UNIVERSITY OF SOUTHERN DENMARK

PhD Thesis

Towards Roma Empowerment and Social Inclusion Through Work-Integrated Learning

Kristine Crondahl
Unit for Health Promotion Research

Faculty of Health Sciences
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In memory of my dearest grandmother and grandfather, Ellen and Odd Husvik who unfortunately did not live long enough to see me fulfil this dream.

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There is an old Romani proverb saying that "Ako mangeja te vazde jek planina korkori tegani ka pere ama ako sijen pobut dzene so dena vast jekh jekhe ytegani tumen ka vazden i planina." Meaning: "If you want to lift a mountain on your own you will fail, but if you are more people then you will succeed. "

The realization of this PhD thesis has been a journey and a memory for life. The journey has not always been easy, but it has always been worth it. Just like the Romani proverb says, I would never have succeeded with this journey without the help, support and engagement of some significant, marvellous people. Some has been involved throughout the whole time, and some have come and gone naturally. I would like to express gratitude to all the people who have crossed my road during this magnificent and developing journey. A special gratitude goes to all the Roma people who in one way or another have been participating in the project; through interviews, workshops, courses, different project activities or just through dialogues and discussions. Thank you for trusting in me and for giving me a glimpse of your life!

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PREAMBLE

It was a warm and nice spring day somewhere in West Sweden. The sun was shining and the birds were singing happily. As we were standing in the middle of the local square looking for a lunch restaurant, one of my colleagues pointed at a restaurant and said "I know for sure that we cannot go to that restaurant". "Why is that?" we wondered? "Because, I went there once with my husband and our kids, but we were thrown out. We were not allowed to eat there." We were chocked and replied that that was some years ago, surely they would let her in this time. So we decided to give it another try and entered the restaurant. Some minutes later we left the restaurant. Just like she had said, my colleague was not allowed to eat there. As the restaurant manager said: "People like you are not welcome here! Gypsy people like you! All you do is to make trouble". However, the restaurant manager admitted she had never seen my colleague before…

Unfortunately, this is not just a single happening, but everyday incidents in Roma peoples' lives. And if this incident was not enough, the Swedish Equality Ombudsman rejected the report as they get too many reports of this kind!

My journey to a PhD started with my master thesis in 2008. In the preamble I wrote:

Before this study my knowledge of Roma people was non-existent. I hardly even knew that Roma and Gypsy were the same thing. When I am sitting here today, it is with a totally new perspective of Roma people and of minority populations on the whole.

These lines have given me and my main supervisor many laughs, yet it is very much true. This journey has not just provided me a new perspective of Roma people and of minority populations, but a whole new perspective of life and the world that we are living in. This PhD thesis is about Roma people. But it could just as well be about any other minority group.

The PhD thesis is based on a 3-year health promotion project carried out in four local settings in West Sweden 2009-2012.

ABSTRACT

The Roma people are the largest ethnic minority group in the EU and all over, they have been subject to prejudice, stigma, discrimination and oppression. Thus, Roma are the most economically and socially excluded and marginalized group in Europe. The Roma living in Sweden are no exception; many are on the margins of society and face problems of social exclusion, institutional discrimination, low education, unemployment, and poor objective health. The Roma have been treated as a helpless group in need of "expert" help and action from the authorities. They have usually not been permitted to actively participate in adjusting efforts to their needs and situation. An alternative approach to the Roma situation is to allow the Roma to take the leading role and to initiate processes and activities concerning the group. These were the foundations for the 3-year health promotion project based on participatory action research (PAR) initiated in West Sweden in 2009. Through work-integrated learning (WIL) and the principle of training the trainers, the purpose of the programme was to strengthen Roma empowerment and participation in society, enabling Roma-led integration. The overall aim of the PhD thesis was to analyse and elaborate a WIL model to be applied in empowerment and adult education for the Roma minority- and other vulnerable groups in similar situation. The thesis is based on five papers:

Paper 1 aimed to examine how 14 Roma adolescents in West Sweden perceive the concepts of health, well-being and quality of life, and further, to investigate the degree to which they consider themselves able to cope with their own life situation within these areas. The data, comprising six interviews, was analysed through qualitative content analysis. The most common understanding of health and well-being was to feel good, secure, happy and having a wide social network of family and friends. Health and well-being were considered in a collective perspective, thus controversy earlier studies, the respondents perceived their health and well-being to be good. Freedom, independency, education and employment were the most important elements of QoL. Social support was the most frequently used coping strategy.

The Roma adolescents preferred the tight relationship within the Roma community and associated mostly with Roma, a phenomenon previously referred to as homophily. The process of homophily seemed to be a salutogenic factor and a general resistant resource of the Roma adolescents and hence health-enhancing. Homophily was suggested as a determinant factor of health.

Paper 2 aimed to explore how Roma people in West Sweden understand health, well-being, and quality of life, and how they cope with their life-situation. The data, consisting of 27 interviews (n = 33), were analysed qualitatively using a phenomenological hermeneutic approach. The findings indicated that the respondents perceived health as a resource and an ability to self-manage. Crucial elements of the respondents' health perception were being employed, having an education, social support from family and friends, freedom and security, and involvement in society. The findings demonstrated that the respondents perceived their health and life situation as good, despite being marginalized and discriminated. A possible explanation to this is what the respondents described as survival strategies. As a result of decenniums of oppression, the Roma have developed survival strategies helping them to cope with the situation and to survive.

Paper 3 aimed to analyse whether there is connection between health literacy and empowerment. The paper is based on a literature search conducted in December 2013. Of the total 303 initial hits, no articles primarily addressing the issue were found; yet five articles were identified taking up on both health literacy and empowerment, hence reviewed in more detail. The five articles acknowledged a nexus between health literacy and empowerment, though the nexus itself was never discussed in specific. The paper suggests that for health literacy to be critical to empowerment, the focus has to be on social determinants of health and the involved individuals', groups and/or communities perceptions on health and health needs defined by themselves. Such a perspective will build on the genuine needs of the people in concern. The paper proposes functional- and interactive health literacy as another way to label capacity building for health and empowerment, and critical health literacy as a way to describe empowerment. Hence, health literacy might be regarded as a tool for empowerment. Health

literacy is considered not to automatically lead to empowerment. Health literacy as such might be increased by health education. Crucial for empowerment is to achieve the critical level of health literacy including an ability to question the prevailing power relations and societal conditions and reflecting on these, a strengthened sense of power, self-esteem and self-efficacy and an ability to utilize these resources to engage in social and political action for change.

Paper 4 aimed to explore how participatory action research (PAR) and work integrated learning (WIL) might function as empowering tools in the Roma inclusion process and to propose a working model to use in empowerment of the Roma minority- and other vulnerable groups in similar situation. The data were collected and produced continuously during the project and consisted of interviews, self-evaluation reports and written essays by the seven Roma participants, participatory observations, research groups' workshop notes, 21 monthly project reports, the project plan, syllabus of the WIL training programme and notes from a joint planning workshop. The data were considered as a whole and analysed in a triangulating fashion using hermeneutical understanding inspired by heuristic research. Through improved abilities to mobilise the local Roma community for social change, the participants' critical health literacy improved, allowing them to experience a greater control over their own lives and integration processes. The results indicate an increased empowerment of the local coordinators indicating that WIL may be a worthwhile approach in strengthening the individual empowerment of Roma people. Based on the findings, health literacy was suggested as a catalyst in the empowerment process, serving as a tool for analyzing and describing the process of empowerment.

Paper 5 aimed to analyse the health promotion project from the Roma participants' perspective. The focus was on the participants' perceived individual empowerment and perceptions on their contribution to the common good and community empowerment. The data, consisting of interviews and self-evaluation reports of the Roma participants, participatory observations, newspaper articles with interviews of the participants and 21 monthly reports, were analysed through an approach that comes closest to hermeneutical

phenomenology. The findings indicate that the WIL approach, the participating nature of the programme, and the trust and support from both the Roma and the non-Roma facilitators, were essential for the development of empowerment. Three main themes emerged portraying the participants' psychological empowerment: strengthened Roma identity, sense of power and sense of enculturated social inclusion. Sense of enculturated social inclusion demonstrated the participants "new" way of understanding social inclusion; turning social inclusion from something they feared to something they embraced. As the participants realized that social inclusion would not require them the let go of their Roma identity and culture, their Roma identity was strengthened, they became more hopeful, felt more in control and felt generally better. Despite of limited time and resources for local community directed activities, the participants perceived that improvements were achieved at the local level.

In conclusions, the findings indicate that when based on the specific health needs of the people involved, basic/functional- and interactive health literacy together comprise the same idea as capacity building for health that might lead to empowerment. What found to be essential for the Roma local coordinators development of empowerment was the combination of the WIL approach, the participatory nature of the project, the trust and support from the non-Roma facilitators and Roma colleagues, and the perception of being respected as human beings and as equals. The local coordinators empowerment consisted of strengthened Roma identity, sense of power and sense of enculturated social inclusion. This indicates that the suggested WIL model/approach, comprising a participatory approach with health literacy as a tool may be a worthwhile strategy in empowering Roma people and enhancing their self-led social inclusion process. A possible road for Roma self-led integration, hence, might be through a process of enculturated social inclusion. This may also be the case for other vulnerable groups in similar situations. Further research and interventions are needed however, in order to elaborate and verify WILs' potential and sustainability in empowering other minority- and vulnerable groups.

DANSK RESUMÉ

Romaer er den største etniske minoritetsgruppe overalt i EU og de har været genstand for fordomme, stigma, diskriminering og undertrykkelse. Derfor er romaerne den mest økonomisk og socialt ekskluderede og marginaliserede befolkningsgruppe i Europa. Romaerne, der bor i Sverige, er ingen undtagelse. Mange lever på grænsen af samfundet og har problemer med social eksklusion, institutionel diskriminering, lav uddannelsesniveau, arbejdsløshed og dårlig objektiv sundhed. Romaerne er blevet behandlet som en hjælpeløs gruppe med behov for "ekspert"-hjælp og handling fra autoriteterne. De har for det meste ikke været involveret i at deltage aktivt i at tilpasse deres behov og situation. En alternativ tilgang til roma-situationen er at tillade romaerne at tage den ledende rolle til at iværksætte processer og aktiviteter vedrørende befolkningsgruppen. Dette er grundlaget for det 3-årige empowerment-projekt baseret på en forskningstilgang kaldet Participatory Action Research (PAP) påbegyndt i det vestlige Sverige i 2009. Gennem den såkaldte Work-Integrated Learning (WIL) og princippet i at "træne trænerne" (training the trainers) var målet med programmet at styrke 'Roma empowerment' og deltagelse i samfundet ved at muliggøre roma-ledet integration. Det ordnede mål med denne ph.d.-afhandling var at analysere og gennemarbejde en 'WIL'-model til brug i empowerment og voksenuddannelse for roma-minoriteter og andre udsatte grupper i lignende situationer. Afhandlingen er baseret på fem artikler:

Artikel 1 er målrettet en undersøgelse af, hvordan 14 unga Romaere i det vestlige Sverige opfatter begreber som sundhed, trivsel og livskvalitet og en videre nøje undersøgelse af graden af hvilken, de opfatter dem selv til at kunne håndtere deres egen livssituation inden for disse områder. Datamaterialet, som omfatter seks interviews, blev analyseret ved hjælp af kvalitativ indholdsanalyse. Den mest almindelige forståelse af sundhed og trivsel var at føle sig godt tilpas, sikker, glad og have et bredt socialt netværk af familie og venner. Sundhed og trivsel med set i et samlet perspektiv, dog i kontrovers med tidligere undersøgelser, opfattede svarpersonerne deres sundhed og trivsel som god. Frihed, selvstændighed, uddannelse og beskæftigelse var de vigtigste elementer i livskvaliteten. Social støtte var den mest anvendte håndterbare strategi.

De unga romaere foretrak det tætte forhold indenfor roma-samfundet og associerede mest med romaere, hvilket er et fænomen der tidligere er refereret til som "homophily". "Homophily"-processen viste sig at være en 'salutogenetisk' faktor og et generelt modstandsvirkemiddel blandt de unge romaere og følgelig sundhedsforbedrende. "Homophily" blev foreslået som en sundhedsfaktor-determinant.

Artikel 2 undersøger, hvordan voksne roma-folk i det vestlige Sverige forstår sundhed, trivsel og livskvalitet og hvordan de håndterer deres livssituation. Dataindsamlingerne, der består af 27 interviews (n = 33), blev analyseret kvalitativt ved brug af en fænomenologisk hermeneutisk tilgang. Resultaterne indikerede, at de adspurgte opfattede sundhed som et hjælpemiddel og en mulighed for selv at kunne klare sig. Vigtige elementer i de adspurgtes sundhedsopfattelse var beskæftigelse, uddannelse, social støtte fra familie og venner, frihed og sikkerhed samt involvering i samfundet. Resultaterne påviste, at de adspurgte opfattede deres sundhed og livssituation som god, på trods af at de er marginaliserede og diskriminerede. En mulig forklaring kunne være, at de adspurgte beskrev dette som en overlevelsesstrategi. Som et resultat af årtiers undertrykkelse har romaerne udviklet en overlevelsesstrategi, der hjælper dem til at håndtere situationen og dermed overleve.

Artikel 3 analyserer en eksisterende forbindelse mellem 'Health Literacy' og empowerment. Artiklen er baseret på litteratursøgning udført i december 2013. Ud af de 303 første udfald fandtes der ingen artikler, der primært tager fat på begrebet. Dog blev der identificeret fem artikler, der omhandlede både 'Health Literacy' og empowerment, derfor blev de undersøgt mere detaljeret. De fem artikler fandt en sammenhæng mellem 'Health Literacy' og empowerment, skønt sammenfaldet aldrig blev diskuteret specifikt. Artiklen indikerer, at hvis 'Health Literacy' skal være kritisk overfor empowerment, så skal fokus være på sociale sundhedsdeterminanter og de involverede individer, grupper og/eller samfundsopfattelser omkring sundhed samt sundhed i sig selv være defineret af dem selv. Sådan et perspektiv vil bero på fælles behov af de mennesker, det drejer sig om. Artiklen foreslår funktionel og interaktiv 'Health Literacy' som en anden måde at fastsætte 'Capacity Building' i sundhed og empowerment, og kritisk 'Health Literacy' som en måde at beskrive empowerment på. Således kan 'Health Literacy' ses som et redskab til empowerment. 'Health Literacy' anses for

ikke automatisk at føre til empowerment. 'Health Literacy' som sådan kan forbedres ved sundhedsuddannelse. Vigtigt for empowerment er at opnå det kritiske niveau af 'Health Literacy', som inkluderer en mulighed for at stille spørgsmål ved de tilstedeværende magtrelationer og samfundsmæssige tilstande og ved at reflektere på disse, en styrket magtsfølelse, selvværd og tro på egne evner samt en evne til at bruge disse ressourcer i et engagement i social og politisk handling for at ændre situationen.

Artikel 4 havde til formål at undersøge, hvordan 'participatory action research' (PAR) og 'work integrated learning' (WIL) kan fungere som empowerment redskaber i romaerne integrationsproces og foreslå en arbejdsmodel til brug i empowerment af roma-minoriteten og andre udsatte grupper i en lignende situation. Dataene blev indsamlet og fremstillet kontinuerligt i løbet af projektet og bestod af interviews, selv-evalueringsrapporter og skriftlige essays af de syv roma-deltagere, participatoriske observationer, noter fra forskergruppe-workshop, 21 månedlige projektrapporter, projektplanen, pensum af WIL-træningsprogrammet og noter fra et fælles planlægningsværksted. Dataene blev betragtet som en helhed og analyseret på en trianguleringsmåde ved brug af hermeneutisk forståelse inspireret af heuristisk forskning. Gennem forbedrede evner til at mobilisere det lokale roma-samfund for social forandring, blev deltagernes kritiske 'Health Literacy' forbedret, så de oplevede en større kontrol over eget liv og integrationsprocesser. Resultaterne indikerer en øget empowerment af de lokale koordinatorer, der angiver, at WIL kan være en god måde at styrke den individuelle empowerment af romaer. På grundlag af resultaterne blev 'Health Literacy' foreslået som en katalysator i empowerment-processen, der skal tjene som et redskab til at analysere og beskrive processen med empowerment.

Artikel 5 har til formål at analysere sundhedsfremmeprogrammet fra roma-deltagernes perspektiv. Fokus var på deltagernes opfattelse af den opnåede individuelle empowerment og opfattelser omkring deres bidrag til fælles bedste ("comon good") og "community empowerment". Dataene, der består af interviews og selv-evalueringsrapporter af roma-deltagerne, individuelle observationer, avisartikler med interviews af deltagerne og 21 månedlige rapporter, blev analyseret gennem en tilgang, der kommer tættest på hermeneutisk fænomenologi. Resultaterne viser, at WIL tilgangen, den deltagende karakter af programmet

og den tillid og støtte fra både romaer og ikke-romaer facilitatorer, var afgørende for udviklingen af empowerment. Tre hovedtemaer opstod og belyste deltagernes psykologiske empowerment: styrket roma-identitet, følelse af magt og følelse af en "enculturated social inclusion". Ved følelsen af "enculturated social inclusion" viste deltagerne en "ny" måde at forstå den sociale integration; vendte social integration fra noget de frygtede, til noget de var i mødekommende overfor. Da deltagerne indså, at social integration ikke ville kræve at de skulle give slip på deres roma-identitet og kultur, blev deres roma-identitet styrket, og de blev mere håbefulde, følte sig i bedre kontrol og følte sig generelt bedre tilpas. På trods af begrænset tid og ressourcer til aktiviteter rettet mod lokalsamfundet, opfattede deltagerne, at forbedringer blev opnået på lokalt plan.

