

Experiences of inclusion and welfare services among Finnish Sámi with disabilities

Project report

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Nordic welfare center's preface

This report is the fourth report out of five within a Nordic project about the living conditions of persons with disability and of Sami descent, the indigenous people in Scandinavia, compared with the general population. It is an important contribution to increased knowledge about the prerequisites for good living conditions for people with disabilities and their environment in the Sami regions in Finland.

There is a lack of knowledge about living conditions for people of Sami background with disabilities. Furthermore there is also very little knowledge about conditions for social inclusion for this group across the whole of the Sápmi geographical area. This was acknowledged by The Norwegian Directorate for Children, Youth and Family Affairs (Bufdir). For this reason the Nordic Welfare Centre was enlisted by Bufdir to coordinate a Nordic project on the situation of people of Sami background with disabilities.

The Nordic project is going on from 2014 through 2017. A central part of the project for The Nordic Welfare Centre is to coordinate five different national studies (two from Norway, two from Sweden and this report from Finland). An important element of the work is to make sure the studies are rooted in the Sami environment and that the results are usable in the context of Sami communities. The aim of the project is to map out this sector's living conditions within areas such as work, education, accommodation, social and health services in the individual countries as well as in the entire region.

Results from the Nordic project are intended to contribute to create good conditions to encourage political decisions concerning the group's rights and public services, amongst other things. The project will present information on how the countries live up to the UN Convention on the Rights of Persons with Disabilities and how this work can be followed up in the future.

The Nordic Welfare Centre is an institution under the Nordic Council of Ministers. Our mission is to enhance social policy work in the Nordic countries through education, communication, research and development, networking and international co-operation.

Researcher's preface

The accompanying report is the Finnish contribution to *Personer med funksjonsnedsettelse med samisk bakgrunn*, a joint Nordic research project funded by the Norwegian Barne-, ungdoms- og familiedirektoratet (Bufdir) and coordinated by the Nordic Welfare Centre. One of two Norwegian and both Swedish studies have already been published. The funding received from Bufdir has enabled what is very necessary research on a crucial topic. The Nordic Welfare Centre has provided very professional coordination of the project; it has been a pleasure working with the Centre's Anna Dahlberg and Jonas Bergström. I would also like to take this opportunity to thank the Norwegian and Swedish researchers involved for fruitful collaboration.

The Finnish contribution to the project was carried out by the Department of Social Work at the University of Lapland. In completing the research, I have turned to many colleagues in the Faculty of Social Sciences for advice. I appreciate the help you have given me and the discussions we have had. The University is working to make research on the Sámi one of the institution's spearheads, and this can be clearly seen in the enthusiasm for and commitment to research efforts in this area.

I have had the pleasure and privilege of being able to tap the project's expert group for a wide range of guidance, brainstorming and support. Heartfelt thanks go out to you all - Pia Ruotsala-Kangasniemi, Kalle Könkkölä, Lahja Johanssen-Lampsijärvi, Anneli Pohjola and Elsa Laiti-Hedemäki. Each of you, as a representative of your particular organization, has kept me aware of the extensive societal ramifications of the research topic. Elsa, who acted as cultural interpreter throughout the course of study, helped me to understand many things from fresh perspectives. Thank you, Elsa.

Reliable library, administrative and translation services are significant components of any research effort. Without the guidance provided by Arja Petäjäsuo and Richard Foley's contribution in translating the report, I would have had far less time available for the research work proper. Also valuable in this regard has been the Sámi Language Office of the Sámi Parliament, whose

expertise made it possible to provide abstracts of the report in Inari, North and Skolt Sámi.

Reaching the people whom I ultimately interviewed would have been impossible without the help of the numerous friends and acquaintances I have gained and networks I have joined in the course of my career. I am not at liberty to mention you by name here but I would like to thank those whom I contacted for advice and support in carrying out the study.

The most profound contribution to the study has been that of the people I interviewed, Sámi living with disability. You have my gratitude for sharing your experiences and lives. Without you, this study would not have been possible.

At the end of the day, however, the decisions and interpretations of results made in the course of the research are my own and I bear full responsibility for any shortcomings.

Rovaniemi, 19 September 2017

Liisa Hokkanen

Vuanõs

Sää'm lää'mes oummi kiõččmõš vuässadvuõđâst da kääzzkõõzzin Lää'ddjânnmest

Taarrjânnam Bufdir (Barne-, ungdoms- og familiedirektoratet) toi'mmepiijmen Tâ'vvjânnmallaš pue'rrvââjjamkõõskõs lij koordinâsttam Tâ'vvjânnmallaš ha'ŋkõõzz, ko'st čiõlgtet sää'mtuâkksaž lämmsi jie'llem vue'jj (Bufdir 2013). Projee'ktest taarr (Melbøe et al. 2016) da ruõcc (Uttjek 2016) vue'sstu'tkõkummuž lie valmštõõvvâm ääi'jben. Vue'sstu'tkõkummuži metoodlaž čãuddmõõžž lie nuu'bbesnallšem ve'rddõõllâm diõtt. Pukin lie õnnum privatnii'kõki mainstâttmõõžž da sii'ske analyys.

Lää'dd vue'sstu'tkõkeem tu'tkõkeemtuâjjan šõõddi tu'tkõkeed Lää'ddjânnmest jâlstei sä'mmlai lämmsi tobddâm da kaunnâm čãrstummuž, si'jji pi'rğgummuž tuärjjei se'lvnemstrategiaid di pue'rrvââjjamkääzzkõõzzi ââ'nnemkiõččlâsttmõõžžid.

Aunstõõzz no'rre muõttpällmõõntõõllmin. Mainstâttmõõžžid tuejjei narratiivlaž teemamainstâttmõõššân. Tãn rapoortâst lie analysõsttum âãu'c oummu mainstâttmõõžž, koi pešttmõš õhttsi'žže lij nenmlo čiãssâd. Mainstõttum oummu lie 20–80-ekksa da sooggbie'li mie'ldd sij juâkkâ'tte tässa.

Mainstâ'ttemaunstõõzzâst lie jeänab sää'm jie'nnkiõllnes mainsteei da dommvuu'dest jâlstei gu mõõk Lää'ddjânnmest aassi sää'mnaroodâst lie takai vue'jjest. Mainstõttum oummin ee'ttkõsttum lämmsijoouk lie tuärjj- da liikkeemorganlää'mesvuõđ, mättjemvaiggõõzz, kognitiivlaž hääi't di vuõivâšnlää'mesvuõđ. Aunstõõzzâst uu'ccben lie miõl puõccmõõžž, aiccvââ'jj di vaiggânji læmmaz.

Lää'mesvuõ'tte da sää'mvuõ'tte kooll takai ä'sšen čãrstummuš, hã't kuhttuin aa'sšin leä't mõnnum õõudâs. Škooulstroittel konkretisâsttnam assimilaatiopolitiikk seu'rrjõõzzi teevvmõš da sää'mkiõli jealltummuš lie kõõskräã'jest. Ääi'jab puõlvvõõggi tobddâm kõrr rajjâz meâldlaž čãrstummuš veekk vuâmmšõõzz da câgg vuâmmše'men tãn poddssaž uu'ccben kuâsttjeei čãrstummuž.

Lämmsi čãrstummuš lij takai eettmõš pirr maai'lm da kuâskk še sä'mmlaid. Čãrstummuš kãunnai škooulstroittlest, tuâjjmarkknin, õhttsallaš da privat jie'llmest. Uu'cces õhttõõzzâst lämmsi sãã'j da vuõiggãdvuõđid kuõskki teãđ

tarbb lij čuu't vääžnai. Lämmsi lokku välldmõš sää'mpolitiikkâst da sää'msagstõõllmõõžžâst lij pääʒʒam vânnsen. Lämmsi vuõiggâdvuõtt jii'jjeskiõõllsa le'be kuõi'tkiõõllsa lämmsikääzzkâ'sttma da frisksmâttmõ'sše ij tiuddu.

Tu'tkõkummšest puä'tte lää'mesvuõđ da sää'mvuõđ lââ'ssen õu'dde še jee'res čârstemtuejjei, tõi kõskknaž vuârrvaaiktõs di tõiđ vaaikteei jie'llemjââ'ttma da pirrõ'sse kuulli tuejjei. Čârstummuš čuä'jtââtt intersektionaal'laž da kontekstuaal'laž eettmõššân. Tõt lij prosessuaal'laž, vuârrvaaikteei da pooddâst kîdd âârrai di mottstõõvvi. Tobddmõõžžin puästtad ââ'nnmest lij õhttvuõtt oummu mõõntõõllma, sij va'lljumšid jie'llmest di identitee'tt šõddma. Kääzzkõõzzi häämstummuš da čâuddmõõžžin kaunnmõš õudldâ'stte vuõ'jji määngbeällsaž vuâmmšummuž.

Mainstõttum oummu kovvee jie'llmes jiõčč rajjum jie'llmen. Tât pohtt õu'dde sij nâânas jii'jjes mäainain vuõ'lğgi toi'mmjemvuõđ, koozz ko'le väimmšõsvuõtt, meä'rmeâldlaž ouddnummuš da čâuddmõõžžin kõskksaž sââ'jest.

Toi'mmjemvuõđâs tuärjõssân sij taarbše sosiaal'laž säi'mmõõzzid da miõõllsaž toimmjummuž. Tobddmõõžžin hue'nnen ââ'nnmest le'be keeu'summšest čau'ne mäנגgsin haal vaaikted le'be vä'ldded beä'l vaaiktummša.

Sää'mvuõtt jii'jjes identitee'tt vue'ssen čuä'jtââtt raavâsvuõđ tuejjee'jen, kââ'tt tuärjjad čâuddmõõžžin kaunnmõõžžin va'žžlõs jie'llempooddin. Sää'mvuõtt lij privat ä'sšen jijstes se'lvven vue'ssen jie'llmest da lää'mesvuõđ kompensõ'stti viõkk. Sää'mvuõđ mie'ldd kaaunâst normaalvuõđ da jou'kõke kuullmõõžžin, koon lää'mesvuõtt lij va'žžtam. Tõt jâârgal čârstem-mäainast jeänab viõgg uvddjen da viõggsmõ'tti tue'jjee'jen mainstõttum oummi jie'llmest.

Läkka kee'rjuum vuõiggâdvuõđ ââ'nned sää'mkiõõll kääzzkõõzzin jeä't äv'kõkuku. Nu'tt lämmez jii'jgu ve'rğgnee'kõkõ lie assimilaatiopolitiikk mie'ldd da kuõi'tkiõõllsažvuõ'tte nuäjjõõđee'l jiõčč ää'sšest luâppam põrggmõõžžin ââ'nned sää'mkiõõll pue'rrvââjjamkääzzkõõzzin. Pue'rrvââjjamkääzzkõõzzin ij še leäkku kulttuursaž fi'ttjõs sää'mvuõđâst le'be lää'mesvuõđ miârktõõžžâst sää'm kontee'kstest. Kulttuurvuõđ lokku va'lddi pue'rrvââjjamkääzzkõõzzin raaj lie dommvuud ouddpeâm- da škooultõskääzzkõõzzin. Kulttuurlânji adekvatt kääzzkõõzzin vuõlltummuš sosiaal- da tiõrvâsvuõttkääzzkõõzzid da lämmsi taarbšem spesiaalkääzzkõõzzid õõlgat ku'kesäigsaž škooultõõzz, resursâsttmõõžžin da täätt.

Alggmeerai čõõđtõõzzin oudldem lämmsid jeä'rben lokku välldmõš suâppmõõžžin piijee'n lij pääccam tän räija vää'ldkani lokku. Lää'ddjânnam teimma ratifiâ'sttem meeraikõskksaž lämmsi vuõiggâdvuõđi suâppmõš õudldâstt

lämmsi k̄iõlluâgga lokku välddmõõžž čõõđ viiggee'n si'jji õõutverddsaž
vuässadvuõđ õhttsažkâdda da čârsteķa'nesvuõđ pukin jie'llemvuu'din.
Meeraikõskksaž suâppmõõžžid âlgg lookkâd palddpaaldi ä'sšĳii'rji
implementâ'sttemvuõ'jjid oo33een.

Čuákankiäsu

Sämmilij vädulij vuáttámuš uásálâšvuodâst já palvâlusâin Suomâst

Taažâ Bufdir (Barne-, ungdoms- og familiedirektoratet) tooimânaddelmist Tave-eennâmlâš pyereestvaijeemkuávdáš (Pohjoismainen hyvinvointikeskus) lii koordinistâm Tave-eennâmlii haavâ, mast selvâtteh tagarij vädulij eellimtile, kiäin lii sämituávváš (Bufdir 2013). Proojeekt taažâ (Melbøe et al. 2016) já ruátálâš (Uttjek 2016) uásitukâmuš láá valmâštum ovdâlist. Uásitukâmušâi meethodliih čuávduseh láá nubijdis nálásiih, vâi taid puáhtá verdidiđ. Puohâin láá kevttum ovtâskâs ulmui sahhiittâlmeh já siskáldâsanalyys.

Syemmilii uásitukâmuš tutkámpargon šoodâi tutkáđ olgoštem, mon Suomâst ässee sämmiliih väduliih láá feerim já kuáhtám, cevzimstrategiaid, moh tuárjuh sii pyereestvaijeem sehe vuáttámušâid pyereestvaijeempalvâlusâi kevttimist. Amnâstâh nurrui muotâpálluvuovvijn (lumipallomenetelmä). Sahhiittâlmijđ tohhii narratiivlâš teemasahhiittâlmijn. Taan raportis láá analysisistum oovce ulmuu sahhiittâlmeh, moi ohtsâšpištem lii neljinubáloh tijmed. Sahhiittállum ulmuuh láá 20–80 ihásiih já suhâpeelijyehim lii täässiv.

Sahhiittállâmamnâstuvâst láá eenâb sâmikielâ eenikiellân sárnooh já sâmikuávlust ässeeh ko Suomâst ässee sâmiaalmugist táválávt. Sahhiittállum ulmui peht ovdâstum vâdđujuávhuh láá tuuvdâ- já lihâdemvááduh, oppâmvaigâdvuodâh, kognitiivliih vááduh sehe vuoigâšvááduh. Amnâstuvâst vyeliovdâstum láá mielâ puácuvuodâh, aiccâvááduh sehe eromâš vâddásávt väduliih.

Vädulâšvuotân já sämmilâšvuotân lahtoo almolávt olgoštem, veikâ kuohuin aasijn lii tábáhtum ovdánem. Škovlâlájádâsân konkretisistum suddâluttempolitiik čuávdusij tivvooim já sâmikielâi iäláskitem láá kooskân. Ovdebij suhâpuolvâi feerim noonâ rááhtuslâš olgoštem váldá huámmâšume já iästá uáinimist taan ääigi eenâb čiehhum olgoštem.

Vädulij olgoštem lii maailmviđosâš almoon, já taat kiärdu meid sämmilij puotâ. Olgoštem tábáhtuvâ škovlâlájádâsâst, pargomarkkânij, siärvuslii já priivaat elimist. Uccâ siärvusist vädulij sajattâhân já vuoigâdvuodâid kyeskee tiäđu tárbu lii eromâš tiäduttum. Vädulij vuotânvâldim sâmpolitiikâst já – savâstâlmist lii

páaccám uccen. Vádulij vuoigâdvuotâ jieijâskielâlii teikâ kyevtkielâlii vâdulâšpalvâlusân já vajoiditmân ij olášuu.

Tutkâmušâst puátih oovdân vâdulâšvuodâ já sâmmilâšvuodâ paaldâst eres olgoštemtahheeh, toi koskâsâš vuáruvaikuttâs sehe eellimjotemân já pirrâsân kullee tahheeh, moh vaikutteh toid. Olgoštem čaittâšuvá intersektionaallâš já kontekstuaallâš almonin. Tot lii prosessuaallâš, vuáruvaikuttâslâš já tilán čonnum sehe ääigi mielh muttojejee. Puástukohtâlem vuáttâmušâst lii ohtâvuotâ ulmui lattiimân, sii eellimvaljiimijd sehe identiteet hammiimân. Palvâlusâi hammim já čuávdušij kavnmâ vâätih tiilij maangâpiälâsâi aiccâm. Sahhiittâllum ulmuuh kovvejeh sii eellim, ete tot lii jieš rahtum. Taat tiäduť sii noonâ jiešráđâlii toimâmvuodâ, moos lahtojeh sinne, ulmetiäđulâšvuotâ já čuávduškuávdašlâšvuotâ. Toimâmvuodâs toorjân sij tarbâšeh sosiaallijd viärmâduvâid já jiermâlii tooimâ. Vuáttâmušah puástud feerejum kohtâlmist teikâ kiivsedmist rávkkih maangâsist haalu vaikuttid teikâ väldid pelee vaikutmân.

Sâmmilâšvuotâ persovnlâi identiteet uáassin čaittâšuvá kievrâvuotâtahhen, mii tuárju čuávdušij kavnmâ hástulijn eellimtiilijn. Sâmmilâšvuotâ lii priivaat äššin jiešmeidlist čielgâ uási eellim já vâdulâšvuodâ tássejejee nahcâ. Sâmmilâšvuodâ peht jukseh normaalvuodâ já juávkun kullum, mon vâdulâšvuotâ lii hástám. Tot muttoo olgoštemtahhest vuáimâsmittee já váldâsmittee tahhen sahiittâllum ulmui elimist.

Laahâm čallum vuoigâdvuotâ kevttid sâmikielâ palvâlusâin ij onnuu. Sehe vâdulâš jiejah ete virgeomâhááh láá suddâluttempolitiik čuávumuššân já kyevtkielâšvuodâ vuáđuld válduääšist luoppâm keččâlmijn kevttid sâmikielâ pyereestvaijeempalvâlusâin. Pyereestvaijeempalvâlusâin ij lah meid kulttuurilâš ibárdâs sâmmilâšvuodâst teikâ vâdulâšvuodâ merhâšumeest sâmmilâi kontekstist. Pyereestvaijeempalvâlusah, moh väldih vuotân kulttuur, rájášuveh sâmikuávu arâšoddâdem- já škovlâpalvâlussâid. Kulttuurilâšvâš ääšimiäldâsâš palvâlus vijđedem sosiaal- já tiervâšvuodâpalvâlussâid já vâdulij tarbâšem sierânâspalvâlussâid váátá meritiätulii škovlim, resursij lasettem já táátu. Algâalmugij julgâštus vaattâm vâdulij eromâš vuotânvâldim sopâmuš olášutmist lii taan rái páaccám huámmâšumettáá. Suomâ moonnmâ ive ratifisistem aalmugijkoskâsâš vâdulij vuoigâdvuodâi sopâmuš váátá vâdulij ulmui kielâtuávvâá vuotânvâldim talle ko olášuttoo sii oovtviärdâsâš uásálistem ohtâšškoodán já olgoštmettumvuotâ puoh eellimsuorgijn. Aalmugijkoskâsijd sopâmušâid kalga luuhâđ paldlúvâi ko oceh äššikiirjij olášuttemvuovijd.

Čoahkkáigeassu

Sápmelaš lámisolbmuid vásáhusat oasálašvuodas ja bálvalusain Suomas

Norgga Mánáid-, nuoraid- ja bearašdirektoráhtta (Bufdir) mearridii Davviriikkalaš buresbirgejumeguovddáža (su. Pohjoismainen hyvinvointikeskus) jođihit Davviriikkalaš prošeavtta, man ulbmilin lea čielggadit sápmelaš lámisolbmuid (davvisámegillii maid doaibmahehttejuvnon olmmoš) eallindili (Bufdir 2013). Prošeavtta norgalaš (Melbøe et al. 2016) ja ruottelaš (Uttjek 2016) oassedutkamušat leat válbmanan juo ovdalis. Oassedutkamušaid metodologalaš vuogit leat sullasaččat, vai daid lea vejolaš veardádallat gaskaneaset. Buot oassedutkamušain leat atnán ovttaskas olbmuid jearahallamiid ja sisdoalloanalysa.

Suopmelaš oassedutkamuša guovddáš dutkančuolbman hápmašuvai guorahallat vealaheami, man Suomas ássi sápmelaš lámisolbmot leat vásihan, sin buresbirgejumi ovddideaddji ceavzinstrategiijaid ja lassin sin buresbirgejumebálvalusaid geavahanvásáhusaid. Dutkanmateriála čoggojuvvui muohtaspábbametodain (su. lumipallomenetelmä). Jearahallamiin geavahuvvui narratiiva temájearahallanmálle. Dán raporttas analyserejuvvojit ovcci olbmo jearahallamat, maid guhkkodat lea oktiibuot njealljenuppelohká diimmu. Jearahallojuvnon olbmot leat 20–80 ahkásaččat ja leat sihke nisson- ja dievdoolbmot. Jearahallanmateriálas leat eanet olbmot, geat hubmet sámegiela iežaset eatnigiellan ja ássat Sámiid ruovttuguovllus go Suomas ássi sámeservodagas dábálaččat. Jearahallon olbmot ovddastit čuovvovašlágan váttuid joavkkuid: dákte- ja deahkkeváttuid, oahppanválttisvuodaid, kognitiiva váttuid ja vuoiŋašvaháguvvamiid. Materiálas unnitlogus leat sihke iešguđegelágan mielladearvvašvuhtii laktáseaddji váttut dahje buohcuvuodát, áiccuide laktáseaddji váttut ja olbmot, geain leat olu váttut dahje buohcuvuodát. Lámisvuohka ja sápmelašvuohka leat ain dábálaš vealaheami sivat, vaikko sáhtta gal namuhit ahte daid eastadeamis leat ovdánan. Skuvlálágádusa systemáhtalaš assimilerenpolitihka čuovvumušaid divvun ja sámegielaid ealáskahttin leat ain hui gaskan. Ovddit buolvvaid vásihan garra ráhkaduslaš vealaheapmi doalvu fuomášumi ja maddái gokčá dálá áigge eanet čihkkojuvnon vealaheami.

Lámisolbmuid vealaheapmi lea máilmmiviidosáš albmoneapmi, ja dat dáhpáhuvvá maid sámiid guovdu. Vealaheapmi dihtto skuvlalágádusas, barggus, searvvušlaš ja priváhttaeallimis. Lámisolbmuid sajádaga ja vuoigatvuođaide guoskevaš dieđu juohkin lea unna servošis erenomáš dehálaš. Lámisolbmot eai leat báljo váldojuvvon vuhtii sámepolitihkas dahje almmolaš ságastallamis. Lámisolbmuid vuoigatvuohta iežasgielat dahje guovttegielat lámisolbmuid bálvalusaide ja veajuiduhttimii eai ollašuva.

Dán dutkamušas bohtet ovdan lámisvuođa ja sápmelašvuođa lassin maid eará vealaheami sivat, daid gaskasaš vuorrováikkuhus ja maid eará bealit, mat laktásit olbmuid eallimii ja birrasii. Dutkamuš čájeha ahte vealaheapmi lea interseksionála ja kontekstuála albmoneapmi. Dat dáhpáhuvvá proseassaid, vuorrováikkuhusaid ja iešguđegelágan dilálašvuođaid ja áiggiid mielde. Olbmo vásáhus eahpevuoiggalaš láhttenvuogis váikkuha su láhttemii, eallinválljejamiide ja maid identitehta hápmašuvvamii. Bálvalusaid huksen ja čovdosiid gávdnan eaktudit dilálašvuođaid sihke fiinnadovddolaš ja mánggabealat geahčadeami.

Jearahallon olbmot govvidit iežaset eallima dakkárin ahte sii leat “daid ieža huksen”. Dát čuvge sin nana iešráđálaš doaimma, masa laktásit sidnáivuohta, ulbmildiđolašvuohta ja čuolmmaid čoavdin. Doaimma doarjjan sii dárbbášit iešguđegelágan sosiála fierpmádagaid ja miela miel bargguid. Vásáhusat eahpevuoiggalaš láhttemis dahje givssideamis boktet mángasis hálo váikkuhit dahje oassálastit váikkuheapmái.

Dutkamuš čájeha ahte sápmelašvuohta persovnnalaš identitehta oassin lea dakkár dahkki, mii veahkeha olbmuid čoavdit čuolmmaid hástaleaddji eallindiliin. Persovnnalaš áššin sápmelašvuohta lea olbmuid eallima lunddolaš oassi ja lámisvuođa geahpedeaddji dahkki. Sápmelašvuohta duddjo olbmui dábálašvuođa ja servošii gullelašvuođa dovdu, maid lámisvuohta lea hástán. Sápmelašvuohta, mii lea leamašan vealaheami okta sivva, badjána jearahallon olbmuid eallimis nanosmahtti dahkin.

Láhkii merkejuvvon vuoigatvuođa geavahit sámegiela iešguđet bálvalusas eai geavat. Sihke lámisolbmot ieža ja maid virgeoapmahaččat leat assimilerenpolitihka dihte ja guovttegielatvuhtii dorvvasteami geažil eanaš luohpan viggamušain geavahit sámegiela buresbirgejupmebálvalusain. Dasa lassin buresbirgejupmebálvalusain ii leat kultuvrralaš ipmárdus sápmelašvuođas dahje lámisvuođa mearkkašumis sápmelaš konteavsttas.

Buresbirgejupmebálvalusat, mat váldet vuhtii kultuvrralaš beliid, rádjašuvvet ruovttuguovllu árabajásgeassin- ja skuvlabálvalusaide. Kultuvrralaččat

áššáigullelaš bálvalusa ollašuttin sosiála- ja dearvvašbálvalusain ja lámisolbmuid dárbbášan sierrabálvalusain gáibida mearrediđolaš skuvlema, resurssaid lasiheami ja dáhtu.

Eamiálmogiid julggaštus, mii eaktuda lámisolbmuid erenomáš vuhtiiváldima soahpamuša ollašuttimis, ii leat dássáži ožžon báljo fuomášumi. Suoma ratifiserii diibmá riikkaidgaskasaš lámisolbmuidsoahpamuša, mii eaktuda lámisolbmuid gielladuogáža vuhtiiváldima dalle go leat ovddideame sin ovttaveardásaš oassálastima servodahkii ja eastadeame sin vealaheami buot eallinsurggiin. Riikkaidgaskasaš soahpamušaid galggalii lohkat seammás go leat pláneme buoremus vugiid ollašuttit daid.

Tiivistelmä

Saamelaisten vammaisten kokemus osallisuudesta ja palveluista Suomessa

Norjan Bufdir:n (Barne-, ungdoms- og familiedirektoratet) toimeksiannosta Pohjoismainen hyvinvointikeskus on koordinoanut Pohjoismaista hanketta, jossa selvitetään saamelaistaustaisten vammaisten elämäntilannetta (Bufdir 2013). Projektin norjalainen (Melbøe et al. 2016) ja ruotsalainen (Uttjek 2016) osatutkimus ovat valmistuneet aiemmin. Osatutkimusten metodiset ratkaisut ovat toistensa kaltaisia vertailtavuuden mahdollistamiseksi. Kaikissa on käytetty yksilöhaastatteluja ja sisällönanalyysiä.

Suomalaisen osatutkimuksen tutkimustehtäväksi muotoutui tutkia Suomessa asuvien saamelaisten vammaisten kokemaa ja kohtaamaa syrjintää, heidän hyvinvointiaan tukevia selviytymisstrategioita sekä hyvinvointipalvelujen käyttökokemuksia.

