

# Outside the System: Life Patterns of Young Adults with Intellectual Disabilities

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**ABSTRACT** *This article reflects some potential possibilities and risks that have been created during the changes in disability policies and general social welfare systems in Sweden over the last year. New ways of life have developed among young people with intellectual disabilities. The paper is based on data from semi-structured interviews with people, who through their profession have wide contact with this group, and from participating observations and interviews with 23 young persons with intellectual disabilities, aged 19–30 years. Three main categories of young people may be distinguished in these subjects: the “cared for and represented”; the “commuters”; and the “outsiders”. For each of these groups, life patterns and contact with service providers will be described and analysed, and strategies and consequences discussed.*

Until fairly recently groups of people with intellectual disabilities lived in a world regulated by the welfare system, cared for and protected in institutions, group homes or in other special forms of housing, supervised and with very limited opportunities to influence their situation and shape their own everyday lives. This seems to have changed during the last ten years.

The aim of this article is to show how different life patterns have been created among young people with intellectual disabilities. The changes are related to structural changes in the general social welfare system in Sweden, but also to the young people's own strategies and intentions, and to the role of the relatives. The groups that are addressed in this paper consist of young people with mild intellectual disabilities. They can largely take care of themselves and perhaps live in society under conditions that are not very different from other people. They do, however, also need support for certain parts of their lives. Their social life, their family networks, their daily activities, contacts with authorities, assistance and other relationships constitute what we call “life patterns”; patterns we try to describe and understand in this article. These life patterns are to a large extent changed and new.

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### **Structural Background**

During the last decades, living conditions for people with intellectual disabilities have changed dramatically in Sweden, as well as in other parts of the Western world. The general idea behind these changes was that people who have need of support and help in their everyday lives should not live in housing environments that are separated and isolated from the rest of society (Mansell & Eriksson 1996). They should instead be given the opportunity to live in their own homes with access to regular social contexts. Living in small-scale units in the local society is supposed to create a higher quality of life and provide the pre-conditions for a sense of belonging, participation and community. During the last decade in Sweden more than 5000 people with intellectual disabilities have moved from institutions to special living arrangements in integrated housing areas (SOU 2004).

We will describe three other structural changes in the welfare state and in society that are important in order to understand the changed conditions these young people encounter. The first structural change is the relative retreat of the welfare state. In international comparisons, the Swedish society has had an extensive public welfare sector and the welfare model, which has been applied in the Nordic countries, may according to Esping-Andersen's (1999) concept be referred to as social democratic. It is characterized by the general public welfare systems, which guarantee extensive benefits to all citizens in many parts of their lives. Until the 1990s, Sweden's general welfare policy was developed successively. Since then it has been questioned and has been the subject of challenges and criticism. Deteriorating government finances, higher unemployment and an increased number of elderly people who need help have led to a restructuring of efforts and fewer undertakings (Rothstein 1998). A new development, where the welfare policy to a high degree is built on a person's participation in the labour force hits young disabled people particularly hard, because they are unemployed to a significantly higher extent than other people and they thereby fall outside the social welfare system (SOU 2001).

Increased freedom of choice and the individual's own responsibility for requesting assistance has to an increasing degree replaced general welfare policies. This is the second big structural change. The aim of the Swedish disability reform of the 1990s, *Act Concerning Support and Service for Persons with Certain Functional Impairments* (LSS), is to make living conditions for people with disabilities and for the rest of the population more equal (SOU 2004). The act is intended, through individual rights, to guarantee that people with severe and permanent disabilities can obtain help when support under other legislation is insufficient. The most common LSS measure is daily activity, in which just over 21,000 people took part, followed by adult accommodation for 17,500 people, and contact persons for 14,000 people. More men than women at all ages, except for old-age pensioners, were covered by the measures. One explanation may be that more men than women have impairments.

