

From a Four-Bed 'Placement' to a New Life

by David Wetherow

Sherie wrote:

This is information I am collecting for a friend whose son has lived at home for 30 years and has been in a 4-person apartment w/24 hour "oversight". He is not terrifically happy with this living arrangement and wants to "come home"--as you all can understand this becomes a problem at this age for both mother and son. I request again that you please keep me informed of any housing you might be aware of that we could look into to fit the above.

Dear Sherie,

Here's an entirely different approach to the design question that you're carrying on behalf of your friend (notice that I didn't say 'housing' question)...

First, last and always, think about who this young man is...

- his interests
- his experience (what has become meaningful for him)
- what makes him 'come alive'
- what creates peace, connection, engagement
- what creates distress, disconnection, disengagement
- what he would love to be doing with his life
- the relationships that are the most important, soul-satisfying and creative for him
- the kind of understanding, acceptance, skill and energy he needs in the people who surround him

Taking these qualities as the hallmarks of what you're trying to create, begin to ask:

- Ideally, who would he live with?
- Who would be able to provide the essential skills, connections, and understanding?
- Who would contribute to his sense of peace and engagement?
- Who would contribute to his sense of safety?
- What neighborhood would offer him the most opportunities to connect with:
 - relationships that are important to him
 - locations that are important to him (focused on relationship, not 'mall therapy')
 - opportunities to contribute meaningfully to the life of the community

Another kind of question (but a crucial one):

- How do we imagine it would help *him* to live with other people who have autism?
 - How would this contribute to his sense of safety and engagement?
 - How would this contribute to the possibility of his maintaining important relationships?
 - How would this enhance the possibility of his contributing to the life of the community?
 - How might living with other people who have autism make things more *difficult* for him?

Then, ask:

🌐 What would be *wonderful* for him?

- ✦ What would be 'a good life' for him? (What makes a good life for you?)
- ✦ People keep talking about 'make a wish' trips... what would he *wish* for?
- ✦ Yearn for?

My guess is that living in a 4-person apartment with 24 hour "oversight" isn't what he'd wish for. He's probably never said, "I want to live in a 4-person apartment with 24 hour oversight".

Go back to the qualities...

🌐 A crucial design question is *who* would be wonderful for him to live with?

🌐 How could good people be:

- ✦ discovered ...
- ✦ invited ...
- ✦ encouraged ...
- ✦ supported ... to live with him?

Then follow a logical sequence of development:

- 🌐 First, find a few good people.
- 🌐 Then together, find a house or an apartment that would create comfort, happiness and connection.
- 🌐 Then talk to the government (or whoever is providing funds).
- 🌐 Work with the funders to find a way to move the money into his hands (or his family's hands, or the hands of a circle of friends).
- 🌐 Make a real home (he wants to go 'home', and he's right).
 - ✦ make the home about relationship
 - ✦ make the home about contribution
 - ✦ don't make the home about 'taking care of John' -- that just exhausts everyone, mostly John
- 🌐 Change it as you make new discoveries.
 - ✦ change people (and adapt to the changes in people's lives)
 - ✦ change how people are engaged (live-in, visiting, cooperative, paid, unpaid, etc.)
 - ✦ change the setting (we change houses as our needs change)
 - ✦ change the way the money works
 - ✦ get creative about thinking through 'problems'
 - ✦ forget about the idea of 'independence' -- we all need to live in companionship

Back in the early 80's, we used this process to create a new life for a man with autism who had been terrorizing (and who was terrorized) in a group home. M. used to 'run'. The group home kept developing more elaborate behavioral programs, incentives, punishments, locks, stronger programs, stronger locks, 'hold-down' techniques, ad infinitum.

When we helped M. move into his own place, we engaged a couple of good young men to be his assistants. When they asked, "What do we do if he tries to run?". We said, "Run with him. Find great places to run. Turn it into a way of discovering what's in his community. Turn it into an opportunity to learn about how you find your way back home after you've been out for a run, how you dress for the weather... but don't get into combat about it."

By the way, this is impossible in a 4-person apartment w/24 hour "oversight". The "oversight" person has only one choice -- to try to keep the person from running -- an absolutely certain formula for combat.

As we learned, and as M. learned, we changed things. By the way, at the beginning it helps to rent, not buy, because you can always walk away from a rental.

That's basically it. We *create it*, one person at a time.

Trying to '*find it*' leads us into the world of 4-person apartments with 24 hour 'oversight', programs, facilities, and all kinds of structures that are not based on the fundamental question of who this young man is. They're based on 'models', expediency, convenience, economics, policies, and a repetition of historical mistakes. But they're not based on 'Who is John and what would a wonderful life look like for him?'.

Stay with the fundamental questions:

- 🌐 Who is this man?
- 🌐 What is his gift?
- 🌐 Where is that gift needed in community?

Try to remember:

- 🌐 There is no such thing as 'people with autism'.
- 🌐 There are no 'places'.
- 🌐 There is no such thing as 'housing'.
- 🌐 The idea of 'beds' is a delusion ... it leads us into distorted 'solutions'.

Don't *do* anything until these questions begin revealing a path.

I'm not suggesting that you do it single-handedly. First of all, nobody can do it alone. But you bring something into the equation that's essential -- two things -- a great question, and the care of a friend, an ally, a champion.

Find other friends who can help, and know that it's being done by hundreds of people, all over the country.

- 🌐 Connect with the self-determination movement
- 🌐 Connect with people who are doing 'microboards'
- 🌐 Connect with the cooperative housing and co-housing movement
- 🌐 Connect with friends in government, who are exhausted with 'business as usual'

It's a journey of discovery, relationship, invention, challenge, frustration, more discovery, fidelity, sorrow, and joy. It's worth the walk.

Enjoy the journey!