases or pictures that may be useful.

During...

Are we supporting Billy to fully participate in the experience?
- Arrive early so Billy can tour recreational center once again and talk to instructors and people at the front desk.
- Have Billy pick up a schedule and take him to observe the different activities going on that day.
- Talk to Billy about activities he would like to try.
- Help him find more resources within the recreation center. For example, maybe they have a nutritionist to give advice on healthy diet.
- After touring, encourage Billy to ask any questions he may have.
- If Billy is interested in membership, encourage and assist him in filling out an application.

Are we supporting Billy to meet new people?
- Staff can model social skills by introducing him/her self to the person at the information desk and encouraging Billy to do the same.
- If Billy is interested in exercise, encourage him to ask if he can join an exercise class or take him to an exercise area and encourage him to ask an instructor for any help he needs. Billy could ask the instructor what classes and/or activities are the best match for him.   The instructor can demonstrate the proper form for exercise. Staff/Instructor should explain language used in the environment, for example, "the spin class uses stationary bikes."

- Introduce yourself and Billy to others who may have the same interests as Billy. Encourage Billy to talk to these people and ask questions. For example, Billy may ask a member how a particular machine works.

After…

- Talk to Billy about what he liked and did not like. Ask why or why not.
- When at home, staff and Billy can go over his schedule once again to decide which activities he would like to try next.
- If Billy would prefer a visual schedule, staff could encourage him to take pictures of different recreation center activities so he can make his own schedule.
- Billy and staff can gather information on other groups with the same interests. For example, if Billy enjoys walking, staff can help him look up community activities in the local newspaper, on the Internet, or listen to local radio for walking groups.
- Plan transportation so he can pursue these new interests.
- Make sure other staff know of the interests Billy has at the recreation center and the names of the people he met!

AT THE PARK

BEFORE…

Are we taking the right people?
- Does this person want to go to the park? Have we given him lots of options?
- Does his or her ISP/meaningful day include spending time there? What does she like to do there?
- Try to support no more than 3 people at the park.

Have we considered the many ways people can pursue their interests in the park?
- Having lunch;
- Playing basketball, playing Frisbee with dog(s), playing or being a spectator for soccer, softball or volleyball;
- Walking or jogging;
- Bird watching;
- Holding parties or picnics;
- Attending concerts or other events.

Have we prepared people to make new community connections?
- Set the person's communication device with language to greet people, or use pictures, whichever is appropriate.
- Have the type of clothing and other supplies (baseball glove, dog treats, binoculars…)
- Make sure the staff supporting the person has a good idea what the person wants to do there and how s/he will connect with others.
- If the individual has therapists, think of how they can be involved. What are some ways they can assist with challenges that may arise?
- It may also be a good idea for each person to bring a small address book to record new names and numbers of people she meets and cards with her own name and contact information.

DURING...

Are we supporting people to pursue their interests?

Some examples

Liz wants to have a small party at the park.
She might invite a couple of neighbors and / or family. She could also invite co-workers or church members. Invitations can be written, by phone or in person. She can plan with others what food, supplies to bring and activities to do. Staff can help her plan budgeting, cooking, communication, being a hostess. Be sure her communication device is programmed for the party.

Other connections can be made through volunteering at places such as the local Senior Center, Boys/Girls Club, or Humane Society. She could arrange to meet people from all these different places and more and have get-togethers at the park. Similar interests may lead to other volunteer and employment opportunities or learning about interesting clubs or groups.

Cindy wants to have a dog.
Some things Cindy might do are: get a dog and walk it there; greet other dog owners when they come to the park; ask people in the park specific questions about their dogs; connect with the local Humane Society to volunteer to walk dogs in the park or connect with a neighbor who has a dog who wants to meet in the park; or toss a Frisbee/ball with dogs.

John likes sports.
At the park John can shoot baskets. Staff can support John to meet others who are shooting baskets. He could watch basketball, soccer, baseball games. If John is interested, staff can encourage him to ask if he can join the group. Staff can connect John to greet others, particularly regulars.

AFTER...

How do we continue to support the person's interests?
- Have a conversation about what they enjoyed about the time spent at the park and encourage Cindy, John, and Liz to communicate this to people at home. This may take place over dinner or later in the evening.
- Ask them what they'd like to do next and support them to make future plans. This could be done with neighbors.
- Check local newspapers and the Internet for activities of interest.
- Plan transportation so they can pursue these new interests.
- Visit other parks.

How can we support the person to maintain the connections that occurred?
- Send thank you cards, or a text message, or maybe an email thank you note to party participants and others who helped.
- Make sure other staff members know about the connections with other people that were made and have the information they need to support the person in keeping them.

At the Local Café and Bookstore

Before…

Does the person want to go?
- Ask the person. Make sure it is an informed choice from a rich selection of options.
- Help the person choose the particular book and music store that interests him or her. Talk about what is available at different stores.
- Does the person's ISP/meaningful day include an interest in what is available at the book or music store?
- Try to support no more than 3 people who want to go there.
- Know why they want to go (drink coffee and socialize, look at books and magazines).
- Talk with other staff: make sure there is not ANOTHER group of 3 going to the SAME store!

Does each person have what she needs?
- Money to buy books or music.
- Supplies needed for positioning and medications.
- Has the person selected appropriate clothing for the day?
- Does his or her communication dictionary support the things s/he may want to communicate there?
- Does the person have the supplies needed for positioning and medications?
- Does the person have other assistive technology devices s/he can use there?

James Places his Order…And Meets the Cashier

James wants to go to Hastings to get coffee and a snack. If needed, be there in line assisting with interactions of others in line ("Hi, how are you today?", or "Don't those cinnamon rolls smell good today?", etc.). If you rehearsed the ordering process on the way, remind James of what he said he wanted; if you didn't rehearse or he changed his mind, explain different choices available. He may need to work on waiting his turn. Help with ordering if needed. This could include: prompting to use communication device, sharing his order with the cashier ("James says he would like to have………today"), or prompting James to use the name on the cashier's name tag when ordering ("Hi Kathy, I would like a cinnamon roll today, please."). After James gets his food, offer choices of where to sit, explaining why each place is unique ("Would you like to sit by the window where it is warmer; would you like to sit over by those three guys who are always here; maybe you could introduce yourself or say hello today, etc…")

During…

Are we always looking for ideas for new opportunities?
- Always be on the lookout for bulletin boards that might have information about other activities in the community or regular scheduled activities that occur there.
- Look for ways to meet new people.

Are we supporting people to be members of their communities?
- If a clerk talks to the staff member instead of the person, look at the person to answer.
- Encourage the person to introduce himself and to communicate his questions, desires and interests to others.

Examples of Supporting a Person through all Parts of an Activity

Marie Selects Magazines…And Meets the Staff
Marie wants to go to Barnes and Noble to look for CDs and/or magazines. If needed, discuss what type of CD or magazine she would like to look for and help her find the correct location in the store. After Marie finds what she is looking for and you and Marie sat down and looked at and discussed the item, you may want to discuss the surrounding area to determine a "landmark" that Marie could remember to find that section of the store next time. You may also want to point out the bookstore staff and where Marie could go in the store to ask for help. ("The staff is the one wearing the red vest with the big yellow round name tag. Do you see that sign with the happy face on it? That is where you can go and ask for help to find what you want.") Remind Marie to use staff's name, explaining that it is on their name tags so people can know what their names are. Hopefully one of these days Rick, who has been helping Marie find magazines with cake recipes, will come up to Marie and say, "you should see the new magazine we have on cake decorating" because he knows that is an interest of hers.

