MOVING TO A NEW HOME

Producing a guide for parents whose intellectually disabled child is moving to a group home

Anna Kuusela Thesis, Fall 2013 Diaconia University of Applied Sciences, Diak South Degree Programme in Social Services

ABSTRACT

Kuusela, Anna. Moving to a new home. Producing a guide for parents whose intellectually disabled child is moving to a group home. Fall 2013. 21 pages. 3 appendices. Diaconia University of Applied Sciences, Diak South, Degree Programme in Social Services. Degree: Bachelor of Social Services.

The aim of this thesis was to produce a guide for parents whose intellectually disabled child is moving to a group home. The purpose of the guide is to offer most of the information the parents might need in this situation. The guide introduces relevant legislation, training for moving, legal guardianship and other matters to consider, and also offers further information in the form of internet links.

The data was collected via a focus group interview of parents whose children have moved to a group home, as well as literature research. The thesis also relies on my own previous and current experiences in working in group homes for the intellectually disabled.

The guide was done in association with Kepakoti group home. In order for the guide to be of use to Kepakoti and other Finnish speaking group homes, I intend to translate it to Finnish after the initial thesis process. The Finnish guide will possibly be produced by Keski-Uudenmaan Kehitysvammaisten Tuki ry., which is an organization I have been in contact with professionally earlier.

key concepts: intellectual disability, group home, assisted living, supervised living, guide, focus group interview

CONTENTS

1 INTRODUCTION	4
2 METHODOLOGY	5
2.1 Data collection method	6
2.2 Data analysis method and results	7
2.3 Ethical aspects	9
3 THE INTELLECTUALLY DISABLED	10
3.1 Housing	11
3.2 Group home as a community	12
3.2.1 Group home Kepakoti	13
4 PROCESS	15
4.2 Planning the guide	15
5 EVALUATION	16
6 SUGGESTIONS TO DEVELOP	18
REFERENCES	19
APPENDIX 1	22
APPENDIX 2	23
APPENDIX 3	24

1 INTRODUCTION

"The brochure would be wonderful to have in circulation for all those whose youngster is planning their move, that has concrete tips of what you need to know to ask and get done. Because there isn't one." – A mother whose child lives in a group home and was interviewed for this thesis.

My thesis is a product development where I produce a guide presenting the basic information a parent might need and want when their intellectually disabled child is moving to a group home.

This idea was originally presented to me by the mother of an intellectually disabled girl who I had been working with a year and a half before she moved to a group home. This particular group home, Kepakoti, gave out information abundantly, but everything that was not theirs to give, the parents had to seek out by themselves. The guide is designed to make the process of the move easier, so that the information is more accessible. Kepakoti also supported this idea and wished to have the guide to hand out to future residents' parents.

2 METHODOLOGY

When a child moves away from their parents' home, it is a big change for both, particularly in the case of an intellectually disabled child. The parents organize the entire move. Help from certain officials can be had, but before that the parent has to do research on what their child is entitled to, applications, deadlines and offices to contact. One has to know where to ask for said help. This is the reason for making this thesis: making the life of the parents of an intellectually disabled child easier.

The reason for producing a guide instead of making a traditional study is concretely aiding the community of the intellectually disabled families and bringing it together, and answering clear working life needs. The staff of group homes can overlook telling parents about even vital things as they are their daily

There is only one guide on this topic that I was able to find. It was produced by The Support Association of the Intellectually Disabled (Kehitysvammaisten Tukiliitto KVTL) in 2010. It is cohesive, but more designed for the mover or the entire family than strictly for the parents' needs. Another guide that is close to this topic is by Jernström and Parkkonen (2012). It is for parents of an intellectually disabled child who have recently discovered the disability, either directly after birth or in the course of developmental stages. That guide could be seen as a prequel to this guide; the child growing up and eventually moving away from home.

