

Research Paper on Community Living and the Support of Independent Living: Costs and Benefits

Debbie Jolly

Lack of proper service provision is not about lack of funds or bad administration. It is about prioritizing the rights of the individual and ensuring that in a democratic society those rights are enshrined and implemented. (Hurst 1995:533)

Introduction

This paper elaborates the human rights argument for the full support of community living and independent living for all disabled people. The paper argues that disabled people do not need to live in institutions excluded from their communities nor have their human rights abused.

The Council of Europe Action Plan which states that disabled people must move from the role of 'patient to citizen'. Action 8 in the Action Plan is devoted to promoting and enacting community living. In addition, the UN Convention on the Rights of Persons with Disabilities (CRPD) promotes independent living through Article 19 which states that disabled people should live where they wish and with whom they wish.

However, demands for disabled peoples' human rights and freedoms are not new, nor were they first voiced through the above documents, they have been a demand of National and European disabled peoples' movements since the early 1960s (Barnes, Mercer and Shakespeare 1999).

In 1989 demands for community living and personal assistance were the basis of the newly formed European Network on Independent Living (ENIL) an organization run and controlled by disabled people. In 2003 a set of demands were presented to the Strasbourg Parliament by The European Network on Independent Living (ENIL), they were re-presented in 2007 and 2009. Indeed, national disability movements around Europe and beyond have been demanding full support for community living and de-institutionalization for decades.

There have been some welcome changes, with the closure of some large institutions in some European countries, but these advances are marred by the building of group homes which house a smaller number of disabled people representing the institution and its systemic problems in microcosm. The records of some newly ascending European member countries, some of whom see institutionalization as the only option for many disabled women, men and children also present challenges to these demands. While community living and the support of disabled people and children is claimed to be the wish of the European Community and the United Nations, the progress is slow and as you read this millions of disabled people and children are likely to be incarcerated in

institutions around Europe. This is a situation which many agree must change. The claim of the Council of Europe in the European Action Plan (2006-2015) that disabled people must move from the role of patient to citizen can only be achieved by prioritizing the rights of the individual and ensuring that those rights are enshrined and implemented.

Existing International and European policy background

The CRPD has been signed and ratified by a number of countries but is still awaiting ratification from others Article 19 says:

“Persons with disabilities should have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community”.

As noted, both the European Action Plan (2006-2015) and the CRPD have guiding principles which must become realities for disabled people to achieve basic human rights as equal citizens. The three guiding principles of the CRPD are:

- 1) Respect for inherent dignity and individual autonomy, including the freedom to make one’s own choices, and independence of persons;
- 2) full and effective participation and inclusion in society; and
- 3) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.

Whilst the Council of Europe Action Plan is guided by three very similar principles:

- 1.) Disabled people achieving the same rights as everybody else
- 2.) Society ensuring access to human rights for all citizens
- 3.) Disabled people becoming equal citizens

In addition, Action line 8 of the Action Plan states that disabled people should be given full support for community living and independent living in the same way that article 19 of CRPD does.

The implementation of article 19 and action 8 will be the duty of national and local jurisdictions in particular countries. Both of these measures support the European Resolution on the Rights of Disabled People (1996) which said that disability rights must be treated as a civil rights issue, which discouraged the building of new institutions and demanded that no person was institutionalized, against their will. In addition, the Charter of the Fundamental Rights of the European Union (2000) said that states should ensure disabled peoples’ independence, participation and inclusion at local, national and European level.

In spite of numerous declarations, policies and demands, continuous problems and barriers have been raised by politicians and local authorities on the costs and outcomes of the full deinstitutionalization of disabled people. In addition, groups who have a vested interest in the continuation of the institutional system are likely to protest against deinstitutionalization, often developing existing local prejudices in the process and thereby gaining further impetus to violating the human rights of disabled people. These groups can include those service providers/charities who would lose contracts, donations, and government subsidies, other groups and individuals with a financial stake in the institution who gain from the system, staff within the institutions and existing trade unions who may wish to protect staff jobs, professional bureaucrats at local, national and European levels as well as those who claim that closures will have a negative affect on the local economy.

