THESIS

PEOPLE WITH INTELLECTUAL DISABILITY AT WORK -
Awareness training for potential employers

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Thesis
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Degree Program in Social Services – Community Development
ABSTRACT


This development oriented product-based thesis produces photos and written material for Finnish Association on Intellectual and Developmental Disabilities (Kehitysvammaliitto) Palkkaa Mut-project’s social media campaign for the spring 2018. Qualitative methods are used in the form or participative methods, as the material is created through one group interview including a photo-shoot.

The material includes five photos of an employee with an intellectual disability and an employer. Short stories were written from the interviews to enhance the information of the photos. This thesis aims to create material that will be used in awareness training by Finnish Association on Intellectual and Developmental Disabilities for potential employers to employ people who have an intellectual disability.

The report outlines the process of this thesis. It also includes information about the developmental needs of the employment of workers with an intellectual disability and a short theoretical background about working life, intellectual disability and relevant regulations and laws.

Keywords: intellectual disability, employment, equality, awareness training
APPENDIX 2: Haastattelukysymykset (Questionnaire) ........................................ 21
APPENDIX 3: Tuote (Product) ........................................................................ 21
1 INTRODUCTION

The main goal of this thesis is awareness training for potential employers and to produce material related to this goal as agreed with Finnish Association on Intellectual and Developmental Disabilities. This development-oriented product thesis is made to enhance the awareness of employers to hire employees with an intellectual disability. The statistics from 2016 show that about 2000 people with an intellectual disability are in work-activity, which is part of the social care and pays 12 euros per day. This type of work is the very same work that is done in work places with a full pay. (Verneri 2016). Instead the work is produced by people who are already in a vulnerable situation due to disability and in some level they are taken advantage of. There is a need for improvement in giving a real job for those who are in work-activity, but could do the same work and get a decent pay for it.

The product produced in this thesis is stories written from a group interview and photos taken of the interviewee’s. They will be used in social media by The Finnish Association on Intellectual and Developmental Disabilities (FAIDD, Kehitysvammaliitto) to promote awareness of hiring workers with an intellectual disability in spring 2018. I interviewed and took photos of one employee and one employer. I aim to provide insights from the real life situations and experiences from the interviews. My intention is to courage future employers to hire a person with an intellectual disability. Bringing real experiences into daylight, both good and challenging, may reduce any possible lack of information or misconception about the matter. Using interviews to reveal ways in which challenges have been met and overcome is one part of this thesis.

There are many research and projects done related to the employment of people with a disability but still there is need for improving the high rate of unemployment. Some information for the employees available are for example; ‘Saatiin töitä! Monenlaisia tuloksentekijöitä-hanke’ and ‘Kehitysvammaisen henkilön työllistäminen’, by FAIDD. (K-kauppiasliitto 2017).
2 BACKGROUND

2.1 DEVELOPMENTAL NEEDS

The reason there is a need for improvement in the employment of people with an intellectual disability lies in the high unemployment number in Finland. There are about 40,000 people in Finland with an intellectual disability. 3000 from the 40,000 could be working but only few hundreds are. This means that the unemployed rate is approximately over 80%. Some part of the work activity that is part of social care is outsourced into regular work places. This type of work is called open work activity. There are about 2300 people in this type of work without getting paid more than 12e a day. The goal is to obtain a status that shifts from social care into paid work when possible. (Kehitysvammaliitto 2017).

People with an intellectual disability have worked throughout times. The industry that produced f.e. assembly and packaging type of work provided a lot of work environments, but after the subcontracting of this type of industrial was moved outside of Finland, many of the work possibilities have decreased. However the biggest barriers for employment lie in the shortage of work coaches and in the tradition of unpaid open-work activity. The best results in other EU countries on increasing the paid work have been resulted in the increase of work-coaches. (Kehitysvammaliitto 2017).

