What Makes a House a Home?

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Goals for the Workshop

- Learn from two families who have successfully navigated the transition to adult life
- Learn about resources
- Gain an understanding of what is possible
- Learn from each other
The Players

- Person receiving services
- Family
- State funding agency
  DDS, MassHealth,
  MRC, MCB, DMH
- Human service provider agency
- State and federal policy makers
Robin & Adam
Adam’s Journey

Robin Kantrowitz – Mother of 30 year old Son with Autism
Founder and creator of the website transition22.org

How did Adam’s Journey begin? Why was this so unique?

- Our family moved from New York to Massachusetts
- Adam was 3 ½ when he became a day and residential student at the Boston Higashi School now located in Randolph Massachusetts
- Adam was the youngest child accepted into this program
- Approximately six months after his 20th birthday I was approached by a group of parents at the BHS to have Adam be the 5th individual to be place in the Group Home they were setting up.
- Adam went to school with the other students for most of his young life.
- Why was this was so important to our family – Familiar environment for Adam, we already knew the parents involved.
- SOUNDS GREAT – THE CHALLENGES BEGAN– he was not turning 22 for another year and a half.
Challenges

- The vendor agency was not convinced this could happen because this type of partial transition was never done before.
- Ashland School district was already providing Adam with a comprehensive education by sending him to the Boston Higashi School.
- I requested that he be partially transitioned – Boston Higashi during the Day and the Group Home experience at night.
- Adam knew nothing else but his routine from School to home for almost 20 years. As a parent I felt this was really necessary to ease him into this new day and evening routine.
- Routine and consistency for Adam was crucial to his OCD.
Challenges (continued)

- School district not on board
- Sought legal advice – found out it was not a legal pursuit because legally the district was not obligated to help me with this unique situation they already were providing Adam with a comprehensive education.
- Transportation was an issue – I solved that problem by arranging my own transportation
- Still I got a NO
- I had to plead my case over and over again and finally it just came down to some creative paperwork to make it happen and some political intervention from a Senator who wanted to help. I was able to prove that it was not going to cost the district anymore money.
Vision planning for your individual's future is essential.
Do not let a “NO” stop you from pursuing a lifelong vision for your loved one.
Embrace the “NO” and see it as a journey to a “YES”. Explore all your options and resources it can lead to a positive change.
When discussing a vision plan focus on their strengths not their weaknesses.
How to make Group Home living manageable – Which includes but not limited to Staffing, schedules, medication, clients clothing, Laundry, Portfolios and visiting. Welcome change and be part of the process to make it work. Remembering that the staff care for our Sons and Daughters work hard and have many responsibilities.
Providers make the final decisions and budget
Parents can give input but are not the final decision makers.
Change is evitable in any living situation and needs to be embraced with a positive twist as to keep our Sons and daughters in living environments that make sense and that are safe.
My journey inspired me to create transition22.org
What I Learned (continued)

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Building A Home
What are the potential challenges? One person’s experiences

- Your son/daughter may want/need his space—without you!
- Resources may limit what is possible and may impact a family’s individual vision or the collective vision
- Families have different perspectives
- Different perspectives may lead to conflict
The catch 22’s in turning 22

1. Needed a group to persuade DDS of viability
2. Couldn’t get a group without a house
3. Couldn’t get a house without knowing our funding
4. Couldn’t get funding until DDS was ready AND until they knew we had a viable group!
5. Couldn’t get a group together until we had a house…
6. Rinse and repeat!!
Working with state agency (DDS, etc.)

- Establish a mutually respectful tone
- Follow up on dates you’ve set
- Be clear about what you want: share your written vision
- Learn your funding agency’s (Area Director) parameters and non-negotiables
Write it down:

- Describe the ideal setting
  - type & number of housemates
  - staffing needs
  - preferred locations
  - activities & schedule
- Describe your degree of involvement
- Determine how the vision meshes with the Agency and other families
So...How do **you** begin, given the parameters and pitfalls?

- Stay in close contact with the other families
- Gather your info for your vision
- Find out what your adult child wants and needs in his adult life: ask, observe, reflect
- Keep your focus on your son/daughter, *not you!*
So how did we begin?

- One year prior to Nat’s Turning 22 in 11/10, we did not know his priority
- Got Nat evaluated for AFC eligibility
- Met with various parents we knew to discuss housing ideas
- Looked for apartments
What went wrong first

- Families disagreed about apartments
- Families were not ready emotionally for the child to move out
At last, DDS funding came through

- Moved into a house owned by one of the families
- Another young man transitioned in
- Friction with homeowners over vision
Three young men left the first home and transitioned to a temporary house while the agency looked to buy a house in Boston.

- Excellent staff helped smooth this period.
- Young men were completely fine!
- Even through a break-in, group and staff stayed intact.
New house: grove street
Now that it’s real, how is it working?

Parents can design overall plans & give input

Provider makes final decisions & budget

DDS sets the parameters (cost, legal, referrals, locations)

Meetings must be orderly, agenda–driven

Emails must include everyone

Follow chains of command

Raise issues directly with appropriate staff
Try not to gossip, leave people out or be divisive
Things to remember

- Families do not make the ultimate decisions
- Families do give input
- Families do disagree about things
- Families must observe certain protocols
Your vision might be different from your child’s...or the other families’ needs
A key question: How do you balance state agency, provider agency, family, and individual needs?
What are the options?

- State awards contract to provider, provider works with families and individuals to develop program
- Family works with State on identifying existing program
- Family (families) link up either directly or with support from state or provider; families choose provider; families get involved in developing and running program
- Self-direction/agency with choice: family (families) run program
What are service options?

- State agency eligibility requirements

Service options:
- Shared Living (DDS, MCB)
- Adult Family Care (MassHealth)
- PCA (MassHealth)
- Group Home (DDS, MCB)
One Option: New Home with Active Family Involvement and Person – Centered

- Research and explore the options.
- Choose a Service Provider that is responsible for hiring, training, and managing the employees who provide care.
- Maintain the connection to home and family.
- Build on the training and care the school has provided.

- Qualification of the provider to deliver services.
- Know your Individual Resource Allocation.
- How are staff trained? When staff understand their role in supporting your loved one its powerful. Staff are more satisfied and productive when they feel engaged in the process.
- Is the agency a good match to meet your needs?
- Are you included in planning and input of care for your son/daughter?
Cultivating Other Families

- Get together with the families you’ve found over the years or from workshops, Special Olympics, school
- Compare visions
- Record non-negotiables
- Remind each other that all is subject to change
- Be ready to work with uncertain conditions
Moving Forward -- Into Reality

- Be up-to-date with DDS liaison about funding, potential settings, potential roommates
- Compatibility of consumers
- Compatibility of families
- Interview and choose your providers
- Cultivate families similar to your own (similar vision, Turning 22 dates)
  - Host a get-together
  - Meet again with provider and group
- Use template to fill in vision, as a group.
Choosing a Provider

- Share your vision document
- Determine how can–do they are
- Visit their other homes
- Talk to other families using them
How will it be sustained?

- Fundraising
- Partnerships
  - State Agency (DDS), Families, and Provider
- Parents support service provider
- Families work together
- Change if needed
Focus on the needs/wants of person receiving services
Not every family can get everything they want, unless it is a single person home
Families need to sometimes put aside their own wants—compromise is needed
It is OK to make “mistakes” and change
Worth the effort
“We cannot solve our problems with the same thinking we used when we created them.”

Albert Einstein