



DEINSTITUTIONALISATION AND COMMUNITY LIVING

Lessons from international experience

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CENTRE FOR INCLUSIVE FUTURES
POLICY, ORGANISATION & COMMUNITY ACTION LEARNING



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SUMMARY

Under the title ‘Living independently and being included in the community’, Article 19 of the United Nations Convention On The Rights Of Persons with Disabilities states clearly the obligation on governments to:

recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and take

effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full

inclusion and participation in the community

As part of its global campaign to advance implementation of this Article for people with intellectual disabilities, Inclusion International hosted two days of consultations with representatives of its members in economically-advanced countries at the end of May 2012 in Brussels. This paper is based on notes from these meetings. It explores the progress made in advancing community living over the last generation and contemporary challenges in delivering the promise of Article 19.

1. INTRODUCTION

The United Nations has both strengths and weaknesses, but dating back to its formation, it is the global forum entrusted with protecting and advancing the Universal Declaration of Human Rights. It was a very significant development therefore when Mexico and Panama among others persuaded the UN to produce a new Convention (formally agreed in 2006) focused on making explicit what this and other human rights instruments mean for the lives of disabled people and the responsibilities of governments. Moreover the UN Convention on the Rights of Persons with Disabilities (UNCRPD) was the first such Convention to be negotiated with the direct participation of civil society associations representing disabled people, including Inclusion International, the global association of organisations like Mencap advocating for people with intellectual disabilities (learning disabilities) and their families.

The UNCRPD is a comprehensive statement of what it would mean for disabled people to enjoy equal citizenship with other members of their communities and when ratified by a country, has the force of law (albeit law which sets a direction of travel until fully incorporated into national law in countries like the U.K). The U.K. ratified the Convention in 2009.

Article 19 of the Convention is fundamental. It sets out the right of disabled people to Living independently and being included in the community. Accordingly, Inclusion International has made campaigning on this Article and producing a global report on its implementation a priority for its global work in 2010-2012. As part of this work, it hosted two consultative workshops in Brussels at the end of May. These were addressed to leaders in the movement for community living in relatively ‘developed’ countries where there has been a history of state investment in institutional services for people with intellectual disabilities and, in many cases, long campaigns – still incomplete – to replace these with the opportunities and support required for people to live included in the community. A common focus of the two workshops was what had been learnt from these efforts at de-institutionalisation (DI) and what now is our vision of community living.

The first of these workshops involved leaders from some of the richest Western countries – Canada, Germany, New Zealand, Norway, United Kingdom and United States. The second included some of these but focused on Europe and especially the situation of countries in Central and Eastern Europe – including Croatia and Romania – which had been part of the Soviet block until 1989 and continue to rely heavily on institutional services for both children and adults.

Both workshops were facilitated by Steve Eidelman (University of Delaware, USA) and Don Gallant (Institutions Watch, Canada). David Towell (Centre for Inclusive Futures, UK) recorded key points from the discussion on flip chart paper and these notes are the basis for this short report.

Inclusion International's more substantial global report, to which these two consultations are a contribution, will be published in October 2012.

These discussions explored six main questions:

1. What is required to achieve successful de-institutionalisation?
2. What is involved in enabling people with intellectual disabilities to live included in the community?
3. What support do families need both in the process of DI and in enjoying an ordinary family life in the community?
4. Has there been a need to reform outdated community services and are there risks of new forms of institutional provision?
5. What are the contemporary challenges to our vision of community living?
6. What is required to fulfill the promise of Article 19 of the UN Convention?

2. STRATEGIES AND LESSONS

All the rich countries represented had a long history of institutional provision, often on isolated sites at some distance from population centres, and dating back at least until the 19th Century. For example, in England, as recently as 1980 there were 50,000 people with intellectual disabilities living in large institutions (the largest of which housed 2-3,000 people). Indeed up until the 1970s families had only the ‘choice’ of providing care themselves or ‘sending their son or daughter away’.

The starting dates for strategic change towards community services varied: the 1970s in some countries and a little later in others, but this policy shift gained momentum so that over a period of 20-30 years complete closure of the traditional large institutions was accomplished (Norway, 1995; New Zealand, 2006; England 2011), although this process is still incomplete e.g. in Canada. (As we shall see however, at least the first generation of community alternatives, typically based on the ‘small group home’ continued some features of the institutional experience; day opportunities continued to be provided in large segregated settings; and in a variety of ways new kinds of institutional provision are still being created.)

