*Social work and deinstitutionalisation*

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*State of art*

Deinstitutionalisation is the process of closure of total institutions, while simultaneously creating services that have the potential to support people in distress and enable them to live as independently a life as possible in the community. While emptying and closing down institutions and resettling the residents are the most obvious process of deinstitutionalisation, it is not the whole story. Deinstitutionalisation is also about gaining sovereignty in everyday life, reclaiming control over their own lives, developing the ability to make decisions, having a home, a room of one's own, acquiring socially valued roles, changing power relations (especially with professionals), enabling and empowering the community and producing new ways of caring that transcend the institutional patterns and prevent them of reappearing in the community settings.

Deinstitutionalisation has a long history, almost as long as the institutions themselves (deinstitutionalisation of monasteries, leper asylums, courts, poor houses and work-houses. Present day deinstitutionalisation started just after World War Two and is based on the war and post war experiences, critique of the concentration camps; the introduction of therapeutic communities for soldiers; and mainly with the introduction of Welfare State after the war (Ramon, 1985). Shortly after the total institution was conceptualised in a philosophical (Foucault, 1961), sociological (Goffman, 1961) and treatment (Barton, 1959) ways and soon the movements of deinstitutionalisation appeared to begin the process of closing the lunatic asylums (Laing, Cooper, Basaglia), prisons (Cohen, Christie), borstals, orphanages, infirmaries and others.

Initiated in the USA deinstitutionalisation swayed to Western Europe and after 1990s across the world. Gradually it has become a universal policy and a global platform of change. This has been declared in a number of international documents, most notably in United Nations Convention on the Rights of Persons with Disabilities (Article 19).

The development was, however, uneven across the globe and was different in various types of institutions (for children, mental health, intellectual disabilities, old age homes). In Europe, the earliest efforts to enforce measures for deinstitutionalisation were seen in Italy and the United Kingdom, to some degree in Scandinavian countries while Central European countries (e.g. Germany and Austria, and also France) lagging behind. More recently, there has been a massive reduction in the number of institutions in countries such as Spain, Portugal and the Czech Republic, while other countries have only just begun the process (Directorate-General for Employment, Social Affairs and Equal Opportunities, 2009).

Deinstitutionalisation was most prominent in the fields of mental health and child care, little less so in the field of disabilities. In the field of old age care has been an issue in the deinstitutionalisation debate from the end of the war. Although institutional care has been down-sized considerably, it still prevails in some countries. Prisons were one of the central

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issues on the outset of deinstitutionalisation, now the discussion or, action to transform them is sparse.

Despite deinstitutionalisation having a long history spanning six decades, there are still many people interned in them. A conservative estimate would place the figure at around 2 million residents in the European Union alone (not counting prison inmates), with the real figure probably being substantially larger than this (Directorate-General for Employment, Social Affairs and Equal Opportunities, 2009). Further, there is evidence to suggest that there has been a re-emergence of institutionalised regimes in residential settings within the community.

The process of deinstitutionalisation usually starts on a local level and begins as an experimental pilot in some institutions. Usual progress is, optimally: from democratisation (or, at least an improvement in the quality) of life in institutions to the resettlement and closure of the facility towards establishment of community based services. As a result of these experiences deinstitutionalisation becomes a national policy. It requires both 'bottom-up' and 'top-down' action, i.e. work on the ground – on one hand and development of suitable legislation, policies and different funding instruments.

Basically, there are two models of deinstitutionalisation: *conversion* and *substitution*. In the first instance, the institution, its resources and staff are converted into community services, while the latter focuses on closing down institutions and establishing new alternative services as a substitute. The adoption of one policy over the other depends largely on the values of key players in a specific country or locality. It is more complex, administratively speaking, to begin with the democratisation process, although it is much more productive to do so because it helps to secure non-institutionalised regimes in the community.