Som konklusion viser resultaterne baseret på de specifikke sundhedsmæssige behov hos de involverede, at de sammenfatter en grundlæggende/funktionel og interaktiv 'Health Literacy' som samme idé som 'capacity building' for sundheden, hvilket vil kunne føre til empowerment. Hvad der har vist sig at være afgørende for de lokale roma-koordinatorers udvikling af empowerment var kombinationen af en WIL-tilgang, deltagende tilgang til projektet, tilliden og støtten fra facilitatorer der ikke er romaer samt roma-kolleger og opfattelsen af at blive respekteret som menneske og som ligeværdig. De lokale koordinatorers empowerment bestod af styrket roma-identitet, følelse af magt og følelse af "enculturated social inclusion". Dette indikerer, at den foreslåede WIL-model/-strategi, der omfatter en deltagende tilgang med 'Health Literacy' som redskab, kan være en god strategi for romaernes empowerment og forbedre deres egen ledelse af den sociale integrationsproces. En mulighed til romaernes egen ledelse af integration kunne derfor være gennem en "enculturated social inclusion". Det samme kunne også være gældende for andre udsatte grupper i lignende situationer. Der er dog brug for yderligere forskning og interventioner for at kunne udarbejde og kontrollere potentialet og bæredygtigheden i WIL-modellen ved empowerment af andre minoriteter og sårbare grupper.

SAMMANFATTNING PÅ SVENSKA

Romer är den största etniska minoritetsgruppen i EU och överallt har de varit utsatta för fördomar, stigmatisering, diskriminering och förtryck. Romer är därmed den mest ekonomiskt- och socialt utestängda och marginaliserade grupp i Europa. Romer bosatta i Sverige är inget undantag; många lever i utkanten av samhället och konfronteras med social exkludering, institutionell diskriminering, låg utbildningsnivå, arbetslöshet och dålig objektiv hälsa. Historiskt sätt har romer behandlats som en hjälplös grupp i behov av "expert" hjälp och insatser från myndigheterna. De har oftast inte tillåtits att aktivt delta i anpassning av insatserna i enlighet med deras behov och situation. Ett alternativt tillvägagångssätt för att förbättra romers situation är att låta romer själv ta den ledande rollen och inleda processer och aktiviteter kopplade till gruppen. Detta var utgångspunkten för det 3-åriga hälsopromotionsprojekt som inleddes i Västsverige under 2009, baserat på deltagande aktionsforskning (PAR). Genom arbetsintegrerat lärande (AIL) och principen om "training the trainers" (utbildning av instruktörer) var syftet med projektet att öka romsk empowerment och delaktighet i samhället, för att möjliggöra romsk-ledd integration. Det övergripande syftet med avhandlingen var att analysera och utarbeta en AIL modell som skall kunna tillämpas i empowerment och vuxenutbildning för den romska minoriteten samt för andra utsatta grupper i liknande situation. Avhandlingen bygger på fem artiklar:

Artikel 1 syftade till att undersöka hur 14 romska ungdomar i Västsverige uppfattar begreppen hälsa, välbefinnande och livskvalitet samt att undersöka i vilken grad de anser sig hantera sin egen livssituation inom dessa områden. Data utgörs av sex intervjuer vilka analyserades genom kvalitativ innehållsanalys. Den vanligaste förståelsen av hälsa och välbefinnande var att må bra, att känna sig trygg, att vara glad samt att ha ett brett socialt nätverk av familj och vänner. Hälsa och välbefinnande sågs ur ett kollektivt perspektiv, och i motsättning till tidigare studier, uppfattade respondenterna deras hälsa och välbefinnande som bra. Frihet, självständighet, utbildning och sysselsättning uppgavs vara de viktigaste aspekterna av livskvalitet. Socialt stöd var den mest använda coping strategin.

De romska ungdomarna föredrog det täta sociala nätverket inom den romska gruppen och umgicks mest med andra romer, ett fenomen som tidigare kallats ´homophily`. Homophily processen verkade vara en salutogen faktor och en generell motståndsfaktor (general resistant resource) för de romska ungdomarna och därmed hälsofrämjande. Homophily föreslogs som en bestämningsfaktor för hälsa.

Artikel 2 syftade till att undersöka hur vuxna romer i Västsverige uppfattar hälsa, välbefinnande och livskvalitet samt hur de hanterar sin livssituation. Data, som består av 27 intervjuer (n = 33), analyserades kvalitativt med hjälp av fenomenologisk hermeneutisk metod. Resultaten visade att respondenterna upplevde hälsa som en resurs och förmåga att hantera sin situation (self-manage). Viktiga aspekter för respondenternas hälsouppfattning var att vara anställd, att ha utbildning, socialt stöd från familj och vänner, frihet och säkerhet samt att vara involverad i samhället. Resultaten visade att respondenterna uppfattade sin hälsa och livssituation som bra, trots upplevelser av marginalisering och diskriminering. En möjlig förklaring till detta ligger i vad respondenterna beskrev som överlevnadsstrategier. Som ett resultat av decennier av förtryck, har romer utvecklat olika överlevnadsstrategier för att kunna hantera situationen och att överleva.

Artikel 3 syftade till att analysera huruvida det finns ett samband mellan health literacy och empowerment. Artikeln är baserad på ett litteratursök genomfört i december 2013. Bland de totalt 303 initiala träffarna hittades inga artiklar som behandlade denna fråga specifikt. Fem artiklar kunde dock identifieras som tog upp både health literacy och empowerment, vilka granskades mer i detalj. De fem artiklarna erkände alla ett samband mellan health literacy och empowerment, även om sambandet i sig aldrig diskuterades specifikt. I föreliggande artikel föreslås att för att health literacy skall vara nödvändigt för empowerment, måste fokus ligga på hälsans sociala bestämningsfaktorer och individernas, gruppernas och/eller samhällens egna uppfattningar om hälsa och deras egendefinierade hälsobehov. Ett sådant perspektiv kommer att bygga på de involverade människornas verkliga behov. I artikeln föreslås vidare basal/funktionell (basic/functional) och kommunikativ/interaktiv (communicative/interactive) health literacy som ett sätt att benämna kapacitetsutveckling för hälsa och empowerment (capacity building for health and empowerment), och kritisk (critical) health literacy som ett

sätt att beskriva empowerment. Health literacy kan därmed ses som ett verktyg för empowerment. Health literacy anses inte automatiskt leda till empowerment. Health literacy som sådan skulle kunna ökas med hälsoutbildning. Avgörande för empowerment är att uppnå en nivå av kritisk health literacy inklusive en förmåga att ifrågasätta rådande maktrelationer och samhälleliga förhållanden samt att reflektera över dessa, en stärkt känsla av makt, självkänsla och självtillit samt förmågan att använda dessa resurser för att engagera sig i social och politisk handling för förändring.

Artikel 4 syftade till att undersöka hur deltagande aktionsforskning (PAR) och arbetsintegrerat lärande (AIL) kan fungera som verktyg för empowerment i den romska inkluderingsprocessen. Och baserat på detta, att föreslå en arbetsmodell som skall kunna användas för empowerment av den romska minoritetsgruppen och andra utsatta grupper i liknande situation. Data samlades in och producerades kontinuerligt under projektet och bestod av intervjuer, självutvärderingsrapporter och skriftliga essäer skrivna av de sju romska deltagarna, deltagande observationer, anteckningar från forskningsgruppens workshop, 21 månatliga projektrapporter, projektplan, AIL utbildningsprogrammets kursplaner samt anteckningar från en gemensam planerings workshop. All data betraktades som en helhet och analyserades triangulerande med hermeneutisk förståelse inspirerad av heuristisk forskning. Som ett resultat av deltagarnas förbättrade förmåga att mobilisera det lokala romska samhället för social förändring, stärktes även deltagarnas kritiska health literacy varpå de upplevde sig ha större kontroll över sina egna liv och integrationsprocesser. Resultatet tyder på ökad empowerment bland deltagarna vilket indikerar att AIL kan vara ett värdefullt tillvägagångssätt för att stärka individuell romsk empowerment. Baserat på resultaten förslås health literacy som en katalysator, ett verktyg för att analysera och beskriva empowermentprocessen.

Artikel 5 syftade till att analysera empowermentprojektet från de sju romska deltagarnas perspektiv. Fokus låg på deltagarnas upplevda individuella empowerment och uppfattning av hur de har bidragit till att förbättra det lokala romska samhällets situation i allmänhet ("common good") samt community empowerment. Data som består av intervjuer och självutvärderingsrapporter av de romska projektdeltagarna, deltagande observationer, tidningsartiklar med intervjuer av deltagarna och 21 månadsrapporter, analyserades genom

vad som kommer närmast hermeneutisk fenomenologi. Resultaten tyder på att AIL som arbetsmetod, projektets deltagande karaktär samt förtroende och stöd från både romer och de icke-romska handledarna var avgörande för utvecklingen av empowerment. Tre huvudteman framkom vilka tydliggjorde deltagarnas (psychological) empowerment: stärkt romsk identitet, känsla av makt och känsla av "enculturated social inclusion". Känsla av enculturated social inclusion demonstrerade deltagarnas "nya" sätt att förstå social inkludering, och vände social inkludering från något de fruktade till något de välkomnade. När deltagarna insåg att social inkludering inte kräver att de skall släppa taget om sin romska identitet och kultur, stärktes deras känsla av romsk identitet, de blev mer hoppfulla, kände sig mer i kontroll och mådde generellt bättre. Trots begränsad tid och resurser för aktiviteter riktade mot det romska lokalsamhället, upplevde deltagarna att viss förbättring uppnåddes även här.

För att konkludera, resultaten indikerar att när fokus ligger på den deltagande gruppens specifika hälsobehov, utgör basal/funktionell och kommunikativ/interaktiv health literacy tillsammans samma idé som kapacitetsuppbyggnad för hälsa (capacity building for health) vilket kan leda till empowerment. Vad som visades vara nödvändigt för de romska lokala koordinatorernas utveckling av empowerment var kombinationen av AIL, projektets deltagande karaktär, förtroende och stöd från de icke-romska handledarna och romska kollegor samt upplevelsen av att vara respekterad som människa och som jämlikar. De lokala koordinatorernas empowerment bestod av stärkt romsk identitet, känsla av makt och känsla av enculturated social inclusion. Detta indikerar att den föreslagna AIL modellen/tillvägagångssättet, bestående av delaktighet och health literacy som verktyg, kan vara en värdefull strategi för romsk empowerment och främjandet av en romsk självstyrd process för social inkludering. En möjlig väg för romsk självledd integration kan därmed gå genom en process av enculturated social inclusion. Detta kan också vara fallet för andra utsatta grupper i liknande situationer.

Det behövs ytterligare forskning och interventioner dock för att utarbeta och verifiera AILs potential och hållbarhet när det kommer till empowerment av andra minoritets- och utsatta grupper.

LIST OF ORIGINAL PUBLICATIONS

1. Crondahl, Kristine and Eklund, Leena. (2012). Perceptions on health, well-being and quality of life of Balkan Roma adolescents in West Sweden. *Romani Studies* 22: 153-174.

2. Eklund Karlsson, Leena; Crondahl, Kristine; Andersson, Åsa and Sunnemark, Fredrik (2013). The meaning of health, well-being, and quality of life perceived by Roma people in West Sweden. *Societies* 3: 243-260.

3. Crondahl, Kristine and Eklund Karlsson, Leena. The nexus between health literacy and empowerment (Submitted).

4. Crondahl, Kristine; Ringsberg, Karin and Eklund Karlsson, Leena (2014). Work-integrated learning and health literacy - catalysts for Roma empowerment and social inclusion? (Submitted).

5. Crondahl, Kristine and Eklund Karlsson, Leena. (2014). Roma Empowerment and social inclusion through Work-Integrated Learning. *SAGE Open*. (Accepted for publication December 17th 2014).

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ABBREVIATIONS

DO	The Swedish Equality Ombudsman
Ds	Swedish Departmental series
FHI	The Swedish National Institute of Public Health, The Public Health Agency of Sweden (from 2014-01-01)
FORTE	Swedish Research Council for Health, Working Life and Welfare
FRA	European Union Agency for Fundamental Rights
GRR	Generalized Resistance Resources
HP	Health Promotion
PAR	Participatory Action Research
PR	Participatory Research
SOU	Swedish Official Government Reports
UNDP	United Nations Development Program
WHO	World Health Organisation
WIL	Work-Integrated Learning

INTRODUCTION

The Roma people have been called by several names throughout the years and in the different parts of the world. The primary names used by the non-Roma society in Sweden have been "Gypsy" and "Tattare". In the historical part of this chapter I will therefore be using "Gypsy" or "Tattare" in quotes as these are the concepts deriving from that era of designations. What comes to the present parts, I will be using the word chosen by the people themselves (Liégeois, 2012), also the term now commonly used in EU policy documents and discussions (http://ec.europa.eu/justice/discrimination/roma/index_en.htm), Roma people, or only Roma. In the Roma language, Romani chib/Romanes, *rom* means 'man, husband' and the Roma females are called *romani*. According to the Council of Europe (Liégeois, 2012), the term Roma incorporate names like Kalé, Gypsies, Travellers, Sinti, Dom and Lom and covers the diversity of groups related to, and identifying themselves to these groups, like e.g. Ashkali, Boyash and Manouches (http://ec.europa.eu/justice/discrimination/roma/index_en.htm).

What is it that makes you knowledgeable about a country, or its people's history? The history can be known through archaeological findings, linguistics, and for the later centuries, written material, and so on. When it comes to the Roma people, there is no easy access to these valuable historical assets. Some time after the Roma left their country of origin; they split up, went separate ways and today they live around the whole world, though under different names like e.g. Dom in the Middle-East, North-Africa, Caucasus, and India; Nom in the areas around China; and Lom in Transcaucasia. There is not a lack of literature on the Roma and their history, but up until recently, not much has been written by the Roma themselves (Fraser, 1995). Noteworthy is that so far, the Roma language, Romani chib/Romanes, has only been an oral language. The Roma history has passed on from generation to generation by storytelling. Keeping in mind that the Roma history goes thousand years back in time and that they during this time have been spread out around the world, it is no wonder their story has been changed with time and place. Consequently, the Roma is not a homogeneous group. The language, religion, culture, traditions and manners of the different Roma groups are influenced by the countries in which they have lived (Government Offices of Sweden 1997). This thesis is based

on Roma living in West Sweden why it felt natural to follow mainly the Swedish sources and research considering the Roma. However, to give a better picture and understanding of the Roma situation, a brief insight in the Roma people's history all back to their origin is presented.

Roma people in Europe

The Roma peoples´ origin from India has been verified by linguistic (Liégeois, 2012), genetic and social anthropological research (Hancock, 2010; Swedish Official Government Reports, SOU 2010). Research suggests that the Roma left India around the 1100th, exactly when and why is somewhat unclear. The Romanes vocabulary is like making a map of the travelling roads from India to Europe (SOU 2010). Already the same century, 1100th, the Roma arrived to the European part of Byzantine Empire (today's Rumanian) (European Commission 2004). In 1322 they came to Crete, Greece and then spread to other parts of Europe. During the Age of Enlightenment in the eighteenth century, several approaches were undertaken in attempt to compel the Roma people to the norms of the wider society (European Commission, 2004; SOU 2010). During the 2nd world war, the Roma were affected as were the Jews. The genocide of the Roma, in Romanes called the *Porrajmos*, was tragic and horrible with the state and bureaucratic apparatuses involved, the technology employed, the atrocities committed, the genocidal intent of the perpetrators and also the great loss of victims (Hancock, 2010).

The Roma people are the largest ethnic minority group in Europe (United Nations Development Program, (UNDP, 2013). An estimated 6 million Roma live in the European Union and approximately 10-12 million Roma live in the whole Europe (Liégeois, 2012). Even though discrimination is banned in the EU countries, many Roma are victims of social exclusion and prejudices. The widespread discrimination, persecution and stigma directed at countless Roma in the whole of Europe (European Commission, 2004; European Union Agency for Fundamental Rights, FRA, 2009) makes the Roma economically and socially the most marginalized and excluded group in Europe (Liégeois, 2012; SOU 2010). The problems facing todays Roma are not new in any way, but are the result of historical abuse, tension and

violent solutions of Roma questions (UNDP, 2003). The acknowledgment of the Roma as a minority group in the 1990´s might according to the European Commission (2004) be seen as a first step towards the elimination of discrimination and the increasing of social inclusion of the Roma people. Most European countries offer today citizenship to the Roma. This has not however, improved their situation substantively (Montesino, 2010). With a historical point of view, Liégeois (2012, p. 28) state: "the desire to assimilate has never precluded the desire to exclude. There has never been so much talk of integration as today, while exclusion has never been so common. There has never been so much said about inclusion, nor so much discrimination in practice."

