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Editorial

Is Social Inclusion Always a Good Idea?

Jelena Vahakuopus, a neuropsychologist in Moscow, has posed two interesting questions: In countries where serious social and economic problems are the current reality, can it be that social inclusion is not always a good idea? Can it be that, for people living in such social environments, institutions can be better and more convenient than community living? The immediate reaction of most readers to the first question, we suspect, is: "Of course social inclusion is always a good idea!" But second thoughts will no doubt emerge, as readers begin to focus on the word "always."

In exploring our thoughts, it will be helpful to take a step back to get a broader glimpse at social inclusion. No doubt, social inclusion is a philosophical objective that reflects deeply held human and social values in modern societies. For example, in a 1999 speech, former UK Prime Minister Tony Blair spelled out a vision of social inclusion that promoted advancement in the labour market, improved education outcomes, reduced health inequalities, higher quality housing, safer neighbourhoods, and, importantly, the reduction of income inequality (Boushey, Fremstad, Gragg, & Waller, 2007). But social inclusion can also be understood from a different angle, as a strategy to combat the social exclusion that is the life reality of marginalized people, such as many people with intellectual disabilities. It is this latter perspective that seems to be more relevant to the questions Jelena posed.

Much of the literature in the field of intellectual disabilities is written by experts who live and work in the more affluent countries of the world. It is natural, therefore, that this literature is based on a philosophical approach that has developed, and found its time, within the economic and cultural contexts of these countries. Social inclusion is a broad construct that both nurtures, and is embedded throughout, this philosophical approach by actively working against exclusion and marginalization. Today, social inclusion is widely accepted in the

more affluent countries of the world, where it is considered to be a very good idea, indeed.

But is social inclusion always a good idea for less affluent countries, where economic and cultural contexts are quite different? The answer to this is not so easy. The authors use their personal experience in Nigeria (Paul), China (Mian), and Russia (Jelena), as well as in other countries they have visited, to illustrate some of the reasons why.

Official Views and Realities Differ

Social inclusion is a construct that is certainly well known in less affluent countries among many policy makers and professionals. Yet, for the most part, it is not acted upon. For example, in China social inclusion is part of the official rhetoric, but social exclusion is the reality for many people with disabilities – especially for most people with severe disabilities, because of the lack, or non-existence, of service systems. Many Chinese with disabilities are kept at home, with almost no access to any services. According to Lynn Todman's (2008) definition of social exclusion, these people with disabilities in China are in fact socially excluded because they "are systematically blocked from rights, opportunities, and resources (e.g., housing, employment, healthcare, civic engagement, democratic participation, and due process" (p. 1) that are normally available in the more developed countries. Ironically, many Chinese families may feel fortunate when their children are accepted in the institutions, residential facilities, or special schools where they have the services and training they need, whereas Westerners would certainly consider this segregation. Having these services might well mean "social inclusion" to them. For people with disabilities and their families struggling on a daily basis to make a living with no access to services, social

inclusion as defined in the western world is most often just a fantasy.

Similarly, social inclusion is a topic that policy makers, professionals, service providers and even parents in Nigeria debate from time to time. Although they support the goal, they are conscious that prevailing economic, social and developmental problems negatively impact special education and rehabilitation services. It is one thing to believe something should happen, and another thing to try to ensure that it does.

Social Inclusion is Not Always Understood

Social inclusion is not always understood or accepted, however. Low levels of political commitment to rights in general, and more specifically to concepts like social inclusion, are fairly common. In a developing country like Nigeria, this low level of political awareness has resulted in meager resources being devoted to promoting the full integration of people with disabilities into society.

Low levels of awareness are also a problem at the front line level. In Russia, professionals like Jelena are specialists in teaching personnel new ideas of social rehabilitation, but new ideas are not always understood or welcome. As Jelena said, "I travel across Russia, in small villages, and I see lots of interesting things happen there. Sometimes there are good staff in institutions, but they have not much information. They are actively against social inclusion and believe that the institution is the safest place for children and adults with intellectual disabilities."

Poverty Works Against Family and Community Support

Even if social inclusion is known and accepted, the supports that are needed to make it happen are often not put

in place due to economic strain. As one rehabilitation director in Romania remarked, “We know what to do. We just don’t have the money to do it!”

At the family level, there is a tremendous amount of poverty in most developing countries. Many families are genuinely concerned about enabling their members with disabilities to acquire skills that will equip them to function independently in society, but are impeded because of abject poverty and the day-to-day struggles they encounter to eke out an existence. Paul noted that, in Nigeria, “for families where finances are non-existent, it is not uncommon to see abandonment or neglect, or the child being institutionalized. Most people see institutionalization as a preferred option to abandonment or neglect.”

