

# Options for housing

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June, 2009

# Current situation for adults with autism<sup>1</sup>

- Majority of adults still live with family members
- Combined annual average staff turnover for programs serving adults with DD is 50%, with a staff vacancy rate of 10-12%
- Lack of access to appropriate service models is driven by lack of funding, and the current economic downturn will make things worse

<sup>1</sup>Source: “The Current State of Services for Adults with Autism”, Organization for Autism Research (OAR), [http://nyc4a.org/pdf/oar\\_survey\\_11309.pdf](http://nyc4a.org/pdf/oar_survey_11309.pdf) 2009.

# The continuum of residential options – most restrictive to least restrictive<sup>2</sup>

- Institution
  - hospital / nursing home placement
- ICF (intermediate care facility)
  - Fernald is considered an example of this
- Group home
  - has been the “default” option in Massachusetts
- Supervised living
- Supported living



“As one moves from a more congregate or institutional placement to supported living the degree of individualization and community integration increase significantly. “

# Default model of 24/7 residential service in Massachusetts

- 4-person group home
- Less than 1:1 staffing
- Home owned or leased by service provider (vendor)
- Residents are assigned to the home by DMR; families have input through visiting homes with available beds and expressing a preference

# Problems with the group home model

- Not designed for people who need 1:1 staffing
  - These individuals may have difficulty in this setting
- Little control over who staff are or where home is located
  - Transportation to day programs can be difficult
- Problems frequently difficult to correct; families have limited leverage
- Individual/family can't fire the provider, but the provider can have the individual removed

# Supervised living<sup>3</sup>

- Home may be self-owned or leased by individuals or families
- Fewer residents per unit; may be several units scattered through a community or complex to allow for unified oversight
- 24 hour crisis management
- Services more tailored to individuals

<sup>3</sup> This definition reflects the OAR survey; the ARC has a slightly different definition, considering the term “supervised living” to refer to a group home, and attributing some of the characteristics listed here to “supported living” (<http://www.thearclink.org/state/system/how.asp?ID=MA>).

# Supported living

- Home owned or leased by residents or their surrogates (e.g. families)
- Residents/surrogates choose to live there
  - Residents who have the same day services provider can choose to live together near the day program, minimizing transportation problems
- Residents/surrogates choose the service provider – and can change provider if necessary
  - Harder for residents to be “voted off the island”

# Other models/terms/features

- “Teaching family model”<sup>4</sup>
  - Core staff (often a married couple) live on site in their own apartment; can result in decrease in staff turnover
- Home sharing<sup>5</sup>
  - Paid supporter lives in the home of the individual
- Shared living<sup>6</sup>
  - Individual lives in the home of the person providing care
  - HMEA is one such provider
  - May be called adult foster care
  - Individual can lose their home if the provider chooses not to participate anymore

<sup>4</sup> OAR survey

<sup>5 & 6</sup> The ARC

# Self-determination

- Idea that individuals should have control over where they live, with whom they live, and who provides them with services
- Grew out of Robert Wood Johnson Foundation project in the 1990s<sup>7</sup>
  - Individuals had better perceived quality of life

<sup>7</sup> Source: <http://www.rwjf.org/reports/npreports/sdpdd.htm>

# DMR Self-Determination Policy (Policy # 2009-1)<sup>8</sup>

- Effective March 9, 2009
- Individuals/families who self direct will not receive money directly; it will be funneled through an Intermediary Service Option

Excerpt:

“In a service system that promotes self-determination, individuals, guardians and families can choose to be served by traditional agency providers through arrangements with the Department, can choose to self direct all aspects of their supports including hiring and managing direct support workers, or can choose any combination of both approaches.”