The process of deinstitutionalisation usually consists of: democratising institutions by giving meaningful roles and activities to residents, by encouraging shared discussions and activities between professionals, residents and community representatives; increasing public awareness about what life inside the institutions is like and reducing the stigma attached to the people with disabilities, by highlighting their capabilities, reducing fears of them as potential disturbing people (killing our children, drug addicts on our streets, shabby in appearance, unpredictable); becoming *re*acquainted with the community (literally going out to see what has changed, revisit families); arranging life outside (having a bank account, furnishing of one's new place, choosing with whom to live, learning to live together dividing responsibilities and demarcate areas of freedom).

While these are the preconditions of resettling the resident and closing the institution it needs to be supported by (re)training staff, equipping them with new ways of working and changing their beliefs about the abilities of the people they are working with. Staff members also need to master personal care planning and care management, work on risk avoidance and on positive, calculated, risk taking, empowerment. Deinstitutionalisation also entails the creation of new services and the diversification of them to suit a variety of needs, including those of past, present and future residents. It also consists of raising awareness in the community and activating community resources, which should be done immediately prior to and after the release of residents from the institutions. To achieve this, a ban on new admissions and investments for existing institutions must be implemented. New ways of financing and commissioning the services have to be put into action, including direct funding of the service users. Meaningful activities for service users in the community are essential to

ensure that they will begin a successful new life, and for the community to become aware of what they can give, not only of what they need.

The cost of good community care seems to be the same or sometimes lower than institutional care. It is true that for those users who require a greater intensity of care, the cost could be somewhat higher, but on average this is not true; for many it is cheaper than the cost of an institutional place. Community care provides, in most cases, a better quality service and is generally more cost effective than institutional care (Mansell *et al.*, 2007).

There are a number of myths associated with deinstitutionalisation that are not true:

- Deinstitutionalisation has mostly failed
- It leads to abandonment and homelessness
- It is a neo-liberal invention designed to cut expenses
- Some residents will always need institutional care
- Community services will make the institutions automatically redundant and they will wither by themselves
- Awareness in the community must be raised before moving people from the institutions
- People need to be able to live independently (on their own) in order to leave the institution
- The ex-residents constitute a risk to the community or to themselves

These myths are usually associated with biological and psychological reductionist ideas of care. They are based on the belief, shared by many professionals in the community, that people with disabilities are an inferior group and unless we change this basic belief we will see the re-emergence of institutional regimes in community services (e.g. group homes in Slovenia).

On the other hand, there are imperatives that sponsor the process and the outcomes. The *no restraint* and *no closure* are two leading ideas that need to be recognised if deinstitutionalisation is to be achieved fully. Ethics of inclusion and non-abandonment are leading concepts, anti-disciplinary and anti-discriminatory positions are necessities of action, transversal and holistic approaches to care and inclusion are needed. The focus on implementing these in practice, rather than remaining at the lip service level, is the key.

The role of social work in deinstitutionalisation is an important one. Social work was invented as a profession in the time of abolition (deinstitutionalisation) of the work houses in the late nineteenth century. Its legacy is profoundly anti-institutional and it is about working in the community, basing the action on self-determination of the people and working on their own terms. Even when social workers were not instigators of the transformation of institutions there were important actors and facilitators in its implementation. Social work has paradigmatic advantages in working transversally, putting people first, working in the community, activating community resources and advocating for the users. Hence, deinstitutionalisation needs social work and social work needs deinstitutionalisation to fulfil the goals of the process and profession. It is social work which has created the strengths approach (Saleebey, 1992); an approach that both argues and implements in practice the belief that most people with disabilities have abilities and that these should be developed further, rather than continuing to focus on a deficit model of human beings which came to us from the medical model of human distress and disabilities.

*Contradictions and challenges*

Perhaps the biggest challenge is to bridge the gap between the declarative statements of the governments, leaders of the services, professionals and the situation on the ground. Even if deinstitutionalisation has become a universal and global policy there are many places where it has not been implemented. The challenge is to start the deinstitutionalisation process where it has not yet begun, support it where it has begun and restart it where it has stopped.

