

A NEW AND BETTER LIFE

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I HAVE BEEN ASKED BY BIZCHUT to make a professional assessment of the content of the current petition – on how to create a better life for people with severe intellectual disabilities and substantial physical disabilities.

For me it is not only a human right for all people to have the chance to grow up and be able to live in the same society as everyone else. It is also an opportunity – the knowledge we have gained through research and experiences shows that it works extremely well – if we want it to! It just becomes much clearer that it is the rest of us who should provide the right conditions for making this a reality. It is not only possible, but also necessary, as we know that there are only benefits to be gained – for the person him/herself, for their family, for the staff and for society as a whole.

I have worked within Swedish care of the disabled for more than 30 years. I am a licensed psychologist and worked as a clinical psychologist for over ten years before coming to the Swedish National Board of Health and Welfare in 1986. There I have worked on, amongst other things, the phasing out of nursing homes and special hospitals in Sweden. I wrote a General Advice that prescribes the forms for how the country councils should phase out these institutions. I have also taken part in various research projects and contributed to the phasing out of a large nursing home in Stockholm. In 1995 I was appointed head of the Government enquiry into the Swedish Disability Reform. In 1997 I led the Government's evaluation of mental health care reform. In 2001 I was appointed to a managerial post at the National Board of Health and Welfare and made responsible for the public authority's work with the disabled, a post I still hold. This means that I am one of the highest ranking government officers in this field. I also have a functional disability.

In May 2000, I was in a major accident in Hawaii – I broke my back and am now completely paralysed from the chest down and sit in a wheelchair. I have written three books, one of which describes my own experiences as a person with a severe functional disability. I am often asked to give lectures. My own experiences, as functionally disabled, as professional psychologist and as a high-ranking government official give me a unique competence.

It is on the basis of this knowledge and these experiences that I am expressing my opinion as to what living conditions should be offered to people with intellectual and functional disabilities and what we know to be most effective.

A normal life for people with intellectual disabilities and extensive physical disabilities is a human right. EVERYONE can live in our society if WE make it possible.

A SMALL GROUP IN A NORMAL INTEGRATED ACCOMMODATION MEANS THAT:

... emotional development improves and it is easier to develop better communication and interplay.

- There is a great need for a family-like environment
- There is a need for an environment and accommodation that is easy to comprehend
- The person's own needs become clear
- The individual's self-determination is reinforced
- The need for a social network can be realised
- Participation in society is made easier with a small group.
- The relationship to family is deepened

...we gain a society where people with functional disabilities are a presence in everyone's life and meetings occur in different places.

- Increased participation in society leads to more meetings
- Social contacts increase
- This leads to more positive attitudes and values
- It also leads to more reasonable expectations and better knowledge

INSTITUTIONS IN SWEDEN were established during a period when the aim was first to protect the intellectually disabled person from their surroundings and then to protect the outside world from the intellectually disabled person. During the post-war period institutions were built with the hope that these, with their expert resources would help the individual in his or her development and later move out from the institution. But we know that once institutions were established and recognized as a way of life for people with disabilities, it has been extremely difficult to move on to alternative accommodation. What I describe in this text is the development in Sweden towards all people with intellectual disabilities having moved out from institutions and the experiences from this process.

*The people I am speaking about are those who have had the **most extensive functional disabilities of all**, often several at once. These are people who often have functional disabilities in addition to their intellectual disabilities; they are blind and deaf, with speech difficulties, with autism or other additional psychiatric handicaps. Many of them had severe behavioural problems, such as self-destructiveness and aggression. Those with the most extreme functional disabilities had lived in five different special hospitals with around 300-500 beds. Many of them had lived in around 20 large central nursing homes in each county council, homes with 100-300 beds. The others had lived in around 200 smaller nursing homes with around 20-100 beds.*

Institutions have thus been built up for different reasons but with the always unavoidable consequence that the person with a severe intellectual disability has become even more isolated. There is sufficient social and psychological research showing that persons with intellectual disabilities do not need to live in the kind of environment offered by an institution. No matter how severe their disability. And not only that – living in normal accommodation in society leads to an increased degree of independence and personal development and to better conditions for all involved. People's prejudices change and in the long term it is more beneficial for society, given the much improved quality of the care.