The reform may be viewed as a new trend in many different ways. Ideals such as fairness, equality of efforts, equity and collective organization have had to relinquish to expressions such as market, individualism and the individual's freedom of choice (Barron, Michailakis & Söder 2000). Another trait that is typical for the reform is also the focus on strengthening the individual's rights and self-determination rather than regulating the obligations of society. Assistance is to be requested by the individual or by his or her representatives. The shift of responsibilities from national to local government also meant that the municipalities have been given more opportunities to shape the welfare services in a way that appears feasible and reasonable in the local context. The consequences have been large differences between municipalities, regarding what kind of support they offer. Studies show that neither the size nor the type of the municipality is a factor that can explain the differences (SOU 2004). Local variation may be due to differing priorities, but for the individuals it has meant that the support from the public sector looks different depending on where he or she lives and how he/she can formulate his/her needs for support and demands for assistance.

Aside from changes within the welfare policy, the traditional patterns of people's everyday lives, norms and social interactions have been weakened. Young people face new challenges concerning qualifying for adulthood and the development of their own life projects, their choice of action strategies and their own self-determination. It is a process of individualization with strong reflexive traits, which opens opportunities as well as creates uncertainties and new forms of risks (Beck 1998, Giddens 1991). This is the third structural societal change, which also affects the life patterns of young people with intellectual disabilities.

### **Researching Life Patterns**

Several studies show that the structural changes that have occurred within society during the 1990s have a high degree of impact on the young people's welfare and that increased differences between different groups of young people are created. Social environment, class, gender and ethnicity appear to constitute decisive factors (Berggren 2001, Bjurström 1997, Hörnqvist 1994, Lundström & Sallnäs 2003, Sjöblom 2002, 2003). Young people from families that are socially and economically vulnerable do now have a significantly lower standard of living compared with other young people and this has created unequal conditions and an increased risk of marginalization (SOU 2000:41, SOU 2001). Within disability research, these issues are hardly ever addressed. In particular there is little knowledge of how the situation and conditions of young people with intellectual disability are influenced by the different existential conditions and circumstances, which are due to their parents' socio-economic background. Several studies indicate, however, that parents of disabled children and young people appear to have taken an increased responsibility for care during the 1990s and the families report more frequently than the rest of the population that they are in financial difficulties (SOU 2004). Little is known about effects of various measures and activities

in care of young disabled people – effects for individuals and for society as a whole, how welfare and society's resources are divided between them and what life is like for the young people who live "outside the system".

For one group of young people with intellectual disabilities, whose parents are strong representatives, the conditions and patterns of life are relatively well known, because their situation has been the target of interest both of research (Conney 2002, Olin 2003) and for assistance from social services (SOU 2000:3, SOU 2001). This group is easy to identify and define and thereby also easier to study. It is a group whose relatives demand actions and influence whereby they also become visible to researchers as well as to actors from the welfare system. Much of the existing research within the area is based on the parents' perspective and their role as representatives for their young adults (Marshak et al. 1999, Thorin Yovanoff & Irving 1996, Tideman 2000). However, we know little about the life patterns and everyday life of people whose parents are not equally visible as representatives in dealings with authorities. This lack of knowledge is expressed in the following way by one of the social workers.

The "well behaved", have many activities, they participate in organizations and they go on prearranged trips. They live in a group housing facility or in their own apartments with assistance and they have a close contact with their parents, we know where they are and the parents know where they are. The ones who are not as well behaved, they socialize with other people with intellectual disability, they socialize at each others' houses, they meet in town, socialize in groups. . . they go out and get into trouble. We know very little about how they are doing, how they live and sometimes we do not even know who they are. These people have a strong internal network, they are like a yarn... but we do not know what the network looks like!

(Interview, former therapist in a "care team", now social worker in the social services)

### **Purpose and Method**

The general purpose of the study, of which this paper is one part, is to describe and understand the everyday life situations and life patterns of young adults, labelled as persons with mild or moderate intellectual disabilities, the conditions of their lives and their participation in public life.