Aineisto kerättiin lumipallomenetelmällä. Haastattelut toteutettiin narratiivisina teemahaastatteluina. Tässä raportissa on analysoitu yhdeksän henkilön haastattelut, joiden yhteiskesto on neljätoista tuntia. Haastateltavat ovat 20–80 vuotiaita ja sukupuolijakauma on tasainen. Haastatteluaineistossa on enemmän saamea äidinkielenään puhuvia ja kotiseutualueella asuvia kuin Suomessa asuvassa saamelaisväestössä yleensä. Haastateltavien kautta edustettuja vammairyhmiä ovat tuki- ja liikuntaelinvammat, oppimisvaikeudet, kognitiiviset häiriöt sekä aivovauriot. Aineistossa aliedustettuina ovat mielen sairaudet, aistivammat sekä erityisen vaikeasti vammaiset.

Vammaisuuteen ja saamelaisuuteen liittyy yleisesti syrjintää, vaikka molemmissa asioissa on tapahtunut edistystä. Koululaitokseen konkretisoituneen assimilaatiopolitiikan seurauksien korjaaminen ja saamenkielten elvyttäminen ovat keskeneräisiä. Aiempien sukupolvien kokema vahva rakenteellinen syrjintä vie huomiota ja estää havaitsemasta tämänhetkistä hienovaraisempaa syrjintää.

Vammaisten syrjintä on yleismaailmallinen ilmiö, ja tämä toistuu myös saamelaisten kohdalla. Syrjintää esiintyy koululaitoksessa, työmarkkinoilla, yhteisöllisessä ja yksityisessä elämässä. Pienessä yhteisössä vammaisten asemaa ja oikeuksia koskevan tiedon tarve on erityisen korostunut. Vammaisten

huomiointi saamelaispolitiikassa ja -keskustelussa on jäänyt niukaksi.

Vammaisten oikeus omakieliseen tai kaksikieliseen vammaispalveluun ja kuntoutukseen ei toteudu.

Tutkimuksessa tulee esiin vammaisuuden ja saamelaisuuden ohella muita syrjintätekijöitä, niiden keskinäistä vuorovaikutusta sekä niihin vaikuttavia elämäntilanteita ja ympäristöllisiä tekijöitä. Syrjintä osoittautuu intersektionaaliseksi ja kontekstuaaliseksi ilmiöksi. Se on prosessuaalista, vuorovaikutteista ja tilannesidonnaista sekä ajassa muutuva. Kokemuksella väärästä kohtelusta on yhteys ihmisten käyttäytymiseen, heidän elämänvalintoihinsa sekä identiteetin muotoutumiseen. Palvelujen muotoilu ja ratkaisujen löytäminen edellyttävät tilanteiden monipuolista havaitsemista. Haastateltavat kuvaavat elämäänsä itse tehdyksi. Tämä korostaa heidän vahvaa omaehtoista toimijuuttaan, johon liittyy sinnikkyyttä, päämäärätietoisuutta ja ratkaisukeskeisyyttä. Toimijuutensa tueksi he tarvitsevat sosiaalisia verkostoja ja mielekästä toimintaa. Kokemukset vääräksi koetusta kohtelusta tai kiusaamisesta herättävät monissa halun vaikuttaa tai ottaa kantaa vaikuttamiseen.

Saamelaisuus henkilökohtaisen identiteetin osana osoittautuu vahvuustekijäksi, joka tukee ratkaisujen löytämistä haasteellisissa elämäntilanteissa.

Saamelaisuus on yksityisenä asiana itsestään selvä osa elämää ja vammaisuutta kompensoiva voimavara. Saamelaisuuden kautta saavutetaan normaaliutta ja ryhmään kuulumista, jota vammaisuus on haastanut. Se kääntyy syrjintätekijästä voimaannuttavaksi ja valtaistavaksi tekijäksi haastateltavien elämässä.

Lakiin kirjattua oikeutta käyttää saamenkieltä palveluissa ei hyödynnetä. Sekä vammaiset itse että viranomaiset ovat assimilaatiopolitiikan seurauksena ja kaksikielisyyteen nojautuen pääasiassa luopuneet yrityksistä käyttää saamenkieltä hyvinvointipalveluissa. Hyvinvointipalveluissa ei ole myöskään kulttuurista ymmärrystä saamelaisuudesta tai vammaisuuden merkityksestä saamelaisessa kontekstissa. Kulttuurisuuden huomioivat hyvinvointipalvelut rajautuvat kotiseutualueen varhaiskasvatus- ja koulupalveluihin. Kulttuurisesti adekvaatin palvelun ulottaminen sosiaali- ja terveyspalveluihin ja vammaisten tarvitsemiin erityispalveluihin vaatii pitkäjänteistä koulutusta, resursointia ja tahtoa.

Alkuperäiskansojen julistuksen edellyttämä vammaisten erityinen huomiointi sopimuksen toimeenpanossa on jäänyt toistaiseksi huomiotta. Suomen viime vuonna ratifioima kansainvälinen vammaisoikeuksien sopimus edellyttää

vammaisten ihmisten kielitaustan huomiointia toteutettaessa heidän yhdenvertaista osallisuuttaan yhteiskuntaan ja syrjimättömyyttä kaikilla elämänalueilla. Kansainvälisiä sopimuksia tulee lukea rinta rinnan asiakirjojen implementointitapoja haettaessa.

Summary

Experiences of inclusion and welfare services among Finnish Sámi with disabilities

The Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) gave the Nordic Welfare Centre the task of coordinating an overall Nordic project to gather more information about the living conditions of persons with disabilities and of Sámi descent as compared with the general population (Bufdir 2013). The Finnish Study has adopted the similar methodological solutions as Norwegian (Melbøe et al. 2016) and Swedish (Uttjek 2016) in order to ensure comparability. All have used individual interviews and content analysis.

The ultimate focus of the Finnish study was to investigate the discrimination experienced and encountered by Sámi with disabilities living in Finland, as well as the individuals' coping strategies and experiences as users of welfare services.

The research data were collected using snowball sampling. The interviews took the form of narrative theme interviews. The present report analyses interviews with nine persons totalling fourteen hours of material. The interviewees ranged in age between 20 and 80 years, with a reasonably equal balance of the genders. The interview data have a greater proportion of native Sámi speakers and residents of the Sámi homeland than in the country's Sámi population at large. The categories of disability among the interviewees include musculoskeletal disabilities, learning difficulties, cognitive disorders and brain injuries. Underrepresented conditions are mental disabilities, sensory disabilities and particularly severe disabilities.

Disability and Sáminess are common causes of discrimination although progress can be cited in combatting both. Efforts are being made to rectify what was systematic assimilation in the school system and to revitalize the Sámi language but this task is far from complete. The manifest structural discrimination seen in the past is distracting in that it prevents one identifying the more subtle forms of discrimination at work today.

Discrimination against persons with disabilities is ubiquitous globally and the Sámi are in no way spared the phenomenon. Discrimination occurs in the schools, the job market and public and private life. In a small community the

need for knowledge on the situation and rights of persons with disabilities is more pronounced than elsewhere. Sámi policy and discussion of the Sámi have paid scant attention to persons with disabilities. The right of persons with disabilities to services and rehabilitation provided in their own language or bilingually is not realized.

The present study reveals factors other than Sáminess and disability that lead to discrimination, the interaction of these factors as well as the related elements in people's life courses and environment. Discrimination proves to be an intersectional and contextual phenomenon. It is processual, interactional and situational and changes over time. The experience of unfair treatment impacts people's actions, the life choices they make and the shape their identity takes. Finding solutions and designing services require a fine-grained and comprehensive observation of people's situations.

The interviewees describe their lives as "self-made". This description highlights their strong personal agency, characterized by perseverance, determination and a focus on solutions. To support their agency they need social networks and meaningful activity. Experiences of unfair treatment, bullying in school and harassment have aroused in many a desire to engage in advocacy or to take a stand on the issue of advocacy.

Sáminess as an element of an individual's identity proves to be a factor that supports people in finding solutions in challenging life situations. As a personal matter, Sáminess is self-evidently part of people's lives and a source of strength that helps make up for their disability. Through Sáminess one can achieve the sense of normalcy and belonging that disability has compromised. In the lives of the interviewees, Sáminess is transformed from a cause of discrimination to an empowering element.

People do not invoke the statutory right to use the Sámi language in services. As a consequence of assimilation and a reliance on bilingualism, both persons with disabilities and officials have given up attempts to use the Sámi language in welfare services. Moreover, the welfare services have no cultural understanding of Sáminess or the implications of disability in the Sámi context. Welfare services that attempt to take culture into account are confined to early childhood education and the schools in the Sámi homeland. Extending culturally adequate provision to the social and healthcare services and the special services

that persons with disabilities need would require long-term training, provision of resources and political will.

The special consideration for persons with disabilities required by the Declaration on the Rights of Indigenous People in implementing the instrument has thus far been neglected. The Convention on the Rights of Persons with Disabilities, ratified by Finland last year, requires that the linguistic background of persons with disabilities be taken into consideration as part of the effort to promote their equal inclusion in society and to protect them from discrimination in all areas of life. One should consult all the relevant conventions simultaneously when seeking the best ways to implement them.

1 Introduction

1.1 Background of Nordic project

The Norwegian Directorate for Children, Youth and Family Affairs (Bufdir) gave the Nordic Welfare Centre the task of coordinating an overall Nordic project to gather more information about the living conditions of persons with disabilities and of Sámi descent compared with the general population. The name of the project is "Knowledge Situation: People of Sámi background with disabilities". Such a project was considered necessary because there was a lack of knowledge about the conditions under which Sámi with disabilities live. Moreover, there was very little knowledge about the opportunities for social inclusion of this group across Sápmi, the collective term for the areas in the North with large Sámi populations. The project seeks to contribute to creating favourable conditions that will encourage sound political decisions regarding the group's rights and public services. The project will report on the extent to which the countries observe the provisions of the UN Convention on the Rights of Persons with Disabilities and how compliance can be monitored and improved in the future (see also About the project 2017).

The project began in 2014 with a study on Sámi with disabilities in Norway. The Norwegian team has completed its contribution proper, which has spawned a number of follow-on projects. The team has published a research report in Norwegian on their work (Melbøe et al. 2016a), an article in English on the methodological solutions they adopted (Melbøe et al. 2016b) and another article about the democratic participation of people with disabilities and Sámi background (Fedreheim, Melbøe & Opsal 2017). They also have a forthcoming publication, to come out later this year. The Swedish contribution to the project was begun in 2015; its results have been published in a research report in Swedish by Margaretha Uttjek (2016) and a report on the cultural knowledge of workers in the Sámi region (Edin-Liljegren & Flykt 2017). The last phase of the project, begun in 2017, was the Finnish component, the subject of the present report. The Norwegian study formulated a set of research questions for the project, which the Swedish and Finnish studies have adapted to their particular subprojects, conditions and resources. The Finnish study has been carried out by the Department of Social Work in the Faculty of Social Sciences at the University of Lapland.

1.2 The Sámi in Finland

According to the records of the Sámediggi (Sámi Parliament) in Finland, the country's Sámi population in 2015 was 10,643 persons. Russia is estimated to have a Sámi population of 2000, Sweden fewer than 20,000 and Norway between 40,000 and 60,000 persons. As ethnic background is not recorded in Finland or other Nordic countries, population statistics do not recognize Sáminess. In 2016, some 2000 persons reported in the population register that their native language was Sámi.

Today there are Sámi living throughout Finland. Approximately half of the population lives in the province of Lapland, but outmigration from the Sámi homeland and Lapland at large is rather intensive. Some one-third of the country's Sámi population live in what is known as the Sámi homeland. The homeland is defined in legislation as the municipalities of Utsjoki, Enontekiö and Inari as well as the area of the Lappi Reindeer Herding Cooperative (the village of Vuotso) in the northern part of the municipality of Sodankylä. With the exception of Utsjoki, the Sámi are a minority even in the municipalities in the homeland. Most of the Sámi living outside of the homeland live in the capital of Lapland, Rovaniemi, in the national capital, Helsinki, or in other large cities in the southern parts of the country (Heinämäki 2017a; Lehtola & Ruotsala 2017).

Most Sámi today do not speak Sámi as their native language, a situation attributable to the very poor situation and status of the language in Finnish society and the school system. The position of the language has improved in recent decades, particularly in the elementary schools in the homeland. Efforts to revitalize the language have succeeded in some locations elsewhere in Finland through language nests and opportunities to study the language and culture in various educational institutions. This positive development is the outcome of long-term national and international efforts as well as of legislation safeguarding the position of the language. Fewer than half of the Sámi in Finland speak Sámi (Heinämäki 2017a). According to information gathered by the Sámi Parliament in 2015, some 25 per cent of Sámi spoke one of the Sámi languages. Three Sámi languages are spoken in the country: there are some 1700 speakers of North Sámi, 400 of Inari Sámi and 340 of Skolt Sámi (Lehtola & Ruotsala 2017). Efforts to revitalize the languages began at the eleventh hour, as it were, as the languages, in particular Inari and Skolt Sámi, are still critically endangered and continued progress will require that opportunities to study and use the languages be expanded.

Revitalizing Sámi culture and the Sámi languages, as well as maintaining the vitality of Sáminess otherwise, requires special consideration of the Sámi and positive discrimination on their behalf (Heinämäki 2017a). Legislation has been enacted nationally to safeguard the status of the Sámi as an indigenous people, the Sámi

language and culture and self-government. In addition, Finland is a party to a number of international conventions that apply to the Sámi. According to the Finnish Constitution (sec. 17, subsection 3), as an indigenous people the Sámi have the constitutional right to uphold and develop their own language and culture. The legislation on Sámi self-government, the Act on the Sámi Parliament (974/1995) and the Sámi Language Act (1086/2003), which safeguards the status of the language, obligate authorities to protect the Sámi language and guarantee Sámi the right to use the language before authorities.

A number of international conventions place obligations on Finnish legislation, examples being the UN human rights agreements (International Covenant on Civil and Political Rights, ICCPR, and International Covenant on Economic, Social and Cultural Rights, ICESCR) and the Declaration on the Rights of Indigenous Peoples (UNDRIP). Also relevant are the Convention concerning Indigenous and Tribal Peoples in Independent Countries (ILO 169), which Finland has yet to ratify, as well as the Nordic Sámi Convention, negotiations on which are still in progress. For purposes of the present study, Article 22 of the UNDRIP has particular significance, as it requires states parties to pay particular attention to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities in the implementation of the Declaration.

Also of central importance for the present project is the UN Convention on the Rights of the Persons with Disabilities (CRPD), which Finland ratified in 2016. According to the Convention, the state is to promote, protect, and ensure the full and equal enjoyment of human rights and fundamental freedoms by all persons with disabilities. This entails prohibition of discrimination on the basis of disability. The aim is full and effective participation, inclusion in society, equality of opportunities, and accessibility on an equal basis with others to an adequate standard of life, independent living in the community, and a possibility to participate in political, public and cultural life. The states parties are entitled to collect information on the situation of persons with disabilities and report regularly to the CRPD Committee through the Secretary-General of the UN.

The point of departure in the UNDRIP is to protect an indigenous people as a group, whereas international human rights agreements such as the ICCPR, the ICESCR and the CRPD focus on the protection of individuals. According to Heinämäki (2017a, 23), there is no conflict between group and individual rights, because individual rights place constraints on the application of group rights. Group rights cannot result in discrimination against individuals; rather such rights apply equally to all members of the focal group.

International instruments and national legislation do not guarantee that all law-drafting will take into account the obligations imposed by previous agreements, such as the UNDRIP (Heinämäki et al. 2017, 516-517). Constant efforts are needed that are geared to influencing decision-makers, monitoring compliance with agreements and researching issues relating to the subject matter of the agreements.

1.3 Disability and Sáminess in the Study

The issue of disability has been approached from a variety of perspectives, being seen as a question of, among other things, charity, morality, illness, medicine, handicap, social policy, human rights, social work and rehabilitation (Järvikoski 1994, 30-60; Kivistö 2014, 57-69). The two extremes seen in today's debate are the medical and social conceptions of disability. The medical model emphasizes disability as medically identifiable physical features through which an individual deviates from the average and which are considered shortcomings. Disability is then interpreted primarily as a characteristic of the individual. The model is a static one and fails to resonate with society, the environment or changes taking place in them. The social model of disability, developed originally by persons with disabilities in Britain (Oliver 1996), is a widely used point of departure today in social scientific research. Its most extreme interpretations view disability as an instance of the normal variation associated with humanity and interpret it as a product of the community and the environment. In other words, disability is a condition created by society. The social conception of disability radically transformed the understanding of disability. It is rare today to find anyone who adheres to the most extreme form of the social model of disability. In general, understandings of the concept of disability and of disability are products of reconciling the two extreme models. Development based on the social model has emphasized the diverse elements, processual nature and interactive nature of factors relating to disability and its manifestations.

The present study has committed itself to the relational model (Melbøe et al. 2016a; Melbøe et al. 2016b), which seeks to combine a view of disability as a characteristic of the individual and as a product of the environment and society. Disability is shaped in the interaction between the individual, society and the environment. The physical dimension of disability is recognized but the significance of physical features is seen as a product of societal and community practices. The model makes it possible to recognize the wide range of interpretations of disability in societies and communities. It helps to understand the social, linguistic, cultural, temporal, local and contextual dimensions of disability as well as the joint impacts of and changes in these dimensions. A different context may produce a different significance and interpretation for the same physical condition.

As compensation for the hindrances associated with disability, the medical model primarily puts forward measures affecting individuals and designed to restore their functional capacity to a level as close to that defined as normal. By contrast, the social conception of disability enables compensation based on changes in communities, society and the built environment. The relational model recognizes the importance of both of these perspectives in enabling persons with disabilities to enjoy life on an equal basis with persons who do not have disabilities. A classic example of the social conception of disability is the replacement of stairs with a ramp. Stairs often make it impossible or difficult for many groups of people to get around. A ramp does not prevent “persons without a disability” from doing so, yet it removes or reduces obstacles hindering “persons with disabilities”.

The societal debate also offers interpretations of Sáminess. The definition of the concept has been the subject of spirited discussion on many occasions in Finland, and the public debate even after the most recent elections to the Sámi Parliament has occasionally taken on extreme tones (Valkonen 2016). The disputed issues relating to the definition of Sáminess have recently been examined as part of an extensive study on the realization of Sámi rights (Heinämäki et al. 2017). The research also explored the origin of the supposedly conflicting interpretations of Sáminess and the relevant case law; it appears that logical explanations can be found for the conflicting views to be seen in the case law (Heinämäki, 2017b).

The present study does not focus on the definition of Sáminess. However, readers might be interested in the Sáminess of the interviewees in light of the present legislation. When we were soliciting interviewees, they identified themselves as Sámi through their participation in the research. According to the Act on the Sámi Parliament (17.7.1995/974), the fact that a person considers him- or herself a Sámi is one requirement for Sáminess, with this complemented by the requirement that a person have a Sámi background in respect of language, livelihoods or official records. The question of Sáminess was taken up in the interviews. Although it was not possible to determine in advance whether an interviewee met the criteria in the Act on the Sámi Parliament substantiating self-identification, the interviews revealed that all of the interviewees could be defined as Sámi in terms of the Parliament’s criteria.

No research has been done in Finland on Sámi with disabilities. In the period 1994-1997 the Sámi Parliament and the association Kynnys ry-Threshold Association compiled a report on the situation of Sámi with disabilities, elderly Sámi and Sámi with chronic illnesses (Magga 1997). The report noted that the position of the three groups was affected not only by the special circumstances relating to the remote and northern location in which the members of the groups lived but also, and especially, their being

members of a linguistic and cultural minority and of an indigenous people. The report put forward recommendations on how the position of persons with disabilities and the availability of services could be improved in concrete terms and how more attention could be paid to the creation of services that are better attuned to Sámi culture and language.

In the same year as Risten-Rauna Magga's report came out, a report on social and healthcare services for Sámi was published, funded by the Ministry for Social Affairs and Health (Välimaa & Laiti-Hedemäki 1997). The latter took up the position of persons with disabilities. It highlighted the need to provide social and healthcare services for the Sámi based on their circumstances and in their language. It also emphasized that legislation should be enacted ensuring provision of such services and appropriation of the required resources.

The factors affecting the position of Sámi and persons with disabilities have changed since the two reports were published. There is no more recent information on Sámi with disabilities, but we do have information on the wellbeing and the use of welfare services among the Sámi (Heikkilä, Laiti-Hedemäki & Pohjola 2013). A study carried out in the Sámi homeland by Lydia Heikkilä, Elsa Laiti-Hedemäki and Anneli Pohjola has shown that Sámi have less access to welfare services and are less satisfied with those services than are Finns at large. In addition, the Sámi have very limited access to services in their own language. Corresponding study of Sámi living outside the homeland is close to completion (<https://saradutkan.fi/>) and similar results have been obtained in studies of Sámi in Norway (e.g. Nystad, Melhus & Lund 2008).

2 Methods

2.1 Focus of Study and Support in the Research Process

The focus of the Finnish study was originally narrower than that of the overall project due to constraints imposed by research resources and the timetable. In keeping with the Norwegian approach, we concentrated on persons with disabilities, their self-perceived quality of wellbeing, everyday life and opportunities to participate in society, with special emphasis on social and healthcare services. In the present study participation means an opportunity to be heard and treated as a citizen, as a Sámi and as a person with disability. The study investigated the nature of the obstacles and linguistic and cultural barriers that the Finnish welfare system and service delivery may pose – or the opportunities they may offer – that affect people's daily life and the equal availability of services. In looking at obstacles, the study focuses on discrimination as a factor detracting from opportunities to participate and in examining opportunities it concentrates on coping strategies.

The research task of the present study as ultimately defined was to investigate discrimination experienced and encountered by Sámi with disabilities living in Finland, as well as their coping strategies and experiences of using welfare services.

In the chapter that follow the focus of study and methodological decisions adapted are discussed as well as data of study is described (Chapter 2). To facilitate comparison with the corresponding Norwegian and Swedish studies, the chapter on discrimination is subdivided into sections on school, working life and everyday life (Chapter 3). The coping strategies identified include social support, meaningful activity, advocacy for oneself and others and Sámi agency (Chapter 4). While the findings here are comparable to those in the national studies that have been completed, the Finnish material also exhibits certain special features. Where services are concerned, the emphasis is not only on experiences of services in general but also school, health and social services that are provided in the Sámi language and give due consideration to Sámi culture (Chapter 5). The study concludes with a chapter summarizing and discussing the results in order to provide a comprehensive picture of the issues and make it possible to better target measures that will improve the situation of Sámi with disabilities (Chapter 6).

A decision was made that the joint Nordic studies would involve interviews of Sámi with disabilities. This is a sound point of departure given that very little information is

available on that group. Recent research has highlighted the value of personal and experiential knowledge in the planning, evaluation and development of welfare services. (e.g. Barnes & Cotterell 2012; Hokkanen et al. 2016; Pohjola et al. 2017). Social and healthcare services in Finland are currently undergoing a radical reorganization, which makes an approach eliciting the views of clients a good basis for designing new services.

Originally, plans called for applying the interview frame used by the Norwegian researchers to Finnish needs and resources. Initially, the Finnish study, like the Norwegian, formulated a carefully structured frame and had it translated into North Sámi (Appendix 1). As the collection of data began, however, we received preliminary information about the course of the Swedish study and this prompted us to change the Finnish interviews to make them more open-ended and narrative-oriented theme interviews like the Swedish. Despite the change, the themes were the same as in the structured framework, that is, Sáminess, offering and receiving help, solving problems and dealing with difficulties, welfare service experiences, experiences of discrimination and social participation (Appendix 2). During the interviews, the interviewees had an opportunity to look at a list of the themes and thus an opportunity to orient themselves to the situation.

In the planning stages, the study was linked to two national ESF-funded projects run by the Department of Social Work: "The Wellbeing and Equality of the Sámi" (SÁRA) (2015-2018) and "Strengthening Participation and Preventing Marginalization in the Social Work Processes of Disability Services" (VamO) (2016-2019). The aim of linking the projects was to achieve synergies by tapping mutual expertise. The collaboration sought to use and reflect on the knowledge and expertise concerning participation of persons with disabilities in services and society (VamO), combining it with the expertise on Sámi wellbeing and use of welfare services (SÁRA). However, each project had separately defined aims, timetables, activities and budgets.

The responsible manager of the Finnish study is Anneli Pohjola (Prof. Social Work) and the project researcher is Liisa Hokkanen (PhD Social Work, University lecturer). In addition, Elsa Laiti-Hedemäki (MA Social Work, Researcher) from the SÁRA project acted as cultural interpreter and interviewer. Consultations with the Norwegian and Swedish researchers helped to clarifying the interviewing methodology.

An expert group was designated for the study comprising Pia Ruotsala-Kangasniemi (Sámediggi – Finnish Sámi Parliament), Lahja Johansen-Lampsijärvi (Kela – Social Insurance Institution), Kalle Könkkölä (Kynnys – Threshold Association), Elsa Laiti-Hedemäki (University of Lapland) and Anneli Pohjola, (University of Lapland). Three of

the members are Sámi and two Finnish. Disability was familiar to most of the members either personally or through a member of their family. As the project researcher Liisa Hokkanen is Finnish, the Sámi members of the expert group played an important role in providing cultural guidance for the work. The expert group met four times, in addition to which the researcher consulted members for advice as necessary. Elsa Laiti-Hedemäki acted as cultural interpreter for her throughout the course of the study. The overall budget for the study was 21,000 euros. It was carried out between January and September 2017. In keeping with the informant agreements, plans call for using the data later such that it will benefit research beyond the present study.

2.2 Snowball sampling

Snowball sampling was chosen as the data collection method. The method is also known as chain referral sampling or respondent-driven sampling. Snowball sampling is based on the idea that when the first informants have been located, they guide the researcher in finding new interviewees. The method is well suited to contexts where there is reason to believe it will be difficult to reach the target group, where there is no straightforward access to the group or where networking among the group is fragmentary. Also cited as advantages of the method are speed and economy (Heckathorn 1997).

The weakness of the method is that each informant can only guide the researcher forward to people the informant knows and that she/he can determine who the researcher contacts next. The result may be a one-sided and selective picture of the phenomenon under study. In order to avoid this shortcoming, efforts must be made to find a number of informants who do not know each other and find contacts belonging to different networks, for these will yield a richer picture of the focal phenomenon than a single network (Heckathorn 1997). The researcher's networks and the networks of her first-hand intermediaries differ a great deal from one another, whereby tapping these reduced the risk of skewing the outcome. Mainly the networks did not include Sámi with disabilities but people through whom it was assumed that informants could be located or people who would know suitable informants.

The snowball technique distinguishes various procedures that differ depending on how many of the people mentioned by the previous informant are contacted and on whether the researcher deliberates whether she/he will contact the people suggested (Heckathorn 1997). On the basis of the experiences in the other countries, we determined that we would contact all the informants suggested to us. We also were prepared to be selective so that the group of 10 interviewees that we sought would

represent different forms of disability, age groups, places of residence, as well as different backgrounds where Sáminess was concerned.

2.2.1 Choice of data collection method

One factor affecting the choice of data collection method was the difficulty of reaching the target group through official channels or associations. First, as authorities in Finland do not register people's ethnic background, sources of information on persons with disabilities contain no information on ethnic background. The Sámi Parliament has information on those eligible to vote in elections to the Parliament but these records have no indication of the people's state of health or disability.

Secondly, we were aware that there is no specific association of Sámi with disabilities. They may be members of Finnish disability associations, which do not distinguish members on the basis of ethnic background, or they may be members of Sámi associations, which do not distinguish members on the basis of disability. The Sámi's own general association in the area of social and healthcare, Sámi Soster ry, works to comprehensively promote the status and rights of Sámi as an indigenous people in the areas of social services, health, wellbeing and culture. The scope of the association's activities is broad and, among other things, it has collaborated with Kynnys ry-Threshold Association to improve the situation of Sámi with disabilities, one outcome of this work being the report mentioned above (Magga 1997). Sámi Soster does not have any project under way focusing on persons with disabilities. Many of its activities nevertheless involve disability issues and through them the association provides advice to persons with disabilities on services to the extent its resources permit it.