After…

Ask the Person What S/he Liked.
- Talk with the people who went and find out if they want to return for another visit or if they want to try another place.
- See what they liked and didn't like about the experience and talk with them to see what could be changed to make the experience better next time.
- Talk about any new interest that may have developed during the visit. For example, Marie decided she was interested in knowing more about Billy Ray Cyrus, so you could help her research him and his music on line or even find a concert to attend. James chose a new drink or snack that he really liked. Where else can he get it?

Have we told OTHERS about this person's interests?
- Encourage Marie and James to share their experience with other staff members so everyone will know what went well, what didn't and any new interests that were developed.
- Add new interests to communication dictionaries.
- Identify any needed therapy supports and schedule them for future visits.
- Brainstorm with other staff how everyone could support them to pursue these interests.
- Plan transportation so they can go when they want to.
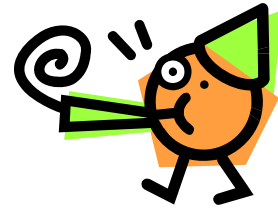
And Yet More: Stories Worth Celebrating

TRANSITIONING FROM FACILITY-BASED SERVICES TO COMMUNITY-BASED SUPPORTS: TOBOSA TELLS ITS STORY

I.   HISTORY OF TOBOSA

Incorporated in 1978, Tobosa was born out of the parental grassroots efforts which established "community-based" agencies to support people with mental retardation in their communities rather than placing them in state-operated, segregated settings. Tobosa was incorporated as a not-for-profit corporation overseen by a volunteer, lay member Board of Directors. In keeping with its original mission, Tobosa took the lead in closing a local state-operated institution known as Villa Solano in the early 1980's and merged its services and staff into Tobosa's operations.

Tobosa also led the way in supported employment, beginning these services in 1981, long before the State of New Mexico acknowledged and funded supported employment for persons with developmental disabilities. The agency closed its sheltered workshop in 1988. Tobosa is now recognized as a forerunner in the employment arena. Tobosa has received awards for its outstanding work in supporting people to find and maintain competitive employment. Most recently the organization supported two gentlemen in developing their own micro enterprises, a new approach to employment services.

Tobosa is considered a leader in the area of community membership. In 2002 the agency was selected by the current Developmental Disabilities Support Division to pilot a meaningful day project in the Southeast Region. Since then Tobosa has been called upon to share best practices and successes with other providers statewide. As of

November 1, 2006, Tobosa closed its facility-based day habilitation services – another milestone in its history of innovation.

Those individuals supported in community living are accustomed to healthy lifestyles and homes characterized by their own personal touch and cultural influences. Many aspects of their living environments have been adapted for greater accessibility. Two (2) couples receiving assisted living services bought their own homes, furthering their independence.

II.   LAYING THE GROUNDWORK

a.   The situation at the time

Originally, Tobosa provided day services in a facility where people came to spend their daytime hours and meet their Individual Service Plan ("ISP") goals and objectives. Staff members came to the facility and stayed there all day, providing supports to the people who attended.

 In 2002, the leadership staff at Tobosa began thinking about ways to offer more activities to people attending the day program but in more integrated settings. Leadership began questioning the practice of segregating people from the rest of the community while attempting to provide experiences that all community members enjoy. It just didn't make much sense anymore. Leadership did not make a big deal out of this concept; they did not announce that the day program would begin engaging in more integrated activities; they did not announce the eventual closure of the day program facility. Instead, they began to think about the things that were offered at the facility and asked the question: "Are there things that we are doing at our facility that can or are being done elsewhere in the community?" If the answer was yes,

> "Are there things that we are doing at our facility that can or are being done elsewhere in the community?"

then they started taking people to those places to do those things.

As time moved forward, leadership took the ideas that staff brought up about new activities, and thought about where other community members might engage in the same activity. Examples include having people use the computers at the local college and the library instead of starting a computer lab at the day program; enrolling people in arts and crafts classes at the local community center and with local artists instead of having staff teach those classes at the facility; using the gym at the community center instead of showing exercise videos at the facility, etc.

During the very early stages of the transition, people still came to the center everyday; the timing was still from 9am – 3pm and staff reported to the facility and left from the facility at the end of the day. People just began to go into the community on occasion to use the community resources that already existed. This practice of using community resources sporadically and naturally set the groundwork for the eventual closing of the day facility.

b.   Planting the Seed (2002-2004)

As time moved on, as more and more people from the day facility began engaging in activities in the community, a number of things began to happen:

❑ Energy was generated – staff members and people served began coming in with ideas about the kinds of things they could do in the community and the list of options continued to grow

Joe getting coffee at the senior center

❑ Many people became more comfortable in the community as friendships began to develop

❑ Some people became regulars at places that they frequented often

❑ Some people began to think about things they wanted to do individually and were supported (when funding and rules allowed) to follow those dreams – one person attended classes in home repair at the Home Depot

❑ People began to understand the value of money more clearly and several people chose to begin looking for work for the first time, explored the possibility of starting their own business or work more hours at a job they already had in order to have more money for community activities.

❑ Staff began dressing up a bit more when coming to work – now that they were in the community more, they felt the need to look better.

As Tobosa expanded its services and began supporting more people in day services, there were staff complaints that there was not enough room for people in the day program. The Program Administrator's response was to simply ask them to spend more time in the community with more people from the day program. There may not have been enough space in the day program, but there was plenty of space in the community!

As success grew and more activities were taking place in the community, staff began asking more often "where would people who have this same interest do this thing in our community?" It became more of the norm to look to the community to find things to do, than to look to the facility to provide those things. During this time, most community activities took place for short periods of time, in groups of five people with one or two staff members and only occasionally. This was a time of learning and experiencing for people supported, staff members and leadership. Thoughts of the future and what might take place were forming but had not yet been given voice. Eventually the day program facility became more of a drop off center rather than a facility in which people spent their entire day.

> *Most activities took place for short periods of time, in groups of five people with one or two staff members and only occasionally.*

c.   Meaningful Day Definitions

Meaningful Day definitions were developed out of the interests that people expressed. Knowing that between funding constraints and rules, people would need to be grouped together, Tobosa staff tried to create groups of three or four people who had similar interests in how they wanted to spend their days. Teams were created around these groups and schedules were developed to meet the interests of each of person in the group. Each person served had a Meaningful Day definition and a personal schedule, while each team had a combined schedule.

> *Meaningful Day definitions were developed out of the interests people expressed.*

In developing these teams, schedules and meaningful day definitions, Tobosa staff worked hard to assure that people who lived together in Supported Living facilities would not spend all of their time together. Whenever possible (within funding and rule restrictions), individuals expressing very specific, individual desires were supported to meet those desires.

Rules and regulations incumbent within the Jackson requirements caused fear for many staff members. People were afraid to try anything that was not specifically stated in the ISP. The Interdisciplinary Teams ("IDTs") rarely thought about specific things that individual people wanted to try, so specifics rarely got stated in the ISP. IDT meetings were generally short and focused on the big picture – the overall services and therapies that a person would need for the coming year rather than focusing on the person's dreams and interests. Staff members were afraid of ever leaving people in community settings with community members in case something should happen. The staff person would be held responsible and there was fear of retribution for not following the ISP. There was a constant conflict between trying to engage people in the things they are interested in and meeting all the rules and regulations that were required. The teams diligently tried to provide balance

> According to one person supported: "The conversation is aimed at what the state requires, not what I want."

between meeting people's needs and desires and meeting system requirements.

    d.   Philosophical commitment

Tobosa has a long history of having a strong philosophical commitment to meeting the needs of the people it serves in the most respectful and integrated way possible. This strong philosophical history has been especially helpful in moving from a segregated day program to community based day supports.

