To lean on the fragile

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Once upon a time, in a not too distant past, many of us lived in traditional welfare states. Reading the country reports I realized that the story I will tell you applies to the Netherlands, the UK and Scandinavian countries, although elements in it may also look familiar to people from other countries. So when I use the word 'we', please bear that in mind. Once upon a time, in a not too distant past, many of us lived in traditional welfare states. We paid taxes and social premiums and our government tried to spend the money wisely. A large part of the money was spent on the weak.

Elderly citizens were given a government pension so they would no longer have to work. Elderly citizens who needed care and company, moved to old people's homes, largely financed by the state. Once they were really old and sick they could move to a nearby nursing home department.

Sick people were taken care of in hospitals where they resided for weeks or even months until they were fully recovered.

Psychiatric patients were transferred to specialized hospitals, usually located somewhere in the mountains, or if your country happened to be as flat as the Netherlands, in the woods or the dunes, near the sea side.

Mentally handicapped children and adults were housed in similar parts of the country.

Children with learning disabilities attended special schools, where specially trained teachers taught them in groups much smaller than the average primary school class of thirty something pupils.

People who were not able to work, due to whatever condition, were granted a disability allowance. Or they were put to work in special workplaces under close

supervision, where they could work in their own pace to the best of their limited abilities.

The traditional welfare state was based on passive solidarity. Able bodied citizens paid taxes, usually according to some progressive taxation logic. 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.

And then things started to get out of hand. For two totally different but coinciding reasons, far too many people were classified as weak and fragile.

1. Due to the economic crisis of the nineteen seventies and nineteen eighties many people lost their jobs. Some of them received an unemployment allowance but many were redirected in different directions. Elderly workers were offered an early retirement exit route, widely used in many European countries. Many others were awarded a disability allowance which usually had two advantages: the allowance was often higher than unemployment benefits and the former worker no longer had to apply for a new job, an exemption clause that seemed to make sense in the nineteen eighties as there were very few vacancies to begin with.

2. The world health organization launched a new definition of health, describing health as "a state of complete physical, mental and social well-being" not merely "the absence of disease or infirmity." As this definition gained more prominence both among doctors and among lay people, more and more people could argue that they were unhealthy in one way or another. Sadness and grief turned into depression, for which one might justly seek psychiatric counselling. Workers who were laid off on a disability allowance were not just grasping the most convenient way to survive unemployment, they were actually suffering from work related diseases, such as lower back pain, burn out or stress related disorders. Children who would have been classified as shy, slow, troublesome or stupid in the past now suffered from conditions officially recognized in the Diagnostic and Statistical Manual of Mental Disorders. An ever growing number of people were classified as mentally deficient,

physically or mentally challenged, sick or disabled. An ever growing number of children were categorized as special needs children, requiring special care in special schools.

Somewhere in the nineteen eighties many welfare state governments (again: I am talking about the Netherlands, the UK and Scandinavian countries) thought that their their able bodied, tax paying citizens would not be willing and able to pay for so many frail, fragile and elderly citizens.
Hence many governments embarked on a project of welfare state retrenchment. Allowances were cut back and eligibility criteria were tightened. But since this is not a very inspiring message to deliver many governments simultaneously launched another project. This project was called deinstitutionalization and active solidarity. In this lecture I want to take a closer look at this particular project and discuss the pros and cons.

The ideology of the new project went roughly like this. In the past decades we, as a society, have shown little true tolerance of deficiencies and disabilities. Persons with physical or mental disabilities were put away in large institutions in the woods, where we would not have to see them, apart from occasional outings to the zoo or the swimming pool. The elderly were likewise set apart rather than living amongst us. Our children did not have to share their classroom and their teacher with special needs children. This whole set up has caused lots and lots of missed opportunities. Missed opportunities for the weak and the fragile, the psychiatric patients, the people with mental disabilities who might have led a relatively normal life, had they not been put away in the forest. Missed opportunities for us, who might have learned to be more patient, friendlier, more grateful or more tolerant if we had laid eyes on our weak and fragile fellow citizens more often. Missed opportunities for our children who would have learned to be more tolerant toward different people if they had met with special needs children in their nursery, their primary and their secondary school. Having weak and fragile citizens in our midst would have appealed to our better nature. We would have been asked – implicitly or explicitly – to help them rather than just pay taxes and be done with it.

