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Bachelor
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Thesis, 2022

MY SEXUAL RIGHTS

**A tool for professionals to explain sexual rights to people with
Autism Spectrum Disorder**



ABSTRACT

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52 pages and 9 attachments
Published April 2022
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Bachelor
Social Services

This project-oriented thesis is carried out with the collaboration of Autism Foundation Finland. The aim was to create a low-tech visual aid to help the professionals of Autism Foundation Finland to explain basic sexual rights to people with autism. The aid consisted in a booklet containing information about sexuality and sexual rights illustrated by pictograms with short, clear, and simple sentences.

Autism Foundation Finland is the Working Life Partner. The foundation's origin is a Rehabilitation Project for Young Adults launched in 1992. The first of its kind that targeted people with autism with the objective of facilitating the independent living of young people on the spectrum. Following the meetings and conversations with the Working Life Partner (WLP) and based on the research carried out on the topic of autism spectrum disorder and sexuality, many elements/problems like the deficit of communication, the lack of accessible sexual education and the sexual abuse exposure of the people with autism spectrum disorder (ASD) emerged as recurrent.

Hence, with the approval of the WLP, the booklet was produced as an answer to that need for education and as a facilitation guide for the service users to understand their basic sexual rights. After interviewing the sexual counselor of Autism Foundation Finland, and after research on the topic it was decided that the sentences for the book would refer to the right to masturbate and where to do it, physical contact consent, and identifying and reporting abuse. The booklet has been planned, implemented and evaluated from September 2021 to March 2022.

Based on the feedbacks received from the evaluation it can be concluded that the professionals in Autism Foundation Finland will use the booklet. The booklet was stated to be useful, easy to understand, and can be beneficial for the service users.

Keywords: Sexual Rights, Autism Spectrum Disorder, Augmentative and Alternative Communication, Pictogram



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1 INTRODUCTION

People with Autism Spectrum Disorder (ASD) are often seen as non-sexual individuals, lacking desires, fantasies or the wish to engage in romantic relationships, but according to research people with autism have desires and sexual interests (Hellemans et al, 2006, 3; Hellemans et al. 2010, 1; Konstantareas and Lunskey, 1997, 2). Sexuality is a universal characteristic to all human lives, regardless the existence or inexistence of a disability.

According to Holmes, Strassberg and Hilme (2019, 8), people with ASD are at a higher risk of sexual victimization. The authors agree that this may be connected to some of the communication impairments typical in autism (e.g., recognizing or reporting abusive behaviours), to the insufficiency of tailored sexual education services, and to the lower sexual knowledge. Besides being a very important right, education is a powerful tool to lower the risk of sexual abuse victimization of people with disabilities. Sexual and Relationship Education often is not appropriate for the specifications of people with autism and must be tailored according to their needs (Hannah & Stagg, 2016, 1; Hatton & Tector, 2010, 1).

The UN Convention on the Rights of Persons with Disabilities (CRPD) in its article 25 dictates the right of people with disabilities to access health care services, with the same range, quality and price as provided to other persons, including sexual and reproductive health. These services must include appropriate intervention as well as raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities. (UN Convention on the Rights of Persons with Disabilities CRPD).

The aim of this product-based thesis is to create a low-tech aid tool for people with ASD, a visual support using augmentative and alternative communication (AAC). The tool's goal is to explain with pictograms the sexual rights of people with autism, to help them to identify abusive behaviours and learn to differentiate socially accepted practices from unaccepted practices such as public masturbation. This product adds versatility to the existent materials since it contains short texts easy to translate to other languages and its simplicity makes it also appropriate for young children with or

without disabilities, youth, and adults with any kind of intellectual disabilities and different levels of communication skills.

As mentioned previously, people with ASD are at higher risk of becoming victims of sexual abuse (Holmes, Strassberg and Hilme, 2019, 8). In an interview with the sexuality counselor in Autism Foundation Finland (Autismisäätiö), she expressed the importance of the workers to “ask in a daily basis to the service users if they have been involved in any dangerous situation, if someone has touched them in an inappropriate manner.” She attributed the need for constant checking to the difficulties some of the service users might have to remember past events, and the issues on communication they have. Due to this factor, according to the sexual counselor of Autism Foundation Finland, reporting an abuse can be difficult, sometimes even impossible. She highlighted the importance of the professionals working with people with autism of “being aware and make people with autism to be aware so they can say of someone did something bad to them” (Sexual counselor of Autism Foundation Finland, 2021, personal communication 7.9.2021).

The consequences of not providing accurate information about sexuality can lead to people with autism being more isolated because they might not behave appropriately in public, engage in sexually inappropriate sexual behaviors, put themselves at risk of sexual transmitted infections and unwanted pregnancies, be at risk of sexual abuse and/or become sex offenders (Reynolds, 2013, 117-118).

2 AIMS AND OBJECTIVES OF THE THESIS

The aim of the thesis is to create a low-tech visual aid to help social service workers of Autism Foundation Finland to explain to their service users their basic sexual rights. The objectives are to use the book published by the Autism Foundation Finland as part of the Alone&Together Sex Education Project, analyse the outcomes of the interviews with the sexuality counsellor in Autism Foundation Finland, and select some other sources from the international studies on sexual education for people with disabilities. We gathered and simplified the information using pictograms with very short, simple, and clear sentences that are easy to understand by people with ASD.

When working on a project the objectives describe the necessary steps to achieve the goals. The objectives of our product are illustrated in Table 1.

Table 1: SMART objectives

Specific	Explaining sexuality and sexual rights using pictograms with very simple and clear sentences.
Measurable	Setting deadlines for every step of the process and a final deadline to finish the booklet. Finalizing the product in March 2022.
Achievable	Focusing on three very specific sentences instead of trying to create an extensive sexual education book was the key to achieve the objectives.
Relevant	Creating sexual education material that will benefit professional and service users of Autism Foundation Finland.
Time-Bound	The booklet was ready in March 2022.

Put very simply, SMART objectives, or SMART goals, are a form of objective setting which allows managers and employees to create, track and accomplish, short-and-long-term goals (Clear review, 2020).

The specific objective is to create a low-tech visual aid to help the social service workers and other professionals working with people with ASD to explain sexuality and sexual rights in a practical way to their service users. Tracking the quality of the

process and setting deadlines allows us to measure the objectives. The availability of the materials and information needed, the task division and the joint work, as well as focusing on very specific topics of sexuality, make the objective achievable. The relevance of the product was emphasized by the WLP during the meetings and interviews occurred during the writing process. The product will help the professionals to deliver tailored sexual education to their service users. The time allocated for the writing process and the creation of the product was from July 2020 to April 2022.

3 BACKGROUND

Background information complements the essential themes provided before. Sufficient background information provides the reader with the necessary context to comprehend the topic and its significance (University of Southern California, n.d.). This chapter details the previous studies related to the topic and informs the reader about the working life partner's background.

3.1 Previous studies and projects related to sexuality and autism

Sexuality is a very important aspect of every individual's life and each one of us should be able to decide how to live that sexuality. Sexuality cannot be understood without sexual health (Sexual Counsellor of Autism Foundation Finland, private conversation, 2021). According to the World Health Organization (2019), sexual health is a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled.

People with autism spectrum disorder are often seen as asexual, lacking interest in sexual or romantic relationships. Latest studies are debunking the myth of the asexuality of people with ASD (Pecora, Hancock, Mesibov and Stokes, 2019; Bush, 2018). Although it is found in a lower rate compared to neurotypical individuals, the interest in sex among people with autism exists and cannot be ignored. The results of the study made by Pecora et al. (2019) comparing the sexuality and sexual experiences of 459 adults (227 typically developed and 232 with autism) support the hypothesis that people with autism are interested in sexual relationships, 85.5% of the males and 72.6% of the females on the spectrum expressed their desire to have sex with other individuals. Regarding sexual experiences 40% of the females and 21.9% of the males with autism reported previous sexual experiences. On the item "I have been the victim of unwanted

sexual advances or behaviour from others” an alarming 78.2% of females and, in lower percentage but still worrying, 47.6% of the males answered “yes”. According to this study females on the spectrum are 2.21 times more likely to be victims of these experiences than typically developed women.

