

JYU DISSERTATIONS 506

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**Leena Hassinen**

# **Funktionaalinen tapauskuvausmalli ja psykologiset interventiot kuurosokeiden ja kuurojen henkilöiden hyvinvoinnin lisäämiseksi**

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UNIVERSITY OF JYVÄSKYLÄ  
FACULTY OF EDUCATION AND  
PSYCHOLOGY

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Esitetään Jyväskylän yliopiston kasvatustieteiden ja psykologian tiedekunnan suostumuksella  
julkisesti tarkastettavaksi Agoran auditoriossa 2  
huhtikuun 23. päivänä 2022 kello 12.

Academic dissertation to be publicly discussed, by permission of  
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JYVÄSKYLÄN YLIOPISTO  
UNIVERSITY OF JYVÄSKYLÄ

JYVÄSKYLÄ 2022

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Cover picture: Osmo Perttula Juhannusmaisema 9/02, savityö

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ISBN 978-951-39-9104-3 (PDF)

URN:ISBN:978-951-39-9104-3

ISSN 2489-9003

Permanent link to this publication: <http://urn.fi/URN:ISBN:978-951-39-9104-3>

## ABSTRACT

Hassinen, Leena

A case formulation model for the assessment and promotion of psychological wellbeing in deafblind and deaf persons

Jyväskylä: University of Jyväskylä, 2022, 66 p.

(JYU Dissertations

ISSN 2489-9003; 506)

ISBN 978-951-39-9104-3 (PDF)

The present research aimed to apply the functional case formulation strategy and analytic case formulation model known as the functional analytic clinical case diagram (FACCD) to describe and understand the behavioral problems and causal variables associated with problems in the population with hearing and vision impairments. The aim of Study I was to describe the group of deafblind people from a psychological perspective by gathering both the knowledge and practical experiences of individuals with hearing and visual impairments. The aim of Study II was to investigate how deafblind people experiencing multiple psychological problems were assessed by healthcare professionals who were trained in functional analyses and in applying FACCD. Two case examples were given to illustrate the complexity of a deafblind person's life situation and the functional relations among problems and possible causal variables. Study III presented a case example of the behavioral assessment and treatment of a person with Prader-Willi syndrome, hearing and vision difficulties, a mild learning disability, diabetes, depression, chronic pain, and an overweight BMI. This case example showed that although inherited disorders cannot be cured, psychological interventions can significantly increase the quality of life of people afflicted with them. Study IV investigated the usefulness and effectiveness of brief treatments delivered by staff members of a rehabilitation center for deaf clients. Staff members ( $n = 9$ ) were trained in acceptance and commitment therapy (ACT) and provided treatment to deaf clients. The results showed positive changes in wellbeing among the deaf clients as well as among the staff members. In sum, the results showed that a clinical case formulation model such as the FACCD can be a useful tool when selecting targets for the treatment of people with vision, hearing, and communication problems and when making further treatment decisions. The findings showed that deafblindness and deafness can be associated with psychological problems that may benefit from more precise psychological assessment and treatment. Thus, cognitive behavioral assessment and intervention procedures should be applied more in assessment and treatment to increase the quality of life of these minority groups.

*Keywords:* Deafblind, deaf, functional clinical case diagram, psychological intervention, cognitive behavioral therapy, acceptance and commitment therapy.

# TIIVISTELMÄ

Hassinen, Leena

Funktionaalinen tapauskuvausmalli ja psykologiset interventiot kuurosokeiden ja kuurojen henkilöiden hyvinvoinnin lisäämiseksi

Jyväskylä: Jyväskylän yliopisto, 2022, 66 s.