Two types of data have been collected. In order to get in touch with the young people, but also to gain a deeper and more systematic knowledge of the young people's situation after they have left special education, a study was made in two cities in western Sweden: one small and the other mid-sized. Semi-structured interviews were carried out with 23 people who through their profession or their involvement in organizations and volunteer groups have a wide and deep knowledge of and contacts with the group. Informants were located by the "snowball technique" (Taylor & Bogdan 1998). We started with our own professional contacts and asked them to introduce us to others. We also sought contact with agencies and social organizations that in some way serve young adults with intellectual disabilities. The professions of the informants were teachers at special schools, job supervisors, therapists,

social workers, counsellors, club leaders, directors of the local social services, people active in volunteer organizations and other groups. The interviews aimed at identifying similarities and differences in the conditions of life and life patterns among young people, concerning housing, occupation and financial situation as well as in relation to where and how they spend their free time, their relationships to relatives and friends, contacts with authorities, assistance and their experiences of the spatial environment. This data has provided an overall picture of the backgrounds, family relationships and current life situation for a group of 60 young adults, ages 19–30 years, who graduated from special upper secondary school in the two cities from 1993 to 2003. All have a mild or a moderate intellectual disability and have, after living the school system, received one or more municipal “decisions” on measures/services under the *Act Concerning Support and Service for Persons with Certain Functional Impairments* (LSS).

The second part of the study, which aims at a more in-depth study of the young people’s lives, was carried out using methods that are inspired by ethnography (Emerson, Emerson, Fretz & Shaw 1995). We followed the young people in their everyday lives, talked to them and interviewed them about where and how they live, what they do and how they spend their days and what kinds of people they meet, interact with and create relationships with. A total of 23 young people (10 women, 13 men) from the group that was identified through the first study were interviewed. The selection of informants has been made based on the intention of getting a broad representation of social background factors, age, gender and the extent of the assistance. The contact with the informants was reached with the help of staff, in group homes, daycare centres and social workers. We asked them to introduce us to daycare centres, clubs and volunteer organizations where these young people spend a lot of time, and when we got to know some informants, we asked them to introduce us to others.

The review and analysis of the interviews have been guided by the main question about what the young people’s life situation is like and they have focused on uncovering differences in life patterns and on how the young people themselves relate to their identified situation. Three different ideal life patterns have been discerned. This obviously constitutes a simplification of real cases, but which in their character reflect well the differences that come out in the material. The next step in the analysis consisted of designing summarizing concepts for the three categories and highlighting aspects that clarify the differences and discussing how they may be understood and explained.

The picture we paint of the three life patterns in the following section is largely taken from interviews with professionals in the two cities, but it has also been supplemented with data from the young people’s own stories. The caseworker’s overview is, of course, limited and it is also to some extent dependent on problematic situations when the young people seek help. They rarely meet people in life situations that function better.

### **Changing Life Patterns**

Interviews both with the professionals and with the young people, indicate large differences between young people with intellectual disabilities, when it comes to how and where they live, their social life, their network and how they manage everyday life and to what extent they have access to societal assistance from the local social services: differences, which do not appear to be related to their degree of disability. We refer to the three ideal approaches as the “cared for and represented”, the “commuters” and the “outsiders”. In the description in the following section, we highlight what characterizes each category and in order to illuminate differences and similarities, one young person from the material was chosen to represent each group.

#### *The Cared For and Represented*

This is a group of young people who have a lot of assistance from the social services. About 15–20 of the young people who are part of the survey belong in this category, approximately as many men as women. They have their own apartments in newly built group housing units, to which they moved directly from their parents’ home. The young people’s apartments are usually in purpose-built, single-storey buildings, located in quiet single-family housing areas on the outskirts of the city. All of the young people in this group have an organized daily occupation and a pre-arranged free time in formally organized forms. They have strong family networks and parents/relatives who have demanded assistance and who in different ways have taken part in the planning and shaping of their living situation. The parents participate actively in the young people’s everyday lives and influence the form and content of the activities. The staff/resident ratio in the housing is fairly high and many of the young people also have help in the form of a personal assistant in their housing and an assistant in their free time. The staff and parents communicate continuously and the young people’s everyday lives are to a high degree controlled by staff and relatives. One of the representatives of the program whom we interviewed expresses the character of the housing with these words: “This is not a form of housing where you can come and do whatever you want”. In the following story about Lisa, we get an idea about the group.

