



Mary Kissel

Mary Kissel is the parent of an adult son with disabilities who lives in his own home. She is the founder of Georgia Options Inc., an Athens-based nonprofit provider of personal support to people with disabilities and has focused her priorities on issues of inclusion and quality of life. Mary was recently recognized as Advocate of the Year by the GCDD.

The opportunity to live in your own home and have control over your life is a person's right...a basic human right.

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Living in Your Own Home

By Mary Kissel

I have always believed that the struggle of people with disabilities to live an ordinary life in the community is at its core a human rights struggle.

I have never heard anyone say they wished to live in an institution. I have never heard any aging persons say they looked forward to going to a nursing home, even though they say they do not want to be a burden to their families. And I have heard parents say they want their family member with disabilities in an institution, but I have never heard a single person wish this for him or herself.

I am not attacking good people who work hard providing institutional care. Rather, I am asserting that, whatever other needed services institutions currently provide, they are not acceptable substitutes for homes. When I reflect on what "home" means to me, I realize having a home is a fundamental human need. When I consider how few adults with disabilities have the opportunity to live in their own homes, the enormity of this injustice hits like a kick in the stomach. Who among us has authority to exclude a whole group of people – especially our most vulnerable citizens, who would surely benefit the most – from this source of stability, security, permanence and safety?

Let me be clear. Small facilities located *in* the community are not homes either. Part of the reality of home for an adult is having your own key, having some say over who else lives there and what goes on there, having privacy and freedom to do routine things on your own terms and in your own time. Your own home usually means that as long as you are law-abiding, no one has authority to make you move. So it is not enough to "place" people in the community. Our work needs to be about supporting people to create and sustain their own homes. With our support, they can then begin the work of finding their rightful place as valued members *of* the community.

I am not naive. Some homes are not automatically good places. But, when supported with vigilance, integrity and creativity, people who live in their own homes seem to thrive. I have seen this happen over and over again within Georgia Options, a small supported living agency in the Athens area. I have seen it with my own son Eric, who, despite needing

total assistance, has lived successfully in his own home for 11 years. Many people work together to make this possible, and the work is never done. We always have challenges to face and problems to solve. But we also experience fun and excitement, pleasure, pride, genuine respect and friendship – in short, the remarkable achievement of an ordinary life. At the core of this achievement lies the certainty of home – not his parents' home or the agency's home, but his very own, where we hope he will be able to live the rest of his life.

This is an achievable dream, not just for my son, but for all people with disabilities as long as they have adequate, flexible support, including provisions for various kinds of crises. I did not invent this powerful idea. I learned about it from inspiring teachers, and I have spent the past decade testing it out in real life. So have thousands of others across the country. Results consistently show that when people have choice, freedom, respect and the opportunity to construct a life that makes sense, they flourish. We should not be surprised. This is, after all, what we would want for ourselves.

I'm not saying this is easy. People's lives are complex, and we have inherited a complex system in response. We have to make many changes in our attitudes, understanding, rules and systems. We need opportunities for dialogue, study, continuous learning and careful planning. We need to rethink the issue of choice not as a smorgasbord of service-delivery models, but as what actually happens in a person's life. We have to know each person well enough to design good supports with that person instead of making yet another program.

We cannot guarantee a perfect life for everyone. But disability is not a crime, and we cannot easily restrict people's freedom in the name of protecting them. The opportunity to live in your own home and have control over your life is a person's right. This right is not based on functional level or on our benevolence. It is, rather, a basic human right. Supporting this right and working together to make it possible are our important tasks. If we commit ourselves to these goals, we may become inspired to the ennobling values that surround the work. In the process, we just might help to create a better world for us all. □