The marginalization of Roma communities show an increasing trend and the Roma living in Central and Eastern Europe are "among the poorest of the poor" (UNDP, 2003). A study conducted in South-eastern Europe, identified Roma ethnicity as a risk factor for Roma poverty and that only 66 % of poor Roma were literate, in comparison with 92 % of the poor majority population (Milcher, 2006). The costs of education were stated as the main reasons for not attending school. A survey conducted on the Roma situation in Europe[1] (FRA & UNDP, 2012) show that 90 % of the Roma in the study live below the poverty line and as little as 15 % of young Roma adults have completed their upper-secondary education. Further, one out of three of the Roma were unemployed and many lack knowledge about their rights as stated in the EU laws. Based on the findings, the FRA and UNDP (2012) emphasise the need for effective Roma integration strategies on national level.

Racism, discrimination (Gee et al, 2012; Sawyer et al. 2012; SOU 2006; Williams et al. 2012), and poverty (European Commission 2004, Minkler & Wallerstein, 2008; Sepkowitz 2006) influences people´s physical and mental health and well–being. Research demonstrate that European Roma have worse health and a life expectancy 10-15 years shorter than non-Roma populations (Parry et al., 2007; WHO, 2012). The UNDP (2003) stress that Roma health in the

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[1] The survey was conducted in 17 European countries: 11 EU member states: Bulgaria, the Czech Republic, France, Greece, Italy, Hungary, Poland, Portugal, Romania, Slovakia, Spain, and six non-EU countries in the western Balkans and Moldova.

six Central and Eastern European survey countries[2] have declined the last ten years. This picture was later confirmed by an inventory on the health of the Roma communities in Europe[3] (Gitano, 2009). Gitano (2009) concluded that factors contributing to the poor health status, lower life expectancy and higher morbidity rate of the European Roma compared to other Europeans, where inadequate education, poor housing, difficulties in gaining access to and using healthcare services and poor health habits.

The UNDP (2003), highlight that the Roma express a desire to integrate in the society rather than to assimilate. The FRA and UNDP (2012:5) state that "The renewed efforts for Roma integration, however, will only bring sustainable results if they engage with the local communities, Roma and non-Roma, building trust, developing social cohesion, and combating prejudice and discrimination." According to the European Commission (2010), the overall objective in combating Roma exclusion is to obtain an inclusive society and not just another form of ethnic segregation. Any progress in such a process, and vice-versa, is to be considered a progress in the inclusion of all European ethnic minorities. Achieving improvements in the Roma situation and enhancing the social and economic integration of Roma, requires the development of a set of model approaches for reaching the various needs of the different Roma communities. The aim is on combating discrimination and improving Roma access to health, education, employment and housing. In increasing the effectiveness of this process, the European Commission emphasizes the active participation of the Roma "…enable the Roma themselves to influence policy processes… (European Commission, 2010:9).

Roma people in Sweden

The first reliable notes of Roma people in Sweden are from the early 1600th century (Montesino 2010). A small group of people called 'Egyptians' arrived to Stockholm in the year of 1512. For many years it was supposed that the Roma originated from Egypt and the term 'Gypsy' has been traced back to this belief (Hancock, 2010). In the 1500´s, the Gypsies

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[2] Hungary, the Czech Republic, the Slovak Republic, Bulgaria and Romania
[3] Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia and Spain

and Tattare were categorized under the authorities' regulations of the care for the poor. Nomadic way of life was considered as disorder and inconsistent with the Swedish way of living. In 1923´s motion on regulations regarding the treatment of vagrants (SOU, 1923), the Tattare were accused of terrorizing the population with their way of moving around, which "should not be tolerated". Based on permanent settlements and controlled mobility, the government tried to create a new structure by forcing the Gypsies and Tattare to settle down (SOU, 1923). Gustav Vasa urged the bishop to get them out of the country (SOU, 1923). In the 1600`s the Swedish Parliament decided that all the Gypsies and Tattare in Sweden were to be dismissed from Sweden (Montesino, 2010) and according to the law, male Tattare could be hang without a trial (SOU, 1923). Every Swedish citizen were obliged by law to benefit to the society with some kind of, according to the prevailing norms, useful occupation (SOU, 1923). Those who did not fit into the "useful occupation" regulations were regarded as vagrants, among which were the Gypsies (SOU, 1923).

Gypsies and Tattare were regarded as problematic and as worsening of the Swedish race. In the 1800´s, the Swedish authorities and politicians wanted to assimilate the Gypsies into the Swedish norms of society. But as the Gypsies were not considered having the required prerequisites for this, the Swedish government saw no other solutions than to dismiss them from the country. In most of the cases however, the Gypsies were Swedish citizens and thus could not be dismissed from the country, nor exterminated. Consequently, the only way to do "get rid of them", was to make their living in Sweden so hard, by e.g. restrictions on freedom of movement, that they left Sweden by their own will. In addition, the Swedish governments' restrictions in acquisition sources were tightened. Even this was a part of making life hard for Gypsies and Tattare and "to finally get rid of them" (SOU, 1923).

The 'foreign Gypsies' were subjects to the 1914`s law on the prohibition of certain foreigners to stay in the country and were to be immediately rejected at the arrival to Sweden (SOU, 1923). Even 'Swedish Gypsies' who already were living in Sweden at that time could be dismissed from the country if they were not living in accordance with the Swedish norms.

Like in other European countries (European Commission, 2004), the Roma children in Sweden were systematically removed from their families and placed in state care as a means to change the 'Gypsies' into useful citizens (SOU, 1923). In 1954, reliefs were introduced to the law of entry ban and the immigration regulations applied to migrant labour from neighbouring countries (especially from Finland) became less restrictive. From 1954 the 'Finnish Gypsies' were able to immigrate to Sweden as migrant labour (Montesino, 2010).

The Roma people are a typical example of "blaming the victim": The Roma have been blamed to be responsible for their marginalized and exposed situation while "the solutions" to this "Gypsy problem" have been suggested by the majority society and the Swedish state (SOU, 2010). Not to behave according to the Swedish norms seems to be an important factor why the negative rumours and prejudices concerning the Roma ever occurred (Lundgren, 2003; Montesino Parra, 2001; Montesino 2010). The Roma did not fit into the Swedish norms on how to live, work, behave, talk and how to socially act (Lundgren, 2003; Montesino Parra, 2001; Montesino 2010). The Roma culture crashed with the Swedish culture in every way. When the Roma did not let themselves to be assimilated into the Swedish normative, then the problem became even more explicit (SOU, 1923; Montesino 2010). The Swedish governments "solution" to the "Gypsy problem" were legislations forcing the Roma to live and behave according to the Swedish norms. Montesino (Montesino Parra, 2001; Montesino 2010) concludes that today's stigmatizing conception of Roma is part of "a story" constructed in order to justify governmental interventions.

Since 2000, the Roma people[4] are an acknowledged national minority group in Sweden (Ministry of Foreign Affairs, 2000). Being recognized as a national minority group means that the group has specified rights in the society. For the Roma in Sweden this means that Sweden has the responsibility to protect their traditions, language, religion and culture which are estimated as being essential parts of their identity. Furthermore the Swedish State is to promote effective and absolute equality between the Roma people and the majority population

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[4] The Swedish government and authorities' has divided the Roma into five groups: Travellers, Finnish Roma, Swedish Roma, Non-Nordic Roma and Newly arrived Roma (SOU, 2010), but according to the Roma themselves they represent a considerable broader range of groups.

within the social, cultural, economic and political domains. There are five national minority groups in Sweden (Roma, Jews, Sami. Swedish-Finns and Tornedalians), but the convention states that a special consideration shall be made to the particular circumstances for Roma persons (Ministry of Foreign Affairs, 2000).

According to the Swedish Equality Ombudsman (DO, 2003) there is a great unawareness concerning the Swedish state's responsibility on the widespread ethnic discrimination. Thus, a white paper describing the abuse and violations of Roma in the 1900's Sweden (Departmental series; Ds, 2014) was published with the purpose to dignify the victims and their families, and, to increase knowledge and understanding of the situation of the Roma minority by highlighting the abuse that Roma have been subjected to. The document describes how stereotypes and prejudices have grown and lived on from generation to generation and constructed the basis for the state politics.

A lot of Roma are today still fighting against prejudice and stigma both in and by the Swedish society (DO, 2008; SOU, 2010). The direct and visible discriminating legislation is gone, but the anti-Ziganism is persistent and remaining. Anti-Ziganism is prejudices, hostility, beliefs or racially based attitudes towards the Roma and is a distinct form of racism (SOU, 2010). Anti-Ziganism results in, and/or seeks to alienate, remove or destroy Roma just because they are Roma (SOU, 2010). Noteworthy is that the discrimination of Roma is not regarded shameful, but is gaining a highly social acceptance (DO, 2003). Roma in Sweden live under worse conditions than the average and are discriminated on all levels of society (SOU, 2010). The Roma are denied full access to the social and economic rights, do not have full access to their political and civil rights (voting, dialogue with government through Roma organizations), are poor in both social and economic welfare and are powerless and lacking influence in the society.

The SOU (2010) states that Sweden has an unresolved under development problem caused by racist structures that affect the entire national Roma minority. To close the welfare gap and improve the situation of the Roma minority in Sweden, the discrimination and structural anti-

Ziganism needs to be fought (SOU, 2010). This calls for making anti-Ziganistic structures in society more visible and to increase Roma participation in decision making as well as in representation. Palmroth and Hermansson (2006) claim that the marginalized situation of the Roma in the today's Swedish society is a consequence of a complex interplay between the Swedish society's rejection and the Roma way of isolating and protecting themselves. The approximated number of Roma people today living in Sweden are 50 000 Roma (SOU, 2010). A precise number is not available due to several reasons. As for one, in Sweden, registration of ethnic origin is prohibited by law (Discrimination Act, 2008; the Personal Data Act, 1998/ The Swedish Personal Register Law) as in in many other European countries. Additionally, due to the stigma of the Roma identity, many fear of being discriminated if they reveal their Roma identity (European Commission, 2004, National Board of Youth Affairs, 2009).

The educational situation among Roma in Sweden is far from satisfactory. More than fifty years have gone since Roma got access to education (Ds, 2014). Still there are far from all Roma pupils who complete primary school with full marks. The reason for this is complex and the consequences are extensive, reaching from generation to generation; consequently, many adult Roma lack of education (SOU, 2010). According to DO (2003), there are some shortcomings in the existing training and labour market systems in Sweden (DO 2003). Palmroth and Hermansson (2006) and Palosuo (2008) claim that traditional educational approaches are not efficient for the Roma people. Besides, the prevailing integration and training methods have not reached set targets (Palosuo, 2008). This is the situation for other immigrant groups too. In a historical view, the Swedish educational system has been based on Swedish traditions and values. Despite the today's ethnic plurality in schools, there are still regulations, traditions and values based on "the Swedish norm" (SOU, 2005). Thus, rather than facilitating adult education, the regulations of Swedish welfare institutions become obstacles for education. Structural discrimination is another way to name this phenomenon. Structural discrimination permeates society and decreases people's opportunities for equal conditions (DO, 2003). According to SOU (2005), structural discrimination (based on ethnic or religious affiliation) creates obstacles for ethnic/religious minorities to achieve equal rights and opportunities as the majority of the population through norms, routines, rules   and

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accepted behaviour and attitudes of institutions and other social structures. Structural discrimination may be hidden and unintentional, but also visible and intentional. Despite regulations and attempts to overcome this obstacle, Sweden still has a long way to go until an optimized educational system that suites all, is in place.

The public health situation of the Swedish population in whole is improving (The Public Health Agency of Sweden, 2014; former Swedish National Institute of Public Health, FHI). Yet, on the other hand, the welfare- and socioeconomic gap in health and well-being between population groups, is increasing (FORTE, 2014); the lower education, the greater risk (The Public Health Agency of Sweden, 2014). Especially women with poor education are at a higher risk in several areas of life including a decline of self-rated health. Studies have pointed out Roma women with low education as being in most risk (The Public Health Agency of Sweden, 2014). These are in line with earlier studies on the social exclusion and health of Roma women in Europe (European Commission, 2008).

SOU (2010) stated that the Roma people living in Sweden have worse mental and physical health than the average non-Roma Swedish population. Most studies on Roma health are quantitative however, measuring the objective health of the informants. Investigating Roma peoples' subjective perceptions of health from a qualitative approach, the Swedish National Institute of Public Health (FHI, 2010) found that health was perceived as an ideal state which the Roma find difficult achieving. The informants were never asked about how they perceived their subjective health for the time being, though. An interview study of Roma (and Sami) women, Alex and Lehti (2013) found that health and well-being were seen in a family- and collective perspective and described as inner strength rather than objective measures, and that the respondents perceived to be healthy. The strong Roma social network yielded support and functioned as a coping strategy enhancing well-being. Cultural identity was identified as a positive determinant on Roma health and well-being, whereas the perceived inequality within the Swedish society as well as between Roma men and women, were identified as negative determinants.

THEORETICAL FRAMEWORK

The main theoretical perspectives behind this study are health promotion and pedagogics; the guiding paradigms are constructionism and critical theory (Lincoln, Lynham & Guba, 2011). The worldview of constructivism guided the question of what knowledge is and how knowledge is formed. Critical theory guided the role and relations of the researcher into the known, the researched, and the methodological choices of the research.

Health Promotion

The concept and approach of health promotion was presented in the Ottawa Charter in 1986 as "… the process of enabling people to increase control over, and to improve, their health." (WHO, 1986, p. 1). Health promotion is the only public health area of action to endorse the positive health definition approaching people`s living conditions and health equity, also stressing the equality of women and men (Potvin & Jones, 2011). In 2008, Nutbeam (2008b) stated that, promoted by the Ottawa Charter in 1986, there has been a paradigm shift concerning the implementation of public health strategies. In today's major public health challenges, the five fields of action for health promotion - building healthy public policy, creating supportive environments for health, strengthening community action, developing personal skills and reorienting health services, are at least taken into consideration. Since the Ottawa Charter, the world has gone through enormous changes in the global economic and social situation. Nonetheless, the Ottawa Charter is still standing strong as a basic document for health promotion (Baum, 2008; Coveney, 2008; Crawshaw, 2008; Dooris, 2008; Gestaldo, 2008; Hancock, 2008; Legge, 2008; Nutbeam, 2008; Samuel, 2008; Springett, 2008).

For health promotion efforts to succeed in reducing inequities in health, the broader aspects of the social determinants of health needs to be addressed rather than focusing on individual behavioural changes (Baum & Fisher, 2014). Health is to a great extent influenced by the socioeconomic, cultural and environmental conditions surrounding people's lives, and unhealthy behaviour and chronic diseases are more common within economically and socially

disadvantaged groups. For health promotion efforts to change focus from individual behavioural aspects to social and economic determinants of health, one of the public health missions should be to promote supportive evidence on the added value of such actions and hence to influence governments' to engage in effective means of promoting equity in health (Baum & Fisher, 2014).

Fundamental for health promotion programmes, policies and activities is that they should be guided by the principles of empowerment, participatory, holistic, equitable, intersectorial, sustainable and are based on multistrategy (Rootman et al., 2001). Empowerment and participation are seen as key elements. Rootman et al. (2001) state that all health promotion initiatives should involve the processes of empowerment, those initiatives lacking empowering elements should not be regarded as health promotion at all. Central for the empowerment process to succeed, is the participation of the involved individuals, groups or community (Rootman et al., 2001). According to the Ottawa Charter, "Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members." (WHO, 1986, p. 3).

As stated, health promotion emphasizes empowerment and people's own participation in the improvement of health and life situation (Rootman et.al., 2001), and has a positive view of health (Potvin & Jones, 2011).

The health perspective of the thesis

According to the salutogenic view of health, health is a multidimensional ease/dis-ease continuum (Antonovsky, 1987). By focusing on developing the health determinants/healthy factors and coping resources instead of risk factors and diseases, the persons' health will be promoted. A persons' health status are influenced by his/her way of coping with tensions, but also on the character of the stressors.

A rather new perspective to health, also encompassing a positive view of health, is health as the ability to adapt and to self-manage (Huber et al., 2011). What constitutes this perspective is the individual's capacity to adopt in accordance to the circumstances. Hence, despite poor objective health in form of illness or disability, a person may adapt to, and cope with the situation and thus, perceive having good health. The perspective is suggested as an alternative to the WHO's definition of health as a state of complete well-being. The WHO definition is regarded by the authors to have lost its relevancy and appropriateness, considering the changing health conditions and the increase of chronic diseases. With this new way of approaching health, health is regarded as achievable for all people, regardless of social, emotional or physical conditions rather than as an ideal state impossible to reach.

Empowerment - a process and an outcome

Empowerment is a popular and often debated term, though without a uniform definition. Along with its growing popularity, empowerment has become a buzzword in risk of losing its essence and original idea (Askheim, 2007). Askheim (2007) distinguishes three positions of empowerment: market-oriented empowerment, therapeutic empowerment and establishment of counter-power. In focus of the *market-oriented empowerment* is the free and independent individual. Independency and autonomy are the guiding principles and policies are to be built around the individual. The welfare state is regarded as limiting the individuals' free choice and responsibility. Thus the goal is to decrease the state discretion for the benefit of market models within the welfare sector. *Therapeutic empowerment* is simply put, authority making of the individual. In different forms and various degrees, power is handed over from experts or authority persons to individuals, intending for the individual to take more responsibility over the own life. The risk is that the real power lies with the expert/authority person who is to decide on how much of the power is handed over and what is right or wrong. Examples of therapeutic empowerment are patient education and compliance. Mastery, e.g. sense of coherence, and health promotion are positioned within therapeutic empowerment. The third, *empowerment as establishment of counter-power,* is the view of empowerment used in this study; empowerment for managing change in the power relations in society.