The family's situation is an important factor when making the decision about the move. For example, if there are siblings, their feelings and experiences are not without effect. Tapani Leander (2009) addresses the experiences of the siblings of the intellectually disabled child remarkably in his research. He states that each child reacts to an intellectually disabled sibling differently, but in most cases there is a strong effect. The siblings may experience the extra attention

the disabled child receives as negative, but at the same time having a disabled sibling can make them more compassionate and caring. (Leander 2009, 13)

2.1 Data collection method

The guide is based not only on my experiences in practical placements and working life, but also on a focus group interview and literature research. I studied literature, previous theses and other research related on the intellectually disabled and their families, community, group homes, and other related topics.

For the guide I needed the opinions of those who have been in the situation of their children moving to a group home. I arranged a focus group interview with five parents from my co-operating group home, Kepakoti.

"Within this history, focus group have been used to elicit and validate collective testimonies, to give a voice to the previously silence by creating a safe space for sharing one's life experiences." (Denzin & Lincoln 2008, 54)

Focus group interview was chosen because it was important for the parents to reflect upon each other's experiences and compare, and thus give me information. This particular focus group worked as peer support as well. The parents also already knew each other, which made the discussion warm and straight to the point, as there was no need for them to get to know each other. I also knew them quite well, because I had been working with one of their children previously for a year and a half, and done a project at Kepakoti in the spring of 2013 about the same child moving in.

There were five parents present. This size for the group proved to be good for this subject. With more people some members of the group might have had trouble with having their voices heard and the comfortable atmosphere of the situation could have been compromised, and with less people there would have been too little discussion and someone could have been too dominating. (CPRC Methods Toolbox n.d, 57.)

The focus group was scheduled so that we would have at least an hour but more if we needed. Eventually the conversation lasted an hour and 10 minutes. The discussion flowed very naturally and there was no need to artificially make it longer.

2.2 Data analysis method and results

The focus group interview was recorded and as transcribed text it was nine pages. In analyzing the data I used thematic analysis. I aimed at finding themes in the discussion, sorting them into those that were applicable to the topic and those that were not, and focusing on those that were relevant to the topic.

'Thematic analysis is a method for identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic.' (Braun & Braun 2006, 6)

The themes I searched for in the focus group interview were the issues the families would have wanted to know before their child moved to Kepakoti group home.

The main issue with each family seems to have been dealing with different authorities and their information blocks. Kansaneläkelaitos (Kela, The Social Insurance Institute of Finland) is notorious for obscurity in instructions, forms

and rules. The register offices were another instance the parents mentioned, as was the municipalities.

Another important topic in the participants' lives has been the issue of guardianship. For others, their disability service manager from the municipality put an emphasis on the matter, saying that it was crucial that the guardianship agreement was done as soon as the child was of age, and to others nothing was spoken of the subject and register office especially told them not to do it if it is only basic money handling. The opinions of whether having official guardianship or just using the child's bank account after the 18th birthday "quietly" the same as before is better or more convenient differed among the group based on personal experience. The ones who were legal guardians didn't consider the task excessively complex, whereas the ones who were not legal guardians were content with their present situations. What everyone agreed on, was that the information was not readily available and one needed to know what to ask. Even a couple whose disability service manager had recommended the guardianship had not been made aware of the fact that both parents need to made guardian if they wish for the other to be able to, for example, use their child's bank account without a yearly fee.

Everyone under the age of 18 in Finland is under the guardianship of their parents unless stated otherwise. The Finnish Law states that a guardian can be appointed to anyone of age who is due to illness, disturbance in mental capacity, deterioration in health, or similar reason incompetent to take care of themselves or their affairs and matters concerning their property that will not be taken care of in an appropriate manner otherwise. (Laki holhoustoimesta/Legislation of guardianship, 1999/442 8 §.)

2.3 Ethical aspects

In the guide pictures drawn by residents of Kepakoti were used as illustrations in the guide. Before the actual drawing session was conducted, permissions were asked of the parents of the residents. Also I received a permit to use the name and description of Kepakoti from its manager.