Social attitudes towards intellectual disability is not to be forgotten in the reasons behind unemployment. Research shows that attitudes towards intellectually disability are somewhat negative and are irrelevant of the persons demographics or contact. (Wilson & Scior 2015). This may also influence the employment of a person with an intellectual disability.
2.2 PARTNERS

This thesis will be made primarily in collaboration with The Finnish Association on Intellectual and Developmental Disabilities (FAIDD) (Kehitysvammaliitto). The material produced in this thesis will be published in spring 2018 at FAIDD’s social media, in Twitter, Instagram and Facebook. The pictures and short stories will be used in FAIDD’s social media within their Palkkaa-mut-project, that has a new campaign coming out in the spring 2018. Palkka-mut is a project funded by STEA during 2017-2018 and aims to enhance the employment of people who have an intellectual disability. The project uses employment coaching and peer support groups as methods and also develops collaboration with employees. The goal of their new campaign is awareness training for employers and hence the very same as the goal of this thesis. Collaboration with FAIDD is fruitful as the material I will produce is needed and will be used in their campaign. (Kehitysvammaliitto 2017.)

Other partners for this thesis are The Helsinki Deaconess Institute (Suomen Diakonissalaitos) Home Maintenance Program, a special education program in general vocational school (erityisopetus yleisessä ammatillisessä laitoksessa), where I intended to interview two students and Supported Employment Services (Tuetun työllistymisen palvelut) that helped me find an employee and an employer to interview.

Through Supported Employment Services another partner for this thesis emerged: Palvelutalo Sagacare, an assisted living building for elderly, whose premises will be used for photo-shoot. Two interviewees, an employee and an employer are working in this place.
2.3 GOALS AND TARGET GROUP

The main goal of this thesis is to produce the material for FAIDD as agreed and described in this thesis. Through the material I aim to reach employers who could benefit from the material produced by gaining more information and encouragement to hire a worker who has an intellectual disability. Decreasing possible prejudices is also a goal of this thesis. It is a hope that through social media the material will reach a wider spectrum of an audience than if the material would be made into a paper-leaflet. FAIDD may also use the material when directly contacting future employers. Supported Employment Services also have the permission to use the material, as long as the information of the original campaign Palkkaa-mut is provided.

I also hope to inform the employers about the process of hiring a person with an intellectual disability and of the support there is available before and during an employment through the stories written from the interviews.

Target group of this thesis are the future employees and the beneficiaries people whose employment is being promoted.
3 REGULATIONS AND DEFINITIONS

3.1. INTERNATIONAL AGREEMENTS AND LEGISLATION

There are many declarations and regulations that define the right to work for people with an intellectual disability. In the following there are some examples of them.

According to the Declaration of Human Rights, Article 23.1, ‘Everyone has the right to work, to free choice of employment, to just and favorable conditions of work and to protection against unemployment.’ (United Nations 2017).

Also a specific section for rights of a person with a disability (Article 27(26)) states the same outcome ‘1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive and accessible to persons with disabilities.’ (OHCHR 2017).

Finland ratified both the above declarations in 10.6.2016. This was very important to Finnish people with disabilities as it made easier to chose their preferred municipality to live in. Overall self-determination was also increased by organization of personal assistance. (Verneri 2017).

‘The Finnish employment supporting services system is well developed but somewhat complex and out of date. The emphasis for persons with disabilities has been to provide them the adequate income support and services. The question is how to find the balance between the policy towards open labor market and sheltered settings.’ (VAMPO, Finland's Disability Policy Programme 2010–2015).
Social care institute for excellence states in the Care Act 2014 that one part of wellbeing is 'participation in work, education, training or recreation'. The concept of wellbeing is broad but it is seen that work is an important part of it. (Social care Institute for Excellence 2017).

It is important that the laws and regulations are taken into action so that the population that is now not meeting their full rights would do so in the future.

3.2 DEFINITIONS

To better understand the dimensions and meanings of the terms used in this thesis, we shall look at some of the key concepts related to employment of a person with a disability.

3.2.1 DISABILITY

Disability is a diverse term that has changed in time. Nowadays it can include different kinds of diagnoses. Below I have collected a few different definitions.

United Nations Human Rights Office of the High Commissioner defines intellectual disability as: ‘Significant impairment of intellectual (cognitive) functioning indicated by a full scale IQ below 70; Alongside significant impairment of adaptive (social) functioning that affects how a person copes with everyday tasks in three areas: conceptual, social and practical domain. These difficulties must be of early onset, i.e. they are not the result of trauma or deterioration experienced during adulthood.’ (United Nations Human Rights Office of the High Commissioner 2017).