The concept of empowerment origin from the 1960´s social action ideology and the self-help perspectives of the 1970´s (Gibson, 1991). Pioneering was Paolo Freire´s work with the oppressed and illiterate adults in the slums of Brazil (Freire, 1996). With his consciousness-raising, dialectic approach and the proposal of a democratic problem-posing education, he paved the way for the bottom-up perspective which has come to be an essential characteristic of empowerment.

Empowerment is about gaining the strength and power to influence the own, groups or communities life (Askheim, 2007). Essential is awareness rising on the societal conditions holding people down and that it is possible to improve and change these conditions. Empowerment cannot be given from one person to another, but has to come from within (Laverack, 2007). However, empowerment looks different in different contexts and different people, thus the outcome may vary. The absence of empowerment however, has said to be easier to define than its presence (Rappaport, 1984). The absence of empowerment might show as powerlessness and/or learned helplessness, or, as a general feeling of not having the control over one's own life. In its presence on the other hand, empowerment is the process through which people in powerless situations gain the power to fight the oppression that is holding them down and thus to gain control over their own lives (Askheim, (2007). This is in line with Rappaport (1984) and Tengland (2008) considering empowerment as both a process and as an outcome. In 1985, Rappaport described the empowerment concept in terms of psychological empowerment comprising the individual's beliefs in own competencies, efficacy and involvement in activities for gaining environmental political and societal control. Accordingly, to be empowered is to be able to critically analyse the political and social circumstances, enabling the person to engage in political and social action for change (Rappaport, 1985).

The conception on empowerment was further developed, hence incorporated a component of personal will and desire for change: "… the connection between a sense of personal competence, a desire for, and a willingness to take action in, the public domain" (Zimmerman & Rappaport, 1988, p. 746). According to Zimmerman and Rappaport (1988) empowerment

constitutes of personality [locus of control, Rotter, 1966], cognitive [self-efficacy, Bandura, 1982], and motivational [motivation to control the environment, White, 1959 and DeCharms, 1968] aspects of personal competence and control. Zimmerman and Rappaport (1988) were not able to determine the causes from the effects however; yet stated a strong connection between empowerment and participation in community life. Another concept related to perceived control and psychological empowerment is the theory of learned hopefulness: "… the process whereby individuals learn and utilize skills that enable them to develop a sense of psychological empowerment" (Zimmerman, 1990, p. 73). According to this theory, through experiences of control, people's ability to cope with stressful life events may improve. As participation and action in community organizing are considered to enhance peoples' skills, competences and psychological empowerment; psychological empowerment is regarded an outcome of learned hopefulness (Zimmerman, 1990).

However, achieving authentic increase of impact and control requires consideration of the social, historical, cultural, economic and political contexts in which people live (Israel, Checkoway, Schulz, & Zimmerman, 1994). Hence, the individual level of empowerment is somewhat linked to the community level:

> An empowered community is one in which individuals and organizations apply their skills and resources in collective efforts to meet their respective needs. Through such participation, individuals and organizations within an empowered community provide enhanced support for each other, address conflicts within the community, and gain increased influence and control over the quality of life in their community. (Israel et al., 1994, p. 153)

Community empowerment has been considered a dynamic continuum evolving at five different levels: individual, group, community organizations, partnerships, and social and political action (Rissel, 1994). The intention is for the process to proceed throughout the five levels reaching the final goal of community empowerment. The process might however stop proceeding somewhere on the continuum, or even go backwards (Laverack & Wallerstein, 2001). According to Eklund (1999) it is not possible to speak about community empowerment before ensuring that a critical mass of people are first empowered individually. The

individuals do not need to be empowered to the same extent, though; empowerment is a group phenomenon and the sum of the empowerment existing in the group is what constitutes the community's empowerment (Eklund, 1999). Rissel (1994) suggested community empowerment to be topic specific; meaning that even though the community is empowered in one issue, it doesn't necessarily mean that they are empowered in others. Rissel (1994) claimed further that the sense of community is enhanced by the processes of psychological empowerment.

Health literacy

The roots of the concept of literacy go way back to the culture among the Greeks and Egyptians and the shift from an oral to written culture (Speros, 2005) and means basically to be knowledgeable and educated (Sörensen et al., 2012). The term health literacy however, was introduced in the US in 1974 regarding health education standards in US (Speros, 2005). Since then, the concept has gone through changes and been the midpoint of numerous discussions in various disciplines, e.g. media health literacy (Levin-Zamir, Lemish, & Gofin, 2011), mental health literacy (Jorm, 2012) and eHealth literacy (Norman & Skinner, 2006). The term health literacy has emerged in the context of health care; focusing on patients' understanding and use of information and how patients navigate in the health care system, and in the context of health promotion; focusing on health determinants and how these might strengthen health literacy (Ringsberg, Olander & Tillgren, 2014). Today, health literacy has been pointed out as a stronger predictor of health status than age, socioeconomic status and ethnic background (Speros, 2005).

Health literacy is to understand the determinants of health, to know how to handle them and to put the health of the individual, family and community into context (Sörensen et al., 2012). A health literate person has the ability to take responsibility for both his/her own health and for the health of the family and community. According to WHO,

> "Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information

in ways which promote and maintain good health. … By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment." (Nutbeam, 1998, p. 357).

With its health promoting basis, health literacy is considered as more than being able to read written material (Nutbeam, 1998; Sørensen & Brand, 2013). By adding the component of social engagement in broader health issues to the health literacy definition, Abel and Bruhin (2003) expand the traditional individualistic definitions. Nevertheless they stress the significance of lay knowledge in connection to health, welfare and everyday experiences. As health literacy includes attitudes, orientations, norms and values that affect people's perceptions of health and disease, health literate persons are more likely to change their health-related living conditions (Abel, 2007). Health literacy may however look different in different contents and contexts, thus it might be showing in various ways (Smith, Nutbeam, & McCaffery, 2013) and developing over time (Edwards, Wood, Davies, & Edwards, 2012). Increasing health literacy requires a reconceptualising of health education; emphasising the social, environmental and economic determinants of health rather than individual behavioural factors (Nutbeam, 2000).

The pedagogic perspective

Established knowledge, skills and traditional integration strategies are not always customized for the today's labor market and society. This becomes apparent in the Roma educational situation (Palosuo, 2008; SOU, 2010). According to Ellström (2006), learning through traditional education efforts are often incomplete; what strongly limit the effects of previous training efforts is that the theoretical knowledge have not constituted an adequate basis for the practical application. Furthermore, the learning activities have often been torn from their context, and there has rarely been room for integrated learning processes enabling the individuals to apply the new knowledge in their practical everyday work. Research indicates that the theoretical knowledge from formal educations might be promoted by the informal learning in daily work and reverse (Ellström, 2006). Learning is a qualitative change in the

way of perceiving or relating to the social or material reality, and differs from the quantitative grows of knowledge (Bron & Wilhelmsson, 2004). Fundamental for the learning is the individuals' attitude and motivation for learning (Ellström, 2006).

Freire (1996) regarded knowledge as a result of an active process: Reflection leads to learning and learning to increased knowledge. Freire emphasized the dialogue, a dialogue between the facilitator and the participant that requires critical thinking. The best learning happens when the divergence between the two of them stops existing and an authentic dialogue occurs. Freire (1996) highlights the bottom-up perspective. Essential for the learning process is that the focus is on the participant; the starting point should always be the participant and his/her perception of the situation. A usual mistake according to Freire (1996) is that the facilitator proceeds from own experiences and perceptions of the situation; often divergent from those of the participant. The participant then will not be able to identify with the supposed issue thus he/she cannot understand the real implication of it. The real learning will be absent. Hence, essential, and the facilitator's responsibility, is to ensure that the facilitator and the participant, speak "the same" language. The facilitator needs to be down to earth and to speak in concrete and practical terms, terms that the participant may understand and relate to.

Paradigms guiding the study

Constructivism

The core of the constructionist theory is that no "true realities" exist (Lincoln, 1992; Denzin & Lincoln, 2011; Guba, 1990; Guba & Lincoln, 1994). The interactional constitution of meaning in everyday life has been in focus of much of the discussions; the world and reality as human see it is actually a constructed world, a constructed reality (Holstein & Gubrium, 2011; Kincheloe, McLaren, & Steinberg, 2011) of which no constructions are more 'true' than the other.

The constructivist perspective on qualitative inquiry is both an empirical research perspective and an intellectual movement that transcends particular disciplines (Holstein & Gubrium,

2011). According to constructionist theory, an inquiry can never be value free (Guba 1990). As reality only exists in the subject's mind, the only way to access the constructions of reality is through subjective interactions. The findings of the inquiry are the creation of the interaction process between the facilitator and the participant (Guba, 1990; Lincoln, 1992) and the facilitators and the participants are considered as one single entity (Guba, 1990). Moreover, the knowing is seen as an interactive process increasing both the facilitators' and the participants' knowledge (Lincoln, 1992). Knowledge is not to be discovered, but to be created by the human (Eklund, 1999). Constructionism is hermeneutic and dialectic, requiring identifying the spectra of existing constructions and bringing them into as much consent as possible. The final goal is for the facilitators and the participants to come to terms with each other's perceptions and to reconstruct their initial constructions (Guba, 1990). This can only be done through the interaction among and between the facilitators and the participants, a process characterized by dialectics and hermeneutics (Guba & Lincoln, 1994). The hermeneutic aspect aims at portraying the individuals' constructions in an as precise way as possible. This is done in a dialectics manner, meaning that the different constructions, e.g. the ones of the facilitators and the ones of the participants are compared, contrasted and confronted by their bearers, generating new constructions (Guba & Lincoln, 1994).

Critical theory

Critical theory has a long tradition extending from a.o. Karl Marx, the Frankfurt School, Michel Foucault, Lev Vygotsky and Paolo Freire (Kincheloe et al., 2011). According to critical theory, and in line with Freire (1996), the way people see themselves and the surrounding world are influenced by historical and social forces (Kincheloe et al., 2011). The use of the word 'critical' refers to an attempt to challenge the injustice in a society or community and to increase emancipatory consciousness. In the battle for a better world, critical theorists proclaim their partisanship rather than neutrality like traditional researchers. Critical theorists consider 'reality' as being shaped throughout years by a range of gender, ethnic, social, cultural economic and political factors, meaning that 'reality' is a construction (Denzin and Lincoln, 2011). They also consider that the researcher and the researched interact and influence each other and that it is unavoidable that their values influence the research.

Thus, the research findings are value mediated. The critical theory requires constantly dialogue between the researcher and the researched (Guba, 1990).

Freire (1996: 30) stressed the need of the oppressed people's participation and emphasized "a pedagogy which must be forged with the oppressed, not for, the oppressed". The oppressed people's participation is a social practice facilitating emancipation as responsible and autonomous members of the society (Freire, 1996). Minkler and Wallerstein (2008a) stress that the activists (the community, group, individuals) are the ones to identify their own problems/issues and should be directly involved in the research and the social change activities. The only way to fight against and to overcome the disparities in health is by truly engaging the most oppressed communities themselves as partners in the fight (Minkler and Wallerstein, 2008a). To address the health and social issues, which the community, not outside experts, cares about most deeply, the exploration and the action taking should be done in collaboration with the communities.

Summary and concluding remarks

The historical treatment and constructed picture of the Roma by the governments and authorities has severe consequences for the health and living situation of the Roma in Sweden (SOU, 2010), likewise as for Roma in other countries. Addressing these problems, there seems to be European consistency on the need for educational efforts and the active involvement of the Roma themselves. The obstacles of Roma empowerment is to be found in the social determinants of health: poor education, unemployment, isolation and low self-esteem but also constrained thinking and structural discrimination in the Swedish welfare system (DO, 2003; Eklund & Crondahl, 2010; Hassler & Eklund, 2012; SOU, 2010). In Sweden, measurements and proposals to improve the situation have been taken, but rather than being involved, the Roma have been treated as a helpless group in need of expert help and support from the authorities (SOU, 2010).

There is a lack of scientific research in Sweden on the Roma in several areas (Palosuo, 2008; Rodell Olgac, 2006). Most of the research of Roma has been of the Roma, not together with

the Roma (Palosuo, 2008; Palmroth & Hermansson, 2006). The Roma need to participate in the building of the knowledge concerning Roma, and in the long run a focus on the Roma empowerment and organizing will lead to increased democracy (DO, 2008; European Commission, 2006; Palosu, 2008; Palmroth & Hermansson, 2006). Sweden is a modern welfare society striving for equality. Unfortunately, the socioeconomic disparities in health (The Public Health Agency of Sweden, 2014) and well-being between different population groups in Sweden are increasing (Swedish research council for health, working life and welfare, FORTE, 2014). The explanation for this is complex, yet one risk factor pointed out is poor education (The Public Health Agency of Sweden, 2014). There is a need for an education model adjusted for the groups of people that fall through the cracks (DO, 2003; Palosuo, 2008). Success in the elaboration of such a model may be one step on the road towards increased inclusion of socially excluded groups in the society. The study behind this PhD thesis was such an attempt, adapting the core principles of health promotion and positive view of health, and the emancipatory and consciousness raising pedagogy within the world views of critical science and constructivism. The way people think about the world is according to constructionism experientially and socially based constructions. According to critical theory, the world is based on a struggle for power, leading to relations of oppression and privilege. These guiding principles place the participants and their subjective perceptions in the centre of inquiry, acknowledging their various backgrounds and realities. With the overall aims to impart social change, equality and social justice, and the constructivist view, that the world is based on socially and experientially constructions, critical theory and constructionism guided the choice of strategies of inquiry – participatory action research and hermeneutic through work integrated learning. By integrating practical and theoretical learning, interpretation and interaction between participants and facilitators, new knowledge is produced and the prevailing believes and perceptions' of the world are changed. New realities are constructed, creating foundations for empowerment and social action. By working with those core concepts of health promotion, empowerment and social action, the purpose is to contribute with new understandings on how these approaches function in a minority setting. Such increased knowledge is of significance for the development of health promotion research within vulnerable groups as well as in multicultural societies. Furthermore, by assigning the leading

role and the process of integration to the Roma people by participatory action research, the effort is to provide added value on the knowledge and experience concerning the empowerment processes among Roma people and how these could be handled.

AIMS OF THE STUDY

The overall aim of the doctoral thesis was to analyse and elaborate a work-integrated learning model to be applied in empowerment and adult education for the Roma minority- and other vulnerable groups in similar situation.

The PhD thesis is based on five papers with the specific aims and research questions:

1. To examine how 14 Roma adolescents in West Sweden perceive the concepts of health, well-being and quality of life, and further, to investigate the degree to which they consider themselves able to cope with their own life situation within these areas.

    - How does Balkan Roma adolescents' living in West Sweden understand the concepts of health, well-being, and quality of life?
    - In what way does Balkan Roma adolescents' living in West Sweden perceive to be able to cope with their own life situation within these areas?
    - What are their coping mechanisms to deal with these issues?

2. To describe how 33 Roma people living in West Sweden understand health, well-being, and quality of life within the Roma context, and how they cope with their life-situation.

    - Within the Roma context, how does Roma adults' living in West Sweden perceive the concepts of health, well-being, and quality of life?
    - What are the coping mechanisms used to handle their life-situation?

3. To analyse whether there is connection between health literacy and empowerment.

    - In what way is the connection between health literacy and empowerment reflected in scientific literature?

- What constitutes the relationship between health literacy and empowerment?
- If empowerment is an outcome of health literacy, what are the mechanisms behind this process?

4. To explore how participatory action research (PAR) and work-integrated learning (WIL) might function as empowering tools in the Roma social inclusion process and to propose a working model to use in empowerment of the Roma minority- and other vulnerable groups in similar situation..

- What constitutes PAR and WIL in the health promotion programme?
- In what way are PAR and WIL applied in the programme context?
- What does the interaction between PAR and WIL look like in the programme context?
- Which are the significance of PAR and WIL for the Roma participants?
- Which are the factors behind the significance of PAR and WIL for the Roma participants?

5. To analyse the health promotion programme from the Roma participants' perspective. The focus was on the participants perceived individual empowerment and perceptions on their contribution to the common good and community empowerment.

- How does the Roma participants' perceive the participation in the health promotion programme?
- In what way does the participants' perceive and describe their own development process?
- In what way does the participants' consider to have contributed to the common good of their local Roma communities?

MATERIALS AND METHODOLOGY

A fundamental aspect when working with Roma is the history-based constructed story of Roma and the consequences this has for the present situation, and for the Roma way of understanding and perceiving their situation. These are in line with the constructivism (Lincoln, 1992; Denzin & Lincoln, 2011; Guba, 1990; Guba & Lincoln, 1994) and critical theory (Denzin & Lincoln, 2011; Kincheloe et al., 2011) forming the worldview behind this thesis.

This PhD thesis has a qualitative approach where focus is human being's own perceptions in natural settings. The goal of the qualitative researcher is to interpret, or to make sense of, phenomenon in terms of the meanings the people themselves brings to them. As a mean to interpret what happened in the interactions between the project facilitators and the Roma participants, and to understand the participants' life world, hermeneutical methods were applied in papers II, IV and V. Content analysis was used in paper 1 to capture the respondents' subjective perceptions and emotions. Through scoping review, paper III abstracted essential concepts from each other to be used in the learning model under elaboration. The specific analysis methods are described separately under the presentation of the papers.

