



**They Said He's  
"Too Dangerous" to  
Succeed: He Showed  
Them How Wrong  
They Were**



# 2007-2012 hospital-based lockdown residential unit in Massachusetts



Admitted from  
psychiatric hospital  
after 9 month wait &  
multiple rejections due  
to level of behavioral  
needs (age 14)

Cornered and held  
behind desk with  
padded walls all day,  
escorted by 2 people at  
all times, not allowed  
outdoors

Full prone  
restraints at the  
rate of 8-10 per day  
for non-compliance  
and self-injury

# Time to transition



Only a  
group home  
didn't work  
Only a

hopeless  
hopeless

incapable  
incapable

*'He's going to need to go someplace  
where he can be*

**MANAGED**


**HANDLED**

**CONTROLLED**

**RESTRAINED'**

dangerous  
dangerous

Too scary  
Too scary



**Remembering  
A life-changing  
meeting**

# REFLECTIONS ON THE DISCONNECTIONS



# A STORY OF CONTRASTS

## How SL is defined

### US Dept of Labor

These are **programs, often funded by Medicaid or other public sources**, called by different names such as adult foster care, paid roommate arrangements, or host homes, in which an **individual receiving services and a direct care worker providing the services** live together.

<https://www.dol.gov/agencies/whd/direct-care/shared-living>

### “Unnamed State” on US East Coast

Shared Living means an **arrangement in which the (State's) program of medical assistance pays** a portion of a person's rent, utilities, and food expenses in return for the person residing with and providing **companionship, support, and other limited, basic assistance** to a person with intellectual or developmental disabilities receiving medical assistance services **in accordance with a waiver for whom he has no legal responsibility.**

### Nonotuck Resource Associates, Inc. (MA)

Shared Living is a service that brings together an individual, a couple or a family in the community with a person who has a disability to share their lives in an authentic, loving and **respectful relationship of mutual dependence.** Shared living is successful when there is a mutuality of love and respect. **A person and caregiver are on equal footing. Each have responsibilities, and they can both depend on each other.** This is where each person has the space to live their most genuine lives, with opportunity, choice and a voice.

[www.nonotuck.com](http://www.nonotuck.com)

### NADDDS Shared Living Guide, 2011

“The term shared living **invites people to have an experience** – rather than to work at a job or provide a service. And ‘share’ means just that – not allow, permit, provide – but, as the Thesaurus offers, to ‘communicate, disclose, let somebody in on.’ This concept of sharing **presupposes a mutual experience not a hierarchical one.** Shared living presupposes mutual respect.”

...“Shared living is also about shifting the balance of power. Done right, with a strong focus on the individual, shared living can alter – indeed eliminate – the power relationship. **In true shared living, both the individual with a disability and the person living with him or her gain mutual benefit, living as equals in the same household.**”

<https://www.autismhousingnetwork.org/moves-part-ii-housing-terms-breed-confusion-disability-community/>

# A STORY OF CONFUSION

Because the definitions of Shared Living are inconsistent and families hear first the systems definition that speaks only of the technical terminology for how it's set up;

Because the systems have appropriated Shared Living as simply a housing option, not a way of living and sharing joy;

Because we are still living in the institutional mindset that it's least expensive and most efficient to use congregate house models and fill beds;

Families are not choosing Shared Living because:

- They believe their loved ones are safer when there are more staff around – shared living makes them more vulnerable to abuse or neglect
- They believe the model decreases opportunities for peer interactions and activities; increases isolation
- They hear stories of people having to move every year or even more frequently, because providers quit
- They are afraid that their loved one will bond with their caregivers and become less bonded with them
- They aren't provided the explanation of the benefits of building authentic relationships that will sustain beyond them

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Families find it confusing because they have been conditioned to believe:

- Their loved ones are unable to live full lives because they need more support than SL can provide
- Communication about care should be within pre-determined guidelines, limited to the hierarchy of leadership created by the provider; there should never be direct communication (never mind relationships) with direct care staff
- The more direct care staff there are, the better
- Only the best behaved, verbally skilled, "high functioning" can participate in Shared Living



# REFLECTIONS ON A ROADMAP TO SUCCESS



# Core tenets of change

- Valuation of relationships and creating spaces where relationships can be fostered and strengthened

Our need and reliance on relationships is what makes us human, period. When that part of our existence is dismissed, we suffer a loss of our humanity.