(JYU Dissertations

ISSN 2489-9003; 506)

ISBN 978-951-39-9104-3 (PDF)

Tämän tutkimuksen tarkoituksena oli soveltaa funktionaalista tapauskuvausmallia (Functional Analytic Clinical Case Diagram, FACCD) kuvaamaan ja ymmärtämään käyttäytymisongelmia ja näihin vaikuttavia tekijöitä henkilöillä, joilla on kuulemisen ja näkemisen ongelmia. Lisäksi tavoitteena oli selvittää, kuinka tapauskuvausmalli voidaan yhdistää kognitiiviseen käyttäytymisterapiaan perustuviin interventioihin ja kehittää siten tälle ryhmälle suunnattuja psykologisia interventioita. Osatutkimus I antoi yleiskatsauksen kuurosokeiden henkilöiden psykososiaalisesta ja psykoterapeuttisesta kuntoutuksesta ja havainnollisti psykologisia interventioita kahden kuvitteellisen esimerkin avulla. Osatutkimuksen II tarkoituksena oli tutkia, voidaanko kuurosokeiden kanssa työskentelevät terveydenhuollon ammattilaiset kouluttaa hyödyntämään psykologisia analyysimenetelmiä, kun he arvioivat kuurosokeiden henkilöiden tilannetta. Tapauskuvausmallien avulla saatiin yksilölliset kuvat 21 kuurosokean henkilön tilanteesta. Osatutkimuksessa II kuvattiin kahden tapausesimerkin kautta kuurosokean ihmisen elämäntilanteen monimutkaisuutta, kun analyysin avulla oli saatu esille ongelmat ja niihin vaikuttavat tekijät. Osatutkimus III esitteli tapausesimerkin psykologisesta arvioinnista ja hoidosta henkilöllä, jolla on kuulo- ja näköongelmia sekä Prader-Willin oireyhtymä. Koska kuurojen tai kuurosokeiden psykoterapiaa tai psykologista hoitoa on vaikea järjestää, osatutkimuksessa IV koulutettiin palvelukeskuksen henkilökuntaa hyödyntämään tapauskuvausmallia ja psykologisia interventiomenetelmiä. Kokeiluun osallistui yhteensä 16 asiakasta ja 9 työntekijää, jotka tapasivat kutakin asiakasta 8–10 kertaa. Tulokset osoittivat, että vaikka kuuroilla asiakkailla oli useita psyykkisiä ongelmia, heidän psykologiset oireensa vähenivät henkilökunnan tarjoaman intervention aikana. Yhteenvedon voidaan todeta, että työn tulokset osoittivat tapauskuvausmallin olevan hyödyllinen työkalu kuurosokeiden ja kuurojen henkilöiden kuntoutuksessa. Kuulo-, näkö- ja kommunikaatio-ongelmien lisäksi kuurosokeus tai kuurous voi liittyä monenlaisiin psyykkisiin ongelmiin, jolloin tarkemmasta psykologisesta arvioinnista voi olla hyötyä interventioita suunniteltaessa. Siksi kognitiivisen käyttäytymisterapian arviointi- ja interventiomenetelmiä tulisi soveltaa enemmän näiden ryhmien elämänlaadun parantamiseksi.

*Avainsanat:* kuurosokea, kuuro, funktionaalinen tapauskuvaus, psykologinen interventio, kognitiivinen käyttäytymisterapia, hyväksymis- ja omistautumisterapia

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## ESIPUHE

Tämän väitöskirjan alkusanat lausuttiin vuonna 2000 Granadassa kognitiivisen käyttäytymisterapian kongressissa, johon osallistuin psykoterapiakoulutuksen ryhmäläisten kanssa. Professori Stephen Haynesin pitämä luento funktionaalisesta tapauskuvausmallista toi suuren oivalluksen niin itselleni kuin muillekin. Ymmärsin heti, että tämä on juuri sitä, mitä tarvitaan kuurosokeiden asiakkaiden ongelmien kokoamisessa.

Olin erityispedagogiikan opintojen jälkeen vannonut, ettei minusta tule tutkijaa. Tein graduni yhdessä Pirkko Rytkösen kanssa kuurojen ja kuurosokeiden tulkkipalvelusta 80-luvun alussa. Sen jälkeen työ näiden ryhmien parissa vei mennessään. Kipinä tutkimuksen tekemiselle syttyi kuitenkin kiinnostuksesta kuurosokeiden kommunikaatioon. Aloittelin aiheesta tutkimusta Johanna Meschin väitöskirjan innoittamana ja professori Jarkko Hautamäen ohjauksessa. Molemmat ovat toimineet tämän työn esitarkastajina, ja professori Johanna Mesch on lupautunut vastaväittäjäkseni. Kiitän sydämestäni molempia ja olen iloinen siitä, että ympyrä näin sulkeutuu.