Key words of this thesis are subjective perceptions, experiences, dialogue, participation, cooperation and empowerment. These are all qualitative values, values that cannot be measured but needs to be described. Values of this kind will be best captured through being near those who are directly affected by the research (Israel, Schulz, Parker, Becker, Allen & Guzman, 2008). When being near, it is fundamental to collaborate, discuss, dialogue, listen, share experiences, and last but not least, to be equals (Springett, Wright, & Roche, 2011). An approach capturing these essentialities is the approach of participatory action research (PAR). In PAR, the data are created as a result of the constantly interactions between the participants and the facilitators (Israel et al., 2008). The approach of the health promotion project behind

this doctoral thesis comes near PAR. As the overall aim of the thesis was to elaborate a work-integrated learning model, as a part of the process, the approach was adjusted along the way.

Participatory Action Research

Participatory action research (PAR) originally steams from two different orientations (Wallerstein & Duran, 2008): The action research tradition of Kurt Lewin from the 1940`s emphasizing a cyclical approach to problem solving involving the people who themselves are affected by it. And the participatory research tradition from which Freire is known, with the emancipatory focus and roots from oppressed people and popular education in the 1970`s Latin America, Asia and Africa. The emancipatory approach is according to Minkler and Wallerstein (2008) the golden standard of (community-based) participatory research and should always take the activists approach. Community-based participatory research (CBPR) has been summarized by by Israel et al. (2008:48) as:

> …a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all respects of the research process. The partners contribute unique strengths and shared possibilities to enhance understandings of a given phenomenon and the social and cultural dynamics of the community and to integrate the knowledge gained with action to improve the health and well-being of the community members."

Despite often varying goals, the different approaches to participatory research (PR) share a set of characteristics and core principles (Israel, Schulz, Parker & Becker, 1998; Israel et al., 2008): The community and its strengths and resources, collaboration and equitable partnership, empowering and power-sharing processes attending to social inequalities and co-learning and capacity building. Moreover, balance between research and action for the mutual benefit of all partners, health issues of local relevance, cyclical and iterative process and to involve all partners in the whole process. And finally, it requires a long term-process and

commitment to sustainability. All elements are not applicable in all interventions why it has been recommended that some of the underlying core values should be applicable in most of the situations (Israel et al., 2008): The principles should occur in the setting of the specific partnership. Doing PR requires constantly rethinking and revising of the principles and the recognition that PR is all about a process in constantly progress (Israel et. al., 2008; Springet, White & Roche, 2011).

In PR, all forms of knowledge are acknowledged, from life experiences to formal education (Springett et al., 2011). The communities and the researchers' knowledge are considered equal, emphasizing the change in perspective from doing research 'on' to doing research 'with'. Knowledge is generated through dialogue and interaction between all involved parties and their perspectives. Knowledge is considered forever dialectic and never fixed; as something always to become. This requires a true focus on power issues in regard to cooperation: how to encourage dialogue, how to make all voices heard and how to create a shared ownership. Participatory research is not a method but an orientation to research (Minkler & Wallerstein, 2008; Springett et al., 2011) emphasizing issues of dialogue, trust, power, collaborative inquire and community capacity building towards the goal of social change for improving community health and eliminating health disparities (Minkler & Wallerstein, 2008). Participatory research is an empowering process through which the participants increase the control over their own lives (Israel et al., 2008).

According to Israel et al. (1998) community based research is based on the perspectives of critical theory and constructivism (Israel et al., 1998). In the context of the health promotion project behind this doctoral thesis and its approach of PAR, facets of constructionism and critical theory have been very much present and significant. As a researcher and facilitator of PAR, the interactional relationship to the participants is substantial throughout the whole process (Freire, 1996; Israel et al., 2008). Constantly dialoguing, comparing, reflecting and reconstructing in a hermeneutical manner are part of the process leading to an increased knowledge and understanding among both the participants and the researcher/facilitator

(Springett et al., 2011). The process as such is at the heart of PAR serving as a tool and an outcome at the same time.

A feature of PAR is participatory evaluation and its effort of including the participants in the process of evaluation (Springett & Wallerstein, 2008). All parties involved are engaged in continuous dialogue, discussions and reflections, exchanging knowledge, resources and skills; thus shifting the power from the researchers to the rest of the participants. The results are new knowledge and perspectives; the aim is for the processes of change and learning to be persistent even after the end of the programme. Referring to Vanderplaat [1995], Springett and Wallerstein (2008:204), state that participatory evaluation is "evaluation for empowerment".

Participatory evaluation has been widely used in areas of education regarding how to become more reflexive and to improve practice. Involving the participants ensures that the right elements of the programme are being measured in the right way and that these elements are meaningful to all involved. When being included in the evaluation process, the participants are more likely to see the added value of the information they are providing. Participatory evaluation has been claimed to be a way of working rather than as a methodology and has its epistemological and philosophical roots from the tradition of hermeneutics (Springett & Wallerstein, 2008).

The hermeneutical approach

Heidegger and Gadamer were both influenced by Husserl and his view of phenomenology (Laverty, 2008). Yet acknowledging Husserl, Heidegger and Gadamer as the founders of hermeneutic and phenomenology, todays researchers seem to refer to the terms in somewhat various ways; hermeneutics (Ödman, 2007), phenomenological hermeneutics (Lindseth & Norberg, 2004) or hermeneutic phenomenology (Laverty, 2008; Ajjawi & Higgs, 2007). Some authors put various emphasis to the terms, others speak of the same term regardless of referring to hermeneutic, phenomenological hermeneutic or hermeneutic phenomenology. However, Laverty (2003) stress that the understanding of hermeneutic (phenomenology) and

phenomenology is of a dynamic kind thus must be seen as changing over time. This may be an additional explanation to the differing ways of labelling the terms.

Gadamer (1994) argue that personal experience results in a truth which cannot be attained in any other way. Through engaging in a hermeneutical circle of understanding, the researcher(s) and the participants cooperate to bring life to the experience being explored. The important is to stay open to the real meaning of peoples' history. Such openness requires seeing others history in relation to the whole of one's own, personal meanings. Knowledge is intersubjective and all the knowing and knowledge happens in the interaction between the phenomenon and the knower. Through a dialectic approach between the whole of, and parts of the history, the true meaning of the text asserts itself. Gadamer (1989) regards interpretations and findings as changeable with time, bringing different horizons and influenced by the historical, social and cultural situation of the phenomenon and the researcher. Hence, it is not possible for the researcher to exclude personal beliefs and values, experiences, ideas, privileges, culture, nor access to power from the interpretive process. When approaching the phenomenon of study, a hermeneutic researcher has to be conscious of this influence, bringing the own pre-understanding to the inquiry. As the researchers' new horizons merges with the previous, a 'fusion of horizons' are induced, enabling new perspectives to emerge. The interaction between new and previous perspectives prevents the researcher from only seeing what she wishes to see. As the researchers' interpretation is dynamic and changes over time, the researcher is bound to discover something new (Gadamer, 1994).

The term 'phenomenon' derives from Greek and means 'to show itself'. Heidegger (2010) state, that 'phenomenon' is "what shows itself in itself, what is manifest" (Heidegger, 2010:27). Thus the phenomena are the total of what there is to see. The purpose of phenomenology is to reveal what from the beginning does not seem to be there; something that does not show itself, though this unrevealed thing is actually something of significance for the thing itself. Unrevealing the hidden truth requires interpretation; hermeneutics.

Work-Integrated Learning

Work-integrated learning (WIL) is regarded as educational activities integrating the theoretical and practical workplace learning, bridging learning and action (Thẳng, 2004). The learning focuses on the action, and the action becomes a natural part of the learning. The underlying focus is to enable and increase the understanding and performance of the participants and for them to learn and to apply disciplinary skills and knowledge in a real-world context. WIL differs however from other terms like 'work-based learning' and 'work experience' as WIL requires learning and integration and application of disciplinary knowledge (Smith, 2012).

One of the main goals with WIL is to provide the participants with authentic experience of work. The working experience makes the participants more prepared to face the challenges of the working life and also more employable (Purdie, McAdie, King, & Ward, 2011; Smith-Ruig, 2013). The WIL allows for a self-directed learning and might be seen as an active learning process involving both performing real work duties and reflection. Smith-Ruig (2013) emphasize that for the reflection to be optimal, it needs to be 'reflection-in-the-midst-of-action', invoking the significance of placing the learning activities to the practice context. The contrary, reflection over events after they have occurred, is separated from the real-world event and is not only less effective, but is also contradictory to the very aim of WIL; to bridge education and workplace. The participants learning are influenced by their motivation and increased by their ability to reflect on their working experiences (Bates, 2003). The real working life experience provides the participants with important tacit and explicit knowledge, which in many cases only can be achieved by being on site (Bates, 2003; Choy & Delahaye, 2011).

The WIL approach enhances and enables the participants' understanding and performance, allows for deeper learning (Freudenberg, Brimble, & Cameron, 2010), and increases self-confidence, hope for reaching personal goals, self-efficacy, self-esteem and self-image (Bates, 2003; Purdie et al., 2011). Furthermore, the WIL approach develops the participants' professional, discipline-specific, problem solving, and analytical skills, as well as their

confidence and maturity (Bates et al, 2013; Freudenberg et al., 2010). The positive effects of WIL increase along with the amount of work-related experiences (Purdie et al., 2011), shows both at the educational, professional and personal level, are influenced by the participants motivation and are increased by their ability to reflect on the working experience (Bates, 2003).

For the WIL approach to be optimal, it is essential to take advantage of all the available skills and knowledge in the various WIL arenas through collaboration (Calway & Murphy, 2007; Choy & Delahaye 2011) and that this relationship should be characterized by equality between the various domains (workplace vs educational institute) (Choy & Delahaye, 2011). WIL might enhance a development from dependency to independency and autonomy thus strengthening the sense of self-efficacy (Bates, Thompson, & Bates, 2013). The sense of self-efficacy is claimed to be influenced by the colleagues' behaviour, attitudes, approval and encouragement. Essential is that that the educational and working climate is of a challenging nature, yet not stressful (Bates et al., 2013). Smith-Ruig (2013) found that the students considered the WIL workplace to be a good place for taking on new challenges and for testing new things. As the WIL was not a real job, the students perceived that it was more allowed to make mistakes and that the mistakes would not interrupt with their professionalism or career. This is in line with Bates (2003) who found that WIL "forces" the participants to move beyond their own comfort zone. Bates (2003) claims that this trigger the participants to "make sense" of the situation and allow for a more transferable, deep and permanent learning and personal development. Moreover, Bates (2003) found that the learning is stimulated by engagement and commitment, as well as by relevancy. Significant for the learning to become transferable is for the participants to be able to link the new experience with their existing knowledge. Flexibility, changeability, willingness and self-confidence in taking risks (Bates, 2003) as well as a sense of self-efficacy (Bates 2013), are suggested as personality resources providing the participants with both professional and personal learning.

Description of the Roma Empowerment Project

The assessment of a 3-year health promotion project in local settings formed the empirical part of this PhD thesis. The project comprised of two phases: I; mapping, planning, pre-course and analysis (September 2009-July 2010) (Eklund & Crondahl, 2010) and II; implementation (August 2010-July 2012) (Eklund Karlsson & Crondahl, 2012) (See figure 1). The initial content and starting point of phase II was based on the findings of phase I and planned by the main project facilitators LEK and KC. LEK was senior level researcher responsible for the overall scientific design and leadership of the study, curriculum development, teaching and, in cooperation with KC, writing the project reports and articles. KC, the author of this PhD thesis was the main coordinator/action researcher, responsible for the WIL activities and the management of the change and research operations of the project. Additionally four senior researchers were involved in the project, too from the field of public health and social sciences. They were involved in the teaching, data collection, analysis and drafting the papers.

The emphasis in this thesis is on phase II. Below is a summarized description of the project. For a more detailed description of the design of the project, see paper IV.
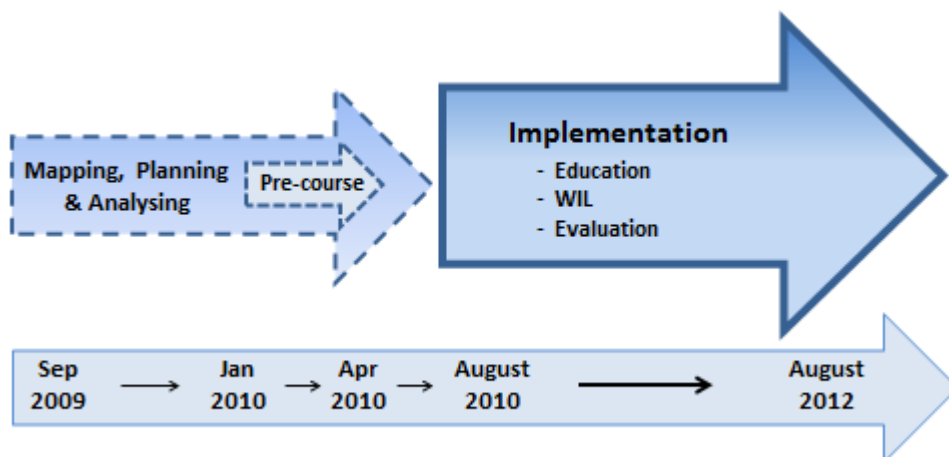

Figure 1. Time schedule of the programme

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In 2009-2012, a health promotion project based on Participatory Action Research (PAR), emphasizing work-integrated learning (WIL) as a tool for Roma empowerment was conducted in West Sweden (paper IV). The overall aim of the project was to enable a group of Roma to take control over their health and life situation, to strengthen sense of community, and to enhance participation and self-led integration in the non-Roma society. The specific aim of phase I was to increase the projects group's understanding and knowledge on Roma people in general, but also regarding Roma peoples' own experiences and perceptions of issues concerning their life situation and involvement in the non-Roma society. Essential was also to establish trust and relationships between the non-Roma project group and the Roma society. This is an important phase in PAR, to get to know each other and to establish trust (Chávez, Duran, Baker, Avila, & Wallerstein, 2008). With the history of the Roma in mind, this is especially important when working with Roma people. According to Minkler (2004), a key step when the initiators of a programme are not members of the priority group/community themselves, is to cooperate with a mediator/gate-keeper from the group of concern. Such a contact person would help the 'outsider' project group in the contact with the community and on behalf of the community be participating in the development of mutual project goals. In this case, the Agnesberg Folk High School in West Sweden became the projects' partner, operating as mediator/gate-keeper. The findings from phase I made the starting point for phase II, the implementation phase (2010-2012).

Training the trainers

Seven Roma were employed and trained to work as local health promotion coordinators and to, through the principle of training the trainers, empower the local Roma community. The work as local coordinators were based on the approach of WIL and consisted of two parts; theoretical WIL training, and the performance of practical WIL training. The theoretical WIL training consisted of monthly reconciliation meetings- and training seminars, including aspects of both theoretical and practical kind, aiming at providing the needed tools for the coordinators to perform their work (the WIL practice). In focus were activities for social change and health promotion; community organizing, participation and empowerment. Throughout the whole process, the programme facilitators (KC and LE) provided support and

guidance to the coordinators, enabling them to perform the WIL practice. The purpose of the WIL practice was for the coordinators to test and to use the working tools provided by the theoretical WIL part. The hypothesis was that adding the knowledge gained from the training seminars and reflecting upon the WIL practice experiences would generate new and developed knowledge and understanding thus increasing the coordinators consciousness.
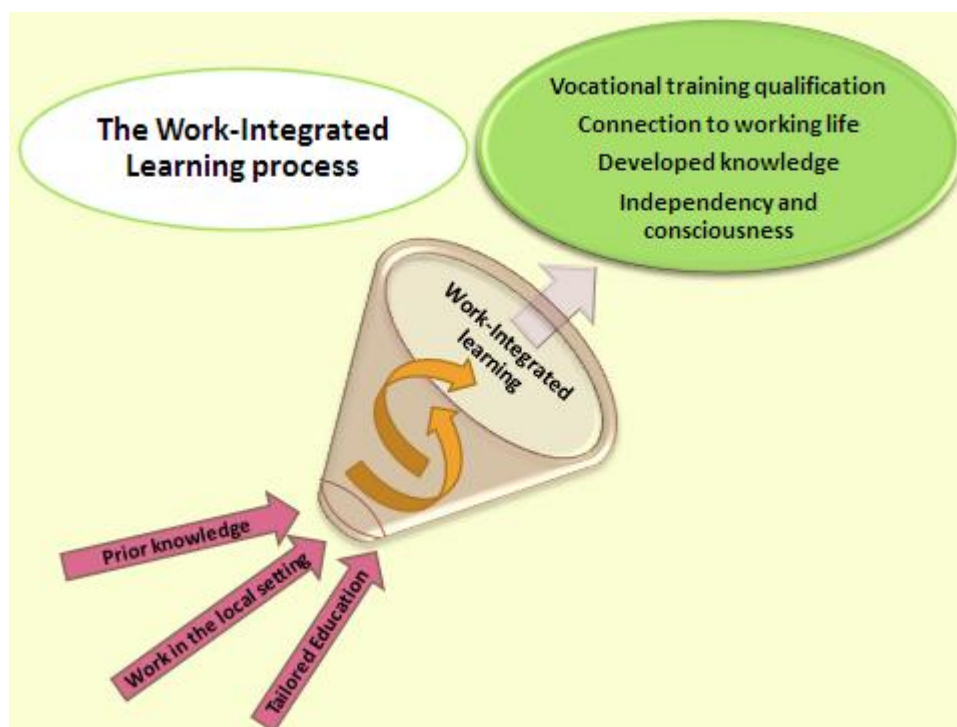
Figure 2. The work-integrated learning process as a spiral and its presumed outcomes

Evaluation of the health promotion project

As the present health promotion project was the point of departure for this doctoral thesis, the evaluation had to meet various requirements; to keep the standard of a good scientific work and to illuminate the scientific qualifications of the thesis author, to meet the requirements of the funding body, and as the project had the approach of PAR, all project participants was to take part of the evaluation process. Thus the evaluation and analysis of the programme were

done in three parallel parts. One part was the scientific analysis done mainly by the author of this thesis KC, and by the project leader of the programme LEK, resulting in paper II, III, IV and V included in this thesis. A second part, and not included in this thesis, was evaluation in accordance with the requirements of the financing body. Two external evaluators, one qualitative and one socioeconomic evaluator were engaged to examine the successfulness of the project according to financing body's measures and requirements. Moreover, monthly, strictly structured reports on the project process and intermediate results as well as a strictly structured final report reporting on the outcomes of the project were written. Before finalising the final project reports, the coordinators checked, corrected and complemented the content of it.

