

Navigating Change: Strategies for Easing the Transition to Managed Care in LTSS for I/DD

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HCBS Conference

Today's Presentation

- Culture, Values, Priorities – I/DD Community
- Culture, Values, Priorities – MCOs
- What do we Know about What Works?
- Engaged stakeholders
- Shared values, outcomes-driven supports

The World is Changing



I/DD Community – Priorities, Values, Cultures

- SABE Just Do It Statement
 - <http://www.sabeusa.org/resources/policy-statements/just-do-it/>
 - End disrespectful labeling
 - Stop “preparing” people
 - Close institutions
 - Real jobs
 - Control of funds
 - Decision-making control
 - Support of Self-advocacy movement

The World is Changing

- UN Convention on the Rights of Persons with Disabilities - **Article 19 - Living independently and being included in the community**
- HCBS Settings Rule – settings can no longer isolate
- WIOA (2014) -- significantly limits placements at sheltered workshops
- Olmstead implementation and enforcement

What is TASH?



- Leader in Disability Advocacy since 1975
- Researched-based, values driven
- Volunteer Supported
- Cross Disability, Cross Sector

What is TASH's Vision?

TASH has a vision of a world in which people with disabilities are fully participating members of their communities.

We envision communities in which no one is segregated and everyone belongs.

TASH Values

a quality of life similar to that available to all citizens

This means all people with disabilities must:

- Be presumed to be competent to direct their own lives
- Have a way to communicate.
- Are fully included in their neighborhood schools.
- Have protections against abuse, neglect, and aversive procedures.
- Have the tools and opportunities to advocate on their own behalf.
- Have a home, recreation, learning, and employment opportunities based on their personal vision of quality of life.
- Have individualized supports that accommodate their functional needs.

“If we do our jobs, people with severe disabilities will live productive, safe, healthy, happy and integrated lives.”

Lou Brown, TASH co-founder, 1975

Agencies that Have Changed

8 Agencies in 7 States

California, Louisiana, Massachusetts, New Hampshire,
New York, Washington, Wisconsin

Changed from Group to Individualized models of
support

Kendrick, Michael. (2009) Some lessons concerning agency transformation towards personalised services. The International Journal of Leadership in Public Services, 5(1), 47-54.

Lessons From Agencies that Have Changed

All 8 agencies:

- All support for all people became individualized; no group programs of any kind were maintained
- Individualization happened without external pressure
- Impetus for change was from values-based leadership
- Change happened one person at a time; agencies learned as they went
- Net costs to support people was within range of normative per capita costs

Lessons From Agencies that Have Changed

All 8 agencies

- Had no guarantees that the change would be supported by funders – it was just the right thing to do
- Maintained a balanced budget throughout change process
- Remained fully compliant with system funder and requirements
- Were comparatively small; less than \$14 MM

Lessons From Agencies that Have Changed

All 8 agencies

- Respected and engaged families and natural supporters
- Served their share of very-difficult-to-serve people
- Had functional individual budgets in place
- Coexisted and thrived through political and economic changes
- Identified principal task as developmental/ ongoing in a person's life

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Become a Member

<http://tash.org/get-involved/become-a-member/>

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MCOs – Priorities, Values and Culture

Merrill Friedman
Vice President of Advocacy
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“Navigating Change: Strategies for Easing the Transition to Managed Care in LTSS for I/DD ”

Lessons and Strategies in Supporting People to Have Valued Lives

Presented by: Gail Fanjoy, Executive Director, KFI
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Katahdin Friends, Inc.

Providing personalized
supports which enable
people to:

Live in homes of their own...



- Flexible
- Own home or apartment
- With or without a roommate
- Home ownership if desired
- Focus on neighborhood and community connections
- Nurture natural supports

Work in regular community businesses...



- Individualized, competitive integrated employment
- Customized through Discovery
- Entrepreneurial
- Pathway to employment activities
- Job coaching and long term supports (Waiver funded or private pay)

Be members and contributors to their communities



- Individualized or interest-focused pairings
- Activity-focused small groups
- Focus on community connections
- Meaningful days
- Blended with the rest of the person's life

It has not always been this way...

KFI is a 54 year old community service agency. We spent the first 20+ years developing programs and erecting buildings that served to segregate people with intellectual disabilities from society, but kept them busy and safe.