There were four main drivers of this small revolution. Value-driven leaderships advanced new visions about better lives for people with intellectual disabilities (e.g. in England, the concept of ‘An Ordinary Life’; in Scandinavia and parts of North America, ‘normalisation’) and sometimes human rights approaches were embedded in legislation (e.g. the Americans with Disabilities Act) making litigation a productive strategy for institutional change. These value-driven campaigns gained more credence as innovators learned from each other and across national boundaries about the design of housing and support services, including for people with the most profound impairments.

Scandal also played (and continues to play) a large part. For 50 years now press, public and politicians are regularly surprised to discover new examples of abuse, being perpetrated by carers paid for by taxpayers (in a

recent English case amounting to torture). Economics also featured as the demand for rising standards made expensive calls on state budgets, either to be spent in institutional renovation or to be used more effectively as investment in community services.

Families (including family members with significant professional status) – and much more recently self-advocates – have played some leadership role in these changes (e.g. pioneering individual budgets in western Canada) but many families whose members already lived in institutions have been cautious about the reliability of proposed alternatives. In most rich countries there has also been an arm of the family movement, sometimes encouraged by institutional staff, actively resisting DI proposals.

The ways in which this large-scale decentralisation of services have been managed necessarily varies with different structures and responsibilities in national ministries and different types of ‘provider’ system. In England, for example, the institutions were all part of a nationalized health system so government was in a position to itself plan and manage – including by funding the ‘double running’ costs incurred as old and new services co-exist – the change process, even though the new providers of housing and support were typically in the housing and voluntary sectors.

More recently, in a number of countries there have been efforts to put more control in the hands of disabled people and their circles of support (e.g. through individual budgets and person-centred planning) and the design of personalized alternatives has required brokerage skills to put together funding from different sources and contributions from different service agencies so as to create a ‘package’ consistent with each individual’s aspirations and needs.

Both localism and complexity have contributed to wide variations in what is available to people in different places and similar variations in the quality of support. In this context, the impact of standard-setting and regulatory agencies has also been mixed: it still seems difficult to regulate service provision in ways which encourage person-centred and mutually respectful support between disabled people and those paid to help them.

As we shall see there are also big questions about how far living in the community has led to inclusion in the full range of activities and relationships which other citizens come to expect.

There is quite a large literature on what is involved in achieving DI (as well as evaluations of quality and cost-effectiveness of different forms of provision). For example, Canadian associations have recently produced a guide ‘The Right Way’ summarising 10 lessons from 25 years of seeking to achieve deinstitutionalisation, as follows:

1. Ensure that champions for community living are involved in leading change.
2. Make the needs and preferences of people central to planning.
3. Respect the experiences and roles of families.
4. Create a real home and personalised support for each individual.
5. Focus on achieving quality services and ensuring people can lead their own lives safely.
6. Recruit and develop skilled staff.
7. Engage a broad partnership in delivering change.
8. Establish a clear plan and time-scale for creating the community services necessary to make each institution redundant.
9. Invest in communicating all this effectively to everyone affected, including in the communities to which people are moving.
10. Support each person in their transition to community living.

However, although now 23 years since the fall of the Berlin Wall, this story of gradual reform in the richer developed countries is still only in its infancy in many countries of Central and Eastern Europe. There has been some progress in reforming child care policies and, for example, promoting foster care, but as Oliver Lewis from the advocacy agency MDAC reported, in the wider Europe there are still 3 million citizens confined in institutions, some of which are being sustained through fresh investment. Despite many promising small-scale initiatives (often supported by international NGOs) this traditional segregation is proving very intractable to national level reform. The 30th May workshop sought to identify the key barriers to national policy change, summarised in Box I overleaf.

BOX 1. BARRIERS TO DEINSTITUTIONALISATION IN CENTRAL AND EASTERN EUROPE

Political cultures which give only weak support generally to human rights.

A lack of commitment to modern approaches to community living.

Hostile public attitudes to disabled people who have been made ‘invisible’ by past policies of segregation.

Declining political support for the European ‘social model’ in the face of austerity.

Inadequate capacity to manage complex change across public agencies.

Mistaken assumptions about the costs and benefits of different patterns of provision.