WHO describes intellectual disability in the following way. ‘Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action;
while a participation restriction is a problem experienced by an individual in involvement in life situations’. (WHO 2017).

Intellectual disability, by AAIDD, means a difficulty to learn and understanding new things and is not to be confused with CP (Celepral Palsy) or other physical disabilities (Kehitysvammaliitto 2017). American Association on Intellectual and Developmental Disabilities (AAIDD) defines the term in the following way: ‘Intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18.’ (AAIDD 2017).

Intellectual disability can also be looked at from different perspectives, for instance, through medical and diagnostic, mobility or social point of views. These all vary from each other in the way we understand disability. The most traditional perspective is the medical one. The latter two, mobility and social aspects are newer. A more humane way of looking at intellectual disability is when you think of it from the social perspective. It emphasizes that instead of the actual disability, it can often be the prejudices, the fact that you depend on other people or discrimination that is in the way of possibilities in life and self-determination. (Verneri 2016).

3.2.2 WORKING-LIFE CONCEPTS

In Finland a large number of people with a disability, who have the capability to work participate in work or day activities. This prevents them to be independent workers but rather dependent social care customers. Some of the downsides to this are that the pay is low, a pension doesn’t accumulate and there is no occupational health care. (Kehitysvammaliitto 2017). To work as a paid worker gives the possibility to build one’s identity based on an independent worker rather than through disability.
TABLE 1. Working-life concepts UNOFFICIAL TRANSLATION

<table>
<thead>
<tr>
<th>WORKING-LIFE CONCEPTS</th>
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<tr>
<td>PAID WORK</td>
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<td>SUPPORTED WORK</td>
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<td>SUPPORTED EMPLOYMENT</td>
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<td>SALARY</td>
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<td>SOCIAL CARE</td>
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<td>OPEN-WORK ACTIVITY</td>
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<td>WORK ACTIVITY</td>
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<td>DAY ACTIVITY</td>
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<td>SERVICE-RELATIONSHIP</td>
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<td>ACTIVITY GRANT (0-12e/day)</td>
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(National Institute for Health and Welfare 2017.)

Employment coach (työvalmentaja) is a crucial part of a successful employment of a person with an intellectual disability. The role of an employment coach is to support both the employee and the employer. Aula Työkötiens Kannatusyhdistys ry has conducted a survey that showed that employers need more information about hiring an employee with an intellectual disability and that they trust the evaluation of an employment coach in the hiring process (Aula Työkötiens Kannatusyhdistys ry 2016).
4 WORK PROCESS OF THE PRODUCT

4.1 RESOURCES

There are multiple resources for this thesis and they are: time, people, venues, programs such as Photoshop Adobe Microsoft Publisher, PDF-edit, excel and word. Material resources were also needed, such as a camera, computer and a recorder. I borrowed a good camera from a friend and took the photos myself. There was no need for a budget, as there were no financial costs.

4.2 SCHEDULE

TABLE 2. Project Plan Timeline Chart 2017-2018

<table>
<thead>
<tr>
<th>Project Timeline</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>August</th>
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<th>October</th>
<th>November</th>
<th>December</th>
<th>January</th>
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Actual Time

Planned Time

Above you can see the timeline for this thesis, both planned and actual times of action.
4.3 RISKS

Risks included but are not limited to; participants not showing up or being able to deliver, stakeholders cancelling participation, sudden need to do more paid work than planned and that causing delay in schedule or schedule difficulties due to applications not being applied in time.

Preparation Project was planned to be made in the as part project studies MCI2 and -3 courses with Finnish Diaconia Institute to collect background information and to make couple of interviews in order to see what needs to be improved. The purpose of this was to show possible needs for improvement to be done in order to make the final products more effective. Because of time conflict the actual test interviews were not made, however much information was gained from the experience of spending time with the student who had an intellectual disability and were studying in a home maintenance program for a profession.

