Active solidarity and its discontents

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Abstract

1. Introduction

In the past many welfare states took care of the sick and disabled by putting them away in institutions: psychiatric hospitals, nursing homes, old folks homes, institutions for people with a mental retardation, special schools for children with severe learning disabilities. These days it is generally felt that this does not do justice to the target groups at issue. It is assumed that it would be much better to include them in mainstream society, to house them in ordinary neighborhoods, amidst ordinary neighbors, to let them go to ordinary schools, and to have them participate in local community life (soccer clubs, baseball leagues, orchestras, pubs and so on). The move toward deinstitutionalization and inclusion was initiated in the sixties and seventies by professionals and patients, notably in psychiatry and taken up by politicians who approved of the idea and/or wanted to cut back public expenses, since the abolishment or downscaling of large institutions and their (partial) replacement by community care was considered to be less expensive as well as morally right. For the disabled, the weak, the frail and fragile the new policy has been characterized as a paradigm shift from welfare “which compensates the disabled for their apparently
unavoidable exclusion from normal social life to the civil rights paradigm, which eschews compensation in favor of directly including them in that life.” (Ingram 2006:217). For healthy minded, able bodied citizens the new policy entails a change from passive to active solidarity. In the past they were asked to pay taxes, to enable the state to take care of the weak. In an era of inclusion fewer taxes are required. Instead the strong have to show active solidarity, by fraternizing with the weak, caring for the weak, helping them cope with daily life, accepting them as class mates, employees, colleagues, neighbors and so forth (Svallfors and Taylor-Gooby 2007; Newman and Tonkens 2011).

In this article I want to assess this policy change from a distributive justice perspective. Who stand to benefit and who will lose out in what way? I will first introduce the inclusion project (section 2). In section 3 I will discuss the consequences of inclusion policy for the targeted groups (the weak). In section 4 I will discuss the consequences for the strong; the pros and cons of active solidarity.1 In the final section I will balance the books on inclusion and active solidarity. Should we move forward or should we pause and reconsider our steps?

2. Deinstitutionalization and inclusion

Miek Smilde is the daughter of a retired mental hospital director. Her father’s hospital was built in the nineteen sixties. In 2009 the entire hospital was dismantled and the buildings were pulled down. Smilde was intrigued by the history of her father’s hospital and wrote a book about it (Smilde 2011). She talked to nurses and doctors, former colleagues of her father, to the present hospital staff and to patients who had spent weeks, months or years of their lives in the hospital. The book starts in the days
of *One Flew over the Cuckoo’s Nest*, the 1962 novel by Ken Kesey, made famous by the 1975 film starring Jack Nicholson as Randle McMurphy (a convicted criminal who seeks to avoid hard labor by applying for mental evaluation in a psychiatric ward, where he is subjected to the authoritarian rule of nurse Ratched). Smilde talked to former psychiatric patients some of whom had been no more than wayward, obnoxious, lovesick teenagers, somewhat addicted to alcohol or marihuana. In the early nineteen sixties they had been admitted to the mental hospital in Raalte (typically located in a desolate part of the country) and subsequently stayed there for years in a row. Some of them had been kept busy with activities such as creative therapy or garden work, receiving very little medical attention in the process. Smilde also visited recently diagnosed psychiatric patients. Present day patients are treated very differently. Effective medication (antipsychotic drugs) has made it possible for patients to lead a relatively normal life with occasional therapeutic consultations. Hospitalization is generally taken to be a negative side effect of long term therapy within the walls of an institution; hospitalized patients tend to lose the capacity to take charge of their lives and their daily routines (cf. also the seminal work by Goffman 1961). Thus short term, preferably ambulatory care has become the dominant form of therapy. Obviously not every patient can be cured; some psychiatric illnesses are chronic conditions. However, institutional care is considered bad, even for chronic patients; hence many of them are left to their own devices outside the mental hospital or provided with some sort of sheltered housing within towns or villages, in mainstream society.