*Lisa – on her way to create a life of her own, with active parents at the wheel.* Lisa is one of the young people whose life situation and pattern of life may be placed in the group “the cared for and represented”. Lisa is 26 years old and grew up in an upper-middle class family with a father who is a lawyer and a mother who is an accountant and partner in a small private business. Lisa lives in a two-room apartment in a newly built assisted living facility, which is located in one of the more attractive areas outside the city. Five other young people live there. All of them have an apartment with their own entrance and Lisa and three of the other young people have a personal assistant in the housing

unit. In the centre of the building there is a common area and a staff area. Lisa's parents have for a few years expressed to city employees, the need for an apartment for their daughter. They now think that they have finally got the "right" form of housing, that is, housing of a good standard in a pleasant and calm area with extensive staff support, which can give them and their daughter the security and care they believe is a precondition for her ability to move away from her parents' home. The parents took it for granted that they would participate in the planning process from the beginning, and they have thereby also been able to influence the location, the form of housing as well as the composition of staff.

Lisa's parents decorated her apartment. It is warm, cosy, well-equipped and tidy with furniture, curtains and other decoration well co-ordinated in shape and form. Lisa spends a lot of time in her apartment where she listens to music, watches television, or takes care of her things. She likes to dress up, have nice clothes and keep things tidy around her. People around her thereby also often acknowledge her, both to the staff and to her parents. Lisa works in a daytime program where she is happy and well adjusted. She is very rarely absent from work. She spends her free time mostly at home, in her apartment, with her parents or in the common areas of the group housing. She takes riding lessons once a week and regularly visits the library, the public swimming pool, and certain organized recreational activities. She has an assistant who helps her to get to her pre-arranged activities. She also sometimes goes to town, to go to a café or just walk around, but always with somebody in her family, with her assistant or a member of the staff.

Lisa has a limited social life and network of contacts outside her family, but she has a few friends among the other young people in her housing unit, with whom she socializes. They meet in the common area, or in each other's apartments, where they talk, listen to music, watch TV or have a snack together. Other than that, her free time is mostly taken up by contacts with her family.

The staff describe Lisa as an independent, strong-willed and positive young woman, confident of her own ability, aware of her resources and limitations and with a stubbornness, which makes her often get her way in relation to the staff and her friends. Even though Lisa has an ability to stress her own will, her parents do have a high degree of control and view of her life. Her parents communicate regularly with the staff and make sure they are informed and have influence over what both their daughter and the staff do. Lisa also appears to a high degree to submit loyally to her parents' attitude when it comes to how her everyday life should be organized.

*A life in the parents' footsteps.* Although it has been studied before, this is a group, where the life pattern may be viewed as partly new. The new is expressed in the fact that parents to a higher degree than before can influence their children's situation by acting as their representatives and demand resources and influence over the planning and the organization as well as the form of assistance, which they believe that their children need. Even though the young people live in the shadow of their parents' life form and within the

area of their control, they have also been given larger opportunities to express their personal preferences, individual choices and their own interests concerning decoration, fashion, style and recreational activities, compared with the situation in the institutions and earlier types of special accommodation for young people with intellectual disabilities.

This means that the young people in this group have become more visible as individuals, not the least with regard to the actors of the welfare society, but it also means that their path to adulthood is characterized by extensive support and strong social control.

### *The Commuters*

The commuters are a group of young people who, above all, are characterized by the fact that they commute between living inside and outside the boundaries of the system. They receive assistance from the social services, although it is not as extensive as the group “the cared for and represented”. About 12–15 people from the studied group belong in this category, a few more women than men. They usually live in a group-housing unit or in their own apartments of the character “assisted living facility”, with access to a common meeting place. The apartments are located in buildings with rental apartments in the centre of town or on the outskirts. Several of the young people previously lived in their parents’ homes or were placed in foster homes. Some of them have lived in their own apartments for a few years, but moved to the assisted living facility when there were problems or when it turned out that they had trouble managing living on their own. The move has sometimes occurred on the staff’s initiative, but sometimes the young people themselves asked for assistance or were given access to it, by moving in with a friend or boyfriend/girlfriend in the assisted housing facility. Most of them have some sort of organized occupation on and off, but sometimes “things mess up” and the young people leave on their own initiative or refuse to participate in the program during periods when they are dissatisfied with something. This means that during certain periods they do not have access to a formally organized daily occupation.