> *This strong philosophical history has been especially helpful in moving from a segregated day program to community based day supports.*

    i. Of Leadership

The leadership staff at Tobosa is firmly committed to empowering people served while providing high quality services and supports. Mid-management staff routinely engages in learning experiences and in taking risks in trying new things. The move from a facility based day program to community based services has led to many conversations and has stretched the capacity of the leadership staff.   All change takes time to become fully incorporated into the life of an organization and this change effort was no different. There were inherent tensions in changing the way the work was done. This struggle between the old way and the new has created a great deal of learning and the need for much insight into each person's own thoughts and the thinking of the group as a whole. Every organization will struggle with this issue – we all learn at different rates and in different ways. Tobosa has managed to bring about significant change while maintaining the focus on the people served and the future while continuing to work as a team.

    ii. Of Staff

Originally, some of the direct support staff were reluctant to spend time in the community, but as more and more activities took place in the

> One staff person came to realize that his role is in "creating memories for the people he serves".

community, staff realized that their days were fuller and more enjoyable. The people they support appeared happier and more energetic. Work time went by faster and success led to more success.

Some staff members were not pleased with the changes and made decisions to accept other employment that better met their needs. Change tested staff beliefs and philosophies regarding service provision and their perception of the their community and the people Tobosa serves.

III. MAKING THE DECISION.

The decision to formally close the day program facility came in early 2005 when it became obvious that the building was being used more as a drop off site than as a day program facility. People were experiencing success in the community and it no longer made sense to spend the money on the building when it was not being fully utilized. The management team made the decision to phase out of the day program over a year's time rather than closing it at all at once.

IV. GETTING OTHERS ON BOARD
      i.   Managers and staff members

Tobosa has moved away from supporting individuals with distinct residential and day service staff to a team support model where direct support staff may fulfill both residential and day habilitation/community membership duties.   Individuals who share similar interests and enjoy spending time together during the day are generally supported to participate in the community in groups of four (4). The number of staff needed for supporting community participation depends on the level of support required by the individuals in the group.

One of the most successful strategies for creating momentum in moving forward was to highlight the successes of people in the community via articles written in the agency newsletter, stories told in the hallways and celebrations at team and staff meetings about all the good things that were happening for people as they spent more time in the community.

Enjoying a good garage sale!

One of the most successful strategies for creating momentum in moving forward was to highlight the successes of people in the community via articles written in the agency newsletter, stories told in the hallways and celebrations at team and staff meetings about all the good things that were happening for people as they spent more time in the community. Concerns were taken seriously, no matter who brought them up. There is a great deal of respect for all staff members within Tobosa's culture and this was especially important during the transition.

Concerns were discussed and issues, rules and regulations were researched. The focus always remained on supporting people to do more in the community.

ii. Families/Guardians

Tobosa supports approximately 80 people in Day Habilitation and Community Access programs. The majority of these people live in residential settings that are managed by Tobosa. Families and guardians have been supportive of people spending more time in the community, in part because the change was brought about slowly, over time and concerns were addressed as they occurred. Families and guardians were invited to attend team planning meetings, though few actually did. For those people who live in host home situations, they are still away from the house from 9am-3pm, Monday through Friday, so the family's schedule has remained the same.

V. HOW THEY DID IT
i. TIMELINE

Tobosa chose to spend a year in transitioning from a facility based day program to providing all day supports in the community. Phase I of the transition process began on November 1, 2005 and included eight people served, homes and three teams. Phase II began January 9, 2006 with 12 people served, four homes and four teams. Three more phases occurred in April, July and September 2006 with the facility officially closing on November 1, 2006. The facility was a rented building, so Tobosa simply ended the lease.

ii.   PREPARING STAFF

The teams were brought together before the formal move from the facility took place. People served and staff members had become accustomed to spending some of their time away from the facility engaged in community activities over the preceding two years. The teams gained knowledge and experience as planning occurred and more community activities took place. Learning occurred within the team settings rather than in formal training sessions.

iii.   RECOGNIZING AND LEARNING HOW PEOPLE WOULD
       SPEND THEIR TIME
       1. What do people want to do?
       2. Developing schedules

The teams that were developed around people include the people served and the day and residential staff members. People spend time getting to know each other and actively talk about the things they like to do. For people who don't communicate with words, staff members look for other ways to determine how people like to spend their time. The teams talk about who likes to spend time outdoors; who likes to be with lots of people; who has cultural ties they would like to develop; who has an artistic flair, who likes to collect what; etc. From these insights, the teams choose activities and places they think the person might like and they try them out. If the activities and places work well, and the person seems happy with the choice, it becomes a part of the schedule. If it does not work out, then the team looks for other things to do. At this time, most people still have daytime hours that occur between 9am-3pm. One person served however, was not a morning person and his schedule was changed to accommodate his desire to sleep later and start his day later than others.

Stories about what people are doing are shared widely within Tobosa. The newsletter, bulletin board and website are full of stories of people working, volunteering, participating in civic groups and having fun.

Personal Meaningful Day definitions are developed out of this shared knowledge and experience base. The teams

work hard to find things that people are truly interested in before adding it the person's definition of a Meaningful Day.

Stories about what people are doing are shared widely within Tobosa. The newsletter, bulletin board and website are full of stories of people working, volunteering, participating in civic groups and having fun. These success stories encourage everyone involved to think more widely about what might be possible for the people served.

3. Partnering people with staff

The teams are comprised of people served, as well as direct support staff along with a team coordinator. Team coordinators work with more than one team. Meetings are held jointly and whoever can attend does and everyone contributes to developing the schedules, looking for new opportunities in the community, problem solving, sharing good practice ideas, engaging in training and anything else that needs to get done.

Tobosa has begun supporting people served to interview and hire their own staff members. One person requested that he develop the interview questions and conduct the interview since the new staff person would be working directly with him. Harry wanted to ensure that his new staff person would share some of his interests and would be able to provide the support Harry requires. Tobosa agreed and worked with Harry to ensure he understood the legal parameters involved. Harry successfully hired a new staff member and is now working on developing assistance for other people to learn to hire their own staff members.

iv.   LAYING COMMUNITY GROUNDWORK: Cultivating activities, opportunities and potential relationships for/with people served.
   1. Using personal networks of managers and staff
   2. Using community resources
   3. Identifying community need and building community's capacity

The Roswell, New Mexico community is mid-sized with a total population of 45,000. Roswell is a fairly well developed community with two active Chambers of Commerce and offers many activities throughout the year. Tobosa is a well known and respected provider of services to people with disabilities in Roswell. Many of the staff members at Tobosa have been employed for a long time and have active lifestyles in Roswell. It has been a fairly natural evolution to provide more services in the Roswell community rather than within a Tobosa facility. It made sense that there were resources available all around the Roswell community that the people Tobosa served were not taking full advantage of but certainly could. People served who are senior citizens are integrated into the local senior center; people who have an interest in working with ceramics take ceramics classes with other community members; people who want to learn to use computers go to the local college or library. As more and more people started using these resources, more people got ideas about other things they wanted to do.