It is important to choose the wording in the guide carefully. Assuming anything in the guide about the family, for example the number or the sexes of the parents of the intellectually disabled child, or the diagnosis or severity of the disability can be offensive. Terms should also be chosen and used carefully. Initially the term 'mental disability' was used, as it is used in some of the literature, but after looking into it more carefully on my supervisor's request, I reached the conclusion that the term 'intellectual disability' is more suitable and appropriate. James Harris (2005) explains:

"Although "mental retardation" is the term used in both the International Classification of Diseases (ICD-10) (World Health Organization, 1992) and the Diagnostic and Statistical Manual (DSM-IV, DSM-IVTR) (American Psychiatric Association, 1994, 2000) systems that describe an intellectual and adaptive cognitive disability that begins in early life during the developmental period, the preferred term is "intellectual disability" internationally, especially in English speaking countries." (Harris 2005, 12)

3 THE INTELLECTUALLY DISABLED

According to the Finnish law of the special care of the intellectually disabled (Laki kehitysvammaisten erityishuollosta / Legislation of the special care of the intellectually disabled, 1977/519), an intellectually disabled person is someone whose development or mental function is inhibited or disturbed due to a innate illness, flaw or disability, or one of them occurring in the developmental age.

The World Health Organization (WHO n.d.) defines intellectual disability as follows:

"Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development."

WHO uses the ICD classification system, a standardized diagnostic tool based on IQ in classifying intellectual disability. IQ stands for intelligence quotient. The David Statt (1998) has a comprehensive definition for IQ:

"A score obtained from an intelligence test by dividing the mental age obtained on the test by the actual or chronological age and multiplying by 100, i.e. IQ= CA / ×100. An IQ score by itself is meaningless; it does not measure intelligence MA the way a tape measures height, for instance. It is only a measure of comparison between all the people who have taken that particular test, with the average range of scores being placed arbitrarily around 100."

The severity of the disability is divided into four degrees: mild, moderate, severe and profound. Those with mild intellectual disability have the IQ of 50 to 69 and the mental age of 9 to below 12 years. They are mostly able to live either completely independently or with support. Moderate intellectual disability indicates the IQ of 35 to 49 with the mental age of 6 to below 9. These

individuals mostly cannot live independently but have, for example, fairly developed communication skills. Those with severe intellectual disability have the IQ of 20 to 34 and the mental age of 3 to under 6 years and need constant care, but may have forms of communication, social relations or mobility, all of which are severely lacking or completely absent in the lives of those with profound intellectual disability and the IQ of below 20 with the mental age under 3 years. The social and communication skills of the intellectually disabled person are often better than their IQ and mental age might suggest. The mental age mentioned refers mainly to abstract thinking abilities and does not mean that the individual in question acts like a child of that age. (International Classification of Diseases n.d.)

Intellectual disability in itself is not a disease. No two people with intellectual disability are the same, even if they share the same diagnosis. This means that no generalizations should be made about the intellectually disabled. It also means that when planning housing in a group setting, settling in may be completely painless and easy for both the child moving and the parents, or it may turn out to be so disastrous that the child might have to move back with the parents. Each child's case is individual and should be viewed as such.

When discussing children in this text, the term 'child' means simply a son or a daughter who necessarily does not fit in the traditional age limits of children, as the children in question need extensive care even when they are not minors anymore.

3.1 Housing

In Finland there are approximately 40 000 people with intellectual disabilities, showing before the age of 18 (Kehitysvammaisten Tukiliitto n.d.). In 2009 approximately 13 000 intellectually disabled persons lived with their parents or

relatives, 9 000 lived in group homes, 3 000 lived with support on their own, 2 000 in institutions and 400 in short term rehabilitative living (Environmental administration 2009).

A group home is a dormitory with multiple residents and where there is a varied number of staff present either at all times or for example only during the day or certain days of the week. It depends on the group home and if it is assisted living, supported living or supervised living.

