

Historical Perspectives and Future Challenges for Services for Persons with Disabilities



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Today, when we think back of what happened in the Twentieth century, many of us are seduced to make use of a rather negative terminology. Influenced by important theoretical developments – like the advent of the social model in thinking about disability – and far-reaching historical events – like the tangible deinstitutionalization processes of the 70's and 80's – we indeed are inclined to describe our past intercourse with persons with disabilities in terms of segregation, discrimination and suppression. One only has to remind the reader of Erving Goffman's influential book *Asylum* to trigger a line of argumentation that is constructed on progress and humanization. It is now much more better than it used to be, isn't?

Current historical research however, shows that the grim picture we often render about our past does not succeed in covering all of the long gone realities. Of course there were some bad things going on behind those huge and often catholic inspired walls, but then again, it was life after all and even in the most cruel parts of those medical labyrinths inmates often found ways to express themselves or even underlined the fact that they rather wanted to be in the institute than outside of it. This remarkable and for many of us counter-intuitive statement can be proved by referring to some of the answers given by deaf respondents in a participative research conducted by one of our students this year with regard to how they have experienced their life in Belgian deaf boarding schools during the heydays of the 60's. One of the respondents e.g. recalled a particular event that showed how cruel life in a 'total asylum' could be:

“One of the deaf boys had wet himself in bed, he couldn't do anything about it, but the Sister was angry. She took the sheets of the bed and laid them over the boy who then had to walk around on the playground so that every other deaf boy could see and tease him. That was really bad, walking around in that condition and with those sheets that stinked as hell”.

Despite the fact that these and other examples are cited time and again the deaf respondents did not completely dismiss the institute of it's value for their personal development. It indeed was not a place where one learned a lot they stated, letters were being censored and punishments were very bodily so to say, but nevertheless it was a place where one could make contact with other deaf persons, where life long friendships were made and where the possibility of resisting the ruling norms and values was never absent as becomes clear from one of the respondent's answers:

“When I was home with my family I could not hear anything, I had to speak. With my brothers I was able to sign, but when my father and mother were trying to tell something, I never was able to understand that. What I'd liked the most? Being at boarding school! There I was able to play, to chat, to work ... At home I always had to help cleaning, washing the dishes, I had to help father ... pfff I preferred to be at school, there I had to do nothing”.

One of the challenges that current historical research poses to us is to find a way – in the past, present as well as in the future – to come to terms to this ambivalence and become sensible for stories told by persons with disabilities themselves for among other things it are these stories that contain the key to the construction and realization of new services that not only are able to take into account the real needs of the persons with disabilities, but which also that can inform politicians, professionals and administrators alike of what now has to be understood when we are talking about so-called human-rights based services.

Arduin: a good example of a fast and efficient de-institutionalization process



Dr. J.H.M. van Loon

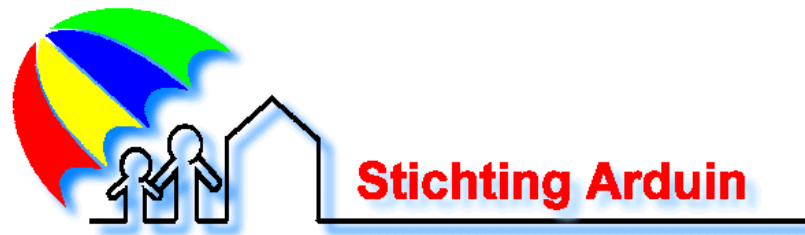
Arduin is a Dutch organization providing services for people with intellectual disabilities. Established in 1969, 'Vijvervreugd' (Arduin), was a residential institution serving persons with intellectual disabilities. When the new management arrived in 1994, there was insufficient quality of care in the structure, so a course of action was drawn up in order to make persons with intellectual disabilities decide for themselves how to live. The action plan was based on a quality of life (QOL) focus. Arduin was transformed from an institution to a new community-based organization, focussing on supporting each individual to determine determines what he or she needs. The process of deinstitutionalisation followed the separation between the three life spheres—living, work/daily activities, and leisure—and the promotion of QOL.

At present, Arduin supports about 720 persons: 516 for 24-hours a day (living and work/daily activities), 21 get periodic support in their homes, 24 short-stay (weekends and holidays), and 159 come to Arduin for (support in) work/daily activities. People live in over 150 ordinary houses, work full-time in a large variety of businesses and daycentres, and they are supported according to their needs.

The concept of quality of life was operationally defined and implemented through eight core domains found in the international literature (Schalock & Verdugo, 2002). Every decision, at the organizational level as well as at the individual client level, had to contribute to the personal outcomes of our clients. This 'from right to left thinking' (Schalock, 2001) was accentuated by the decision to dismantle the institution and in choosing a coaching style of management focus towards autonomy and self-direction. Key elements of the move towards deinstitutionalisation were the abolition of unnecessary bureaucracy, the development of a person-centred support system, the introduction of a housing bureau and a vacancy bank for clients .