The free time looks slightly different for the young people in this program, but it is only formally organized to a small degree. Some spend a lot of time in their apartments, relax, watch television and spend time with their friends in their common meeting place, while others move about a lot in town, on the square, in stores, kiosks and cafes. Many more people spend time in the meeting place than those who have an apartment in the assisted living facility. The staff do not have full control over how the young people spend their free time, with whom they socialize and what they do and representatives for the program say that the residents do not let themselves be controlled. The young people have a lot of contacts with each other and with people who belong to what we will call the “outsider group”. Most people also have contact and interactions with other people in the environment close to their housing unit as well as in town and some of them socialize with what the representatives of the program call “people who are a bit strange”. Some of the young people in

this group have a strong family network, but unlike the group “the cared for and represented”, staff and relatives do not have the same close and continuing contact, which means that the staff do not have the same view over what the contact between the young people and their families looks like. The staff/resident ratio is lower and none of the young people have assistance in the form of an assistant in their free time. The young people in this group have a higher degree of mobility and more free zones than the group above.

*Rita – lost but strong-willed.* Rita is 23 years old and grew up with her mother. The family moved to Sweden from Finland about 15 years ago. Her mother is single and works part-time as a maid at a nursing home. Even though they have lived in Sweden for many years, her mother speaks Swedish only reluctantly. She can barely understand and make herself understood in the Swedish language and she mainly socializes with other Finnish-speaking people and speaks only Finnish with her daughter. After upper secondary school for pupils with intellectual disabilities, Rita got a job in an outsourced daytime program, where she met Ronny. Ronny had his own apartment in an assisted living facility and Rita often stayed with him during the weekends. Apart from Ronny, seven other people live there. The assisted living facility consists of a number of different freestanding apartments, housed in a few apartment buildings not far from the city centre. A common meeting area belongs to the unit on the ground floor in one of the buildings.

After a few months Rita moved in with Ronny without asking either her mother or the staff in her housing facility. When the relationship between her and Ronny ended, she asked the staff in the housing facility for help to get her own apartment in the area. She now lives in a small one-room apartment in the same building as Ronny and a few of the other women in the assisted living facility. She has decorated her apartment with furniture from her old room in her parents’ home, some items are newly bought and she also has things that the staff has given to her. It is sparsely furnished with a mixed style, but she is happy and proud of her apartment. She is, however, not very interested in cleaning, the staff tells us; the closet is mostly used for magazines and rubbish and she mostly keeps her clothes in a corner on the floor.

Rita is usually able to cope with her work at the daytime program, but sometimes during some periods she “is truant” and instead she goes to the library to chat online with friends and acquaintances from near and far. The staff says, that she meets shady male contacts online, and they worry quite a lot about her chatting. The staff describes Rita as active, extroverted and strong, but also as a lost and troubled soul. She has problems being by herself, she always wants company, but hates feeling controlled. If the staff tries to rule her existence too much she pulls away and avoids coming to the meeting area and refuses staff assistance in her apartment for a while.

Rita is active in her spare time, but not in the form of organized and pre-arranged activities. She does, however, move a lot around town, she goes shopping, looks at clothes, sits at cheap cafes or just walks around with friends from the housing facility or walks and talks with other people she knows in the neighbourhood. She has many friends and acquaintances both

inside and outside the housing facility and the staff do not really have any idea what her social circle looks like. Her friends are important to Rita and they socialize both in each other's apartments and in the meeting place, but mostly in town. Her mother is a palpable and important person in her life and they meet quite often, but her mother does not actively participate in the housing program and she does not initiate contact with the staff.

