
Nuts and Bolts of Staying Afloat: How to Ride the Wave of Organizational Change in a Sea of Economic Crisis

North Carolina Council of Community Programs
Shifting Gears to Stay on the Fast Track
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Like This?



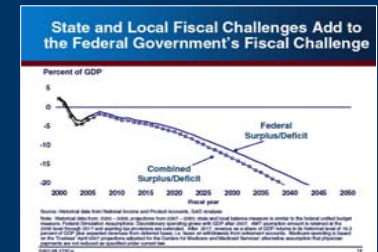
NASDDDS
National Association of State Directors of Developmental Disabilities Services

Or Like This ?

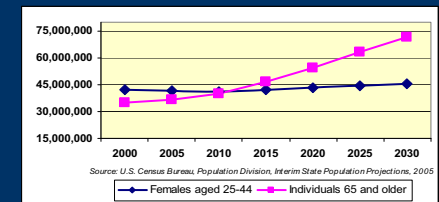


Confronting Reality

- We can't afford to pay for 24 hr. residential services for everyone.
- We can't staff 24 hr. residential services even if we could afford to.
- We have waiting lists but can't afford a 20% increase.



Persons Waiting-Under reported	Residential Services Recipients	Growth Needed
88,349	437,707	20.2%



Confronting Reality

- ✓ We can't afford to pay for 24 hr. residential services for everyone.
 - ✓ We can't staff 24 hr. residential services even if we could afford to.
- Do we expand residential services?
 - Or ride the wave to alternatives?



“Necessity, who is the mother of invention.”

Plato, *The Republic*
Greek author & philosopher in Athens
(427 BC - 347 BC)

What Can We Do?

- Put person-centered thinking skills into practice
- Help people get a job
- Support people and the families they live with
- Create Shared Living Options

Put Person-Centered Thinking Skills into Practice

Use Person-Centered Thinking Skills

- Listen to what is important to people as well as what is important for them
- Listen to the staff who support them
- Listen to the staff who support the staff who support people
- Remove barriers to people “having a life” they want
- Recognize and incorporate natural supports

What are the Benefits of Person-Centered Thinking and Practice?

- People with disabilities and staff are happier
- People with disabilities gain skills
- People with disabilities develop relationships
- Less challenging behavior
- Less incidents
- Less staff turnover
- Reduced costs

Ask the agencies that have put person-centered thinking skills into action.

Help People Get a Job

Help People Get A Job

Working

“It's what most of us do for half our waking lives. It's how we feed and clothe ourselves and how we support our families. It shapes our sense of who we are, and of where we fit in the scheme of things.”

Market Place American Public Media

<http://marketplace.publicradio.org/segments/working/>



Focus on Employment

- **Policy and Clear Goals**
- **Leadership - key players with shared values**
- **System Level Strategies**
 - Employment first policies
 - Flexible funding – support innovation, incentives
 - Using data to communicate goals and progress
 - Training programs that diffuse innovation throughout the state

Employment First Policies

Washington Working Age Adults Policy

Supports to pursue and maintain gainful employment in integrated settings in the community shall be the primary service

Florida:

Divert 25% of people receiving Adult Day Training services into competitive employment across the next 5 years

Tennessee:

At least every three years individuals who are not in integrated employment participate in a community-based work assessment

Vermont

- 1999: Funds can not be used to increase the capacity of sheltered workshops
- 2002: Funds can not be used to increase the capacity of group employment settings (enclaves or work crews)
- 2005: Funds can not be used to fund sheltered workshops

Flexible Funding

✓ Developing effective rate/reimbursement policies and practices that include incentives

- Provider rate based on the no. of hours consumers work *Ok.*
- Higher rates for employment supports *Tenn. Ok.*
- Requiring consumer wages on the provider monthly invoice *Wash.*
- Rates reward natural supports *Conn.*

Training and Using Data

✓ Improving access to high quality training and workforce development

✓ Using data to inform decision making and planning

- Contracting for job coach training *Maine*
- Public reporting *Wash. Penna.*

Supporting People and the Families They Live With

Supporting People and the Families They Live With

The question is not whether people with disabilities will be living with and relying on their families for support but whether people and their families will struggle alone or have a great life because the supports are there for them and they are part of their community.

