

BREAK-UP AND CHANGE – WHEN YOUNG PEOPLE WITH INTELLECTUAL DISABILITIES MOVE AWAY FROM HOME

Key words: intellectual disabilities.

This study is about a group of young people with intellectual disabilities, who move away from home to a staffed housing facility. It highlights the interaction between the young people, their parents and the housing staff, both during the process of moving and in the new everyday life in the housing facility. The housing facility to which the young people move is a newly established group home. The building contains 13 apartments, twelve rental apartments and one apartment for the staff. In the building there is also an office for the staff as well as common areas, a common room with an attached kitchen, a hobby room and a laundry room.

Background

The young people, who are part of the study, have grown up during a period of time when many extensive reforms took place within the area of Swedish disability policy. Among other things, they have brought about the dismantling of the institutions, which earlier constituted a common form of living for people with intellectual disabilities. In Sweden, more than 5000 people with intellectual disabilities have moved from institutions into new types of integrated housing areas during the last decade¹. This means that children with intellectual disabilities grow up with their families and are expected, like other young adults, to leave the home of their parents and move to a house of their own. When children without intellectual disabilities move away from home, the first home usually constitutes an adult-free zone, which means that the young person is largely free to shape his/her everyday life according to his/her own desires². These opportunities

¹ SoU, *Handikappomsorg – lägesrapport 2003. (Care of the disabled. Status report 2003)* Stockholm: Socialstyrelsen, 2004.

² C. Mångård, *Livet kan börja. En etnografisk studie om när ungdomar flyttar hemifrån. (The life can begin. An ethnographic studie about young people leaving home).* Växjö: Växjö universitet, institutionen för samhällsvetenskap, 1999; Raymore, L.A., Barber, B.L., Eccles, J.S., *Leaving home, attending college, partnership and parenthood: The role of life*

are different for young people with intellectual disabilities, because they have a significant need of support and help in their everyday life³. The presence of the staff may constitute a condition for the independence, but it may also create the experience of unwanted control⁴. The overall goal of the modern Swedish disability policy, except normalisation and integration, is to increase individual self-determination for people with disabilities⁵. The time of youth and adulthood gives increased importance to circumstances, which may be associated with autonomy and self-determination⁶.

Purpose and questions

The overall purpose of the study is to study what happens when young people with intellectual disabilities move away from their parents' home to an apartment in a staffed housing facility.

Main research questions are:

- How are everyday life and the rules and norms, which affect the different actors' room for action, shaped in the housing facility?
- How are power structures and emotional relationships between the actors created and developed and how do they change?

transition events in leisure pattern stability from adolescence to young adulthood. *Journal of Youth and Adolescence*, 30 (2), 2001, 197-223.

³ D.S. Bjarnason, New voices in Iceland. Parent and adult children: Juggling supports and choices in time and space. *Disability & Society*, 17 (3), 2002, 307-326; J. Blacher (2001) Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, 106 (2), 173-188; B.F. Cooney (2002) Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation*, 40 (6), 425-435; B. Jordan, G. Dunlap, Construction of Adulthood and disability. *Mental Retardation*. 39 (4), 2000, 286-296

⁴ S. Deely, Professional ideology and learning disability: An analysis of internal conflict. *Disability & Society*, 17 (1), 2002, 19-33; J. Mansell, E. Elliot (2001) Staff members' prediction of consequences for their work in residential settings. *American Journal on Mental Retardation*, 106 (5), 2001, 434-447.

⁵ K. Barron, Disability and gender. Autonomy as an indication of adulthood. Uppsala: Acta, Uppsala Universitet, 1997; K. Barron, D. Michailakis, M. Söder, Disabled and the welfare state. In M. Szebehely & K. Barron (ed) *Welfare and care*. Stockholm 2000, Fritzes offentliga publikationer; B. Mannergren, Independent living- ett självständigt liv. En social rörelser bland handikappade. Independent living- a independent life. A social movement among disabled people Jönköping 1993, Institutionen för undervisning, kultur och information.

⁶ I. Duvdevany, H. Ben-Zur, A. Ambar, Self-determination and mental retardation: Is there an association with living arrangement and life-style satisfaction? *Mental Retardation*, 40 (5), 2002, 379-389; J. Sprague, J. Hayes, Self-determination and empowerment: A feminist standpoint analysis of talk about disability. *American Journal of Community Psychology*, 28 (5), 2000, 671-695.