Essentially, there are two main principles behind the developments in Sweden – the so-called **Normalisation principles** and **The small group principle**. These two describe the fundamental needs that apply to all of us – to have an everyday life where I can be seen, can develop, can feel secure, develop relationships and have my personal needs met – i.e. the principle of being able to grow up and develop like everyone else.

The overriding principle is that all children, young people and adults with intellectual disabilities should have access to the daily patterns and living conditions that are as close to the normal social patterns and the living conditions that apply to all those without functional disabilities. This applies to everyone and perhaps primarily to those with severe functional disabilities. Living like other people brings a normal daily rhythm – when one gets up, goes to one's day program, has free time and then goes to bed. The more normal daily rhythm leads to a more normal weekly rhythm with the possibility of taking part in various activities. Similarly, it facilitates contacts with parents, relatives and friends. One example is how an integrated own apartment enables a visitor to stay overnight, something that is quite unthinkable in most institutions.

The other main principle – a practical consequence of the normalisation principle - is to endeavour to achieve **smaller groups**. As both research and experiences have given us new knowledge of what significance personal relationships have for the intellectually disabled person's wellbeing and development, the size of the group has come into focus. For each reduction in the size of the group, new sides are discovered to the people with intellectual disabilities, even those with severe disabilities. Individuals who were previously considered to be quiet, passive and depressed have

become more open and active when the world around them became easier to understand, thanks to fewer people. The more severe the functional disability, the most important it is that the size of the group is kept down; this has been proved in research.

*What kind of alternative accommodation am I talking about? Most of those who have moved out from the institutions have **moved into group housing**. Not all of them, but some of them live in apartments of their own with a staff of their own who work as their personal assistants. Group housing can be in multi-family dwellings, in terraced houses or in detached houses in ordinary residential areas. In most cases, 4-5 persons live together, each with an apartment of their own. Persons with intellectual disabilities can receive support from 5, 10 or up to 15 staff members who rotate on a schedule - all depending on how much support they need, including night-time care.*

A DAY-TO-DAY LIFE WITH FEW PERSONS IN IT HAS CONSIDERABLE BENEFITS

Not only the experiences of the institutions that have been closed down, but also research shows unequivocally that there are considerable benefits in living in a small group, for the individual him or herself, for their family, and for society as a whole.

WHY IS IT BENEFICIAL FOR PERSONS WITH INTELLECTUAL DISABILITIES to live in a small group and preferably in normal, integrated accommodation? Both social and psychological research and many years of experience show how important it is that the group is small. Research has shown in particular that for persons with severe intellectual disabilities and with multiple problems, such as psychological problems or communication difficulties, a smaller group is an absolute necessity. The most important thing with a small group is that day-to-day life becomes more manageable and gains context for the individual. It is worth mentioning that the same positive effects can be noted for the staff.

The limitations in the capacity of people with intellectual disabilities to communicate and predict reactions require a small number of persons. Research and experiences show that the optimal number is around four persons. A small group also means that the physical accommodation is smaller and more easily melts into its surroundings. In a small group the conflicts and care routines are fewer and the participation in society is greater. The staff resources can be more efficiently adapted to the needs of the individual, which reduces costs. It is not only the number of persons with intellectual disabilities that is important in this context; the number of staff is also important. If the number of persons with disabilities living together increases, then the number of staff also increases.

In large groups, individual problems are not picked up as quickly and the contact between the persons becomes increasingly anonymous. When the staff group becomes too large, this also has consequences for the content of their work.

There are three main reasons behind the aim of reducing institutional living and increasing the possibilities for persons with intellectual disabilities to live in small, integrated housing. The social and psychological research confirms and forms a basis for these theories as do experiences gained in Sweden.

- **The person with an intellectual disability shows better emotional and physical development.** Communication and interplay with other people is facilitated and deepened.
- **Institutional routines are prevented.**
- **Other people's meetings with the persons with intellectual disabilities are normalised and lead to an improvement in attitudes and treatment,** making it easier for the persons with disabilities to take part in a meaningful way society.