When an intellectually disabled person lives in their own individual or group apartment with a worker available to them, it is called *supported living*. Supervised living means living in a group home where there is staff present guiding and supporting during the day but not at night, and where the residents are more independent than in assisted living. Assisted living means living in a group home with staff present at all times, and where the residents need more assistance with every day activities. (Suhonen & Timonen 2010-2012, 7.)

3.2 Group home as a community

Guttmacher, Ruiz-Janecko and Patricia (2010) define a community as follows:

"A community is a group of people connected by visible and invisible links. Communities are defined in different ways. Geographic communities have geographic, physical or political boundaries, whereas communities of interest are connected not by physical space but by sharing of an interest, behaviour, risk or characteristic, and professional communities share knowledge as well as interests."

A group home for the intellectually disabled is a community where the residents are not only connected by the fact that they reside on the premises, but by the

fact that their background, situations and/or characteristics are similar to one another.

The intellectually disabled are not only a part of their physical community (city, town, country), or their family, but also the disabled community. Some intellectually disabled children are more involved with the disabled community than others before their move to a group home. After their move the children are not only involved with their co-residents. They also interact with other peers in hobbies and social events organized by parents' associations, the group homes or other such instances. Being involved with the community reinforces the intellectually disabled children's identity and gives them peer support.

3.2.1 Group home Kepakoti

Kepakoti is a private company that has provided housing for the intellectually disabled since the beginning of March 2013. Kepakoti is located in Pornainen in a specifically built house of its own. It has two units, both with five residents. One unit is for autistic residents and the other for other intellectually disabled young people. The latter group has one worker at all times, the other group has two. There is also a temporary care unit that is active both during the week and the weekend. All residents in both permanent units have no major physical disabilities. Their functioning levels differ, but most of them can dress themselves, go to the bathroom and eat themselves, but need help with the shower for example. Their fine motor skills differ more, and if and how well they can read.

The staff consists of practical nurses, sosionoms and a nurse. The director also works shifts in both units, which is an important factor in keeping him a sound part of the community.

Kepakoti has been co-operating during the thesis process. Through them I have been able to stage the focus group interview, gather illustration for the guide from the residents and receive support.

4 PROCESS

4.2 Planning the guide

When planning the guide it was important to keep in mind that it would be impossible to give each and every answer to each possible scenario and question, which is why it was important to try to not give all the answer, but provide references to and tips about places where to find further information, and how. Of course the guide also describes the most common issues parents faced with the important move discover.

The guidebook features the key legislation about housing and what it means in practice and where to ask more about it. It also explains in simple terms becoming a legal guardian, which becomes a relevant matter when the child turns 18 or when they move to a group home, if after the 18th birthday. In addition the guide encourages the parents to rely on the group home and ask them as many questions as possible; after all, the staff there is who their child will be living with. Training for moving, in addition to effects to siblings and parents, is also discussed.

5 EVALUATION

The thesis process has been a valuable opportunity to reflect on both my studies, practical placements and past working life experiences. It has also been an excellent point to begin my future career with the intellectually disabled. At my current work in a group home I am more prepared to co-operate with the parents of the residents due to the research made for the guide. I also consider any reading of materials related to the intellectually disabled an advantage in practical working life. Constant reflection during the process has been exceptionally important.

"While programme service evaluation and evaluation about social work are necessary for service development, they have often suppressed aware-ness of the necessity of evaluation as a part of practice, in a self-critical reflexive appraisal of process and outcome." (Shaw & Lishman 1999, 1)

The focus group discussion was challenging to organize. In the summer of 2013 I tried to schedule the four mothers from Kepakoti (and myself) to find a time that suits everyone, and it turned out to be more difficult a task than I had anticipated. But when we managed to find the time and the discussion was fruitful. I was also dreading if four people would be enough, but afterwards I came to the conclusion that more than four or five would have been too many. We were eventually five and I present, as one of the fathers also participated, which was very good because he brought a father's perspective to the discussion.