- What opportunities do the young people have to achieve self-determination in their everyday life in spite of their need for extensive help?

The format and method of the study

The study has a qualitative approach. The main methods of data collection consist of participating observation and qualitative interviews⁷. The participating observations were carried out during two and a half years at the same time as 28 qualitative interviews were made. The material has been analyzed according to a few concepts from social psychology, which mainly focus on the relationship of the individual to the group, the relationships of groups to each other and different aspects, which may be related to the concept of social situation⁸.

Results

Before a new phase of life

When young people without intellectual disabilities move away from home, it is generally the result of the young person's own initiatives and actions. For the young people in this study however, it is the parents who have initiated and organized the move. The parents nevertheless have ambivalent feelings as the time for their child's move approaches. When the parents talk about their hopes and fears in face of the upcoming move, two contradictory images of the child, both as competent and helpless, appear. All parents do tend to view their adult children as more incompetent than they are. The difference is, however, that the young people in this study are not able to cope without the support and help of other people in their everyday life. This contradicts the idea that a young person should have reached a certain level of competence and independence in order to move

⁷ H.S. Becker, Cases, causes, conjunctures, stories and imagery. In C.C. Ragin, H.S. Becker, (red) What is a case? Exploring the foundations of social inquiry. Cambridge 1995, University Press; R. Bogdan, S. Taylor, Inside out. The social meaning of mental retardation. New York, 1994, Teachers college press; M. Miles, M. Huberman (1994) Qualitative data analysis. Thousand Oaks, Calif: Sage Publications; M.Q. Patton, Qualitative Evaluation and Research Methods. Newbury Park, 1990, Sage Publications.

⁸ H. Blumer, Symbolic Interactionism, perspective and method. Englewood Cliffs, N.J: Prentice-Hall, 1969; R. H. Lauer, W. H. Handel, Social psychology - The theory and application of symbolic interactionism. Boston 1997, Houghton Mifflin; E. Goffman, The presentation of self in everyday life. London 1990, Penguin Box.

away from home. The parents relate to this contradiction by referring alternately to “young people in general”, which is associated with competence and independence and “people with intellectual disabilities”, which brings to mind more the idea of deficient competence and dependency. The ambivalence of the mothers’ descriptions thereby constitutes a logic consequence of the fact that the child is not leaving the home of his/her parents of his/her own accord.

Preparations for the move

Before the young people move into the housing facility, different preparatory activities take place, which are supposed to facilitate the transition for the young people and make it possible for the staff to work efficiently. The work in the housing facility is to be carried out as a service adapted to each individual. It is therefore of utmost importance that the staff receives information about every young person’s need for assistance. Certain complications arise when the parents are to describe their child’s need for help. The parents believe that the child by and large can manage all everyday tasks as long as somebody is present who can “push” and “look after”. In the family’s everyday life, the young people’s need for help is woven into their relationship to the members of their family. The social relationship also coordinates the child’s need for help in an everyday structure. It is therefore difficult for the parents to formulate their child’s need for help quantitatively. Based on the different perspectives, which exist between the professional staff and the parents, certain communicative difficulties arise and the interaction gets the character of a social negotiation. They negotiate whether the everyday life of the housing facility should be similar to, or different from what the young people are used to from the home of their parents. The parents advocate the importance of some similarities, while the professional staff has an opposite opinion. The various actors’ different positions are revealed, among other things, through their use of language. In some situations, representatives of the housing facility use concepts, which have a large symbolic value to the professional context. Because the parents do not have the same understanding of the meaning of the concept, this use of language contributes to complicate the interaction and the parties may have difficulties understanding each other.

In order for the young people to get to know each other and even have the opportunity to discuss different issues before the move, they meet in small groups, so called companion groups. The interaction between the young people is focused on finding common ground, but also to try to find out what everyday life will be like. The young people appear to be conscious

of the fact that certain changes will occur when they move away from home and are eager for the changes to happen. In order to maintain some stability, some want their parents to continue to perform certain tasks. The young people thus define the future both in terms of similarity and change.