*A life that challenges the actors in the welfare system.* According to the actors we have spoken to, the commuters is a group of young people whose life patterns and action strategies are perceived as something new and unknown, which both scare and fascinate. The actors believe that the lifestyle that the commuters lead, with a relatively high degree of independence and withdrawal from social control, has not previously been accommodated within the framework for the special forms of housing that were offered to young people with a special school background. Having their own apartments in different buildings, but within the same block, with access to a common meeting place for common socializing and proximity to the city centre have created increased "room for opportunities" for the young people (Mørch 1996). These free zones have given them opportunities to develop other interests and create a lifestyle different from the one of their parents, as well as from the staff around them. The young people have created a life, which to a large degree is separate from the view and control of staff and parents and this worries the staff at the same time as they see the positive aspects of the increased independence. Because they do not know a lot about the young people's life outside and what happens in their contacts with their friends, they worry that the young people do not receive the support they need in the process of establishing themselves in the adult world. The worry that the staff express also has a gender-related pattern; they mostly worry about the young women creating contacts through online chatting and the young men belonging to gangs and that they will end up abusing drugs or as criminals. The images of the problems in the young people's lives may be likened with what Swärd (1993) describes in a study about young people in custody as "gang boys" and "trashy girls".

### *The Outsiders*

This group, which we call the outsiders, comprises young people who received secondary school for pupils with intellectual disabilities, but who after graduation receive no assistance from local social services, either with regard to housing, employment or free time. About 25–30 of the people who are part of the survey belong in this category. They live in the home of their parents, have their own apartments or live temporarily with friends or boyfriends and girlfriends. Some of them work, but many have no or only temporary access to a formally arranged daily occupation. The social services know about this group, but know very little about how they are or what their situation is like. They only get noticed by authorities when problems arise, for example, financial problems, when they repeatedly receive bad credit reports, get

evicted, when it becomes known that they have substance abuse problems, participate in criminal activities, when they have children and they have trouble with the responsibility and care of their child.

There is also a clear pattern of gender roles, which is evident in the program representatives' stories about this group. The financial problems, the difficulty of finding employment and handling the demands of the jobs is the same for both young men and young women. However, there are differences in their way of dealing with their everyday lives and existence. This is how one of the program representatives describes the existing gender-related differences.

The boys gravitate toward gangs, sit on the park benches with other destitute people, borrow cars, drive without a license, get substance abuse problems and get into a lot of debt. The girls move in with some guy, pick up boys on the internet, have children and then the relationship doesn't work out. . . but they keep away in a different way. There may be more boys than girls, or it is possible that we know more about the boys' situation, because they are louder and more visible. The boys get into trouble and mess up, refuse to do what they are told, the girls pull away and do not make contact.

When problems that trigger actions from the authorities arise and the records show that the young people have a background from upper secondary school for pupils with intellectual disabilities, the local social services are contacted. But many of these young people do not feel disabled and do not want any assistance from the social services, or perhaps the assistance that they are offered does not suit this group. The program representatives say that the young people do not fit in traditional group housing or assisted living facilities, but they do not always manage their own apartment either.

*Jimmy – a survival artist or lost in the freedom of choice?* Jimmy is a member of the so-called outsider group. He is 25 years old and has his own apartment. He rarely sleeps there because he is afraid of the dark, anxious and afraid of being alone. Instead, he leads a peripatetic life living out of a suitcase and he looks for a temporary roof over his head at his friends' houses, with an older brother who like Jimmy received special upper secondary school education, or he meets a girl that he spends the night with. Jimmy grew up with his family, but was periodically placed in foster care, because both of his parents have substance abuse problems. His parents are divorced and he has no contact with his father anymore. He meets his mother every now and then and when he has nowhere else to go, he spends the night at her house. After he finished special school, he received practical occupational training at a manufacturing plant, but he had trouble managing the demands of the job and the pace and he had to leave after a short time. He then lived on welfare for a while, but when first contacted in this study he works with six other young men with mild intellectual disabilities in an outsourced daytime program, where they mostly repair bikes, scooters, lawn mowers and similar things. He is fairly happy there, but during certain periods, things do not work at all. He can then disappear from work for long periods of time, without telling anyone where he is or when he is coming back. Then he returns a month or so later as unexpectedly as when he disappeared. When his