Lastly, a third part was evaluation in consistency with PAR (Springett & Wallerstein, 2008); involving the Roma participants in the evaluation process. Evaluation requires adaptation, matching the evaluation process and approach to the specific context, the people involved and the purposes of the project. As a mean to ensure the bottom-up perspective of the project and to assure the development and quality of the project process and content, the process and content were constantly discussed, evaluated and adapted in cooperation between the Roma coordinators and the project facilitators. The principles guiding the evaluation were participation in the project on equal terms; the evaluation was process- and learning driven and should be supportive to individual empowerment.

Adapting the evaluation process in accordance to the PAR approach, the project group (the facilitators and the employed local coordinators) were at the same time programme evaluators. In addition to having monthly reconciliation meetings, the project group were designated by an open and allowing climate bringing constantly dialogue and reflection. Crucial for the evaluation process to be creative and fruitful is the evaluators' (here the project groups') ability for critical thinking. This requires asking questions on what makes sense. Additionally questions asked were e.g. "How is our reactions/how do we feel about what we do and how we do it? What have been missed? What is needed? What could been done differently? Based on our so far experiences in the project, how should we proceed? How? Why? With who?"

Through asking such questions, the facilitators'/group's own progress and proceeding with the process were intensified and increased hence enhancing new assumptions, hypothesis and testing new ways. This part of the evaluation was an important part of the project as such, yet beyond the scope of this thesis.

Participants and co-researchers

The total number of Roma involved in the project during 2009-2012 was around 355 (205 phase I, 150 phase II). Approximately 40 of these participated in two or more of the various data materials collected, out of which, five have participated in all main events; five of the seven local coordinators. The participants have been participating to different extent in the workshops and other health promotion activities performed in the local Roma communities during the programme period 2009-2012.

Right from the beginning of the project, the Roma participants acted as co-researchers contributing with a Roma perspective. During phase I, the 11 Roma participants of the pre-course collected and analysed data from their own local communities, contributing to the foundation of and health perspective behind phase II. During phase II, the seven Roma local coordinators contributed in the production and the evaluation of the data. About 200 Roma participated in the "future workshops" arranged in the four local Roma communities contributing to data gathering concerning perceptions on local Roma issues in need of improvement.

Overview of the five papers

This section describes the aims, data materials and methods used for the scientific analysis of paper I-V included in this PhD thesis.

Tabel 1. Overview of the data material: aims, number of participants, data collection methods and analysis.

Study period	Preceeding the project: 2009	Phase I: 2009-2010	Phase II & after: 2012- 2014	Phase II: 2010-2012	Phase II + one year after: 2010 - 2013
	Paper I	Paper II	Paper III	Paper IV	Paper V
Aims	Examine how Roma adolescents in West Sweden perceive the concepts of health, well-being and quality of life, and further, to investigate the degree to which they consider themselves able to cope with their own life situation within these areas.	Describe how adult Roma in West Sweden understand health, well-being, and quality of life, within the Roma context, and how they cope with their life-situation.	Analyse whether there is connection between health literacy and empowerment.	Explore how PAR and WIL might function as empowering tools in the Roma social inclusion process, and, to propose a working model to use in empowerment of the Roma minority- and other vulnerable groups in similar situation.	Analyse the HP project from the Roma participants' perspective. The focus was on the participants' perceived individual empowerment and perceptions on their contribution to the common good and community empowerment.
Data	14 Roma adolescents, 8 girls, 6 boys; 6 qualitative interviews: 2 focus groups, 2 paired and 2 individual interviews;	33 adult Roma, 16 women, 17 men; 27 qualitative interviews,	5 peer-revieweed articles	qualitative interviews, self-evaluation reports and written essays by the 7 coordinators, research group's workshop notes, monthly project reports, project plan, syllabus of the WIL training programme and notes from a joint planning workshop	qualitative interviews and self-evaluation reports of the local coordinators and monthly project reports
Method	Qualitative content analysis	Phenomenological hermeneutical method	Scoping review	Hermeneutical understanding inspired by heuristic research	Hermeneutical phenomenological methods

Aims and methods

Paper I

The aims of this study were to examine how a group of Roma adolescents in West Sweden perceive the concepts of health, well-being and quality of life, and further, to investigate the degree to which they consider themselves able to cope with their own life situation within these areas. This study functioned as a pilot study to help refine future interviews with Roma people in West Sweden (paper II).

The study focus was Balkan Roma adolescents in the age of 13 – 18 years. The respondents, eight girls and six boys, were all living in the same area of West Sweden. The choice of adolescents as interviewees was made as they are the tomorrow's students and laborers and it is important to include their perceptions on health issues. The data were gathered via six, about one hour long in-depth interviews; two focus group interviews, two paired interviews and two individual interviews, with a total of 14 interviewees. There were several reasons for the variation of interview form. For cultural reasons as boys and girls according to Roma culture were not to be mixed in the same groups, for practical reasons; the participants did not all know each other and went to different schools, and considering some of the interviewees' young age, it was found suitable to arrange focus group interviews to increase the interviewees sense of feeling calm and relaxed in the interview situation. Additionally, two participants asked specifically for individual interviews. A Romani chib mother tongue teacher working in several schools in the area helped with requiting the adolescents and provided assistance throughout the whole process of interviewing. In order to maintain coherence through the various interviews, all the interviews were done by the same interviewer, the author of this thesis KC. A thematic interview guide was used with themes based on the salutogenic perspective on health (Antonovsky, 1979). The interviews were tape-recorded and transcribed verbatim.

The coding of the data for this paper was done by KC using qualitative content analysis (Elo & Kyngäs, 2008). This approach was found the most suitable as the intention was to identify subjective perceptions and emotions (Bryman, 2008; Denzin & Lincoln, 2008; Salazar, Crosby

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& DiClemente, 2006). In this inductive approach the categories raised from the data thus made the structure for the analysis.

Firstly, the text were read repeatedly to obtain an overall impression of the data. Secondly, words, frases, whole meanings or sometimes several meanings or even whole paragrahps important for the reseach questions were identify, so called open codes. At this point even the latent content was noted. The open coding went on untill no more codes arised. The codes then were structured and labelled into sub-categories. The goal when creating categories is to give an description of the topic investigated and to improve the understanding and the knowledge of the topic (Elo & Kyngäs, 2007). The sub-categories were structured and labelled into categories and the categories into main categories, formed by the four main areas of the research question.

Paper II

The aim was to describe how a group of adult Roma living in in West Sweden understand health, well-being, and quality of life, within the Roma context, and how they cope with their life-situation. The study was the qualitative part of the baseline mapping of perceptions on health and life-situation of Roma living in West Sweden before the implementation phase of the health promotion project.

The study focus was adult Roma living in West Sweden. The sampling was done by convenience- and snowball sampling and with the assistance of a Roma gatekeeper. The data consisting of 27 qualitative interviews with 33 Roma people, were analysed inspired by a phenomenological hermeneutical method (Lindseth & Norberg, 2004). The method is phenomenological in the sense that the researchers try to grasp the meaning of the experiences expressed in the interviews, which then need interpretation. The method is hermeneutical in the sense that it includes dialectic movement between understanding and explanation through reflection towards literature. Lindseth and Norberg (2004) emphasize the researchers pre-understanding as a tool for constantly revising the pre-understandings during the interpretation of the interview texts. However, by bracketing the researchers' judgments about the factual

data, not the pre-understandings however, the researchers become open to the essential meanings implicit in the respondent's expressions.

The analysis started with reading through the material for obtaining a 'naïve understanding' of the text after which the text was divided into meaning units that were condensed and abstracted to form sub-themes and main themes. However, after the first rough filtering of about half of the data, the researchers compared their coding to ensure the validity and reliability of the analysis. In cases of disagreement in coding an item, the coding rules were sharpened in terms of the specification of the codes. After this, the final detailed coding within the main areas of the study was conducted in an inductive manner. The themes were reflected on in relation to the literature after which a comprehensive understanding is formulated. The ATLAS.ti computer programme was used as assistance in the analysis.

Paper III

The aim of the study was to analyse whether there is connection between health literacy and empowerment.

The paper is based on a scoping review conducted by the first author of this paper in December 2013. The purpose of a scoping review is to acquire a better understanding of a phenomenon rather than to obtain a detailed and rigorous answer to a focused question (Arksey & O'Malley, 2005). Unlike systematic reviews, scoping reviews do not assess the quality or design of the included studies and thus may include studies with various approaches. There are four main reasons for undertaking scoping reviews: examining the nature, extent and range of research activity, determining whether a full systematic review would be valuable, summarising and disseminating research findings and revealing research gaps in the existing literature. The latter two were the goals of this literature review. Databases used were ERIC via Ebsco Host (Academic Search Elite, Eric, Medline, Cinahl), PubMed, and Social Sciences Abstracts (SSA, PsykInfo, PsykArticles, Sociological articles). Initial inclusion criteria's were that the articles should be peer reviewed, published in English, available in full text and the key words included in the abstracts. No time limitation was used

as both concepts are relatively new, resulting in matches from 1992-2013. The initial search using the key words empower* and "health literacy" resulted in 101 hits after eliminating duplicates. No abstracts were identified however, meeting the inclusion criteria's. After several attempts, widening and modifying the search and inclusion criteria's, the criteria's were reduced to searching for any content that might help answering the research questions. The initial 101 hits were taken up on again and the abstracts read more thoroughly, resulting in 23 articles to be read in its whole. As the previous literature search had revealed a lack of articles addressing the research question, the one inclusion criteria used for this last step was for the articles to in some way address any connection between the two concepts, health literacy and empowerment. The literature search did not reveal any articles explicitly addressing the issue of how health literacy and empowerment are connected. However, five articles (Mogford, Gould, & DeVoght, 2011; Nutbeam, 2000; Porr, Drummond, & Richter, 2006; Schulz & Nakamoto, 2013; Sykes, Wills, Rowlands, & Popple, 2013) were identified taking up on both health literacy and empowerment. Nutbeam (2000), a frequently used reference within the health literacy field, also was the starting point of the analysis in all these five articles.

Paper IV

The aim of the study was to explore how participatory action research and work-integrated (WIL) learning might function as empowering tools in the Roma social inclusion process. Second, the aim was to propose a working model to use in empowerment of the Roma minority- and other vulnerable groups in similar situation.

The starting point of the study was the above described health promote programme. The main data, the qualitative interviews of the local coordinators were conducted in 2013, one year after the officially end of the programme. Most of the data however, was produced continuously during 2010-2012 and comprised of self-evaluation reports and written essays by the seven local coordinators, participatory observations, research groups' workshop notes, 21 monthly project reports, the project plan, the syllabus of the WIL training programme and

notes from a joint planning workshop. All the data was considered as a whole and analysed using a hermeneutical understanding in a triangulating fashion.

The analysis can be likened as a reflexive journey, circling between the empirical findings and the theory. The road and the final station were created and revealed as the process went on. In this process, the evolving theoretical ideas and explanations were discussed and elaborated, or rejected, by the researcher group before ending up in the model as presented in paper III. The researchers had active and interpretative roles in the constructing of a meaningful explanation, rather than striving for a realist's objectivity in which they risked becoming biased in the search for "the real truth", (Hodkinson, Biesta, Gleeson, James, & Postlethwaite, 2005). Through this subjective approach, the researchers were allowed to make the best use of their insights and experiences, transforming the data into something meaningful. The analytic process was inspired by heuristic research (Kenny, 2012; Moustakas, 1990), exploring phenomena in depth from the researchers' own and personal experiences of the investigated phenomena. During the whole interpretation process, the 'self' of the researcher(s) was present and tacit knowing and intuition considered essential. Regarding the subjective approach of the process, it has been argued that what is important is that the findings are supported by the collected data, that they make practical and theoretical sense and that they might be potential tools for future improvements (Hodkinson et al.,, 2005). Hence in this particular case, that the findings help improve future health, education and integration efforts.

Paper V

The present paper analyses the above described health promotion programme from the seven Roma participants' perspective. The focus is on perceived individual empowerment and perceptions on their contribution to the common good and collective empowerment.

The main data, comprised of qualitative interviews of the Roma participants, were conducted in 2013, one year after the end of the project. The rest of the data were collected continuously during the health promotion project 2010-2012 and consisted of fourteen self-evaluation reports of the seven Roma project participants, participatory observations and 21 monthly

project reports, which were used as complementary data. However, the qualitative interviews, conducted and analysed by the author of this thesis, were audio recorded, transcribed and analysed using ATLAS.ti software. The analysis of the main data was inspired by Lindseth and Norberg (2004)s', and Ajjawi and Higgs (2007)'s, approaches to phenomenological hermeneutic /hermeneutic phenomenology. The purpose was to explore and understand the Roma participants' personal experiences and the subjective meaning of these rather than to reveal objective and true essence of meaning. The focus of the analysis thus lies more in the hermeneutical than in the phenomenological approach; the approach applied for the analysis comes closest to hermeneutical phenomenology. The supplementary data was used for complementing and verifying the findings from the main data.

First step was immersion (Ajjawi & Higgs, 2007) or naïve reading (Lindseth & Norberg, 2004) of the data. Rather than doing a verbatim transcription, the transcribing took the form of naïve understanding. To ensure a trustworthy transcription of this kind, the researcher took on a phenomenological approach, striving for an open-minded and nonjudgmental understanding of the meaning of the data. To validate the naïve understanding, repeatedly throughout the whole analysis process, the recordings and transcriptions were listened to and read simultaneously, ensuring a thoroughly and complete understanding and for making sure that nothing was missed or left out. The researcher's emerging thoughts were noted as memos linked to the relevant text section in the Atlas ti. software. The second step to validate the naïve understanding was performing a structural analysis with the purpose of conveying an "essential meaning of lived experience" (Lindseth & Norberg, 2004, p. 149). Meaning units were identified, descriptive labels were given (rather than abstract concepts), and the meaning units read and reflected on against the whole text thus shortened, detailed and described in everyday words capturing their essential meaning. The process of structural analysis, or stage of abstraction as Ajjawi and Higgs (2007) call it, was done involving the knowledge and interpretation of the researcher. The process was repeated until nothing new appeared thus at the same time, the sub-themes started emerge. The themes then were reflected upon against the naïve understanding hence validating the naïve understanding. These first steps were

conducted directly after each of the interviews thus allowing the researcher to follow up on early ideas and thoughts in the next interview.

Inspired by Gadamer, the interviews and analysis were put aside for eight months, allowing for new perspectives and interpretations to rise. The interviews and analysis then were taken up again and the above process was repeated with additionally meaning units and sub-themes emerging. The analysis process was like the hermeneutical circle; a journey back and forth between the data, analysis, literature and the researcher's pre-understanding, involving a constant move between the whole and the parts. Sub-themes were elaborated, main themes developed and finally, all themes were compared to previous literature. Thus, the researchers understanding of the phenomena/on evolved and the findings were theoretically supported/ validated.

The assessment of the collective empowerment was limited to the subjective perceptions of the seven employed participants' concerning their contribution to the common well.

Ethical Considerations

A special attention has been given throughout the whole research process to protect the participants' integrity even though this thesis does not include any personal data or sensitive information about the participants. The protection of participants' integrity is considered especially important as regard to the Roma history of persecution and the still today marginalised situation. In Sweden, Roma people have status as a national minority group and thus considered a vulnerable group in society. Apart from having special rights for securing the language, traditions and culture, being recognized as a national minority also calls for special efforts from the government, authorities and civil servants regarding protection against discrimination, abuse and other behaviours that may cause harm. Researchers' responsibility is to ensure that the research does not cause any harm for the participants of a research (SFS, 2003).

