

MY SON OR DAUGHTER IS NOT THE SAME AS YOURS: HOW TO ANSWER THAT QUESTION

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We often hear that people in institutions are “the most disabled,” and that community living only works for people with “mild” disabilities. The facts don’t back this up: people who live a decent life in the community have a full range of disabilities including very fragile medical conditions and complicated neurological conditions. People might believe the myth just because it is repeated a lot—or maybe it seems true because:

- In the past, we used to think of institutions as “hospitals” and of residents as “patients.” That attitude led to thinking of institutional residents as “sicker.” Now we know that disability is not the same as illness. So nobody is “sicker.”
- When you put disabled people all together in one place, they each seem more disabled. So people in institutions seem more disabled than people who are participating in the community. People in the community can work and have friends, so they automatically seem less disabled.
- Sometimes people who have lived in a segregated setting for a long time do in fact develop serious secondary disabilities. Loneliness and boredom can be terribly disabling, not to mention the effects of not being moved or cared for properly. And some people are abused, which can add to a person’s disability. If people become more disabled inside these institutions, then we should not make them live there.
- The bottom line is this: Everybody is human. Even the most severely disabled people are human, each and every one—because all human parents have human children. And all human beings have human rights. We do not accept the idea that there are some people who are so disabled that they lose their human rights—to have a name, to have an identity, to grow up in a family, to have relationships, to be free of abuse, to have property, to participate in the community. To be who you are. These rights are threatened by institutional placement—so no matter how disabled someone is, they should not be institutionalized.

Questions & Answers

<p>Q. But these places look so nice!</p>	<p>A. Yes, and some prisons look like country clubs. But they are still prisons. You can make it clean, you can make it big, you can even make it beautiful, but you can't change the fundamental fact that the purpose of an institution is to lock people with disabilities away. When one governor closed the institutions in his state, he said it was unbelievably easy to convert them to prisons. Doesn't that tell us a lot?</p>
<p>Q. Don't more people have more freedom on the institutional grounds?</p>	<p>A. Webster's says freedom is: "1: the quality or state of being free: as (a): the absence of necessity, coercion, or constraint in choice or action; (b): liberation from slavery or restraint or from the power of another." Typically in an institution, someone will be told when to get up, when to bathe, with whom to talk, when, what and how to eat, when to go to the bathroom, what to look at, what to say or not say, and when to sleep. They may be able to take a short walk in the open air, but people who have lived "inside" tell us they are only free in their dreams. Their day is a nightmare. By the very nature of institutions, the people who live there have days that consist of constraints, necessity and coercion. In the best places, it may be a gentle program of habit and control. In the worst places, force is used to achieve compliance, and drugs are often used to achieve compliance in any case. No, there is not more freedom on the institutional grounds. The best institution cannot be as free as somebody's own home.</p>
<p>Q. Aren't they more home-like than they used to be? Aren't people safer?</p>	<p>A. This is like arguing about the degree when the real issue is one of a fundamental principle. It is a waste of time and money to make an institution seem like a home if the institutional controls stay in place. It is like trying to make a silk purse out of a sow's ear. How much better it would be to make an actual house seem like a home: to take the funding that would have been used to create the illusion of a home in an institution and use it instead to create the trustworthy supports that someone really needs to be comfortable and safe at home.</p>
<p>Q. How can we close institutions and put all those people in the community on waiting lists?</p>	<p>A. Systems can only do so much at once. The hard part is not figuring out how to serve everyone in the community—it is figuring out whether to do so. Once the decision is made, the organization can stop wasting energy pursuing multiple strategies and focus instead on achieving fair and equitable supports for everybody. We have waiting lists because we waste so much agency time and expertise trying to 'manage' the inevitable closure of the institutions. We need to turn the agencies' attention entirely to community supports. Plans</p>