Similar results were obtained in the study conducted by Bush (2018), where 248 women with ASD were compared to 179 neurotypical women. Sexual desire levels and interest in partnered sex were lower, but yet present, among women with autism. Regarding the sexual activities and behaviour, both studies show different results, On Pecora’s et al. study (2019), differences between typically developed women and women with ASD on their sexual experiences do not show any significant difference. On the other hand, in Bush’s study (2018) the number of sexual activities reported by neurotypical women is slightly higher than the reported by women on the spectrum, and women on both sides of the diagnose reported similar rates of sexual satisfaction.

The existing literature establishes the connection between low sexual knowledge and unsafe sexual practices and victimization; however, little attention has been paid to individuals with ASD (Brown-Lavoie, Viecili and Weiss, 2014, 1). At this point seems correct to clarify the difference between actual sexual knowledge and perceived sexual knowledge. According to Ryan, Franzetta and Manlove perceived knowledge is the amount of information that an individual believes they have (cited by Brown-Lavoie et al., 2014, 1).

Brown-Lavoie's study (2014) unveil a correlation between low sexual knowledge and victimization of people with autism spectrum disorder. The results indicate that the chances of experiencing unwanted sexual contact are 3 times higher for people with ASD and poor understanding of sexuality, 2.7 higher of suffering sexual coercion, and 2.4 more of being raped than the comparison group. (Brown-Lavoie et al., 2014, 9). Their study reveals that the level of actual sexual knowledge is a factor on the incremented risk of victimization (Brown-Lavoie et al. 2014, 7). Several studies have demonstrated that people with autism are at higher risk of becoming victims of sexual abuse (Pecora et at. 2019, Brown-Lavoie et al. 2014,). On this line, the sexual counselor of Autism Foundation of Finland agrees that the insufficiency of factual data regarding sexuality puts people with ASD in a vulnerable situation, where others can

take advantage of them (Sexual counselor of Autism Foundation of Finland, personal communication, 12.1.2022).

We live in the era of information, where every imaginable piece of data is available on the internet, yet it is still difficult for professionals and people with autism to find information adapted to their needs. Recent studies have proved the importance of creating appropriate sexual and relationships education materials, and how this very important aspect of every individual's life has not received proper attention. According to Stokes and Kaur (cited by Hanna and Stagg, 2016, 1) people with autism receive less sex education than typically developed individuals. In a study made by Hanna and Stagg (2016, 6) they compared the feelings towards sex education of 20 young adults with autism and 20 typically developed. The results show that all the participants with ASD were dissatisfied with the sex education received at school, the way the information was presented to them was not clear enough and the content and value offered was unsatisfactory for the participants.

The study by Holmes, Strassberg and Himle (2019) addresses the issue of family sexuality communication (FSC) and how girls with autism and their parents approach sexual education. The results show that a low proportion of parents were using visual materials such as pictures or drawings while discussing sexuality and relationships with their daughters. According to Hadley, Houck, Barker, Garcia, Spitalnick, Curtis and Brown (cited by Holmes et al. 2019, 9) this might be due to the lack of access to the resources, lack of knowledge of techniques, and lack of time to create or find visual aids. The view that easily understandable, and accessible tools for sexual education is needed, is in line with Mademtzi's, Singh's, Shic's, and Koenig's study (2017, 5), in which the parents participating reported being concerned about the approach to follow when teaching sexual education to their daughters, and how this topic raised the worry of the girls becoming victims of sexual exploitation or assault.

Besides the need of creating tailored sexual and relationships education material for people with autism, the need of creating adequate trainings for professionals has been pointed out by several experts (Hatton and Tector, 2010; Villamayor 2020). According to Hatton and Tector (2010, 1-2), the teachers on the Coddinton Court School in the United Kingdom were having difficulties finding appropriate materials to teach sexual education to their pupils with ASD. In her article, Hatton (2010, 2) admits finding

challenging, as responsible of the Personal Health and Social Education curriculum, to find or create adequate materials suitable for a diverse group of students. On the same line, a study made by Villamayor (2020,6) reports that professionals usually consider themselves not trained enough to evaluate and analyse the different needs regarding sexual education of people with autism, as well as not experienced enough on the field. From this affirmation arises a very important question, why are professionals not experienced or trained enough on the field of sexuality and disabilities? Referring to the views of the sexual counsellor at Autism Foundation of Finland (2021, personal communication), educational programs for professionals and future professionals where sexuality and disabilities are integrated are scarce. Not holding enough information, and own tabus are the reason why many professionals feel uncomfortable talking about sexuality with the service users.

As claimed by Reynolds (2013, 87), to reduce the chances of people with severe autism of being sexually victimized it is needed to provide them with sexual knowledge. Furthermore, this will also serve to prevent them of becoming sexual offenders. The author continues this line of argument by highlighting the importance of receiving quality sexual education in early stages of life since the absence of knowledge might lead to inappropriate behaviour in public and might cause their involvement with the legal and judicial system. (Reynolds, 2013, 102). By providing information about sexual intercourse, for example, people with autism will find easier to know what they are consenting to if they have a relationship and agree to have sex with their partner, as well as help them to prevent unwanted pregnancies (Reynolds, 2013, 102), and to be able to differentiate an abuse from consented sex and report it if needed (Sexual Counsellor at Autism Foundation of Finland, personal communication, 12.1. 2022).

Academics and professionals seem to agree on the urgent need for adapted sexual and relationship education materials and the importance of adequate and more extensive training for professionals. We can agree that more studies on disabilities and sexuality are indeed in need, not only on the question “what is needed?”, but also on “what has worked, and what has not?”, in order to analyse current sexual education programs and their impact on the people with disabilities knowledge on sexuality.

Regarding the use of pictograms to facilitate the communication and understanding of the surroundings of people with autism, several projects have been created. For

instance, in several cities in Spain, the local government in collaboration with autism associations, have placed pictograms in public buildings and shopping centers to help people with autism to identify what type of building it is and its main activity (Autismo Madrid, 2013). Another great example of the use of pictograms is the case of the National Police of Spain every agent carries a two pages guide with pictograms and the questions “how are you feeling?, what happened?, where it happened? who did it? how was he/she dressed?” and several pictograms offering different options to reply those questions. This Spanish project has been translated into 200 languages and it is being used in many countries (El Periódico de Aragón, 2022). In Finland, the city of Helsinki in collaboration with several associations launched the Accessibility Symbol project as part of the Helsinki for all project in 2011. The purpose of this project was to compile and design pictograms indicating accessible functions and public services that need to be accessible and clearly signposted. The pictograms in the databank are organized by the following categories: accessibility, public transport, leisure time, premises and services and standardized symbols (Helsingin Kaupunki, 2016).

3.2 Working Life Partner’s background

Autism Foundation Finland is the working life partner. The foundation’s origin is a rehabilitation project launched in 1992. The Rehabilitation Project for Young Adults was the first rehabilitation project targeted to people with autism with the objective of facilitating the independent living of young people on the spectrum. The project led to the establishment of the Autism Foundation in 1998. In the year 2000 the service activities started being provided. Autism Foundation Finland has units in Helsinki, Espoo, Vantaa, Kotka, Tampere, Seinäjoki and Kuopio, where more than 370 professionals are committed to safeguarding the wellbeing of people with ASD (Autism Foundation Finland). Among their staff they count with a sexual advisor that offers support and coaching to the services users and seminars to the rest of the workers.