Thirdly, difficulties were anticipated in reaching informants because a considerable amount of research has been done on the Sámi and much of this has used questionable research designs and had dubious motives (e.g. Drugge 2016). Our assumption was that finding people willing to be interviewed would not be easy. When starting the study we knew that similar research in Norway (Melbøe et al., 2016a) and Sweden (Uttjek, 2016) had encountered difficulties in reaching Sámi with disabilities – despite the fact that both countries have larger Sámi populations than Finland.

When the present study began, we had no information on how well Sámi with disabilities were networked. Our supposition was that they would have met one another and would know each other, for example from using health and welfare services relating to disability, becoming disabled and rehabilitation. On the global level, organization and networking among persons with disabilities has been hampered by

the secrecy and discrimination involved. Now that the dignity and rights of persons with disabilities is being recognized internationally and nationally, persons with disabilities have formed networks and associations (Oliver 1996; Kökkölä & Saraste 1996; Clay et al. 2006). It was also a reasonable assumption, given that no specific association had been established, that networking among Sámi with disabilities might have taken place within Sámi or disability associations. In addition, authorities and service providers may have come by information on the Sámi background of clients even though such information is not officially recorded. By choosing the snowballing technique we sought to gain access to any networks that had formed as well as to fragmented, unofficial information.

Fourthly, the research project had a strict timetable and limited resources and one of the benefits that had been appended the snowballing method is economy. In anticipation of the difficulty of reaching interviewees, we began looking for people who might know potential informants even before the final decision had been made on funding for the project. The project researcher told people in her various networks about the study. The networks were located for the most part in Finnish Lapland but it was assumed that through them information on the project would spread readily to other locations in Finland. The project aroused interest and many of the professionals in the networks noted that they found the study necessary. They had experience of the need and difficulty of tailoring services and rehabilitation to give due consideration to Sáminess.

2.2.2 The role of public and organizational service providers in locating interviewees

A bilingual brochure on the project was made to aid in the search for informants (Appendix 3). Potential informants received the brochure through intermediaries. The researcher contacted, by phone or in online meetings, people who might know Sámi persons with disabilities. They then asked around in workplaces and on their own networks in order to locate potential interviewees.

Authorities were reluctant to inform their clients directly, as authorities do not officially have information on their clients' ethnic background. The matter was taken up in staff meetings, for example. The places contacted were the disability services in one municipality, a network consisting of social workers from a number of municipalities, a federation of municipalities and a network of social workers involved in a national project on disability (VamO). These contacts prompted two responses that ultimately yielded two interviews. In both cases a member of staff acted as an active intermediary.

Other replies were that the people asked had no interest, did not have the stamina to participate or had no desire to be involved in Sámi affairs any longer.

Organizations were approached as peer networks and as service providers. There were fewer intermediate levels of communications to deal with in organizations than in the public sector. Two organizational service providers yielded a total of five interviewees.

2.2.3 The role of private contacts, active members of organizations, and projects in locating interviewees

Staff at and active members of organizations other than service providers approached potential interviewees through email lists, online newspapers and closed Facebook groups as well as through personal contacts. In the case of each organization, the contact persons mentioned that their notice would reach between 50 and 200 members, some of whom might be Sámi with disabilities. The online notices sent out by the organizations did not yield any informants at all but the direct contacts undertaken by members of the organizations yielded two. One informant was located through the contacts undertaken by private individuals.

The staff of two projects with which we had collaborative arrangements (SÁRA and VamO) did not identify any persons who directly fulfilled the criteria of being Sámi and having disabilities, or the people they suggested had been reached through other contacts, or reaching them did not succeed. The information session on the VamO project provided a presentation of the project and secured some contacts. In addition to the use of researchers' networks an opportunity presented itself to attach a request for an interview to a questionnaire being used by the SÁRA project (<https://saradutkan.fi>). The questionnaire was sent to all of the Sámi on the electoral roll of the Sámi Parliament who were living outside the Sámi homeland; in keeping with a decision of the Executive Board of the Parliament researchers had no access to either the information in the electoral roll or the information on whom the questionnaires were sent to. The survey took place close to the time when data in the present study were being analysed. Most of the interviews had been conducted when the questionnaire was sent out and made available in Webropol. The questionnaire was sent to 2910 Sámi and yielded two contacts – a surprisingly small number indeed. A researcher on disability cannot help thinking that the lack of contacts is related to the nature of disability as a taboo. Collaboration with other projects yielded less in the way of synergy than expected.

Simultaneously with the present project a research project began at the University of Lapland, funded by the human rights division of the Ministry for Foreign Affairs and

titled "The Rights and Multiple Discrimination of Minorities within Minorities: Sámi persons with disabilities and sexual and gender minorities"(Olsén, Heinämäki & Harkoma 2017). The project examined the position of minority groups within the Sámi minority and the situation with regard to fundamental and human rights. The research focuses on the position of not only persons with disabilities but also members of sexual minorities. Initially the two projects had no knowledge of one another but the researchers met when the projects were being carried out.

2.2.4 Informants located by informants

In keeping with the snowball technique, informants were asked if they knew of other Sámi with disabilities whom we might contact. The informants knew persons with disabilities and had connections with other Sámi but could rarely – or rarely wanted to – name other Sámi with disabilities. Two of the names we did get yielded interviews.

2.2.5 Keeping the snowball rolling

Making use of the researchers' networks proved to be a good solution in looking for informants although the informants could not be approached directly this way. Most of the contacts and discussions did not lead me to potential interviewees. The contact persons told me of other organizations through which they thought informants might be located. Most often they were referring to SámiSoster and councils for persons with disabilities that operate in the municipalities in the Sámi homeland. Despite the substantial effort involved, the contacts undertaken through the researchers' networks yielded the best results. The networks allowed us to proceed via authorities, organizations and private persons alike, which prevented the sample from being skewed. In looking for informants the researcher had an opportunity to talk with people working with Sámi and persons with disabilities and to meet Sámi with disabilities whom she did not interview. These discussions formed a secondary set of data that served to contextualize the results obtained in analysing the primary data. Despite the variety of channels through which we located the informants, they cannot be considered a representative sample of Sámi with disabilities.

Looking for informants through varied channels proved to be beneficial for the study. It is very likely that Sámi with disabilities have no official or unofficial network. Building such a network would make it possible to provide peer support for people with "multiple minority" status and support should be provided for forming such a network.

2.3 Carrying out the interviews

2.3.1 Prior to the interview sessions

Where it was possible, informants were sent an e-mail or a letter with the themes to be taken up in the interview as well as written material regarding the study. The informants also received information in advance face to face or over the phone from the project researcher in addition to what others had told them about the study. It is the researcher's impression that written or spoken information is important because persons with disabilities vary in their ability to prepare themselves for interviews. The informants had gone over the details themselves and decided, in a manner of speaking, what they wished to bring up in the interview. Two of the informants had notes with them at the interview to help them remember. In retrospect it would have been beneficial if the basic information on the study had been made available to the informants ahead of time in the form of an audio recording, as several of them find it easier to understand speech than written text.

The informants chose the interviewer and the language in which the interview would be conducted. There were two interviewers available, of whom one is a native speaker of North Sámi (See Appendix 3). As most of the contacts were handled by a researcher who only knew Finnish, the interviewees generally chose Finnish as the language of the interview even where they had a sound command of Sámi. Two of the interviews were conducted in North Sámi and the rest in Finnish.

At the interview it turned out that one of the two Sámi did not fall within the target group and the translation of the second interview was not completed in time for inclusion in this report. Thus all of the interviews analysed here are interviews conducted in Finnish and by the same interviewer. There was no need for interviews in the other Sámi languages.

There were also situations in which efforts were made to support the choice of Sámi as the language of the interview. In two of the sessions where information on the study was presented, Sámi was the primary language used and both interviewers were present. In these sessions some of those who spoke North Sámi fluently opted for the Finnish interviewer. One thing that contributed to this was the difficulty of talking about disability, a matter that will be taken up in the chapter discussing the results. The sensitivity and taboo nature of disability are associated with disability in general and are not particular to Sámi. In a small community discussing a matter that is taboo with other members of the community may be trying (see also Wallenius-Korkalo 2013). Presumably, before persons with disabilities can muster the courage to discuss their

disability they need more time and more discussion of the topic in the community, as well as more support for such research on disability. A similar conclusion has been put forward in the recommendations of the Plan for Suicide Prevention among the Sámi People in Norway, Sweden and Finland (2017). Discussing matters with professionals, local communities and among Sámi is one means to improve the position and life of those who are living in demanding life situations. The ongoing project “The Rights of Minorities within Minorities” has achieved success in dealing with taboo matter using online focus group. An online focus group allows people to participate anonymously but does not force them to do so (Olsén 2017).

A number of the interviews were conducted in the premises of service-providing organizations; three took place at the interviewee’s home, one in a library, one at the university and one online. The interview conducted online was not entirely successful, as the interviewee’s difficulty in expressing her/himself orally combined with a poor connection to make it difficult to hear what the interviewee had to say.

With some of the informants the interview was a clearly delimited situation. Most often, however, it was preceded or followed by informal discussion as the interviewee and I walked from the library to the train station, when I offered the interviewee a ride home or we had a snack or a meal together.

The interviews were recorded. None of the informants seemed uncomfortable being recorded. The duration of the recorded interviews varied, with most lasting some two hours. The shortest lasted approximately half an hour and the longest over two hours. The course of the interviews also varied. Most of the interviewees went straight to the point and spoke the whole time with emotion and commitment. As disability is a sensitive matter, some spent the beginning of the interview getting to know the interviewer. Toward the end of the session, they then brought up more sensitive and silenced matters. This can be seen in the fact that in the beginning, some of the interviewees, for example, said that they had never felt a need for therapy, but later in the interview they mentioned counselling that they had received as well as counselling that they had sought but were denied.

2.3.2 Theme interviews with a narrative orientation

The readiness and desire of interviewees to share experiences surprised the researcher. Most of the interviews ultimately took the form of narratives, which were primarily guided by information the interviewees had received in advance. The specifying questions and thematic guidance presented by the interviewer generally ended up playing a rather minor role. In general, the interviewees had a strong desire to be heard,

to share their experiences and to have an impact on the future by bringing their experiences to the fore. Had the timetable been different, it would have been desirable to interview some of the informants on two separate occasions. Two hours was probably the longest time that any of interviews could speak at one go and the longest period of time the researcher could maintain a focused presence.

The impetus for applying a narrative approach in theme interviews stemmed from discussions with persons familiar with the field and researchers as well as from findings in the research and methodological literature (e.g. Melbøe et al. 2016b; Drugge 2016). I felt that the narrative orientation would respect the Sámi narrative culture and way of communicating, in which questions dealing with difficulties are not given direct answers (e.g. Järvensivu, Pohjola & Romakkaniemi 2016). Research in the social sciences on interviewing offers more of an approach which considers it ethically appropriate in the case of difficult and silenced matters to proceed slowly and to listen attentively, to bring out things openly and to respect the interviewee's style of narration (e.g. Granfelt 2009; Hurtig 2013; Souto, Honkasalo & Suurpää 2015; Mikkonen, Laitinen & Hill 2016). Through the narrative approach to interviewing I was able to give space to the interviewee's personal narrative preferences such that she/he could talk about and examine different aspects of the topic at hand.

"I will say quite a lot about this because it cannot be [explained briefly, LH]: there's no sense in looking at the time right away...otherwise some of my points will be lost...and will be [misunderstood, LH] in the end."

If necessary, I pursued the themes through topics the interviewee brought up rather than directing the discussion to a fresh topic. Often the material sent out in advance helped the informants take up the interview topics on their own initiative.

Disability could be seen in the course of the interviews in that the interviewees took medicine during the session or took a short break. Some of the informants mentioned the cognitive challenges they face or difficulties they have in concentrating, producing a logical narrative or speaking clearly. In such situations it was helpful to recall what had already been discussed and for the researcher to confirm her interpretation by repeating what she thought the interviewee had said, giving the interviewee a chance to correct anything that the researcher might have heard or understood incorrectly. Before beginning the interviews, I was hesitant about applying narrativity due to my position as a researcher who is not Sámi and has no disability. In the first interview narrativity proved to be the appropriate orientation for a theme interview. My coming from outside the Sámi community defined my role and I acknowledged this as an explicit standpoint. Accordingly, my point of departure was to act as the informant's

audience and recipient of what they had to say. I am deeply grateful to interviewees for their willingness to share their life experiences with me.

2.4 Data and analysis

In the initial stages of the study, the researchers attached to the project at the University of Lapland engaged in intensive and time-consuming collaboration in formulating the frame for the interview and the interviewee agreements. The researchers with a knowledge of Sámi (Elsa Laiti-Hedemäki and Tuuli Miettunen from the SÁRA project) also translated the bulletin (Appendix 3), the structured interview frame (Appendix 1) and the interviewee agreement (Appendix 4) into North Sámi. The researcher with funding from the project then went on to collect data and analyse and interpret it. Facilitating the implementation and analysis were discussions with the study's expert group as well as with researchers and experts on disability and Sáminess. A total of twelve interviews were conducted, of which nine have been analysed. The transcription of two of the interviews had not been completed before the analysis was carried out. One of the interviewees did not identify as a person with a disability. From this point on in the study "interviewees" will refer to those informants whose interviews were analysed. The interviews analysed were all conducted in Finnish.

2.4.1 Description of the informants

Two of the informants are young adults, two middle-aged persons, and four persons of retirement age. The youngest is over 20 and the oldest under 80 years of age. This age distribution means that the all of the data on childhood and early youth in the study have been produced retrospectively. Four of the informants are women, and five men. Five of the informants live in the Sámi homeland, two elsewhere in northern Finland and two in the southern part of the country. One of the informants has lived her/his entire life in the south. The others who live outside the Sámi homeland lived there at one time. Those living in the homeland have essentially lived there continuously, with the exception of being evacuated during the war and periods of study or work elsewhere. The majority of Finnish Sámi, who live outside the homeland, are underrepresented, which should be taken into account in interpreting the results of the study.

Most of the interviewees learned Sámi as their first language. One has been in a Finnish- and Sámi-speaking environment since early childhood but the language used in her/his home was Finnish. One of the informants is a native speaker of Finnish. The data is skewed in the sense that exclusively Finnish-speaking Sámi are underrepresented.

I did not ask the informants what disability they had been diagnosed as having other details of their medical condition. They talked about the medical background of their disabilities and illnesses to the extent that they wanted to. They mentioned musculoskeletal disabilities, learning difficulties, sensory disorders and brain injuries, a wide variety of syndromes affecting them neurologically or cognitively, or illnesses impacting their functioning. In addition to what they related directly the rehabilitation facilities and services they mentioned, as well as observations during the course of the interview, yielded details of the individuals' disabilities. Almost all of the interviewees cited more than one disability that they lived with. Three had had disabilities since childhood. For the others disability had come later in life, after they had reached adulthood.

None of the informants uses a wheelchair at present nor did any need assistive devices for the interview. In all cases the informants' physical, mental and cognitive health permitted them to participate in the interview, a situation to be taken into consideration in interpreting the results of the study. The informants are survivors, most of whom were recounting retrospectively the most strenuous times in their lives as they adjusted to becoming disabled and to disability.

I carried out the analysed interviews between January and May of 2017. There were phases in the collection of data when the interviews I had conducted yielded details that corroborated one another. However, as the interviews progressed, it became apparent that there would be room for additional analysis and research. In fact even in the last interviews new information emerged on the extent to which the rights of Sámi living with disabilities had been realized and on the group's experiences of services. The interview data ultimately comprised 14 hours and 17 minutes of material. The interviews were transcribed verbatim, with the transcriptions totalling 244 pages. In addition to the interviews, I used secondary sources of data consisting of a research diary and the conversations I had while looking for informants, of which I kept no written record. I contacted many people involved with disability and Sáminess in their work and civic activities as well as public service providers. In these interactions I was able to form not only a general picture of the phenomenon but, through individual cases, deeper insight into the need for services occasioned by a particular form of disability and the means for addressing that need.

2.4.2 Thematic analysis of the data

The analysis phase of the study overlapped with the networking required by the search for informants, conducting interviews and familiarizing myself with additional literature, this last being a need prompted by the interviews. I first analysed data based

on what I could remember and by listening to the recordings and later by reading the transcriptions. I analysed the interviews both individually and thematically. Summaries of each interview helped me to manage and delimit the rich narrative data. Examining the data thematically made it possible for me to better identify phenomena amid what was multifaceted, free narration.

The research task and the interview themes served to guide the thematic analysis. The themes which emerged were Sáminess, disability, agency, discrimination and services. These can be elaborated as follows. Discrimination was referred to as discrimination, bullying, treatment perceived as unfair and feelings of injustice. It encompassed discrimination relating to disability and Sáminess as well as the special case of discrimination associated with time spent living in school dormitories. Sáminess was associated with language, one's extended family, traditions and customs, as well as identity. Accounts of disability mentioned identifying as having a disability, becoming disabled, living with disability and attitudes toward disability. The topic of services was taken up somewhat unevenly in the interviews. Interviewees emphasized the difficulty of receiving services and highlighted good service. Services in Sámi were generally brought up only when the interviewer mentioned them first. Agency was a theme that seemed to run through all of the narratives. The interviewees produced themselves as actors as well as the context of their agency. I will present the results in this report in terms of the research task and the thematic categories. The material collected is richer than this research report can do justice to; there is thus a need for additional work.

2.4.3 Ethical choices and position of the researcher

The study observed the ethical guidelines for research in the social sciences and took account of the ethical practices for research on indigenous peoples. There is no separate set of ethical guidelines for Sámi research that would cover the particular challenges of indigenous research and Sáminess, but such guidelines are currently being drawn up (e.g. Nygård & Saus 2016). The practices for agreements and procedures in ethically sustainable research are being formulated in discussions among a broad base of researchers, research institutes, influential figures and other actors, as *Ethics in Indigenous Research* edited by Anna-Lill Drugges (2016) effectively shows. It has been established that the interaction, inclusion and holistic approach required by the ethical code for indigenous research requires more time and resources than traditional research (e.g. Heikkilä 2016). In the present study, the tight schedule determined the extent of interactivity possible. The search for ethically sustainable practices in indigenous research is akin to the discussion in circles doing research on disability. The guiding principle of the movement for persons with disabilities "Nothing about us without us" has been applied in some cases not only to the production of

services (e.g. Solomon & Draine 2001) but to research activities and there have been calls for research that is defined, directed and carried out by persons with disabilities (e.g. Beresford 2008).

As researcher my aim has been to recognize my place as a researcher on disability and Sáminess but as one who is not Sámi and has no disability. As noted earlier, my position was that of outsider and active listener. I pointed out to the informants that they had to explain things to me in somewhat more detail than they ordinarily would and that they even had to explain things that were self-evident so that I would be sure to understand what they wanted to say to me. My position did not make it possible to adhere to all of the principles of the ownership of knowledge and self-definition that have been set down for indigenous research (for more e.g. Juutilainen & Heikkilä 2016). I have presented tentative results of the study at conferences in order to fulfil the expectation of indigenous research that the knowledge gained in the research is returned to those who have participated in it.

As the Sámi population is small and people know one another well, and those with disabilities are a minority within this minority, the study had to pay particular attention to protecting the anonymity of the informants. For this reason, I will not be mentioning their exact ages, diagnoses, places of residence or other people, places or particulars they mention that might provide details making it possible to identify them. I have replaced the words referring to such details with some other expression, indicated in the text by enclosing it in square brackets followed by my initials (LH), as in the following excerpt.

“What does it require to be a Sámi? Let’s say that if both parents are Sámi, Sámi-speaking or have a Sámi background or at least one does then you’re a Sámi. So [name, LH] had heard that my [relative, LH] has a Sámi background and called me.”

I have had to choose the excerpts I use carefully so the anonymizing doesn’t make them too difficult to read. One factor contributing to anonymity is that a distinctive way of expressing oneself is lost in the process of translation.

Three dashes in an excerpt (---) reflect a situation where the interviewee is formulating and looking for the right words to express his/he thoughts due to challenges of producing speech. An ellipsis (...), for its part, indicates that text has been removed from the excerpt. I use short excerpts as part of the effort to ensure anonymity. An expression in square brackets without my initials indicates emotions, as in the following.

"I get a chance...to learn...even the university is sort of an institution full of old fogeys [laughs]."

I wanted to use excerpts from the interviews because these play a significant role in conveying the informants' voice - even though I have had to scrupulously anonymize and otherwise redact them. To ensure anonymity I have decided to present all excerpts in this report without identifiers of any sort, which is a departure from what is considered sound practice in the social sciences. I have opted for this solution so that the reader would not be able to connect the excerpts to one another. If a reader feels that she/he can identify the informant from a particular excerpt, she/he cannot connect that information to excerpts marked as those of the same interviewee elsewhere in the study.

All of the informants are adults and consent forms were drawn up and signed that were in keeping with the informant agreement (Appendix 4), which is based on the written and oral information given on the study and on the use of the data. The informants themselves chose whether they wanted the agreement to be in Finnish or Sámi. One wanted the version in North Sámi. In one case the consent of the informant's guardian was also required and was obtained. The informants each received a personal copy of the informant agreement as well as the description of the personal data file for the study required by the Personal Data Act (523/1999).

3 Discrimination

I will begin my discussion of the results with discrimination. It was discussed in all the interviews and the narratives provided justification and context for the cases cited. This does not mean that discrimination figures prominently in everyday life or that it is consciously present. Nevertheless it affects the informants' world of experience, formation of their self-image as well as their relation to the community and society. The diversity of experiences of discrimination makes it easier to understand the chapters that follow this.

One of the informants had not encountered discrimination. Others connected discrimination or mistreatment to one, two or three factors. For the most part, treatment perceived as unfair was linked to being Sámi and living with a disability, which is to be expected given the focus of the study. Generally there is one form of discrimination that dominates experientially and others appear, if they do, in its train. The experiences of discrimination among the younger informants differ from those of the older. The experiences of older informants are most closely associated with being Sámi and those of the younger with disability. The core of older informants' experiences of discrimination is found in the policy of assimilation directed against the Sámi in the schools. The younger informants' experiences of discrimination associated with disability are more wide-ranging, affecting many areas and phases of their lives. When older informants talked about their childhood, their accounts rarely mentioned discrimination based on disability, because they became disabled or became aware of their disability later in life. Most experiences of unfair treatment due to disability that older informants mentioned occurred when they were in working life.

The discrimination associated with Sáminess that younger generations experienced took on more subtle forms than that experienced by the older generations. More subtle discrimination is harder to recognize and in the case of the younger informants is overshadowed by the discrimination they experience due to disability.

In the sections that follow I first deal with discrimination related to Sáminess and then discrimination related to disability. In both instances I follow the division into school and working life used in the other Nordic reports, replacing the topic of free time with that of everyday life. After discussing disability and Sáminess, I take up discrimination as an intersectional and contextual phenomenon, as this is how it appears in the informants' experiences.

3.1 Discrimination based on Sáminess

3.1.1 School as a site of assimilation

Research has been done in Finland on the assimilation of the Sámi that occurred through the school system (e.g. Aikio-Puoskari 2014). Mention of assimilation policy in the interviews is most often most closely associated with the Fennicization that occurred in the school, in particular elementary school, which was compulsory, and the dormitories in which the pupils lived. Nearly all of the elder or middle-aged interviewees who spent their childhood in the Sámi homeland had experiences of living in the dormitories and of being taught and having to learn in a foreign language. The reason why pupils had to live in dormitories was not always the distance from their homes; the distance might have been difficult to cover. At their longest, these trips to school could take several days in autumn and spring. In some cases, during the school year the informants only spent time at home during long holidays; for some it was possible to go home for the weekend depending on the season and the weather.

Having to live in dormitories while attending school did not affect Sámi pupils only. Dormitories were necessary in many locations around Lapland, where distances are considerable and there are many large rivers. Even though experiences of dormitories vary widely, today it is generally acknowledged that it is not good for children's development if they are separated from their parents for long periods of time at elementary school age.

Memories of life in dormitories are more positive the more they are associated with Sáminess. Life in the dormitories seemed easier if one could use one's own language, if one knew the others in the school and the dormitory and if the attitude towards one's cultural background was positive. Where this was the case, the dormitory and school became part of a community that was supportive of a child.

"The textbooks were in Finnish...But our community was strong... The teachers who came to the school adjusted to the fact that we were all Sámi and many of us were related... Everyone there was Sámi and the dormitory supervisors...we spoke Sámi when we lived there."

As living in the dormitories involved rejecting one's native language and a change of community, it was a very different experience. Entering an environment where a foreign language was spoken and not being able to speak one's own language were described as a considerable culture shock. It generally took years to learn Finnish. The interviewees pointed out that children had no other choice than to submit to the

situation, controlled by adults, and to adjust to it using the means available to them. When starting school, children are not ready to look out for their interests, take care of themselves or stand up for their rights. In general the informants did not tell even their parents about the problems and treatment they encountered. They noted that they could not, did not dare to or did not want to tell their parents that things were difficult for them. The parents had no knowledge of what going to school was like; this remained the children's secret. Even though one of the informants decided to tell her/his parents, the problems were not corrected, so the informant stopped doing so.

“Yes, the time in school, it was awful. All of a sudden a Sámi child ends up in places like that not knowing the language, it's absolutely...”

The accounts of forced language shift stress the loneliness the children experienced. Where informants had sisters or brothers or relatives or there were children from the same village in the same school, these provided for some an experiential safety net even when it was not allowed to speak. Some of the children came up with various solutions so that they could speak Sámi for at least a minute in order to get through a difficult situation.

“We tried to go off somewhere a bit farther away so that the supervisor wouldn't hear us but...”

It was common to try to be as inconspicuous as possible and to put up with the situation. In the interviews there is an alternation between a need and desire to speak about becoming the targets of discrimination and avoidance of what is a sensitive subject. Life in the dormitories also involves many painful memories, referred to in the interviews but with the comment that the interviewee still cannot or does not have the courage to deal with them. With the learning materials in Finnish and not being allowed to speak Sámi, the first years at school were difficult.

“I determined that I would speak only if asked something, would learn the assignments backwards and forwards even though I didn't even understand all the Finnish words... In the third grade we were allowed to say something in Sámi if we didn't know what it was in Finnish.”

The interviews indicate that the practices of the schools, teachers and other staff varied. There might have been different rules in different schools and dormitories. Several interviewees said that it was forbidden to speak Sámi both in the dormitories and the school, that this ban was monitored and violations were punished. In some

instances, the dormitory supervisor knew Sámi and one of the teachers allowed pupils to speak some Sámi.

“Yes, life in the dormitory wasn’t like that but the school...it was torture...most of us were Sámi-speaking [pupils, LH].”

“The Finnish-speaking [teacher, LH] didn’t speak any Sámi to us. You got hit with the pointer and she/he said ‘Don’t you...understand?’ but I didn’t understand what she/he was saying at all. ”

“[As punishment, LH] we didn’t get anything to eat. We had to stand in the corner during the lunch break and for another hour on top of that.”

According to the informants no attention was paid to eliminating bullying in the dormitories. The interviewees mentioned other forms of bullying, in addition to the structural violence in the form of not being allowed to speak Sámi. They identified the bullying as caused by family, extended family or home background or some personal characteristic. Tensions within the community and between extended families spilled over into the children’s lives and the world of the school.