Fortunately, we can mend our ways. We can dismantle the large institutions in the woods, we can invite the weak and fragile to live in our midst, to be our colleagues in the shops, the factories and the offices where we work. To be our fellow pupils and students at school. To be our friends at the local soccer club, or the bird watching society. To be our next door neighbour in the street. Let us start immediately.

Such was the conviction of politicians and policy makers at some point in the nineteen eighties or nineties and then they set out to implement their plans. Large psychiatric hospitals were dismantled. Large institutions for people with mental deficiencies were scaled down. The frail elderly could apply for home nursing or home help, using a cash-for-care budget. Workers in sheltered workplaces were asked to apply for jobs on the regular labour market. Special needs children were given a personal budget which would allow them or their parents to buy some personal tuition while they were attending regular schools. In the Netherlands secondary education for special needs children suffering from learning disorders or behavioural disorders was rearranged as part of a large general reorganization of secondary schools. Henceforth classes for special needs children were included in regular comprehensives.

For those of us who are not frail, fragile or especially needy this policy means a change from passive solidarity to active solidarity. We don't have to pay as much taxes and premiums as before, but we are asked to be good Samaritans instead.

In the UK, the Netherlands and Scandinavia this policy has been around for quite some time now, so it is time to evaluate the results.

Let us first have a look at the effects of the policy change on people who used to be institutionalized: psychiatric patients, people with mental disabilities, the frail elderly, special needs children.

On the plus side.

1 Research in Amsterdam has shown that most people enjoy having privacy: not just a room of their own but a flat or apartment, or even a house of their own, where you

can choose what to watch on the television without having to consult with other inmates.

2 Research also indicates that many special needs children learn more when they attend regular schools, along with ordinary class mates. Not just in terms of being able to cope with ordinary life, but also with regard to grammar and maths. Their grades are higher and they reach higher end levels.

On the down side.
1 Many 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. In the Netherlands many former residents would like to go back to their old institution and find a place of their own over there. But this is not always possible. The old institutions have been dismantled and there are waiting lists for former inmates with regrets. Parents of grown up children with mental deficiencies are very 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. 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 are worried that their sons and

daughters will not look after themselves properly and may fall victim to drug dealers or other criminals.

2 The policy of deinstitutionalization started out as a policy that was to give 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 has become smaller and smaller over the years. 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. 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. If I were a seventy-five year old widow, I would rather not stay in my regular neighbourhood, where all my neighbours would be at work during the day, and where I would miss my deceased husband every time I looked into my once well tended but now decrepit garden. I would prefer to start a new life in a nice home for the elderly where I could play scrabble, attend lectures, do some sports with other old women and start a debating society. But if my fellow seventy-five year olds would all decide to stay in the neighbourhood and make do with home nursing as long as they could, I would not find any new companions in the old people's home. The home would probably be filled with ninety-something year olds who were deaf, blind, bed-ridden and or struck with Alzheimer's disease.
Likewise if my son would suffer from a mental disability I might want to find him a nice institution in a safe environment where he could make himself useful on the institution's terrain, where he would have friends who would not disrespect him and where he could do politics at his own level in the institution's client council. But if all other mildly retarded adolescents would be housed in ordinary neighbourhoods supervised by their parents and an occasional social worker, my son would not find friends in the institution. Hence I would have to choose to look after him myself, or he would be institutionalized with people in a much worse condition.

There are huge collective action problems involved that make a mockery of the free choice ideal in long term care.

3 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 the Netherlands, the UK, and in Scandinavian countries there are still nursing homes for people with advanced Alzheimer's, and institutions for people with very serious mental and physical disabilities. Nursing staff in the institutions 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 the better off 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 can't be made agreeable, the patients who have 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.