The first probing attempts

During the time immediately after the young people have moved into the housing facility, the professional staff develops strategies for providing adequate assistance to the young people in an appropriate manner. The professional staff tries to maintain the same routine that the young people are used to from home. On an overall level there is thus a large structural similarity between how everyday life is organized in the family and the housing facility. There are however some basic differences in how the everyday structure is developed and maintained. In their family, the young people's need for help was integrated in an everyday structure with the help of the social relationships. When the young people move into the housing facility, the relationship is detached from the need for assistance and the everyday structure. The professional challenge therefore consists of trying to find other integrating factors, which connect the young people's need for support with an everyday structure. In order to find out about every young person's habits and need for assistance, an intensive effort of mapping and documentation is initiated. This leads to the development of an extensive written culture of information, which may risk reducing the young people's room for negotiation and which also portrays the young people's need for help in static terms.

The housing facility may be described as a combination between individual and collective living. Regulating the relationship between the young people's private and public spheres is therefore a recurring theme in the housing facility. One example is that the professional staff believes that the young people's socializing in the common areas should not be of a private and intimate nature. This type of interaction should instead take place in the apartments. The staff therefore tries, in different ways, to direct the young people's internal socializing in the common areas and thereby "force" what is private into the apartments. The young people do however appear to want to use the common room as a place where they can meet friends in a relaxed atmosphere.

The professional staff does however insist that the young people should preserve their private relationships and pays attention to situations, which may threaten to replace private relationships by professional ones. The professional relationship is thus defined as being an opposite of the private

one, which may be viewed as an aspect of how the relationship between the private and public may be defined.

Community, belonging and independence

The young people try, in various ways, to handle the socialization related to the other youths. The way, in which they spend time together in the common areas, may be viewed as an expression of how they want to position themselves in relation to each other. The young people display two patterns of interaction, the steady visitors and the mobile visitors. The young people who are part of the first group indicate through their interaction, that they wish to develop a community with all members of the youth group. The mobile visitors do however wish to be more reserved toward the community. This is expressed through them spending time in the common room only if certain people are present. Among the mobile visitors there are also examples of forms of interaction, which aim at marking a distance. There are however certain situations, which connect the two styles of interaction. During these occasions the young people help and support each other.

The young people have an ambivalent view of their parents. They wish to achieve greater independence, particularly regarding the more practical sides of everyday life, at the same time, as they are eager to preserve the emotional aspects of the relationship.

“We and them” – a precondition for the constitution of the staff

The professional staff faces several challenges. They are to develop a common position toward the young people, define future tasks, but also position themselves as a group. Staff conferences and training sessions are occasions when the entire staff is together and they thus have a large symbolic significance for creating a common social identity among the members of the staff. On these occasions, the professional staff discusses various difficulties and dilemmas of the work. There are different opinions within the staff of how the work is to be carried out. In order to resolve these differences in opinions, certain problems are redefined and are portrayed as problems that may be solved by establishing clear boundaries between the young people and the staff. Staff conferences and training sessions have a strong socializing function, which by being based on a “we and them” perspective incorporates the professional staff in a social sphere with a specific professional culture, which creates a sense of belonging.

An everyday life between habilitation and party

One strategy for strengthening the young people's influence and self-determination in their everyday life is to create so called habilitation plans. The goal is for the young people's needs to be described in concrete goals, which are possible to evaluate and which are to be followed up a couple of times per year. The habilitation plans are created in connection with habilitation meetings, which take place between the young people, their parents, and the young people's contact staff. The interaction during the habilitation meetings are based on the idea that all participants have an equal amount of power, have the same interests and even the same possibility to make their voices heard. The actual interaction within the concrete situation provides a different image. If the parents and the young person in question do not have a similar idea of how everyday life should be organized, there is a great risk that the young person's wishes are ignored. It is also revealed that the young people are unwilling to promote and uphold an idea that is different from the one of their parents. The demand for an ability to formulate concrete goals also makes it difficult for the young people to make their voices heard. A person is required to be able to distinguish his/her own need for help from social relationships and context, which requires an ability to objectify the self.

Situations that are characterized by a relaxed social interaction between the staff and the young people constitute a contrast to the interaction, which takes place during the habilitation meetings. They consist of internal parties either with or without invited guests and even of activities outside of the housing facilities, like camps. During these times, the social boundaries between the staff and the young people are relaxed and the social situation is defined by the concrete events that occur. This type of situations offer a common breathing space for the staff and the young people and gives the young people the opportunity to perform activities suitable for their age.