Autism Foundation Finland gets its service users from municipalities that organize social services for people with ASD. When a social worker considers that one of their clients could benefit from the services offered in Autism Foundation Finland, they contact the unit leader and if there is any space available an interview is conducted in

order to check whether the unit would be a good fit for the service user's need or not. (Sexual Counsellor of Autism Foundation Finland, personal communication, 8.1.2022)

A day time activity unit of Autism Foundation Finland offers a wide range of activities, all adapted to their clients' personal needs. They have group and individual activities. Art and culture play a big role on the design of the activities available. Physical activities such as walks in the nature, media-activities and communication groups and exercises are also offered to the clients. (Sexual Counsellor of Autism Foundation of Finland, 8.1.2022)

At the unit three groups of sexual education and individual meetings with the sexuality Counsellor are offered. These meetings are not organized within the regular services, but as an extra and by referral of the social worker. These services are charged separately. (Sexuality Counsellor of Autism Foundation Finland, personal communication, 8.1.2022)

Many of the service users can communicate only with AAC, and those who can speak have very narrow vocabulary and still need AAC. The methodology implemented to encourage the service users to have a healthy sexual life consists in focusing on the client's interests. For instance, when a service user wishes to masturbate, the professionals do not tell them "You cannot do it," they explain where and how it can be done and provide with the necessary devices if needed. (Sexuality Counsellor of Autism Foundation Finland, personal communication, 2021).

4 KEY CONCEPTS

This chapter focuses on the definition of the different key concepts. Defining them will give the reader a better understanding of the thesis.

4.1 Sexual Rights

The European Institute for Gender Equality defines Sexual Rights as Human Rights already recognised in international laws, international human rights documents including the right of all persons to the best quality possible of health regarding sexuality, including, among other rights, the capability to seek and receive information regarding sexuality as well as access to sexual education.

The Convention of the Rights of Persons with Disabilities in its article 16.2 declares that the States Parties must ensure appropriate forms of gender- and age- sensitive assistance and support for persons with disabilities by providing information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. The article 17 states the right of every person with disabilities for respect for their physical and mental integrity on an equal basis with others. About the access to information, the article 22 declares that the State Parties must take the appropriate measures to ensure that persons with disabilities can exercise the right of freedom to seek, receive and impart information and ideas on an equal basis with people without disabilities. The article 25.a ensures the equal access to health care programmes as provided to other persons, including the sexual and reproductive health.

The World Association for Sexual Health, on its Declaration of Sexual Rights reaffirms that sexual health cannot be defined, understood, or made operational without a broad understanding of sexuality. Also states that sexual health cannot be obtained without respecting everyone's sexual rights (World Association for Sexual Health, 2014). However, how can someone have a healthy sexual life without knowing their own sexual rights? How can someone protect their own sexuality and pursue a healthy sexual life if they are not aware of their own sexual rights? How can a victim of abuse

report such horrible situation if they don't know that what happened was wrong, or they don't know how to do it?

In the Finnish context, the definitions and legislations support the international ones. The Family Federation of Finland has defined sexual rights as universal rights that relate to human rights and refer to the rights of individuals to make informed and responsible decisions about their own sexuality. Rights are based on freedom, equality, privacy and sovereignty. They include seven rights regarding sexual rights, the right to one's own sexuality, the right to information about sexuality, the right to protect oneself and to be protected, the right to sexual services, the right to appear, the right to privacy, and the right to influence (Seksuaalioikeudet. The Family Federation Finland, 2018).

4.2 Autism Spectrum Disorder

Autism Spectrum Disorder is a neurodevelopmental disorder characterized by complications on the social communication and social interaction and restricted and repetitive patterns in behaviours, interests and activities. The symptoms are present at early stages of the development and affect daily functioning. (American Psychological Association). Some of the traits of autism that can affect greatly the sexuality of those in the spectrum are the deficits in social communication and social interaction, deficits in social-emotional reciprocity, difficulties understanding and using the non-verbal communication, hyper- or hypo-reactivity to sensory input such as adverse response to specific textures or touching, and difficulties developing and maintaining relationships. (American Psychiatric Association, 2013).

Currently, it is unknown why or how ASD appears, but it is known that genetics have a strong implication on it. Autism Spectrum Disorder is an invisible disability with no physical traits, lifelong lasting that affects differently to each person on the spectrum, the personal development and the services and support available will play a major role on it. Having associated an intellectual disability and the level of language development impact greatly on the severeness of autism. ASD has its own defining characteristics that manifest heterogeneously throughout the entire life cycle. This specificity has been reflected in the health international classification systems, including DSM-

5 and ICD-11, which have replaced the term “Generalized Developmental Disorder” for “autism spectrum disorder”. (Confederación de Autismo de España).

A standardized criteria to diagnose ASD is provided by the American Psychiatric Association’s Diagnostic and Statistical Manual on its fifth edition (DSM-5). In order to be diagnosed with ASD, according to the DSM-5, a child must have persistent deficits in each of the three areas of social communication and interaction plus at least two of four types of restricted, repetitive behaviours. Within the area of social communication and social interaction, the child must have deficits in social. Emotional reciprocity, nonverbal communicative behaviours used for social interaction and in developing, maintaining, and understanding relationships. In the restricted, repetitive patterns of behaviour area the child must show at least two of the following: stereotyped or repetitive motor movements, use of language, or speech; insistent on sameness, low tolerance for change of routines or ritualized patterns of behaviour; restricted and fixated interests; hyper- or hypo- reactivity to sensory input. (Centres for Disease Control and Prevention, 2020).

4.3 Alternative and Augmentative Communication

The product created for this thesis is a non-tech, aided, symbol set AAC tool. The Augmentative and Alternative Communication (AAC) refers to the methods, tools and theories of the use of nonstandard linguistic and non-linguistic forms of communication (Loncke, 2014, 1) used to compensate communication deficits typically present in people with disabilities (Aragonese Center of Augmentative and Alternative Communication – ARASAAC). The methods include the use of non-standard modalities, “materializing” the act of communication with pictures or tokens, and the modification of any parameter in the communication.

ACC tools include materials and devices that can be non-tech, such as symbol cards, low-tech such as one-message switches, high-tech such as computer-based communication devices, or any other communication form as manual signs, eye signalling, and basic non-linguistic vocalizations. The symbols systems are tailored to the needs

of people of different ages and motor and cognitive and linguistic abilities (Aragone Center of Augmentative Communication – ARASAAC).

ACC is meant for persons without speech or very limited functional speech, and it is not used as a tool to help the users to achieve standard ways of communication (Loncke, 2014, 3), but to compensate for the lack of capability in communicating in a standard way. In other words, ACC's objective is not to "teach", for example, a non-speaking deaf person to talk, but to provide them with the necessary tools so they can communicate at the same level as hearing people when possible. Another application of AAC is to help the user to understand that specific behaviours can have a meaning and can be consequential (Loncke, 2014, 10).

Other terms worth to mention is aided communication and unaided communication. Aided communication refers to the use of aids external to the communicator's body, such as symbol cards, a notebook, or a speech-generating communication device. Unaided communication refers to communication that does not use external aids and is performed entirely with the communicator's body, such as natural speech, sign language or gesturing. The importance of distinguishing between the two communication forms lies on the fact that unaided communication is available to the person at all times, and that might be more natural and easier to for maintaining eye to eye communication. However, the technological advances and the new devices being smaller it is not clear if the difference is as important as it was before (Loncke, 2014, 4-5).