The thesis is based on an action research project were seven Roma were employed to work as local coordinators. Working as local coordinators, the participants stood up as Roma, giving the Roma a face and a name in the local societies. Thus, the coordinators never were anonymous, but civil servants, yet at the same time, they were also research subjects/study participants as the tradition is in a participatory research. Prior to their employment, they were provided oral and written information about the project, its aims, approaches and possible implications as well as the research processes involved including the principles voluntarily, confidentiality, and usufruct (Humanistic science of society´s scientific council of research, 1990). After receiving this information the coordinators gave a written, informed consent. This procedure was repeated prior to the project evaluation and the final qualitative interviews. An ethical clearance for the programme was maintained by the local ethical committee of the University West (2012/903 B22). The respondents in paper I and II were provided oral and written information about the study and the research implications. They were not asked to sign a written, informed consent. Time and place for the interview where agreed upon and if the respondent showed up and orally consented in the interview after receiving the thorough information about the study and its aims, this was considered as consent for participating in the study. The Roma fear for ethnic registration has been an issue also for previous studies, e.g. FHI (2010), and thus we purposefully opted for an oral informed consent.

RESULTS

Paper I

The results of the study showed that the Roma adolescents considered health as feeling good, being healthy and having good self-confidence. Well-being was expressed in terms of social support, security and happiness, being proud, having financial freedom and as being comfortable with their lives. Factors reported to ensure a good quality of life was feeling well, social network and - support, the freedom to do favourite activities and, education and employment. Health was considered in relation to their overall family- and life situation, most of the interviewees reported to feel fine or good, some stated to feel very good, and they reported to be satisfied with their life situation and living in Sweden. The most common coping strategy was stated to be leaning on social support from family, followed by positive thinking, and to hold on to traditions and life values, helping the adolescents maintaining their self-confidence and self-esteem. The adolescents told that they mostly associated with other Roma and preferred the tight relationship within the Roma community. Hence, in conclusion, a suggestion was that a determinant factor of health can be found in the process of homophily, which seems to be a salutogenic factor and a general resistant resource of the Roma people and thus health-enhancing.

Paper II

The findings showed that the Roma respondents considered having a job and an education as the main factors influencing health. The respondents saw health, well-being, and QoL through a family perspective rather than through individual experiences. Furthermore, the findings indicated that the respondents perceived health as a resource and an ability to self-manage. As reported by the participants, a result of decenniums of oppression is that the Roma have developed what they called as survival strategies. With the help of these, the Roma have, and probably will continue to survive. Anyway, against all odds, despite being discriminated and marginalised, the respondents perceived a good subjective health, well-being, and quality of life. It seems like that the strong sense of community, staying close to family and social

networks, as well as holding on to traditions, were significant parts of the coping mechanism behind that paradox. However, the data also revealed that the respondents went back and forth between the inside (Roma) and outside (non-Roma) worlds, and that their health indicators differed depending on the context they spoke of. And further, at the same time as they described health problems, they argued that they have a good subjective health and quality of life.

Paper III

The findings of the scoping review revealed a gap in research literature concerning the knowledge on the mechanism behind health literacy leading to empowerment. The literature search in electronic databases faced problems in identifying relevant articles and identified Nutbeam (2000) as a frequently used reference within the field of health literacy. Nutbeam (2000) was one of the five final articles to be reviewed in depth and was also used as the starting point of the analysis in all these five articles. This was reported as a bias of the study. However, none of the reviewed five articles addressed the research question in specific.

Based on narrative analysis of the findings and the authors own reflections on the issue (Arksey & O'Malley, 2005), the paper suggest that for health literacy to be critical to empowerment, it requires encompassing the social determinants of health emphasizing peoples subjective perception on health and health needs. Such a perspective will build on the genuine needs of the people involved and for them to be empowered. Functional- and interactive health literacy is suggested as capacity building for health and empowerment, and critical health literacy as yet another way to describe empowerment. Health literacy thus might be regarded as a tool for empowerment, yet it is not considered to automatically lead to empowerment. Being empowered means having reached a state of critical consciousness and social and political engagement; including questioning and reflecting, a sense of power, self-esteem and self-efficacy and an understanding of how to make use of all ones available resources to engage in social and political action. This makes the critical point between health literacy and empowerment.

Paper IV

The findings of this study are two folded; the researchers' reflections on the study design, including a suggested working model for empowerment, and, in the framework of the suggested model, the successes of the PAR and WIL approach is illuminated.

A working model of empowerment for social inclusion?
The findings indicated that the health promotion programme functioned as a platform allowing for higher-level learning processes (interactive and critical health literacy) to take place. The various elements of the programme interacted and intertwined in a way that seemingly led to increased health literacy and empowerment of the local coordinators. The development of health literacy and empowerment occurred in three parallel tracks: 1. the continuation of previous/ongoing basic education, 2. theoretical training on health promotion and social determinants of health, and 3. practical adaptation of the training in work. The participants' interactive health literacy increased as a result of the PAR that involved training efforts (track 1 and 2). Also the participants' critical health literacy developed, allowing them to experience a greater control over their own lives and integration processes through their improved abilities to mobilise the local Roma community for social change (track 3). The results indicated an increased empowerment of the local coordinators.

The assessment of PAR, WIL and health literacy as tools for empowerment
An important factor behind the local coordinators development was according to themselves the WIL approach. As they were first trained in relevant topics and then had the opportunity to directly test this out in reality, they felt more competent in performing their work. Through the WIL approach, their skills and knowledge improved and their self-confidence, self-esteem and sense of independence increased. The combination of WIL and PAR was reported as having a positive influence on the coordinators learning process and personal development. The coordinators reported to have felt being trusted by, and equals with the non-Roma colleagues, additionally factors strengthening them and improving their self-esteem and sense of independence. The working climate was perceived as good, open and permissive, making the

coordinators feel treated like co-workers and equals. Working in groups was stated to be inspiring, developing, strengthening and increasing their self-confidence.

Being *employed* rather than just *participating* made the coordinators feel like equals with the non-Roma programme employees, increased their self-esteem, made them feel important and, feeling like role models in their local Roma society. Key issues and strengths in the project were the emphasis on a bottom-up perspective and equality. With a starting point of different cultures, norms and values, the process was not free of challenges, thus highlighting the importance of such approaches in reaching an understanding of each other's views, instead of making them obstacles.

Paper V

The findings demonstrated that the WIL approach, the participating nature of the programme, and the trust and support from the Roma colleagues and the non-Roma facilitators, were essential for the Roma participants' development of empowerment. Three main themes emerged portraying the participants' psychological empowerment: Strengthened Roma identity, sense of power and sense of enculturated social inclusion. These showed as attributes indicating increased sense of control and learned hopefulness and as a strengthening of: self-acceptance, (self-esteem, self-confidence); internal locus of control (sense of personal development potential, independence) self- and political efficacy (questing, arguing), cultural awareness and critical political- and societal consciousness including motivation for, and involvement in, social and political action, and enhanced sense of (Roma) community as well as participation in the non-Roma society. Despite limited time and resources for local community-directed activities, the participants felt that improvements were made at the local level.

Sense of enculturated social inclusion was a significant finding, demonstrating the participants "new" way of understanding social inclusion; turning social inclusion from something they feared to something they embraced. As the participants realized and perceived, that social

inclusion does not require them the let go of their Roma identity and culture, their Roma identity was strengthened, they became more hopeful, felt more in control and felt generally better. Hence, a suggestion is that the Roma way towards self-led integration might be through a process of enculturated social inclusion.

DISCUSSION

Serendipities

The results of paper I show that the Roma adolescents considered health, wellbeing and quality of life in social, cultural, economic and environmental terms and in relation to their overall family- and life situation. Rather than individualistic behavioural factors like e.g. eating habits, physical activity and smoking, the emphasis was on factors like self-confidence and proudness, freedom and security (including not being bullied or discriminated against), education and employment, and social network and – support. Leaning on social support from family was the most common coping strategy followed by positive thinking and holding on to traditions and life values, the latter two perceived by the adolescents to enable the maintenance of sense of self-confidence and self-esteem. Despite having personally experienced being bullied and discriminated, the adolescents expressed feeling good. The adolescents mostly associated with other Roma and preferred the tight relationship within the Roma community. Rostila (2010) refer to this as homophily "the phenomenon that people principally form relationships with those who are similar to them". The paper concludes with the suggestion that a determinant factor of health can be found in the process of homophily, which seemed to be a salutogenic factor and a general resistant resource for the Roma adolescents' and thus health-enhancing.

Paper II confirms several of the findings from paper I. The findings show that education and employment are considered as keys to a better health, that health, well-being, and QoL are seen through a family - rather than an individual perspective, and in terms of social, cultural, economic and environmental factors rather than behavioural and clinical factors such as e.g. blood pressure, cholesterol or illness. Despite personal experiences of being discriminated and marginalised, and contrary earlier research (Hassler & Eklund, 2012; WHO, 2012), just like the Roma adolescents, also the adult respondents expressed perceiving good subjective health, well-being, and quality of life. An explanation may be the adult respondents' perception of

health as a resource and an ability to self-manage, serving as a coping strategy. The strong sense of community, staying close to family and social networks and holding on to traditions seemed to be significant parts of their coping strategies. The findings indicated that the respondents felt good and confident when being within their Roma community; positive feelings that seemed to decline when stepping out of their safe and secure Roma network. It was concluded that the findings indicate that the perceptions on health and wellbeing take place within the process of identity construction.

Paper III reveals what seems to be a gap in the research literature. The connection between health literacy and empowerment are acknowledged in scientific literature (Nutbeam, 1998; Mårtensson & Hensing, 2012). Still, as to the knowledge of the authors and shown in this study, what constitutes the nexus between the two and the mechanism behind health literacy leading to empowerment, has yet not been verified by empiria, questioned nor discussed in detail. Rather, the relationship seems to be taken for granted. However, based on the findings of this paper, health literacy is suggested to be capacity building for health and empowerment through functional and interactive health literacy. Reaching the highest level of health literacy, critical health literacy, that is when people are empowered. The emphasis is on the involved peoples' subjective perception on health and health needs, encompassing the social determinants of health. These are also in line with findings of paper IV.

Paper IV describe and propose a work-integrated learning model (based on paper I and II and experiences and findings from the health promotion project) for improving the empowerment of individual Roma as well as other vulnerable and/or marginalised groups in similar situations, allowing for greater control over the integration process. Health literacy was proposed as a catalyst, serving as a tool for analysing and describing the empowerment process. The findings demonstrate how the Roma participants' health literacy developed as a result of the WIL approach. Significant for their development was the continuously alternated theory and practice and the combination with PAR. Herein lies also the programmes' identified key issues and strengths; the emphasis on equality and bottom-up perspective, focusing on the Roma people' own health perspective and needs.

Paper V confirms the findings from paper III and IV. The effects of the applied WIL model might be likened as a positive spiral of increasing sense of control, enculturation and learned hopefulness. The engine behind the spiral seemed to be the improving health literacy levels, enhancing the participants' cultural awareness, self-efficacy, sense of control and motivation for working with Roma issues.

The participants' empowerment was portrayed as strengthened Roma identity, sense of power and sense of enculturated social inclusion. This indicates that the suggested WIL model in paper IV, comprising of health literacy as a tool (health literacy as capacity building, based on the participants subjective perspectives and needs; paper III) and a participatory approach, might be a worthwhile strategy in empowering Roma people and enhancing their self-led social inclusion process

Discussion on the findings

A threefold issue

The research on the Roma peoples' health is limited in Sweden as well as in the rest of Europe. The research that has been carried out has mostly focused on quantitative, objective and clinical measures that concluded that the Roma in virtually all concerns, have lower health status than those of the non-Roma population. This could be questioned though. Firstly, Roma is not a homogenous group why it is not possible to compare Roma with Roma in general; the health of Roma living in Sweden should not be compared with the health of Roma living in other European countries. Many European Roma live under greatly different living conditions than Roma in Sweden, and are consequently, facing different daily issues and health problems. Thus, comparisons of different groups should be used for highlighting widespread general problematic situations rather than as confirmation of specific problems. Secondly, the research that has been done has focused on measuring blood pressure, the degree of physical activity, lack of education etc, which then becomes the primary focus of health interventions. However, people living under poor living conditions do not focus on such issues. As commented in

Estacio (2013: 1064)'s study, 'how can you expect us to fill our brains when our stomachs are empty?' Clearly, these have implications for the undertaking of health initiatives pointing at the importance of focusing on the genuine needs and perspectives of the specific group in question. Thirdly, as demonstrated in paper I and II, the question of Roma health might be a question of homophily (paper I) and identity construction (paper II). Rostila (2010) claim that social networks comprising of people with various origin, culture, and so on, are the most health enhancing, while Hyppää (2007) on the other side, claim that homogenous social networks are the most health enhancing. Both paper I and II of this thesis found that the Roma prefer relationships with Roma rather than non-Roma as this makes them feel safe and relaxed. When being with other Roma they know what is expected of them and they can be themselves. Also, paper II indicates that the Roma perceive their health and wellbeing as good when they are within their Roma community, while stepping outside this safe area, reduces their wellbeing. This is in line with Hassler and Eklund (2012) and points to homophily as an health enhancing factor in the case of Roma.

Towards empowerment and social inclusion

People choose with whom they want to associate; a natural choice is people who make them feel good, safe and happy. Being part of a (positive) social network is health-enhancing (Hyppää, 2007) and might function as a generalized resistance resources (GRR) and coping strategy (Antonovsky, 1987). According to Portes (1998), among immigrants, family support and the preservation of the home country's culture might counterweight the negative impact of loss of outside community bounds. This seems to be what the Roma has done as a survival strategy for centuries; fighting the acculturation and counterweighting the historically treatment, discrimination and oppression that has led to the todays constructed history and marginalised situation of Roma people. If being a part of the non-Roma society meant to let go of the Roma identity, then they did not want to be a part of it; isolation from the non-Roma society was the only choice. The findings of this thesis indicate that Roma homophily might be a health enhancing factor helping the Roma to cope with the discrimination and oppression. However, in the long run, this probably is not a healthy situation as the Roma still feel weaker and more powerless in the non-Roma society. Overcoming this complex situation, the WIL

model described in paper IV (fig. 4, p. 56 in this thesis) is suggested as a worthwhile strategy. Paper V demonstrate the effects of the WIL model as a positive spiral of increasing enculturation, sense of control and learned hopefulness. Together with the WIL approach, the participatory nature of the programme, the trust and support from the non-Roma facilitators and Roma colleagues as well as to feel being respected as humans and be equal were found to be essential for the participants' development of empowerment (paper IV and V).
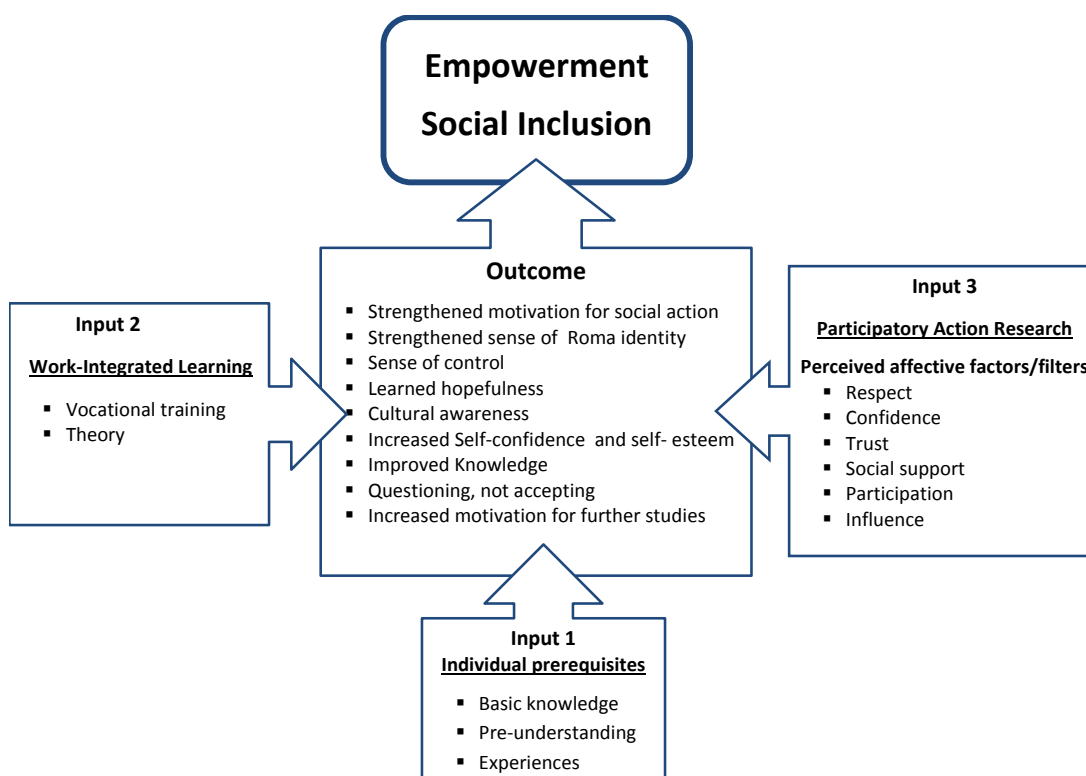
Figure 3. Illustration of the input and outcome of the project