To date most of the community involvement has been utilized to provide people served at Tobosa with more options to fulfill their desires and interests. The positive experiences people have had has encouraged thinking about how Roswell community life has been enhanced by including people with disabilities. Participating in building a better Roswell community for everyone is an exciting thought. Some of the questions now being considered include – what are Roswell's needs and how can Tobosa participate in meeting some of those needs? What are Roswell's strengths and how can Tobosa build on those strengths? Where these questions will lead Tobosa in the future remains to be seen.

v. REDESIGNING INFRASTRUCTURE TO SUPPORT TRANSITION

Tobosa totally redesigned the infrastructure of their residential and day programs in order to transition from facility based to community based day services. Previously, residential and day services were autonomous with staff assigned to one program or the other from the direct support level all the way to the Program Manager. Though all services were provided through Tobosa and the administrative functions were combined, the residential and day programs were separate. When the transition began, it was very clear that the two programs would need to become one in order to best meet the needs of the people being served.

From:

| Residential programs | & | Day programs |

To:

Work teams around people within houses and in the community

Tobosa accomplished this though the creation of work teams around a number of people served. The day and residential staff now belong to one team, inclusive of people served and that team includes people from multiple residential programs. Each team has a team coordinator who assists with scheduling, assuring compliance with regulations, supervising staff, etc.
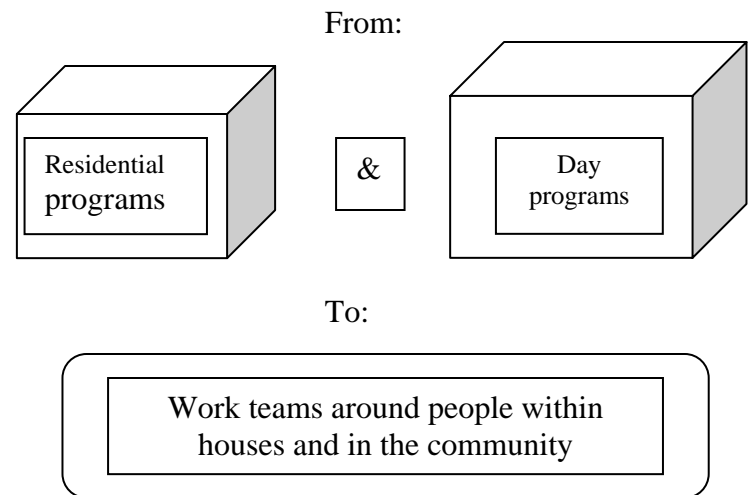
Redesigning the infrastructure and creating unity among the teams and coordination between the teams was one of the biggest challenges Tobosa faced in making this transition. It took time and perseverance, especially on the part of the Program Directors, to keep people focused on the goal: supporting people to have better lives and create more opportunities for people to engage in community life. Literally everyone had to begin thinking differently about their roles. Job descriptions had to be changed, lines of authority were changed, and the how, and why and where of specific jobs changed dramatically. Staff members who used to complain about each other (the residential staff won't… or the day staff won't…) began working together and relying on each other in a totally different way.

Additionally, the people served by each of these teams were included as members of the team. People served regularly attend team meetings, and staff meetings are held for everyone as a time to share information and catch up on any changes to regulations, etc.. People served as well as Tobosa staff members are beginning to take a more active role in these meetings, participating in the decisions that affect their lives.

vi.   MAKING THE MONEY WORK

Money was not the guiding force steering the transition from facility based to community based day services at Tobosa. The Program Manager and the teams approached the work with spirit and good intentions. Making this transition was the right thing to do and they set about doing it. The billing office took the responsibility to make sure the money would work. New documentation forms were developed to assure that all services were captured no matter where they were provided. Support staff kept daily activity logs to capture all that was done.

VI.   SPECIAL CONSIDERATIONS

a. Supporting people with significant medical needs

People who have significant medical needs often have a one to one staffing ratio which allows them more flexibility in meeting their complex medical needs. People may use in-home day habilitation when their medical condition requires.

b. Transportation

Transportation has been an issue in the transition from facility based to community based day services for Tobosa. Public transportation is utilized when it makes sense to do so. Tobosa manages most of the residential programs where people receiving day services live, and most often each residence has a car or lift van, owned by Tobosa, at its disposal,. Gas costs are challenging. Too much time spent in vehicles each day is a constant worry. Tobosa is currently considering how staff might be

reimbursed to use their own vehicles for service transportation. Some people get rides to community events with other community members who also participate in the activity. For example someone who belongs to the Kiwanis club gets a ride to meetings with another Kiwanis Club member.

c. Working with residences

Tobosa's new seamless model of team support blends community living (supported living, home based and assisted living) with day habilitation and community membership services, so the emphases are the same. The teams work to assure that people can access the daytime schedules they desire without having much impact on their supported living programs.

VII. SO, HOW IS IT GOING?

The outcome has been very positive. People served are happier. Staff members are happier. Assisting people to be in their community seems to be empowering, based on the requests from people to do more and be more involved.

One of Gerri's favorite summertime activities is garage saling. Having frequented the "garage sale circuit" this summer, many of the other regular shoppers have become familiar with Gerri and the other women she hangs out with during the day. Here, Gerri shows a small item that she found pleasing to the eye and sports a new visor she bought to keep shaded from the sun.
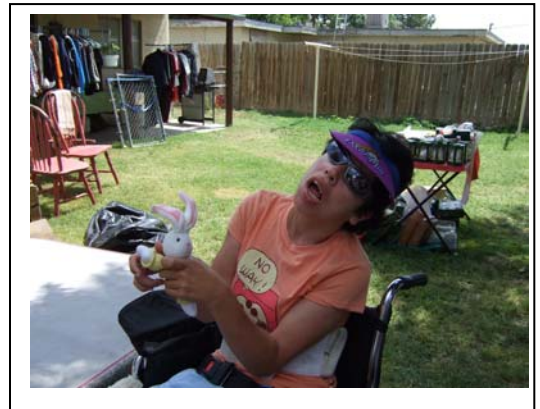
Jesse and other folks supported by Tobosa routinely use the resources at the public library. Aside from books, there are newspapers, magazines and internet. People may join fan clubs, research favorite topics or email friends and family members at the library.

Toby, Tim, Domingo and Paul are supported to volunteer at the Boys & Girls Club. Here they have met many young people and other youth-minded people in the community who appreciate their contributions. Tobosa recognizes that volunteerism offers the opportunity to meet people, learn skills that can help get a job, and share gifts and talents with the community.

Joe and James are regular members of the Roswell Joy Center, where they join in activities daily with other senior citizens from our community. This setting is a great place for James to hang out with and flirt with people his age. Here James makes "yoohoo" gestures at a couple of lady members.