4.4 IMPLEMENTATION

The intention for collecting material was to interview 2 students and 1 employed person who have an intellectual disability, 1 work coach and 1 employee. Altogether I aimed for 5 interviews to be made. The number of interviews was originally higher but when the project started, it became clear that for better quality of the material produced, it would be better to keep the interviews at this number. I planned to take photos of the interviewee’s and create short stories from the interviews. The material is produced to be posted in FAIDD’s facebook and Instagram, pictures with stories with FAIDD’s social media campaign within the Palkkaa-mut-project in spring 2018.

The interviews were intended to be two different kinds. One group interview and three individual interviews. I ended up using only one group interview. More specifically the interview was semi-structured. ‘Semi-structured interviews are often preceded by observation, informal and unstructured interviewing in order to allow researchers to develop a keen understanding the topic of interest necessary for developing relevant and meaningful semi-structured questions.
The inclusion of open-ended questions and training of interviewers to follow relevant topics that may stray from the interview guide does; however, still provide the opportunity for identifying new ways of seeing and understanding the topic at hand.’ (Journal of Social Health and Diabetes, 2013).

Galletta describes semi-structured interviewing in the following way: ‘Characteristic of its unique flexibility, semi-structured interview is sufficiently structured to address specific dimensions of your research question while also leaving space for study participants to offer new meanings to the topic of study.’ (Galletta 2013, 1-2).

Semi-structured interviews allow the pace and space to ebb and flow with some particular questions in mind. Also depending on the situation and state of mind of the interviewee, the questions can be quid and stretched in a way that can feel comfortable for all participants. This was important to me as I felt that there should be a lot of consideration to make the interview as comfortable as possible due to the interviewee being a vulnerable participant due to intellectual disability.

The one group interview took place at Sagacare’s conference room. It was kept in the morning of 25.10.2017 before the the work shift started. The situation was build around a breakfast, which one interview always had in the work place before starting the work day. In the interview, the participants where an employee who has an intellectual disability, employer and myself. The interview lasted about 30 minutes after which I took pictures of the employee in her job activities. Before the activities, I also took pictures of her discussing with the elderly of the resident, as this was something the employee did every morning before starting her work day. The photo-shoot lasted for about 30 minutes, from which the employer took part in the beginning of it for 5 minutes. After the photo-shoot the participants work day continued as normal.
4.4.1 CHANGES OF IMPLEMENTATION

Due to time conflicts with research permits, I needed to make quite a lot of changes to the original plan. Most importantly I changed the amount of the interviews from five to two. I interviewed one employee who has an intellectual disability and one employer. The reason I chose to do this, was that to interview these two, I did not need the research permits that I was going to get later than my schedule permitted. This means that I did not interview any students or a work coach.

Another big change was, that since I only had one employee to interview, I changed the photo-shoot to be more of an story of her work day, rather than having only one or two pictures of her. The written part that I attached to the pictures still included information that I intended for the possible audience to have, but also followed more of the interviewee’s work tasks and work day than originally planned.

4.4.2 RESEARCH PERMITS

Below you can find a chart of the permits that I applied, and eventually used to create this thesis. In the end, I only used two permits. You will find more detailed information about each of these in the later part when I go through the challenges of this thesis.
### TABLE 3. Research permits

<table>
<thead>
<tr>
<th>Permit</th>
<th>Applied</th>
<th>Not used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diak research permit</td>
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<tr>
<td>Helsinki City’s Permit</td>
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<td>HDL ethical board permit</td>
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<tr>
<td>Individual permits</td>
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<tr>
<td>Sagacare permit</td>
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#### 4.5 FINAL PRODUCT

The final product includes five pictures and for them, written stories. I took altogether 32 pictures from which I chose the best 5 to be used. Four of the pictures are of the employee in her work and one picture is with the employee and the employer shaking hands. In one picture, also a resident from Sagacare is participating. The residence for the pictures is in Sagacare Helaapuisto. I am fairly satisfied with the pictures, although in the making of them, I needed to act very instinctively and create as I go, since from the first time I visited the place and got familiar with the interviewees as well, I did not plan to shoot the employee’s many work tasks, but only one. However the day went quite smoothly and the atmosphere was relaxed. There were three residents who were willing to be ready to be in the pictures with the employee, if needed. They all signed individual permits and also had self-determination. However I only ended up using one picture that included one resident. I have attached the final product in the Appendix.
5 DISCUSSION