Self-determination, dependency and adaptation

Both the young people and their parents are in a position of dependency toward the staff. They therefore develop different strategies to achieve increased room for action. The young people successfully use certain circumstances in the ideological and organizational context to increase their freedom of action. The parents use a more general and conventional strategy, namely to maintain a front, which does not reveal the feelings behind it. In spite of a great inventiveness and creativity there are however a few circumstances, which appear difficult to influence, for example receiving certain forms of assistance, socializing in the way one wants and

deciding which circumstances should be discussed during the habilitation meetings.

The parents' and the young people's internal relationship is characterized by a close contact and mutual dependence. This close communication works as a channel of information for the parents who hereby receive continuous information about their child's well being. When the parents perceive that their child's well being is threatened, they return to the role of the caregiver. Some parents do however believe that it is inevitable that certain changes occur when young people move away from home.

Individual service, institutional learning processes and community, which supersedes boundaries

The young people's happiness over having their own apartment is obvious. Most of them say that they have increased room for action and more opportunities for privacy than when they lived in their parents' home. The young people are very eager to protect their apartment's private character, among other things, by deciding who is allowed access to their home. The young people also have more opportunities than before, to socialize with friends of their own age. The young people's internal relationships are however, of a contradictory character. They may constitute a potential for liberation and support, but may also contribute to the experience of increased vulnerability. There are nonetheless, situations where all the young people appear to enjoy each other's company and benefit greatly from it. These occasions may be related to the young people's experiences of having a disability and the fact that they are all in the same phase of their lives. They also appreciate opportunities to plan and participate in various activities, both inside and outside of the housing facility, with people of the same age as well as with the staff. The young people prefer to socialize in the common areas. Some use them as an extension of their own home and want to spend the majority of their spare time there. Others use the common area as a meeting place to meet certain preferred people, or to talk for a while. The access to the common areas may serve to regulate the relationship between closeness and distance to their friends.

The young people have an ambivalent relationship to their parents. They wish to have more independence at the same time, as they are very dependent on their parents' care. This dependence is reinforced by the fact that the young people may have trouble getting certain needs fulfilled by the housing staff, in particular of an emotional and intellectual character.

The young people's right to exercise individual self-determination in their everyday life and have a protected private life is emphasized in different

contexts in the housing facility. The staff therefore develops various strategies to define or rather to separate the everyday life into public or private spheres. This may create certain complications, in particular in cases where the young people do not have the same idea of how the relationship between private and public is to be regulated. If the staff's interpretation is given precedence, it may mean that the young people's private spheres risk developing into an empty social space.

Even the young people's possibilities to achieve individual selfdetermination in their everyday life are however connected to certain difficulties. A few processes are created, which contribute to maintain the myth of individual self-determination, despite the fact that the young people are subjected to collective disciplinary structures. They may be viewed as institutional learning processes, which force the young people into a collective individuality. The processes aim at regulating how the young people should take care of their apartments, what type of assistance they may receive and how the young people should socialize in the common room.

When there are previously established ideas of what an everyday life should be like, there is a risk that the relationship between the young people's need for assistance, their social relationships and context is separated. These situations also contribute to reinforce the staff's position of power. The everyday life in the housing facility is however also characterized by the opposite, when there are situations, which integrate the young people's need for assistance in an everyday structure. These situations are characterized by a flexible process of definition, which is based on concrete circumstances and events. During these occasions, the young people and the staff have more equal positions.

The differences that exist, between the family's everyday life and the life, which is established in the housing facility mean vast changes for the young people who may appear in more need of assistance than before. The staff attributes this to the young people's deficient personal competence, while several parents believe that the staff works in a way, which is not sensitive enough to the problems, created by the young people's disability. Even though the parties represent contradictory perspectives, they do however have a common stand point, which is to let the practical sides of everyday life symbolize and constitute a way to measure the young people's ability to be independent. An alliance is thus created, which may unintentionally limit the young people's developmental opportunities.

But how do the young people handle these demands? Some of the young people are defiant and refuse to let the practical sides of everyday life dominate their existence. Because they thereby reject their legitimacy, they do not allow their personal competence to be judged according to these

criteria. They often try to avoid these types of demands and mark their dissatisfaction with anger, grumpiness or obstinate silence.

There are however also young people who do not openly challenge the established demands, but who appear to accept the interventions of both parents and staff. They generally, but not always perform the tasks that are given to them. In cases, when this does not occur there are no open protests or other obvious signals, but they instead “slide away”.