VIII. CONTINUED CHALLENGES
  a. Building strong understanding of person-centered, community-based supports

Tobosa leadership realizes that the potential of responsible person centered planning has not been fully experienced at Tobosa.   The intention to learn about what people want and need and how best to support people to get there is very strong at Tobosa, but the full implementation of person centered plans is not yet in evidence. Tobosa leadership is currently struggling with the tensions that exist between state-mandated formal systems requirements and the best practice reality. Person centered planning must be independently facilitated and separated

from the ISP process in order to assure integrity in the planning process. The results of the person centered planning process can be used to guide the ISP development, but one process is not interchangeable with the other. A person centered planning process is inherently different than an ISP process in every way.

b. Still some grouping

Most of the people served in Tobosa's community based day services are still grouped with other people who are also served. Most services are still provided during the hours of 9am-3pm. The resources and experience to support individual people in realizing their dreams are not yet fully in place at Tobosa. Many of these challenges are around funding and regulatory issues, while some of the challenge is inherent in the philosophical underpinnings of the issues around providing safety and protection. Tobosa leadership is struggling to balance safety and protection with dignity of risk while still meeting all regulatory requirements. It is a difficult struggle and one that will not abate quickly.

c. Clinicians

Clinicians, including therapists, nurses, case managers, and auditors have had to make some major adjustments to how and where they do their work. When the center was open, the clinicians and auditors simply showed up and provided their service at the center. Now a great deal of coordination is necessary to find people and to find the appropriate space in which to provide the clinical service. The teams struggle to meet the clinicians and systems needs while meeting the needs of the people they serve.

d. Money
    i. Accessing available funding (community access vs. day hab)

Tobosa has designed new documentation forms and support staff to complete daily activity logs that accurately capture the work they are doing and the services they are providing. At this point in time, the funding is

adequate to provide community based services, primarily in groups of three or four.

ii. Covering costs

Accessing enough funding for people to engage in the activities of their choice has been a challenge. Some people served have adequate cash (perhaps from their benefit checks, perhaps from working) while other people do not have adequate cash. Several people served have expressed the need for more cash and are actively searching for more work or new work. Many people go home for lunch most days, in part due to a lack of funds to eat out that often. The issue of funding must be taken into consideration when the teams plan schedules for future activities.

Tobosa covers the costs of activities for staff when necessary, but does not cover the cost of staff meals. Tobosa does engage in some fundraising to assist in covering costs. Staff will often ask if they can attend an activity for free when supporting a person they serve to attend. They have had moderate success with this request, but can not always count on that community support.

e. Other

Some of the people served did express a concern that without having a facility to go to everyday, they would not get to see their friends as often as they would like. The teams try to take this into consideration and build time for friends to be together into the schedules. There are also some segregated activities available in Roswell that some people have chosen to attend, including a dance held every Wednesday and bowling on Fridays. Both of these activities are available to the people Tobosa serves, but are not organized by Tobosa.

The administrative staff members also feel that they do not get to see people as often as they used to when everyone was together in one place. They sometimes experience a feeling of being out of touch with the people they serve. Individual administrative staff members are finding new ways to keep in touch.

IX. SOME CRITICAL POINTS
   a. Importance of cell phones, regular meetings and other things
      to ensure logistics

Every staff person carries a cell phone. Team meetings are held monthly
and full Tobosa staff meetings are held bi-monthly. Team coordinators
share information regularly and there are a number of other
communication methods available, such as bulletin boards at the Tobosa
administrative office and a Tobosa newsletter.

   b. Importance of being well-trained

In addition to providing the required trainings, Tobosa has participated in
and supported the work of the Southeast Self-Advocacy coalition in
developing a two-day training module that will be provided for all staff
members as soon as it is completed. The training has been designed by
people who receive services and will be presented by people who receive
services. The training is designed to assist staff members in seeing the
world through the eyes of the people they serve. It includes many sections
that detail the history of services to people with disabilities in New Mexico:
the kinds of things that people who receive services find helpful in their
staff and the kinds of things that are particularly unhelpful. There is a
video and there are role plays to assure that participants fully understand
the issues involved. This type of training will provide staff members with a
much broader view of the work they in which they engage and offer
opportunities for better partnerships between people served and staff
members.

   X. THE REGRETS: THINGS TOBOSA WISHES THEY HAD DONE
       FROM THE BEGINNING

❑ In the beginning, decisions were made internally and with upper level
   staff only. Now they try to include everyone as much as possible in
   every decision.

❑ Wishing that the timing could have been faster – change seems to take
   a long time.

❑ Would have done a complete cost analysis of before and after the transition.

❑ Would have used the public transportation system earlier

❑ Would have liked to have measured staff morale and turnover rates before and after the transition

❑ Would have liked to measure behavioral data and incident reports before and after the transition

❑ Would have spent more time early on making sure that people who are good friends or are dating get enough time together (doing a better job with this now).

XI.   VISION FOR THE FUTURE

- Having more freedom to act – not having to have meetings to discuss every aspect of a person's life.

- Sharing power more equitably with the people we support – Tobosa not having so much control over people.

- All Tobosa staff have a high commitment to the people we support and the work.

- Sharing a well-defined vision, philosophy and direction for all Tobosa staff and board members.

- The people we support are treated like other citizens in our community.

- Sharing a culture that is supportive when things do go wrong and does not rush to attach blame.

- Health and safety issues are determined individually based on the person and their unique circumstances.

- Sharing a culture that understands and balances risk with accountability.

- Having the freedom to share ideas and take action without fear of retribution. Working in a system that searches for the good things that happen and works to find solutions to problems rather than having a "gotcha!" mentality.

- Supporting people we support to understand and experience their rights AND responsibilities.

- The people we support are in positions of power and are involved in all decision making.

XII.   CLOSING

The transition from facility-based services to community-based supports, has been long, sometimes painful, but ultimately very rewarding for Tobosa, their staff, the people they support and the Roswell community. The positives far outweigh the negatives. The agency has learned a lot about itself, its capacities, its staff and the people it serves. Tobosa also realizes that this transition is only the beginning and the first of many transitions as they move toward the vision they have outlined for their future.
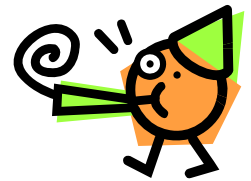
CREATING COMMUNITY-BASED SUPPORTS:
TOBOSA'S TIMELINE OF TRANSFORMATION

2002: THINKING ABOUT COMMUNITY-BASED SUPPORTS
- Meaningful Day Pilot
- Organization begins rethinking segregated day services
- "If it's done in a facility, how can it be done in the larger community instead?"
- Facility is still people's hub—people go to community for specific activities.

2002-2004:   VENTURING INTO THE COMMUNITY
- People increasingly using community instead of facility
  - o Energy increases
  - o People become an increasing part of their community, joining associations and making friendships
  - o Increased thinking into individualized supports
  - o Staff morale improves
- Created meaningful day definitions
- Worked with teams
- People supported in small groups, based on mutual interests
- Tension within the organization between old and new ways of working
- People using the center less and less

2005:   FORMAL DECISION TO CLOSE THE DAY CENTER

- As people began being served in the community, the day center utilized less and less
- Management team decides to ultimately close the center in phases
- Continued building teams around each person, with the person being an active leader/participant. "Day" and "residential" staff were centered around the person, not the service location. Teams brainstormed, problem-solved and worked together to create new opportunities
- Continued to learn how people would like to spend their time
- Infrastructural Changes:
  o Realigning day and residential staff to be centered on each individual
  o Job descriptions changed
  o Lines of authority changed
  o Budget implications assessed
  o Developing new documentation that better ensured that all available funding was captured
- Day facility officially closed on November 1, 2006

TODAY: IN AND OF THE COMMUNITY

The Good
- People enjoying completely community based supports
- People making connections, getting jobs, becoming engaged citizens
- Staff more engaged, more energized

The Challenges
- Still some grouping based on mutual interests
- Supporting clinicians and others outside the organization to rethink how they perform their roles
- Making sure the organization captures all available billing
- Making sure the people who use services have enough money
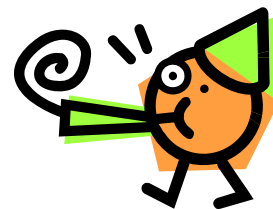
BRINGING THEM HOME:
Paula, Sandra and Tresco-Socorro's Story

Sandra and Paula Celebrating their Housing Loan Approval

INTRODUCTION

For most people, owning one's home is an assumed right of passage in life. Grow up. Get a job. Rent an apartment. Then swallow hard and get a 30-year mortgage, having never been so proud to call that humble house *home*. It's yours. You pick the paint color. You decide if dogs are allowed. You finally have a place that you control completely.   And while somewhat scary, owning one's home produces a sense of stability and accomplishment that few other things in life do.