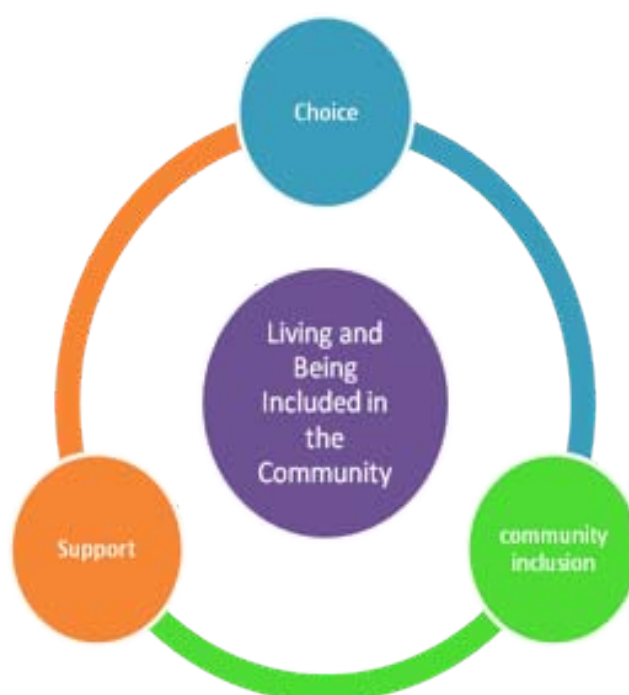
Misuse of the EU structural funds.

Inadequate professional leadership.

Weakness in family associations and a lack of parent belief in the viability of community services.

3. COMMUNITY LIVING

Article 19 offers a broad definition of what it means to live included in the community built upon three main elements (where support refers both to support to disabled people and support to families) and their inter-relationships, summarised by Connie Lauren-Bowie (Inclusion International) in the following diagram:



Linking back to our review of the experience of DI, it was recognised that the alternative community services typically fell (and in many places still fall) rather short of supporting choice and inclusion. In England for example, 1980s provision was dominated by (most commonly) six-place group homes where residents had limited rights, limited autonomy and often limited engagement with other ordinary members of their local communities. Subsequent reforms encouraged more people to become tenants in their own small homes, sometimes sharing with one or two other people of their own choosing, and more recently put people ‘in control’ of their own lives through individual budgets and personally-tailored support plans.

Looking then at choice, the aspiration is that individuals increasingly get to live the lives they want as valued community members with support to take as much control as possible of how they live. Many people, not least those leaving institutions, have limited experience on which to make choices and so need the flexibility to change their minds as they learn more about community life. Moreover discussions of choice need to be placed in the context of inclusion and not used as the rationale for new forms of segregation.

Typical choices for all of us, for example about the age and method of leaving the family home, are of course shaped by culture and class. Support for autonomy also needs to be offered in the context of ‘what is typical round here’ as well as being sensitive to aspirations to be different.

Inclusion refers not just to presence in ordinary flats and houses in ordinary streets (and so is significantly impacted by wider housing policies) but also to participation in the full range of opportunities enjoyed by other citizens – in education, in work and at leisure – and to good support from services, like health, which we all use. It also means being included in similar patterns of ties and connections as other non-disabled people of similar age. Advancing inclusion requires therefore policies and practices which both remove the barriers to participation (e.g. through disability rights legislation) and encourage mainstream agencies and communities more generally to open their doors to diversity.

Three Romanian self-advocates who participated in the 30th May workshop were able to share their experience of the huge positive changes in moving from institutional living, characterised by ‘block treatment’ in large groups, inactivity and punishment, to now living in small apartments and working in social enterprises with support from the NGO Pentru Voi and the municipality of Timisoara.

Support to disabled people then, whether informal through family, friends and colleagues or through paid supporters, is what is required to enable the person to pursue their choices in living included in the community. For example, another self-advocate from England was able to describe the way in which he is able to lead the work and family life he wants through the support he gets from other disabled people and a volunteer assistant in his KeyRing supported living network.

For the majority of people with intellectual disabilities and typically in much of their lives, families are the main providers of this support – although often of course, especially for adult ‘children’, in part because of the lack of available alternatives. Family support is then the pattern of mutual aid (i.e. with other families), information, cash benefits, respite opportunities etc. which enable families to both live their lives like other families and play their chosen role in supporting their disabled family members.

Family associations have an important function in promoting such support and developing the capacity of families and their networks to enable people with intellectual disabilities to live included in the community. In New Zealand, for example, there have been efforts (sometimes using e-communication technologies) to help families develop their aspirations through contact with other families and learning about person-centred planning and community mapping.