The move toward deinstitutionalization in psychiatric care started in Italy and the United States and then spread rapidly to Western Europe (Raalte is a village in the
Netherlands) and the Antipodes. It did not just widen over the globe, it also spread to other parts of the health care sector. Deinstitutionalization was deemed to be good for people with a physical handicap or chronic disease, for people with a mental retardation, for frail elderly people and for people suffering from Alzheimer’s disease. If it were remotely feasible frail and fragile citizens should stay in or move to ordinary neighborhoods, where they could share in the hustle and bustle of ordinary life (Fakhoury and Priebe 2002; Pavolini and Ranci, 2008, Glendinning 2008; Plemper & Van Vliet 2003; Mechanic & Rochefort 1990). Similar arguments were made with regard to work. Before the days of deinstitutionalization people with physical and mental disabilities were put to work in sheltered workplaces. Following the deinstitutionalization wave, these people were thought to be better off in the regular labor market alongside able bodied, normally intelligent colleagues (Brussig and Knuth 2010; Melke 2010).

Similar arguments were also made with regard to children and youngsters. As much as possible children with a physical disability (e.g. blindness, deafness), a mental retardation (e.g. Down’s syndrome), a learning disability (e.g. dyslexia) or behavioral problems (e.g. ADHD, autism, Asperger syndrome) ought to go to regular schools along with regular classmates. Visiting ordinary schools, often with some extra tuition (or money to buy extra tuition) provided by the city council or the state, was taken to be a much better preparation for mainstream adult life than specialized training in school for special needs children (despite the added advantages of specialized schools such as smaller classes and specialized teachers) (Hodkinson 2010; House of Commons Education and Skills Committee 2006).
In many countries the move toward deinstitutionalization was actively supported or even initiated by the government and this seems logical. On the one hand deinstitutionalization opens up vistas of an inclusive society, which was an inspiring ideal. On the other hand deinstitutionalization might save a lot of tax payer money since long term care institutions and specialized schools are notoriously expensive. The policy of deinstitutionalization has been around for several decades now (the precise duration varies between countries and between health care sectors). It seems high time to assess the outcomes and effects of this policy in terms of distributive justice. In sections 3 and 4 I will discuss who stand to benefit from inclusion and deinstitutionalization and who will lose out.

3. The fate of the frail and fragile in times of deinstitutionalization

Lonely in the crowd

Let us start on the bright side. For some formerly institutionalized patients moving out was a blessing. People who did not know how to take care of themselves turned out to be cleverer than doctors and social workers had given them credit for (Widrick, Brambley and Frawley 1997). Sophia Wong discusses impressive transformations of groups of people who were categorized as seriously retarded, but who developed remarkable moral competences after having been included in mainstream society (Wong 2007). Sociologists Duyvendak and Verplanke studied the lives of people with a psychiatric illness and people with a mental retardation after deinstitutionalization. They observed that all of the former inmates were happy to have their own television set, their own bathroom and their own front door (Verplanke and Duyvendak 2010).
Educational experts studied the effects of different types of school regimes on children with learning disabilities. They conclude that many of them learn more when enrolled in regular schools along with ordinary classmates. Not just in terms of being able to cope with daily life in mainstream society, but also with regard to grammar and maths. Their grades are higher and they reach higher end levels (Jepma 2003; see however, House of Commons Education and Skills Committee 2006; they find the research results at this point inconclusive).