This is not the case for all families, however. A handful of educated and elite families can be found in some Nigerian towns and cities. These are the privileged few who have good jobs and have access to health care and other essentials of life. They are well-positioned to educate their children with disabilities in privately-run day centres, and their children with special needs have the opportunity to grow, socialize and develop with their siblings and to interact within their community settings. Such families may be favourably disposed toward social inclusion because, from their standpoint, they have the wherewithal to make social inclusion work, and they can readily perceive its multiple advantages. But most families live in poverty, and a majority of family members—especially in the rural towns and villages—are unable to provide quality home care and training for their children with disabilities. Additionally, because of the need to work constantly to fend for the rest of the family, these indigent caregivers opt for sending their children with disabilities to an institution where

they may acquire vocational and social skills training that might ultimately result in independence and self-sufficiency.

Related Social Problems Work Against Community Support

It is well-known that numerous social problems typically emerge when there is poverty and economic strain. Such is the case in Russia, where overcrowded and inadequate housing, alcoholism, and unemployment too often accompany the poverty that has hit so many families in recent decades. These problems can be so overwhelming both to professionals and to family members who face them that, at times, they come to believe the best place for children with disabilities is in institutions. This can be very discouraging for those trying to promote social inclusion, because they often feel they are working in isolation. As Jelena remarked, “I felt myself so lonely with all these problems...” The flip side of the same coin, for professionals in Russia who promote social inclusion, is the ethical question of whether or not it is in the best interests of children with disabilities to live with their families in their home communities if that means living in poverty, amid alcoholism, in unsafe circumstances, and among people who are understandably focused on far more basic needs than promoting social inclusion.

When they are widespread, the day-to-day problems associated with poverty can result, in some countries, in a broader social integration crisis: exclusion or marginalization of certain groups, social and civic disenfranchisement, absence or weakening of support networks, and frequent inter-cultural conflicts. These broader consequences make it all the more difficult for governments to take effective action. It seems clear that the care and training of people with disabilities in Russia will not be able to improve until the

government is in a position to effectively address and reverse such a crisis, but this is an enormous undertaking that may take a long period of time. Mian concurred that, likewise, the Chinese government will have to adopt social inclusion as a long term goal, because it takes enormous and persistent government efforts to plan and allocate resources to establish all the social service systems that would be necessary to meet the needs of eighty million Chinese with disabilities. Nigerian government policies have been able to do very little to improve the quality of life of the majority of families, most of whom reside in urban centers where infrastructures such as electricity, clean water, good roads, affordable health care, and others have proven to be inadequate. The majority of families with members with an intellectual disability may experience difficulty in transporting their child to a school or day center where she/he may be included in the training curriculum. In such circumstances, the primary caregiver may decide to send the child to an institution where there is a concentration of expertise and resources for social, vocational, and academic skills training.

Safety in the Community is a Concern

One of the realities of everyday life in some parts of Russia, and in many other less affluent countries, is that community living is simply not safe. Social acceptance of people with disabilities is low, and there is a very real danger that people with disabilities will be discriminated against, oppressed in a variety of ways, and physically beaten. When this is the case, it is understandable that even many disability professionals feel strongly that communities outside institutions are often social environments that are too dangerous for people with intellectual disabilities. Such views have led many Russian professionals to believe that de-institutionalization is not suitable for their country.

At the same time, safety is a concern within institutions as well. Poor living conditions, including many forms of abuse, have been known and discussed for several decades now, and these very conditions were the catalyst for the deinstitutionalization movement in more affluent countries. But in less affluent countries such conditions often still exist because no alternative can be put in place. Jelena provided a poignant example: "I was just in an institution where the head of the rehabilitation unit told me—as if it were a funny thing—about tens of forced abortions she had ordered." The unsettling ethical question here, then, is whether people with intellectual disabilities are better off in unsafe community environments or in unsuitable institutional settings.

Families and Communities Feel Shame and Guilt

Another difficulty in promoting social inclusion in less affluent countries is that some families and communities still feel shame and guilt about disability. Even in Japan, a parent rose at a seminar for 200 parents who had a son or daughter with an intellectual disability to ask, "How can people like my son have friends and even get married when so many families just keep their children with disabilities hidden away in their houses because they are ashamed for them to be seen?" Similarly, a special education professional remarked of the Philippines, "So many families, especially those who have money, are ashamed to admit they have a child or adult with intellectual disabilities. They just leave them at home and don't take them anywhere they go." There is no doubt that shame is at least partly based on an economic reality. Paul explained of Nigeria:

In some communities, the presence of a child with a disability brings shame and guilt to the entire compound or village.

This is because the child who was expected to provide economic support on the farm or in the local industry will never be able to assume such a supportive role, but becomes a drain on the limited resources required to support the entire family.