	<p>are important, and goals, and decent funding: with these, we can get people the support they need. And somebody needs to figure out who gets served when: people coming out of institutions or people who have always lived in the community and need more help than they used to. Or both. It is probably a mistake to put all of the new resources behind people who are coming out of institutions, because people on the waiting lists need help, too. But, yes, it is possible to help everybody be safe and live a decent, ordinary life.</p>
<p>Q. Do we have the capacity to serve greater numbers of people?</p>	<p>A. Each state and local community has different capacity. When we bring large numbers of people out of very large institutions, we must think through issues that affect where the person will live and where the capacity will need to be created: Near their retired parents? Near a sibling? Which sibling? In a house with other people? In the community, people should not be dropped into “slots” or assigned to “beds.” Since community capacity is best created based on a person-centered plan, it is true that the “capacity” can’t really exist in advance. Community providers and families work together to create capacity one person at a time. If the funding is there, the supports can be built. Almost anywhere, almost any time. What is needed is the will to do it.</p>
<p>Q. What do quality community supports look like? What would you see if you were seeing quality?</p>	<p>According to the Council on Quality and Leadership (see their mission statement at http://www.thecouncil.org/), quality community supports use person-centered processes to keep people safe; offer people choice; and direct dollars wisely. So if you are seeing quality, you would see a lot of variation from person to person based on the person’s wants, needs, dreams, challenges and dangers. You would see systematic, ongoing measurement, monitoring and reporting, and you would see system improvements over time. You would see open reporting and lots of communication. You would see that community and family life provide lots of informal “monitoring” as family members and neighbors just naturally “keep an eye on things.” You would see a system that asks the person with the disability and their family: “How are we doing?” “What would you change?” People would have the ability to determine for themselves, with support, how to live and what to do. They would be engaged.</p>
<p>Q. Aren’t there problems in the community?</p>	<p>A. There are problems everywhere in human life. People with disabilities can’t be expected to live a perfect life any more than anybody else can. What we need and want is the right to live an ordinary, decent American life, just like</p>

	<p>everybody else. We know there will be frustrations, problems, and even some risks. But there will also be respect, challenge, achievement, friendship and even love. These are what make risk worthwhile. We hope, like everyone else, to minimize the risks and maximize the rewards. We don't want to live in the community with everyone else because we think it will be perfect: we want to live there because it is right. Vaclav Havel said, "Hope does not consist in being assured that the outcome will be perfect: it exists in knowing that the process is right."</p>
<p>Q. Why are centers of excellence in state institutions a bad idea?</p>	<p>A. Access to decent health care—medical and dental—is a huge problem for Americans with disabilities. People with developmental disabilities have the same range of other health concerns as all other people—plus they have to deal with the disability. For many decades, substandard or unlicensed care was provided to residents of institutions. This new model would suggest that “developmental specialists” could be trained in institutions. There are several problems. First, people with developmental disabilities need access to a full range of generalists and specialists—surely this model would not suggest that we could train specialists who are expert in the needs of people with developmental disabilities, too? We also would not want to train doctors who can practice “well enough to treat developmentally disabled people.” And even if he or she is by chance a wizard, it is too easy for the one “developmental” specialist to prescribe a way of life along with a nutrition plan and anti-seizure meds. It is too easy to slip into “life as treatment,” which negates the personhood and abrogates human rights. People with disabilities remind us that a disability is not a disease. Many are acutely aware of the attitudes of physicians being otherwise. The choice of a personal physician is a personal choice. People should not be “assigned” to someone by the state. Once you segregate health care, even for training purposes, you run the risk of developing attitudes that are not supportive of a person's rights. An institutional setting teaches acceptance of a "hospital" model as a way of life. And that way of life negates freedom and basic rights. When doctors back up that attitude that a hospital existence is OK for some people, or that is OK to imprison people who have not committed crimes, then it gains credence with legislators, who may or may not have enough expertise in the civil and human rights of disabled people. If developmental specialists of any stripe think that institutionalization or a medical model is OK, or if they overtly support it, then they are incompetent to</p>

	<p>practice medicine or dentistry in this century, whether or not their support is based on strong personal empathy for individuals they treat, and whether or not they were trained in a time when the only way to support people was in a hospital environment. Few, if any, persons require that kind of support in this century, and if they do, then the technology and medical support should be engineered to meet their individual needs. More physicians with this hospitalization/institutionalization mindset must not be trained in 2004. A person with a disability is more than a medical patient, even if they have a specific and debilitating “syndrome.” People should not be in a position where a medical professional dictates their life.</p>
<p>Q. Will my son or daughter be rejected by the community? Isn't there a place for segregation where he or she can be with their kind?</p>	<p>A. It is hard to be the parent of a son or daughter with disabilities—not so much because of the child’s disabilities but because of your own expectations. First, you feel sad because you weren’t able to give your son or daughter the perfect life you were aiming at. Then, you have to struggle to teach them what you never had to learn yourself: how to live a decent life with a disability. It is normal to worry about whether your child will be “accepted” or not. But it is better to teach them to be strong and to realize that there are almost no young people in America who don’t get teased. Kids get teased and adults get rejected because they are too fat or thin, too short or tall, too white or too black, because they are disabled or even because they are too smart or “too perfect.” Should we have segregation to solve all of these problems? Segregation has been the answer for kids who have disabilities too often. We need to teach our sons and daughters to love themselves—which is possible no matter how disabled they are—and how to stand up for themselves and take care of themselves when someone hurts their feelings. The best way to learn how to teach this to our sons and daughters is to develop friendships with disabled people ourselves: even one such friendship can open our eyes to what is possible, and to our common humanity. Getting to know someone with disabilities can help us see that our sons and daughters are with their own kind whenever they are with other human beings.</p>