<sup>8</sup> [http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Government&L2=Laws%2C+Regulations+and+Policies&L3=Department+of+Mental+Retardation+Statutes%2C+Regulations+and+Policies&L4=Policies&sid=Eeohhs2&b=terminalcontent&f=dmr\\_g\\_policy\\_2009\\_1&csid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Government&L2=Laws%2C+Regulations+and+Policies&L3=Department+of+Mental+Retardation+Statutes%2C+Regulations+and+Policies&L4=Policies&sid=Eeohhs2&b=terminalcontent&f=dmr_g_policy_2009_1&csid=Eeohhs2)

# The group home is no longer the default option –now what?

- Options are not mutually exclusive; it's possible to mix and match features
- What have other people done in Massachusetts?
  - Higashi parents
  - Creative Living house
  - Katydid Foundation
  - Larkin family
  - Andover families
  - Specialized Housing

# Higashi parents

- Approached DMR as a group
- Selected CMARC as a vendor
- Higashi trained CMARC
- CMARC owns the house

# Creative Living House

- Group of parents wanted a religious setting for a home; approached DMR
- Selected Lutheran Social Services as a vendor
- Lutheran Social Services built home on land owned by Creative Living, a respite provider
- LSS got a federal Section 811 grant for construction
- Home consists of 8 small individual apartments, along with a common area that includes a full kitchen.

# Katydid Foundation

- Founded by parent of an adult with autism with severe behaviors, who had been through two different group homes
- Parent formed non-profit to buy/renovate a home for her daughter and others
- After the first housemate moved out, discovered her daughter calmer; now renovating home into studio apartments for each resident

# Larkin family

- With three other families, approached DMR with Request for Proposal
- Land is owned in trust for the residents
- Home was built by a DMR-approved builder
- The families/individuals selected their own vendor; they also have some say in the hiring of individual staff
- Located close to day program

# Andover families

- Bought house together
- Hire all staff themselves

# Specialized Housing

- Each individual/family owns their own condo in a building managed by Specialized Housing
- Condos can be bought and sold
  - Initial price based on square footage and other amenities
- Specialized Housing works with families to determine staffing model
  - Staffing usually provided by Specialized Housing, but condo association could choose a different vendor
  - Price based on level of staffing
    - Inclusive price includes food, utilities, housekeeping, etc.
    - For relatively independent individuals, staffing and services run about \$1700 per month

# Common denominator

Almost without exception, all these models  
involved

**approaching DMR as a group**

# Pros and cons of models

- Land owned by families or in trust
  - Individual cannot be thrown out
  - A condo or co-op model would allow for turnover if desired
  - Not eligible for Section 811 grant, so families must put up more money
    - Note, however, that each adult child can pay some rent out of SSI, and may also be eligible for a Section 8 housing voucher

# Pros and cons (continued)

- Families form a non-profit to own the property
  - Theoretically possible an individual could be thrown out
  - Property owner is not the same agency as the service provider; can change service providers
  - Eligible for Section 811, and other public financing, so possibly less upfront costs for families
    - Applying for public financing means hiring a housing consultant
      - Need to know exactly what you want before hiring a consultant

# Pros and cons (continued)

- Families approach DMR as a group to pick a vendor
  - No capital costs to family
  - Families can choose a vendor committed to a service model that fits
  - An individual could be thrown out

# Pros and cons (continued)

- Families (or a non-profit they form) hiring individuals directly to provide services
  - Have complete control over staffing
  - Also own all the headaches
  - Greater potential for internal disagreement among families

# Pros and cons (continued)

- Acting proactively on any option other than the traditional group home
  - Create something that will fit your child and that will be available when he/she turns 22
  - If child is approved for 24/7 residential, it may be possible to move in before age 22 if the house is ready
  - Chance DMR may not approve your child for 24/7 residential support, meaning you have less money available to cover costs
    - Have to consider other funding sources: PCAs, Section 8 housing voucher
    - Note, however, that the cost of the actual housing is always far less than the cost of services

# Our kids

- Far more likely to require 1:1 staffing than the typical group home resident
- Tend to need their own space to retreat to
- Need for highly-trained staff with minimal turnover
- Residential survey of NLG families three years ago indicated a preference for
  - a location within walking distance of certain amenities (stores, fast food, recreation, etc.)
  - opportunity for social interaction when desired

**What do we want?**

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