

Wyomissing Behavior Analysts, Ltd.

2032 Lincoln Court • Wyomissing, PA 19610 • 610-777-5459

INCLUSION or SECLUSION ??

Gary Champlin, Ph.D.

I recently was asked to consult regarding the case of a 21-year-old man (boy?) with Pervasive Developmental Disorder and Severe Mental Retardation. He was in a residential/institutional placement subsidized by his home school. His parents were very pleased with this placement. They would argue that he made significant progress there.

But he turned 21 and had to graduate. The funding stream changed from the School District to the County MH/MR. The parents were convinced by the County that it would be good for him to move into the community. He was placed in a 8-bed Community ICF-MR. He was scheduled to attend a nearby Adult Training Facility with a pre-vocational emphasis.

His adjustment was not dramatic. He seemed to be doing okay. But then it became apparent that the frequency of his head banging was increasing. His parents saw some holes in the drywall at the ICF. They became very concerned. They started looking closer at what was (or was not) going on. They lost faith in the Provider Agency. They wanted their son back at the residential institution where they believe he was happier and got better care.

This is not an unusual story. There are many stories of people who blossom when they move into a more inclusive setting. But there are also many stories like this one. Why the difference?

The individual in this story moved to an ICF-MR in a rural setting. Arguably, he was not included at all. A van took him from the ICF to the ATF and back. He needed an escort to leave the house. There were 3 staff, but 8 people needing their attention. They had a van, but it needed to be shared by the 8 people. Going out was a big event.

His parents suggested that he moved from the city to suburbia. That's okay if you have some wheels, but not if you need to rely on others for transportation. At the institution everything was within walking distance. At the ICF, he was trapped.

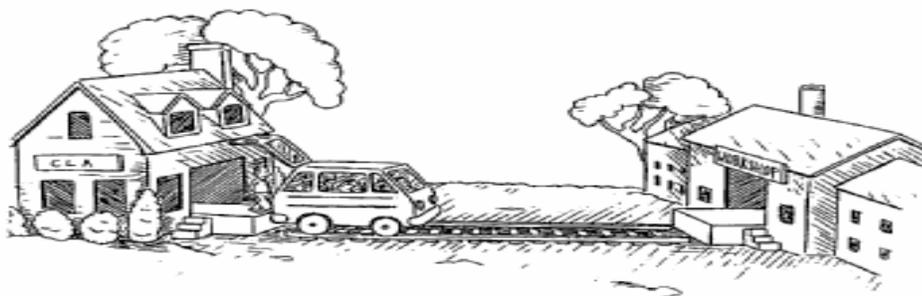
The Staff at the ICF seemed nice enough, but they were always new, seemed to be just passing through, upwardly mobile, in transition themselves. At the institution, there seemed to be more stability. Staff were accumulating years toward retirement. They knew the clients for years. Relationships were established.

The one place this individual did get to go was to the Adult Training Facility. He spent time there doing his favorite puzzles. The same ones he liked to do at the ICF. He did some pre-voc work. His co-workers were the same guys from the ICF. There were 3 program areas so he would not get too bored being in one place. He looked forward to the ride home. Once back at the ICF, he got upset waiting for someone to cook dinner. At least at the institution he did not have to smell the food cooking. He was free to do his puzzles some more. He seemed to like them. After all, he did them all the time! It was his choice!?

What's the message(s) here? Deinstitutionalization does not necessarily lead to Community Inclusion. A Community Home is not necessarily less restrictive. Quality of Life is not automatically improved by a community placement. Not everyone is cut out for suburbia. There is a difference between necessity and choice. Institutions are not all evil. Little ICFs are sometimes nothing more than big ICFs but without many of the amenities.

All this said, should the individual discussed here go back to the institution like the parents are insisting? If his head banging is bad enough, I'm hard pressed to argue. Maybe his quality of life was better there. Maybe he was happier. If we are really Person-Centered, I think we really need to consider it. It's only when we become Cause-Centered that we know better and insist the community is the only choice.

But there is more than one community. There are a lot of places where each of us would not be happy living either. Some people like green pastures. Others like the bustle of the city. The community is sometimes what we make of it. The challenge in this case may just be to find more things for this fellow to do in his new community. Moving is an adjustment for anyone. It takes some work. He needs to meet some people. He needs to check out what is around for him to do. Maybe he can even get a part-time job and meet some people. On the way home he could stop and do some shopping for something to cook for supper. Or he could splurge and eat out with some co-workers. Afterwards, he could rent a video to watch at home. Or maybe there's a game scheduled and he volunteers as an assistant coach for the local tee-ball team. Now we're starting to talk about inclusion! Maybe he'll even forget about that head banging. No time. Too many other things to do.



Reprinted from The Arc of Berks County Newsletter (June 1998). For subscription information call 610-603-0227 or e-mail berksarc@ptd.net.