What KFI Looked Like 30 Years Ago:

- Segregated Special Purpose School
- Segregated Preschool
- Sheltered Workshop
- Segregated Day Program
- Foster Homes or Living With Family
- Everyone Transported To One Location
- Agency Owned and Operated Vans
- Services Provided In KFI Owned Buildings
- Nothing customized
- *Groups, GROUPS, GROUPS*

Notes from a KFI Management Team Meeting on July 8, 1987:

“The ideal program would use an individual formula to address vocational, personal, social, and recreational needs of each individual. Where do we begin?”

KFI Today...

- **Public School Education**
- **Real Jobs In Businesses for Real Wages**
- **Community Life Engagement**
- **Support Individuals to Live In Their Own Apartments or Homes (including home ownership)**
- **Services In the Individual's Community**
- **Public Transportation Or Staff's/Own Vehicle**
- **Customized Services**
- **Nothing Provided Within Space Owned by KFI**
- **Individuals, INDIVIDUALS, INDIVIDUALS**

If a person had the right kind and amount of supports, would he/she need to go to a day program, work in a sheltered workshop, or live in a group home?

How do we build those supports?



WHOLE LIFE SUPPORTS



Defining Supported Living...

“Finding and securing a home that is not agency-owned or agency operated and then providing the flexible supports that people need to live successfully in the community.”

Taylor, Racino & Lutfiyya (1987)

“people with disabilities living where and with whom they want, for as long as they want, with whatever support necessary to make that choice possible.”

Bellamy and Horner (1987)

“The participant is typically the person who makes decisions about:

- When to go to bed;
- When to get up;
- When to eat;
- What to eat;
- What to wear;
- When to do activities;
- What activities to do;
- With whom activities are done;
- How personal money is spent, and
- When the participant works.”

Dan, the Pioneer



- Behavioral challenges resulted in being kicked out of his 7th foster home in approx. 11 years.
- 27 years old
- Never had spent any time without family or paid supports.

Today Dan has a full life which revolves around owning his own home



39 hours of paid supports/week; hot line to state crisis line; warm line to KFI staff working 24/7



Strategy:

Helped Dan move into his *own home*; initially it was a rented room in a large home owned by the local taxi service. KFI changed the location of his supports from a day program to his own home/community; celebrated when we couldn't keep track of who he knew, where he went, and what he did!





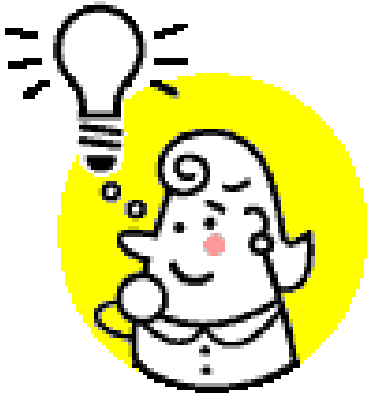
JACKIE



The state had
the dollars...

But we had the *sense*.

Why apartments are better
than galvanized washtubs.



Marie's Challenge to KFI 1991

- Had been institutionalized since the age of 11.
- Lived in an ICF/ID nursing home for the last 10 or so years.
- Had been kicked out of her day program for people with challenging behaviors due to challenging behaviors.
- Was supported by one-to-one aides who worked in 4 hour shifts because her behaviors were so challenging.
- Was considered extremely self-abusive, failure to thrive, profoundly cognitively disabled.
- Was given a 30 day notice to leave the ICF/ID nursing home and was on her way to the state's large institution for people with intellectual disabilities in the closing days of that institution.



Marie, circa 1992

“Somebody has got to do something, and it’s incredibly pathetic that it has got to be us.”