On the down side, however, loom serious disadvantages. A lot of formerly institutionalized patients do not manage to find regular employment or friends in mainstream society. For many of them the social worker, who visits them every day or twice a week depending on their condition, is their closest friend. Others tend to see their family – parents, siblings – often and yet others try to stay friends with other former residents whom they knew from when they were in the institution. Stories about blooming friendships or useful employment are scarce (Roulstone and Morgan 2009; Verplanke and Duyvendak 2010; Kwekkeboom 2001; Kwekkeboom and Van Weert 2008; Kwekkeboom 2004; Van Lange and Wajon 2007) In the Netherlands many former residents would like to go back to their old institution and find a place of their own over there (Rood 2008). But this is not always possible. The old institutions have been dismantled and there are waiting lists for former inmates with regrets (Trappenburg 2008). Parents of grown up children with mental deficiencies are worried about their children’s fate in mainstream society. People with a severe deficiency cannot be allowed to go out on their own when they live in an ordinary street with a lot of traffic passing by. They used to be freer in the institution in the woods, where they could go out on their own to play or walk around in the gardens or
the woods surrounding the institution. Many parents of grown up children with a mental deficiency see their sons and daughters more often than they used to when their children were institutionalized, but this is not always due to the fact that they now live nearby; sometimes it is sheer worry that makes them visit their children so often (Tabatabainia 2003). It is debatable whether the whole deinstitutionalization contributes to people’s independence if they come to rely much more on family members.

Similar worries have been reported by parents and family members of psychiatric patients who are left to their own devices and have to make do without the routines and discipline of the mental hospital. Parents fear that their sons and daughters will not look after themselves properly and may fall victim to drug dealers or other criminals. American authors have pointed out that deinstitutionalization in mental health care in the US went hand in hand with an increasing prison population, thus suggesting that these people have not been deinstitutionalized at all; rather they have been moved from one institution to another (Lamb & Bachrach 2001; Brown 1985; similar results were found in the Netherlands with regard to adolescents with intellectual disabilities; they are no longer institutionalized but end up in the criminal justice system instead, cf. Teeuwen 2012; cf. however, for a contrary view Okin 1995). People who would have been diagnosed with a psychiatric illness leading to forced institutionalization in the past now often deny that they are sick and in need of help. Sometimes they end up impoverished, homeless, living on the streets (Mechanic & Rochefort 1990:317). In notorious albeit exceptional cases they end up as murderers. In 2011 six people were killed and seventeen wounded in Alphen aan den Rijn (the Netherlands) by a 24-year old psychiatric patient. In 2012 fifteen year old
Ximena was stabbed to death in The Hague (the Netherlands) by 25 year old Stanley, a psychiatric patient who had been institutionalized after an earlier criminal offense, but had been released. Fragments of his diary were published on the Internet and indicated that he had had a good time in the institution but could not cope with the social intricacies of daily life (he suffered from Asperger syndrome) and was desperately seeking help (Ramesar 2012; on the other hand, a British inquiry into “avoidable deaths” by mental patients did not find a connection between homicides by mental patients and an increase in deinstitutionalization or community care (Appleby et al. 2006: 101)) An Australian study of crime rates among schizophrenic patients did find an increase of crimes after deinstitutionalization but researchers attribute this to a general rise in crime and do not think “turning back the clock on community care” would “contribute to any positive outcome” (Mullen et al. 2000).

It has also been found that a decrease of beds in psychiatric hospitals goes along with an increase in suicide rates (Yoon & Bruckner 2009). In terms of health and happiness, it seems fair to say that for the targeted groups deinstitutionalization has been a mixed blessing at best.