Relationships in institutional living models are non-existent; indeed, the opposite is cultivated – direct care workers are discouraged from building relationships because they get in the way of care.

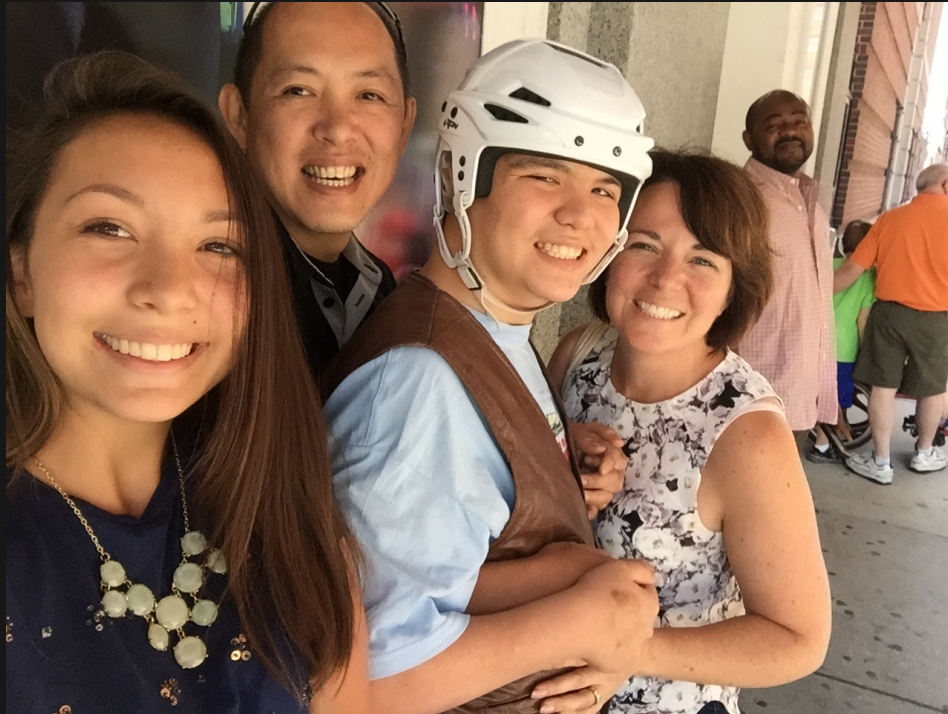
How ironic...

# Core tenets of change

- Presumption of capacity first and the removal of dependence as a reward

Capacity lies in possibility; not just in what a person can do in this moment, but what they could be capable of with appropriate supports and providers who embrace lifelong learning and opportunity rather than “keeping people fed and housed.”

Right now, services are divvied up according to who needs them the most. This has created the “golden rule” among families: when they come to visit and evaluate need, don’t tell them about the good stuff – tell them the worst stories you’ve got. That will get you more. The seeds of distrust are planted the moment services begin.



Back to our  
story...

# The core needs before the vision



Find a Provider Agency willing AND READY to take on a challenging individual in a Shared Living setting.