Väliin on mahtunut paljon muutakin. Psykoterapiakoulutuksen yhteydessä Joensuussa lähdin hakemaan kuurosokeiden kanssa tehtävään kuntoutustyöhön teoreettista viitekehystä ja tein jatko-opintoja erityispedagogiikan laitokselle. Aloitin myös kuurosokeiden elämänpiirin tutkimusta, mutta se ei oikein ottanut tuulta, kunnes oivallus syttyi Granadassa! Tutkimus siirtyi tapaustutkimuksen suuntaan, ja sain ohjaajiltani kannustusta jatkaa aiheen parissa.

Ensimmäisen artikkelini kirjoittamiseen osallistuivat professori Stephen Haynes, dosentti Tero Timonen ja professori Raimo Lappalainen. Kaikki ovat omalla panoksellaan ohjanneet väitöskirjaani. Stephen kävi myös Suomessa luennoimassa ja antoi toiseen artikkeliini arvokasta tietotaitoaan, mistä olen hänelle todella kiitollinen. Teron kanssa veimme teoriaa käytäntöön ja koulutimme Kuurosokeiden toimintakeskuksessa Tampereella alan työntekijöitä funktionaalisen käyttäytymisanalyysin käyttöön, mitä on kuvattu kolmannessa artikkelissa. Muistan lämmöllä yhteisiä automatkojamme halki Suomen!

Koulutustyön mahdollistivat Kuurojen Palvelusäätiön kaksi projektia, josta sydämellinen kiitos säätiölle; Mieli-projekti ja Psykososiaalisen tuen projekti, joka toteutettiin yhteistyönä Honkalampi-säätiön ja Suomen Kuurosokeat ry:n kanssa. Prosessista vastasivat Marja-Leena Saarinen ja Eeva-Marja Loukola, jotka loivat hyvät puitteet työskentelylle. Lämmin kiitos molemmille sekä myöhemmin mukaan tulleelle Jouni Riihimäelle. Projekteissa ohjasin myös erilaisia ryhmiä ja tapasin monia kuurosokeita ja kuuroja asiakkaita terapiatyön lisäksi. Asiakkaitten kohtaaminen onkin ollut yksi kantava voimavara ja on sitä edelleen. Tähän ja väitöskirjatyössä jaksamiseen on tullut erityisesti tukea Hannele Salomaalta ja Anneli Tynjälältä sekä muilta kollegoilta Tampereella ja Jyväskylässä.

Koska väitöskirjani alkoi painottua entistä enemmän psykologiaan, ”loikkasin” erityispedagogiikan puolelta Joensuusta jatkamaan työtäni Jyväskylän yliopiston psykologian laitokselle. Tällöin professori Raimo Lappalaisesta tuli pääohjaajani. Raimon taito auttaa artikkelien kirjoittamisessa ja kannustaa

tekemiseen on ollut avainasemassa. Hän on myös "down to earth" - ihminen ja tuntee tutkimustyön lisäksi käytännön koulutus- ja terapiatyötä. Näitä yhdistimme, kun koulutimme Kuurojen Palvelusäätiön Sampolan ohjaajia hyväksymis- ja omistautumisterapian menetelmien käyttöön. Tämän intervention tulokset on dokumentoitu neljännessä artikkelissa. On erityisesti Raimon ansiota, että tämä väitöskirja on nyt valmis, mistä olen hänelle ikuisesti kiitollinen.

Sain psykologian laitokselta pariin otteeseen tutkimusapurahan, mistä haluan kiittää lämpimästi laitoksen johtoa. Lisäksi tutustuin Raimo Lappalaisen jatko-opiskelijoihin. Oli todella kannustavaa saada kirjoittaa yhdessä ja jakaa väitöskirjatyön iloa ja tuskaa. Kävimme Raimon ohjauksessa kirjoittamassa viikonloppuja tai "kirjoitusviikkoja" niin Suomessa kuin ulkomaillakin. Nämä jaksot olivat paitsi luovalle prosessille huikean hienoja, myös huikean hauskoja. Muistot hymyilyttävät edelleen, ja osa tuosta ryhmästä on kulkenut kanssani siitä lähtien. Sydämellinen kiitos Anu Kangasniemi, Riikkasisko Kirjonen, Katariina Keinonen ja Päivi Lappalainen. Loppumetreillä ovat Anu, Katariina ja Päivi kannustaneet ja antaneet hyviä neuvoja. Päivi on tehnyt paljon työtä väitöskirjani kanssa oikolukemalla tekstiä. Riikkasisko on avustanut artikkeleiden esille kaivamisessa.