5.1 ETHICS

Research ethics are very important, considering that the project is done with a vulnerable group of people. For example, the participants need to understand what they are participating in, including the partition in the social media. This is important and I did my best in making conscious and ethical decisions when putting together the pictures and writing. To reach this goal, the participant with an intellectual disability signed an agreement form that has been written in plain language. Specific and detailed information of the participant will be used with care and avoid. Only when something is necessary, I use specific information, to bring out the ideas and thoughts I am hoping to share with this project so that the outcome will be influential. Permission from possible guardians were be obtained when necessary.

Edwards explains that one of the biggest benefits of open-ended questions is that they allow respondents to use their own set of reference. This will take away any pre-stated alternatives and can lead to answers that are closer to the real views of the interviewees. (Edwards 1997, 26).

Questions were mostly open-ended so that they did not lead to a predetermined or guided answers. A good example of how ethics are used in this project is, that the work coaches from Supported Employment Services already have assessed, who is a good candidate for this project and able to participate so that participation will not be too much or effect poorly on the individual's life. This is done before even bringing me and an interviewee together and from there on I will explain the project in more depth so that I can be convinced that the process and possible influences of the project are understood by all. During the project, confidentiality is applied, and information that will be used in the final work is agreed with all participants.
When writing the short story about the interviewee I will use first name only. I believe it brings credibility to the work when people will see and read it but will not give too much personal information, such as a last name. Also addresses and phone numbers will not be written in the final produced materials. Participants faces will be shown in the pictures. They will however have a right to see the pictures before they are published. One reason the participant was chose to the project is age. The interviewee is not a teenager, but an adult with many years of life and work experience.

5.2 CHALLENGES

Research permits and time management have been the biggest challenges for this thesis.

In the beginning, I did not apply the research permits early enough and later that became a challenge that made me make some changes into the original plan of this thesis. I applied for the Diak’s research permit, but it turned out that I did not need that for my thesis. This permit I had already promised to one partner, Finnish Diaconia Institute (SDO), and since I did not get that, they understandable wanted another type of permit, which was HDL’s ethical boards permit. I applied to that one, but for this thesis to be made within the year 2017 it was not going to come through in a timely manner.

I also applied to Helsinki city’s research permit for the sake of taking a picture and interviewing one employment coach that work for Helsinki city. This permit also would have taken more time so I ended up letting go of interviewing a employment coach.

Time management has been challenging throughout this thesis. In the beginning of this process I knew I was going to work full time until the mid-way of summer. I had planned that after stopping my full-time work I would have enough time to finish all my thesis work by the end of September 2017. I got a job offer in the
beginning of September that manifests the whole purpose of why I started to study social services so I took the job and decided to aim to graduate later.

5.3 CRITICAL VIEW

When I look at the final products critically, one aspect comes particularly in mind. The original aim was to provide more diverse material to do the final product from. Perhaps interviewing only one employee and employer is not as ethnographic as interviewing also students and an employment coach. The latter would have given more broad perspectives and views on the matter.

Another critical point I find is the amount of pictures of only one employee. There is a slight concern about if that one employee will gain too much publicity with 5 different pictures of her in social media. I am solving this concern with letting FAIDD decide of how many pictures they chose to use out of the ones I’ve produced now that there only is one person interviewed, who has an intellectual disability. FAIDD has high professional understanding and evaluation skills in evaluating, weather is is better to use less pictures than provided. The agreement regardless is, that they can use the material produced in ways that they see fruitful.

5.4. PROFESSIONAL DEVELOPMENT

The reason I wanted to do a development-oriented thesis is that I believe it will teach me more skills in project management. This would help me in the future to do more projects in the field of social service. I feel I chose the right type of thesis work as there has been many important teachings I have gained throughout the process.

My wish was to learn more about project management and the biggest learning has been about the research permit procedures in more detail, I have learned what is needed for the permits, how long different types of permits
need time to be processed and most significantly, to put effort on researching well enough of what permit are required. Even thought the learning came through the challenges with the research permits, I feel it only deepened the actual learning. It has been very valuable to have first hand experience about it.