The time I had planned for writing was not as sufficient as I had thought, as I was fully employed from the spring of 2013 on. I also had other studies in the autumn.

The guide has seven chapters in accordance with the themes that the focus group interview raised. The chapters in the guide could be longer, but the information is concentrated for the purpose of accessibility. When the guide is short and to the point, the reader can reach the key information quickly and can be more interested in even picking up the guide.

Even though the plan is to translate the guide into Finnish, the English guide is not obsolete outside the thesis process. It is useful to students researching the intellectually disabled and their housing, as well as those already working in the field. It can serve as a reminder of all the things that a staff member takes for granted in their day to day work but that is new and strange to a new resident and their family. It is also essential to not forget the growing population of immigrants, whose first language is not Finnish and who also have intellectually disabled children. All these groups will benefit from this guidebook and especially the English version.

The contents of the guide have been discussed with the Kepakoti staff as well as the parents interviewed throughout the thesis process and am confident that it will answer to the need it was developed for. After translating it to Finnish, before printing, the guide will be given to the parents to be read and have them suggest any improvements.

6 SUGGESTIONS TO DEVELOP

Individual guides for group homes would be an excellent next step that I strongly recommend for each group home as they can answer questions specific to them. This way the group homes can better serve their customers.

The question of updating the guide will be relevant in the near future. This guide is published in both print and online, and the online version can and possibly should be updated. Some of its content is subject to aging and expiration, for example the links and laws, which is why updating is crucial for the guide to remain relevant.

REFERENCES

- Asuntoja asunnottomille. Kehitysvammaisten Tukiliitto. Accessed 2nd of October 2013.
 - http://www.kvtl.fi/media/Projektit/AsuntojaAsunnottomille/Omaa_koti a_kohti.pdf
- Baxter, L., Hughes, C. & Tight, M. 2006. How to research. 3rd Edition. Open University Press. Buckingham, UK.
- Braun, V. & Braun, V. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology 3. Accessed 16th of October 2013. http://eprints.uwe.ac.uk/11735/2/thematic_analysis_revised_-final.pdf
- CPRC Methods Toolbox. Chronic Poverty Research Center. Accessed 23rd of August 2013. http://www.chronicpoverty.org/page/toolbox
- Denzin, N. K. & Lincoln, Y. S. 2008. Collecting and interpreting qualitative materials. Sage Publications. Los Angeles, USA.
- Environmental administration. Accessed 23rd of August 2013. http://www.ymparisto.fi/default.asp?node=25198&lan=fi
- Guttmacher, S., Ruiz-Janecko, Y., Patricia J. K. 2010. Community-based health interventions. Jossey-Bass. Hoboken, NJ, USA.
- Harris, James C. 2005. Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment. Oxford University Press. Cary, USA.

- International Classification of Diseases. 2010. The World Health Organization.

 Accessed 17th of October 2013.

 http://apps.who.int/classifications/icd10/browse/2010/en#/F70-F79
- Jernström, Nina & Parkkonen, Pia. 2012. Lapseni on kehitysvammainen Opas kehitysvammaisen lapsen perheelle. Lahden ammattikorkeakoulu. Accessed 2nd of August of 2013. http://urn.fi/URN:NBN:fi:amk-2012111915628
- Kauppinen, Minna. Keskeistä lainsäädäntöä. Accessed 25th of September 2013. http://verneri.net/yleis/arki/keskeista-lainsaadantoa.html
- Kehitysvammaisten tukiliitto KVTL / The support association of the intellectually disabled. Accessed 29th August 2013. http://www.kvtl.fi/
- Kotikuntalaki/Home municipality legislation, 11.3.1994/201 3 a §. Accessed 23rd September 2013. http://www.finlex.fi/fi/laki/ajantasa/1994/19940201
- Laki holhoustoimesta/Legislation of guardianship, 1999/442 8 §. Accessed 23rd September 2013. http://www.finlex.fi/fi/laki/ajantasa/1999/19990442
- Laki kehitysvammaisten erityishuollosta/Legislation of the special care of the intellectually disabled. 23.6.1977/519 1§. Accessed 28th August 2013. http://www.finlex.fi/fi/laki/ajantasa/1977/19770519
- Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista/Legislation of services and support measures provided based on disability, 3.4.1987/380 8§ & 9§. Accessed 23.9.2013 http://www.finlex.fi/fi/laki/ajantasa/1987/19870380
- Leander, Tapani. 2009. Kehitysvammainen sisaruksena rikkaus vai rasite?