Three key discriminating arguments which act against both the European Action Plan and the UN Convention on the rights of people with disabilities persist

- a) The costs of de-institutionalization and community living are higher than institutionalizing disabled people.
- b) Disabled people, especially those with perceived higher support needs will be unable to support themselves outside the institutional context, be it a large institution or a small group home institution.
- c) The process of community living and independent living will take time and require a change in the local systems.

The form of these arguments can vary due to state and local processes, systems of government, levels of decentralisation, economics, and any welfare systems already in place, while these factors are beyond the scope of this paper they are factors that should be considered in any protest or challenge around deinstitutionalisation.

In the next section we will explore current research and findings on de-institutionalisation.

A summary of research and findings from the United States of America and Europe

The United States of America program and policy of deinstitutionalisation effected a change to the numbers of disabled people incarcerated in institutions from 1977 to 1998. For example large state run institutions decreased numbers of residents from 154,638 to 52,488. Institutions with 16 or less people with perceived intellectual or cognitive impairments decreased from 52,718 to 35,247 but institutions with 6 or less people increased from 20,400 to 202, 266 over the same period (Prouty and Lakin 1999). Effectively while the larger institutions were closed those holding 6 or less

individuals increased, however differences were made to the overall population with many living in the community.

In Europe research has been conducted which shows decreases in the numbers of disabled people institutionalised in large institutions of many established European countries. However, figures from different countries vary in availability and validity (Mansell et al 2007). For example there were clear problems in obtaining information and usable data from Greece, Cyprus, Malta and Austria at the time of the Mansell et al study. However, the study found that in most countries data was available on the types of institution and how they were funded. For example in 16 of 25 countries state funds were being used to support institutions of more than 100 places. In 21 of 25 countries state funds supported institutions of more than 30 places, and in 12 of 25 countries partial state funding was supporting institutions of 1-30 places, with the remainder provided by non-governmental organisations. Yet, as in the U.S, countries which decrease populations in large institutions often show an increase in the building of smaller group homes or supported homes.

In addition, newer European Union countries and ascending European countries can continue to build larger institutions (Holland 2003, 2008, Vann and Siska 2006). The publicity around the often harsh conditions endured by women, men and children is welcome to provide advocacy for those individuals and raise publicity of human rights abuses, yet we should not be misled into thinking that this makes the situations of adults and children in institutions elsewhere acceptable. This is not the case. The next section begins to tackle the first argument against deinstitutionalisation by examining the financial cost differences of institutionalisation and community living.

Financial Cost differences: Institutionalisation vs. Community Living

In the U.S. the average cost per person per annum for those housed in state institutions was \$104,000 but for those living in the community it was \$30,000 in the late nineteen nineties. The cost of living in the community for those with cognitive impairments was therefore on average 66% cheaper than the costs of their counterparts living in institutions (Pouty and Larkin 1999). Similar findings have been replicated elsewhere, for example an Australian study comparing costs per patient per day, showed that cost savings were made of between one half and one third when individuals were moved from long-stay institutions to the community (Lapsley et al 2000).

American studies clearly show the improvements in quality of life and self-determination, the lower costs of community living, and that the economic contributions of disabled people are maximised once they begin to live independently with the proper support. In many cases European studies confirm this view (Zarb 2003, JAG 2006, Evans and Hasler 1996), however some living costs can be higher in the community (Mansell et al 2007), this can be linked to the escalation of costs over-time rather than the comparative costs of institutionalisation and community living, but it also highlights the fact that the worst institutions will reduce their running costs to unacceptable levels.

That is, the cheapest institutions achieve the illusion of economic efficiency only through the severest violation of 'residents' human rights by bypassing basic needs. These violations include the lack of adequate nutrition, clothing, heating, basic health needs and clean environments. Sitting on a chair all day or being tied to a bed in such conditions does indeed save money. However, the abuse of people in this way saves money, and will make institutions appear the cheap option. Also in instances where countries and localities lack a service infrastructure to provide adequate community support, cost differences on the budget sheet between cheaper institutionalisation and community living will be more pronounced. The human costs of maintaining what can be perceived as the 'cheap' options are limitless while the costs of maintaining institutions per se are incalculable in terms of abuse of dignity, human rights and individual choice.