What I learned about time-management is also mentioned to be one of the common challenges of a project manager, specially when the project manager is also the one maker of the project. Heagney explains that when project managing and technical work of the project is combined, there is a danger for the technical work to be in the focus and the managing in the background. Retrospectively this was also my challenge and a big learning point. (Heagney 2011, 30-33.)

Even though I have felt to be an ethical person, I've also learned during this thesis process, to dig even deeper into my assumptions on what I think is ethical. To this I have my thesis supervisor to thank for. Hanna Lamberg has provided efficient and relevant insights throughout this process and helped me to question the questioned. When working with a vulnerable group of people, this really is high of an importance.
6 REPORTING AND PUBLICATION

Thesis report will be one way of reporting. I will include agreement forms and interview questions in the appendix. The permit from Sagacare is verbal and therefore will not be in the appendix.

The material produced in this thesis will be used by FAIDD in spring 2018, but the actual publication of this thesis is 29.02.2018. The pages where FAIDD will use the material are the following; https://twitter.com/KVLiitto, https://www.facebook.com/kehitysvammaliitto/ and https://www.instagram.com/kehitysvammaliitto/. Material might also be used at FAIDD’s own web-page http://www.kehitysvammaliitto.fi. FAIDD has all the rights to modify the material I have produced, as long as modifications are provided to the interviewees before publishing.
REFERENCES:


https://plato.standford.edu/entries/peirce-semiotics/#SigEleSig


APPENDIX

LIITE 1: SUOSTUMUSLOMAKE

LIITE 2: HAASTATTELUKYSYMYS

LIITE 3: TUOTE
LIITE 1: SUOSTUMUSLOMAKE

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<tr>
<th>Nimi</th>
<th>Päivä</th>
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Jos haastateltavalla on laillinen edustaja, hänen suostumusensa:

<table>
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<tr>
<th>Nimi</th>
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<th>Paikka</th>
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LIITE 2: HAASTATTELUKYSYMYSKSET

Semi-structuroidun haastattelun runko

Työntekijälle
1. Mitä sinun työsi sisältää?
2. Mikä on parasta työssäsi?
3. Millaisia haasteita olet kohdannut työssäsi?
4. Mitä kautta kuulit työpaikasta?
5. Millaista tukea työvalmentajasta on sinulle?
6. Mitä haluaisit sanoa mahdollisille työnantajille?

Työnantajalle
1. Mikä on parasta työntekijässäsi?
2. Millaisia haasteita olet kohdannut? Jos niitä on ollut, miten ne on voitettu?
3. Mitä haluaisit sanoa mahdollisille työnantajille liittyen kehitysvammaisen palkkaamiseen?
4. Mistä palkkasit työntekijäsi?
5. Miten koet työvalmentajan roolin?
Reijan työnkuvaan kuuluu mm. ruokalan siisteydestä vastaaminen astioiden keruun merkeissä. Sagacressa on tilavat ja valoisat tilat joten työmpäristö on viihtyisä. Työssä on mukana myös kaupungin työvalmentaja, joka käy työpaikalla n. kerran kuukaudessa. Silloin työvalmentaja, Reija ja työnantaja istuvat alas kahvittelemaan ja käyvät läpi edellisen kuukauden kuulumisia. Työvalmentaja tukee niin työntekijää kuin työnantajaa esimerkiksi työsopimukseen liittyvissä kysymyksissä ja kulkee mukana koko työsopimuksen ajan. Tuettua työllisyttä voi hakea kaupungin Tuetun Työllistymisen Palveluista ja se on työntekijälle sekä työnantajalle maksutonta.
Mieleinen työ ja kiva työyhteisö saavat Reijan viihtymään työpaikallaan, jopa niin paljon että hän tulee joka päivä töihin etuajassa ja syö aamupalan Sagacaressa asuvien ikäihmisten kanssa. Eeva-Liisa kertoo että on mukavaa kun Reija tulee halamaan aamuisin ja toivottaa hyvää huomenta. Reija on Sagacaren hengen luoja.