Augmentative and Alternative Communication includes various systems of symbols, both graphic (photographs, drawings, pictograms, words or letters) and gestures (mimicry, gestures, or manual signs) and, in the case of the former, also requires the use of products from support for. Graphic symbols range from very simple systems based on drawings or photographs to progressively more complex systems such as pictographic systems or traditional spelling (letters, words and phrases). Thanks to the support products for communication and the various resources for access, graphic systems can be used by people with reduced mobility, even in cases of extreme gravity. (Aragone Center of Augmentative and Alternative Communication - ARASAAC). Sometimes a distinction is made between a symbol set and a symbol system. A symbol set is a collection of graphic symbols that do not have any internal principles regarding how the symbols are created, for example, a professional who uses drawings,

photographs, and pictures from magazines or books to create their own collection. On the other hand, a symbol system has rules to create the pictures, for example, the Bliss words system for the word “man” uses a stick figure, and for the word “woman” uses the same figure with a triangle on the legs (Loncke, 2014, 6). Symbols and manual signs are often used in AAC because of the easy learnability, they are more iconic. Iconicity means that the symbol has image-value. Transparency implies that by looking at the symbol one can extract its meaning immediately, for example, the picture of a house means house, and the manual sign of drinking (pretending to drink from a glass) means drink (Loncke, 2014, 6).

Support products for communication include technological resources, such as artificial speech communicators or personal computers and tablets with special programs, which allow different forms of access, some adapted for people with very reduced mobility, and also facilitate the incorporation of the different systems of pictographic and orthographic signs, as well as different forms of output including voice output. They can also consist of non-technological resources, such as communication boards and books. (Aragones Center of Augmentative and Alternative Communication - ARASAAC).

4.4 Pictogram

According to Maharaj (1980) The Pictogram symbol set was originally developed in Canada and consists of 1,500 white-on-black “picto-images” that are designed to reduce figure–ground discrimination difficulties. Pictograms have been found to be less translucent than PCS but more translucent than Blissymbol (Bloomberg et al., 1990). Leonhart and Maharaj (1979) reported that adults with severe to profound intellectual disabilities learned Pictograms faster than Bliss symbols. A recent study suggested that school-age participants with intellectual disabilities learned to recognize animated Pictograms of action words more readily than their static equivalents (Fujisawa, Inoue, Yamana, & Hayashi, 2011). (Cited by Beukelman 2012, 55).

Indeed, without symbols, we would not be able to communicate in writing or send nonverbal messages conveying empathy, warmth, and approval. There would be no

golden arches! No mouse ears! No labels, no warning signs, no newspapers, and no textbooks! Without the ability to send messages via gestures, body language, written words, and other symbols, communication as we now know it would be a vastly different—and much less rich—experience. (Beukelman, 2012, 37)

According to Lloyd and Fuller (1986), symbols can be divided into those that are aided, which require some type of external assistance such as a device for production, and those that are unaided, which require no external device for production (cited by Beukelman, 2012, 38). Aided symbols include real objects and black-and-white line drawings, and unaided symbols include facial expressions, manual signs, and natural speech and vocalizations. In addition, some symbol sets incorporate the use of both aided and unaided elements; we refer to these as combined symbol sets e.g., the Makaton Vocabulary created by Grove & Walker in 1990. (Cited by Beukelman 2012, 38). Pictograms are part of aided symbols. They are drawings or graphic signs that allow to express ideas and concepts. ‘

After reading these definitions, the reason why pictogram has been chosen for the booklet is apparent. It helps people with communication deficit, especially those with severe autism to understand and express themselves.

5 PRODUCT PROCESS

In this chapter, we will bring up who is the target group, the services users of Autism Foundation and we will detail for a better understanding the whole process of making the final project ready.

5.1 Target group of the product

The service users of Autism Foundation Finland are our main target group. They all have autism spectrum disorder that causes for them complications on their social communication and social interactions. Indeed, the sexuality counsellor at Autism Foundation Finland (2022) highlighted during the second interview (see Appendix 8) the communication challenges their service users have. The professionals at the unit must use very simple, short, clear, and straightforward sentences when they are talking with them. Irony, sarcasm, double meanings, and jokes are something to avoid when communicating with the service users since their understanding is literal. For instance, if someone says: “it’s raining cats and dogs”, a service user will most probably think actual cats and dogs are falling from the sky.

As said on a previous chapter, these deficits on social communication and social interactions, in social – emotional reciprocity, the difficulty to understand and use non-verbal communication can affect greatly on their sexuality. Due to all these impairments and deficits, people on the spectrum are exposed at higher risk of harassment, abuse, and horrible sexual treatment. Reynolds agrees that by providing a good sexual education, the risk of becoming victims of sexual abuse and becoming sexual offenders unknowingly are reduced (Reynolds, 2013, 87).

5.2 Product Planning

Every project follows a life circle of four stages, initiation, planning, execution and closure (Basu 2012, 9). Before there is a project, there is some sort of need (Dobson, 2015, 7), in our case the need is creating adapted sexual education materials for people with autism. This need is defined during the initiation stage of the project life circle. During the planning stage the tools necessary to define, reorganize and develop the course of action that must be taken to achieve the project goals are included. (Dobson, 2015, 9.). During the planning stage, the questions what, why, who, where and when should be answered to define the goals and the purpose behind (Spolander & Martin 2012, 93). In table 2, the five W's of our planning process are defined.

Table 2. The five W's

WHAT	Create a sexual education booklet. The booklet is aimed to explain sexual rights and health to people with autism.
WHY	The lack of adapted sexual education materials adapted for people with autism calls for the creation of this product. Autism Foundation Finland welcomes the initiative since it covers a need.
WHO	Elena Mayans Umbert and Ngaty Seck in collaboration with Autism Foundation Finland.
WHERE	The booklet will be delivered to Autism Foundation Finland.
WHEN	The booklet will be developed during 2021-2022. The final product will be delivered in Spring 2022.

The first meeting with the working life partner took place the 9th of September 2020, and the first idea proposed for the thesis was to create and implement a peer support group for non-Finnish speaking parents with children with autism. But considering the importance of the sexual rights of people with autism and the needs of the WLP, after starting the research and reading the material, the topic changed to the current. On January 2021 our request to change the topic was approved by the WLP supervisor. She showed great interest in the product and offered help and support during the process, as well as authorization to interview one of the workers, expert in sexuality and disabilities.

After these meetings with the working life partner, the thesis topic was approved by the thesis supervisor teacher and the process of gathering background and theoretical information began. For ethical reasons and as requested by Diak thesis writing guidelines, we signed the collaboration form and the permits with the WLP supervisor. At this stage, we considered also the ethical aspects related to the target group, which are explained in detail in subchapter 5.5, as well as all related to the thesis writing process. Some of the ethical questions were the vocabulary used throughout the text, data protection, compromise to use factual and science-based information, right of self-determination and following the thesis supervisor's and WLP supervisor's wishes, feedback and guidelines.

Several academic articles on the topic of sexuality and autism, books about alternative and augmentative communication have been reviewed during the information gathering stage of the thesis. We started writing the thesis idea on the beginning of January and presented the thesis idea paper 21.1.2021. Just after that we continued with the thesis proposal on 17.2.2021 which was approved by our teacher supervisor. We started then drafting the thesis. An interview with the sexuality and disability expert of Autism Foundation Finland was conducted 7.9.2021 and the information obtained was analyzed and combined with the theoretical background. From the information we got and based on the interview, drafts of the pictograms have been made. The booklet was sent to the working life partner for its evaluation alongside with the feedback questionnaire. Once we received the feedback we did the necessary changes and presented the preliminary thesis 12.4.2022. The final thesis was submitted 25.4.2022. In the Table 3 we present the timetable of the process and the task division.