① A SMALLER GROUP gives better emotional and physical development, as well as better communications and interplay.

There is substantial research into the psychological and social effects of living in an institution, and the difference between small integrated housing and institutions – even small ones. Being involuntarily separated from parents, friends and the familiar home environment creates a fundamental conviction of being undesired and powerless and the separation has undesirable effects in many areas. Some of the aspects of living in large groups are described below.

The most important aspect is that large groups make *emotional personal development* more difficult, with regard to how this is expressed in terms of feelings and relations with other people. The development of a normal emotional life is complicated by an indigent and often single-sex environment, high staff turnover, a lack of private life, of self-determination and of personal integrity. The emotional immaturity leads to a delayed and incomplete development of identity. Children and young people may develop different forms of self-stimulation, sometimes in the form of self-destruction. Adults may show varying psychiatric symptoms, with depression being the most common, although these may be of a different nature than those shown by persons without disabilities.

In particular persons with severe handicaps are often at a premature stage of development. The need for *family-like surroundings* with considerable closeness, continuity, trust and so on is much greater and is necessary for a positive personal development. The more people living together, the more often there are separations. The importance of being able to develop in interplay with *a few* close persons is shown in the psychodynamically-oriented research and in research into emotional attachments. To summarise, the research shows that emotional and cognitive development is made much more difficult if there are not a few persons that one can relate to on a deeper level over a longer period of time.

A small group *replaces the family* that most adult persons with intellectual disabilities cannot form. Internally the small group therefore satisfies strong psychological needs. *Externally* most people need a broad social network in order to make friends, enjoy their spare time and have a social life, that is, to satisfy different social needs. Communication has a clearer social function in smaller groups, which is important for the individual. In small groups both social ability and communication skills increase, which leads to more and more lasting social contacts.

The intellectual handicap in itself leads to difficulties in interpreting and organising numerous impressions and therefore requires structure and continuity. *The surroundings and living environment must be easily intelligible* and make it easier for the individual to be able to communicate. A large group has a negative effect on these factors. Studies show how the staff's communication with persons with disabilities in a large group often taken on a collective, controlling and instructive content, while communications in a smaller group become more individual and more discussion- and needs-oriented.

The needs of the persons with disabilities become clearer and the staff have greater opportunity to meet these needs on a more personal level in a small group than is possible in a large group. This is particularly important for persons with intellectual disabilities who have difficulty in communicating. Research has shown that in smaller groups initiatives to various activities are more often taken by the group members themselves, while in larger groups the decisions are taken by the staff and the individual becomes passive.

Similar results can be seen with regard to *the individual's self-determination*, which is one of the most important elements for a good life. Both research and experiences have clearly shown how undeveloped the individual's influence often is in larger groups and how much remains to be improved within this area. However, a small group is often a necessary condition for making progress here.

It is also the case that *family relationships* are affected by the size of the group. The contacts with family increase when the group is smaller; this has been shown in research. It is always a strain for family members if there are a large number of persons with disabilities in the group as it is difficult to obtain calm and privacy during visits.

② A SMALL GROUP means that institutional routines are prevented

Large groups lead to collective routines quickly developing – for instance, to simplify the routines regarding hygiene, cooking, birthdays and leisure activities. It becomes necessary to organise the work in a more formal manner when the group is larger and it becomes difficult to take individuals into consideration when everyone often has to do the same thing for the group to function. In a smaller group this all changes! A small group *prevents the accommodation from becoming an institution*.

③ INTEGRATED, SMALLER ACCOMMODATION provides greater participation in society, which means that attitudes can improve.

The persons with disabilities' *participation in society is made easier by smaller residential groups*. If one lives in society together with several persons with the same functional disability, there are obvious risks of being labelled. One is seen as a homogenous group and not as individuals. The surrounding world sees the person as more different than would otherwise be the case with a smaller number of people, where each one can be regarded as an individual with their own personality, interests, etc. The persons themselves may also feel stigmatised as different if they live with many other persons with the same functional disabilities.