At present there are many countries (as a result of more pronounced European platform and policy), where the process of deinstitutionalisation is beginning. The challenge is to avoid the traps and pitfalls we are already aware of and to give the support needed for these fresh efforts. Internationally speaking, it is not only the divide between the East and West, North and South, as there are pockets of institutionalisation and re-institutionalisation Western Europe (France and Germany). Even in those countries where policies have been successfully implemented there are closed units, segregation, but above all institutional practices surviving in the community.

The processes of trans-institutionalisation and re-institutionalisation are likely to continue unless values are upheld in everyday practice. These are demonstrated when people from one kind institution (e.g. mental hospitals), after closure, find themselves in another institution (e.g. prison, old age home), or after initial deinstitutionalisation, people find themselves in an institutional setting again, because the process of deinstitutionalisation did not continue or has not been done thoroughly.

It seems that deinstitutionalisation, being a dynamic process, needs to have the momentum of a social movement, if it stops, it goes sour and starts turning in the opposite direction.

There are many reasons for arrest of the process – on diverse levels. At the macro level we are witnessing a 'mixed regime' of post-industrial society, while the containment of a population is not needed as much as it used to be, the capital now needs a free flowing work-force, yet, it seems that apartheid, segregation and control of a physical kind is still needed. We witnessed that some new deviant phenomena are not contained in closed spaces (e.g. AIDS), but the machinery (Foucault's dispositives) of closing and containing is used to prevent work-force overflow (e.g. detention centres for the 'aliens' and asylum seekers).

Some of the (legal) measures and financial arrangements imposed by deinstitutionalisation herald a different paradigm, not only for caring professions but for civilisation as a whole. The imperative of 'money following the user' directs money to the users and can be seen as re-appropriation of state/public alienated resources. The new logic of entitlement allocates the funding according to people's needs, not their merits. Opening the closed spaces articulates penal and civil responsibilities in an entirely new way. Reintegration of deviants rephrases the issue of (legal, civil) capacity and guardianship and reframes the professions, who traditionally assume a guardian stance of patronage into more advocate role giving users a voice of their own.

Paradigmatic shifts in methods used in post-institutional settings emphasise the person, her or his will, desire, ability, and enables the achievement of ambitions and desires to become a criterion of well-being and welfare. Deinstitutionalisation is a celebration of diversity of expression. It dis-closes, explores and praises not only the folly but all the idiosyncrasies people can invent, which were previously categorised by labels and put out-of-sight – into the bins. Thus it deconstructs the values created by exclusion of people, abstraction of their deeds

and puts them into the open to be re-valued and re-appraised. Classical rationalist values of sanity, reason, honesty, ownership, able-bodies, age and youth can be retranslated from categories of conduct into notions of communicative action (Flaker, 2014).

At process level there are a number of possible impasses. The most common one is the practice of *skimming and parking* – implying that either the more able, well behaved, residents of the institutions are either first to leave or worse, the only ones to leave. This logic is not only discriminatory (all people with disability regardless their impairment have the right to live with others in the community and can develop the ability to do so) but also highly impractical and anti-productive.

Another obstacle is maintaining parallel systems of provision. While necessary in the transition from institutional to community provision, some consider it as a permanent solution. Not only is it expensive financially, but it also subverts the logic of deinstitutionalisation itself. If the parallel system of community and institutional provision runs more than few years, it leads to re-institutionalisation, it transforms, what are to be alternatives to institutions, into their complementary, subsidiary services that support institutionalisation and does not replace it.

Likewise the process of metonymy of community provision can be a means of trans- and re-institutionalisation. While 'intermediary structures' like group homes, day centres are useful in the initial stages of resettlement since they provide a quick and efficient way of emptying the castles of power they can become a burden and an obstacle for the development of more capillary and diversified responses to people's distress. If those people using them do not move to more independent arrangements, with enhanced sovereignty, they will become new, although small institutions, burdened by dependence on staff, disciplinary logic and the like.