Table 3. Workplan and task division

DATE	TASK	ESTIMATED DATE AND PERSON RESPONSIBLE	DETAILS	COMPLETED
JULY 2020	First contact with the WLPS	July 2020 – Elena&Ngaty	Proposal of the thesis topic to Autism Foundation Finland and request of partnership	July 2020

SEPT 2020	First meeting with the WLPS	July 2020 – Elena&Ngaty	Presenting the thesis topic	July 2020
AUG 2021	Thesis agreement and permits	August 2021 – Elena&Ngaty	Signing the agreement and permits with the WLPS	August 2021
SEPT 2021	Interview with the sexual counselor at Autism Foundation Finland	September 2021- Elena&Ngaty	Online interview with the sexual counselor of Autism Foundation Finland.	September 2021
DEC 2021	Interview with the sexual counselor at Autism Foundation Finland	December 2021 Elena&Ngaty	Second interview with the sexual counselor at Autism Foundation Finland.	December 2021
JAN 2022	Sentences for the booklet	January 2022 – Elena&Ngaty	Formulating the sentences that will be included in the booklet	January 2022
	Creation of the pictograms	January 2022 Elena&Ngaty	Creating the pictograms for the booklet	
FEB 2022	Final product and feedback questionnaire	February 2022 Elena&Ngaty	Sending the final product and the feedback and evaluation questionnaire to the professionals of Autism Foundation Finland.	February 2022
APR 2022	Submission of the final thesis	April 2022 Elena&Ngaty	Submitting the final thesis to the thesis supervisor teacher.	April 2022

Due to Covid19 face to face meetings have not been possible, all our meetings with the working life partner have been held online. Nonetheless we tried to meet every

time possible for the most part after our first supervision with our teacher supervisor late September, where we noticed that we had many parts to rewrite in our thesis. The work has been divided equally, all chapters discussed and finalized together.

5.3 Product implementation

While during the project planning is described what one is supposed to do, the project execution is the process of doing it (Dobson, 2015, 10). To move forward from the planning stage to the implementation stage it is essential to get the plan approved by key stakeholders to avoid potential miscommunication about objectives. It also helps stakeholders understand the costs and risks associated with the project and ensure that the partners in the project are in alignment (Dobson, 2015, 124). During the interviews with the sexual counsellor of Autism Foundation Finland we got all the information needed regarding their wishes and hopes about the final product, we followed their guidelines and informed them of the advances made during the entire process. In our case the final target group was not involved in the creation of the product, as explained in subchapter 5.5 Ethics. Nevertheless, the workers, who will use the product with the service users, were heavily involved. Their vast knowledge about the service users and their expertise on sexuality and autism were key on the creation of the process.

One question that appeared when planning the thesis was what sentences should be included in the booklet. Due to time limitation, it was unrealistic to create a book with all the information related to sexual rights and sexual health. After reading several academic articles and books and analysing the interview with the sexual counsellor at Autism Foundation Finland (see Appendix 7) we concluded that the most important aspects were the places where one can masturbate, consent to be touched, and report any case of sexual abuse. Hence the sentences chosen to be part of the booklet are focused on these aspects. Per request of the WLP, we have translated the original sentences from English to Finnish, and both versions will be given to the workers at the unit.

The first step was to decide the text, what words to use and in what order. Due to the fact that the target group of this product has limited vocabulary, the sentences had to

be very simple and easy to understand. After brainstorming we decided that the sentences related to the masturbation would be “You have the right to masturbate. You can masturbate alone, in private. Do not masturbate in the street, the bus, the shop or in front of other people”. The sentences regarding consent are “Do not touch other people’s chest, penis, vagina or butt without asking permission. No one can touch your chest, penis, vagina or butt without asking permission”. For the report aspect, we chose “If someone touches your private body parts or has sex with you without your permission, tell it to your supervisor or the police”.

Once the text was decided, we had the base to choose the pictograms. At first, we tried the sentence creator of ARASAAC, but some of the pictograms suggested were not completely what we were looking for. For instance, for the word “permission” the pictogram was a hand signing a paper. In our understanding this pictogram was specifically showing “legal permission”, which was not the message we wanted to express in our booklet. For this reason, we had to use the word bank on ARASAAC website, which works as a searcher. By typing the word one wants to find, the website will give several options, including related words. For instance, when we searched for the word “permission” also the pictogram for “asking permission” showed in the results list. When searching for pictograms related to reporting abuse, when we typed “abuse” it showed several pictograms of unwanted physical contact but also one for the word “rape”, and this gave us the idea of adding it to the original sentence.

Once all the pictograms were chosen, the initial plan was to add them to a Word document and write the text underneath. However, due to some technical challenges Canva was used instead. The booklet consists in 6 A4 pages, one for each sentence in English and one for each sentence in Finnish. The text is placed right under the pictograms, in capital letters. Font size is 17, and font style is Open Sans. In the page only the pictograms and the text are included, any other element has been added in order to avoid distractions. The booklet does not need to be beautifully decorated; it needs to be precise, concise, simple and clear to meet its purpose.

For the implementation of the product, a link to the Canva document will be sent to the responsible of the unit of Autism Foundation Finland. The link will give them rights to edit the document and translate the text to other languages and change the font size or font style if needed. It will be also possible to add the professionals’ names

and/or pictures in the sentence regarding reporting abuse “If someone touches your private body parts or has sex with you without your permission, tell it to your supervisor or the police”. In case the professionals at Autism Foundation Finland are unfamiliar with Canva, a short workshop can be organized to teach them how to modify the original document.

The file can be downloaded, saved and printed by anyone who has the link. We recommend laminating the pages individually, to ensure a long lasting and safe use of the product. Choosing an A4 size paper facilitates its use since is the most common paper size used. Although the pictograms are in colour, it can be printed in black and white, and it will not affect the understanding of the materials by the services users

The professionals can decide, according to their service users’ needs, when and how to use the materials. It can be added to the available materials at the unit or it can be used individually. According to the service user’s previous knowledge on sexuality, we recommend presenting the material, and read the sentence aloud pointing the pictograms at the same time. For the first sentence (Appendix 1 and 4) we recommend to first talk about masturbation with the service user if they are not familiar with the term. Teaching them the differences between public space, private space and privacy while using this material is also advised. The second sentence (Appendix 2 and 5) requires previous knowledge of body parts, and the identification of private body parts. Teaching the service users what means consent it is suggested since is one of the keywords of the sentence. We want to emphasize the importance of the professionals making sure that the service users understand that just asking for permission does not automatically give one permission to touch anyone else’s body. It is equally important to receive a “yes, you can touch me” when asking if it is ok to make any physical contact with someone else. As well as not assuming that if someone has asked the service users’ permission to touch their bodies that means that they are authorized to do so. For the third sentence (Appendix 3 and 6) we strongly advice to stress the meaning of sexual abuse, unwanted physical contact and rape. It is also advised to provide the service users with the necessary tools to make a report. These tools can be identifying abuse, identifying trustworthy people such as supervisors, social workers, health care workers, or police, and showing them the steps to follow in order to report an abuse.

Although the target group of the booklet is people with autism, the professionals can use it with anyone having any other neurodevelopmental disabilities, communication deficits, or even by people learning a new language.

5.4 Product evaluation

Organizations use the evaluation to improve their performance and abilities, plan future projects, obtain funds, demonstrate accountability, and fulfil the organizational objectives. The evaluation is also used to communicate with every faction involved in the project about the benefits and success of the evaluated area. Not communicating the results of the evaluation is a waste of the organization's resources (Zarinpoush, 2016).

Evaluation is a systematic investigation of the worth or significance of an object. It normally involves some standards, criteria, measures of success, or objectives that describe the value of the object. It can also identify criteria for success, lessons to learn, things to achieve, ways to improve the work and the means to move forward (Zarinpoush, 2016).

It is also part of the evaluation to consider the risk because, no matter how well planned and organised a project is, risk cannot be eliminated as a potential project concern. Project risk management involves establishing risk management policies and systems, identifying risks, analysing, and prioritizing those risks, developing responses and strategies to deal with them, and monitoring and controlling the risk environment throughout the project. (Dobson, 2015).