**Collective action problems**

In policy documents deinstitutionalization is often presented as a policy that gives patients a choice. A choice between living in the institution and moving to an ordinary neighbourhood. Or vice versa, for the frail elderly: a choice between staying at home and moving to an old people’s home. However, the choice element should not be overstated. Once an institution embarks on a policy of decentralization or deinstitutionalization, patients find that they have to go along. Or their parents find
that they no longer have a say in this matter, because their mentally deficient children
have been manipulated into choosing to live in mainstream society, without really
understanding what this would entail.\textsuperscript{2} And once ever more people are
deinstitutionalized, once ever more elderly choose to stay at home in their own
neighbourhood, choosing the institution becomes a different choice altogether.
Suppose you are a seventy-five year old widow. You try to make up your mind about
what to do after your husband’s death. Starting a new life in a nice home for the
elderly where you can play Scrabble, attend lectures and do some sports with other
old ladies does not seem like a bad idea. In fact you think it might be better in many
respects than staying in your home where the absence of your husband is tangible. But
then you learn that other seventy-five year olds choose to stay in the neighbourhood
and make do with home nursing as long as they can. This changes the odds for you. It
is less likely that you will find new companions in the old people’s home. The home
will probably be filled with ninety-something year olds who are deaf, blind, bed-
ridden or struck with Alzheimer’s disease. Or suppose you are a parent of an adult son
with a developmental disability. You know your son and you think he will be happiest
in a nice institution in a safe environment where he can make himself useful on the
institution’s terrain, where he can have friends who will not disrespect him and where
he can do politics at his own level in the institution’s client council. But then you are
told that at present mildly disabled adolescents are housed in ordinary
neighbourhoods supervised by their parents and an occasional social worker. Again
this changes the odds. Your son will not have as many friends in the institution,
because the other inmates will probably be more severely afflicted than he is. You
may reconsider your options and then ‘choose’ to house your son in an ordinary
neighbourhood and do much of the caring yourself after all.

Collective action problems interfere with many choice options in the public
sector. Individuals do not just base their own preferences regarding schooling or care
on quality information and subsequently choose an arrangement that suits their
preferences. In many cases they have to make an educated guess about other citizens’
choices and then adapt their preferences before making their own. Long term care is a
sector where collective action problems interfere with the free choice ideal.

*The frailest of the frail*

A related problem has to do with those who remain in the institution despite the
collective action phenomenon. Many institutions have been scaled down, but they
have not disappeared entirely. In Western countries there are still nursing homes for
people with advanced Alzheimer’s disease as well as institutions for people with very
serious developmental and physical disabilities. There are still mental hospitals too
and they care for “the most difficult, troubled and violent patients.” (Mechanic &
Rochefort 1990:313). Nursing staff in these institutions usually have a rather low paid
job. Many of them did not choose their profession for the money; they need their
work to be intrinsically rewarding. At present nurses often complain that their
workload has become much heavier, because all residents suffer from severe
conditions and need quite a lot of care. It seems plausible that this not only makes the
nurses’ job heavier, but also less rewarding, as many residents will be too sick to show
joy or gratitude. Nurses might respond in different ways to this situation. Some of
them will choose to do home nursing for healthier patients. Others may get depressed
or indifferent when they have to take care of ever more seriously afflicted patients. It is difficult to keep your moral compass straight if there are no clients around who are still able to question or criticize your behaviour. It is difficult to make life in an institution relatively joyful and fulfilling without mildly afflicted residents who can help you do that. And if life in the institution cannot be made agreeable, the residents who have no choice but to stay there will be worse off.

The same problem applies even more in schools for special needs children. If all mildly afflicted special needs children attend regular schools with a bit of cash for care tuition, only the most severely afflicted children will remain in specialized schools. While their former classmates are challenged by more intelligent ordinary children in their regular classroom the remaining special needs children will no longer be challenged by slightly better off class mates. The worst off probably lose most in the whole deinstitutionalization process.

4 Active solidarity

Before the days of deinstitutionalization the bargain for able bodied, healthy minded citizens was clear. They paid taxes and social premiums and in return the welfare state took care of the weak. The traditional welfare state was a two sided safety net. On the one hand it was reassuring to know that one would be taken care of in times of sickness or misfortune. On the other hand it was really comfortable to know that one did not have to take care of the weak oneself because this was seen to by the state (Krieg 2001; Lerman 1982; Schuyt 1998). The distribution of passive solidarity among the strong was usually skewed. Citizens who made a lot of money paid much more than people with a low income. This seemed to suit our intuitions about justice
and fairness; the ability-to-pay principle was a solid foundation on which to build a welfare state. The move toward deinstitutionalization has changed the bargain between citizens and the state. Deinstitutionalization requires active solidarity. Able bodied citizens will pay less taxes and premiums. Instead they are asked to help, care for and tolerate physically disabled, intellectually disabled or mentally ill patients in their midst. This raises at least three important issues with regard to social justice.