“There was no bullying. Maybe others had it... It wasn’t between Finns and Sámi but between extended families, that can happen too.”

“The village community was strange, the name [surname, LH] meant quite a lot there and told you a lot...you had better believe what they said.”

School experiences differed given that local and individual circumstances varied as well. One of the older interviewees did not live in a dormitory and she/he had no unpleasant memories of the time in school. In her/his school it was allowed to speak Sámi and allowance was made for the conception of time and practice of the livelihoods associated with the Sámi way of life.

Some of interviewees attended schools when teaching in Sámi came to the schools. They noted that at first there were occasional lessons in Sámi. Sámi-speaking children found the lessons childish or odd. They had a better command of their language than the teacher did. The children were not taught to write Sámi at that time nor was the skill learned later, a fact which many of the older interviewees found regrettable. Where interviewees did know how to write and read their native language, they described their skills as limited. The younger interviewees who attended Sámi-medium schools mentioned that they had an opportunity to learn how to write the language and this seemed to them to be a right, one with which they are satisfied and of which they are proud.

Although it is very challenging to demonstrate the existence of an intergenerational trauma in the case of indigenous peoples in research, its existence is obvious. As Amy Bombay, Kim Matheson and Hymie Anisman (2009, 7) observe, if cultural practices and competence are transferred from generation to generation, then presumably the impacts of difficult experiences are too.

A collective intergenerational trauma does not mean that everyone experiences a traumatic event in the same way. A collective trauma means a greater likelihood that there will be factors and ways of doing things that diminish wellbeing in an individual's life. A historical trauma indicates a higher probability that the impacts of traumatic events will be transferred to the next generation as a result of the patterns of behaviour and education adopted as well as shared environmental factors (for more see Bombay, Matheson and Anisman, 2009).

The spectrum of consequences of historical trauma on the individual level is reflected in how the interviewees' experiences of structural discrimination while in school affected them as parents when they guided their own children's language choices. Several had the opportunity to affect their children's choice of language of instruction in school. Some of the children have attended Finnish-medium schools, some Sámi-medium. Those who opted for Finnish mentioned that they did not want their children to encounter discrimination and wanted to give their children a better starting point in life than they themselves had. Those who chose Sámi indicated that their experiences prompted a need to see to it that their children would be ensured a chance to be taught in Sámi.

"If I live to adult age, I am going to work actively to see that my children will have the chance to speak Sámi freely."

"If I ever have children I'll never speak Sámi... I suffered so much that there is no need for the children to suffer."

"It's good that my children have the chance to learn Sámi, as I never had teaching in my native language."

The foregoing experiences date from the time that the older informants were in school. Choosing Sámi as the language of instruction has become easier and more acceptable over the years. The consequences of a historical trauma is not a given. Through collective action it has been possible to begin restoring the culture and making it whole again. In the families and the environment of several interviewees, the Sámi language had been lost during the previous generation or the generations before it but the interviewees, their parents or their children had studied the language and brought it

back. The younger generations are proud of the Sámi language skills they have acquired.

Where Sáminess is concerned the younger informants encountered unfair treatment when studying in vocational school. Although it is no longer forbidden to speak Sámi in school, Sáminess in school still leads to discrimination. One of the young interviewees noted that she/he later found out that the unfair treatment experienced at the hands of the dormitory supervisor had to do with the employee's generally racist attitude toward Sámi.

It was noted that the situation in the schools has improved but that progress has been rather recent and there is work left to be done. It is not acknowledged in decision making and allocation of resources that work to revitalize the language is a long-term effort. The realization of linguistic rights varies greatly from one locality to another, little provision has been made for the resources this requires and knowledge of the language and culture is inadequate.

3.1.2 Working life as an arena of discrimination

The interviewees rarely took up discrimination in working life based on Sáminess. This can probably best be explained by the fact that there is no need to bring out one's Sáminess in the workplace. Occasionally, however, the informants mentioned that they had a need to hide their ethnic background. This is a sign that structural discrimination still exists. It is difficult to recognize that the need to conceal one's ethnicity is caused by discrimination because what is involved is the adoption of an agency required by one's environment as a way of acting that is no longer questioned.

“[In the workplace, LH] I was never referred to by my first name or last name. I was always just called ‘the Laplander’.”

In the interviews it was seen as self-evident that Finnish was spoken in the workplace and no one expected that their culture would be given consideration. Exceptions were tasks where Sáminess and the use of Sámi were integral parts of the job. In such situations it became apparent that bringing out one's Sáminess in the workplace requires quite a bit of practice. The interviewees describe how Sámi speak Finnish with one another in the workplace or how hard it is to try and get service in Sámi when one is not used to doing so. When work involves having a knowledge of the Sámi language and culture it is hard to determine the boundaries involved. The need for services delivered by Sámi becomes visible when, contrary to expectations, such services are made available.

"Hey, you know Sámi. I said, 'yes, of course', since I was born a Sámi... the client was happy but there was doubt as to whether a [professional, LH] could speak Sámi."

Researcher: "But don't all the others there know Sámi as well?"

Informant: "Well, every one of us there does but how do you revitalize the language such that [it is used, LH]."

It was brought out in several interviews that the opportunity to get a vocational education was not always a given for the older generations. The family objected to its young members leaving to live in another culture. The vocational backgrounds of the interviewees vary widely. After compulsory schooling some have done various courses or completed part of programmes of study. Others spoke of long educational paths through which they tried to achieve and maintain the competencies needed in working life. The interviewees had also encountered situations where Sámi considered work associated with Sámi culture more suitable for Sámi than occupations where they worked for others and which they acquired through education. This the interviewee found offensive.

"What are you doing...you don't have to do [this kind of work, LH]."

"I am from a family which has a long history in [a traditional livelihood, LH] but I don't have [equipment needed in practicing the livelihood, LH]."

In the above situation the interviewee also brought out that disability is part of the reason she/he do not do traditional work. Here one sees the intersectional nature of discriminatory factors, which we will take up in chapter 3.3. Several of the interviewees discuss the course of their children's education or their attitude towards young people's educational choices. In these cases, too, one can see, on the one hand, the interviewees' own experiences reflected in the value they ascribe to education and, on the other, encouragement for solutions that improve the position of the Sámi.

"I have tried to say to many young people that if you want a guaranteed job, you should specialize in these [types of work among Sámi, LH]."

The interviews with younger informants suggest that discrimination encountered in working life was more often and more closely associated with disability than with Sáminess. By contrast, the narratives of older informants indicate that Sáminess prompted more discrimination than disability. In any event, it appears that where one encounters an extreme form of discrimination based on one factor, this experience tends to obscure more subtle discrimination based on another.

3.1.3 Discrimination in everyday life

Experiences of unfair treatment related to Sáminess are not confined to education and working life. In the interviews, discrimination in everyday life was dealt with mainly when talking about language. The interviewees related that by the end of their compulsory schooling at the latest they had a solid command of Finnish and also used the language. It was common that they confined their use of Sámi to situations where they know others would look upon it favourably. Previously Finnish was the language used everywhere in services and extensively outside the home. It was pointed out that one could not speak Sámi in shops, the bank, the post office or in official contexts. Today it is possible to do so in the Sámi homeland but the language is still generally ascribed a secondary status. In particular the older generations became accustomed to using Finnish in public contexts and it is not easy to unlearn such a habit.

Informant: "Well of course at least in those public offices and bars, shops. It wasn't appropriate to go in there and speak Sámi. That's the way it was."

Researcher: "Do you have an idea when or if a change has taken place?"

Informant: "There certainly has. They started talking constantly about Sáminess and gradually, gradually in public offices, shops there were local salespeople and employees and that's how Sámi started to be spoken in those shops."

Anneli Pohjola (2016) has discussed the central importance of language for culture and identity. She observes that the language used in welfare services is a powerful tool in implementing assimilation and that bilingualism exposes a minority culture to colonialism, which endangers their cultural identity because language not only reflects but also constructs culture and life. Bilingualism figured prominently as a topic in the interviews. The fact that the Sámi Language Act (1086/2003) guarantees a person the right to use the Sámi language before authorities in the Sámi homeland even when the person knows Finnish prompted surprise and confusion but also understanding and respect among the interviewees. They interviewees recognized the importance of language for the survival of Sámi culture and the courage some have to insist on their right to use the language in services is considered crucial for efforts to revitalize the language.

"I have not demanded [service in Sámi, LH]. I do understand Finnish... But it [service in Sámi, LH] is good, because it helps the language survive."

Young adults and middle-aged persons are more aware of their rights and exercise their right to use Sámi more determinedly and consciously. Their more open use of the Sámi language can be seen as associated with a mission to preserve the language and

culture, acknowledge their roots, show respect for the previous generations and exercise the rights now enshrined in laws and international agreements. Rights become rights only when people begin to exercise them.

Family life is another domain that has become Finnish speaking or is bilingual. Finnish has become the dominant language in life. Living in a bilingual environment is perceived as both demanding and enriching. Preserving one's own culture requires constant effort but then again the anonymity offered by the majority culture might make it easier for people to deal with the rejection that comes with being different that they encounter in a small community.

Outside of the homeland knowledge of Sámi culture is less common and revealing one's culture requires courage or daring. One generally needs to arrange situations involving the Sámi language and culture oneself or seek them out; one also has to be prepared for a wide variety of reactions.

"We have sometimes [spoken Sámi, LH] while having a coffee at a petrol station and when there aren't too many people around...yes, it makes them wonder... But it hasn't bothered me. The fact that I keep up my [language skills, LH]— I like that much more. I don't care about others, don't worry about them."
"I have sometimes [spoken Sámi, LH] just on a lark; it's a language like any other [laughs] and sometimes I have clowned around by speaking Sámi."

Outside of the homeland, people limit the extent to which they bring out their Sáminess in everyday life and in this way do not encounter discrimination. Sáminess represents difference, which prompts fear and curiosity. Prejudices and stereotypes have not disappeared. The interviewees related how sometimes they may talk in Sámi and they notice that others present are somewhat puzzled. Another source of wonder is celebration of the Sámi national day by dressing in traditional Sámi costume (*jákti*).

"I have a *jákti* on and I haven't been treated badly exactly but people have wondered why that person is wearing Sámi dress. They just don't understand... On the Sámi national day I wear my *jákti* the whole day, just as one is supposed to."

The difficulty in tolerating difference reflects a broader cultural shift, one which occurs slowly. Finland has long been a country striving to have a uniform culture, a trend which requires life in diversity to have the courage to adopt a new orientation (Pohjola 2009; Souto, Honkasalo & Suurpää 2015; Witkin 2017, 73-92). The special nature of indigenous

peoples encounters the same curiosity, prejudice and reluctance to change as diversity more generally.

3.2 Discrimination based on disability

The aspects of a person's life impacted by having a disability or becoming disabled are largely determined by the phase of life in which she/he becomes disabled and the form of disability in question. In the case of the three younger interviewees, disability has been part of their lives since childhood. For two others their disability was only established when they had reached adulthood. When the disability was noticed and named, they received an explanation for the symptoms, ailments and difficulties that they had been having since childhood. In three cases the disability was the result of an accident or illness. For one interviewee the situation was a very recent development. Four of the interviewees, drawing on their work experiences or personal contacts in addition to personal experiences, mentioned the experiences of disability of other Sámi with disabilities.

3.2.1 School and difference

For those who have lived with a disability since childhood acknowledging their disability has been a long process, one with many different phases, of which a crucial one is the first years of school. It is a time when the attitudes of society and the community are concretized. The interviewees reported cases of discrimination and bullying in school. The interviewees have had experiences of special needs classes and schools as well as of tailored teaching. Occasionally these arrangements were associated with foster homes, children's homes and living with acquaintances. Their experiences varied and the crux of the matter is the ability of a child's environment to see her/him as a person with a particular background and yet as a unique individual and to take this into account when making particular arrangements for her/him.

Experiences of a special needs school were positive when the change of environment and locality brought an end to bullying. Disability might be a wholly alien phenomenon to one's friends and family, making it easier for a child to live surrounded by people who understand disability. Yet, bullying occurred in special needs classrooms as well, as the following excerpt indicates. However, the special needs teacher intervened and put an end to it.

Researcher: "And why do you feel that you have been discriminated against?"

Informant: "Well, it's because I have this [disability, LH]---when I was in that school and in the upper grades, in a special needs class --- the others, my classmates --- the ones behind the bullying."

Researcher: "Did it go on for a long time?"

Informant: "A year – the teacher there then intervened."

The other interviewee who had lived with a disability since childhood told how bullying ended thanks to an active parent. Seeking out learning and studying solutions that compensate for disability requires active pursuit of rights throughout one's school years. The interviews indicate that realization of the rights of a child with a disability requires the parents or a parent with the opportunity, skill and desire to pursue the child's case as well as teachers and officials who invest time and effort in the situation and finding solutions.

At a later age, a young person's own tenacity takes on an important role. If she/he has had a model in her/his parents of how to insist on one's rights and work to find solutions, it is easier to develop these skills further in one's youth and adulthood. If one's support networks in childhood are poor, no one intervenes to stop bullying or succeeds in stopping it, one sees no models for how to pursue one's rights and a young person doesn't develop the skill to find solutions either.

"I was bullied at school for a very long time, from second-third grade on till I finished school."

The advantages of special arrangements in the school are obvious, where these are successful but, on the other hand, the special needs schools were located far from the Sámi homeland. Families and professionals face a demanding situation when weighing the advantages and disadvantages of special needs schools. Even today a special needs school entails a change of language for children, as well as long distances from close family and their culture.

"I'd say that if I had been transferred back then to that [special needs school, LH] it [Sáminess, LH] is the biggest thing that would have been taken away from me."

In the schools discrimination was also caused by teachers who did not have sufficient competence or interest to invest themselves in the schoolchildren's situation. Discussions with the interviewees and with service providers reveal that the problem was a shortage of assistive devices and insufficient efforts to see if such devices were available. Other aspects of the work of teacher commanded teachers' attention, taking

it away from looking into assistive devices. Even today devices easily obtainable via the Internet may fail to be used.

“[There is a shortage of, LH] devices and staff... I suggested to the school that [a device, LH] be acquired and even the school was surprised that it [existed, LH].”

All three informants who had lived with disability since childhood have attended vocational school, one or more courses in their entirety or in part. In each case the education took place at most ten years ago. In vocational school as well, the importance of support compensating for disability is obvious. One of the interviewees attended a school preparing her/him for vocational school in which her/his needs could be addressed. Elsewhere schools failed to take the special situation of the interviewees into account unless the student and her/his support network showed particular initiative. Initiative was rewarded in that in later stages of schooling the arrangements were easier. If the student's special needs were not acknowledged, it led to a weakening of motivation in school. Finding solutions requires the courage to bring out one's special needs and competences as well as efforts to ensure that one is heard.

“It was mind-numbing... I am from the Sámi area and there these basic tourism things come up naturally, so I fell asleep most readily in those classes. Then the math classes – I said to the teacher that I don't know math very well and this is where I'm likely to have the most problems. It was no big deal, though, and I passed the class easily.”

“You have to know the legal end of things pretty darn well when you start pursuing benefits and services for persons with disabilities.”

“The school was – and I was surprised – used to working with persons with disabilities...they began to experiment.”

The lack of educational opportunities in the Sámi homeland is one factor which still steers young people in a very early stage of their lives into study settings where it becomes difficult to maintain the use of Sámi on an everyday basis.

3.2.2 Working life and disability

No research has been done on the position of Sámi with disabilities in the job market but features of the Finnish job market affect opportunities for employment for Sámi with disabilities. Finnish working life discriminates against disability. This characteristic is not national but rather international. In Finland persons with disabilities are less likely to be members of the workforce but those who are part of the workforce are less likely to be employed. Breaking into the job market takes longer, the importance of

education is greater and salaries are lower than for Finns at large (Suikkanen et al. 2006). Similar findings have been obtained in international research (Nevala et al. 2017), but in Finland, for example, three per cent of working-age persons with disabilities are working whereas in the United States and Great Britain the corresponding figure ranges from five to ten per cent. The benefit of work activities has been criticized because it has proven to be a poor route to getting a job on the open labour market without any customized vocational training (Nevala et al. 2017). In labour market-oriented research the other benefits of rehabilitative work activities – improved participation and quality of life – tend to be overlooked (Klem 2011). Such studies fail to notice that the alternative to work activities is not employment on the job market but exclusion from it. Where persons with disabilities are viewed as a single group, opportunities are overlooked for accommodating their needs in the workplace or for their entering working life at all.

A focus on the job market was clearly seen in the interviews. Work is meaningful both for those who have worked in traditional Sámi livelihoods and for those who had educated themselves for and were working in other occupations. The many meanings of work and activity came out in the interviews. Working was an economic consideration but there were clear indications as well of its value in terms of participation, equality and fulfilment of one's role as a citizen. The value ascribed to working hard has been transferred from generation to generation.

“We were involved as soon as we could stand up. [As children, LH] we were taken along to work and taught how to do it. And I have [taught, LH] my children the same thing, and they have worked.”

The interviewees noted, however, that working life has changed and work is not as easy to find as it once was. Disability and becoming disabled usually mean a lengthy wait before one can enter the job market. On the one hand, one has to find a place to study where studies are possible and, on the other, a job that one can work at. Young people are just beginning to get an idea of what kind of an occupation might be most suitable for them. A person's own view of what work would be enjoyable was not the first thing that guided the course of her/his education or work.

“When they say, you won't learn [the skills required for studying and working, LH] you are beaten, beaten, and you pick any occupation around and try to see how it turns out.”

A choice of what to study and of occupation that is fraught with numerous uncertainties will not be successful, and not surprisingly the young adults tried out a number of

different schools and jobs. The attitude they encountered on the chances of persons with disabilities to get a job on the job market is a significant factor. Encouraging feedback may be decisive in seeking out a new career and, by the same token, the discouraging effects of a dismissive attitude are obvious. If young people do not have the support of persons or organizations willing to invest effort in their situation, if the training they end up getting is for occupations that they are not interested in or which they feel unable to handle, or if they become preoccupied with coping with the burden of earlier phases in their lives, they may have difficulty entering working life.

Work that accommodates the situation and abilities of a person with disabilities provides a strong bond to the community and society (Kivistö 2014, 88-97). This is how a person who has had a disability from birth describes it as well. She/he has experiences of work and day activities in an activity centre as well as work in a workplace. Work in a true work environment is very meaningful. This the interviewee calls "work" and describes in detail the tasks, responsibilities and, in particular, their importance to other members of the workplace community. One can sense the pride in her/his voice at having had a chance to do work in varying circumstances and to take the responsibility for doing her/his share. On the other hand, where social relations and comprehensive self-actualization are concerned, the varied programme at the activity centre guaranteed both meaningful activities and a richer social life outside of the centre as well.

Becoming disabled brings either sudden or gradual exclusion from working life. Even though one can return to working life soon, over time the challenge of work becomes clear inasmuch as the work environment remains the same and one's physical difficulties increase rather than decrease. Then again a person with a disability may end his or her working career immediately and face a search for an entirely new one. One interviewee who became severely disabled as an adult has a long and demanding course of rehabilitation behind her/him, the goal of which now has become to go from rehabilitative work activities to the open job market.

"I can see light in the thicket... Now they have started looking for a job for me on the open market... I am not up to being a manager, no one would dare hire me...when I get myself into shape where... I can still work somehow... I'll be satisfied."

"All this happened, a little "repair job" [chuckles] and then [just before going on disability pension, LH] I was able to work with these shots to kill the pain. The doctor wouldn't let it go on any longer. The pain was so severe."

Persons with disability try to get off pension for many reasons even though it provides some level of income when the job market is inaccessible to them. Older persons with disability ended up on a disability pension very much against their will. They tried out different solutions and showed more flexibility than other employees but working life did not prove flexible enough that they could keep working. In retrospect persevering in working life involved unreasonable considerations. People made excessive demands of themselves.

“Which is of course dangerous [due to the disability, LH]... Later I have been astonished; it is crazy to have done such work which is absolutely hazardous.”
“If I hadn’t been infirm I certainly would never have agreed to it [job description, LH]... I’m sure I wanted to prove to myself that, yes, I can do it.”
“They told me, at the Social Insurance Institution, that there is no work for you that you can do. Well, that made me cry. I of course had a tough time [at work, LH] towards the end.”

What has been said above about discrimination against persons with disabilities and disability on the job market reflects the general findings of research on working life. The special nature of Sáminess appears in the fact that, unlike in the occupations learned in school, the traditional Sámi livelihoods are part of the people’s lives even where they do not provide a living. The boundary between work and free time and between occupation and civic activity is fluid. The special Sámi livelihoods are still part of the Sámi way of life and contribute a great deal of meaning to it. People herded reindeer and fished as much as they could and made handicrafts such as *duodji* as much as their resources permit. They adjust the extent to which they can engage in traditional livelihoods as a pastime to their functionality and such activity helps to maintain social relations and membership in the community.

A similar fitting together of work and functioning was not possible in paid work in other livelihoods. Noteworthy here is the increasing tendency of work to creep into free time. The Sámi community is able to make good use of the occupational skills of those who are outside of working life, and those who are working use their free time to benefit the community with the skills they have. The boundary between paid work and the community is a tenuous one in what is an economy where services are bartered.

3.2.3 Discrimination in everyday life

Persons with disabilities commonly encounter discrimination. According to a report by the Non-Discrimination Ombudsman (Yhdenvertaisuusvaltuutettu 2016), some one half of persons with disabilities feel that attitudes towards persons with disabilities are

negative. Attitudes vary, however, and are assumed to be linked to the extent of people's experiences of difference. Discrimination is a self-perpetuating spiral. People who are discriminated against avoid being visible and cover up their disability, with the surrounding community then being less able to recognize them and their disability. It is a fact that attitudes toward disability in the past were harsher than they are today.

"They thought that if someone has a [sensory, LH] impairment or some other disability, she/he also has a mental disability."

"It [disability, LH] is a sensitive subject...and it is quite rare that Sámi have the courage to make disability public... [When I was younger, LH], I was afraid to do so and was ashamed of it."

As can be seen from the excerpts, the situation is improving but there is still work to be done. The expression "disability" itself prompts associations in the interviewees and saying it aloud is often difficult for them. More often they are ready to use a more specific term through which disability is delimited and distinguished from one's identity. A name of a diagnosed disease is felt to be more objective and by choosing what diagnosis one mentions, one can choose what treatment and "label" one gets. As the study progressed, it became abundantly clear that "disability" in the title of the study and as a topic reduced people's desire to take part in the research and discouraged contact people from passing on information to persons with disabilities they knew. One might say that the study itself encountered discrimination on a variety of bases. On the one hand, the justification and ethicality of research on the Sámi are subjects being discussed intensively and, on the other, bringing disability to the fore is still considered a very delicate matter. "Disability" is still used as a derogatory term, which causes considerable damage to people's self-esteem.

"I was tormented with that word – retarded...to me it's like pressing a button. If you want to irritate me, I can deal with 'disabled' just barely but..."

Seeking services for persons with disabilities as well as special rehabilitative services based on disability becomes difficult when a person has experienced bullying as a result of disability.

Learning difficulties and cognitive impairments and symptoms are subjects which the interviewees rarely if ever talk about with people and when they do they are very selective about what they say. They are even more likely to remain silent in the case of mental health problems. Indeed, in the interviews the informants focused for the most part on somatic problems, and mental health problems were dealt with circuitously, after the interview had gone on for quite a while or when it was not being recorded. The

point was made that mental health issues in particular are difficult to address and accept. Earlier, the solution was to send a person with mental health problems off to a hospital. Now, it is more likely the case that the person's abilities are questioned due to her/his mental illness. For some interviewees their experiences as persons living with disabilities have given them greater tolerance towards mental illnesses and problems. They noted that anyone can suffer a mental breakdown. Nonetheless, they were hesitant and evasive when the topic was broached.

In addition, interviewees found it difficult to bring up various cognitive impairments or illnesses and factors limiting functionality that were not readily visible. Somatic ailments and doctors' diagnoses were the primary focus and were felt to be more acceptable than experiences of mental breakdowns and cognitive difficulties.

"There's a tendency to cover up the mental illness with booze."

"Of course, I had a slight urge I should tell so they would know what has happened to me. But anyway I haven't said anything if they ask."

Then again, lessening the stigma associated with disability can be seen in the interviews in the interviewees' emphasizing that several of the interviewees wanted to be heard specifically in their special situation as a person with a disability and as a Sámi. The interviewees thus represent people who have the readiness and courage to bring out their disability. Three of the interviewees said that the reason why they took part in the interviews was to improve the position of other persons with disabilities.

"I have a desire to influence things, yes. That's why I've come here as well, precisely because my experiences might have something to tell."

Generally one sees an emphasis on the communal nature of Sámi culture and the significance of the concept of family as extending beyond the immediate family. This is also reflected in the interviews. When talking about their family and those closest to them, the interviewees talk about closer and more distant relatives, those engaged in the same livelihood and a livelihood typical for the extended family. They recognize community norms and ways of acting. They know what things one may talk about, how and with whom. This also means that the extent to which disability is discussed is restricted. On the one hand the community might serve as a source of support; on the other it might not necessarily be prepared to deal with disability and the particular type of difference it entails. The community has expectations with regard to its members and fulfilling those expectations is no easy task. Living when shunned by the community is painful.

“But above all what has affected me is that my relatives have let me down... I have got so many, ultimately judgemental looks there that '[interviewee's name, LH] is again doing nothing, she/he is unemployed again... there at home, doesn't even do [his work, LH], even though she/he is part of that family' [derisively imitates].”

“Somehow I [covered it up, LH] now and again because they don't understand the reality, what has happened to me.”

“Although I was once stigmatized as the stupidest person in the village.”

Then again the strong sense of community means that relations with relatives may replace relations with parents. An extensive family creates security as well as insecurity. The interviewees refer to living with grandparents and serving as models for cousins and to aunts and uncles as people providing security, finding solutions and putting the punishments in to practice. One point they made was that even distant relatives may be significant figures in their lives whom they rely on for advice sooner than their immediate family or close relatives.

Among the interviewees who were living with their parents or alone, mention was made twice of finding a partner, establishing a relationship, starting a family or fulfilling their sexuality. Having a disability since childhood makes it difficult to have an intimate relationship with new people, in particular people other than persons with disabilities. There is an assumption that a relationship or sexuality is not part of life for a person with a disability (Eriksson 2015; Teittinen 2017). Research on people belonging to sexual minorities and living in sparsely populated regions, on the restrictions on sexuality in Lestadianism and on the position of Sámi women suggests that Sáminess in transformation has involved denial or concealing of sexuality and covering up of sexual abuse even more extensively (Kuokkanen 2004; Peltomaa 2013; Wallenius-Korkalo 2013).

Becoming disabled or falling ill changes people, relationships and the functioning of the family, at which point a relationship may either become stronger or fail. The importance of spouses for people's life courses, participation as persons with disabilities and rehabilitation is considerable. In addition to the companionship they offer, spouses try to sort things out, improve the family's economic prospects, provide transportation and establish relationships outside the world defined by disability.

3.3 Intersectional discrimination and contextuality

Discrimination has been studied and interpreted to an increasing extent as an intersectional phenomenon. An intersectional perspective takes into account that

discrimination may occur on many bases and the dynamic that obtains among the factors that affect what discrimination is directed against (e.g. Valkonen & Wallenius-Korkalo 2016; Olsén, Heinämäki & Harkoma 2017). On the individual level life situations are involved a complex of different positions, roles and identities. If one examines a question in terms of a single factor, the result is an inadequate picture of how discrimination takes shape as well as of the means for preventing it (Kuokkanen 2004). When discrimination emerges in a particular situation, the shape it takes is determined by not only individual factors but factors relating to the environment, community and the given situation. In this respect, intersectionality fits in well with the relational model of social disability, which deepens the social understanding of how the phenomenon occurs.