Koko väitöskirjaprosessin ajan ovat ystävät jaksaneet kannustaa ja tukea. Kiitos meidän "Ylirasittuneiden" eli entisten kuulovammaistyöntekijöiden ryhmälle: Aune Kulmala, Päivi Lehtinen, Helena Nieminen-Ortiz, Raili Ojala-Signell, Ritva Sandelin, Marjaana Suosalmi sekä Päivi Fredäng. Aune Kulmalalle kuuluvat mitä suurimmat kiitokset, koska hän ohjasi minut kuurosokeiden pariin. Kuurojen tai kuurosokeiden työn kautta ovat tulleet myös läheiset ystävät Liisa Romo, Airi Kärpänen, Antti Mäkipää, Marjo Nikkola, Hilikka Heiskanen, Elina Lehtomäki, Saili Korhonen, Marja Virtajoki-Tyrväinen sekä Anna-Maija Löytty. Elina, Hilikka ja Marja antoivat arvokasta palautetta työstäni. Opiskeluajalta ovat läheiset ystävyys-suhteet säilyneet Anne Hujalaan ja Riitta Pakariseen. Kiitos tuosta ja naurun täytteisistä tapaamisista!

Kirjoittamisen viimeiset kaksi vuotta ovat olleet korona-aikaa. Kiitos Marjo-Riitta Olander, Pirkko Riikonen, Elina Argillander ja Henri Hekanaho sekä Pertti Vehkavuori. Teidän apunne on ollut korvaamatonta, että keho ja mieli ovat pysyneet tänä haastavana aikana kunnossa ja energiaa on riittänyt väitöskirjaan.

Lopuksi palaan synnyinkaupunkiini Joensuuhun. Koulutoverini Pirkko Erämetsä, Leea Häkkinen ja Lea Kilpeläinen, tätini Arja Laine ja Sirkka Martikainen sekä serkkuni Liisa Laine, Sari Martikainen ja Seppo Martikainen ja vaimonsa Marita ovat seuranneet kiinnostuneina ja ihmetelleetkin työn etenemistä. Viimeisimmäksi halusin jättää tärkeimmät tukijani eli isäni Eskon ja äitini Meerin. Valitettavasti kumpikaan ei ole enää näkemässä väitöskirjani valmistumista ja väitöstilaisuutta. Molemmat ovat kannustaneet minua lapsesta asti opiskelemaan, ja siitä olen heille ikuisesti kiitollinen. Koen myös, että karjalaisuudessa olen perinyt sitkeyden ja elämänilon. Ilman huumoria en selviäisi! Kiitänkin kaikkia edellä mainittuja erityisesti huumorin täytteisistä hetkistä!

Jyväskylässä 3.3.2022

Leena Hassinen



## ALKUPERÄISARTIKKELIT

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- III. Hassinen, L., Lappalainen, R., & Timonen, T. (2012). A case formulation: Psychological assessment and treatment of a person with a Prader-Willi syndrome and hearing and visual difficulties. *International Journal of Mental Health and Deafness, 2*.
- IV. Hassinen, L., & Lappalainen, R. (2018). Acceptance and commitment therapy using Finnish sign language: Training counselors in signed ACT for the deaf. A pilot study. *Journal of Contextual Behavioral Science, 8*, 74-81.

Olen kirjoittanut alkuperäisartikkelin I. Artikkeleissa II-IV olen kirjoittanut kuurosokeiden ja kuurojen osuudet ottamalla huomioon muiden tekijöiden antamat kommentit. Artikkelissa II professori Stephen Haynes antoi arvokkaan panoksensa tapaustukimusta koskevissa osioissa. Artikkeleissa III-IV ovat muut kirjoittajat lukeneet ja kommentoineet tekstiä, minkä olen ottanut huomioon. Tutkimusaineiston olen kerännyt itsenäisesti.