During the early stages of the thesis writing, a SWOT analysis was conducted, and the results are shown in Table 4.

Table 4. SWOT analysis.

STRENGTHS	WEAKNESSES
<p>The booklet uses simple graphics/symbols to explain basics sexual rights.</p> <p>It will be useful for all professionals working with people with disabilities specially ASD people.</p> <p>A very easy and accessible language for the service users to understand it.</p>	<p>The booklet will not be tested with the service users before the end of the thesis.</p>
OPPORTUNITIES	THREATS
<p>This booklet will raise awareness on sexual rights.</p> <p>Professionals who were not trained to talk about sexuality will have a good guide.</p> <p>The booklet will participate in sexual education inside organization.</p>	<p>Misunderstanding of the product.</p> <p>Lack of interest of professionals for the booklet.</p> <p>Face to face meetings not possible during the thesis writing process due to Covid-19.</p>

The simplicity of the booklet is based on the use of simple and understandable sentences for all people with disabilities and especially those with autism spectrum disorder. This is a strength especially since translating into other languages will be very easy and professionals using other languages than English and Finnish will be able to use the booklet.

Something that can constitute a weakness is that the booklet will not be tested with the service users. Covid-19 has made the process of thesis complicated. We could not have easy access to the Premises of Autism Foundation Finland even meeting with the working life partner supervisor was difficult.

Raising awareness on sexual rights among professionals, developing skills of all persons working with people with disabilities, providing good guide are the opportunities

that the booklet will bring in the social field. The booklet will assist professionals of Autism Foundation Finland in their sexual education.

Besides covid 19 being a real threat for the implementation and evaluation of the product, a lack of interest from the professional can also be a threat. As simple and clear it might sound to us (writers), the service users can still misunderstand the product.

Although the product has not been tested with the service users, it has been evaluated by professionals. A feedback questionnaire has been sent to them alongside the booklet. Based on the 5 questions listed in that questionnaire, the overall feedback was positive. Two workers have replied to the questionnaire (see Appendix 9). The professionals consider the booklet easy to use and easy to understand by the service users and that the pictograms chosen are adequate. One professional believes the service users will engage with the product while the other worker could not confirm this statement. Only one replied to the question “will you use the booklet?” with an affirmative answer. If we come back to the objectives fixed at the beginning, we can say based on these feedbacks that they were reached. We produced a booklet containing relevant and appropriate information about sexuality and sexual rights, for the services users of Autism Foundation Finland within the timeframe and resources available. That booklet will be used by the professional to facilitate the understanding of the basic sexual rights to their clients.

The key words chosen helped us to narrow doing the research in this thesis but also to gain more broad knowledge on the topic. We both writers agreed that literature in this topic strengthened our ethics concerning people with disabilities and to enhance our communication skills. AAC taught us a lot on how to tackle communication impairments using aided and unaided symbols. Due to covid 19, it was difficult to stick on the initial plan. We needed to adjust our schedules to follow the recommendations from the Finnish Institute for Health and Welfare. it was sometimes challenging for us writers to meet or to set a meeting with our WLP but we managed to finish the booklet and present the final thesis on time.

6 ETHICS

Disability research ethics are located within the wider research ethics framework. Ethical principles require that any research involving human subjects is framed and conducted in a way that respects the human rights of the individuals concerned. (National Disability Authority, 2009, 9). The core values of research with people with disabilities are dignity, representation and inclusion, and autonomy. Firstly, dignity refers to the participants' right to decide to be part of the research or not, and for how long, is something that must be respected, as well as their privacy and confidentiality. Provide accessible materials is also a must when researching with people with disabilities. Secondly, in order to be truly representative, research has to be equally eligible to participate for everyone, regardless of disability or other aspects of human diversity. That means taking steps, where possible, to facilitate such participation. Thirdly, autonomy is related to every individual's right to make their own decisions in the research process and the need to take this right seriously. Autonomy and mental capacity are considered under voluntary and informed consent (National Disability Authority 2009, 11-12).

According to the Finnish National Board on Research Integrity, anyone's capacity may be reduced temporarily or more permanently. Ethical principles must be observed also when conducting research with a research participant whose capacity is limited, e.g., due to illness or age. However, people who, owing to a mental health disorder, a developmental disorder or other similar reason, do not have the capacity to give their consent to research are defined as being unable to consent in the Medical Research Act (488/1999). According to the same act, written consent may be given by a close relative or other person closely connected with the person or by their legal representative (TENK 2019). In this thesis we did not work directly with the service users and there was no need to sign any consent with them. Nonetheless, for ethical reasons and as part of transparent credible writing process we signed an agreement with Autism Foundation Finland and with Diakonia University of Applied Sciences.

Ethical principles for research involving people with limited capacity include the need to inform them in a comprehensive manner about the research. Even if their participation in the research requires the approval of a legal representative, the person with

limited capacity primarily gives their consent to participate in the research themselves. Also, researchers must always respect the autonomy of research participants with limited capacity and the principle of voluntary participation, irrespective of whether the consent of the legal representative has been obtained for the research. If participating in the research is not in the best interests of a person with limited capacity and if they do not wish to participate in the research, the researcher must discontinue the person's participation (TENK, 2019, 11).

Ethical works and good practices are paramount when conducting a project and writing a thesis. For that reason, it seems important to raise here the professionalism of the workers of Autism Foundation Finland. How aware they are about the sensitivity of their service users. How they pay attention using the right terminology for instance using "people with disabilities" and not "disabled people or handicap". Ethics were deeply discussed during our meetings with the WLP. It is possible that the service user's relatives are against providing sexual education because of their religious beliefs, cultural aspects, or other personal reasons. Due to lack of education, relatives can provide incorrect information regarding sexuality. In these cases, according to the sexual counsellor of Autism Foundation Finland (2021, personal communication), the service users' sexual rights prevail over the relative's wishes, and science-based sexual education will be provided if needed.

We also emphasized as writers of the thesis, that we have paid attention to the ethical values expected in academic text. The expressions used are respectful and inclusive, avoiding ableism and judgements during the entire writing process. Indeed, we have been adamant on finding factual research and using only academic peer reviewed studies and literature in order to avoid the spread of false information that can be harmful for the autistic community. In the thesis work, and in all research and development activity, the author has the ethical responsibility. It concerns each choice at the different stages of the work. It is important to be careful with data collecting, data use and data storage (Kuula 2006).

That is why for legal and ethical duty, confidentiality has been highly considered, how to keep anonymity and respect data protection of all participants. Permission was asked from the sexuality counsellor of Autism Foundation Finland (the interviewee) before recording our meeting sessions and they have been informed of the destruction of the

data after publication of the thesis. Also, their name was not used in order to protect their privacy. All files have been kept on the personal students account which can be accessed only by password. Autism Foundation Finland guarantee the accessibility of the product to their service users. They assure that it will be applied appropriately and in a sensitive manner.

The sessions for sexual counselling and sexual education offered at Autism Foundation Finland are not scheduled in their regular routine. These meetings are agreed beforehand by the service users, their social workers and the sexual counsellor of Autism Foundation Finland (Sexual Counsellor of Autism Foundation Finland, personal conversation, 2021). The requisite of pre-planning the sessions eliminated the possibility of including the service users in the evaluation of the product. Nevertheless, the workers of the unit of Autism Foundation Finland have evaluated the usability and appropriacy of the product.

7 PROFESSIONAL DEVELOPMENT

In this chapter, we as writers of the thesis are explaining our personal development during the process.