The study highlights the contextual, processual and interactive nature of discrimination. It does not take the same shape for people who share the same characteristics; rather it is also determined by structures in the environment, attitudes and ways of doing things as well as the individuals' other characteristics, how they interact with each other and over time, and changes in the interaction. Contextuality is particularly meaningful when examining a phenomenon from the standpoint of individuals, as in the present study. The approach is not blind to the fact that intersectional discrimination comprises a variety of factors, and social measures to eliminate discrimination are generally directed against each factor separately. In international human rights agreements intersectional discrimination is recognized in the special attention paid to children, persons with disabilities and women and in the reference to the special protection they require, one example being the Declaration on the Rights of Indigenous Peoples (UNDRIP).

The point of departure in the present study is the simultaneous occurrence of two things causing discrimination – being a member of an indigenous people and living with a disability. The factors prove to be separate in the sense that encountering discrimination caused by one of them does not mean that one encounters caused by the other. There is a cumulative aspect to the factors although the interviewees said very little of the joint impact of discrimination connected with Sáminess and disability. Yet, both forms of discrimination are present in the lives of the interviewees, tending to occur in different areas of life.

“Because I have a [disability, LH] I cannot necessarily do everything and people don't really like that, people who are used to working constantly and so forth; and then as a Sámi I have had to be a bit careful about what all I say.”

“You are a Sámi, a minority and then if on top of that you have a disability then you are even more of a minority.”

It becomes apparent in the interviews that there are additional factors affecting the occurrence and experience of discrimination in the lives of Sámi with disabilities. These factors are not associated with disability or Sáminess as such but they cause discrimination, affect the shapes it takes and form part of the lives and experiences of the interviewees.

Previously I dealt with the challenge, cited in indigenous research, of producing evidence of intergenerational and historical trauma. The existence of the connection seems likely in light of how several of the interviewees described their childhood and experiences of the previous generation as well as the hardships they have encountered or the environment in which they grew up. Being a parent is very demanding under traumatizing circumstances. Older people convey not only knowledge that sustains the culture but also knowledge of injustices that could not be averted. The intergenerational dimension can be seen in the risk factors associated with the interviewees' childhood, such as drinking problems of their parents' or other people close to them, the difficulty these people had in taking care of their children, or violence. When these are combined with disability, they increase the likelihood of being discriminated against and the feeling of ill treatment is intensified when a child is not cared for properly or is exposed to violence.

“Yeah. I was lying on the floor and [relative, LH] put a [piece of clothing, LH] on top of me and sat down, drunk...[another relative, LH] came over and said ‘Don’t sit on her/him, she/he might suffocate’.”

From time to time or for most of the time some of the interviewees had been placed in foster homes. As such they had nothing negative to say about these placements but did not really accept the particular reasons that had prompted them. They recognized not only their disability but also their own behaviour as contributing factors, which reflects children's tendency to blame themselves for the challenges of their environment and the behaviour of people close to them. After reaching adult age, the interviewees recognized in some measure that their having to live outside the home was not solely a consequence of their disability but also of other risk factors in childhood.

“It is not easy [for a parent either, LH]...seeing that I was a very energetic child on top of it all...a little problem child...especially when [the parent, LH] was a relatively heavy drinker.”

“The reason given [describing the reason for placement, LH]...and it is pretty rich...and coming from [the parent, LH] but, but...wild youth I was a little child then.”

In listening to the interviewees, it is obvious that they have encountered challenging intergenerational situations as well as a combination of special circumstances associated with their disability. Occasionally they found a place to live within the Sámi community. Sometimes a placement meant being separated from their culture and sometimes their culture has ended up having no significance in the situation.

The interviewees also recognize – or at least have an inkling – that their experiences are intergenerational. Those who have been the objects of multiple discrimination react to the treatment they have encountered in a wide variety of ways and preventing repetition of the aggressive behaviour they experienced as children would require more support than they have been getting. One of the interviewees, who experienced violence and neglect as a child, describes her/his way to handle aggressive feelings as follows.

“I screamed my frustration out into a pillow or pounded the wall or something, but I tried to remind myself, ‘Don’t do anything more than that’.”

The interviewees’ life courses also reveal factors intensifying exclusion. Drinking comes up in some cases as a phase connected with adjustment to becoming disabled or to a disability. In order to avoid stereotypical conceptions I should point out that, for some, teetotaling is a self-evident choice (see also Orjasniemi 2011). Drinking indicates both a search for inclusion and the challenge of gaining it. It may be linked to social situations and personal relationships that one does not want to give up on despite one’s disability or its related medication. It is associated with difficult phases in a person’s life as a source of comfort.

“You could say I was sinking into depression, it would have taken me with it.”

The matters brought up by interviewees varied not only from individual to individual but between the genders. Shared themes in the narratives of both genders are a focus on working life and the overpowering need to find solutions to problems. However, gendered expectations regarding one’s life course can be seen in the narratives. Men do not emphasize their gender in the tight squeeze between their courses of action and the constraints affecting their lives. They talk about the tight finances caused by their becoming disabled and the significance of engaging in traditional livelihoods. They point out the help they have received from their spouses and the importance of support but they do not describe women’s choices as constraining theirs.

The women’s narratives reflect the strong and wide-ranging agency they require of themselves as well as the difference in expectations placed on the genders. The

position of Sámi women has generally been considered strong. The harshness of the traditional way of life has required all members of the community to contribute to their fullest to ensure the living conditions the community needs. The radical change in the way of life, the shift to a money economy and the rise of Christianity have changed traditional circumstances. The role of women has come to entail new and to some extent conflicting expectations (Kuokkanen 2004). Other people's conceptions of women's role guide the course of their lives. Expectations linked to gender and challenging those expectations have an impact on women's life choices. Parents had influenced or tried to influence choice of spouse and decisions as to where to study. When decisions had been made about matters affecting the entire family the family's choices had affected women's opportunities to choose. However, women had not submitted but rather created their own position. Some of the women challenge the position designated for them and take a different course of action (see also Rantala 2013). For others, the courage to make the choices they want becomes stronger as they get older or in situations where they receive support from other women (also Kuokkanen 2004). Women come up with their own ways of negotiating difficult situations and claiming their rightful place. Women noted that carrying out solutions contrary to the expectations made of them demands more effort from them than it does from men.

"But I never finished my education. My father thought 'Just get married'."

"[A parent said, LH] 'She doesn't have to leave, girls don't go anywhere' [to school, LH]."

"Listening to those old geezers just toughens me up; no way will they crush me... I sometimes went off [to be alone, LH] and cried at all the unfairness there was and then I just went back there."

"They thought they could go ahead and beat me and oppress me. Well, I've shown everyone it doesn't work that way [laughs]. And I am now perfectly happy with the situation here."

One aspect of a community-oriented culture is that the community creates a picture for individuals of how to live acceptably and properly. The older interviewees described situations, changes and choices in life in which the way they led their lives differed from the conventional one. They said that one just had to have the strength to continue and swallow one's sorrow and anger.

"There was never any mention of what happened at home.... I think that they will remain hidden, those particular things."

The private nature of setbacks and difficulties was mentioned by younger interviewees as well. The younger ones have perhaps not developed the tenacity nor is their confidence in their ability to survive as strong as the older ones'. Living one's own life seems to be the only option but this does not necessarily meet with the approval of the local community. This is one factor which makes it attractive for younger people to change the environment in which they live, to choose with whom they communicate and to limit the contacts they have with the community around them.

4 Coping strategies

4.1 Social support

Social support is constructed in personal relationships and communities. Networks of social support refer to people and organizations from which a person can seek assistance relating to knowledge, services and help or look to for emotional support (Cohen, Underwood & Gottlieb 2000; Kumpusalo 1991). The opportunity to receive support is a feature associated with networks but networks can just as readily provide ways of living which are not considered suitable or can reject their members. Networks comprise close relationships as well as people and organizations that one may potentially contact. It may be meaningful in a relationship that it involves a particular person or that it involves occupational or religious support, in which case the personality of a single individual is not as crucial for the support. Social support is known to entail a buffer effect, which means the support has the effect of protecting a person from the negative consequences of a hardship she/he has encountered; for example, social support in the case of illness is associated with successful rehabilitation (e.g. Kumpusalo 1991; Somerkivi 2000).

Social support networks are not static. Research has been done by the Finnish Federation for Social Welfare and Health (nowadays SOSTE Finnish Federation for Social Affairs and Health) on how people in general and certain groups of persons with disabilities produced social support (e.g. Eronen et al. 1999; Wikman 2000). The studies observed that the networks used by persons with disabilities differed from those used by the population at large as well as between groups with different disabilities. The importance of family relationships as sources of support figured prominently and living with disabilities created a need for official and peer networks. Disability posed a risk of falling outside networks that offered social support.

A study done by Petri Kinnunen (1998) divided users of social support networks into five categories: those who rely on (1) their immediate family, on (2) the immediate family, friends and close relatives, on (3) public officials and on (4) a broad-based group consisting of family, friends, the extended family and public officials, referred to as a welfare mix network. Lastly, category (5) consisted of people who reported having no support networks. I will be drawing on this categorization in the analysis that follows. Social support networks underwent dramatic changes as a result of becoming disabled or in the course of a person's life. The change in networks is a natural consequence of changes in one's life situations but disability or becoming disabled exerts a particular

pressure that tends to change networks. For most of the interviewees, their present situation was far less anxious than earlier phases in their lives.

“[sighs] Well, in the beginning there was nothing. I was high and dry... It requires money and a lot to go off and get rehabilitation... But I felt all alone. My friends left me and I ended up [relying on, LH] my family...that’s when all hell broke loose, when I became disabled...but I have made a lot of progress since then.”

The informants’ present support networks feature their immediate and extended families, relatives, other close persons, friends, organizations, professionals and social media. For half of them their networks include all of these. This result cannot be generalized as applying to all Sámi with disabilities. Many of the informants mentioned that they were far more isolated in earlier phases of their lives and that they had experienced loneliness. They speculated that at that time they would not have had the courage to take part in the study.

“If you had asked me [earlier, LH] to take part, I would not necessarily have been answering my phone.”

The extensive support networks generally included both Sámi and Finnish contacts and relationships. The informants with such networks consciously seek out networks and invest effort in maintaining them. Getting services, achieving a meaningful life and making progress in life are not possible without extensive support. Every contact in a network is asked for help, support and information for particular aspects of life and particular needs. Where a person has an extensive network, the depth of the relationships with her/his contacts will naturally vary. The buffer effect that shields people from setbacks on such a network is beneficial. The networks described here fall into the category of welfare mix (4) in terms of Kinnunen’s model. One difference, however, is the particularly broad interpretation of “extended family”. The notion covers the place where one lives as well as one’s language group or people engaged in the same livelihood. The informants with such networks had relatively sound social capital to begin with and have built it up during their working career and through their previous networks.

“[Former colleague, LH] called me and said ‘Now there’s some help [available, LH] here. [‘Are you interested?’, LH] I said, ‘Certainly’.”
“I have developed a [way to cope, LH] myself, which [a relative, LH] suggested.”

None of the interviewees described situations in which public assistance was not used at all. All of them needed public services relating to disability, becoming disabled or rehabilitation. The support on the official level might well have been thin, with the support network proper consisting of family and relatives. Even in such cases the interviewees noted the need for support in the form of public services. The situations most closely match the immediate family type (1) in Kinnunen's categorization, although again "family" might refer to a larger group than the immediate family (2).

"My family and relatives stand firmly around me. They won't abandon me."

Some of the informants had less extensive networks and spoke more about the problems with support networks, experiences of loneliness and difficulties that they had not dealt with. Scant contact with family and relatives was associated with feelings that they had received too little official support. Confining relationships to individual relatives or one's immediate family was linked to earlier experiences of negative feedback from networks and becoming alienated from members of one's family and relatives. Networks were built with new friends and acquaintances who had not played any part in the informant's earlier life or local community. Networks comprised selected contacts, with new ones not added until the need arose.

"I have great friends...we write, we call. But I don't go out and visit anyone around here... I don't spend time with them [family, LH], they are like strangers to me."

Where the networks are limited, the contacts in them take on greater importance. If such a relationship breaks off, it is challenging to overcome the loss. Often the informants brought out either directly or suggested that their situation could be better if they had a chance to be heard in public services or if they had some trustworthy contacts with whom they could share the painful experiences in their life. Where networks are limited, they produce too little social capital to recognize or realize one's rights.

When a person had scant contact with family and relatives or the support they offered was conflicting, interviewees received or at least sought help from professionals. These networks correspond to Kinnunen's category (3) – those who rely on officials – or who at least desire more extensive official support.

"Well, what I need most of all, is some company now and again...only checking how everything is going, so I remain in good shape mentally, then of course a

shop where I can get food and then blood tests and medicine have to be taken care of too.”

“[I’d need, LH] counselling so I could talk about things confidentially.”

Several interviews clearly highlight the tendency to keep to oneself difficult matters relating to the immediate family, violence or disability. In some instances dealing with things alone is a habit adopted in childhood – partly as a result of separation from one’s closest family members. In these cases, one can see a connection to the intergenerational traumatization and intersectionality of traumatic experiences, discussed in previous sections. Disappointment experienced in relationships with other people and in the community makes people cautious and distrustful.

“I am a very cautious person and I don’t trust others. I have been beaten so many times... If I think of myself, I have very few people I trust.”

On a more general level, the interviews revealed that sharing one’s problems was not a familiar way of acting. Many linked the feature to the traditional Sámi style of living and mentality. Presumably, another consideration is the risk of being misunderstood in one’s immediate community, given that it has not developed an understanding of disability. Experiences of alienation or ill treatment by the immediate community result in withdrawal or escape. This describes the situation of those who fail to receive support, those in category (5).

“I noticed that [a significant relative, LH] was going to come and help me but then didn’t.”

Almost all of the interviewees mention organizations for persons with disabilities as one source of support. They provide information, rehabilitation and peer support. Peer support organizations play a role in learning to live with disability, improving one’s self-esteem and the shaping of one’s identity. The role of the organizations in networks that produce support is more visible in the present study than in Kinnunen’s, and corresponds better to the findings of studies done on the social help received by different groups of persons with disabilities (e.g. Somerkivi 2000).

The organizations for persons with disabilities do not recognize the special nature of Sámi culture. This highlights the need, mentioned earlier, to support the creation of a network among Sámi with disabilities. The study suggests that this network should have close connection with organizations for persons with disabilities so that the knowledge they have accumulated could be made available to Sámi more easily. Dealing with disability and Sáminess at the same time would be productive in terms of

increasing knowledge both in Sámi communities of the rights of persons with disabilities and in the disability organizations of the rights of indigenous peoples.

4.2 Meaningful activity

The means adopted by the interviewees for dealing with the hardships of their daily lives were situation- and individual-specific in nature. In addition to support from other persons, meaningful activity is important. This takes the form of work, study or work activities as well as physical exercise, being outdoors in nature and hobbies.

On the one hand, the importance of exercise and sport lay in physical rehabilitation and maintaining one's functionality. Interviewees who improved their quality of life through exercise demonstrated control and a willingness to challenge themselves as well as tenacity in long-term continuous rehabilitation. Disabilities restrict exercise but assistive devices allowed interviewees to overcome and even defy obstacles. Moreover, they recognize the psychological boost provided by exercise, which encourages them to continue with it.

"Yes, anyway I, using a roller-walker, went out for a walk... And I do all the work that has to be done around the house."

"There you can find them, things where you control yourself and your body, those positive thoughts, that you're not thinking the whole time about this rehabilitation and nothing but rehabilitation."

It is well known that the Sámi have a special relationship to nature and that this is a crucial element of the culture. The traditional relationship to nature is characterized by activity. In the case of several interviewees, disability posed a challenge to this relationship, for they recognized how demanding and harsh nature and nature-based livelihoods are as well as the challenges posed by their own disability for maintaining their relationship to nature. In the Sámi homeland people are out in nature to the extent it is possible under the conditions in the north. In cities nature and outdoor life are very different than in the homeland. The conditions make it possible to spend more time outdoors. Getting around in the city is comparatively barrier-free and help is nearby if needed.

"I have a habit of always walking down to the shore or into the woods and that's where I let out my worries, the woods."

"I have to say it's not the same as living in the forest... I don't like it, when here walking and exercising has not real point. I have to have some reason before I leave the house to go [into nature, LH]."

“Here [in the city, LH] I have had a chance to walk around, different places, to look around and get to know a lot of new people... I walk a lot more here than in [the country, LH]... It is very likely that if I [need help, LH] then I'll get some.”

Paid work is highly valued and sought-after as a form of meaningful activity. People are reluctant to go on pension and living without income from a job means living on a tight budget. The significance of work goes beyond its financial importance, however. It brings content to daily life, contact with people, as well as status in the community and society. These meaningful aspects of work carry over into the time when one no longer has paid work. Previous experience in working life plays a role in improving self-esteem and one's participation in community life.

Rehabilitative work activity is ascribed meanings somewhat akin to those associated with paid work. The value of both paid work and work activity is obvious, also when one has to give them up. Rehabilitative work activity and work placements form entryways via which one expects access to the labour market. On the other hand, work activity pilots reveal the limitations imposed by one's functional capacity and the labour market. According to the interviewees, in light of their experiences, the ability of the open job market to accommodate workers based on their capacity to work is poor.

When disability causes one to become excluded from the job market, one has to develop a suitable style of living through activities normally associated with free time. Volunteer work, work in associations and hobbies serve to bring meaning to a person's life. The choice of hobby reflects a person's attitude towards people and communities. Those who enjoy the company of others seek out group-oriented activities outside the home. They draw strength from doing things and pursuing hobbies together. Communal activity helps people stay on track with time and yields relationships through which one can perhaps get help when it is needed. People look for hobbies they can pursue alone if the company of people in the immediate community is not perceived as promoting their welfare. In such cases, activities such as property management, housework, handicraft, watching TV and using the Internet are considered entertaining and beneficial ways of spending one's time. Observing nature and pursuing nature-oriented hobbies is a source of pleasure and heartening. When people adjusted to the fact that they are no longer part of the labour market, their quality of life improved markedly.

“You go to a pleasant event, [meetings of hobby groups, LH], the neighbouring village, and have fun chats...if you stay and listen to the aches and pains, it'll break you.”

“You might get too interested in watching TV or knitting, doing handicrafts... I have often thought that I like to be alone and then I read a lot and listen to music... I like to listen to music.”

For many of the interviewees social media and the Internet offered meaningful activity and contacts with other people, when the immediate community and activities available nearby did not provide them with a feeling of wellbeing or caused feelings of being different and of rejection. Contacts with distant friends or relatives also became easier. Moving no longer hampered maintaining relations with other people as much as in the past. The Internet also makes it easier to create and maintain friendships with people outside one’s immediate community. Enthusiasm about the Internet could also be sensed in the comments of older persons once they had gotten over the threshold of starting to use it. Contrary to the conventional view, the contacts that older people had were not confined to children and grandchildren; rather, social media helped them form friendships with people outside their own locality.

Researcher: “Do you ever experience loneliness?”

Informant: “No... With the kids as far away as they are it is lonely, but we have Skype.”

The sense of community on the Internet takes on a dimension that is felt to be personally enriching. Social media offer opportunities for intimacy, normalcy and belonging, which persons with disabilities found lacking in their lives. On social media one can keep disability to oneself as much as one wants. The games and arenas on social media offer forums where a person can be just anybody. No one can see a person’s disability and she/he has better control over the limitations it imposes. The world of games was appreciated particularly by the younger generations since it gave them a chance to be “normal” or in fact to be a victorious conqueror or team leader.

“It improved self-esteem when I got to be a hero and...got to hide...nobody can see your disability and then you find these [people, LH] and you learn English. People communicate better there because they don’t see the reality... I stayed in [a game, LH] for a long time...and was the best.”

“For me what’s therapeutic is to go to the game store...and I’m there among all the games, because games were a big deal to me. And there it felt like I could relax there and could breathe, I could be normal.”

The world of games and social media are not sufficient sources of support in their own right but gave the interviewees some breathing room in a community they found oppressive or represented a way to detach oneself from the daily routine. In a variety of

ways, the Internet and social media offered new support networks for the wellbeing of persons with disabilities in what is a geographically rather far-flung Sámi community.

4.3 Advocating for oneself and others

The interviewees' experiences of discrimination and injustice awaken in them a desire to change things. They advocate for change in the position of Sámi and persons with disabilities and, in particular, Sámi with disabilities, but also in other matters where they have encountered injustice. Advocating and trying to make a difference alone are not enough to enable one to adjust to a difficult life situation but it is an effort to change one's circumstances.

A desire for change was reflected in the language choices made for children by older people, as has been discussed above. The aim was to prevent a repetition of discrimination, regardless of whether their preference was that their children would become Finnish speaking or Sámi speaking. The interviewees' own experiences have made them quite sensitive when it comes to recognizing difficult life situations. They show a special empathy and readiness to help in their behaviour towards others who are going through difficult situations.

"I tried to work things such that everyone could come and see me and that no one would experience the loneliness I had, due to the discrimination."

"The fact that you recognize that someone has is worried, is afraid, disappointed...but afterwards they feel really good about themselves because someone cared and sorts things."

The interviews show that living as a member of a minority entails a demand that one should try to make a difference beyond one's own situation. All of the interviewees had reflected on their own attitude towards advocating. The choices they made were individual. Three chose working through a political party or municipal politics. Others became involved in organizations in the field of social and health care, as active members of the parish or as ordinary members. For some this advocacy took the form of helping individual people going through difficult situations through their own networks. Looking at the way in which the interviewees took part in promoting social solidarity, one sees a spectrum of the operation of democracy from decision making to implementing decisions all the way to being ordinary good citizens.

"I was the member of [the committee, LH]."

"It's never been my style to rise up in protest and start making a fuss. I go like... which just goes where it is headed. I don't start making a lot of noise because confrontation only produces conflict. It irritates those who think differently."
"I'm not involved in anything else but the Sámi association... I do vote."

The interviewees include people well-versed in the whole range of popular democratic involvement. They represent a broad range of fields and arenas. Their work has also provided arenas for advocacy.

All of the interviewees pointed out that advocacy is necessary, at least in principle. If they feel they are not the right people to bring about a change they hope that others will. This appears for example as a desire to take part in research and the hope that their voice might help others in a similar situation. Two of the interviewees pointed out that they had taken part in other studies relating to Sáminess. One found participating in the studies tiring but even she/he found them necessary as a form of advocacy. The interviewees feel that their voices as persons with disabilities were not heard in the studies on Sáminess.

The public debate on Sáminess has seen rather extreme tones and as well as conflicting opinions, which have attracted publicity and some of the interviewees find these alien to Sámi decision making. The image that spreads in the media of the Sámi community as a discordant one discourages visible political activism. Although they understand the need for political activity aimed at realizing Sámi rights, they have sometime internalized experiences of discrimination to the extent that they have developed an aversion to issues relating to Sáminess.

"I ended up with the nagging feeling that after all I had go through [in the dormitory, LH]...it leaves you disgusted... I have never really gotten too excited about any Sámi celebrations or festivals and stuff like that; I've steered clear of them."

"With all due respect, they spoil some good things with their extreme positions."

"I don't really pay attention to the debates about Sáminess...because I don't think they are really part of what it means to be a Sámi... I'm used to arguments being settled by the people involved talking things over, with no one making a big deal of things. They settle things between themselves and then everyone's talking to one another again and working together."

Even though they are seriously committed to advocacy and spend time on it, the present social atmosphere brings on a certain fatigue. The interviewees feel that there is again less acceptance of diversity and that the Sámi are once again objects of racism.

“There has been a clear increase in racism...diversity is not as readily accepted as it was 10 years ago.”

4.4 Agency and Sáminess

Advocacy requires courage and strong agency. A robust self-image is by no means self-evident for persons with disabilities. People who have lived with disability since childhood or those who have suffered a serious injury speak quite a bit about accepting themselves and the identity work involved in accepting that their basic circumstances in life are different and that they have to live with their own special situation. For those who have been living with disability since childhood this phase lasts well into adulthood. In the case of those who become disabled, identity work has an intense initial phase which usually lasts several years, sometimes longer. Any significant changes in one's life after that phase require a rebuilding of one's identity on changed bases.

“Pretty certainly up to the age [in adulthood, LH], I had to learn myself... I accepted myself the way I am. After that life started getting easier somehow.”
“[The new, LH] diagnosis, it was humbling, on top of everything else.”

Finding one's own place is a matter of giving something up; it's more and very much a matter of building something new. The accounts of the interviewees stress a self-built life. This does not mean a life one has built alone. One's circumstances are so different that one has to craft one's life differently from the way most people do. There are many situations calling for choices and decisions, and accomplishing things requires more work than it ordinarily would.

“I have invested so much effort in getting my life back [recovery, LH]...what if it had failed after all that.”
“I was thinking, 'I have to get out of here'... I was wondering whether I wanted to and so on... I doubted whether I could make it, whether it was the right decision. Ultimately, I have to say that it was the right decision to come here.”

Disability creates special needs and requirements in life for which solutions have to be found. Sometimes the interviewees' situation involves a total change of environment, as above. They are in different phases in their search for solutions. Their narratives mention situations which have required them to have the courage to seize new

alternatives. Most interviewees could have died, lost their desire to live or ended up in even more difficult situations than they are presently in. They said that things could have turned out differently if they had not changed their environment or their living habits or come up with appropriate solutions where rehabilitation and assistive devices were concerned. An equitable life is in no way a given or guaranteed for persons with disabilities – regardless of the international conventions and national legislation. Rather, achieving equality seems to be a struggle for survival in which one encounters a constant stream of surprising challenges.

Finding solutions appropriate to one's own life through experimentation and setbacks is rewarding. Belief in one's own agency is strengthened. As a rule, the interviewees' accounts emphasize an active search for ways out of a situation. Although the realities imposed by disability and one's environment are restrictive and the means of coping limited, one finds appropriate and feasible solutions. The informants recognize the limits of their agency even though these limits and the environment are tested. A number of interviewees discovered qualities in themselves which they found closely associated with Sáminess. A reluctance to mention difficult matters and problems as well as a tendency to deal with them alone are connected with Sáminess in some contexts (e.g. Järvensivu, Pohjola & Romakkaniemi 2016). In other instances, these tendencies are associated more closely with small communities than with Sáminess as such, and the interviewees emphasize a desire and ability to share difficult matters with their family and others they are close to. Avoiding mention of one's problems is not always viewed as promoting coping; rather, efforts are made to overcome this tendency.

"I had to learn to unlearn a tendency where I kept everything inside, all possible sadness, anger, frustration and...then [I met a new person, LH]. I mean they're easy to talk with."

Other qualities associated with Sáminess are tenacity, perseverance, persistence and being solution oriented, all of which are perceived as supporting a person's ability to cope (also Miettunen 2013). Nature-based livelihoods and living in harmony with nature are underlying factors in the development of these qualities. Tenacity is a facet of the persistence and perseverance required to find solutions. The interviewees want to hold on to these qualities. They are coping resources.

"I am so tenacious, I don't know if it is genetic, part of the Sámi genetic heritage."

"One thing that has also helped me to cope and go on is that I haven't stopped and dwelled on matters, depressing matters."

“And I have never given up such that I can’t take it anymore and do anything. I didn’t have a whole lot of energy of course when you think of what the situation was.”