Without fail all institutions, including those smaller institutions called 'group homes' or the inappropriately named 'community living homes' deny individual choice. They deny choice, independence, basic rights, dignity and privacy. They include for example the time to get up, go to bed, the time to eat (and what to eat) what to do with ones own money (as cash and government benefits can be withdrawn from individuals and siphoned into the institution), the option to go into the community, the likelihood of education, training, employment, developing skills, and the right to social relationships (Evans 2002).

Quality of Life and Skills: Institutionalization vs. Community Living

A large number of studies examining the effects on the skills of individuals moving from institutionalization to community living show improvements in quality of life and self esteem as well as improvements in communication, academic and social skills. Comparative research studies have also found that physical health and life span increases when comparing those in institutions and those living in the community, with those living in the community securing health and longevity gains. Those in institutions suffer greater health costs in both physical and psychological health (Shaville et al 2005, Michelle et al 1990, Roberts et al 2005). Forester-Jones et al (2002) studied people who were institutionalised and assessed their views twelve years on when they had engaged in community living. The findings show positive aspects on several counts for individuals, for example: individuals noted immeasurable gains in terms of self determination and choice, independent living, sociability, employment, leisure and training. These represent economic gains for the community as they validate that those living in the community are able to contribute in a number of ways to the local economy.

These findings can be combined with longitudinal studies taken over a number of years (Kim et al 1999) which provide positive outcomes for individuals living in the community in terms of social contributions, economic contributions and health outcomes which represent a long-term cost saving on health system and other state resources (see Evans 2002 for a breakdown on the costing). Taken together, existing research provides strong evidence not only on the human rights and equality arguments for

deinstitutionalisation, but also on the lowered long-term costs and better economic outcomes for individuals and their communities. These gains and the gains which promote independent living can be achieved in a number of ways with the most effective being personal assistance (PA) support.

Personal Assistance and Independent Living

Personal assistance is a system to enable independent living and it should be paid for by the state. It is a system which should take the place of the dated and abusive system of institutionalisation and be funded accordingly.

"Personal assistance" means that:

- funding of services follows the person and not the service provider,
- users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences and aspirations.

Their range of options includes the right to custom-design their own services, which requires that the user decides who is to work, with which tasks, at which times, where and how.

Therefore, a policy for "personal assistance", among other solutions, enables the individual to contract the service of his or her choice from a variety of providers or to hire, train, schedule, supervise, and, if necessary, fire his or her assistants. Simply put, "personal assistance" means the user is customer or boss.
(Ratzka 2004: 2-4)

Moreover eligibility should be granted universally as an independent living need and not dependent on income or assets of the potential user or their family. Disabled women, men and children should fill out a self-assessment form in which **they** assess their needs and the time that particular tasks may take (with support if necessary), as disabled people are the experts on their needs. The funds for their personal assistance must extend to any equipment or technical aids that will make independent living a reality, and they should be given peer support in handling the employment of their own chosen personal assistants.

The Swedish organisation of disabled people JAG conducted a three year study into these issues and found that personal assistance was cheaper than group homes or the smaller institutions. This was true of all types of impairment including those perceived as 'high need'. Personal assistance goes beyond community living it is a process where an individual chooses and employs a personal assistant to provide support so that they can live independently, thus generating employment for others, contributing to the

national income through payment of national taxes. At the same time this gives the option for personal assistant user to be employed too. Those with perceived higher support needs become contributors to society through the employment of a team of P.A.s, instead of a perceived drain on resources while imprisoned in institutions. One of the key issues in the deinstitutionalisation argument is that Personal Assistance schemes are available to all throughout Europe (ENIL 2007). It is only through personal assistance that financial and humanity gains are maximised for the individual, the community and the economy.

There is therefore an overwhelming amount of evidence that community living and personal assistance represent the best options to achieve independent living gains in financial costs, in human rights, equality and independence. However this is not about institutionalising disabled people and children in smaller 'group homes' or community homes, and saying they are living in the community-it is about support from the community for personal assistance schemes and full control, independence and dignity.

