

A CALL TO ACTION FOR PARENTS

Getting a loved one with disabilities established into an independent housing situation can be a difficult process for families and caregivers. The road can be long and because each person is so different, there are no "one-fits-all" solutions.

This guide doesn't have all of the answers, but hopefully, it will give an idea of where to start.

You <u>Need</u> to know

In Connecticut, there is no housing plan for people with disabilities currently reaching ages of independent living.

Years ago, state institutions and group homes were the answer. Today, the majority of these are being shut-down without being replaced with alternative options.

Unfortunately, this means responsibility falls back on the families, many of whom have spent years struggling through an assortment of challenges including medical, educational & social issues.

Step 2: Finances

The planning process for a successful housing situation may take to years bring your vision to reality. **Early planning is key.**

If your loved one is eligible for CT Department of Developmental Services (DDS) benefits, the first step is to contact the agency. You will be either assigned a case manager or provided with the main Helpline number.

They <u>may</u> develop a plan and / or "level of need or LON number.

But be aware, this doesn't

mean you'll receive any funding. This

just registers you into the system so the

case workers can advise you.

In reality, there isn't direct annual funding for anyone except for extreme emergency cases.

What can happen is for the DDS Case Manager to identify Family Grant opportunities available an annual basis or place the individual on a waitlist. (DDS contact info is listed in Resources section on reverse side).

For most people, income will be Social Security (SSI or SSDI), job income, food stamps and any available housing individual & family grants (if possible).

Step 3: Plan B

Here's where the story gets interesting. Across the country, because of similar agency funding situations, families and supporters of people with disabilities are taking a different approach and working together to combine resources and supports.

Step 1 Creating the Vision

The first step of planning independent living is to define an ideal situation. Talk about what's critical then fill in the details later. It also helps to start with a few basic needs to get the overall picture.

- **Physical & psychological safety** is at the top of the list. Is the neighborhood safe to travel alone? Are family or friends within walking distance or a quick bus ride?
- Location: Is the home in a central location nearby to jobs, grocery stores & neighborhood supports?
- What kind of maintenance would be manageable? Houses with yards need constant care & upkeep while an apartment or condo requires less care.
- What kind of supports are needed & how often? Personal care, housekeeping, cooking, groceries & errands, time prompting. How many hours per day or week?
- **Financial considerations**: How do we pay for the vision? Understanding financial supports like SSI, housing vouchers, grants, etc. is key to building the framework of a living situation. (For details, see resource section on reverse).
 - **Transportation:** Does the location have safe reliable transit (bus stops/ride assistance), and/or safe enough for walkability? How will the person get around?
 - Management Team: Who needs to be involved? Who will find, train & manage staff? Pay bills? What about medical care? Job coaches?
 - Roommates or not? Would having roommates provide social interaction or is living alone a better plan?

Modeled after the "World Café", the CT version was started by the DDS-South Region in collaboration with the Family Support Network.

Housing: Café To Go".

One of these efforts is the "Creative

The DDS Housing Forums & Cafes gather families & support services to discuss creative ways to combine resources into workable solutions.

vide now supported across the six Family Support Network regions in the state. DDS staff is on hand answer any service questions. (See reverse side to find the group closest to you.)

See reverse side for more >>>>

Learning from a Parent's Perspective

We cannot build the future without tapping into the richest wealth of knowledge available on the subject: the individuals with disabilities & their families. These people experience the reality of living with disabilities everyday with no political agendas or preconceived notions.

"One thing you have to think about is the social factor for those living alone or in small apartments," says Susan M* who's daughter has been living in an state group home for 5 years with a range of 1 to 3 roommates.

"Frequent staff and roommate changes are a factor that will never go away. Each change creates a new dynamic residents must adapt to, and that is stressful."

"My ideal solution would be an assisted living approach as is done for the elderly, with 5 or 6 residents living together, each with their own room, and shared social spaces."

This offers the residents a choice to be involved in social and group activities or not. "There are challenges when you live with a disability. The ideal solution is to give the amount of support needed but to also allow individuals to have as much control as possible."

* Name changed for privacy

Step 4: Model Programs

If you're feeling apprehensive about this whole process, Check out some model programs in other states for inspiration, like Neighbours (below).

- Neighbours Inc.— www.neighbours-inc.com Patti Scott— (908) 581-3998 (N.J). Begun in 1995, Neighbours' goal is to support people with disabilities as citizens -- individuals, with gifts, skills, dreams, goals, and the ability to be participating members of the communities where they choose to live.
- Hope House Foundation, (VA) www.hope-house.org. 757-625-6161 This agency provides services, community participation, and advocacy for individuals with disabilities

The Future: A Push for Change

This generation of individuals with disabilities is on the verge of experiencing a new mindset in which people are now understanding and accepting the concept of self-determination.

While this is a welcome change, state agencies and legislators have not taken a leadership role in providing direction, reliable funding sources, affordable housing opportunities & other supports which are needed.

It will take active participation of individuals, families, advocate groups

and others to be part of the dialogue guiding the future framework.

You don't have to struggle alone.

Contact the groups and agencies listed in

the Resources section here for information

on participating in ways to make a

difference & change the future.

Step 5:

Resources

Contact these resources to gather as much information as you can:

- o **DDS Statewide Helpline** (Eligibility) 1-866-433-8192
- o **DDS Regions:** South (New Haven) 877-437-4567 North (Newington) 877-437-4577 West (Cheshire) 877-491-2720
- o **Consumer Corner** (info on support)www.dds.ct.gov/ consumercorner
- Qualified Provider List: http://www.ct.gov/dds/lib/dds/ operations_center/providers/qualified_providers_list.pdf

Resources (continued)

 CT Family Support Network (CT FSN) South Region Creative Housing Cafes April DiPollina,(support group leader): 860-271-4371 adipollina@Imhosp.org www. Ctfsn.org

> o UCONN Center for Excellence in Developmental Disabilities Linda Rammler, PhD 860-679-1585 Irammler@uchc.edu

> > o The Arc Connecticut 860-246-6400 facebook.com ("The Arc Connecticut") www.thearcct.org www.twitter.com ("TheArcCT")

> > > o Your Local Legislators Make sure they know your family's situation

o Community Support Don't forget

bont forget to establish relationships with critical people in your community: Town Officials State Legislators, Local Police Church Groups, Friends, Libraries, Shops, Restaurants, Post Offices & Neighbors

Created by a mom to help other families

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