Jerry Garcia



Boating on one of Maine's many lakes



There was only one paid person at Marie's last person-centered planning event

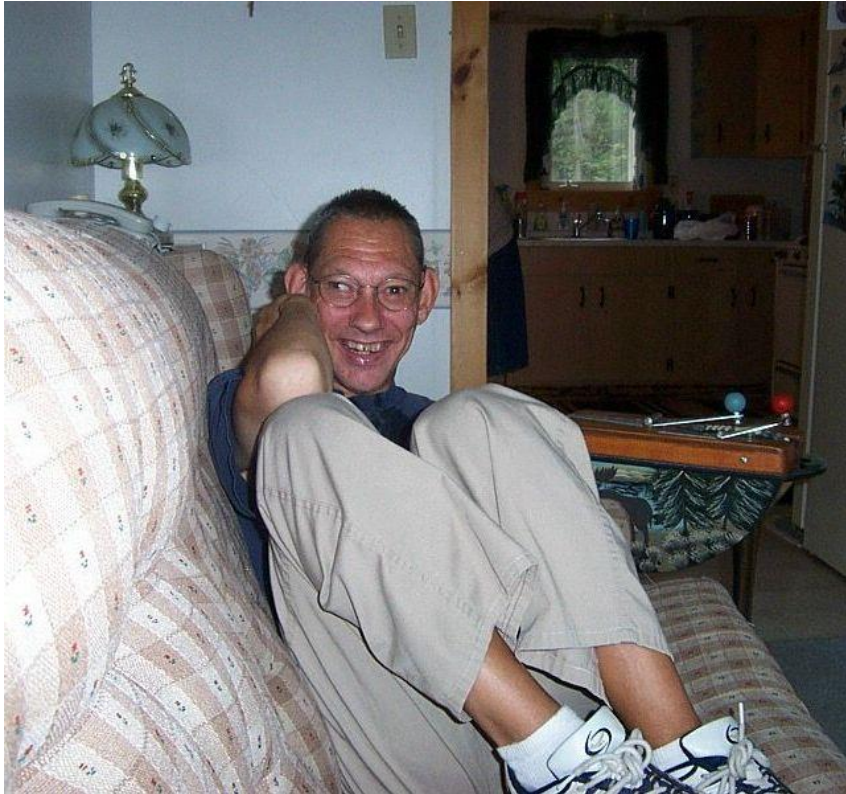


Some members at Golden Key enjoy the shade of the side lawn. C'mon up and grab a chair!

MARIE

- **Lesson:**
 - Supporting people – no matter the complexities of their disabilities – to live in their own home and giving them control, can produce miracles.
- **Strategy:**
 - “Treatment” took the form of real home, family connections, paying attention to what she showed us she wanted and needed, and less about her behavior and deficits.

BRENT



- Spent many years in KFI's day program.
- Spent some time in the state institution following his father's death.
- Was unhappy and continually ran away from his group home residence.
- Said he wanted to "go home".

Purchased his childhood home from his mother



Pursued his interest in camping



Lesson:

Brent taught us that “home” is where the heart is. Home is not “home-like”, it’s not a “residential program”, it’s not “group housing”. “Home” is where Brent grew up, established roots, and where everyone knows his name.



Strategy:

Listen, Listen, Listen!

Brent was telling people with words and actions that he wanted to “go home”. His family made his dream come true by helping him buy his childhood home. KFI supported him to continue living his dream through adversity.

Courtney

- Graduated from high school June 2012.
- Owns her own home.
- Enjoys hanging out with her friends.
- Volunteers in her community.
- Has her own credit card and checking account and is building excellent credit.
- Established a vending machine business.



Courtney



- Cyr Vending established in December 2013
- 4 donated high end vending machines placed in area businesses and establishments
- Amazing team which included KFI Customized Employment Coordinator, KFI Support Coordinator, 3 KFI DSP's, VR Transition Councilor, Community Case Manager, Benefit Specialist, Maine Small Business Council representative, and most importantly, **Courtney and her family**



Courtney's Labels

- Profound cognitive impairment
- Autistic disorder
- Cerebral palsy
- Seizure disorder
- Static encephalopathy
- Ataxia with low tone
- Nonverbal
- Does not have self-protective reflexes
- No reliable communication system

KFI's Strategic Plan

- **We support individuals**
- **To lead regular lives**
- **In their communities**

The same, not different

We support individuals:

KFI supports individuals and not groups. We begin by asking people what they want and need. Supports are designed to meet the individuals' requirements; the individuals do not need to fit into a group.

To lead regular lives:

Our supports are to assist people to live in the same places as anyone else, in ways that fit their life style, which includes respecting people's desire to live by themselves; to have jobs in typical businesses at minimum wage or higher; to access services, recreation and community resources which are available to all citizens.

In their communities:

KFI recognizes the importance of community, particularly in rural sections of Maine and so brings supports to the persons receiving services. Our supports must help people become included into the fabric of the community, to be viewed as contributors and valuable members of it.

The same, not different:

People with disabilities have the same needs as any citizen and those needs must be addressed in regular, inclusive ways.

“The bottom line of the social sector organization is ‘changed lives’.”

Peter Drucker

A scenic view of a forested mountain range with a lake in the foreground. The mountains are covered in dense green forest, and the sky is clear and blue. The lake is calm, reflecting the surrounding greenery.

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