Changed attitudes – Increased contacts and meetings in day-to-day life mean that people in general can better understand what a functional disability – even a severe disability – means in practice. *Improved relations* are often one effect of living in smaller, integrated accommodation. Studies have shown that many persons with intellectual disabilities have a large capacity to make friendships and exchange greetings with other people. One example of improved relations is *contacts with neighbours*. The problems that initially arose with neighbours no longer occur in the same way. The negative reactions often disappeared after the persons had moved in to the neighbourhood. In many cases there were positive relations built up instead.

At the same time, we should not hide the fact that problems can sometimes arise. It is sometimes *hard work for the staff*. In a nursing home it did not matter if someone screamed loudly or sat down in the street. But out in society there are other eyes watching and it may be difficult for the staff when people around them think they are acting too brusquely or too passively.

SWEDEN HAS PHASED OUT ALL OF ITS INSTITUTIONS

In Sweden, all nursing homes for persons with intellectual disabilities and substantial functional disabilities have been closed down. Integrated accommodation, day-care activities and personal support have been extended over a twenty-year period as an alternative to institutional care.

IN SWEDEN, ALL INSTITUTIONS HAVE BEEN PHASED OUT. At the highest peak of institutionalization, Sweden had around 5 000 children and young people, and 12 000 adults in institutions. In most cases, these were people with intellectual disabilities and extensive needs. Many also had additional handicaps in the form of functional disabilities, psychological illnesses, impaired vision, impaired hearing, and so on.

Today 19 000 adults with intellectual disabilities live in small, integrated group accommodation. This development took place during approximately 20 years, from 1975 to 1995. Almost all children with intellectual disabilities below school age now grow up in their own family. We have gained a completely new generation of children with functional disabilities, more emotionally mature and aware, and a new generation of parents, who understand their children's needs and society's obligations. Only 1 400 children and young people live in small, integrated school boarding houses and a few hundred in foster homes.

In 1985 the Riksdag (Sweden's Parliament) decided that all nursing homes should be closed down and a prohibition on registering new clients was written into the act. This was a dramatic, but well-founded decision supported by research and by several important public authorities. There was financial assistance for extending the integrated accommodation alternative. Finally, persons with intellectual disabilities – including those with the most extensive needs, could live like other citizens!

How has it worked out? There have been some protests – understandably from *the staff* that were afraid of losing their jobs. When they discovered that they had the opportunity to work in the new group accommodation for adults or in the smaller school boarding houses for children, the protests soon disappeared. At first, there was also an understandable concern from many *parents* who were sceptical, but they soon changed their minds too, as they gradually saw how the alternative accommodation functioned and that there were at least as many members of staff in them. The loneliness that many people feared was not realised, and nor did the accidents occur, or problems with traffic, drugs and loneliness that many were concerned over.

A large number of studies have been made regarding the actual moving out from the institutions and living in group accommodation for adults and the results confirm the enormous value of the reform, not only for individuals, but also for their families and the staff. And please note that *those with the most severe functional disabilities showed the largest relative improvements*. In the follow-up studies, the number of satisfied families was around 80 per cent. What they most appreciated, apart from the fact that they could see that their child generally had a much better life, was that their

family member had his or her own apartment, telephone, privacy during visits, with the possibility to cook and the chance to meet spontaneously. In many cases there were reactions from neighbours when they heard that persons with intellectual disabilities were going to move in. However, these negative reactions often disappeared after they had moved in, and in many cases positive relations were built up with the group accommodation instead.

It is the persons with intellectual disabilities who have the most extensive needs and the most additional handicaps who experience the greatest benefits in moving to a small group in group accommodation integrated in society!

THEREFORE IT IS MY CONCLUSION that the living setting in the community (rather than in an institution), that the petitioners in the Bizchut petition request, is in line with processes that have already taken place successfully in Sweden regarding people like the petitioners (people with intellectual and physical disabilities and extensive functional disabilities). The gain for these individuals by living in the community over living in an institution, is, and has been proven, on every front: The physical and emotional development of the individual is far enhanced, communication and interplay with other people is facilitated and deepened, the individual's self determination is reinforced and real participation in society is made possible – in other words these individuals gain A NEW AND BETTER LIFE!