## KUVIOT

KUVIO 1	Laajan funktionaalisen tapauskuvauksen malli (alkuperäinen FACCD Haynes, O'Brien & Kaholokua, 2011). Kaaviossa X = alkuperäinen muuttuja, jota ei voi muuttaa, X <sub>1-5</sub> vaikuttavia tekijöitä, Y <sub>1-3</sub> käyttäytymisongelmia ja Z <sub>1-2</sub> ongelmien seurauksia. Nuolilla osoitetaan eri tekijöiden väliset kausaalisuhteet ja eri symbolien viivan paksuudella niiden vaikuttavuuden vahvuus. ....21
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# 1 JOHDANTO

Ihmisten kokema psyykkinen hyvinvointi on heikentynyt viime vuosina ja psykoterapian tarve on samalla lisääntynyt. Vuonna 2020 Kelan yleisin kuntoutustoimenpide olikin psykoterapia (Kelan kuntoutustilasto, 2020). Alle 65-vuotiaat henkilöt, joilla on vamman tai sairauden vuoksi huomattavia vaikeuksia selviytyä arjen toiminnoissa ja osallistua niihin ovat oikeutettuja Vaativaan lääkinälliseen kuntoutukseen. Tähän kuuluu myös osa kuurosokeiden tai kurojen ryhmästä. Kuntoutuksen tavoitteena on, että henkilö pystyy sairaudesta tai vammasta huolimatta tekemään töitä tai selviytymään arkielämän toiminnoista paremmin. Vaativaa lääkinällistä psykoterapiaa saaneita henkilöitä oli vuonna 2020 tehtyjen myönteisten päätösten mukaan 5593 (Kelan kuntoutustilasto, 2020).

Psykoterapiaan hakeutuvilla on usein samanaikaisesti useita ongelmia, esimerkiksi fyysisiä sairauksia tai kielellisiä vaikeuksia, jolloin hoidon kannalta tilanne on monimutkaisempi verrattuna siihen, että apua haetaan yhteen yksittäiseen ongelmaan, esim. fobiaan (Glickman, 2009a; Hassinen, 2009). Kuurosokeiden tai viittomakielisten kurojen psykologisten ongelmien määrästä ei ole tarkempaa tietoa olemassa, mutta voidaan olettaa heilläkin esiintyvän useita elämän haasteita samanaikaisesti. Esimerkiksi kommunikaatiovaikeudet tai vaikeudet tiedon saamisessa ja liikkumisessa voivat heikentää elämänlaatua

Psykoterapiatyössä ja kuntoutustyössä joudutaan punnitsemaan asiakkaan ongelmien arviointitapoja, jotka parhaiten kuvaisivat kunkin yksilöllistä tilannetta. Tällöin otetaan huomioon niin henkilön heikkoudet kuin vahvuudetkin sekä interventiolle asetetut tavoitteet (Haynes ym., 2011). Lisäksi tulisi löytää tapa koota eri tietolähteistä löytyvä aineisto. Yksi tällainen on laaja-alainen funktionaalinen analyysi (Functional Analytic Clinical Case Diagrams, FACCD; Haynes ym., 2011; Haynes & O'Brien, 2000; Lappalainen, ym. 2007;). Mallista käytetään nykyään suomeksi termiä funktionaalinen tapauskuvaus. Se on kehitetty nimenomaan tilanteisiin, joissa asiakkaalla on paljon erilaisia ongelmia. Ongelmia kartoitetaan käyttäen erilaisia tietolähteitä ja ne kootaan visuaaliseen, graafiseen muotoon. Tätä kautta niin asiakkaan itsensä kuin työntekijöiden on helpompi hahmottaa ongelmat ja niihin vaikuttavat tekijät. Lisäksi voidaan löytää ne seikat, joihin voidaan vaikuttaa ja löytää niihin soveltuvat interventiot.