In paper III it is concluded that when based on the specific health needs of the people in focus, basic/functional- and interactive health literacy is the same as capacity building for health and might then lead to empowerment. The proposed WIL model in paper IV is built on this premise. In paper II it was found that the health needs of the Roma are to be found in the

social determinants of health rather than within the individualistic health behaviour. This made the starting point for the health promotion project and the included theoretical WIL training education. This is important; the theoretical WIL education provided to the local coordinators in the programme was adjusted in accordance to the specific health needs and wishes of Roma living in West Sweden and to the group of employed coordinators themselves. Also the activities directed at the local Roma communities were direct result of the communities own wishes and needs. Hence, all programme activities at all levels were directed at the specific needs of the involved Roma. This was an essential characteristic of the described programme and an aspect behind health literacy enhancing empowerment. If the WIL education had been focused at individual health behaviours like eating habits, exercising and smoking stop, the outcome probably would not have been the same. Paper IV and V demonstrate the successfulness of the WIL model and confirm the suggestion in paper III that functional and interactive health literacy is capacity building for health and empowerment. This was showed by findings portraying the local coordinators empowerment as strengthened Roma identity, sense of power and sense of enculturated social inclusion (paper V). This indicates that the suggested WIL model (paper IV), comprising of health literacy as a tool (health literacy as capacity building, based on the participants subjective perspectives and needs; (paper III) and a participatory approach, might be a worthwhile strategy in empowering Roma people and enhancing their self-led social inclusion process.
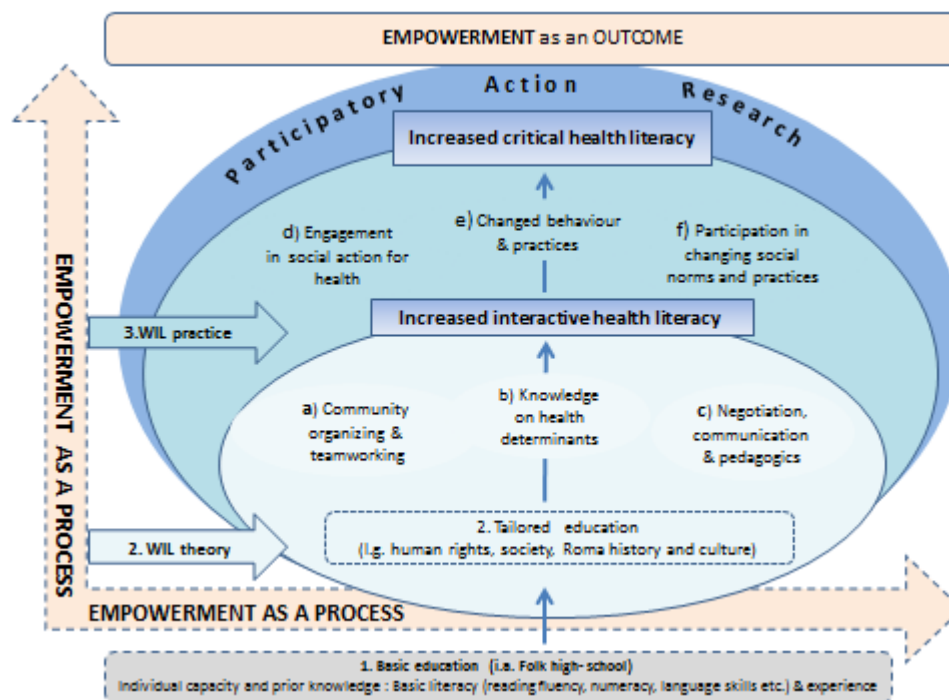
Figure 4. Working model of WIL, PAR and health literacy as catalysts for empowerment

From acculturation to enculturation

Roma people have been used with being forced into relations of dominance and sub ordinance, requiring them to let go of their heritage culture to the benefit of that of the non-Roma society (Montesino, 2010; SOU, 2010). This is what has been called as acculturation (Kincheloe et al., 2011; Soldier, 1985). This is also the case in the today's integration debate concerning Roma. Most often the debate is articulated and desired by non-Roma, not taking into consideration the Roma peoples own perspective, health-enhancing homophily, traditions and culture as described in paper I. The question is whether such integration, on the premises of the non-Roma, is good or bad?

Roma people want to integrate, but not on the cost of their Roma identity as showed in paper V and also by Eklund and Crondahl (2010) and the UNDP (2003). The integration process has to be on their premises too and not only those of the non-Roma population and society, as

acculturation. Opposite to acculturation is the process of enculturation: The process by which individuals learn about and identify with their traditional ethnic culture (Soldier, 1985). Enculturation may also be a state: "… the extent to which individuals identify with their ethnic culture, feel a sense of pride in their cultural heritage, and participate in traditional cultural activities" (Zimmerman, Ramirez-Valles, Washienko, Walter, & Dyer, 1996: 296). Acculturation has been related to stress and negative health outcomes whiles enculturation to health, coping, happiness, (Wolsko, Lardon, Mohatt, & Orr, 2007) and self-esteem (Zimmerman et al., 1996).

The findings demonstrate that the local coordinators' Roma cultural awareness and Roma identity were strengthened, thus they were enculturated. An assumption is that through strengthened Roma cultural awareness and identity (enculturation) the perception of control improved which showed as improved self-esteem, self-confidence and turning from accepting to questioning. Improving peoples' sense of control and impact requires consideration of the historical, cultural, social, political and economic contexts in which they live (Israel et al., 1994). A noteworthy finding was that the Roma participants' perceptions on inclusion changed during the programme. Rather than being something they feared, inclusion became a process they embraced. The coordinators realized that they did not have to 'acculturate', but could 'enculturate'. This made them feel more in control, hopeful and generally better. Suggested in paper V is that enculturation is a process that through the individual's perception of control might influence the sense of learned hopefulness. Contrary, through the sense of lack of control, the process of acculturation might trigger the sense of learned helplessness.

A finding related to the participants' enculturation process, shown in paper V, was changes in the participants' attitudes and behaviour, and what we have labelled as 'internalised racialization'. This term points to a tendency to embody the socially constructed and suppressive perception of their Roma identity; 'internalising' the racialization they perceived from the non-Roma society. The internalised or embodied racialization portray itself as e.g. self-hate and blaming "negative" behaviour on the Roma ethnicity. However, a finding was that the participants "internalised racialization" clearly reduced, or even disappeared during

the programme period, and instead the participants developed towards a sense of enculturated social inclusion and empowerment.

Enculturation might also be linked to health literacy; presuming a relationship between enculturation, learned hopefulness and perception of control. In paper III, health literacy is suggested as capacity building for health, emphasising the social determinants of health and in paper IV, as a tool for empowerment which through building on the genuine needs of the people involved, enhance empowerment. Empowered people have the power to fight the oppression that is holding them down (Askheim, 2007). So, health literacy might function as a tool in the processes of enculturation and social inclusion/integration. The integration process needs to proceed slowly, enabling for the Roma to perceive not being discriminated but considered as equals and accepted as they are, enhancing a feeling of security and safety; factors that was pointed out as influencing Roma health and well-being in paper I and II, and also by the FHI (2010). Thus for Roma, a possible road towards self-led integration might be through a process of enculturated social inclusion.

Power relations

The power disparity and its consequences become explicit in the case of Roma people. For generations, the Roma have had to relate to the construction that resulted in them being regarded as a group of unwanted and less worthy people than non-Roma. Living with such labels has severe consequences and influences the Roma individuals' personality in a large extent. The way many Roma tend to normalize their marginalized situation and the among many Roma widespread learned helplessness leading to giving up before even trying as shown in paper I and II, are only two examples of the results of the constructed history of Roma. Roma isolating themselves from the rest of the society, having low trust in others outside their own community and fear for authorities as also demonstrated in paper I and II, and in line with earlier research (Crondahl & Eklund, 2012; Palmroth & Hermansson, 2006; SOU, 2010) are other examples. For generations, the Roma people have been regarded as "the weaker" group and inferior to the non-Roma (SOU, 1923, 2010), as lower educated (FRA & UNDP, 2012; SOU, 2010) and as having worse health than the non-Roma (Hassler and Eklund, 2012; Parry

et al., 2007; WHO, 2012). The question is, who sets the standards and who decides on the measurements? It probably is not a black, Muslim, Roma woman! This is a question of power relations and influences not only the way non-Roma look at Roma, but also the way that the Roma look at themselves; manifested as e.g. learned helplessness (paper II) and "internalized racialisation" (paper V). However, throughout the present health promotion project emphasis always was on the participants' points of view and their perspectives, and equality between the facilitators and the local coordinators. This thesis demonstrates how a change in perspective might influence the participants' self-image, behaviour and attitudes. Also, through ambitions of equality between the facilitators and the local coordinators the power relations were minimized (paper IV and V). Yet how much we strive, we all are humans that are influenced by our past and the constructed world around us, hence the power relations can never be totally erased. Essential is though, to be aware of the constructions, the power relations and the consequences of such in order to overcome them as much as possible, striving for equity and equality.

Discussion on the methodology

In the best of all worlds, when doing PAR, all the principles of PAR are followed from the very beginning until the end. In reality though, it usually does not work like that as the principles are not applicable in every situations and interventions (Israel et.al. 2008). The present PAR is not an exception. A lot of issues may be discussed concerning PAR. Some are both methodological and ethical considerations at the same time as the process of PAR is both the method and the project at the same time. For this reason, in the following text it might sometimes be difficult to completely distinguish between the two.

A principle within traditional research is that the method are supposed to be repeatable and the findings generalizable. Doing PAR, it is not possible to just copy a project or intervention from one setting to another. The major focus of PAR is the local setting with place-, personal- and time specific goals. The local setting differs from place to place with different people and different knowledge and values. Transferring an intervention from one place to another

becomes impossible without adjusting it to its new contextual conditions (Springett et al., 2011). Participatory action research, with its hermeneutic perspective is a dynamic process requiring constantly dialoguing, reflecting and re-thinking putting the local context and the participants in the first row. The process itself is part of the outcome and the outcome would not have been the same without the equal and interactive relationship between the group members. As a project coordinator in the present health promotion project I worked close to the participants like an "equal" colleague rather than a leader. This provided me with highly valuable insight regarding the participants' development process as well as their perceptions on Roma issues. Some of these insights are documented in written words, but most of them are carried inside me, constituting a new way of interpreting the world.

An important issue for researchers to take into consideration is what part, or how big part of the participants' world do they have access to? Researchers will probably never have full access to the study phenomena, but through cooperation and shared knowledge with the participants, they may deepen their understanding of the world (Minkler & Duran, 2008). The understanding of the world is based on education and previous experiences, but also on the history. Successful PAR interventions acknowledge the importance of the history (Chávez et.al. 2008) and especially regarding the relationship between the researchers and the community. One might think that the relationship starts with the project, but it does not. The relationship started way back in the history (Chávez et.al. 2008). When it comes to Roma people, this is a fundamental issue. As the Roma have been marginalized and excluded for more than thousand years, and researchers, authorities and civil servants have had a central role in the categorizing of the Roma in more than one negative way, it would be of outmost importance to acknowledge this as influencing the relationship. The Roma people's distrust towards non-Roma civil servants, authorities and researchers was shown in paper II and was also established by earlier studies (DO, 2003; Montesino, 2010, SOU 2010). In PAR, the relationship between the partners is relying on mutual respect, dialogue and sharing of lived realities (Chávez et.al. 2008). It is not hard to understand that the researchers need to "work" hard to be trusted and respected by the Roma. The trust and respect can only be built by showing a true respect and interest for those issues identified by the Roma themselves, as

demonstrated by the findings of this thesis (paper IV and V) and earlier stated by Palosuo (2008). Using the PAR approach, attention should be brought to issues like ethnicity (race), culture, gender and class which influences and intertwines with the aspects of research enterprise (Minkler & Wallerstein, 2008). One can never be an expert in another culture, that can only the culture bearers themselves. What one can do however is to be humbled by others' cultures. That is, one should be open for a genuine cooperation, for the learning and reflection on the others cultures as well as for the biases they bring along. Without the culture humility, I would say implementing a decent PAR is difficult.

Strengths and limitations

Paper I is based on my master thesis and served as a pilot for paper II. The data in paper I, based on a rather small sample (N=14) were collected previous the upstart of the present health promotion project. The qualitative content analysis was done by me alone. There is neither possible to draw any conclusions from a sample of 14 respondents, nor to generalize. These might be regarded as limitations of the study. However, none of these were the aims of the study; the study served as a pilot and generalization is seldom the aim of qualitative inquiry. Aspects still pointing at the trustworthiness of the study though are that the findings of the study later were confirmed by the findings of paper II as well as by additional studies (Alex & Lehti, 2013; FHI, 2010). Furthermore and contrary paper I, paper II is based on a larger sample (N=33) and analysed through phenomenological hermeneutic by four researchers, me included. Together, these are assumed to strengthen the trustworthiness of both studies, paper I and II.

Paper III is based on a scoping review analysed through narrative-review approach. The initial literature search faced difficulties in identifying relevant articles. Arksey and O'Malley (2005) emphasize reflexivity and an iterative research process, thus the review process were adjusted and repeated along the road. This is assumed to have strengthened the trustworthiness of the study. The dependability (reliability) was ensued by describing the research process in a clear and detailed way, enabling the replication by others. Anyway, even after adjustments and

repetitions, only five articles were identified as somewhat relevant for the review. This might be a question of bias, or quite simply demonstrate a scientific research gap.

In paper IV, a hermeneutical understanding of the project process and content was applied in a triangulating fashion. As I as both a project facilitator and an action researcher had been very much involved in the project and the participants throughout the whole project period, the analysis of the data was inspired by heuristic research, allowing for making use of myself and personal experiences of the phenomena question. This means that I as a researcher in no matters am objective. My opinion as a qualitative researcher is however, that being objective in this kind of inquiry is both impossible and unwanted. Stating objectivity would call for bias. The question is then; does this paper reveal the one and only truth? The answer is no. What I have revealed is my truth about the effectiveness of the project and the working model as I interpret it. As a criticalist and constructionist, I believe that there are many different realities and that the truth changes with time. So in another time, and with another interpreter, what is to be revealed from the data might be different. However, with another interpreter and another time, even the participants will be different and hence the prerequisites for the study will look all different.

The qualitative interviews of the local coordinator I analysed by myself. I was not alone however in interpreting the project process and the content leading up to the suggested model. That was done by additionally one researcher. This and the findings of the study being in line with earlier studies on WIL (Bates, 2013; Freudenberg, 2010, Purdie et al., 2011), PAR (Springett et al., 2011) and empowerment (Wallerstein, 2006; Wiggins, 2011), enhances the trustworthiness of the study.

The analysing method applied in paper V is based on a mix of hermeneutical phenomenology and phenomenological hermeneutic. As the purpose was to explore and understand the Roma participants' personal experiences and their subjective meanings rather than to reveal any objective and true essence of meaning, the focus was more on the hermeneutical than the phenomenological approach. The approach thus came closest to hermeneutical

phenomenology. The analysis was done in several steps and validated throughout the process (for details, see paper V). In any cases of invalidation, the entire process was repeated until validation occurred. As a mean to enhance the trustworthiness of the analysis, in a "Gadamerian" fashion, the interviews and analyses were put aside for eight months, allowing for new perspectives and interpretations to arise, before the final analysis was done. The analysis process was described in a detailed and clear way, ensuring the dependability (reliability) of the study. Additionally an aspect enhancing the trustworthiness of the study is the confirmation of the findings by earlier studies in empowerment (Rissel, 1994; Zimmerman & Rappaport, 1988; Zimmerman, 1990), WIL (Bates, 2003; Smith-Ruig (2013) and by Freire (1996).

CONCLUSION AND PERSPECTIVES

The overall aim of this doctoral thesis was to analyse and elaborate a work-integrated learning model to be applied in empowerment and adult education for the Roma minority- and other vulnerable groups in similar situation. Achieving this, a health promotion project based on participatory action research (PAR), emphasizing work-integrated learning (WIL) as a tool for Roma empowerment was conducted.

The findings demonstrate that when based on the specific health needs of the people involved, basic/functional- and interactive health literacy together comprise the same idea as capacity building for health that might lead to empowerment. What found to be essential for the Roma local coordinators development of empowerment was the combination of the WIL approach, the participatory nature of the project, the trust and support from the non-Roma facilitators and Roma colleagues, and the perception of being respected as human beings and as equals.

The local coordinators empowerment consisted of strengthened Roma identity, sense of power and sense of enculturated social inclusion. This indicates that the suggested WIL model/approach, comprising a participatory approach with health literacy as a tool may be a worthwhile strategy in empowering Roma people and enhancing their self-led social inclusion process. A possible road for Roma self-led integration, hence, might be through a process of enculturated social inclusion. This may also be the case for other vulnerable groups in similar situations.

Future implications
Participation, influence in the society and economical and social safety have been pointed out as fundamental for public health development by the Swedish National Institute of Public Health (FHI, 2012). These are areas that the Swedish Roma are lacking (SOU, 2010). The UNDP (2003) has pointed out that improving the living conditions of vulnerable groups is not only beneficial to the priority group, but equally benefits also the majority population; hence

efforts addressing the issue must be regarded as long-term investments. Through strengthened empowerment and sense of social inclusion, the presented WIL model may be a worthwhile strategy for improving the Roma situation.

Further a suggestion is that the presented WIL model/approach might be used not only as a model for empowerment and adult education, but also as a model for social inclusion and integration. Many immigrant groups with differing backgrounds, calls for a more individual- or group- oriented approaches in integration and social inclusion processes. The presented WIL model with its bottom-up perspective focusing on the individual/group needs and perspectives may provide a starting point for such an approach. However, the model presented in this thesis, needs to be further tested in order to be elaborated upon and for the findings to be verified.

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