Sáminess as a personal identity experience is profoundly present in all the interviews. Sáminess is an experience in its own right regardless of how the interviewees relate to the way Sáminess is featured in activities advocating for the Sámi in society at large, in their community or in their lives in relation to other people. Sáminess is something that simply exists and that no one can take away.

“I was born a Sámi and am a Sámi. Full stop.”

“I know someone who has gone so far as to lie and say she/he is not a Sámi. I said, ‘For goodness’ sake, I have never once thought that I should say I am something other than what I am’.”

“My style of living is 100% the Sámi style.”

“Even though we were oppressed and they tried to make us, it was, I guess, they tried to make us Finns [laughs]. But we have Sáminess there inside us – no two ways about it.”

“I am a Sámi, and I’ll do fine with that, I don’t have to ask anyone anything.”

Even where Sáminess did not figure prominently in the lives the informants live today, its existence or revitalization as a personal experience was part of their lives.

“I’m very proud of Sáminess but I am not proud of my relatives.”

“I at least try as hard as I can to engage with my Sáminess.”

“Sáminess is important. It is pretty important here.”

The previous chapter, chapter 3, dealt with rather intense experiences of discrimination associated with assimilation policy. The last eight interview excerpts show profound experiences of Sáminess as an element of one’s identity. This seems to be associated with recovery from assimilation policy, difficult events in life, such as coping with becoming disabled and creating a life with disability for oneself. A personal experience of Sáminess reinforces one’s identity and provides strength for coping with hardships. Other research has yielded similar indications that belonging to an indigenous people may act as a resource compensating for disability (King, Brough & Knox 2014; Uttjek 2016).

5 Service experiences

In the interviews we concentrated mainly on the interviewees' own experiences of welfare services. Occasionally we also mentioned service experiences of their acquaintances and, in particular, of experiences offered in Sámi. Welfare services offered in Sámi came up to the extent that the interviewees had experiences of them. The results of this study are not comprehensive from the standpoint of the welfare service system; they provide a picture of the experiences of a particular group. The results do not describe the provision of welfare services in the Sámi language as a whole in Finland; a study of welfare services in the Sámi homeland was carried out several years ago (Heikkilä, Laiti-Hedemäki & Pohjola 2013) and a corresponding one of Sámi living outside the homeland is close to completion (<https://saradutkan.fi/>). Research has also been done in Finland on the meanings given to social work tailored to Sámi needs by the social workers in social services offices in the Sámi homeland (Järvensivu, Pohjola & Romakkaniemi 2016) and on the experiences of staff in the Lapland Hospital District of taking Sáminess into account in health care (Kinnunen & Kitti 2013). These studies did not deal with the position of persons with disabilities or with their service experiences.

5.1 Sámi-oriented school services

Of the services provided in Sámi, the interviewees mainly cited educational services. The availability of early childhood education and other educational services for children in the Sámi language has improved in the Sámi homeland; elsewhere in Finland availability is haphazard.

There were two older interviewees who had an opportunity to use Sámi in schools but in their school, like others, the teaching and learning materials were in Finnish. In the case of the other older interviewees, the use of the Sámi language was forbidden and they were afraid of being punished if they broke this rule. After such experiences, one feels no need to be able to use one's native language in welfare services, nor is it possible in all contexts without a sufficient command of the written language. The use of Finnish is an automatic habit learned when one was forced to speak it as a child.

“Yes, at home I speak Sámi for the most part and Finnish when I have to... If we had had a Sámi-speaking teacher, we would have studied Sámi [in school, LH], we would have learned to write Sámi. We didn't learn anything. I can't read or write Sámi, it's so hard. And I don't even like to, for the most part what I do I do in Finnish and write.”

The interviewees are satisfied with the development that has taken place in the schools and in opportunities to learn the Sámi languages. But there is still work to be done; opportunities are limited to the homeland and bilingualism has resulted in pupils speaking Finnish during recess, when involved in traditional livelihoods and in their families.

“The boys speak Finnish to the reindeer.”

“At first I wanted us to start speaking Sámi to [person, LH], and [other persons, LH] said, ‘You can’t because that will leave us out’—so then I couldn’t do it.”

Even in the homeland, the experiences of the younger interviewees are confined, with a few exceptions, to the schools. Their significance in potentially preserving and revitalizing Sáminess and the Sámi language is beyond dispute. School services make the learning of Sámi possible for those who for the most part have spoken Finnish at home or in whose home no one knew how to read or write Sámi.

“Then it got so quiet in the classroom that no one even took a breath...then everybody I’m sure, thought, now there’s going to be a war [laughs]... In situations like this you notice that [the right to Sámi-medium instruction, LH] is a hot issue.”

Interviewees living outside the homeland had had no experience with public-sector school services. They worked on revitalizing the language in the activities of Sámi associations, at their own expense, among friends and on studying the language on their own.

With one exception, school gave all of the younger interviewees an opportunity to learn to read, write and speak Sámi. However, the school services in Sámi do not meet the special needs of pupils with disabilities. Elementary school lacks the equipment and skill – or the understanding – needed to take into account the special situation associated with their disability or they are offered a place in a special needs school. Teaching in special needs schools is in Finnish and the support materials for pupils with learning difficulties are in Finnish.

“The proposal was that they would send me to a school for pupils with disabilities... I would have become completely Fennicized there.”

The interviews indicate clearly that the interviewees are aware that a good deal of progress has been made in the homeland since they were in school in accommodating pupils who need special support. However, this support is still contingent on the

awareness that individual workers have of the special needs of pupils with disabilities and on their desire to help pupils and guarantee them an equal right to Sáminess. As far as the interviewees were aware, in the homeland the special needs of children with disabilities are still not addressed systematically nor are services for the purpose adequately funded.

In principle the younger interviewees had an opportunity for vocational education in Sámi at the secondary level at the Sámi Education Institute. For the most part, however, vocational education has been provided in Finnish. As all of the interviewees know Sámi and Finnish at least, this is not considered a problem. However, they do mention that attending school in a less familiar language is particularly demanding when the teacher does not invest time in the special needs of Sámi students with learning difficulties.

5.2 Sámi-oriented social and health services

The interviews indicate that the provision of social and health care services in the Sámi language is poor. Two could cite situations in which they received health care or rehabilitation services in Sámi. No one had used an interpreter to receive services. The interviewees used Finnish in dealing with officials because they were used to doing so, through force of circumstances. Using Finnish is the most convenient option, since other alternatives require special arrangements. It is hard for the interviewees to imagine things being otherwise although they remember how grim things were in the past when no interpreters were available. Nevertheless, they note that services in Sámi are a sign of respect and good client service; they are also important for preservation of the language (see also Pohjola 2016).

“Nowadays they use an interpreter as a matter of principle. Some do... Too bad there weren’t any when they were really needed... The [service in Sámi, LH] feels good even though you understand Finnish... ‘It’s wonderful’ that we are being acknowledged.”

“I do understand Finnish. It doesn’t seem that it [provision of services in Sámi, LH] is absolutely essential. But it’s good of course, because the language is kept alive.”

The again, the interviewees recognize that there can be situations where Finnish, if learned as a second language, is not sufficient for taking care of one’s affairs verbally. In addition, several of the interviewees identified a need for services in Sámi in situations where they had to deal with sensitive and intimate matters (see also Järvensivu, Pohjola

& Romakkaniemi 2016). At such times a worker is needed who knows Sámi. Using an interpreter is not appropriate in such situations.

“[Services in Sámi is needed, LH] I don’t know...the psychological...maybe the medical end... I can’t say.”

“Yes, the doctors could [speak Sámi, not Finnish, LH]; [with Finnish, LH] you end up thinking, ‘What did that mean?’ It would be a lot easier to talk about things in Sámi.”

Numerous studies have observed that among Finns the threshold for seeking help in difficult life situations is generally quite high (see e.g. Rantalaaho 2006; Törmä 2009). For many of the interviewees in the present study living in a small community raises this threshold even higher. Members of the community who seek help are easily identified and they are not necessarily convinced that their privacy will be protected. Another thing that was seen as possibly limiting the use of a Sámi worker was that people did not want to share their affairs within what is a small community. The interviewees in fact noted that in the case of sensitive matters it is easier to seek services from farther away rather locally. The services located farther away are also often special services, and the interviewees have more confidence in the support these offer than they have in local basic services.

“The problem with the officials in [own community, LH] is that most of them are relatives, so I don’t really have confidence.”

“These, you know, are ones that will really look into things, some of the specialists or some special, disability [services, LH], they really understand right away how hard things are for us, but a normal doctor doesn’t, no way.”

Previously it was pointed out that talking about difficulties, problems or things that revealed any kind of weakness is not considered natural for Sámi, which might make it difficult for them to seek services more generally as well. Within the community this characteristic becomes readily visible. Nevertheless they recognize that seeking and receiving help is important for one’s wellbeing.

A number of the interviewees have acted as support persons for Sámi in service situations or offered services in Sámi in the homeland. Those who have done so describe situations where a Sámi-speaking client’s or patient’s situation was incorrectly interpreted before a support person was involved. The crux of the matter was both linguistic difficulties and the cultural distance between the Sámi client and Finnish-speaking worker. Stereotypical conceptions of Sámi might prevent people from seeing the true situation. A patient might receive an incorrect or incomplete diagnosis when

she/he understands the things that are asked differently from the professional doing the asking. The client does not always receive sufficient care or her/his need for rehabilitation is not recognized. Even though the client has a fluent command of Finnish for everyday matters, she/he does not understand the language used in services. The service providers do not realize this and the client may leave a situation without having understood what happened (also Miettunen 2013). This may be as difficult for the worker as it is for the client.

"The [worker, LH] called and said 'Won't you come, this just isn't working ...'
The client says [later on, LH] 'Oh, it's great that you exist, I was already panicking'."

"I was with [client, LH] there [with a special expert, LH]... With [the client's, LH] Finnish skills...that would have been a complete disaster."

"[I made a suggestion, LH] as to whether it would be possible... I interpret [the matter, LH] for this [person, LH]... This is what we did and [the diagnosis changed, LH]."

"Then a nurse came to apologize, asking what you thought when they asked you such...a things. I said it's not anything for me to be ashamed of, it didn't bother me."

When a person becomes disabled, a person who was bilingual may lose one of her/his languages and the language lost might be Sámi even if Sáminess remains a significant part of the person's identity. Disability and rehabilitation services have failed to notice the opportunity of using the study and recovery of Sámi as a form of rehabilitation. One gets the impression from the interviews that language skills have a beneficial effect on self-esteem and thus on rehabilitation as well.

"And Sámi...it disappeared altogether [upon becoming disabled, LH]... Nothing but a few bits and pieces left... I am working hard to get to the point where I have the courage to start speaking it again...and I would be able to bring out my Sámi identity for myself from that."

Being bilingual does not mean that one can engage with services in both of the languages. In particular, in life's crisis situations and in using special services a client's bilingualism requires more focused work on the part of the service provider than usual. One should make a special effort to determine in which language the service in question should be provided. If the service cannot be provided in the desired language, opportunities to use an interpreter or a support person of one's own choosing should be ensured. Sometimes a support person is a preferable as a solution to an interpreter, since the support person may help out in both linguistic and cultural interaction.

In several interviews we referred to support persons using the term “cultural interpreter” and the interviewees found the expression to be a better description than “support person” or “interpreter”. Support persons who have been interviewed note that they acted more as interpreters of culture and ways to communicate than of language. Crucial to the role of support person is consideration for the special nature of the culture involved.

“It's easier for me because I also know these families... When people are talking, a Finn starts interpreting incorrectly right off the bat [even though she/he knows Sámi, LH]... You [a Finn, LH] have the language but the other half is totally missing. I grew up [a Sámi, LH]... The trust comes right away and you know that you belong this family, you have the knowledge. And then there is a certain hierarchy, you could say it is admirable, sort of democratic in a way.”

The cultural interpreters had known their clients for a long time and they had other information about the clients' life history and situation, information on which they based their expertise. Three of the support persons interviewed had at some point received payment or some form of compensation for their work but monetary compensation covers only a fraction of the work they end up doing. Cultural interpreters have knowledge based on training, experience of how the system of services works and a mastery of the language the system uses.

“I understand both cultures pretty thoroughly.”

The Sámi community makes good use of these cultural interpreters and the interpreters are generous with their help. The interviewees noted that they were called on short notice to help out in client situations where some form of crisis arose or in situations where certainty was needed on what to do. Volunteer work is hectic and cultural interpreters mentioned how they grew weary from time to time of their unpaid “second job”.

“I'm pretty tired right now in fact.”

“Much more is demanded of us than of so-called outsiders.”

People have confidence in the ability of cultural interpreters to help them. There is a clear need for culturally adequate service guidance in the Sámi language and from within Sámi culture, and it is also clear that this need must be officially recognized and properly resourced.

In discussions, welfare service professionals have mentioned how their organizations are inadequately prepared to give due consideration to Sáminess when providing services. Maija Faurie (2011) has also noted that knowledge of Sámi culture in decision making on social security is inadequate. The attention given it has largely focused on language, with the special nature of the culture not being recognized in client encounters or in interpretations and decisions that have been made. In discussions, the contact persons said that the organizations lack assistive devices that accommodate the Sámi language and that professionals need more knowledge on the special characteristics of Sámi culture. The various pieces of equipment used to facilitate communication operate almost exclusively in Finnish and have to be tailored to the needs of a Sámi client each time. The resources available for such work are insufficient. Many service providers admitted that Finnish is often used because the client speaks it fluently. Where Sámi clients have become accustomed to taking care of their affairs in Finnish, professionals have become accustomed to Sámi clients' Finnish skills. Bringing about any change in this situation would require efforts to undo routines and dismantle colonialist structures (Pohjola 2016).

5.3 Universal Finnish welfare services

Even where provided in Finnish, public welfare services were perceived as essential to the interviewees coping. Unfulfilled cultural and linguistic expectations aside, shortcomings were noted in the client-orientedness of the services. Persons with disabilities or their close networks did not have sufficient information about services or their right to them, nor did they have the support structure for locating the services. A number of other studies of services have reached similar conclusions (e.g. Järvikoski, Hokkanen & Härkäpää 2009; Metteri 2012; Kivistö 2014; Martin 2016). The lack of knowledge on disability in the welfare services results in clients not being treated as they should be. There is a need for social advocacy both with and for persons with disabilities (Hokkanen 2014). This means both advocacy for individuals with disabilities resulting in their situations being considered holistically and more general, structural advocacy relating to disability and the rights of persons with disabilities.

“But who do you ask for services when you don’t know, when nobody lets you know what services you can get?”

Social and health services in general, and medical expertise and rehabilitative services in particular, have proven to comprise one-off actions. On the one hand, they lack a long-term perspective and, on the other, they fail to adequately comprehend the patient’s situation as a whole. When a person becomes disabled or a disability is detected what is required, in addition to an accurate medical diagnosis, is a correct

social appraisal of the significance of the diagnosis for the person's life, her/his immediate environment and its implications for her/his need for help, support and services. Becoming disabled, admitting that one is a person with a disability and rehabilitation represent long-term processes in the interviewees' lives. Disability is part of life and its impact over the course of a person's life changes as life situations change and a person gets older.

"I have such a dread of Social Insurance Institution after dealing with them that I am not going to ask them for a single euro. I have...paid for stuff out of my pocket... I had to fill in the forms myself and they promise [service, LH], then comes the decision that I have to [provide more information, LH], noting. They bounce me around...no psychological support, nothing. I had to get through all the paperwork the same as everyone else. "

Informant: "Once I received [a period of care, LH]...now I have applied for two years [for a continuation of the care, LH] but haven't received any reply from [the municipality, LH]. The [professional, LH] recommended that the care be continued, it was beneficial."

Researcher: "Did you find it beneficial?"

Informant: "Yes, it was."

Finding a solution that fits the situation of a person with a disability, realizing what opportunities she/he has and supporting them requires experimentation and determination. An individual's resources and hidden skills are best found by working together. Long and diverse paths of rehabilitation bring about significant progress and assistive devices appropriate to a person's situation enable her/him to enjoy equality.

"There I had the chance to gradually begin aquatic therapy and physical therapy and...then [a third form of rehabilitation, LH] started and then along came the [special, LH] department... Three years later came [the fourth form of rehabilitation, LH] and then I spent time [in several periods of care in several rehabilitation facilities, LH]...and I got the results there and the magnitude of these disabilities and everything else that [earlier, in my home community, LH] they didn't know."

The interviewees spoke of the great significance the diagnosis takes on in the system of services. Arriving at the right diagnosis might take years and getting it requires resources and skill on the part of the person with a disability and those closest to her/him or her/his support persons. A lack of a diagnosis is problematic in that without one it becomes difficult to get services. Getting rehabilitation and services becomes a

hard and haphazard process, which compounds the consequences of the disability, hampers efforts to devise compensatory services and reduces their availability. An incomplete diagnosis may lead to unsuitable forms of care.

“Gradually all the pieces seemed to have sort of come together but it took [many, LH] years. So I partly paid for it myself.”

“In my opinion what [the professional, LH] went ahead and did, it was a mistake, I mean.”

Often disability involves medication in addition to services and rehabilitation. A person’s attitude towards the medication she/he has been prescribed varies. There are situations in which they mention unequivocally that they have stopped taking their medication rather than put up with its side effects. Then again there are situations where people emphasize decision making together with the care staff. The staff offer, among other things, cutting-edge care or medication and in modern care methods one is “dependent” on a client’s own assessment of the suitability of the care. Third, situations occur in which people trust the doctors and the care decisions made by staff because they are experts in their field.

“Sometimes there are more, sometimes fewer [side effects, LH]... I have been a guinea pig – whenever there is a new drug out, we go ahead and give it a try... I have had reactions right away... I have had to stop taking the medication right then and there... Yes, the doctor is good. She/he has time to discuss things and talk long enough that I can ensure I understand and...it takes a lot for the doctor to listen and try to figure out how these [symptoms, LH] can be reduced.”

Many of the interviewees spoke about the appropriateness or inappropriateness of medication. Looking for medication that is suitable is complicated and has an impact on one’s life. Unsuitable medication reduces one’s functionality, causes health problems and is harmful socially. From time to time working out the right medication becomes a significant part of one’s life. Effective medication makes life easier.

Once made, a given diagnosis guides the interpretation of situations and the actions taken. When disability changes over time, or a person develops a new health problem, the service system has difficulty acknowledging the change. The diagnosis and the assessment of a person’s situation seemingly accompany the person in the service system as an identifier and determine the way in which she/he is viewed. Diagnoses are static and their gaze is turned towards the past. The life of a person with a disability on the other hand is directed forward and towards change.

“When I had these [earlier diagnoses, LH], they didn’t believe I had a problem [elsewhere in my body, LH] as well.”

A diagnosis might also be a stigma which constrains a person’s life because it prompts prejudices and ideas about what a person is capable of. In this way diagnoses can also limit the possibilities that a person with a disability and the community envisions. This is one reason why people sometimes do not disclose that they have a disability.

The interviewees included persons who consciously broke down the barriers imposed by their diagnosis. It is possible that arriving at the correct diagnosis is particularly challenging in multicultural situations. This can be seen as an indication of how common it was in the case of the interviewees that their lives had not taken the course that one might have assumed on the basis of their diagnosis.

“[The doctor asks, LH] ‘Have you been leading an orderly life?’ I said I have been driving a snowmobile ‘You know you’re not allowed to do drive a snowmobile’. I said that I have driven one anyway.”

There are more shortcomings in services when it comes to giving due consideration to culture than a lack of services in Sámi. On a more general level, services lack an understanding of Sáminess, as well as the special style of communication and way of life in Sámi culture. The lack of adequate services seems at least in part to stem from the inability of services to engage with people in their special, individual life situations and to see the joint impact of this situation and disability.

6 Conclusion

6.1 Evaluation of the study

6.1.1 Methods and research practices

The material for the present study was gathered through interviews. There has been very little research done to date on Sámi with disabilities. As the study progressed, it became clear that the members of the target group who ended up being interviewed were people who had a readiness to act as informants. They were more ready to take part and capable of taking part and had networks through which they found out about the study. This should be taken into account when applying the results of the research. People living in extremely serious situations are a minority in the material.

In doing research on persons with disabilities and members of a linguistic minority, disseminating information, informant agreements and setting up interviews all require a considerable investment of effort. Critical assessment of the research procedures employed is needed when considering linguistic and cultural circumstances as well as the situations of the individuals involved. The solutions are considered on a study-by-study and situation-by-situation basis. The many implications of the solutions adopted are reflected in the fact that the written materials of the present study have been produced in two languages, a measure taken to acknowledge the right of Sámi-speaking informants to material in their own language. Producing the material in both North Sámi and Finnish was relatively straightforward thanks to colleagues who know North Sámi. If it had become necessary to accommodate all three Sámi languages spoken in Finland, the study would have been delayed and extra costs incurred. When embarking on such a research project and applying for funding it is impossible to fully anticipate the special circumstances that will emerge as it is carried out.

In principle, having material in two languages supports the status of the Sámi language but on the level of the individual interviewee, the use of both languages may take on unintended meanings. Older Sámi-speaking persons speak their native language but can neither read nor write it well. For some of them the practice with regard to the language was more of a reminder of skills they lacked than of skills they had. In addition, many disabilities make it difficult to understand written text. Supplementing information on the research by materials in plain language, pictorial aids, Braille and sign language would have ensured more equitable treatment, but would have entailed more time and expense; even then the special circumstances of many groups of persons

with disabilities would have been overlooked. The arrangements were covered in the interviews and in meetings preceding these, but people cannot revisit such orally communicated material on their own. Compromises must be adopted on a study-by-study basis. As regards follow-on research, multilingualism can be considered a sound approach but the information could have been made available live in spoken form and as a recording through email and the Internet.

The snowballing method is well suited in cases where the target group is difficult to reach. Although the snowball did not roll too readily, trying to reach potential informants through a number of different channels yielded a variety of views and experiences. More time would have been needed for reaching the target group, given that disability is known to be a sensitive topic. The timetable for the research was tight, with the analysis of interviews taking place as new informants were sought. Disseminating information quickly and through various intermediaries increases the risk of the intermediaries or potential informants making flawed interpretations or feeling that they have been bypassed. This makes implementation of the research more difficult and may prevent a particular subgroup being reached.

The personality of the researcher also has a bearing on the implementation of the study. I am not a Sámi nor do I have a disability but I do have some familiarity with both – more with disability, less with Sáminess. The interviews were conducted in Finnish. In some cases one could clearly see the influence of the Sámi language, of disability and of the mode of discussion characteristic of Sámi culture. Taking these into account in interpreting the data requires time and sensitivity. Every reading yields new meaning for the matters discussed. The analysis of research material is always a matter of the researcher's interpretation. In the present study this consideration figures quite prominently.

- Accommodating the linguistic, cultural and individual factors pertinent to the target group involves a situation- and study-specific solution.
- Working out research solutions that respect and give due consideration to the particular nature of disability and multilingualism requires an investment of effort, interest and resources.
- The diversity of disabilities poses challenges to research that in practice cannot be addressed exhaustively.
- Acquiring comprehensive information using the snowballing method requires a number of fresh starts and time.
- A risk of misunderstandings exists, particularly when doing research on value-laden topics.
- The standpoint of the researcher as an insider and outsider with respect to the

phenomenon being studied is always partial and changes over the course of the research.

6.1.2 Research data

All of the interviewees are over 18 years of age. Matters relating to their childhood and youth came out through experiences heard from others or through personal retrospection. The study deals partly with past experiences. The past is significant for people's experiences in the present; this particularly true for groups of people who have experienced structural violence, as is the case with persons with disabilities and Sámi.

Using snowballing that taps extensive networks reaches Sámi with disabilities who are living in a variety of situations. The method also yields information on the phenomenon of interest that serves to complement the interviews. Reaching prospective interviewees is easier in northern Finland than elsewhere. All in all, those who ended up being interviewed were people who have or have had a strong attachment to Sáminess in their everyday lives. The group of interviewees includes relatively many people who live in the Sámi homeland and speak Sámi as their native language. The informants do not represent Sámi persons with disabilities at large in Finland. Sámi who live outside the homeland and are Finnish speaking are underrepresented.

Where disability is concerned, the interviewees represent a diversity of backgrounds. Almost all have several disabilities and chronic illnesses. Well represented among the interviewees are groups of persons with musculoskeletal disabilities, learning difficulties, cognitive disorders and brain injuries. The material almost totally lacks person with mental illnesses, sensory disabilities and very severe disabilities. These disabilities are discussed largely through the experiences of acquaintances. Some of the shortcomings in the material can be attributed to the interview and snowball method chosen, the desire to speak primarily with the persons with disabilities themselves and the use of the word "disability".

- All interviewees are over 18.
- The material is rich in relation to its size; it exemplifies the views of different age groups, both genders as well as people with a variety of disabilities.
- The material reflects in qualitative terms the diversity of the phenomenon being studied, although it cannot be considered a representative sample of Sámi or of people with disabilities.
- Gathering a more comprehensive set of material would require a longer-term study.

6.2 Evaluation of results

Even as the snowballing proceeded, it became obvious that Sámi persons with disabilities are not well networked either officially or unofficially. Scattered groups can be found among people in certain life situations and with particular disabilities, especially in the Sámi homeland, but these have only reached few people. The interviewees feel that they have received support from Finnish disability associations for building their identities and finding solutions. In these situations Sáminess gets overlooked in the peer support relating to disability. There is an obvious need to support networking among Sámi persons with disabilities as well as among disability associations and Sámi associations. Networks make it possible to take disability and Sáminess into account at the same time in advocacy and providing support. In forming networks, attention should be paid to the diversity of disability as well as the shared and special needs of Sámi living in and outside the Sámi homeland.

It is surprising that a national survey (SÁRA project) yielded only two interviewees who were willing to take part in a study dealing with disability. The interviews also indicate a hesitancy and unwillingness to become defined through one's disability. Disability still brings with it Otherness and shame and people living with disabilities are discriminated against. For this reason disability-related issues should be readily brought to the fore and individual Sámi should be supported to discuss their disability openly as examples to others. In this way disability would become more visible, more accepted, more readily noticed and better accommodated.

Both Sáminess and disability are complex issues. The Sámi speak several different languages. Among the other areas where diversity is found are special cultural features, extended families and the traditional livelihoods of families, places of residence, and relation to religion, political activity and multiculturalism. In the case of people with disability, one sees diversity within the group caused by the consequences of different kinds of disabilities in the community, society and life politics and the attitude of the environment towards the consequences. Dealing with the Sámi and with persons with disabilities as distinct groups on the level of international agreements and legislation is understandable. In the implementation of the agreements and in providing services, acknowledging the heterogeneity within the two groups is a condition if services and practices are to suit people's life situations.

- Sámi persons with disabilities lack a reference group or network through which they can receive support attuned to their special needs and have influence on matters that affect them.
- The rights of persons with disabilities have been largely overlooked in

discussions on the Sámi although the Declaration of the Rights of Indigenous Peoples requires that special attention be paid to persons with disabilities.

- The Sámi are a people and as such an entity. The Sámi languages and their dialects, as well as Sámi culture and changing ways of living, appear in forms whose diversity is part of living Sáminess.
- Disability is a category that gives rise to many biases and much discrimination. Implementing the rights of persons with disabilities requires advocacy that pursue the shared interests of persons with disabilities and pursues the special interests of different groups of persons with disabilities.

6.2.1 Discrimination

Both disability and Sáminess still cause discrimination. At issue in the present case is not only discrimination occurring today but the impact of past events on people alive today. Recognizing and dealing with discriminatory practices from the past is one aspect of eliminating their impacts from today's practices as well as creating non-discriminatory practices and seeing them become firmly established. Discrimination is not necessarily recognized by those discriminated against any more than it is by the people, organizations and services that perpetrate discrimination. Addressing the issue requires opportunities to do so at the communal and individual levels (Herring et al. 2013). The opportunities available for this are insufficient and to some extent also inappropriate for dealing with historical traumas.