_Burdening the benevolent_

First of all, active solidarity is not a legal obligation. It is a moral call: help your neighbour! Do the groceries for the elderly lady down the block. Go take a walk with a psychiatric patient. Take this friendly, or moody and grumpy for that matter, person with an intellectual disability to your local soccer club. Pretend to like the old man in the flat and go talk to him once in a while. Or better still: make an effort to really like the old man in the flat and invite him over to your place every now and then. These are all moral calls for active solidarity. The problem with moral calls is that they are heard and answered by some and disregarded by others. And not in a random fashion, which would lead to Mr. A taking the person to the soccer club, Mrs. B visiting the old man in the flat and Mr. C doing the shopping for the elderly lady. Chances are that Mrs. B will hear and answer all calls whereas her equally able bodied neighbours tend to disregard them all. Stadelman-Steffen studied the effects of welfare state retrenchment on volunteering and neighbourly help. She concludes: “public welfare services cannot be retrenched and civil society will just ‘take over’; a stronger role of civil society may be at the expense of an increase in unequal participation.” (Stadelman-Steffen 2011:150). Handbooks or manuals for social
workers accept unequal participation as a given. If you want to build more community
feeling in a neighbourhood, the first tip for social workers is to identify the people
who are the pillars of the community. They will probably be willing to take on some
extra tasks thereby setting an example for everybody (Linders 2010). Though this
may be common sociological wisdom it is at the same time spectacularly unfair. What
you do is take advantage of kind hearted, good willing people while letting their lazy,
less altruistic citizens free ride on their efforts. A similar logic can be found if you
study the literature on the integration of developmentally disabled people in the labour
market. For a placement to be successful, one needs an employer who is dedicated
and motivated to give it a go. If the boss does not believe in the project, it is doomed
to fail from the beginning (Commissie Fundamentele herbezinning WSW 2009;
Inspectie Werk en inkomen 2007).

Research shows that people who are willing to help psychiatric patients are
people who have relatives with a psychiatric disorder. They have helped their son,
sibling or parent in the past and they can do the same for psychiatric patients in their
community (Kwekkeboom 2001; Giaglis, Michaillidou & Angelidis 2008). Again:
not illogical, but definitely unfair. Active solidarity burdens those who are burdened
already, who were burdened before, those who are used to burdens. Fellow citizens
whose yoke was always light are let off the hook very easily.

_Burdening the poor_

Chances are that active solidarity will burden the socioeconomically disadvantaged
more than their well to do fellow citizens. Usually people with a mental disability or a
psychiatric disorder are not rich and will not be able to make a lot of money. The
government is committed to welfare state retrenchment, so it will not be eager to spend a fortune on housing formerly institutionalized residents in ordinary neighbourhoods. Thus the new small scale housing may end up in the neighbourhoods of the less advantaged, leaving the rich and famous alone in their privileged neighbourhoods and villages. In 1985 sociologist Phil Brown investigated the outcomes of the policy of deinstitutionalization for psychiatric patients in the US. He observes that many people do not want to have psychiatric patients as neighbours, because this may decrease the value of their house. Brown dismisses this fear, because houses for psychiatric patients are usually located in run down areas to begin with, so the downward effect of a few special neighbours will be negligible (Brown 1985).