7.1 Elena Mayans Umbert

My interest in sexuality and autism arose during the Disability in Diverse Context of my bachelor's in Social Services studies. During the writing process of this thesis, I realized that my perspective and understanding of sexuality and autism was ableist and I was not aware of it. I realized that the interest came from an unconscious ableist point of view. I was interested to know how people with autism can understand sexuality, how can they live their own sexuality, as if it was a strange thing that people with autism were able to understand and live their own sexuality. I believed the old myths of the asexuality of people with autism, and I never bothered to look further and learn more until now. After studying the subject, I concluded I was asking the wrong questions.

Now I understand that the sexuality of both, people with autism and neurotypical people, do not differ in the general aspects. The writing process of this thesis has helped me to have a better understanding about ableism, it made me reflect on my own actions and I learned to detect it. It has helped me to rephrase the questions to others more inclusive and respectful, such as “what are the challenges people with autism has regarding their own sexuality? And what needs to be done to help them overcome said challenges?” Now I know, up to a certain extent, the answer to those questions, but there is still so much more to learn.

During the process I have learnt how broad the topic of sexuality and disability is, and I hope to learn more in the future. This itself presented a challenge for me during the process. It has been difficult to keep the focus on the main topic of the thesis and not to include other topics, e.g., pregnancy and autism, other AAC systems, how sensory process disorders can affect sexuality, or assisted sex for people with disabilities, among others.

I have also learned about the ethics for research purposes with people with disabilities, as well as the working ethics and the importance of being aware of them. I have improved my knowledge of project management, but due to COVID restrictions and insufficient time, the product could not be tested by the service users. Therefore, I did not fully learn the practicalities of involving service users, including the process of requesting feedback, creating accessible feedback forms, and analyzing them. I do hope to learn it in the future. Effective time management, setting boundaries of self-care, and setting realistic goals and objectives is something that has improved substantially during the writing process, and this will be very beneficial for my professional future as social services worker.

It is my hope to build my career on the sexuality and autism field. I will, for sure, keep learning about human sexuality and disabilities. I will advocate for people with disabilities sexual rights even if I am not working on that specific field. In the future, I would like to establish an association to help non-Finnish-speaking parents of kids with autism to navigate the Finnish system, create free-time activities, peer support groups for parents and relatives, and sexuality workshops.

7.2 Ngaty Seck

I started this thesis with a lot of assumptions and uncertainties, autism spectrum was a vague unknown area I needed to explore. an old African adage says: “if you know that you don't know, you will learn. If you don't know that you don't know, you're not going to learn”. All I knew in the beginning is that I don't know anything, so I was ready and willing to learn during all the process of the thesis.

Indeed, that is what I did, from the impairment of social communication and social interaction of people on the spectrum, to how genetics have a strong implication on the spectrum. I learned how the symptoms are present at early ages and can affect the sexuality of the people with autism spectrum and their perception of sexual rights.

I knew that communication is the key, but I did not know much about Augmentative and Alternative Communication before I started to work in this thesis. That AAC was the norm used to compensate communication deficit that people with disabilities are facing. I discovered that all symbols, cards, images, pictograms and other communication form as manual signs and basics non-linguistic vocalizations are part of AAC. I understood that with ACC, I do have the necessary tool to give to people with disabilities so that they can communicate at the same level as everybody else. Also working with Autism Foundation Finland our working life partner helped me develop my critical thinking, it helped develop my ethical approach on how to work with sensitive target group. Many of my ethical principles was challenging during the thesis process because both the topic and the target group were sensitive.

I furthermore developed my knowledge about project management process. Planning, implementing, and evaluating a product are now assimilated process for me. For sure these competences will be beneficial in my career as social worker. Like I said, I started this thesis with assumptions and uncertainties, but I am finishing it with a load of knowledge, more competences and humility.

8 CONCLUSION

Extensive research and literature can be found on the topic of autism and sexuality. Several studies have been carried out to investigate the differences between people with autism and neurotypical people related to sexual desires and wishes (Bush, 2018), to highlight the increased risk of becoming victims of sexual abuse when having Autism spectrum (Holmes, Strassberg and Himle, 2019), and their dissatisfaction with the sexual education received at schools (Hanna and Stagg, 2016). However, we have not found studies where the outcomes of tailored sexual education for people with autism were proven. We believe that it is important to evaluate the improvement on sexual knowledge of people with autism after receiving sexual education, this would benefit the understanding of the service users' needs, what works and what not.

After reviewing literature and interviewing the sexual counsellor at Autism Foundation Finland we understood that professionals lack training on the specific field of disabilities and sexuality. It is our hope that soon this type of education programs is offered in an extensive manner to the professionals on the social and health care services, maybe also in the form of a specific bachelor's degree or masters program.

The key words chosen helped us to narrow down the research in this thesis but also to gain more broad knowledge on the topic. We both writers agreed that literature in this topic strengthened our ethics concerning people with disabilities and to enhance our communication skills. AAC taught us a lot on how to tackle communication impairments using aided and unaided symbols.

According to Craft and Craft (1987) for sexual health to be attained and maintained, the sexual rights of all individuals must be respected, protected, and fulfilled. They cited the right to grow up, to know, to be sexual and to make or break relationships, the right to be free from the individual sexual attitudes of different caregivers, the right to be free from abuse, the right to humane and dignified environments, as basic sexual rights (Cited by Reynolds 2013, 41). To make these rights more accessible, clear and understandable to people with disabilities and specially those having Autism Spectrum was the aim of this thesis. To achieve this aim, objectives were clearly set; we created

the booklet which contains pictograms and very simple and short sentences explaining basics sexual rights.

In previous chapters we explained the reason why we choose the professionals of Autism Foundation Finland to do the evaluation and it was mainly because we could not test the booklet with the service users. The booklet was well received by the professionals of Autism Foundation Finland. They validated its utility by confirming that they will use it with their service users.

The partnership with Autism Foundation Finland had a major impact in the realization of this thesis, since their support has been one of the main reasons for the success of the product. As well as the effort and compromise we, the writers, showed throughout the entire writing process. Tasks were divided and performed equally, and the teamwork was one of the main reasons for the successful outcome on achieving the objectives stated in chapter 2.

At the beginning of the writing process of the thesis, we had limited knowledge of autism and sexuality. After reading several books and academic articles on the topic, we can say that our knowledge has increased substantially. Not only we learned about autism and sexuality, but we also learned about sexual health, sexual rights, neurodevelopmental disorders, autism, alternative and augmentative communication. We were able to combine all the learning to create the booklet. We have been adamant as well about the ethics of working with vulnerable groups, and doubtlessly this will be very beneficial for our futures careers.

During the information-gathering phase of the thesis, a few questions and ideas unrelated to our main topic arose. These questions concerned, for instance, pregnancy and childbirth for women with autism, and how doulas, midwives and other health professionals could explain the body transformation to them, and how they can make this experience more comfortable for them. This is a topic that we hope to investigate further in the future.

All in all, we can say that we have grown professionally by writing this thesis, and that all the steps taken led to a successful product that will benefit the service users of our WLP and its professionals.

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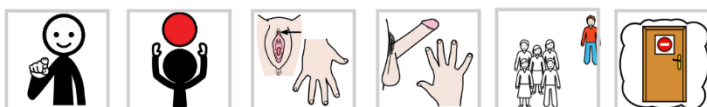
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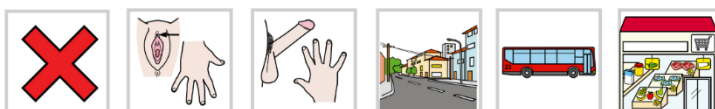
APPENDIX 1. Right to masturbate. English version



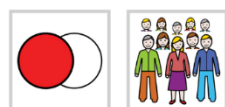
YOU HAVE THE RIGHT TO MASTURBATE.



YOU CAN MASTURBATE ALONE, IN PRIVATE.