 Lahden ammattikorkeakoulu. Accessed 13th of October 2013.

 http://urn.fi/URN:NBN:fi:amk-201004066128

- Shaw, Ian & Lishman, Joyce. 1999. Evaluation and social work practice. SAGE Publications Ltd. London, UK.
- Statt, David A. 1998. Concise Dictionary of Psychology. Routledge. London, UK.
- Suhonen, Leena & Timonen Kirsi. 2010-2012. Oma koti, yksilöllinen tuki. Pohjois-Karjalan vammaisten asumisen suunnitelma 2012-2017. PohjoisKarjalan sairaanhoito- ja sosiaalipalvelujen kuntayhtymä. Accessed 13th of September 2013. http://www.pkssk.fi/c/document_library/get_file?uuid=1336a826-892d-486b-a478-e6c083853f0a&groupId=14730
- The World Health Organization. Accessed 13th of October 2013.

 http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

APPENDIX 1

Permission to use the grouphome's name

With my signature I give the student Anna Kuusela permission to use the group home Kepakoti's name and description in her thesis about a guide to the parents of intellectually disabled children moving to a group home and the research describing the process of making said guide.

signature

print name

Lupa käyttää ryhmäkodin nimeä

Allekirjoituksellani annan opiskelija Anna Kuuselalle luvan käyttää ryhmäkoti Kepakodin nimeä ja kuvausta, sekä omaa nimeäni, opinnäytetyössään kehitysvammaisten nuorten vanhemmille suunnatussa oppaassa ja sen tekemistä esittelevässä tutkimustyössä.

allekirjoitus

nimenselvennys

APPENDIX 2

Permission to use pictures			
With my signature I give the permiss my child	dren who a usela. The g	illustration in the guid	de for the up home,
signature	print name)	
Kuvankäyttölupa Allekirjoituksellani annan	luvan	käyttää	lapseni
•		iä kuvaa / kuvia kuv	•
sosionomiopiskelija Anna Kuuselan	·		
•		•	
vanhemmille suunnatussa oppaassa Kaikkia kuvia ei välttämättä käytetä.	, joka on n	іуоѕ папен оріппау	tetyonsa.
allekirjoitus	nimense	lvennys	

MOVING TO A NEW HOME



A GUIDE TO PARENTS WHOSE
INTELLECTUALLY DISABLED CHILD IS
MOVING TO A GROUP HOME

SO YOUR CHILD IS MOVING TO A GROUP HOME

Any child moving from their parents' home is an enormous change to both child and parents, let alone in the case of an intellectually disabled child. There are several matters to consider and find information about. This guide is for you, to make this transition phase in your life a little easier and to make your child's move to a group home more seamless and unproblematic.

The illustrations are pictures of Kepakoti group home, drawn by its residents.



TRAINING FOR MOVING

Training for moving is a training period that takes place before the actual move to the group home. The length of the period varies depending on the organizer, participants and overall situation. The training can include meetings of with the entire family and only those moving, visiting an getting to know the group home and its staff and residents, practicing skills needed in the group home and possibly spending a night or nights in the group home.

In addition to the mover practicing for the new chapter in their life, moving training also aims at strengthening the skills their parents need to support their child in the process, as well as for themselves as their lives are changing as well. Participating in training for moving is highly recommendable.

Training for moving is arranged by municipalities, group homes and different organisations, such as the Service Foundation for People with an Intellectual Disability (Kehitysvammaisten Palvelusäätiö) most prominently.