While passive solidarity was a moral obligation first and foremost for the rich, active solidarity seems to fall on the poor. This effect may even be strengthened by another piece of sociological wisdom, discovered by sociologist Lilian Linders, when she investigated life in a disadvantaged neighbourhood in the Netherlands. Linders found that needy people prefer to be helped by people who are a bit needy themselves, or only slightly better off. If you are sick and vulnerable you don’t want to be confronted by rich and fortunate neighbours who will obviously never need any help from you in return. Pure charity is extremely hard to swallow (Linders 2010). As plausible as this may seem, this is again a big disadvantage of active solidarity. Former big tax payers stand to benefit from this new policy.

The redistributive effects of active solidarity have also been documented with regard to education. Dutch researcher IJsbrand Jepma studied pupils with learning disabilities in different school classes. If you are a special need child in a classroom full of bright and very bright children you will probably be referred to specialized
education for special needs children. But if you have the same learning disability in a classroom where many pupils are less talented or slightly below average chances are that you may stay at the regular school. Again, as logical as this may seem, this means that below average pupils have to put up with children who are autistic or who suffer from behavioural disorders, whereas above average children (who are probably also blessed with highly educated high income parents) do not have to share their teacher’s attention with children with learning disabilities (Jepma 2003)

A similar effect took place at secondary schools in the Netherlands. The Dutch secondary school system consists of two parts. On the one hand there are selective schools who only allow pupils above a certain grade point average, comparable to grammar schools in the UK. On the other hand there are less selective schools, roughly comparable to regular comprehensives in England. When the special tracks for children with learning disabilities were integrated in the regular system they were not integrated in the grammar school half but in the bottom half of the school system. Again, active solidarity became a burden for the least advantaged pupils in the system. Their schools now suffer from a negative stigma which was caused at least partly by unruly pupils with behavioural disorders (Bronneman-Helmers 2008; Prick 2006). In the UK the House of Commons’ Education and Skills committee studied the number of children eligible for free school meals among special needs children. More than 25 percent of British special needs children have a lower socioeconomic background (compared to roughly 15 percent of all children and youngsters) (House of Commons Education and Skills Committee 2006: 88). We can safely assume that schools in poor neighbourhoods have more special needs children than schools in
wealthier areas. A policy of inclusion is therefore bound to affect the socioeconomically worst off much more than their well to do fellow citizens.

Hampering economic growth

Thirdly. The call for integration and active solidarity sits uneasily with societal developments and general government policy in many countries. The private sector in many regions of the globe faces ever harsher competition from a globalising economy. Companies have to make profits and keep their shareholders happy. Adopting social goals – employing workers with a chronic illness, a psychiatric illness or an intellectual disability – may be laudable but is often perceived as a luxury companies simply cannot afford (cf. e.g. Reich 2008). In the last decades the public sector in many countries has been restructured and reorganized to make it look much more like the private sector (Pollitt & Bouckaert 2004). The so-called New Public Management hype has introduced business principles in public organizations: target figures, profit margins, entrepreneurialism, and competitiveness. Public organizations have to be transparent about their performance; they have to measure their every move in performance indicators. The performance indicators serve as input for rankings of all sorts to be published in journals, weeklies and on the Internet. Whether or not this is a development to be cheered is not the issue in this article. What seems clear in this respect is that the focus on cheap and speedy service delivery does not seem to leave much room for investing large amounts of money in extra equipment, adaptations, individualized working schedules or coaching that may be necessary to give physically or intellectually disabled or chronically ill people a chance to succeed on the labour market.
Similar trade offs exist in the educational system. The UK House of Commons Committee that investigated the effects of inclusion at schools states that the presence of pupils with learning disabilities in class (especially pupils with behavioural disorders) hinders the learning process of other students (House of Commons Education and Skills Committee 2006). Giving the fact that educational output is deemed ever more important by many governments (a well-educated labour force is supposed to be an advantage in the global competition), this is a serious problem.