Over the years, an increasing number of people with developmental disabilities have become homeowners. Programs and funding incentives that open the door to home ownership continue to expand to a group of people traditionally excluded from the experience.

People with significant physical and developmental disabilities are often the most vulnerable in our communities and the most likely to live in provider-run residential facilities. While people may enjoy competent staff and a supportive agency, they often don't experience the same level of "residential" stability that homeowners do. They can be "moved" at the provider's whim and they usually must leave the residential facility if they choose to change providers.   As a result, some of the most *vulnerable*

people in our communities experience the least amount of stability in where they live.

However, more and more people with significant disabilities are getting the support needed to access home ownership. The process of achieving this outcome may be slightly different and involve a few more people, but it *is* possible for some of the most vulnerable people to live in their own homes and enjoy the security and stability that accompanies it.

This is a story about Paula, Sandra, the organization that supports them and a collective desire for the two long-term friends to live in a home of their own.

> "Sandra and Paula have always looked to us for their security; why *wouldn't* we help them get their own home??"
> –Arleen Lindsey
> Director of Tresco-Socorro

A LITTLE ABOUT PAULA AND SANDRA

Paula and Sandra are middle-aged women who live in the small town of Socorro, New Mexico and have been a friends for over 30 years. They lived together at Los Lunas State School and Hospital and have been supported by the Socorro branch of Tresco Services ("Tresco-Socorro") for over 14 years.

Both women communicate with a few words, lots of gestures and facial expressions. The women require 24-hour assistance, have significant developmental disabilities and need support in nearly every dimension of their lives. Paula uses a wheelchair that requires accessible housing. Both have full corporate guardians.

For a long time, the women lived in an apartment complex that had some accessibility features and a very supportive complex manager. Yet, even with this supportive arrangement, the women didn't have the level of accessibility and long-term security they deserved. As a result, Tresco-Socorro began the journey of supporting the women to purchase a home of their own.

A LITTLE ABOUT TRESCO SERVICES
Throughout the country, people with developmental disabilities live in provider-run facilities or "group homes." Yet, Tresco has long believed that people are best supported when they live in their own homes and are fully included in community life. Tresco is deeply committed to supporting everyone it serves to have typical living experiences: renting an apartment, buying a house, living with family. And despite a national shortage of affordable and accessible housing, Tresco has successfully supported people to live in their own homes its entire history.

Yet, even with such a demonstrated commitment to serving people in homes of their own, Sandra and Paula's journey to home ownership took Tresco into new territory.

Tresco had never supported two women with such significant disabilities to *buy* their own home. Rent? Yes. Buy? Never before. Many organizations would have looked at Sandra and Paula's living situation in their partially accessible apartment and said "good enough." But despite the "unknowns" of doing so, Tresco was willing to stretch its own organizational experience and say, "we can do better."

1998: A JOURNEY THAT BEGAN WITH SOMEONE ELSE
Originally, Paula and Sandra had a longtime friend and roommate, Isabella. And according to Tresco-Socorro staff, Isabella was the "driving force" behind Tresco-Socorro's efforts to support the women to secure their own home. Isabella was a sassy woman with a job and a desire to buy a home in which her "sisters" Paula and Sandra could also live. Isabella wanted to own a home that would meet Paula's accessibility needs. As she witnessed other people with mild disabilities become homeowners, she grew increasingly interested in becoming a homeowner herself.

Tresco-Socorro began supporting Isabella's dream of living in a fully accessible home of her own. They supported her to get a job and budget her finances to help plan for her home. Tresco staff's supported Isabella by researching low-income home ownership initiatives.

A HOUSING ROADBLOCK, A STAFFING SUCCESS

Tresco had supported several people with mild disabilities to become homeowners through the US Department of Agriculture's rural home ownership initiatives. They relied heavily on strong working relationships with staff at the local USDA office to navigate the special considerations that potential homeowners with developmental disabilities pose. However, the USDA was not a viable option for Isabella, Paula and Sandra because they had not established any credit.

Tresco continued to explore other viable funding options and learned of another home ownership option available to people with low incomes through HOME New Mexico. This initiative required all potential applicants to attend preparatory classes one night every two weeks for two months. The classes were held in the evenings in Albuquerque, New Mexico--an hour away from Socorro. For two months, one of Tresco-Socorro's managers, Julie Marquez, assisted Isabella, Paula and Sandra to attend these classes, making the trip with them after her regular workday ended.

Though Sandra, Paula, Isabella and Julie dutifully attended all of the required classes, they were not able to move forward with home ownership. The home ownership organization required only *one* person own the home. When posed with the decision, the ladies' teams and guardians were reluctant for *any* of them to assume ownership. As a result of this stalemate, Isabella's dream of living in a home of her own with her friends was put on hold.

OTHER ROUTES ATTEMPTED

Determined to support Isabella's dream, Tresco-Socorro staff continued talking with women's teams about the viability of home ownership. The staff also provided the teams with research and information showing it was possible for the women to live in a home of their own. The staff also continued exploring housing options. They explored how Isabella could purchase a doublewide trailer, but without any credit history, she was unable to secure the necessary home loan.

2003-2004: A SAD DETOUR

In 2003, Isabella's health began declining drastically. Throughout the year, she was in and out of the hospital. As supports were focused on

supporting Isabella and her failing health, her dream of living in a home of her own home had to be set aside.

Isabella was ultimately placed in a nursing home to ensure she received round-the-clock medical support. Although no longer her provider, Tresco-Socorro's staff's commitment to Isabella was undiminished. Volunteering their time, Isabella's former staff regularly stayed with her to provide her company and to ensure she received the supports she needed.

On December 13, 2004, at the age of 28, Isabella died.

2005: TAKING TIME FOR REFLECTION AND REGROUPING

Isabella's death had a significant impact on Paula, Sandra, and the Tresco-Socorro staff. It was clear to staff that Paula and Sandra missed their friend. The women would often choose to simply sit in Isabella's bedroom. As is often the case with people with significant disabilities, Paula, Sandra and Isabella had been a trio for a long time and had become family to one another.

Isabella's death also called into question the effort to support Paula and Sandra in securing a long-term home of their own. Did Isabella's passing mean that Paula and Sandra would never be able to enjoy the long-term security of home ownership? Tresco had never supported anyone with such significant disabilities and medical complexities to pursue home ownership. Additionally, the staff remained concerned about the impact Paula and Sandra's corporate guardianship status would have on the process. Who would sign the mortgage? What happened if a guardian wanted to "move" one of the women to another city?