THE GROUP HOME

The particular group home your child is moving to is of course in a significant role. It is vital to be able to objectively observe your child's competence and cognitive skills and discuss them with your disability service manager. Keep these skills in mind when deciding on a group home: it might ensure that your child fits in and finds the suitable new home. Also remember that the decision is ultimately always yours.

Do not be afraid to ask the group home anything and everything! The only stupid question is the one not asked. The things you might want to ask about are the daily schedule, what are the general rules/restrictions of the group home, hobby possibilities, where does food come from and how is the menu planned, what is the environment of the group home like, does your child need their own linen and towels, who does the shopping for clothes, just to mention some examples. About the staff you might want to ask how many of them there are per shift, their education, work backgrounds and extra skills like sign language if needed.

LEGAL GUARDIANSHIP

A legal guardian is someone, most often a parent, who looks after the intellectually disabled person's affairs, most prominently their finances. It does affect other matters as well, for example certain information isn't given out to others than the legal guardian or the person themselves.

The parent is a child's legal guardian until they turn 18. Because usually an intellectually disabled person cannot take care of their affairs, it is advisable that the situation doesn't change after this birthday. The parent must apply for the renewal of the guardianship after it automatically ends when the child turns 18. Notice that should you wish for both parents to be guardians, you must apply for it separately. A legal guardian can also be a sibling, or some other person close to the youth.

The register office is the place to apply to be a legal guardian, and to ask any questions related to it. The register office monitors the client's (as the youth is called when talking about guardianship) affairs and how the legal guardian is handling them.

LEGISLATION CONCERNING HOUSING

The legal jargon concerning the intellectually disabled and especially housing in this case can be confusing. The legal text also leaves room for interpretation, which is why it is always important to find out how things are in your child's particular case and to discuss your child's care and services thoroughly with your own disability service manager. Here are some of the key points in more simple terms.

Based on the disability services law the municipality is responsible for providing the intellectually disabled person's housing. If the disability services law does not cover everything, the housing will be provided based on the intellectual disability law. The law that provides better terms for the person in question is always used. The municipality does not have to have a group home (or other housing) of its own, but it can buy services from an already existing source. The "normal" payments that come with housing and life in general (rent, water, electricity, medication) are paid by the disabled person themselves. The municipality is responsible for different services and support measures that the person needs in order to guarantee the organizing of the housing, i.e. the help with (among other things) eating, personal hygiene and getting dressed cannot be charged for, but the food, hygiene products and clothes are charged for.

According to the home municipality legislation, a person can choose their home municipality when in a long term care relation. Long term here means that the care has lasted or is estimated to last at least over a year. For instance, when moving to a group home in a different municipality, a disabled person's home municipality can be changed to be that same municipality to make health care and transportation issues simpler.

OTHER MATTERS TO CONSIDER

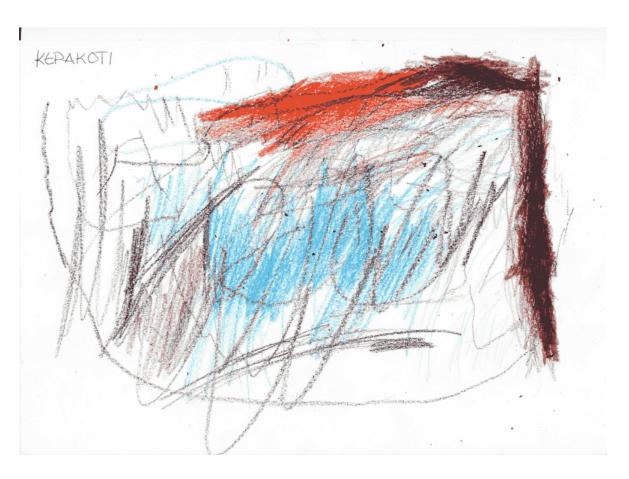
There are a number of matters to consider. Your child deserves the chance to become independent and for most intellectually disabled people, moving to a group home is as independent as they can become. They have a right to a home of their own. Being apprehensive is only natural and you should remember that it is a universal feeling shared by anyone whose child is moving away from home.