Although shame and guilt afflict some families, and thus limit their capacity to fully integrate such people with disabilities into the family milieu, others refuse to succumb to such ill-feelings. They either keep and provide for their members with intellectual disabilities at home, or provide a thriving work environment in whatever way they can. People who are blind or deaf are mainly in the latter category.

Community Services are Lacking

In the majority of less affluent countries, there are no safety nets like social security support or free education, even though national policy of some of these countries includes statements to that effect. In Nigeria, for instance, the National Policy on Education (Federal Republic of Nigeria, 2008) advocates, *inter alia*, that “Persons with special needs shall be provided with inclusive education services (as far as possible) in schools which normal children attend, in age appropriate general education classes directly supervised by general teachers” (paragraph 100). While such a policy is intended to equalize educational opportunities for all children, regardless of their physical, sensory, mental, psychological or emotional disabilities, the reality is that concrete supports have not been put in place to actualize such a goal.

In a similar vein, Mian reported that the Chinese government has set a lofty goal for embracing and realizing social inclusion. But the implementation falls far short of the goal in terms of establishing a service system. That is why we observe

a major dilemma in China (and many other developing countries as well): people with disabilities or families of children with disabilities opt for services offered in segregated environments (e.g., institutions, residential programs, and special education schools) because they would otherwise have no service at all if they choose to be “socially included” at home and in their communities.

Institutional Services are Seen as a Good Alternative

It has been noted in a number of cases above that institutional services are seen in many less affluent countries as a good, and sometimes the best, alternative. But one core aspect of social inclusion is acceptance of the belief that people with disabilities are better living in communities than in institutions. How, then, is institutional living viewed in less affluent countries? Further, can it be in some circumstances that the benefits of segregated living and the detriments of community living are such that social inclusion is not always a good idea?

In Nigeria, centuries-old cultural and religious practices dictated that family members catered to the needs and well-being of all their children, including those with disabilities. Paul noted that this was the prevailing philosophy and the traditional approach long before the advent of European practices that emphasized institutional care in centres removed from the larger population. European missionaries introduced residential centres or institutions that soon became the main settings for training children with disabilities. The custodial idea was antithetical to traditional values of family togetherness, even though in most cases a family might be ill-equipped to provide the best form of training for their child with a disability. “Today,” Paul said, “the care and rehabilitation of people

with disabilities in Nigeria is carried out in a variety of settings, including institutions. Most observers would say that not all institutions are bad, and that with proper oversight institutions can effectively provide vocational and social skills training, which family members rarely have the time or inclination to develop, to children, youth and adults with developmental disabilities.”

There are a great many large institutions in Russia for people with intellectual disabilities, a tradition that has built up over the last century in keeping with the prevailing philosophy of the time throughout the world. Jelena noted that Russia is a “mysterious country” regarding its attitude toward institutions. She said, “In the last 15 years, there have been a lot of press articles, films, seminars, conferences, projects, and government meetings concerning rights of people with disabilities. But there are no changes.” And it is not that there is a lack of official documentation. She continued, “A report on the situation of children with disabilities in institutions was published in 2006 by Russian Ombudsman, Vladimir Lukin. Terrible things were described in that report, but very little has changed since. In public they say one thing, but in reality their actions say another. It looks like no changes will be made in the near future.” It is a common opinion among disability professionals and authorities in Russia that social inclusion of people with intellectual disabilities is wrong and a dangerous idea, because society is not ready for accommodating such people.

What Can We Do to Promote Social Inclusion?

The preceding discussion provides ample evidence that when pondering the question “Is social inclusion always a good idea?” we have to be aware that the very definition of social inclusion is

contextual, especially when considering it in less affluent countries. Social inclusion does not mean the same thing in different social and cultural contexts.

Still, we cannot dismiss social inclusion altogether, because it is a construct that has found a firm home to varying degrees in both the philosophies and practical objectives of governments and the disability profession around the world. It is likely to have an ongoing influence on the way we think and act. What, then, can we do to ensure that the social and cultural problems that militate against social inclusion in some countries do not overtake its acceptance to the point of making it irrelevant and ineffectual?

We need to begin by acknowledging and respecting the doubts and fears that people in less affluent countries express about de-institutionalization and social inclusion. Similar concerns have been heard in all countries, because de-institutionalization does represent a major change for people. Social acceptance of disability as part of the diversity of human life is not an easy idea for many people to accept, especially if they have believed something different all their lives. In countries where there are so many factors working against the success of community living, not only are the doubts and fears understandable, but also they are, arguably, justified.

It is one thing to say that less affluent countries need to begin by adopting a policy of social inclusion, and gradually to set up the systems that support that policy. This has certainly worked well in the more affluent countries, and may work to some degree in those that are developing. In Canada, the United States, Australia, the United Kingdom, and elsewhere, community-based living arrangements are provided for people with disabilities, and vocational training programs are now being implemented within community work settings that facilitate interaction

and development and appropriate work habits. These inclusive ideas have been backed by effective regulations and funding to guarantee positive outcomes, including the development of social skills training that enable people with disabilities to integrate better into the wider society. But such an approach may not be practical or achievable for many less affluent countries.