Finally, both Paula and Sandra were experiencing some episodic health issues that needed the staff's full attention.

It seemed the effort to support the women to live in their own home needed to be put on hold temporarily. Yet, the staff was clear that this was simply a *break*—an opportunity to re-center and regroup—but not the end of the effort.

Later that year, Paula and Sandra moved into a partially accessible apartment, subsidized with Section 8 funding. While not fully accessible, the apartment was the best option available in the small town.

A Side Story about a Community's Commitment to Accessibility
While apartment complexes are legally required to make basic accommodations to meet a tenant's accessibility needs, these modifications are typically minor and rarely result in *fully* accessible spaces. While the management at Paula and Sandra's new apartment complex had made basic modifications for Paula, Paula still did not have full use of her apartment.

Not surprisingly, community members often develop an increased sensitivity to accessibility considerations after getting to know a person who relies on them. As Paula and Sandra's apartment complex staff got to know the two women, they became increasingly committed to meeting the women's needs. And as a result, the complex allocated the necessary resources to make additional modifications. Although the apartment was not as accessible as a customized home, the management's efforts reflect a growing desire among community members to meet the needs of their neighbors with disabilities.

AUGUST, 2007: AN EFFORT RENEWED
The plans for Sandra and Paula to secure a permanent home stopped for about a year and half while the women and their staff re-centered themselves after Isabella's death. However, the process was jumpstarted when Tresco-Socorro staff learned that the local USDA office with which it had such a strong working relationship would be closing later in the year and with it a potential window of opportunity for Paula and Sandra to become home owners. The Tresco–Socorro staff and USDA staff worked together diligently to complete the application needed for Sandra and Paula to be considered for a loan. Tresco-Socorro submitted the final application the same day the USDA office was packing its office to close.

An Important Note: Keeping Teams in the Loop
Throughout both the original and renewed efforts, Tresco-Socorro staff consistently kept the women's teams updated on the process.

It's important to note that throughout this effort, Tresco-Socorro struck a critical balance between *collaborating* with teams and seeking *permission* from teams. Often, staff would take action and let the teams know they had done so, but would not seek the teams' "permission" before taking it. They were very careful not to usurp the guardians' roles and duties and would seek guardian permission when appropriate. Tresco saw its overarching purpose to do what was right for Paula and Sandra, to show team members what opportunities were available, to address any team concerns and to generate enthusiasm within the teams about the effort.

> "We wanted to make sure teams saw the same possibilities we saw."
>
> -Arleen Lindsey

THEY GET A LOAN!
On December 17, 2007, over five years after the effort began, USDA authorized a loan to Sandra and Paula for over $110,000.00 towards purchasing an accessible home of their own!   Because of this award, Sandra and Paula had the leverage needed to secure an additional $15,000.00 from Home New Mexico. This funding would help both purchase a home and make any necessary modifications to it.

THEY FIND A HOUSE!
Working closely with a local realtor, Sandra and Paula and their teams explored local affordable housing options. Tresco-Socorro staff credit the women's local realtor's persistence for finding the house that would ultimately become the women's home.

In the spring of 2008, after lots of looking, Sandra and Paula found their home: a single-story, stucco house with plenty of space for accessible bathrooms and a back yard. The house had the added benefit of being close to the home of the longtime Tresco manager, Julie, who had so tirelessly worked on the effort.

After several months of accessibility renovations, Sandra and Paula's house—Sandra and Paula's *home* – was ready.

A Side Note About Important Allies in the Effort: The Roles of the Corporate Guardians

While home ownership creates stability, security and a sense of belonging, it also involves risk. In order to achieve the "dream," people must ask uncomfortable questions and move forward without any guaranteed answers. How will the mortgage be paid? Who will fix the roof if it leaks? Will the neighbors be welcoming? Will the neighborhood be safe?

Home ownership is an experience that raises questions of risk for **any** homebuyer. Yet somehow, these questions are often asked more loudly when the potential homeowners have disabilities. People who make decisions on behalf of people with developmental disabilities-guardians, parents, providers, case managers- are often unwilling to struggle with the idea of homeownership. Too risky. Too many unknowns. Too…inconvenient.

Yet Sandra and Paula's story reveals lessons in what is possible when decision-makers make a commitment to find answers to the hard questions and look beyond initial obstacles.

Both Sandra and Paula have corporate guardians. These guardians make every legal, medical, and financial decision for these women. These guardians have full authority over any decision that could be construed to impact the welfare of their "wards."

They would have had the full legal authority to block Tresco-Socorro's efforts to support Sandra and Paula to live in their own homes.

They didn't.

In fact, Donna Canion and Brendon Gould became champions of the effort—supporting Tresco staff where needed, helping in decisions about home modifications, finding funding resources to help with the costs.

These two guardians did not know each other. They work for different organizations. And each told the story separately. Yet, Donna and Brendon had the identical response when asked *why* they supported the effort: "I ask myself, what would I want for my sister? My mother? My friend?" And at that point, the answer became clear.

Both took their roles of protecting Sandra and Paula's interests very seriously. They asked questions about the financing. They carefully reviewed documentation about the housing. They met the realtor. They worked with Tresco to consider the house's location and layout.

Yet, they recognized their role as a guardian was not to be a gatekeeper to typical life experiences, but rather to encourage and facilitate them.

As Donna noted, "When I was learning about becoming a guardian, I learned that being a guardian is about supporting people to have as many normal experiences as they can. What's more normal than owning your home? "

> **Things Sandra's and Paula's Guardians Noted About the Experience**
>
> - The guardians both cited Tresco's deep commitment to Sandra and Paula and the organization's transparency throughout the process as key reasons the process went so smoothly.
> - While the strong collaborative spirit among team members made the process work more easily, everyone involved noted that their primary commitment to the process came from wanting to do the right thing for Sandra and Paula.

WE *ARE* THE COMMUNITY

Sandra and Paula's story reveals a reality that is often overlooked in the disability service community. Disability organizations and the staff who work in them are also members of the community. Organizations build community relationships and each staff person has his or her own networks, resources and relationships. Sandra's and Paula's story holds a number of examples of how Tresco and its staff used their own community connections to create the home for Sandra and Paula.

- Sandra and Paula live down the street from Julie, a member of Tresco-Socorro's management team. This proximity helps keep the women safe and ensures they know at least one of their neighbors.
- Tresco-Socorro knew the realtor who assisted them. She was willing to think creatively about what the house would require.

- They had a relationship with the staff person at the local USDA office. He supported the loan application, despite the somewhat unconventional circumstances.
- Julie knew the guys who installed Sandra and Paula's cable. The guys have offered to help with future projects around the house.

THE OUTCOME: COMING HOME
Thirty years after moving into an institution,
fourteen years after starting a new life in their local community,
Sandra and Paula celebrated the milestone desired by so many. They moved into their own home.

By the end of the first day, the women had put their knick-knacks on the shelves. By the second day, Sandra was dancing in her living room.

With the support of committed direct support staff, persistent managers, supportive guardians and a far-reaching community network, two middle-aged women who had lived in places that were

Sandra, Paula, their staff and Julie, enjoying a laugh in the new kitchen.

controlled by others their entire lives finally had a place they could truly call their own.