Tässä tutkimuksessa on sovellettu Haynes ym. (2011) ja Haynes & O'Brien (2000) analyysimallia kuurosokeiden ja niiden kuurojen henkilöiden kuntoutustyöhön, joilla on monenlaisia ongelmia. Analyysien perusteella tehdyt interventiot perustuvat kognitiiviseen käyttäytymisterapiaan (esim. Heimberg ym., 2008; Lehtonen & Lappalainen, 2005) ja hyväksymis- ja omistautumisterapiaan (esim. Hayes ym., 1999; Hayes & Smith, 2008; Lappalainen ym., 2004;).

## **Kuurosokeat**

Kuurosokeutta eli yhdistettyä kuulo- ja näkövammaa tarkastellaan nykyisin toimintakyvyn näkökulmasta, jolloin korostuvat henkilön yhteiskuntaan osallistuminen ja suoriutuminen sekä vastaavasti yhteiskunnan ympäristö- ja palvelujärjestelyt (Pohjoismainen kuurosokeuden määritelmä, 2011). Tämä pohjautuu WHO:n (2001) julkaisemaan toimintakyvyn, toimintarajoitteiden ja terveyden kansainväliseen ICF-luokitukseen, International Classification of Functioning, Disability and Health (Paltamaa & Anttila, 2015). Kyseisessä luokituksessa toimintakyvyllä tarkoitetaan laajaa ja kokonaisvaltaista näkemystä selviytymisestä tärkeistä arjen toiminnoista siinä ympäristössä, jossa ihminen toimii. Toimintakyky kuvaa sitä, miten sairauden ja vamman tai kontekstuaalisten tekijöiden yhteisvaikutukset näkyvät ihmisen arjessa ja elämässä. Kontekstuaalisia tekijöitä ovat erilaiset yksilön ulkopuoliset ympäristötekijät, kuten fyysinen, sosiaalinen ja asenneympäristö sekä yksilölliset tekijät, kuten ikä, sukupuoli, elämäntavat ja luonteenomaiset käytöspiirteet.

Vuonna 2011 uudistetun Pohjoismaisen määritelmän mukaan kuurosokeus on erityinen kuulon ja näön toimintarajoitteiden yhdistelmä, joka rajoittaa henkilön suoriutumista ja täyttä osallistumista yhteiskuntaan siinä määrin, että se edellyttää yhteiskunnalta tukea erityispalveluihin, ympäristön mukauttamiseen ja/tai teknisten apuvälineiden saamiseen. Määritelmässä on lähtökohtana kuvata ominaisuus "kuurosokeus", joka on vain yksi henkilön ominaisuuksista. Määritelmä keskittyy toimintaan, osallistumiseen sekä ympäristöön ja sen merkitykseen, kun taas aikaisemmin tarkasteltiin lähinnä yksilöä ja hänen vammautumistaan.

Kuurosokeus aiheuttaa mukauttamistarpeita erityisesti seuraavissa toiminoissa: tiedonsaanti, sosiaalinen vuorovaikutus ja kommunikaatio, tilaan orientoituminen ja itsenäinen liikkuminen sekä jokapäiväisen elämän taidot ja tarkka lähityöskentely, mukaan lukien lukeminen ja kirjoittaminen (Pohjoismainen kuurosokeuden määritelmä, 2011). Tiedonsaannissa korostuvat kaukostaisten alenemisen vuoksi tunto-, haju- ja makuaisti sekä kinestetikka (liikemallien ja aistitoimintojen ymmärtäminen) ja haptiikka (kokonaisvaltainen liikkeeseen perustuva tiedon hakeminen ympäristöstä), kuten myös muisti ja päättelykyky (Lahinen, 2008; Pohjoismainen kuurosokeuden määritelmä, 2011). Erilaisissa tilanteissa kuurosokeus vaikuttaa henkilön toimintaan eri tavalla, jolloin jokaista toimintaa ja tilanteesta selviytymistä on arvioitava erikseen.