Assimilation policies are also responsible for experiences of individual mistreatment and experiences of violence, the processing of which requires particularly intense effort due to the complexity of the experiences involved. The study revealed evidence of experiences that had not been dealt with fully due to unclear boundaries between organizations and the costs involved, resulting in a situation making life difficult for the people affected. The system of services must exercise conscious, positive and responsible discretion when putting together client-specific solutions for processing difficult experiences.

Experiences of discrimination take on an individual character. Discrimination relating to disability or Sáminess may become combined with other factors resulting in unfair treatment. Experiences of discrimination in one aspect of life may make people susceptible to it in others or in regard to another personal characteristic. The intersectionality of different factors causing sustaining discrimination must be taken into account in efforts to prevent it in dealing with and compensating for its impacts.

Forms of discrimination based on different factors cannot be compared with one another because the effects are felt in different ways and in different aspects of life. Generally speaking, the impacts of discrimination associated with Sáminess and disability are wide-ranging and it is difficult to single out an area of life that they impact in particular. Nevertheless, certain core affected areas can be identified. In this study the principal manifestation of discrimination based on Sáminess is the failure to realize the linguistic and cultural rights of the Sámi. Discrimination based on disability appears most prominently in the realization of educational rights and the rights relating to working life, mobility and care. Discrimination based on gender is most apparent in the area of working and family life as well as in the failure to ensure physical integrity.

Discrimination based on disability is a global phenomenon, elimination of which has been furthered by international cooperation, increased awareness and active efforts to realize the rights of persons with disabilities. For Sámi with disabilities the risk of being discriminated against does not seem to be any lower than for other persons with disabilities. Discrimination based on disability may be combined with the poor treatment that Sámi encounter, and in the homeland persons with disabilities must deal with the particular challenges of receiving adequate services in a remote rural area. Multiple discrimination makes Sámi with disabilities susceptible to consequences that are not related to either Sáminess or disability as such. Extending to Sámi the measures that have been taken to reduce discrimination of persons with disabilities and shaping these measures to respect and promote the culture are a matter of utmost importance.

- The situation of and attitudes towards the Sámi have improved, a fact which is reflected in the experiences of the young people in particular.
- Historical experiences of discrimination impact Sámi lives today.
- Structural discrimination increases the likelihood of tolerating unfair treatment directed at individuals.
- Recognizing the intersectionality and contextuality of discrimination requires particular perceptiveness and aids in fighting discrimination.
- The impacts on life of different factors leading to discrimination vary in relation to one another.
- A serious experience or instance of discrimination may prevent one recognizing a more subtle situation as a case of discrimination.
- The Convention on the Rights of Persons with Disabilities and the Declaration on the Rights of Indigenous Peoples must be read side by side when looking for ways to implement the documents.
- The rights safeguarded by international agreements and national legislation are not rights until they are exercised in everyday life.

6.2.2 Coping

Factors that proved crucial to managing one's everyday life and to realizing wellbeing were personal relationships in the local community and the support received there in the form of information, services and help, as well as emotional support. In many instances, the local Sámi community expands to cover not only the immediate family but also the extended family, the area where the extended family has traditionally lived and the family's traditional livelihoods. The local community's understanding of disability and its implications supports the possibilities of persons with disabilities to adjust to their disabilities and their life situations and to find their own way to live. Implementing the rights of a person with a disability requires commitment, skills, outspokenness and tenacity on the part of her/his immediate network. The local community needs information and support in order to be able to offer persons with disabilities support appropriate to their needs.

If persons with disabilities are to achieve a good life, they need societal services, support and measures. Medical support is rarely sufficient as a service. In order to ensure equal participation, a broad-based social view is needed on the implications of disability and becoming disabled for life, participation and finding new opportunities. If the support received from one's close social network is insufficient or conflicting, services and professionals are expected to provide a broader range of support than usual. Professionals do not necessarily recognize the complexity and significance of their role in the lives of persons with disabilities.

The work of disability organizations plays an important role in enabling participation for persons with disabilities. The advice, guidance, services and peer support received through the associations support people in forming their disability-related and in finding ways to cope. The support that the associations provide is significant although today it does not fully appreciate the special nature of Sáminess.

Inclusion is realized in participating. For persons with disabilities participation on equal footing means opportunities for meaningful activities. Study and work are considered the primary arenas. They are perceived as ensuring communal and societal participation. Because the labour market is discriminatory, other types of activities take on heightened importance. The attitudes of the environment and the system of services do not always show an appreciation of how important these arenas are in the lives of persons with disabilities, contributing as they do to a broad range of needs, such as maintenance of the home, housework, physical exercise, hobbies or social media.

The Internet and social media offer arenas to Sámi persons with disabilities that bring to their lives participation, activities, personal relationships and a new agency. Social support networks created through these channels enrich the persons' lives. Internet-based arenas will only grow in importance and they are likely to bring solutions to the problems of receiving support although they cannot offer a comprehensive solution to the need for support in everyday life.

Experiences of unfair treatment fuel the interest of Sámi persons with disabilities in advocacy activities. A person with a disability rarely musters the courage for visible advocacy as a person with a disability but they embrace advocacy, ready to act as supporting figures or work at the grassroots level or with individuals. Even if advocacy does not prove successful personally, the need for it is recognized. This can be seen for example in the fact that one hope where this study was concerned was that participation in it would have an impact on the position in society of persons with disabilities, Sámi with disabilities in particular, and contribute to their having an equal position as members of the Sámi community.

Disability does not render life static; rather, life becomes more surprising, complicated and dogged by setbacks than it is ordinarily. The interviewees exhibited a certain tenacity that helped them in dealing with setbacks. This enabled them to pursue matters with perseverance and resolve as they sought greater wellbeing and stronger participation. One's life is built of elements that are somewhat out of the ordinary; this being the case, one's own agency takes on heightened importance, even when support is available through networks.

There is a clear difference between identifying as a Sámi and as a person with a disability. The Sámi are a people and all the interviewees accept this form of identification. Disability on the other hand was perceived more insistently as one component of a person's identity. Most of the interviewees showed a categorical aversion to being called disabled and only several were ready to appear in public as persons with a disability.

Sáminess is strongly linked to personal agency and identity. Although one might disagree with the work of the Sámi Parliament or take no interest in the public debate on Sáminess, this does not undermine one's Sámi identity. The diversity of Sámi culture is seen as making room for difference as well. Sáminess is a supportive force for persons with disabilities and a factor reinforcing their identities.

- When support from their closest network is thin, persons with disabilities expect professionals to provide particularly broad-based support.

- Meaningful activity is the foundation for participation on equal footing. Work and study are perceived as the principle means for enabling participation. Where these are not available, other types of activities take heightened importance.
- The arenas of participation and support provided by the Internet and social media will grow in importance.
- The interaction between a person living with disability and her/his local environment is a factor having significant influence on the impacts of disability.
- Discussions of Sáminess and Sámi advocacy have largely overlooked persons with disabilities.
- Life as a person with a disability requires a more conscious building of one's life than is ordinarily the case.
- The Sámi identity is a strongly personal experience.
- The personal experience of Sáminess and a Sámi identity support coping and reinforce experiences of participation.

6.2.3 Services and shortcomings in them

The provision of services in the Sámi language is an unfulfilled promise. In order to revitalize the language services for persons with disabilities require solutions that support the use of one's own language and of two languages. The point of departure should be to provide services in the client's own language whenever the nature of the service makes this possible. It is not acceptable, however, to offer Sámi clients inferior services by arguing that considerations of language so dictate. Competent services take on heightened importance in the lives of persons with disabilities. Revitalizing the language and culture requires the right to rehabilitation and service that takes bilingualism into account. A person speaking her/his native language or a bilingual person should have the right to revive her/his knowledge of Sámi as part of the services and rehabilitation he/he receives.

Services for persons with disabilities lack sufficient service practices and assistive devices that would accommodate the Sámi language and Sámi culture. Developing appropriate practices and services and tailoring them to individual needs requires constant support. The conception of participation and a good life in Sámi culture may differ from that in Finnish culture, and this should be taken into account when making decisions on what devices and services are considered acceptable. Examples that could be mentioned are broadening the interpretation of "family", the acquisition of devices that support the culture and extending support for mobility not only to access services

but also to spend time outdoors and to provide opportunities to be involved in traditional livelihoods.

There is a shortage of Sámi staff and staff with Sámi skills in the social and healthcare services, in particular in services for persons with disabilities. The availability of cultural services is dependent on the efforts of individual people willing to invest time and effort for the purpose. Implementing services in a culturally adequate manner always requires special effort, a factor to be taken into account. One thing that would facilitate the recruitment of staff with a knowledge of the Sámi language and Sámi culture would be to earmark a sufficiently large wage supplement. In particular, attention should be paid to the availability nationally of culturally, linguistically and professionally adequate services and the extending of cultural competence to services for persons with disabilities and different groups of persons with disabilities.

Given the complexity of Sáminess and the work left to be done in revitalizing the language and culture individual professionals at the forefront of cultural services find themselves in an onerous position. Networking among people familiar with the Sámi language and Sámi culture would facilitate efforts to extend culturally adequate service across the board into basic and special services both nationally and among the Nordic countries. Networks would make it possible to strengthen professional and cultural expertise as well as peer support, which in turn would help practitioners better handle what is demanding work.

There would also be need to complement the network of professionals familiar with the Sámi language and Sámi culture with similarly skilled support persons who could assist persons with disabilities when using welfare services. The practices seen today are scattered and temporary and based on either volunteer efforts or the occasional fee. Permanent arrangements should be established for such work and national availability of the network should be taken into account from the outset. Efforts to revitalize the culture should be extended from early childhood education and the schools to social and healthcare services and should encompass revitalization of wellbeing and enjoyment of culture for people of all ages. There is a need for culturally adequate welfare services and, in particular, culturally adequate case management for Sámi clients. Genuine implementation of equality requires that general services are readily available and to persons with disabilities as well.

- Linguistically and culturally produced services must also be professionally adequate.
- Services for persons with disabilities that are geared to revitalizing the language can also be bilingual to accommodate those whose native language is Finnish.

- Assistive devices and services should support maintenance and revitalization of the culture.
- Cultural expertise must be taken into account on the job market in terms of the education, financing and working hours required.
- Special consideration should be given to supporting the revitalizing all of the Sámi languages also in welfare services.
- Networking among professionals highly competent in the Sámi language and Sámi culture would improve opportunities to make use of and enhance the expertise available.

References

- About the project (2017) <http://www.nordicwelfare.org/sv/Projekt/Funktionshinder/Samer-med-funktionsnedsattning/About-the-project/>. Last accessed 1.9.2017.
- Aikio-Puoskari, Ulla (2014): Saamelaisopetus peruskoulusäädöksissä – Palapelin rakentamista kansallisen koulutuspolitiikan marginaalissa. In Pigga Keskitalo & Veli-Pekka Lehtola & Merja Paksuniemi (eds.) Saamelaisten kansanopetuksen ja koulunkäynnin historia Suomessa. Siirtolaisinstituutti. Tutkimuksia A 50, 214–240.
- Barnes, Marian & Peter Cotterell (eds.) (2012) Critical perspectives on user involvement. Policy Press.
- Beresford, Peter (2008) Esipuhe suomenkieliseen laitokseen. In Peter Beresdorf Peter & Markku Salo: Kokemuksen muodonmuutos. Mielenterveyden keskusliitto [Finnish Central Association for Mental Health], 9–14.
- Bombay, Amy, Kim Matheson & Hymie Anisman (2009) Intergenerational Trauma: Convergence of Multiple Processes among First Nations people in Canada. Journal of Aboriginal Health (November), 6–47.
- Buadir (2013) Slik har jeg det I dag. Rapport om levekår for mennesker med utlingshemming. Rapport 1/2013. Barne-, ungdoms og familiedirektoratet. Oslo.
- Clay, Sally with Bonnie Schell, Patrick W. Corrigan & Ruth O. Ralph (2006) On our own, together. Peer programs for people with mental health illness. Vanderbilt University Press.
- Cohen, Sheldon, Lynn G. Underwood & Benjamin H. Gottlieb (2000) Social support measurement and intervention. A guide for health and social scientists. Oxford University Press.
- Drugge, Anna-Lill (ed.) (2016) Ethics in indigenous research. Past experiences – Future Challenges. Vaartoe – Centre for Sami research. Umeå Universitet.
- Edin-Liljegren, Anette & Kia Flykt (2017) Förutsättningar och villkor för samer med funktionsnedsättning i de samiska förvaltningskommunerna i Sverige. Projektrapport. Nordens Välfärdscenter. Stockholm.
- Eriksson, Susan (2015) Poikkeavan ja normaalin performanssi – vammaisten seksuaalisuus elämäntarinoissa. In Joel Kivirauma (ed.) Vammaisten elämä & elämäkerta: tulkintoja vammaisuudesta 1900-luvun Suomessa. Kynnys ry-Threshold Association, 154–198.
- Eronen, Anne, Riitta Jauhiainen, Petri Kinnunen & Paula Tiermas (1999) MS-yhdistys apuna arjessa. Helsingin ja Uudenmaan MS-yhdistys. Sosiaali- ja terveysturvan keskusliitto [The Finnish Federation for Welfare and Health].
- Faurie, Maija (2011) Saamelainen Kelan asiakkaana. Saamelaisten oikeudet ja asema alkuperäiskansana Kelan toimeenpanemassa sosiaaliturvassa. Kelan tutkimusosasto. Sosiaali- ja terveysalan selosteita 75. Kansaneläkelaitos [Social Insurance Institution].

- Fedreheim, Gunn Elin, Line Melbøe & Kari-Anne Opsal (2017) Demokratisk deltakelse blant mennesker i en dobbel minoritetssituasjon som same og funksjonshemmet. *Norsk Statsvitenskapelig Tidsskrift* 33(3), 234–255.
- Granfelt, Riitta (2009) Syllisyyden sanoja. In Merja Laitinen & Anneli Pohjola (eds.) *Tabujen kahleet*. Vastapaino, 164–176.
- Heckathorn, Douglas D. (1997) Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. *Social Problems* 44(2), 174–199.
- Heikkilä, Lydia (2016) Welfare services in enhancing good life for the Sami: A reflection on conducting ethically responsible research and developing an improved sense of culture. *International Social Work* 59(5), 653–665.
- Heikkilä, Lydia, Elsa Laiti-Hedemäki & Anneli Pohjola (2013) *Saamelaisten hyvä elämä ja hyvinvointipalvelut*. Lapin yliopisto. Lapland University Press. University of Lapland.
- Heinämäki, Leena (2017b) Saamelaismääritelmä kansainvälisen oikeuden ja KHO:n tapausten valossa. In Heinämäki, Leena, Christina Allard, Stefan Kirchner, Alexandra Xanthaki, Sanna Valkonen, Ulf Mörkenstam & Nigel Bankes, Jacinta Ruru, Jérémie Gilbert, Per Selle, Audra Simpson, Laura Olsén (2017) *Saamelaisten oikeuksien toteutuminen: kansainvälinen vertaileva tutkimus*. Valtioneuvoston selvitys- ja tutkimustoiminnan julkaisusarja [Publications of the Government's analysis, assessment and research activities] 4/2017. Valtioneuvoston kanslia [Prime Minister's Office], 86–175.
- Heinämäki, Leena (2017a) Saamelaisten oikeudet Suomessa. In Heinämäki, Leena, Christina Allard, Stefan Kirchner, Alexandra Xanthaki, Sanna Valkonen, Ulf Mörkenstam & Nigel Bankes, Jacinta Ruru, Jérémie Gilbert, Per Selle, Audra Simpson, Laura Olsén (2017) *Saamelaisten oikeuksien toteutuminen: kansainvälinen vertaileva tutkimus*. Valtioneuvoston selvitys- ja tutkimustoiminnan julkaisusarja [Publications of the Government's analysis, assessment and research activities] 4/2017. Valtioneuvoston kanslia [Prime Minister's Office], 22–85.
- Heinämäki, Leena, Christina Allard, Stefan Kirchner, Alexandra Xanthaki, Sanna Valkonen, Ulf Mörkenstam & Nigel Bankes, Jacinta Ruru, Jérémie Gilbert, Per Selle, Audra Simpson, Laura Olsén (2017) *Saamelaisten oikeuksien toteutuminen: kansainvälinen vertaileva tutkimus*. Valtioneuvoston selvitys- ja tutkimustoiminnan julkaisusarja 4/2017. Valtioneuvoston kanslia [Prime Minister's Office].
- Herring, Sigrid, Jo Spangaro, Marlene Lauw & Lorna McNamara (2013) The intersection of Trauma, Racism, and Cultural Competence in Effective Work with Aboriginal People: Waiting for Trust. *Australian Social Work* 66(1), 104–117.
- Hokkanen, Liisa (2014) *Autetuksi tuleminen*. Valtaistavan sosiaalisen asianajon edellyttämät toimijuudet. *Acta Universitatis Lapponiensis* 278. Lapin yliopisto [University of Lapland]. Dissertation.

- Hokkanen, Liisa, Anna Nikupeteri & Merja Laitinen (2016) Individual, group and organized experiential expertise in recovery from intimate partner violence and mental health problems in Finland. *British Journal of Social Work* 47(4), 1147–1165. DOI: 10.1093/bjsw/bcw074.
- Hurtig, Johanna (2013) Taivaan taimet. Uskonnollinen yhteisöllisyys ja väkivalta. Vastapaino.
- Juutilainen, Sandra & Lydia Heikkilä (2016) Moving forward with Sami research ethics: how the dialogical process to policy development in Canada supports the course of action for the Nordic countries. In Anna-Lill Drugge (ed.) (2016) *Ethics in indigenous research. Past experiences – Future Challenges*. Vaartoe – Centre for Sami research. Umeå Universitet, 81–104.
- Järvensivu, Linda, Anneli Pohjola & Marjo Romakkaniemi (2016) Locating Sami social work in Finland: Meaning produced by social workers in working with Sami people. *International Social Work* 59(5), 600–613.
- Järvikoski, Aila (1994) Vajaakuntoisuudesta elämänhallintaan? Kuntoutuksen viitekehyksen ja toimintamallien tarkastelua. Kuntoutussäätiön tutkimuksia 46/1994. Kuntoutussäätiö [Rehabilitation Foundation]. Dissertation.
- Järvikoski, Aila, Liisa Hokkanen & Kristiina Härkäpää (eds.) (2009) *Asiakkaan äänellä. Odotuksia ja arvioita vaikeavammaisten lääkinnällisestä kuntoutuksesta*. Tutkimuksia 80. Kuntoutussäätiö [Rehabilitation Foundation].
- King, J. A., M. Brough & M. Knox (2014) Negotiating disability and colonization: the lived experience of Indigenous Australians with a disability. *Disability & Society* 29(5), 738–750.
- Kinnunen, Oskari & Henri Kitti (2013) Saamelaiden kielellisten oikeuksien toteutuminen Lapin sairaanhoitopiirissä. Opinnäytetyö. Rovaniemen ammattikorkeakoulu [Lapland University of Applied Sciences].
- Kinnunen, Petri (1998) Hyvinvoinnin ruletti. Tutkimus sosiaalisen tuen verkostojen jäsentymisestä 1990-luvun lopun Suomessa. *Acta Universitatis Lapponiensis* 20. Lapin yliopisto [University of Lapland]. Dissertation.
- Kivistö, Mari (2014) Kolme ja yksi kuvaa osallisuuteen. Monimenetelmällinen tutkimus vaikeavammaisten ihmisten osallisuudesta toimintana, kokemuksena ja kielenkäyttönä. *Acta Universitatis Lapponiensis* 283. Lapin yliopisto [University of Lapland]. Dissertation.
- Klem, Simo (2011) Vammaisten henkilöiden asema välityömarkkinoilla. Loppuraportti. ASKEL-hanke. VATES-säätiö.
- Kumpusalo, Esko (1991) Sosiaalinen tuki, huolenpito ja terveys. Raportteja 8/1991. Sosiaali- ja terveyshallitus.
- Kuokkanen, Rauna (2004) Saamelaisnaiset, feministinen analyysi ja saamelaisyhteiskunnan dekolonisaatio. In Kaarina Kailo, Vappu Sunnari & Heidi Vuori (eds.) *Tasa-arvon haasteita globaalin ja lokaalin rajapinnoilla*. *Northern Gender Studies* 5. University of Oulu and Lapland, 143–159.

- Könkkölä, Kalle & Heii Saraste (1996) *The world became my room*. Werner Söderström Osakeyhtiö.
- Lehtola, Riitta & Pia Ruotsala (2017) *Saamenkielisten palveluiden nykytilakartoitus. Saamelaisten lasten-, nuorten ja perheiden palvelut. Saamelaiskäräjät [Sámi Parliament]. Pohjois-Suomen sosiaalialan osaamiskeskuksen Saamen yksikkö.*
- Magga, Ristenrauna (1997) *Geas diedu, Gos doarjaga. Saamelaisten vammaisten, vanhusten ja pitkäaikaissairaiden Tiedotus- ja tutkimusprojektin loppuraportti. Sámediggi–Saamelaiskäräjät. Kynnys ry.*
- Martin, Marjatta (2016) *Nuoruus, vammaisuus ja kuntoutuksen merkitys. Acta Universitatis Lapponiensis 328. Lapin yliopisto [University of Lapland]. Dissertation.*
- Melbøe, Line, Bjørn-Eirik Johnsen, Gunn Elin Fredreheim & Ketil Lenert Hansen (2016) *Situasjonen til samer med funksjonsnedsettelse. Nordens Velfærdscenter. Stockholm.*
- Melbøe, Line, Ketil Lenert Hansen, Bjørn-Eirik Johnsen, Gunn Elin Fedreheim, Tone Dinesen, Gunn-Tove Minde & Marit Rustad (2016) *Ethical and methodological issues in research with Sami experiencing disability. International Journal of Circumpolar Health 75(1). DOI: 10.3402/ijch.v75.31656.*
- Metteri, Anna (2012) *Hyvinvointivaltion lupaukset, kohtuuttomat tapaukset ja sosiaalityö. Acta Universitatis Tampereensis 1779. Tampereen yliopisto [University of Tampere]. Dissertation.*
- Miettunen, Tuuli (2013) *Saamelaiset kansaneläkeläiset toimeentulojärjestelmän reunamailla. In Ilpo Airio (ed.) Toimeentuloturvan verkkoa kokemassa. Kansalaisten käsitykset ja odotukset. Kelan tutkimusosasto. Kansaneläkelaitos [Social Insurance Institution], 168–178.*
- Mikkonen, Enni, Merja Laitinen & Cath Hill (2016) *Hierarchies of knowledge: Analyzing inequalities within the social work ethnographic research process as ethical notions in knowledge production. Qualitative Social Work. On line first DOI: 10.1177/1473325016629542.*
- Nevala, Nina, Irmeli Pehkonen, Antti Teittinen, Hannu T. Vesala, Pia Pörfors & Heidi Anttila (2017) *Kuntoutuksen vaikuttavuus kehitysvammaisten henkilöiden toimintakykyyn ja työelämään osallistumiseen sekä työllistymistä estävät ja edistävät tekijät: järjestelmällinen kirjallisuuskatsaus. Kansaneläkelaitos [Social Insurance Institution]. Finnish abstract of accepted manuscript available at http://www.kela.fi/documents/10180/3908005/Nevala_Kuntoutuksen_vaikuttavuus.pdf/bd6879a3-ac67-4783-b356-40bbd1fc4bd3. Last accessed 15.9.2017.*
- Nygård, Reidunn H. & Merete Saus (2016) *Emphasizing indigenous communities in social work research ethics. International Social Work 59(5), 666–678.*
- Nystad, Tove, Marita Melhus & Eiliv Lund (2008) *Sami speakers are less satisfied with general practitioners' services. International Journal of Circumpolar Health 67(1), 116–124.*
- Oliver, Michael (1996) *Understanding disability. From theory to practice. MacMillan Press.*

- Olsén, Laura. Personal communication. May 8. 2017.
- Olsén, Laura, Leena Heinämäki & Assi Harkoma (2017, forthcoming) The Rights and Multiple Discrimination of Minorities within Minorities: Sámi persons with disabilities and sexual and gender minorities. *Juridica Lapponica*. University of Lapland.
- Orjasniemi, Tarja (2011) The wet province – Drinking in Lapland. *Journal of Drugs: Education, Prevention & Policy* (April), 32–39. DOI: 10.3109/0987637.2011.565824.
- Peltomaa, Hanna (2013) The Only Gay in the Village? Lesbians, Gay Men and Bisexuals Living in Rural Communities in Finnish Lapland. In Seija Keskitalo-Foley, Päivi Naskali & Pälvi Rantala (eds.) *Northern Insights. Feminist Inquiries into Politics of Place, Knowledge and Agency*. Lapland University Press. Lapin Yliopisto [University of Lapland], 153–173.
- Plan for suicide prevention among the Sami people in Norway, Sweden and Finland (2017) Sami Norwegian National Unit on Mental Health and Substance Abuse (SANKS) & Saami Council.
- Pohjola, Anneli (2016) Language as a cultural mediator in social work: Supporting Sami culture with services in Sami. *International Social Work* 59(5), 640–652.
- Pohjola, Anneli (2009) Yhteenveto – Tabujen purkamisen kysymykset. In Merja Laitinen & Anneli Pohjola (eds.) *Tabujen kahleet*. Vastapaino, 247–253.
- Pohjola, Anneli, Maarit Kairala & Asta Niskala (eds.) (2017, forthcoming) *Asiakkaasta kehittäjäksi ja vaikuttajaksi – Asiakkaiden osallisuuden muutos sosiaali- ja terveystaloudissa*. Vastapaino.
- Raltala, Pälvi (2016) Näskämatic – a Sami Spinning Jenny? Sami Handicraft, the Gender System, and the Transition of Culture. In Seija Keskitalo-Foley, Päivi Naskali & Pälvi Rantala (eds.) *Northern Insights. Feminist Inquiries into Politics of Place, Knowledge and Agency*. Lapland University Press. Lapin yliopisto [University of Lapland], 102–139.
- Rantalaiho, Ulla-Maija (2006) Kun ei tule kuulluksi – lapsiperheiden vanhempien kokemuksia arjesta ja avuntarpeesta. In Liisa Hokkanen & Maritta Sauvola: *Puhumattomat paikat*. Pohjois-Suomen sosiaalialan osaamiskeskuksen julkaisuja 22, 46–77.
- Solomon, Phyllis & Phyllis Draine (2001) The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal* 25(1), 20–27.
- Somerkivi, Pirjo (2000) "Olen verkon silmässä kala". *Vammaisuus, kuntoutuminen ja selviytyminen sosiaalisen tuen verkostoissa*. Kuopion yliopisto [University of Eastern Finland]. Dissertation.
- Souto, Anne-Mari, Veronika Honkasalo & Leena Suurpää (2015) Kuuntelemista, sanoittamista ja näkyväksi tekemistä. Tutkijat kiistellyn rasmin äärellä. In Antti Häkkinen & Mikko Salasuo (eds.) *Salattu, hävetty, vaiettu. Miten tutkia piilossa olevia ilmiöitä*, 136–162. Vastapaino.
- Suikkanen, Asko, Viktor Savtschenko, Lauri Virta & Ritva Linnakangas (2006) Uuden alussa vai umpikujassa? *Vammaiset matkalla yhdenvertaiseen kansalaisuuteen*. Stakes. Raportteja 15.