Yet another trade off accompanies the call for active solidarity in the neighbourhood. This call seems to be answered predominantly by women, who used to be carers and housekeepers in the past (Newman & Tonkens 2011). The more caring obligations and neighbourhood fraternizing women take upon themselves, the less time and effort may be spent on paid employment. This may go to the detriment of at least female productivity, but possibly also economic growth at large.

Inclusion and productivity or good results are incompatible, or at least clashing policy aims.

5 Social justice

Let us assume that this empirically grounded list of effects of deinstitutionalization is largely correct. Deinstitutionalization slightly enhances the health and happiness of the frail and fragile, but it is certainly not a definite improvement for all of them in every way. Deinstitutionalization cannot simply be presented as an extra option for the targeted groups because the move toward deinstitutionalization changes their menu for choice: the fact that the better off among the frail often choose to deinstitutionalize makes institutions less attractive. This effect weighs heavily on the
worst off among the fragile, who have no choice but to live in an institution. Their social environment will change for the worse. On the other side of the solidarity bargain, deinstitutionalization tends to burden the kind hearted who answer moral calls for active solidarity and the socioeconomically disadvantaged whose housing environment is less expensive and who may be perceived as more similar by the frail and fragile.

For social justice scholars imbued by Rawlsian thinking, this seems quite a challenge. Assuming that the target groups of deinstitutionalization can be classified as ‘the least advantaged’ in Rawlsian terms, is it fair to raise their level of well-being if this goes to the detriment of the slightly better off, the socioeconomically least advantaged? Or alternatively, assuming that those remaining in the institution, the frailest of the frail can be classified as the uttermost least advantaged, is it fair to lower their level of health and happiness on behalf of the slightly better off? In the days before deinstitutionalization care was distributed from each according to his ability to pay to each according to need. In times of deinstitutionalization care will arguably still be distributed according to need (although the presence of mentally ill patients wandering the streets may suggest that this is not always the case), but it will certainly not be organized according to ability to pay, but rather in accordance with a scale of kindness or altruism. The kinder your heart the more you will do. Is it fair to let the rich and selfish off the hook so easily?

I would be inclined to answer ‘no’ to all of the questions mentioned above. The policy turn toward deinstitutionalization is not a win-win operation (although it is often presented and perceived as such). If we want to continue the policy of active solidarity we should find a secure and fair way to involve the rich and selfish. We
might consider enrolling people in tours of caring duties akin to military service, although this would open up new cans of worms: how does it feel to be taken care of by fellow citizens who are forced to do so? Or we could offer tax rebates to citizens who voluntarily take up duties of active solidarity; but taking this option might be at odds with the policy goals of welfare state retrenchment i.e. lowering costs.

We might also consider to turn back to institutionalization, sadder and wiser. The psychiatric hospital that many of us remember from One Flew over the Cuckoo’s Nest or from the works of Erving Goffman was a terrifying institution to which we do not want to return. However, it may be possible to build different institutions, with more privacy and more autonomy for patients, and more sympathetic staff. Such new institutions might still be built in the woods, in the mountains or on the moors; it does not seem very likely that psychiatric patients, people with a mental disability or fragile elderly people would feel more comfortable in the hurly-burly of cities like Amsterdam, London or Paris, amidst big city traffic, and with drug dealers, prostitutes and junkies around them. It may be worthwhile to think about ways to build friendly institutions. Hans Becker is the head of a chain of elderly homes and nursing homes in the Netherlands. He has developed one new way of building such institutions with art on the walls, pets walking around, things to do, things to talk about and much less attention for safety and hygiene in the kitchen than required by the health inspection authorities (Becker 2003). Apparently elderly people who are chronically ill and have been weary of life for some time change their mind once they are admitted to one of Becker’s institutions, because life there is more fun than just waiting for death to finally fetch you in the privacy of your own home. For many fragile fellow citizens loneliness may be a worse problem than their sickness or disability. There may be
more ideas like Becker’s about institutional care. Back to institutionalization and passive solidarity would again enable us to burden the rich more than the lower income groups and it would hopefully improve the lot of the frailest of the frail by giving them more better off companions. A clear downside to taking this direction would be the negative stigma that weighs upon people who have been put away or locked up for their own good. Perhaps this might be remedied somewhat by reframing the policy of building institutions e.g. by referring to them as – in the famous terms of John Stuart Mill – experiments in living. ‘These people run a non profit cheese farm together with a little government help’ has quite a different ring to it than ‘These mentally deficient people are put away in the country for their own good.’ ‘The old folks in this large building try to help each other; the lame reading to the blind and the deaf doing groceries for the lame’ sounds much better than ‘These people need 24/7 supervision, hence we put them away in a nursing home’. The Mill metaphor should not be driven too far, of course. Mill’s experiments in living referred to competent adults running their lives in their own mode, whereas institutional care is organized for people who are not or no longer competent to shape their own life. Obviously we should not tolerate professionals and institutional managers to conduct dangerous experiments with vulnerable people without proper supervision from mainstream society.