Ympäristön mukauttamisen ja erityispalvelujen tarpeisiin vaikuttaa se, missä vaiheessa kielen kehitystä aistien toiminta on alkanut heiketä, mikä on

kuulon ja näön toimintarajoitteiden aste sekä onko kuurosokeus muuttumaton vai etenevä. Kuurosokeana toimimiseen ja osallistumiseen vaikuttavat sekä yksilöön että ympäristöön liittyvät tekijät. Kuurosokeiden henkilöiden osalta palvelujen tuottaminen ja ympäristön muutostyöt edellyttävät moniammatillisia työtapoja ja erityisosaamista kuurosokeudesta. Erilaisia ratkaisuvaihtoehtoja on suunniteltava yhteistyönä niin, että toteuttamisvastuu on yhteiskunnalla. (Paltamaa & Anttila, 2015; Pohjoismaainen kuurosokeuden määritelmä, 2011)

Suomen kuurosokeiden henkilöiden lukumäärää ei tarkkaan tiedetä, koska kuulo- ja näkövammaan yhteisvaikutusta ei aina tunnisteta. Näkövammarekisterissä oli vuonna 2018 yhteensä 1005 henkilöä, joilla oli näkövamma lisäksi kuulo- ja näkövamma (Ojamo, 2018). Suomen Kuurosokeat ry:n arvion mukaan Suomessa on noin 800 kuurosokeaa. Kuurosokeutumisen syitä ovat ikääntymisen aiheuttamat näön ja kuulon alenemat, eri oireyhtymät, kuten CHARGE ja Usherin syndroma sekä erilaiset sairaudet ja onnettomuudet ([www.kuurosokeat.fi](http://www.kuurosokeat.fi); Lahtinen, 2008; Rouvinen, 2001).

## **Kuurot**

Suomessa on n. 4000–5000 henkilöä, jotka ovat kuuroja ja käyttävät viittomakieltä äidinkielenään (Malm & Östman, 2000). Kuurojen yhteisöön kulumisen ja siihen hyväksytyksi tulemisen kannalta tärkeitä tekijöitä ovat yksilön asennoituminen myönteisesti viittomakieleen, kuurouteen ja kuurojen kulttuuriin (Jokinen, 2000). Kuurojen ryhmä ei ole yhtenäinen, niin kuin eivät ole vähemmistöryhmät yleisestikään. Sen sisällä on monenlaisia alaryhmiä, joilla saattaa olla vaikeuksia liittyä kuurojen yhteisöön ja saada tarvittavat palvelut. On myös muistettava, että kuurojen yhteisön merkitys ei yhteiskunnan muutosten myötä ole enää niin vahva kuin aiemmin (Jokinen, 2000; Luukkainen, 2008)

Kuurojen ryhmän sisällä olevasta vähemmistöstä on yhtenä esimerkkinä Corbettin (2003) kuvaus erilaisiin etnisiin ryhmiin kuuluvista kuuroista naisista, jotka olivat taustaltaan mm. latinalaisamerikkalaisia, afrikkalaisamerikkalaisia tai aasialaisia. Heidän viittomakielentaitonsa vaihteli, mikä vaikutti siihen, että he jäivät ulkopuoliseksi ja arjen käytäntöihin vaikuttavista tiedoista paitsi. He tasapainoivat etnisen identiteetin ja kuurojen yhteisön identiteetin välillä, jolloin saattoi tulla yhteentörmäyksiä. Corbett (2003) nostaa esille myös vaikeudet tiedon saamisessa liittyen perheen sisäisiin tapahtumiin sekä oman terveyden hoitamiseen. Mielenveysongelmat lisäsivät ulkopuolelle jäämistä entisestään.

Osalla viittomakielisistä henkilöistä on muita kielellisiä vaikeuksia, esimerkiksi dysfasiaa ja liitännäisvammoja, kuten näköongelmia, CP-vammaisuutta ja kehitysvammaisuutta (Lindfors, 2005). Nämä vaikuttavat myös henkilön viittomakielen ja puhutun kielen kehitykseen. Glickman (2009a ja 2009b) huomauttaa, että vaikeampi ongelma on kielen kehittyminen erilaisissa kielellisissä ympäristöissä kuin se, että kuurot käyttävät viittomakieltä ja kuulevat eivät. Suurin osa (n. 90 %) kuuroista syntyy kuuleville vanhemmille (Takkinen & Rainó, 2016), joten vanhemmat joutuvat valitsemaan, opettelevatko he itselleen vieraan kielen ja miten he siirtävät sen lapselleen. Lapsen kasvaessa koulutusvalinnat ja –