There are things they can do, although strong leadership is required. This leadership most likely will emerge from families who begin to insist that their children receive community-based services, rather than segregated services. It will emerge from disability professionals who are committed to social inclusion and who are willing to advocate strongly for community living rather than institutional living. In addition, there needs to be political leadership in order to alter the way services are funded and structured. It is not enough to want social inclusion to take place. Leaders need to provide a rationale for a viable alternative, and work hard to set it up in very concrete ways.

Cost is always an issue, particularly so in less affluent countries. It has been our collective experience that community services do not cost less than institutional services, but neither do they cost more. Political leaders and other authorities who approve funding for disabilities in these countries might be persuaded—especially with strong professional and family leadership—by examples of success in other countries that for the same cost they can move toward the goal of social inclusion. They may not have thought that it was achievable.

Four Steps Toward Social Inclusion

The four steps briefly outlined below need to be accompanied by a robust campaign to change general attitudes

toward disabilities. In some cases, such a campaign may best be carried out in a local area where success is more likely, although in other cases a broader audience may be more beneficial. The easiest and most straight-forward way to demonstrate the value of such a campaign is simply for people with disabilities to be seen in public doing everyday things: shopping, walking in the park, swimming, or having a picnic. Activities such as these need to be backed by a great many people doing a great deal of advocacy. If it is possible to get media support, it helps immensely to publish success stories of people who are blind, deaf, or physically disabled and who are leading productive lives. There will be resistance, because it is not easy to get people to change their attitudes quickly. There will be many people who object, but eventually most people realize that disability does have a place, and needs to take its place, among all of us.

These four steps may be introduced simultaneously or consecutively, although they should be carried out so that they all overlap:

1. Start with children who live with their families, and who would probably be eligible for segregated care. Instead of spending money on them in institutional care, spend the same money on community-based schooling, training, and day activity programs. Most families can handle their children at home if they have somewhere to go during the day. Children whose parents do not want to, or are not able to, care for them can be grouped into small housing units of about 4-6 children living together with 2 caregivers. This costs money, but no more than having them live in an institution. The caregivers will need training in how to have the children experience their communities and develop their skills.

2. Continue with adults who live with families, and who would probably be eligible for segregated care. As in the program with children, divert funds that would have been used for segregated care to community supports, including housing if required. Adults should not just be sitting at home. They should be going to day activity programs or volunteering at something, and some are able to have paid jobs. Support workers will require training to help each person reach his or her objectives for community involvement.
3. When there is sufficient leadership, people can gradually move from institutions to community living. It has been our experience in the more affluent countries that most people who make such moves live in shared community residences (a few people share an apartment or several people share a house). Few move back to their family homes for a variety of reasons. It should be emphasized again that this does not save money, and that it will take government people, professionals from the field, and families all pushing hard to make it happen. Before moving, it is essential to ensure that people are moving into an environment that is friendly, safe, and has opportunities for those with disabilities to enjoy life. The location has to be chosen carefully, and support workers need to be in place to see that the move continues to be successful. Finally, patience is required for moving people from institutional living to community living. Even in countries where such moves have been accompanied by ample funding, the process has usually taken considerably longer than expected. De-institutionalization is a long term, and gradual, process.
4. Gradually reach out to children and adults living with families in communities where there are no services.

Countries need to find their own solutions to their own challenges, but it would be naïve to think that less affluent countries of the world can move quickly toward social inclusion without some outside help. Fortunately, there are numerous experts who might provide assistance and advice. They can provide examples of strategies that have worked well elsewhere, and suggest ways they can be adapted. The success of others can be a strong motivation to those who have doubts or other priorities.

Everyone—disability professionals, family members, advocates, government authorities, experts, and others—needs to be conscious of the contextual meaning of social inclusion, especially in countries where the factors working against social inclusion seem insurmountable at times. Full and sudden social inclusion may not always be a good idea, but, if carefully planned, some aspects of social inclusion surely will improve the lives of people with intellectual disabilities. Nothing gets better if we don't try to make it better.

References

- Boushey, H., Fremstad, S., Gragg, R., & Waller, M. (2007). *Social inclusion for the United States*. Retrieved June 10, 2008, from <http://www.inclusionist.org/files/socialinclusionusa.pdf>.
- Federal Republic of Nigeria. (2008). *Federal Republic of Nigeria National Policy on Education*. Lagos, Nigeria: NERDC Press.
- Todman, L. (2008). *Social exclusion – Its relevance to the US social policy context*. Retrieved June 10, 2008, from <http://www.adler.edu/about/ISESuggestedReadings.asp>.