Now let's move to the other part of the equation. What does the move from passive to active solidarity mean for the able bodied, healthy citizens? On the plus side we may say that the idea of inclusion and deinstitutionalization is very appealing. Right wing oriented citizens will like the idea that their fellow citizens do not just get a

welfare check without having to do anything in return. In the inclusion regime everybody has to contribute according to his or her abilities however limited. Left wing oriented citizens tend to appreciate the idea of an inclusive society in which people are welcome despite their disabilities.

On the down side, however, the move from passive to active solidarity comes with risks and disadvantages. The one big advantage of passive solidarity was that it concurred with our intuitions regarding a fair distribution of burdens. Big money makers paid a lot of taxes, while people with a modest income paid much less. Active solidarity is not at all like that.

1 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 a mental deficiency 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. If you don't believe me, try reading handbooks or manuals for social workers. If you want to build more community feeling in a neighbourhood, first tip 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. 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 mentally 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.
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. 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.

2 Second. Chances are that active solidarity will burden the socioeconomically disadvantaged more than their well to do fellow citizens. Here's how. 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 entrenchment, so it will not be eager to spend a fortune on housing formerly insitutionalized 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. This effect may even be strengthened by another piece of sociological wisdom, found by 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. As plausible as this may seem, this is again a big disadvantage of active solidarity. Former big tax payers stand to benefit way too much 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.
A similar effect took place at secondary schools in the Netherlands. Our 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, probably comparable to grammar schools in the UK. On the other hand there are less selective schools, roughly comparable to the 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.

3. Thirdly the call for integration and active solidarity sits uneasily with the general government policy. We are used to be admonished to be ever more competitive, to work hard, to go the extra mile, to make an effort, to improve our school results. These are laudable aims but they do not seem to match very easily with a call for tolerance toward less productive colleagues who suffer from mental deficiencies, chronic illnesses or psychiatric disorders. The call for active solidarity in the neighbourhood likewise seems to contradict the call for economic productivity, especially for women, who – as all of the country reports show – are the ones who still take on most of the caring work.
Inclusion and productivity or good results are clashing policy aims. One of my master students did a comparative research on schools in Flanders and in the Netherlands. Children in Flanders are better in grammar and maths at age twelve. We assumed this was caused by the school system rather than by, say, the innate intelligence of our southern neighbours. Steenman looked at a lot variables and found only two that were statistically significant. The government in Flanders spends more money on education, which leads to smaller classes and children in Flanders are more often

referred to special needs schools, which enables the teachers in ordinary schools to keep order more easily.

I conclude. The policy turn toward deinstitutionalization and active solidarity is a political choice, with pros and cons, like every other political choice. It is not a win win operation. I think we need to look more closely at the disadvantages of deinstitutionalization. If deinstitutionalization means redistributing the burden of care for the fragile to the slightly less fragile on the one hand and to the most altruistic amongst us on the other, that seems a serious problem. If we want to continue the policy of active solidarity we should find a way to involve the rich and selfish, because it seems wrong to let them off the hook this easily. But perhaps we need not necessarily go forward on the route toward further deinstitutionalization. Perhaps there is something to be said for a place in the forest or the mountains after all. Of course the psychiatric hospital that we all remember from *One Flew over the Cuckoo's Nest* was a terrifying institution to which we don't want to return. But it may be possible to build different institutions, with more privacy for patients and more sympathetic staff. Such a new institution might still be built in the woods, in the mountains or on the moors; it doesn't seem very likely that psychiatric patients would feel more comfortable in the hurly-burly of cities like Amsterdam, with drug dealers, prostitutes and junkies around them.
Henk Becker is the head of a chain of elderly homes and nursing homes in the Netherlands. He has developed a whole 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. Apparently elderly people who are chronically ill and have been thinking about euthanasia for some time change their mind once they are admitted to one of Becker's institutions, because life there is much more fun than just waiting for death to finally fetch you in the privacy of your own home. It may be worthwhile to develop more ideas like Becker's about institutional care. For many fragile fellow citizens loneliness may be a worse problem than their sickness or disability. People have a need for privacy and autonomy but they are not meant to live alone.