



### ***Letter to a Young Parent: Searching for Community***

by David Wetherow

When my niece was born with Apert's Syndrome, I had to do some quick thinking about what was the 'bottom line'. I knew that her parents were in a state of shock, and would only be able to hear one or two things. One of the things I told my brother and his wife was this: "The thing that will contribute the most to her quality of life, both now and in the future, is if she is surrounded by people who know her, who love her, who aren't afraid to touch her and be touched by her, and who understand that they will be part of her life and that she will be part of their lives, forever."

That was sixteen years ago, and it's still true. It meant that when making decisions about things like therapy, school, housing, etc., one of the most important considerations should be, "Will this take her away from that circle of support, commitment and understanding?" Regardless of the type, nature or severity of 'the disability'.

It means that one of the major creative roles one can play as a young parent is to be an 'on purpose' bridge-builder, inviter, and circle-maker for your son or daughter. Regardless of the type, nature or severity of the disability. It means that you need to be expressing your dreams for him and your family to people who care about you, and eventually, helping your son express his own dreams.

It means finding powerful ways of giving expression to your vision. We happen to like Jack Pearpoint, Marsha Forest and John O'Brien's PATH process, because it's a great planning tool and also a powerful tool for invitation and commitment-building.

It means embedding yourselves in a community that you love, building your lives there, and building his life there. If you move, that circle is broken, at least for while - but you have the capacity to rebuild it. If he moves without you, that circle is shattered, probably forever, because he may not be able to rebuild it alone, and most of the 'residential services' I've seen in 30 years in this business don't have a clue.

It means helping him learn to feel safe, loved, loving and engaged with many people, and helping them feel safe, loved, loving and engaged with him. It means expanding the family circle, inviting more people in, in contrast to focusing on trying to figure out ways for him to survive 'outside'.

It means finding the 'sweet places' in his community (your community) where the threads of his interest - his delights, his gifts - can be woven into a fabric of companionship and contribution. It means staying available to him as a family. This can take many forms as he gets older, including the possibility of figuring out ways to continue to live together with increasing amounts of autonomy in all of your lives.

We have a friend who turned part of their home into a great separate apartment where their daughter lives with caregiver/companions. Another friend created a small cooperative household in a nearby neighborhood where her daughter lives with support from a service co-op.

We have a number of friends who have established 'microboards' for their children (something that we invented in the 80's) and continue to play a major role in directing their supports.

One of the things that this means coming to terms with the limitations of the service system. You'll discover that the biggest limitation is that we inevitably end up in competition with other people for diminishing resources (we call this 'competitive misery') - you may be already seeing it in the "waiting lists".

It means taking steps towards financial security, sharing your vision, building a network of support, working on alternatives to formal guardianship, etc.

The good news is that you're a young family, and this is a good time to start on these things. You've got lots of time, and the time to start is now. I can tell you this as an older dad of a child with major challenges. You have the vision, the love, the commitment, the creativity, the power of definition and the power of invitation. It's true that none of us can do this alone, but it's also true that you have the capacity to invite and engage friends.

What this all comes down to is that the answer to your question is to build the future you want for him, bit by bit. This means finding allies who understand all this, or maybe creating the place where this shared learning starts.

The answer to "Where is the best community?" is that the best community is one that you create.

The answer to "Where can he live?" lies in what you know in your heart - that he needs to live in companionship, with people who are loving, creative, and connected. We can almost never 'find' that - but we can build it. 'Housing' is the last piece of the puzzle. When I talk about 'building it', I'm not talking about building it for 'the handicapped'. I'm talking about building it for your son. If what you build is good, it will grow by example, rather than by 'administration'.

Wendell Berry says that in the long run, "[what we need to do is] ...to love each other, trust each other, and help each other. That is hard. All of us know that no community is going to do these things easily or perfectly, and yet we know there is more hope in that difficulty and imperfection than in all the neat instructions for getting big and getting rich that have come out of the universities and ... corporations in the past fifty years."

The faith is that if we pay enough attention to our children and reflect on what is in our own hearts, we will discover what we need to discover, invite who we need to invite, and invent what we need to invent, it turns out to be an exciting journey.

David Wetherow is the creator of the first microboard in Winnipeg, Manitoba, Canada 30 years ago, and currently is the advisor of the Illinois Association of Microboards and Cooperatives. For more of his writings, visit his website at [www.communityworks.info](http://www.communityworks.info). For more information on microboard or cooperative development, contact the IAMC at 217-778-5388.