At any rate it seems time to study the disadvantages of deinstitutionalization for the targeted groups. It is also time to evaluate the consequences of deinstitutionalization for society at large. It is time to assess the discontents of active solidarity. It may even be time to retrace our steps and reconsider institutionalization or, in better words, to advocate new experiments in living which happen to take place
within the walls of an institution. Deinstitutionalization is an idea that came up in the roaring sixties, along with permissive theories of child rearing, student democracy in universities, the use of cannabis and LSD, communal living, open relationships, no fault divorce and promiscuous sex. Many of these new ideas of the sixties were a reaction to repressive, authoritarian conventional social norms. One may think of men and women trapped in loveless marriages, authoritarian university professors who could play God in their own classroom and harsh disciplining techniques for children. The new ideas of the sixties set out to rectify these societal practices. However, with regard to most of these practices a partial reappraisal has taken place. For sure people should not be trapped in a marriage forever, but divorce is very cumbersome for children and should not be taken lightly. Children need love and freedom but they need rules and boundaries as well, hence child rearing should not become too permissive. And university professors should have some authority to maintain quality standards in education. Deinstitutionalization was possibly a useful antidote to the total institutions depicted by Goffman, but after several decades of community care we might revalue the pros of institutions and find out whether we can redesign them in such a way that they do not harm or hurt, but benefit the vulnerable groups who need them to live a full life.

Notes
1. In this article I shall refer to people with a chronic illness, a disability or a mental retardation as ‘the weak’, ‘the frail’, or ‘the frail and fragile’ and to the healthy minded, able bodied citizens who have to help them in one way or another as ‘the strong’. I am aware that this may be stigmatizing. I know that many people with a disability can be remarkably strong in other respects and that many able bodied citizens lack courage and perseverance. I hope the reader can forgive me. I intend to discuss the distribution of care obligations and that means that I have to distinguish between people receiving care and people who give care. Pointing out that everybody needs care during certain stages in life or that care giving can be very rewarding, although both very true, clouds the distributive issue. It is like talking about raising children. This is, most parents will readily say, the most rewarding experience life has to offer. But sometimes we must nevertheless discuss the distribution of caring obligations between fathers, mothers and the state and we cannot do that if we constantly have to mince our words because
otherwise we get reminded that children are the best thing that ever happened to us. If we are only allowed to talk in terms of ‘our bundles of joy’ the social justice issue will elude us.

2. A recurring pattern in research on deinstitutionalization is that parents disapprove of the whole idea. Usually the plans are carried out regardless and after a while parents tend to come around and see the move in a more positive light. This pattern makes hospital directors and policy makers dismiss the initial resistance as cold feet. Cf. Tossebro 1998.

3. On a more general note Shelley Burtt observes that “people become advocates of robust inclusion not from an abstract impulse of benevolence or compassion or justice, but from an experience of relatedness to individuals with disabilities.” Burtt 2007.

References