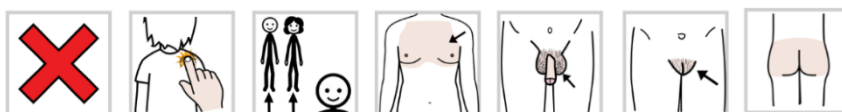


DO NOT MASTURBATE IN THE STREET, THE BUS, THE SHOP,



OR IN FRONT OF OTHER PEOPLE.

APPENDIX 2. Physical contact consent. English version



DO NOT TOUCH OTHER PEOPLE'S CHEST, PENIS, VAGINA OR BUTT



WITHOUT ASKING PERMISSION.



NO ONE CAN TOUCH YOUR CHEST, YOUR PENIS



YOUR VAGINA OR YOUR BUTT WITHOUT ASKING YOUR PERMISSION

APPENDIX 3. Reporting abuse. English version



IF SOMEONE TOUCHES YOUR PRIVATE BODY PARTS



OR HAS SEX WITH YOU WITHOUT YOUR PERMISSION,

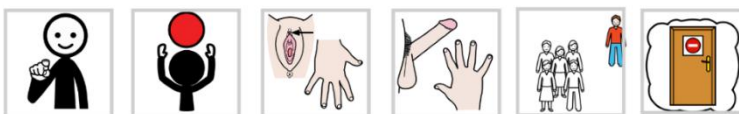


TELL IT TO YOUR SUPERVISOR OR THE POLICE.

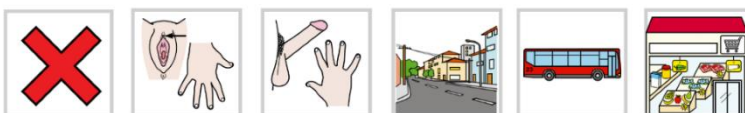
APPENDIX 4. Right to masturbate. Finnish version



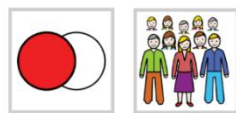
SINULLA ON OIKEUS TYYDYTTÄÄ ITSEÄSI.



VOIT TYYDYTTÄÄ ITSEÄSI YKSIN OMASSA RAUHASSA.

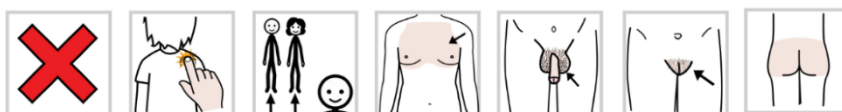


ÄLÄ TYYDYTTÄ ITSEÄSI ULKONA, BUSSISSA, KAUPASSA



TAI MUIDEN LÄSNÄOLESSA.

APPENDIX 5. Physical contact consent. Finnish version



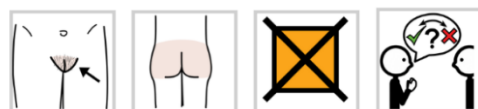
ÄLÄ KOSKE MUIDEN RINTOJA, PENISTÄ, VAGINAA TAI TAKAPUOLTA



ILMAN ETTÄ KYSYT LUVAN.



KUKAAN EI SAA KOSKEA RINTAASI, PENISTÄSI,



VAGINAASI TAI TAKAPUOLTASI ILMAN LUPAASI.

APPENDIX 6. Reporting abuse. Finnish version



APPENDIX 7. Interview 1 with the sexuality counsellor of Autism Foundation Finland

1. In your professional opinion, what is the aspect of sexuality presenting more challenges/difficulties to understand to the autistic community? What is the best approach for explaining sexual rights and sex ed to people with autism? What are the more common challenges/difficulties the professionals have?
2. Since we have limited amount of time and resources, we might need to focus in few specific topics (masturbation in private, don't touch without permission/no one can touch you without your permission, etc). Which ones would you say are the more important?
3. In a literature review made by Solomon, D., Pantalone D.W., and Faja, S. about adults with autism and sexual education found that several authors have come to the conclusion after different studies that adults on the spectrum were less likely to report learning about sexually transmitted diseases, contraceptives, and sexual behaviors from social sources, such as parents, teachers, and peers, as would be expected for non-ASD individuals.. First, some parents and health care providers feel hesitant to discuss sexuality. This may be due to a fear that such discussions will increase interest in or likelihood of sexual behaviors, lack of confidence in their own ability to teach sexual content, or the misperception that individuals on the autism spectrum are unmotivated to have romantic or sexual partnerships. , more than half of healthcare providers viewed their lack of training and access to accurate information as an obstacle to providing information about sexual health to patients on the spectrum.
 - a. What is your perception about Finnish health care providers' and social service workers' knowledge about sexuality and autism/disabilities?
 - b. What challenges do you find when having a sexuality consultation with a service user?
4. In your professional opinion, would a comic-type story (like the draft attached) where the story of character is told in a more elaborated way be easy to understand for those with a not so limited communication skill? Would it be better use only pictograms? Could it work to use both combined? Would it be a product that professionals would be using with their service users?

5. What apps/tools/software could we use to create our social story? For the comic we used Canva, and for the pictograms we are using Papunet and ARASAAC.

APPENDIX 8. Interview 2 with the sexuality counsellor of Autism Foundation Finland

1. What kind of center is the unit you are working at?
2. How the service users go there? Is it private application or the public services?
What is the criteria followed to determine who goes there?
3. What kind of activities are offered to the service users?
4. What kind of sexual and relationship education is offered? Who is providing it?
5. How is the initial knowledge on sexuality of the service users when they arrive to the unit? What are the main challenges of the service users regarding sex. Ed.? How are those challenges addressed by the professionals?
6. How do you encourage the service users to have a healthy sexual life (use of masturbation devices/pleasure time/etc)?
7. What specific characteristics do the service users have? Of course, respecting their privacy, can you tell us a bit more about their communication challenges, understanding of speech, need of supportive communication methods, etc?

APPENDIX 9. Feedback questionnaire for the professionals at Autism Foundation Finland

2/21/22, 2:25 PM

Sexuality and Relationships Education Materials Evaluation and Feedback

Sexuality and Relationships Education Materials Evaluation and Feedback

This feedback form it will be used to measure the efficiency of the sexual education aid we created in our product-based thesis during our Bachelor of Social Services studies. The results will be included in the final text, which will be available in Theseus after its publication. Theseus gives you online access to theses and publications from Finnish Universities of Applied Sciences.

Anonymity is guaranteed, and professionals can not be identified by their replies on this form. Nevertheless, the form will be erased once the results have been analyzed. Only those with the link to the form have access to it, and only us, the students, have access to the results.

The results will be used to complete the product's evaluation process in our thesis by analyzing the usability of the product by professionals and service users, and to include guidelines for improvement for future education materials development. It will also be beneficial for our learning on the topic of sexual and relationship education for people with autism spectrum disorder.

Please fill this form giving your professional opinion on the Sexuality and Relationships Education materials created for our thesis.

1. In your professional opinion, are the materials presented easy to use for the professionals?

Mark only one oval.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- Don't know

2/21/22, 2:25 PM

Sexuality and Relationships Education Materials Evaluation and Feedback

2. In your professional opinion, are the materials presented easy to understand for the service users?

Mark only one oval.

- Strongly agree
 Agree
 Neutral
 Disagree
 Strongly Disagree
 Don't know

3. In your professional opinion, do you think the service users will engage and/or be interested in using the materials?

Mark only one oval.

- Strongly agree
 Agree
 Neutral
 Disagree
 Strongly Disagree
 Don't know

4. In your professional opinion, do you think the text and pictograms chosen are appropriate?

Mark only one oval.

- Strongly agree
 Agree
 Neutral
 Disagree
 Strongly Disagree
 Don't know

5. Will you use the booklet?

Mark only one oval.

Yes

No

6. Please leave here any other comment about the product you might think it is important or could help us to improve the product.

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