What is essential in this system is the involvement of those we support in the developmental implementation of their individualised service plans. Arduin created an evidence-based Supports System, in which the Supports Intensity Scale (SIS; Thompson et al., 2004) and the Personal Outcomes Scale (POS; van Loon et al., 2008) were used to create a model for a web-based person-centered support methodology, based on a validated quality of life framework. First, a structured interview is held with each person regarding their desired life experiences and goals. Then the Support Intensive Scale is used to evaluate quality of life: the results of this evaluation show the goals and supports needed to realise

individualised service plans. This approach demands extensive creative thinking from service providers, which are positively challenged to create a good environment and an appropriate quality of life for persons with disabilities according to their needs and wishes.



Making social innovation work in Ireland: forging alliances to an inclusive society



Madeleine Clarke, Executive Director, Genio

Genio works with the public, private and non-profit sectors with the aim of stimulating and supporting social innovation in Ireland that makes economic sense.

With the support of the Atlantic Philanthropies Genio has been working in the disability and mental health fields since 2008. Many disability and mental health services are group-focused, institutional and stigmatising. Almost 4,000 people with disabilities and over 1,100 people with mental health difficulties in Ireland still live in outmoded institutions, many of who are isolated from their families and society. Thousands more are grouped together in segregated settings away from mainstream life in their communities.

Within the international context, the Convention on the rights of persons with disabilities, adopted by the United Nations General Assembly in December 2006, includes the general principle 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.'

National policy in Ireland seeks to transition towards individualised supports that integrate people in their communities. However, the challenge of reconfiguring resources to modern services is significant. This is where Genio can help. The current economic downturn in Ireland presents an opportunity to refocus resources in a more strategic, cost-effective direction. By working with key stakeholders including individuals who use the services and their families; voluntary organisations; Government and philanthropy; Genio backs innovative ways of reconfiguring personal and social services, which are sustainable, cost-effective and put people with disabilities in the driving seat of their own lives.



The Genio Trust currently combines Government health innovation funding and contributions from the Atlantic Philanthropies. Grants totalling almost €3m have been awarded in 2010 and 2011 to support over 400 people to move from, and to avoid, institutional care. Where possible we assist in the closure of whole institutions to release resources that can be refocused on developing supports in the community.

A further €2.45m in grants has been awarded to develop the capability of those who use services, families, advocates and service-providers to develop and implement plans that will make individualised, community-integrated supports a reality for many more - now and in the future.

In addition to working in the disability and mental health fields, Genio has now begun a project aimed at improving services and supports to older people with dementia in collaboration with Government and the Atlantic Philanthropies. We are continuing to explore opportunities with Government and with philanthropic, private and corporate investors interested in supporting cost-effective innovation that increases human and social capital.



A look to developing countries

Interview with Dr Indumathi Rao BSc, DEHC, Phd, Chair of the Global Partnership for Disability and Development.

Are there any common needs for persons with disabilities in developing countries? What are the services available in order to answer to these needs?

Persons with disabilities in developing countries are similar to their counterparts (with diversity across disabilities and within each disability group) in industrialized countries. The difference arises in the way social-cultural-economic factors affect the quality of life.

In developing countries governments are still struggling to provide basic rehabilitation services, primary education, and livelihood opportunities. In general, they follow the example of strategies existing in industrialized countries' and the ideas promoted by the United Nations. However, the huge differences in the situations at grassroots level (from the economic, social and cultural points of view) lead to implementation issues, as the solutions proposed fail to have the same positive effects on the field.

What makes the difference, in terms of service structure and management, between a service in a developing country and a service in an industrialised country?

In developing countries there are very significant interdependent societies based on well knit families where the needs of a person with disabilities are mainly addressed. Therefore services must be community-based and treat family as a unit while planning services. For that reason, individually focused poverty reduction and improved lives for persons with disabilities are not enough: there is a need to create rehabilitation services on a community level. This can be done via the creation of a network or of a public and private partnership.

In India, governments are the main source of funding for social policies as they allocate specific budgets in proportion to the number of persons with disabilities in each province. Consequently, there is a need to have accurate database and information on the needs of persons with disabilities. Developing countries usually lack funding for mainstream services, and they do not have specialized care and support systems dedicated to people with disabilities with different needs.

We can classify five types of funding mainly used to finance services to people with disabilities in the country:

1. Government funding (Central level)
2. Government funding (local level)
3. International funding (Bilateral cooperation for development such as NORAD, SIDA, DANIDA, USAID)
4. International private funding (INGOs)
5. World Bank large scale support programmes
6. Community driven (Local donors, community contributions)

There is still a lack of full participation and inclusion of persons with disabilities in services. Among the poorest and most powerless section of society, persons with disabilities face a double discrimination. Several examples can be made: women with disability belonging to poor communities, children with disabilities in rural areas, elderly persons with disabilities. These persons barely know their right to participate in policy development, planning of budgets, implementation, monitoring and evaluation of the programmes they are targeted by. Whereas services have now moved away from the old medical model

(considering disability as a defect), in developing countries there still is a trend to talk about people's perspective and not yet citizen's perspective.

Are services moving towards being more community based ?

From my experience, inclusive education is the field where community-based services are the most developed. For other areas such as employment, early intervention and assistive technologies, we still are far away from such a model. However, we can mention some initiatives taking place in order to mainstream disability issues in livelihood activities under rural employment guarantee programmes.

Despite the significant degree of public commitment to the disability issue, in practice there is a lot more that needs to be done. More than 80% of people with disabilities live in rural/tribal areas and they are usually the poorest of the poor, the most marginalized in the society.