You as well deserve the chance to live a new adult life after taking care of your child for so long. But you are not leaving your child forever or vice versa: there will be visits, as many as you would like. Remember however that your child may not always want to see you or come for a visit, as they now have that option as independent adults.

If there are siblings, they are usually strongly affected by an intellectually disabled sibling, both in positive as well as negative ways. They may be bullied in school or be required to behave more maturely than their age in many cases, but they also receive plenty of joy from their disabled sibling and learn to become responsible by

helping their parents care for their sibling. Some distance, both physical and mental, to the disabled sibling might do some good. The negative aspects fade as the positive become stronger.

Also, your child will not be moving to a home without any friends: they will have many new friends from their co-residents and the staff. Peer interaction and support are great advantages to group home living, not only for your child but for you as well. If the group home does not already organize relatives' evenings or something like it, it is an easy and fun way of peer support.



By Aatos

FURTHER READING AND INFORMATION

Legal guardianship

Register office http://www.maistraatti.fi/fi/lomakkeet/#Holhoustoimi/,

Verneri.net http://verneri.net/yleis/arki/kun-haet-palvelua/edunvalvonta.html

Legislation

The disability services law

http://www.finlex.fi/fi/laki/ajantasa/1987/19870380

The home municipality law

http://www.finlex.fi/fi/laki/ajantasa/1994/19940201

The legal guardianship law

http://www.finlex.fi/fi/laki/ajantasa/1999/19990442

The intellectual disability law

http://www.finlex.fi/fi/laki/ajantasa/1977/19770519

Essential legislation

http://verneri.net/yleis/arki/keskeista-lainsaadantoa.html

Kehitysvammaisten Tukiliitto RY – Inclusion Finland KVTL legal guidance http://www.kvtl.fi/fi/lakineuvonta/

Peer support

Blogs of parents of special needs children – Erityislasten vanhempien blogeja

http://www.blogilista.fi/avainsana/erityislapsi/1/suosio

Family Federation of Finland's siblings' discussion forum – Väestöliiton sisarusten keskustelufoorumi

http://www.vaestoliitto.fi/perinnollisyys/sisaruus-keskustelupalsta/

Inclusion Finland KVTL Peer support online – Kehitysvammaisten Tukiliitto RY Vertaistukea verkossa

http://www.kvtl.fi/fi/perhesivut/vertaistuki/vertaistukea-verkossa/

Leijonaemot RY https://www.leijonaemot.fi/vertaistuki

Peer support families of the Finnish association for Autism and Asperger's syndrome – Autismi- ja Asperger –liiton vertaisperheet http://www.autismiliitto.fi/liitto/vertaisperheet

Relatives of special needs children, ELO registered association – Erityislasten Omaiset ELO ry

http://www.erityislastenomaiset.fi/vertaistuki/vertaisperhetoiminta/

Others

Kynnys.fi, personal assistance – henkilökohtaista avustamista http://www.kynnys.fi/content/view/616/606/

Ministry of social affairs & health – quality recommendations of housing services for the disabled - Sosiaali- ja terveysministeriö, vammaisten asumispalveluiden laatusuositus http://www.stm.fi/julkaisut/nayta/-/_julkaisu/1066353

Training for moving by KVPS – Kehitysvammaisten palvelusäätiön muuttovalmennus http://www.kvps.fi/perheille/muuttovalmennus

Sentteri.fi, personal assistance – henkilökohtaista avustamista <a href="http://sentteri.fi/index.php?option=com_content&view=article&id=2<emid=1">http://sentteri.fi/index.php?option=com_content&view=article&id=2<emid=1

Service plan – Palvelusuunnitelma http://verneri.net/yleis/arki/palvelusuunnitelma.html