Now let's do it right : With community support and planning, de-institutionalization can work

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Note

De-institutionalization conjures up a variety of images. For many, it is associated with "dumping" people back into the community from large psychiatric facilities without any support. We know the results of such social policy; people living in run-down boarding homes and an increased number of people living on the street.

For others, de-institutionalization has meant freedom, more opportunities and a chance to begin a real life in community. This happens when de-institutionalization has been carefully planned and included the development of community resources for support .

After a decade of frantic de-institutionalization in the late 1970s and '80s, there was a lull in activity. There is now a resurgence in downsizing large facilities. This is expressed in Ontario through mental health reform, which has identified the need to shift resources from institutions to the community. The goal is for institutions, which now have about 80 per cent of mental health budgets, to be shifted to 40 per cent by the year 2000, with the additional resources going into community supports.

Similarly, in the area of developmental disabilities, Oxford Regional Centre in Woodstock will be closing in March 1996 and other institutions are being downsized. De-institutionalization is also active in the aging area, where construction of new nursing homes has virtually stopped and more resources for senior citizens are going into homecare and supportive housing in the community.

The impetus for more de-institutionalization today comes from two interacting influences. First, strong advocacy from disability networks (such as the mental health associations and the associations for community living) and other groups, who have pushed for increased community support and a decrease in the number of people in asylums. Second, governments have been looking for ways to cut back expenditures in social services and there is the common perception that institutionalization is more expensive than community support. Studies indicate that it is more cost-effective to support people in the community in the long term, although in the short term additional expenses may be required to build the necessary community supports.

Communities and agencies in Waterloo Region already have an opportunity to participate in the process of de- institutionalization from Oxford Regional Centre or London Psychiatric Hospital. As de-institutionalization accelerates again, it is important

to reflect on policy and service issues developed by earlier research and practice. Unfortunately, there are already signs that some of those lessons are being ignored.

In earlier efforts to downsize and close large facilities, the main strategy was to move people back to their local communities in small groups. The result has been a large number of group homes in congregated settings that are often referred to as "mini-institutions."

Several studies have shown that, while quality of life for people in group homes is better than in the institution, people are still disconnected from community life. Most people have few friends and little participation in their neighborhoods or in the services that are designed for them. This practice of placement in groups continues, but is being challenged on several fronts.

The Ontario De-institutionalization Partnership Project, which has a demonstration project in Waterloo Region, for example, is designed to develop an individualized planning approach combined with community building to break the cycle of group placement. In reality, this issue is difficult to resolve because funding and support for de-institutionalization is almost always tied to placement and programs.

Planners and communities that sponsored de-institutionalization efforts a decade ago worked with people who were most ready to return to the community--individuals with minimal disabilities or people with moderate support needs.

In this current wave of downsizing, people with more severe disabilities and extensive support needs will be returning to the community. The dilemma is that the group placement approach will likely be much less successful with these individuals. Having four or five individuals with challenging behaviors live together will likely exacerbate their behavior problems. Similarly, housing six or seven people with chronic mental health problems will inevitably become a "mini-institution" where individuals will have limited say and responsibility concerning their lives.

Citizens with complex support needs require a comprehensive approach which is individualized. De-institutionalization is most effective when the major partners in the person's life come together to assist in the planning for community living and support. This means family, friends and significant service providers, including institutional staff where appropriate. These partnerships are essential. For this kind of transition planning to work, institutions need additional money in the short-term to plan and support de-instit-

utionalization without reducing the quality of support for people still in institutions.

In many ways, communities are ahead of social policy in this area. Communities, in fact, welcome people back from institutions when the process is carried out in a sensitive, individualized manner. What citizens often resent is the dumping and congregate living that is often associated with large group homes.

The irony is that current practice needs to reflect the shift in thinking of citizens and people with disabilities to ensure that in this wave of de-institutionalization we do it right.

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