supervisor tries to contact him to see why he is not at work, he does not answer the telephone, and is not in his home. When he does show up, it is because he needs money or help because he messed up his life in different ways. It could be anything from ordering mobile phones for which he cannot pay, to being taken into police custody because he was drunk in town or because he was caught in different kinds of petty crime. When he is asked where he has been, what happened or how things ended up like that, he answers “that is none of your damned business”. Jimmy does not view himself as disabled and does not want any contact with either the municipal social services or the local authorities. He has some sporadic contact with his legal guardian, a caseworker at the social services and with his supervisor, people he knows and trusts from his school years, and in whom he can confide. He sometimes turns to them when there is something he does not believe he can handle by himself, but the contact always has to occur on his terms and in a way that does not make him feel controlled and trapped. Jimmy’s peripatetic existence worries the welfare actors, because they believe that he is sometimes mistreated – he has problems, gets used and lives in the margin of what society views as an acceptable life pattern. They also have trouble seeing how they can help him, because he does not want to submit to existing assistance.

Jimmy’s supervisor describes him as verbal, open, social and charming, but also as a real “troublemaker” who always manages to end up in difficult situations and mess up his existence in different ways. It is easy for him to make contact with people in his surroundings, he is liked by his friends and can be very convincing when there is something he wants, but it is difficult to get close to him and he pulls away as soon as he feels that someone is trying to control him. Jimmy largely leads his life in town and in environments about which his supervisor, his legal guardian and his caseworker know nothing. He has many contacts among different groups of people and a large network of friends whom he meets more or less regularly. Many of them are other young people who Jimmy has known since his time in upper secondary school, but he also seeks out and meets other groups of people who in various ways are a little bit different from the rest of society. They often meet in town, on the square or hang out by the port, but they sometimes meet in Jimmy’s apartment, which at times works as a free zone for different groups of people.

*A life on the periphery of the margin.* The outsider group’s situations and way of life have been made possible through the individualization process, which followed the change in the welfare society. On the one hand, this group of young people has been given increased opportunities, with a smaller degree of control from the welfare authorities, at the same time; their problems, difficulties and need for support have been made invisible. Several people in this group may be viewed as temporarily homeless, in the sense that in spite of having a formal address, they lead a peripatetic life because they have a home in which for different reasons they cannot, or will not, spend time. We know very little about whether their new-found freedom “outside of the system” has meant increased opportunities for them to realize their own life projects

and create a personally based way of life, or whether it rather has led to a risk of marginalization and increased vulnerability.

### **Societal Changes and Life Patterns**

We initially described three changes in Swedish society, which have had a particular impact on young people with intellectual disabilities. The first change concerned the retreat of the welfare state; the second concerned individualization and the requirement for self-determination and finally, society's new reflexivity, which is expressed not least among young people.

The retreat of the welfare state is obvious in our material. A significant number of the young people, at least one-third of them, receive largely no support or assistance from authorities and for additional individuals the assistance is limited. There are two mechanisms behind this phenomenon. The reorganizations that have been made at the local level mean that the responsibility and the oversight are divided between several people. But, above all, the withdrawal has been made possible by the fact that the disabled people themselves must request assistance. The new freedom of choice means that knowledge and experience are required in order to take advantage of society's resources.

This constitutes a problem for the group that is focused on in this article, and their parents are often the ones who advocate their case. Today, active parents have more opportunities than before to obtain resources for their children from the authorities, both when it comes to access to housing and other kinds of support efforts. On the other hand, if parents lack the experience to deal with authorities, or perhaps do not care and thus fail to promote their children's cause, in many cases nobody else will.

This means that the role of the representatives becomes central. It also means that efforts by authorities tend to become class structured. The ability of members of the middle class to get what they need has consequences for the type of care and support given to the young. Some fall through the cracks and do not receive any help at all. The same tendencies are apparent in a study of elderly people who receive assistance from the city authorities (Larsen 2004). It shows that the role of the representatives – the relatives – is central to the allocation of assistance.