However this discussion only served to underline that, even in the richest countries, support to families mostly falls a long way short of what would be required for them to lead ‘an ordinary life’ and, for example, the question ‘what will happen when we die’ remains an unresolved concern for a great many.

More generally, this discussion suggested that there is much more to be done to fill out and demonstrate what these three Article 19 building blocks for community living mean in practice.

4. REFORM OR REGRESSION

As this commentary suggests, our understanding of community living has been evolving over the thirty years in which DI has been a major strategy in the richest countries. Early service models have been found wanting and there has been a wide and continuing need to invest in ‘second order’ deinstitutionalisation, for example to enable people to live in homes of their own choice alone or with others of their own choice, supported also by staff of their own choosing. One question therefore is whether countries still engaged in DI can ‘leap over’ some of these less satisfactory group living approaches in their transformation to community living?

Indeed institutionalisation has cast a long shadow. As we have seen, in some countries traditional institutions persist and so do the scandals associated with them. Small group living, not chosen by disabled people themselves, persists and some of the groups are not so small: indeed in some places they are getting larger as ‘austerity’ takes its toll. Moreover institutional practices in staff support remain very common.

Worse, there is evidence in all the rich countries, even in Norway which completed DI first, of new forms of segregation and institutionalisation emerging, sometimes even encouraged by families (e.g. under the banner of creating special residential schools or ‘intentional communities’). Given the prevalence of segregated services for elders (retirement communities, nursing homes) in most of our countries, there is also the possibility of people with intellectual disabilities, sometimes while still young, being cared for in these excluding settings.

And as we have seen, DI is still in its infancy in many countries of Central and Eastern Europe.

5. CHALLENGES

Reinforcing these weaknesses, we identified two inter-related and major contemporary challenges in many of the countries represented in these workshops.

The first of these is ‘austerity’ in public policy, following the global financial crisis, as governments seek to balance their books in low-growth economies with significant cuts in public expenditure. Cuts in welfare spending are adding to the poverty of people with intellectual disabilities and their families. Changing eligibility criteria and longer waiting lists are leaving more on the shoulders of families. Services are under pressure to cut costs without necessary protections for quality. And typically, ratification of the Convention seems to have little impact on these policies undermining community living.

Second, in some of our countries at least, there is a longer run trend to the weakening of local communities as sources of mutual support, including for disadvantaged people. Greater individualism, more cosmopolitan life-styles and declining solidarity may all be contra-indications for building more inclusive communities. And there is worrying evidence of continuing public prejudice against disabled people, reflected for example in the incidence of bullying and ‘hate crime’.

6. CONCLUSION

A key task therefore for Inclusion International's Article 19 global report and campaign is to articulate the potency of the Convention on the Rights of Persons with Disabilities as an instrument for positive change and seek to support regional and national family associations, often still attempting to be both advocacy organisations and large-scale service providers, in sustaining vigorous family leadership in meeting these 21st Century challenges.

As we have seen from Box I, there is a particular need for the inclusion movement to magnify the efforts already being made in Europe to address the challenges of implementing Article 19 in the countries of Central and Eastern Europe.

One significant asset in this endeavour is the urgent need we all have to build sustainable, fair and inclusive communities with the capacity to ensure well-being for everyone while protecting the biosphere on which all life depends.

ABOUT US

Centre for Inclusive Futures

The mission of the London-based Centre for Inclusive Futures is to support the development of sustainable communities which include everyone as equal citizens. It works locally and globally with individual leaders, organisations, public agencies and social movements to create inclusive spaces for reflection on contemporary challenges and support action designed to make a positive difference.

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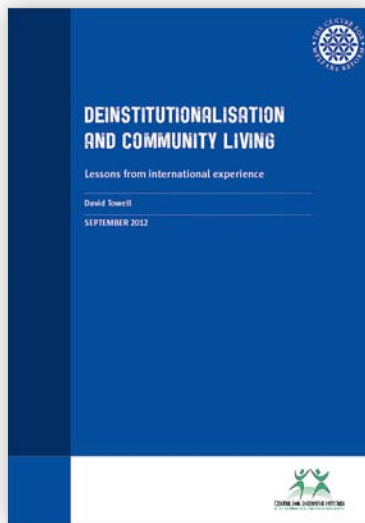
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