The young people’s internal relationships are of a contradictory character. They may constitute a potential for liberation and support, but also contribute to the experience of increased vulnerability. The socialization with the others does however give the opportunity for spontaneous friendships, which is something the young people did not have access to when they lived at home.

Some concluding reflections

We have in this study, received an insight in the everyday life of a housing facility directed by the “good principles”, because the professional staff has expressed ambitions to respect the young people’s right to personal integrity and to work in a way, which allows for increased self-determination. In spite of this, certain complications do arise.

Moving away from home means a great adjustment and change for the young individual. It also constitutes the beginning of a process that means that the young persons should be given the opportunity to explore themselves and their relationships with their families and the rest of the world based on earlier experiences, personal qualifications and wishes. But the young people’s room for action is at risk of being limited because other people have preconceived notions of what the everyday life should look like.

The study does however also indicate that there is potential within situations of social interaction between the young people and the staff, which are characterized by flexibility, continuity and mutuality. The young people then have access to events that give new experiences with regard to their own ability, to other people and to the rest of the world.

ZAKOŃCZENIE RELACJI CZY ZMIANA – KIEDY MŁODZIEŻ Z NIEPEŁNOSPRAWNOŚCIĄ UMYSŁOWĄ OPUSZCZA DOM RODZINNY

Słowa kluczowe: niepełnosprawność umysłowa

Streszczenie

Artykuł dotyczy sytuacji grupy młodych osób z niepełnosprawnością intelektualną, którzy po wyprowadzeniu się z domów rodzinnych rozpoczęli nowy etap swojego życia w hostelu dla osób z niepełnosprawnością intelektualną. Należy zaznaczyć, iż w krajach skandynawskich hostele takie są powszechnie dostępne i większość osób z niepełnosprawnością po osiągnięciu pełnoletności przeprowadza się do takich domów – w ostatnich latach zamieszkało w nich ponad 5 000 osób. Przeprowadzone badania mieszczą się więc w nurcie współczesnej polityki społecznej Szwecji, w której podkreśla się zwłaszcza idee integracji, normalizacji i zapewnienia możliwości samostanowienia osobom z niepełnosprawnością intelektualną.

Hostel w którym prowadzone były badania składał się z 13 samodzielnych, jednoosobowych pokoi oraz szeregu pomieszczeń wspólnych (pralnia, pokój dzienny, kuchnia, pokój rekreacyjny). W artykule omówiono w szczególności sposób kwestię relacji pomiędzy osobami niepełnosprawnymi, personelem hostelu i rodzicami osób niepełnosprawnych. W prowadzonych badaniach szukano odpowiedzi na pytania o to, jakimi normami i prawami kieruje się młodzież mieszkająca w hostelu, jak kształtują się relacje emocjonalne i zależności międzyosobowe oraz jakie są możliwości samostanowienia mieszkających tam osób. W badaniach zastosowano metodę jakościowej analizy danych, zebranych dzięki trwającej dwa i pół roku obserwacji uczestniczącej oraz 28 wywiadach z mieszkańcami hostelu, ich rodzicami i personelem. Zebrany materiał poddano analizie i zaprezentowano w zakresie następujących zagadnień: uwarunkowania dojrzałości do nowej fazy życia i podjęcia decyzji o zmianie miejsca zamieszkania, warunki powodzenia pierwszych prób samodzielnego zamieszkania osób z niepełnosprawnością, zakres poczucia przynależności, wspólnotowości i niezależności odczuwany podczas mieszkania w hostelu, rola i zakres zadań personelu, możliwości samostanowienia, zakres zależności od personelu i warunki dobrej adaptacji osób niepełnosprawnych i ich rodziców do nowych warunków życia. W podsumowaniu autorka stwierdza, że chociaż możliwość zamieszkania w hostelu jest postrzegana jako szansa samodzielnego życia i samostanowienia dla osoby niepełnosprawnej, pomimo dobrej woli personelu i ich kompetentnej pracy, osoby z niepełnosprawno-

ścią mają zbyt mało szans na samodzielne podejmowanie decyzji o własnym życiu i realizację własnych planów. Warunkiem zmiany tej sytuacji może być zmiana relacji społecznych między personelem a mieszkańcami, które w większym stopniu powinny opierać się na zasadach stałości, wzajemności i elastyczności.

(streszczenie Ewa Domagała-Zyśk)

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