Table 1: Impacts of Institutionalisation, Community Living and Personal Assistance

Impacts on disabled people and localities of institutionalisation, community living and Personal Assistance					
Institutionalisation		Community Living		Community Living and Personal Assistance	
Cost	-	Cost	+	Cost	++
Independent Living	-	Independent Living	+	Independent Living	++
Human Rights	-	Human Rights	+	Human Rights	++
Autonomy	-	Autonomy	+	Autonomy	++
Equality	-	Equality	+	Equality	++
Inclusion	-	Inclusion	+	Inclusion	++
Contributions	-	Contributions	+	Contributions	++
				Generation of employment	++
				Economic contribution	++
<i>Key: - negative, + positive, ++ extremely positive with enhanced economic contributions to the locality</i>					

Conclusions:

Institutionalisation, community living and personal assistance

Through the media we have consistently witnessed how many disabled adults, older people and children in large institutions have been exposed to human rights abuses in Europe. (Vann and Siska 2006, Holland 2003, ECCL) and how some within the institutions attempt to silence those that have been subject to such abuses (Malacrida 2006). Research on community living shows many gains for the individual and for the community, whilst research on personal assistance schemes shows additional gains for the individual and the locality.

Clearly, institutionalisation in large or small settings is often more costly in financial and quality of life terms for localities and for disabled people. Institutionalisation contravenes article 19 of the UN Convention on the rights of persons with disabilities and the European Action Plan whether that institution holds 600 people or 6.

Community Living and Personal Assistance systems promote independence, better health outcomes and allow disabled people freedom of choice and greater equality, as well as allowing them to contribute to the local and national economies as active and valued citizens.

Where systems have been slow or negligent in developing PA options, laws and full human rights for disabled people this has been caused by the failure of the deinstitutionalisation process, and a failure in setting up adequate alternatives and supports rather than the failure of community living and independent living options per se (Hudson 1991).

The key issues often raised by politicians and others on cost and the inability of those with perceived higher support needs to obtain independent living outside of institutional settings have been severely undermined by academic research and by the actions and existing personal assistant schemes undertaken by disabled people to make independent living a reality.

Will the process require a change in local systems? Yes it will. It will require monies currently used for institutionalisation to be transferred to support community living and personal assistance schemes, it will require formal laws where they do not already exist on the right to personal assistance for all disabled people in Europe; it will require mobilisation of the independent living community to launch extensive peer support programs and training schemes for disabled people

The phrase it 'will take time' is a cliché'. The process will be speeded by listening to disabled experts on inclusion and independent living policies (many of whom have organised and developed successful schemes of personal assistance) and by allowing them to advise and help develop schemes in those areas that lack the knowledge or will to appreciate the human rights of disabled people. Clearly, time must be taken to

ensure that such schemes are effective and efficient but not as an excuse to delay the process or avoid beginning the planning process for deinstitutionalisation, personal assistance and independent living.

Recommendations for effective implementation of independent living in all member states

Base line data for all EU member states on number of institutions and size of institutions needs to be compiled to monitor change and identify actions on achieving the goals of independent living.

Monies paid by governments to run institutions needs to be effectively monitored to ensure ring fenced budgets are transferred to the aims of independent living, the development of personal assistance schemes, and training of personal assistants programs run and controlled by disabled people.

States that do not have a Personal assistance law need a target date to develop one in consultation with national or European organisations of Independent Living which are run and controlled by disabled people.

Training in the social model and training for personal assistants needs to be developed along with support mechanisms for those that wish to use personal assistance.

Independent Living organisations run and controlled by disabled people and their members should be consulted at local, national and European level, as they are the experts on disability.

It is only with well resourced Personal assistance systems for all types of impairments that the criteria of UN Convention and European Action Plan on independent living can be achieved by member states.

Disabled people have a role to play in monitoring their governments and asking them what they are doing to achieve independent living.

Continuous excuses are unacceptable because the solutions are available, the blueprints are there and the expertise is there to make community living and personal assistance for all disabled people in Europe possible.

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For further issues on deinstitutionalisation see European Coalition for Community Living <http://www.community-living.info/index.php?page=214>
Especially <http://www.community-living.info/index.php?page=286>

See also European Network on Independent Living
http://www.enil.eu/enil/index.php?option=com_content&task=view&id=111

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This is a working paper prepared for the European Network on Independent Living please contact Debbie Jolly if you wish to use paper
debbie.jolly@virgin.net

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