According to Beck (1996), individualization is assumed to create increased room for action and opportunities for a person to realize his or her life project, but the process of individualization involves both winners and losers. With the concept of "full value individualization" and poverty individualization he paints a picture of individualization, as at the same time both a destiny and a choice. The concepts refer to the fact that people who live under different social and class conditions also have different opportunities to benefit from the increased freedom of choice. Beck says that the modern reflexivity pre-supposes a director who is in control of the action, which inevitably leads to difficulties for a person who does not have the experience or the capacity to promote his or her own cause.

However, this is not the entire story. Many young people with intellectual disability sometimes perceive that help or category assistance makes them passive, controlled or stigmatized, because they want to live like everybody else. When the control from authorities decreases, there are opportunities for them to live fully or partly outside of the control and view of the authorities, and seek ways of living that do not label them and keep them in their place. New room for a person's own reflexivity is opened up. Many of the young people in our study have developed strategies to avoid or minimize control and have found alternative ways to live like other people in society, some of them like other marginal people.

The pulling away from contacts with authorities may be seen as a conscious strategy of the young people "they do not do what we want them to anymore". Two strategies may be distinguished from the material: to confront the system, circumvent the rules and use it in one's own way and to withdraw and reject contacts that require control. There are those who so to speak use the system when it suits them, who join activities and use the opportunities to get housing or other types of support and help – but not exactly in the way the authorities had planned and have control over. This is a strategy that appears mainly to be used by the young men. The second strategy in relation to authorities appears to be to stay away as much as possible. This is a strategy that is mainly used by young women.

It is difficult for society's actors to counteract these types of strategies. The representatives of the commuters and the outsider group challenge the image of how young people with a special education background are expected to live. Assistance in the form of demands to adapt to rules and increased discipline appears only to lead to an even higher degree of rebellion or withdrawal. The resources, efforts and solutions that are offered by the system are such that in the first hand are demanded by the active and prosperous parental representatives. The absence of other alternatives means that some people choose to be without help.

### **The Consequences**

We have shown that new or at least partly new ways of life have emerged among young people with intellectual disabilities. We do not know what the long-term consequences of this development will be. It may, however, still be appropriate to make a few educated guesses about the future of the groups that we have earlier called commuters and outsiders. Here, we may discern opportunities for positive development. By spending time in other social environments than is traditional for their group, in more socially varied and open spaces, they may perhaps have opportunities to develop other roles and gain important social and cultural competence. In that case, it may have an impact on their opportunities to master various everyday situations and shape their own lives and lifestyles.

There are however, clear indications of a more negative kind. Some of the young people have trouble managing their new life. They have difficulties, have "bad friends", they are abused and cannot always estimate the risks of

their actions. For some, criminality, alcohol and other drugs will make them end up outside of the employment and housing markets. It appears probable that many will end up in a very problematic situation, with which they will have trouble coping. This may perhaps be a serious and growing problem. The debate, which is currently taking place in the Swedish media, may support this notion, after it was discovered that several people with a mild intellectual disability have been sentenced to prison over the last few years. During the period 1997–2004, at least 35 people who had been evaluated and judged to have intellectual disabilities were sentenced to long prison terms, but several directors within the Swedish Criminal Justice System who were interviewed in connection with the debate in the media, claim that the actual number is much higher (*SvD* (Swedish newspaper) September 11, 2004). In an ongoing but not yet published study that was made in co-operation with the National Board of Institutional Care, there are results, which claim that more than 20% of the young people who have been sentenced to mandatory care and placed in closed institutional youth care have a mild degree of intellectual disabilities (*SvD* October 11, 2004).

Finally, we may conclude that for young people with intellectual disabilities, becoming an adult appears to include increased inequalities in their conditions of life, opportunities and risks. This opens a range of new research questions about what the consequences are of the changes in the welfare policy, class- and gender-related patterns and the young people's own strategies; for opportunities for them to create their own path toward adulthood.

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