Yet another challenge lies in the domain of methods. Empowering methods using the users' perspective and strength perspective, providing person-centred care with professionals as advocates and allowing calculated risks to be taken and address life-issues transversally were developed and need to be developed fully. Yet, they are still competing with the disciplinary and demeaning ways professionals were trained for many years.

In order to achieve inclusion and empowering, two major targets of human rights have to be dealt with. One is implementation of *no restraint and closure*, the other is the *abolishing of guardianship and mental incapacity.* Practice has demonstrated that these are not necessary and can be substituted by productive support (Vallazza & Toresini, 2013).

The medication of social distress is one of the most important contradictions (not only in mental health) and the most obvious structure upheld by neo-liberal capitalism (though predating it). It is a reductionist and very expensive practice, with doubtful benefits to the users. Changing this system is a huge challenge. Though it was demonstrated that distress can better deal with other (non-chemical) methods, that deinstitutionalisation decreases use of medication, but the industry still holds a large segment of population hostage to its gains – supported by the popular 'pill culture' of 'instant cure' of all our problems.

Long-term care is also a major challenge. It is not only a necessary solution for growing needs and for continuous and organised care, but also an opportunity to introduce major innovations on diverse levels of action: new pillar of social security, entitlement logic based on people's need and wishes, integration of health and social care sectors, as well as the

formal and informal arrangements (relatives, peers, neighbours and friends) care, based on the personal approach and person's goals, direct funding, community actions (Flaker, 2011).

Unfortunately, a community within the deinstitutionalisation discourse refers more to the location rather than the people and their relations. The challenge is to invent new communities and recreate existing ones. The shift from an isolated space into community spaces enables the consideration of new forms of solidarity, new division of labour in caring for each other and is a prerequisite of inclusive and a socially cohesive society. More so, it can serve as a model for resolving other problems inherited from industrial society and to establish new ways of living together.

*Programme for the future*

Deinstitutionalisation is a transversal process cutting across diverse planes of existence. It is addressing abstract issues and schemes on cultural, economic, legal and ethical plateaux, changing the organising principles and operating schemes, introducing new form of services, organisations, producing new methods and procedures in order to make a person more sovereign in his or her life-world, in order to re-own the power to govern one's own life (Flaker, 2014).

The future of deinstitutionalisation platform should seek to:

Continue and strengthen the international efforts on the issue of deinstitutionalisation.

Create interregional networks of expertise, training and support for transition from institutional to community based practices.

Establish international and national monitoring of the rates of institutionalisation and deinstitutionalisation.

Abolish by law, restraint and detention in social and health care and in education in EU.

Promote practice of care that does not consist of any restraint and detention.

Abolish total legal incapacitation and substitute it with focused measures of restrictions with a vision of totally abolishing the institute of incapacity itself.

Create research and education capacities for the deinstitutionalisation and long-term care.

Abolish institutional hard-core– secure units, forensic hospitals.

Develop ways of working with groups of users that need the most care and support, and are hard to reach (multiple labels and disabilities, challenging behaviour, dementia…)

Strengthen advocacy function of the professionals and other carers

Promote holistic, contextual and empowering methods like recovery, person centred care planning, enabling risk taking, family conferences, open dialog, users led services, gentle teaching…

Use deinstitutionalisation as a means of inciting community action, community cohesiveness

Link to community initiatives in order to secure common responses to the users' needs together with responding to the needs of the community – by community organisations, associations, cooperatives, networks, neighbourhood actions, grass-root initiatives

Connect to the present day social movements – deinstitutionalisation being an important issue and tool for change of the society.

*Deinstitutionalisation never provides final solutions – there is always need for empowerment, inclusion, role valorisation, prevention of closing and restraining people in their basic human rights.*

*For these, deinstitutionalisation must provide an infinite number of solutions* ☺

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