While people with developmental disabilities are becoming homeowners more than ever before, it still remains rare for people with significant disabilities to own their own homes. Yet home ownership may be the *most* critical for the most vulnerable people. As homeowners, Sandra and Paula have a place they can call their own for the rest of their lives. As homeowners, Sandra and Paula will enjoy a new level of respect and credibility in their community. As

homeowners, Sandra's and Paula's identities have expanded beyond their disabilities.

But no one achieves her accomplishments by herself. And perhaps this is the most critical lesson in Sandra and Paula's story. This story reflects how a group of committed people, determined to do the "right thing" and guided by the belief that home ownership is truly possible for everyone, made *home* possible for two people.

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APPENDICES: A BREAKDOWN OF HOW THE HOME OWNERSHIP WORKS

Sandra in front of her and Paula's home.

APPENDIX A
GETTING TO THE FIRST STEP OF HOME OWNERSHIP:
HOW TRESCO-SOCORRO DID IT

- They believed it *could* be done and never lost sight of the dream for Sandra and Paula to live in a home of their own.

- They did whatever was necessary to make it work: working after- hours, arranging for flexible staffing, etc.

- They were persistent and found ways around obstacles.

- They used their own contacts, networks and relationships in persuading *others* it could be done.

- They seized opportunities.

- They struck a balance between keeping people informed but not necessarily asking permission for every phase of the process.

- They acknowledged how scary the process could be.

- "When someone told us 'no,' we responded "tell us why."

APPENDIX B
THE FINANCIAL NUTS AND BOLTS of SANDRA'S AND PAULA'S HOME

Amount of the Loans:	$110,486.00 from USDA $15,000.00 from HOME New Mexico
The Monthly Mortgage Payment:	Amount: $411.66. Each woman pays $206.00
Making it Accessible:	They used resources secured through HOME New Mexico. They will use resources through their Medicaid waivers if additional modifications become necessary.
Who Owns the House:	They both do.
Who Pays the Bills:	Sandra and Paula pay their utilities with SSI income. Paula has a job at Domino's Pizza distributing promotional flyers. She uses this income to help pay the bills. The women also participate in fixed income programs that reduce their utility expenses.
If a Major Expense Emerges:	• Both women have a modest amount of money in savings. • Tresco has supported them to access income-contingent utility and repair services. • They have a home warranty on their home.
Do they have to move if they change services?	No. Sandra and Paula will be able to remain in their home, regardless of their support provider.

And Yet More: Stories Worth Celebrating
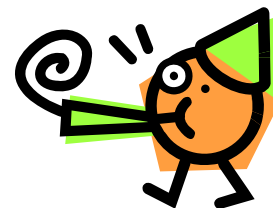
HENRY'S SUCCESS STORY: TAKING CARE OF THOSE WHO TAKE CARE OF THE DOGS

THE PERSON: A LITTLE ABOUT HENRY

Henry is a middle-aged man who most would say has significant disabilities. While he vocalizes his thoughts and feelings, he doesn't communicate with words.

Henry spent much of his life at Los Lunas State School and Hospital. He now lives happily and very comfortably with his longtime family living provider, Monica, and her family. He is supported during the day by the Los Lunas Community Program ("LLCP") and enjoys staff who care about him and are among his biggest fans.

Henry is a man of simple pleasures: he enjoys good food, feeling safe with the people around him, being outside, and observing others. Everyone enjoys Henry but sometimes struggle to discover new things he likes and to build a full schedule of activities that Henry enjoys.

While there are lots of people in Henry's life who care about him, nearly are all paid.

A group of people who care about Henry came together to begin thinking about how they could support him to deepen the experience of something he enjoyed doing in order to build new connections in his community.

THE INTEREST: HENRY ENJOYS BEING AROUND THE ANIMALS

In their effort to support Henry to try new things, the LLCP staff realized that Henry loves going to the local animal shelter. It's not always clear why, but something about being around the dogs seems to calm him.

Because of this interest and because the shelter staff seemed like nice people, the group began

thinking of ways Henry could become more meaningfully involved with the animal shelter.

THE QUESTION: WHAT DID THE SHELTER NEED?

The very friendly receptionist said that they always needed help walking and bathing the dogs. The group knew that doing physical labor probably wasn't how Henry would best contribute. He often needs assistance to walk and will often sit down on the ground unexpectedly. Walking dogs or bathing them would be unpredictable and not necessarily an enjoyable process for anyone involved.

So the group kept thinking and realized that maybe Henry's role wasn't to support the *dogs* but maybe the *staff*. The staff who work so hard, have a difficult job with little recognition, had been so friendly to Henry and who could potentially be part of Henry's informal community network of unpaid relationships.

THE BRAINSTORMING: HOW COULD HENRY CONTRIBUTE?

The group brainstormed on ways Henry could contribute that:
a) staff would always appreciate;
b) Henry could do on a regular basis; c) didn't cost a lot; and d) could easily be done regardless of who supported him.

Through brainstorming with Henry's direct support staff person, Linda, a simple idea with nearly universal appeal emerged:
cookies.

HOW EVERYONE CONTRIBUTED TO THE IDEA

Virginia, The LLCP Manager: A Commitment to Provide the Staffing

The LLCP day manager, Virginia, fully supported the idea and made a commitment that Henry would have the staff needed to pursue this idea at least every other week.

Linda, Henry's Support Staff:
Using Her Own Resources to Build Community for Henry

The group decided that if Henry could afford it, it'd be great if Henry could get his cookies from a local bakery: the cookies would be fresher than buying prepackaged cookies at the grocery and he'd make more community connections than baking them at home.

Linda mentioned that her church has a community coffee shop and she thought they made cookies. Sure enough, they did and Henry placed an order. Through using this local coffee shop affiliated with his staff's church, Henry was more likely to be welcomed and had a better chance of building community connections.

Henry now knows the friendly, hospitable clerks at the coffee shop in addition to the staff at the animal shelter!

Monica, Henry's Home Support Provider:
Helping Henry Stretch his Resources and Contributing to the Good Will

While the bakery cookies are not excessively expensive ($6 for a dozen), like most people with developmental disabilities, Henry is on a fixed income.

In order to make sure Henry could afford to bring cookies for a long time, Monica offered to help Henry bake cookies at their home, every other visit!

SUCCESS! APPRECIATION AND COMMUNITY THROUGH FOOD

So, with the idea of bringing cookies to the staff on a regular basis, the group started thinking how it could it. Working together, Henry now brings cookies to the hardworking staff at the animal shelter who:

1) now know Henry by name and are able to say "hello" to him on the street when they see him;
2) really appreciate the cookies; and
3) know Henry's personality and preferences!

For example, without being asked or reminded, one of the staff remembered that Henry has a tendency to sit down on the shelter floor and remarked during one visit "Hold on a sec, Henry, I'm going to go squeegee the floor before you go back to see the dogs so you don't get wet if you sit down!"

Henry now has a new regular activity that 1) he enjoys; 2) connects him to other people; and 3) allows him—someone with significant disabilities—to give back in informal ways!

Great Lessons from Henry's Story

- Appreciating and recognizing other people's good work is always a good way to build connections.

- When teams agree on the importance of building community connections, they can create better ideas as a group than any one member can.

- The key to success is consistency: organizations and staff must be willing to restructure supports to ensure people can make connections with the same on a regular basis.

- Good ideas often are developed outside an ISP meeting.

- "Giving back" doesn't have to mean formal volunteering. Simple, "small" acts of kindness are easier to organize and often more meaningful!