- Teittinen, Antti (2017) Tabu? Katsaus kehitysvammaisten seksuaalisuuden tutkimukseen. In Hanna Kiuru & Sanna Strömbeg-Jakka (eds.) *Seksuaalisuuden tabut suljetussa yhteisöissä*. Unipress, 267–279.
- Törmä, Sinikka (2009) *Kynnyskysymyksiä: Huono-osaisimmat huumeiden käyttäjät ja matala kynnys*. Sosiaalikehitys. Hämeenlinna. Dissertation.
- Uttjek, Margaretha (2016) *Levnadsförhållanden bland samer med funktionsnedsättning i Sverige*. Nordens Välfärdscenter. Projekt rapport. Stockholm.
- Valkonen Sanna (2017) Kuvaus saamelaisen itsehallinnon kehittymisestä sekä saamelaisuuden määrittelyn ja saamelais- ja alkuperäiskansakeskustelun taustoista ja tapahtumista Suomessa. In Heinämäki, Leena, Christina Allard, Stefan Kirchner, Alexandra Xanthaki, Sanna Valkonen, Ulf Mörkenstam & Nigel Bankes, Jacinta Ruru, Jérémie Gilbert, Per Selle, Audra Simpson, Laura Olsén (2017) *Saamelaisten oikeuksien toteutuminen: kansainvälinen vertaileva tutkimus*. Valtioneuvoston selvitys- ja tutkimustoiminnan julkaisusarja [Publications of the Government's analysis, assessment and research activities] 4/2017. Valtioneuvoston kanslia [Prime Minister's Office], 176–223.
- Valkonen, Sanna & Sandra Wallenius-Korkalo (2016) Practising postcolonial intersectionality: Gender, religion and indigeneity in Sámi social work. *International Social Work* 59(5), 614–626.
- Välimaa, Aimo & Elsa Laiti-Hedemäki (eds.) (1997) *Birge ja eale dearvan*. Saamelaisten sosiaali- ja terveyspalveluprojektin loppuraportti. Sosiaali- ja terveysministeriön monisteita 25/1997. Sosiaali- ja terveysministeriö.
- Wallenius-Korkalo, Sandra (2013) *Laestadian Girls in Forbidden Fruit: Representation of Gender, Place and Agency*. In Seija Keskitalo-Foley, Päivi Naskali & Pälvi Rantala (eds.) *Northern Insights. Feminist Inquiries into Politics of Place, Knowledge and Agency*. Lapland University Press. Lapin yliopisto [University of Lapland], 174–200.
- Wikman, Minna (2000) *”Jos kaikki kuulevat osaisivat viittoaa”*. Tutkimus suomalaisten kuurojen kokemasta hyvinvoinnista. Kuurojen palvelusäätiö. Sosiaali- ja terveysturvan keskusliitto [The Finnish Federation for Welfare and Health]. Dissertation.
- Witkin, L. Stanley (2017) *Transforming Social Work*. Palgrave.
- Yhdenvertaisuusvaltuutettu (2016) *”Vammaisena olen toisen luokan kansalainen”* Selvitys vammaisten kokemasta syrjinnästä arjessa. Oikeusministeriö ja syrjinnän seurantajärjestelmä.
https://www.syrjinta.fi/documents/10181/40035/Vammaisselvitys_uusin/2506b079-2a76-4aff-ae1d-5e9728f38657. Last accessed 15.9.2017.

Appendixes

Appendix 1 The structured interview frame in North Sámi and in Finnish

Structured interview frame in North Sámi

A: DU DUOGÁŠ JA EALLINDILLI

1. Gii don leat ? Gos leat eret?

(ahki, bearaš, orrun, skuvlejupmi/bargodilli/eará doaimmaide oassálastin/birgen ja vejolaččat váddu, buozalmas/ erenomáš dárbu)

B: SÁPMELAŠVUOHTA

2. Mo don jurddašat, maid áššiide sápmelašvuohta lea váikkuhan du eallimis?

3. Mo sápmelašvuohta oidno du eallimis? (vai oidnogo?)

4. Maid sápmelašvuohta mearkkaša dutnje?

C. ÁRGABEAVI JA VEAHKEHEAPMI SIHKE ČUOLMMAID JA VÁTTISVUOĐAID ČOAVDIN

5. Makkár lea du dábálaš beaivi? Sáhtášitgo mitalit omd. du ievttá beaivvi birra?

6. Mis lea buohkain sihke buorre ja heajos beaivvit. Makkár áššit laktásit du mielas erenomáš buorre beaivái? Naba heajos beaivái?

7. Makkár áššiide dárbbášat iežat eallimis doarjaga ja veahkki? Geat veahkehit du? Mo?

8. Dalle dus go dus leamaš du eallimis čuolmmat dahje váttut, makkár čovdosiid leat gávdán?

9. Geaid don ieš doarjut dahje veahkehat?

10. Leatgo muhtumin dovdan ahte leat okto? Háliidatgo hállat das eambbo.

D. VÁSÁHUSAT (ALMMOLAŠ) BÁLVALUSAIN JA VEAHKIS

11. Makkár bálvalusaid geavahat iežat árgabeaivvis? (almmolaš/gieldda/priváhtta)

Makkár vásáhusat dus leat bálvalusain?

(Huomioiden, mitä aiemmin on tullut esiin: veahkkeneavvut, fysio/doaibma/hállan/luondu/psyko/ dahje eará terapiija, bargonávccaid árvoštallan/ bargoiskadeapmi/ veajuiduhtti bargodoaibma/ bargui bagadeapmi dahje eará heivehuvvon bargu, veajuiduhttinursat, veahkkebargi, čorgen, biebmobálvalus, ruoktoveahkki, ruoktobuohccedikšun, johtin)

12. Leago dutnje goas nu dahkkon mii nu plána daid bálvalusaid ektui maid oažžut? (bálvalanplána, veajuiduhttinplána, áššehašplána, bargoohcanplána dahje mii nu eará plána mii laktása bálvalusaid oažžumii)

13. Mo gulahalat go ohcat dahje geavahat bálvalusaid? Áddetgo olbmot du? (dalle go ozat bálvalusa, dalle go mearridit bálvalusa birra, dalle rievdadit bálvalusa ja go geavahit bálvalusa)

Mo leat gávdnan bálvalusaid? Veahkehiigo soames du?

Leatgo sáhttán válljet makkár bálvalusa dahje veahkki oažžut ja mo dat ollašuvvo?

Makkár váttisvuodát dus leamaš go leat ohcan bálvalusa dahje veahki?

Leatgo ohcan veahkki, muhto it leat ožžon dan?

Leatgo háliidan váikkuhit dan veahkkái ja bálvalusaide maid leat ožžon? Leatgo beassan váikkuhit?

14. Dalle go dus leamaš lossa áiggit eallimis, leatgo háliidan háleštit geainna nu dan birra? (joatkkagažaldat: geainna? Leago fállán dutnje veahkki)

E. VEAHKKI JA DOARJJA, MAT VÁLDET SÁPMELAŠVUOĐA VUHTII, VEALAHANVÁSÁHUSAT.

15. Leatgo goas nu ožžon man nu bálvalusa sámegillii? (man, makkár vásáhusat)

Leago dus leamaš sámegiela dulkka veahkin? (mii bálvalus, vásáhusat, áddejitgo olbmot du, mii sámegielaid)

Leatgo ieš leamaš dulkonveahkin dahje doarjjaolmmožin nuppi sápmelažžii? (mii bálvalus, vásáhusat)

16. Leago sápmelašvuohta moge bohtán ovdii go leat ohcan bálvalusaid? (manin ii, vásáhusat)

17. Leago du sápmelašvuohta váldojuvvon vuhtii bálvalusain? Leago dat váikkuhan daid bálvalusaide maid leat ožžon? Sáhtášitgo mitalit, mo dat lea váldojuvvon vuhtii dahje váikkuhan bálvalusaide? Mo livččet háliidan, ahte dat livččii váldon vuhtii dahje váikkuhan bálvalusaide?

18. Makkár lea buorre bálvalusa, mii váldá sápmelašvuođa vuhtii? (almmolaččat ja iežát eallimis)

18. Leatgo vásihan vealaheami dahje givssideami bálvalusa dahje veahki oažžuma oktavuodas? Vealaheapmi.

Gii vealahii/givssidii, mo?

Naba leamašgo diekkár dilit, ahte olbmot eai lean ádden du?

F. OASSÁLASTIN SERVODATLAŠ ÁŠŠIIDE

19. Leatgo oassálastán searvedoibmii? Sáhtátgo mitalit masa ja mo?

20. Figgatgo man nu láhkai ovddidit sápmelaččaid, lámisolbmuid dahje eará sierra joavkkuid áššiid? Mo don doaimmat?

21. Man dehálažžan oainnát oassálastima servodatdoaimmaide?

G. MÁHCAHAT JEARAHALLAMIS JA VEJOLAŠVUOHTA DIEVASMAHTTIT

22. Makkár vásáhus dat jearahallan lea dutnje leamaš?

Mo dat lei earálágan go ledjet ovddalgihtii vuordán?

23. Háliidivččetgo vel lasihit dahje deattuhit maid nu dain áššiin maid birra mii leat ságastallan? (vásáhusat bálvalusain, sápmelašvuođas, váikkuheamis, veahki dahje doarjaga dárbu)

Structured interview frame in Finnish

A: TAUSTASI JA ELÄMÄNTILANTEESI

1. Kukas sinä olet? Kertoisitko aluksi itsestäsi, taustastasi ja elämäntilanteestasi

B: SAAMELAISUUDEN MERKITYS

2. Mihin asioihin sinun elämässäsi ajattelet saamelaisuuden vaikuttaneen?

3. Missä asioissa saamelaisuus näkyy elämässäsi

4. Millainen merkitys saamelaisuudella on sinulle?

C. ARKI JA AUTTAMINEN SEKÄ ONGELMIEN JA VAIKEUKSIEN RATKAISEMINEN

5. Millainen on tavallinen päiväsi? Voisitko kuvata vaikka eilistä?

6. Meillä kaikilla on hyviä ja huonoja päiviä.

- Mitä asioita liität erityisen hyvään päivään?

- Mitä asioita liität erityisen huonoon päivään?

7. Millaisissa asioissa tarvitset elämässäsi apua tai tukea?

- Ketkä sinua auttavat?

- Miten sinua autetaan?

8. Kun sinulla on ollut elämässä vammaan liittyviä ongelmia ja vaikeuksia, millaisia ratkaisuja olet löytänyt?

9. Ketä sinä itse autat tai tuet?

10. Koetko joskus tai usein olevasi yksinäinen? Haluatko kertoa siitä lisää?

D. KOKEMUKSET (JULKISISTA) PALVELUISTA JA AVUSTA

11. Millaisia palveluja (julkisia/kunnan/yksityisiä palveluja) käytät arjessasi?

- Millaisia kokemuksia sinulla on palveluista?

12. Onko sinulle joskus tehty joku suunnitelma saamaasi palveluun liittyen?

13. Miten tulet kuulluksi ja ymmärretyksi (palvelua hakiessa, siitä päätettäessä, sitä muutettaessa, palvelun kuluessa)?

- Kuinka olet löytänyt palvelut? Auttako joku sinua?

- Oletko voinut valita, millaista palvelua tai apua saat ja miten se toteutetaan?

- Millaisia vaikeuksia sinulla on palvelun tai avun saamisessa?

- Oletko hakenut jotain apua, jota et ole saanut?

- Onko sinulla ollut tarvetta vaikuttaa saamaasi apuun tai palveluun? Miten se on toteutunut?

14. Oletko saanut, onko sinulle tarjottu tai oletko halunnut keskusteluapua?

E. SAAMELAISERITYINEN AUTTAMINEN JA TUKI, SYRJINTÄKOKEMUKSET

15. Oletko joskus saanut jotain palvelua saamenkielellä?

- Oletko käyttänyt saamenkielen tulkkia palvelussa

- Oletko toiminut palveluissa tulkkiaapuna tai tukihenkilönä toiselle saamelaisella?
- 16. Onko saamelaisuus tullut esiin palveluja hakiessasi?
 - (Kyllä > Millaiset ovat kokemuksesi? En > miksi et?)
- 17. Onko saamelaisuutesi vaikuttanut tai huomioitu joskus palvelussa jollain tavalla?
 - Kertoisitko, miten se on huomioitu tai vaikuttanut palveluun?
 - Miten olisit toivonut, että se olisi huomioitu tai vaikuttanut?
- 18. Millaisista asioista muodostuu hyvä, saamelaisuuden huomioiva palvelu? (yleensä ja omakohtaisesti)
- 18. Oletko kokenut syrjintää tai kiusaamista palvelun tai avun saamisen yhteydessä?
 - Voitko kertoa kenen taholta ja miten?
 - Entä ymmärtämättömyyttä?

F. YHTEISKUNNALLINEN OSALLISTUMINEN

- 19. Osallistutko (tai oletko osallistunut) johonkin yhdistystoimintaan?
 - Voitko kertoa mihin, miten?
- 20. Pyritkö jotenkin muuten edistämään saamelaisten, vammaisten tai muiden erityisryhmien asiaa?
 - Miten toimit?
- 21. Kuinka tärkeänä näet yhteiskunnallisen osallistumisen?

G. PALAUTE HAASTATTELUSTA JA MAHDOLLISUUS TÄYDENTÄÄ

- 22. Millainen kokemus haastattelutilanne on sinulle ollut?
 - Miten tämä tilanne oli erilainen kuin etukäteen odotit?
- 23. Haluaisitko vielä lisätä tai korostaa jotain, asioista joista olemme keskustelleet? (kokemuksesi palveluista, saamelaisuudesta tai vaikuttamisesta, omakohtainen saamelaisuutesi, avun tai tuen tarpeeseesi)

Appendix 2 The themes for narrative-oriented interviews in Finnish

TAUSTASI JA ELÄMÄNTILANTEESI

SAAMELAISUUDEN MERKITYS

AUTTAMINEN JA AVUN TARVE ELÄMÄSSÄ

ONGELMIEN JA VAIKEUKSIEN RATKAISEMINEN

KOKEMUKSET PALVELUISTA

SAAMELAISERITYISYYS PALVELUSSA

SYRJINTÄKOKEMUKSET

YHTEISKUNNALLINEN OSALLISTUMINEN JA OSALLISUUDEN KOKEMUS

PALAUTE HAASTATTELUSTA

Appendix 3 The bulletin in North Sámi and in Finnish

Leatgo beroštuvvan oassálastit sámi doaibmahehttejuvvon olbmuid sajadaga ja vásáhusaid guoskevaš dutkamuššii?

Mii dutkat Lappi universitehtas sámi doaibmahehttejuvvon olbmuid vásáhusaid eallimis doaibmahehttejumiiguin, sápmelašvuodas, veahkeheamis ja oassálasvuodas ja das, mo dat áššit laktásit dasa, mo olbmot geavahit bálvalusaid. Ulbmilin lea čielggadit, mo doaibmahehttejuvvon ja sámi olbmuid vuoigatvuođat ollašuvvet geavatlaččat. Mii ohcat dutkanjearahallamiid várás sápmelaččaid, geat háliidit mitalit sin vásáhusaid ja oainnuid birra.

Dutkamušas ii leat mearkkašupmi, makkár doaibmahehttejupmi dus lea. Dat sáhtta leat rupmaša, miela, áiccu dahje neuropsykiatralaš váddu dahje diekkár dilli, mii váikkuha du doaibmanávccaide dahje oasálašvuhtii.

Dat dutkanprošeakta lea Suoma bealde ollašuhtti oassi davviriikkalaš prošeavttas **"The Study about participation and social inclusion of the Sámi with disabilities in Finland"** (1.11.2016-31.8.2017). Dan kordinere Nordens Välfärdcenter. Dutkamuša vástolaš jodiheaddji lea sosiálabarggu professor Anneli Pohjola. Jearahallamiid barget dutki Elsa Laiti-Hedemäki ja universitehtalektor Liisa Hokkanen, geaid lassin prošeavtta dutkanjovkui gullá dutki Lydia Heikkilä. Jearahallojuvvon olmmoš sáhtta ieš válljet, leago jearahallama giella suomagiella vai sámegiella. Jearahallama geavahit dušše dutkamuša várás.

Jearahallama ollašuhttin

Jearahallan ollašuhitto friija ságastallamin. Jearahallojuvvon olbmui soahpat sierra, man giela ságastallamis geavahuvvo, gii jearahallá, goas ja gos. Davvisámegillii jearahallá Elsa Laiti-Hedemäki ja suomagillii Liisa Hokkanen. Ságastallan báddejuvvo vai dat seailu nu eaktin go vejolaš. Ságastallama guhkodat lea gitta das, maid áššiid jearahallojuvvon olmmoš buktá ovdan. Dasa lea buorre várret guovtte diimmu.

Dutkanmateriála giedahallamis ja seailuheamis čuovvut dutkanehtalaš rávvagiid. Buohkain, geat giedahallet materiála, lea jávohisvuoda geatnegasvuohta dain áššiin, mat dahket vejolažžan dovdat olbmuid. Dutkanraporttat čállojuvvot diekkár hámis, ahte ovttaskas olbmuid ii sáhte dovdat.

Váldde roahkadit oktavuoda midjiide vai oaččut lassedieđuid ja sáhttit soahpat jearahallama birra.

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Oletko kiinnostunut osallistumaan saamelaisten vammaisten asemaa ja kokemuksia koskevaan tutkimukseen?

Teemme Lapin yliopistossa tutkimusta, jossa selvitetään saamelaisten vammaisten henkilöiden kokemuksia saamelaisuudesta, vammaisuudesta, auttamisesta ja osallisuudesta sekä niiden yhteyksistä palveluiden käyttöön. Tarkoitus on kartoittaa, kuinka vammaisten ja saamelaisten oikeudet toteutuvat käytännössä. Etsimme tutkimushaastatteluihin saamelaisia, jotka haluavat kertoa kokemuksistaan ja näkemyksistään. Vammaisuutta emme ole rajanneet vamman laadun tai lainsäädännön mukaan. Kyse voi olla fyysisestä, psyykkisestä tai älyllisestä vammasta, aistivammasta, neuropsykiatrisesta oireesta tai muusta vastaavasta tilanteesta, jolla koet olevan vaikutusta toimintakykyysi tai osallisuuteesi.

Suomessa toteutettava tutkimushanke **"The Study about participation and social inclusion of the Sámi with disabilities in Finland"** (1.11.2016-31.8.2017) on osa Norjassa, Ruotsissa ja Suomessa toteutettavaa tutkimuskokonaisuutta, jota koordinoi Nordens Välfärdscenter. Tutkimuksen vastuullinen johtaja on sosiaalityön professori Anneli Pohjola. Tutkimushaastattelut tekevät tutkija Elsa Laiti-Hedemäki ja yliopistonlehtori Liisa Hokkanen, joiden lisäksi hankkeen tutkimusryhmään kuuluu tutkija Lydia Heikkilä. Haastateltava voi valita keskustelukieleksi pohjoissaamen tai suomen. Haastattelua käytetään vain tutkimustarkoitukseen.

Haastattelun toteutus

Haastattelu toteutetaan vapaasti keskustellen. Keskustelun kieli, haastattelijä, aika ja paikka sovitaan haastateltavan kanssa hänen tilanteeseensa sopivasti. Pohjoissaamenkielinen haastattelijä on Elsa Laiti-Hedemäki ja suomenkielinen Liisa Hokkanen. Keskustelu nauhoitetaan, jotta tilanne tallentuu mahdollisimman aitona. Keskustelun kesto riippuu haastateltavan esiin tuomista asioista. Siihen on hyvä varata kaksi tuntia.

Tutkimusaineiston käsittelyssä ja säilyttämisessä noudatetaan tutkimuseettisiä ohjeita. Kaikki aineistoa käsittelevät ihmiset ovat salassapitovelvollisia aineiston sisältämistä

tunnistamisen mahdollistavista tiedoista. Tutkimusraportit kirjoitetaan sellaisessa muodossa, että yksittäiset vastaajat eivät ole tunnistettavissa.

Ota rohkeasti yhteyttä meihin haastattelun toteutukseen liittyvistä asioista sopimiseksi sekä halutessasi lisätietoja tutkimuksesta.

Ystävällisin terveisin

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Appendix 4 The interviewee agreement in North Sámi and in Finnish

SOAHPAMUŠ JEARAHALLANMATERIÁLA GEAVAHEAMIS DUTKANMATERIÁLAN

Addán lobi dasa, ahte mu jearahallama, mii guoská sámi doaibmahehttejuvvon olbmuid árgabeaivvi ja sajadaga, oažžu geavahit dutkamuššii Lappi universitehta dutkanprošeavttas "***The Study about participation and social inclusion of the Sámi with disabilities in Finland / Selvitys saamelaisten vammaisten henkilöiden osallisuudesta, 2017***". Dutkamuš lea oassi davviriikkalaš Nordens Välfärdscentera kordineren dutkanprošeavtta "*Personer med funktionsnedsattningar med samisk bakgrund*".

Lassin jearahallanmateriála geavahuvvo guovtte Lappi universitehta prošeavtta analyseremis: "***SÁRA - Saamelaisten hyvinvointi ja yhdenvertaisuus***" (2015-2018) ja "***VamO - Osallisuuden varmistaminen ja syrjäytymisen ehkäiseminen vammaissosiaalityön asiakasprosesseissa***" (2016-2019). Jearahallanmateriála anonymiserejuvvo nu, ahte olbmuid ii sáhte dovdat. Prošeavttain ovttasbargguin geahččalit čiekŋudit gova sámi doaibmahehttejuvvon olbmuid árgabeaivvi guoskevaš erenomáš gažaldagain ja veahkehit buoridit sin sajadaga bálvalusain.

Prošeavttaid vásttolaš jođiheaddjin doaibmá professor Anneli Pohjola ja sámi doaibmahehttejuvvon olbmuid prošeavtta geavatlaš ollašuhttimis vástideaba Liisa Hokkanen, Elsa Laiti-Hedemäki ja Lydia Heikkilä. Lassediđuid dutkanprošeavttain addiba Elsa Laiti Hedemäki (tel. 040 484 4162) ja Liisa Hokkanen (tel. 040 484 4242).

Jearahallanmateriála gieđahallamis ja seailluheamis čuovvut heaggadiehtolága geavádagaid, mat gusket hearkkes áššiid gieđahallama. Dutkamušas čuovvut dutkanehtalaš rávvagiid ja ollašuhttit eamiálbmogiid dutkanehtalaš rávvagiid. Dutkanmateriála geavahuvvo nu mo registtarčilgehusas lea govviduvvon ja dan gieđahallat dat dutkit, geat leat čilgehusas namuhuvvon (registtarčilgehus mielddusin). Báddit čállojuvvojit girjjálaš hápmái ja sámegielat materiála jorgaluvvo suomagillii. Buohkain, geat gieđahallet jearahallanmateriála, lea jávohisvuohtageatnegasvuohhta.

Materiála geavahuvvo ovdal máinnašuvvon prošeavttaid dutkamušaide, mat čuvvot prošeavttaid dutkanplánaid ja bohtosat almmustahttet raporttain ja dieđalaš artihkkaliin. Raporttat ja artihkkalat čállojuvvo dakkár hámis, ahte ovttaskas vástideaddji ii sáhte dovdat njuolga iige eahtenjuolgat ja dutkit fuolahit, ahte dutkamuš ii stigmatisere sápmelaččaid álbmogin. Dutkanmateriála seailluhuvvo Lappi

universitehtas. Jearahallojuvvon olbmos lea vejolašvuohta gaskkalduhttit jearahallama ja ráddjet, mo jearahallama geavahuvvo.

Vuollin čállojuvvot erenomáš doaivagiid ja dárkkástusaid, mat gusket soahpamuša. Ovdamearka dihte mo jearahallama oažžu geavahit ja seailuhit.

Beaivemearri: _____ (Deavdit guovtte stuhka: okta
jearahallojuvvon olbmui ja nubbi dutkanprošektii)

Vuolláičállosat: _____
Jearahallojuvvon olmmoš Jearahalli

Nama čielggadus: _____

SOPIMUS HAASTATTELUAINEISTON KÄYTÖSTÄ TUTKIMUSAINEISTONA

Annan suostumukseni siihen, että saamelaisten vammaisten arkea ja asemaa koskevan haastatteluni aineistoa käytetään tutkimustarkoitukseen Lapin yliopistossa toteutettavassa tutkimushankkeessa: *"The Study about participation and social inclusion of the Sámi with disabilities in Finland / Selvitys saamelaisten vammaisten henkilöiden osallisuudesta, 2017"*. Tutkimus on osa pohjoismaista Nordens Välfärdscenterin koordinoimaa pohjoismaista tutkimushanketta *"Personer med funktionsnedsattningar med samisk bakgrund"*.

Lisäksi haastatteluaineistoa käytetään kahden Lapin yliopistossa hankkeen analyyseissä: *"SÁRA - Saamelaisten hyvinvointi ja yhdenvertaisuus"* (2015-2018) ja *"VamO - Osallisuuden varmistaminen ja syrjäytymisen ehkäiseminen vammaissosiaalityön asiakasprosesseissa"* (2016-2019). Haastatteluaineisto anonymisoidaan siten, että henkilöitä ei voida tunnistaa. Hankkeiden yhteistyön avulla pyritään syventämään kuvaa saamelaisten vammaisten arkea koskevista erityiskysymyksistä ja edesauttamaan heidän asemansa parantamista palvelujärjestelmässä.

Hankkeiden vastuullisena johtajana toimii professori Anneli Pohjola ja saamelaisten vammaisten hankkeen käytännön toteutuksesta vastaavat Liisa Hokkanen, Elsa Laiti-Hedemäki ja Lydia Heikkilä. Lisätietoja tutkimushankkeista saa Elsa Laiti-Hedemäeltä (p. 040 484 4162) ja Liisa Hokkaselta (p. 040 484 4242).

Haastatteluaineiston käsittelyssä ja säilyttämisessä noudatetaan henkilötietolain mukaisia tietosuojakäytäntöjä, jotka koskevat arkaluonteisten asioiden käsittelyä. Tutkimustoiminnassa noudatetaan tutkimuseettisiä ohjeita ja sovelletaan alkuperäiskansan tutkimuseettisiä käytäntöjä. Aineiston käsittely tapahtuu rekisteriselosteessa kuvatuilla tavoilla ja siinä mainittujen tutkijoiden toimesta (rekisteriseloste liitteenä). Nauhoitteet kirjoitetaan kirjalliseen muotoon ja saamenkielinen aineisto käännetään suomen kielelle. Kaikki haastatteluaineistoa käsittelevät henkilöt ovat salassapitovelvollisia.

Aineistoa käytetään yllämainittujen hankkeiden tutkimussuunnitelmien mukaisten tutkimusten tekoon ja tutkimustulokset julkaistaan raporteina sekä tieteellisinä artikkeleina. Aineistosta tuotetut julkaisut kirjoitetaan sellaisessa muodossa, että yksittäiset vastaajat eivät ole suoraan tai välillisesti tunnistettavissa ja huolehditaan, että saamelaiset eivät leimaannu kansanryhmänä. Tutkimusaineisto säilytetään Lapin yliopistossa. Haastateltavalla on mahdollisuus keskeyttää haastattelu tai rajoittaa haastattelun käyttöä.

Alapuolisille riveille kirjataan sopimusta koskevat erityistoiveet tai tarkennukset esimerkiksi haastattelun käyttöön tai säilytykseen liittyen.

Päiväys: _____ (Täytetään kaksi kappaletta: haastateltavalle ja hankkeelle)

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