Find a Shared Living Caregiver willing to take on the challenges



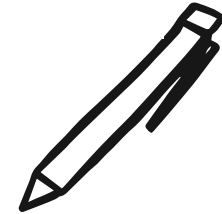
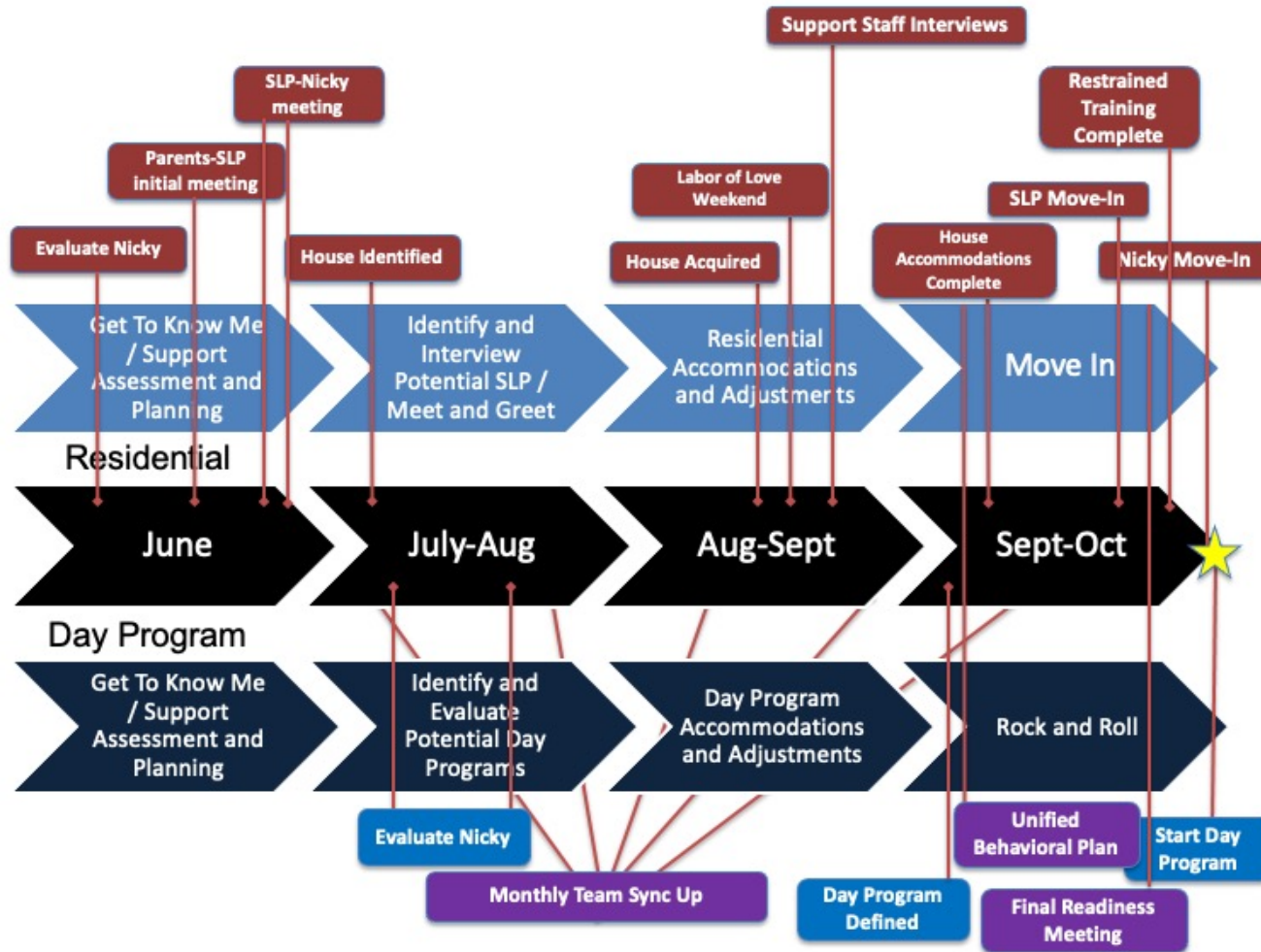
Family owns the house: Caregiver will have to move, rent from family