Supporting People and the Families They Live With

- ❖ Recognize that most people live with their families as the core concept; Think of family broadly – parents; siblings; grandparents; other relatives
- ❖ The family is the context; personal outcomes will be influenced by the family
- ❖ Start to plan with the person & family early – be proactive to reduce worry and service demand
- ❖ Focus on the person's desired outcomes...with consideration of family members' needs too; The individual's identity, personal preferences and dreams must be primary

Supporting People and The Families They Live With

- ❖ Assume employment and plan supports
- ❖ Use innovation - self directed services; individual budgets; hiring relatives; paid peer support; home ownership; using state dollars for things not Medicaid eligible
- ❖ Develop and maintain essential non-direct services:
 - Support coordination – small ratios; training in family dynamics; conflict resolution; strong clinical supervision
 - Self Advocacy organizations as peer support

Services and supports should result in...

- The person and their family have a great life,
- Siblings and other family members opening their homes and hearts because they have confidence in the supports,
- When a bed is available, they say “never mind.”

Create Shared Living Options

Create Shared Living Options

- Shared Living is exactly that: people sharing their lives by living together under the same roof as a family. Rhode Island
- An arrangement in which an individual, couple or family in the community share life's experiences with a person with a disability.
- The person who lives with and provides support to the person with a disability is typically referred to as the Shared Living provider. Other terms include mentor, host family or family home, foster care or family care, and life sharing.

- A Shared Living arrangement is usually in the Shared Living provider's home/apartment, but it could also be in the individual's home/apartment too.
- The Shared Living Provider lives with the person and provides whatever support the person needs in their day-to-day activities. It may be couple, a single person or a family. Individuals supported in Shared Living include children and adults with a wide variety of needs and challenges.
- Shared Living providers are of all ages, genders, races, nationalities, and religions. They are single people, single parents, empty nesters, and two-parent families with children. They may even be related to the person. Shared Living Providers may or may not work outside the home.
- Generally states limit the number of people with disabilities to two.
- Most people with disabilities in Shared Living arrangements either work, volunteer or are involved in their community in some way.

Why Is It Called Shared Living?

The name we give services communicates the vision and expectations for the service. The term Shared Living emphasizes the expectation that people will live together and share experiences. It communicates mutuality and a real *community life*, not a *service life*, is the expectation. The term Shared Living invites people to have an experience rather than to work at a job or provide a service.

What Shared Living is Not

Shared Living is not a “facility,” a group home, foster care or a bed in a boarding home. It is important to understand what Shared Living is not because many of the practices and routines built into our system to manage residential facilities make no sense to citizens living in their own homes. We run the risk of undermining the core features of Shared Living if we do not appreciate the difference.

Health, safety and quality are as important in Shared Living as they are in any arrangement but relationships and commitment play a much stronger role in meeting these expectations.

Shared Living requires a new and different approach in recruitment and training, in assessing and managing risk, in record keeping, in monitoring and mostly in the type and amount of support provided to the Shared Living Provider.

The Benefits of Shared Living

- The most important benefit of Shared Living is the quality of life that people enjoy from living with people who care about them, who share life's ups and downs with them, where they have the dignity of having a role and responsibilities.
- Relationships are at the heart of Shared Living. Relationships extend beyond the Shared Living provider to friends, extended family members and neighbors. Many states report Shared Living arrangements that are going on ten and twenty years. These relationships have survived deaths in the family, divorce, relocations, and even natural disasters. People become committed to each other.

The Benefits of Shared Living

- Stability and permanence are additional benefits. Living in a real home, seeing the same people everyday, and enjoying predictable holiday rituals provide a constancy that is not part of life in a group home.
- What about belonging to each other—and each other's families and friends—opens opportunities to become part of larger networks of families and friends—which is hard to do with shift staff who leave every six months.
- Done right shared living can shift the power relationship from beneficiary and provider to a more mutual arrangement

What makes it work?

- **The Match** - The first most essential component of Shared Living is the “match.” . Penna. States take great care in the process of introducing people to each other and assuring the relationships work.

Matching means a harmonizing of values, interests, and mutual commitments. Penna.

- **Support** - The second most essential component of Shared Living is the support provided to the Shared Living provider. The goal of support to the shared living provider is to give them the information, resources and assistance that enables them to focus on the person they are supporting. They Shared Living provider and the person must be buffered from the bureaucracy and its requirements for paper work, regulations and other “system” requirement.

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