The Master

Plan



# 8 MONTHS OF PLANNING



**Meantime,  
relationships are forming.**





# October 20, 2012: the king arrives



# October 20, 2012: the king arrives





# October 20, 2012: the king arrives



# October 20, 2012: the king arrives



# Within 3 months

## 71% decrease

In aggressive behaviors

## 90% decrease

In self-abusive behaviors





10 years later

**2-4 significant  
behavioral  
episodes per  
year**



# 10 years later

2 SL caregivers in 10 years  
5 additional staff in 10 years

Strong, authentic bonds

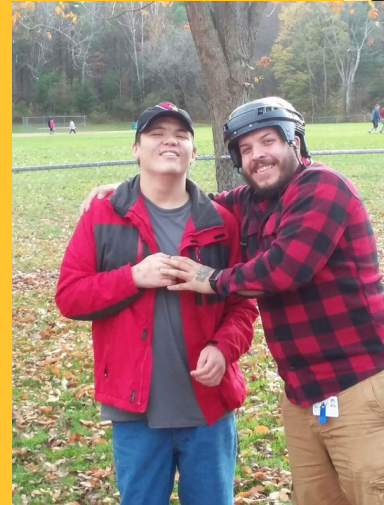
Extended family (caregiver's family nearby)

Community relationships

Shared decision-making in the home

Frequent family visits

Shared experiences  
between family & caregivers



This was NO  
MIRACLE





# The Elements of Success



Families and Citizens:

- ✓ Ready to embrace new relationships between their loved ones and others
- ✓ Willing to work with the process
- ✓ Willing to use civility, practice mutual respect and respect boundaries that won't interfere with relationships
- ✓ Committed to regular communication with providers & agencies

# The Elements of Success



A Provider Agency:

- ✓ Willing to support a challenging individual
- ✓ Willing to spend the time & resources needed to plan thoroughly
- ✓ Willing to work with a family – owned home
- ✓ Willing to collaborate with the family & day program providers at every step

# The Elements of Success



## A Provider Agency:

- ✓ Asking the family to participate in caregiver interviews & hiring
- ✓ Training the caregivers in safe de-escalating and emergency restraint techniques
- ✓ Seeking & training backup caregivers in the event of a sudden need
- ✓ Providing strong, consistent support to the caregivers on an on-going basis

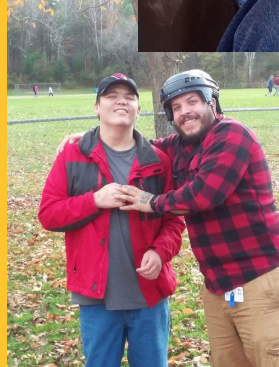
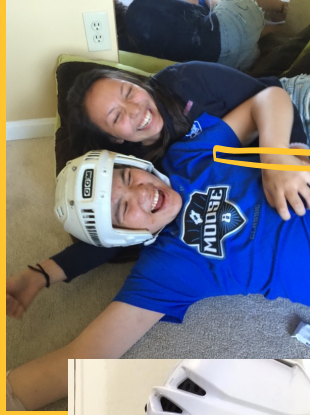
# The Elements of Success



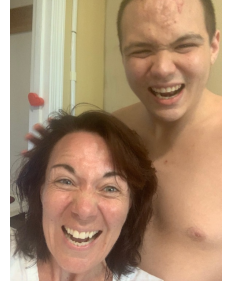
A Provider Agency whose core values, and thus its practices, are firmly grounded in the beliefs that every human being has the capacity to love and the desire to be loved, valued and respected.

When working from this framework, success is expected and creativity, compassion and civility are part of everyone's daily practices.

# The Elements of Success



A young man who loves to be with people he loves & who love him;  
who is a neat-freak,  
loves to try new food,  
wants to play chase & wrestle,  
keeps track of the date & time,  
can't get enough rollercoasters,  
can find ANY video on YouTube,  
worries when someone is hurt,  
loves a good singer,  
knows all the Disney movie lines ever written,  
gives the best hugs,



And is the best friend anyone could have.



Nicky's Family

“We all know well that we can do things for others and in the process crush them, making them feel that they are incapable of doing things by themselves. To love someone is to reveal to them their capacities for life, the light that is shining in them.”

-- Jean Vanier







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