mahdollisuudet (esim. viittomakielinen ympäristö) vaikuttavat osaltaan kielen kehittymiseen, samoin kuin lapsen mahdolliset liitännäisvammat (Marschark & Spencer, 2010). Glickman (2009a) kuvaa yhtenä tällaisena ryhmänä henkilöitä, joita voidaan kuvata termillä ”perinteisesti vähän palveluja saaneet”. Long ym. (1993), mukaan ”perinteisesti vähän palveluja saanut” tarkoittaa henkilöä, joka on kuuro ja hänellä on rajalliset kommunikaatiotaidot. Henkilö ei voi kommunikoida tehokkaasti puheella, huulioluvun avulla tai viittomakielellä, ja hänen puhutun kielen taitonsa ovat heikot. Lisäksi henkilöllä voi olla puutteita sosiaalisissa taidoissa ja tunne-elämän säätelyssä sekä ongelmanratkaisukyvyssä. Tuen tarvetta voi olla työ- ja asumisjärjestelyissä, erityisesti siirryttäessä itsenäiseen asumiseen. Glickmanin (2009a) mukaan henkilöillä, joilla on edellä mainittuja kielellisiä haasteita ja oppimisvaikeuksia on yleisesti neurologisia, emotionaalisia ja käyttäytymisen ongelmia. He tarvitsevat terapeuttisempaa ja viittomakielistä ympäristöä, jossa on muita viittomakielisiä asiakkaita sekä viittomakielistä henkilökuntaa 24 tuntia vuorokaudessa. Corbettin (2003), Glickmanin (2009a ja 200b) ja Longin ym. (1993) kuvaukset kuurojen ryhmän heterogeenisuudesta on hyvä huomioida puhuttaessa kuurojen ryhmästä tässä työssä.

## **1.1 Kommunikaatio kuurosokeiden ja kuurojen hyvinvointia edistävänä tai heikentävänä tekijänä**

Monilla kuurosokeilla henkilöillä on kommunikaatiotilanteissa käytössään usean kommunikaatiotavan yhdistelmiä, varsinkin näkö- ja kuulovamman muuttumisen aikana (Taulukko 1).



TAULUKKO 1 Yhteenveto kuurosokeiden kommunikaatiotavoista (Hassinen, 1998; Lah-  
tinen, 2004).

<b>Viittomakieliset</b>	<b>Puhekieliset</b>
Viestien vastaanottaminen	Viestien vastaanottamiseen
Näön avulla:	Kuulon ja näön avulla:
<ul style="list-style-type: none"> <li>■ viittominen vapaassa tilassa</li> <li>■ viittominen lähelle</li> <li>■ viittominen ”putkeen”</li> </ul>	<ul style="list-style-type: none"> <li>■ puhe</li> <li>■ huulioluku</li> </ul>
Näkö ei riitä viestien vastaanottami- seen:	Kuulo ei riitä viestien vastaanottami- seen:
<ul style="list-style-type: none"> <li>■ taktiili viittominen</li> </ul>	<ul style="list-style-type: none"> <li>■ huulioluku</li> <li>■ viitottu puhe</li> <li>■ sormiaakkoset</li> <li>■ kirjoittaminen paperille tai tietoko- neella</li> </ul>
	Näkö ei riitä viestien vastaanottami- seen:
	<ul style="list-style-type: none"> <li>■ puhe</li> </ul>
	Näkö ja kuulo eivät riitä viestien vas- taanottamiseen:
	<ul style="list-style-type: none"> <li>■ viitottu puhe taktiilisti</li> <li>■ sormiaakkoset taktiilisti</li> <li>■ pistekirjoitus</li> </ul>
Viestien tuottamiseen	Viestien tuottamiseen
<ul style="list-style-type: none"> <li>■ viittominen vapaassa tilassa</li> <li>■ taktiili viittominen</li> </ul>	<ul style="list-style-type: none"> <li>■ puhe</li> </ul>

Taulukossa 1 on kuvattu erilaisia kuurosokeiden kommunikaatiomenetelmiä. Kuurosokeista henkilöistä enemmistö eli noin kaksi kolmasosaa käyttää puhekielistä kommunikaatiota (Kuurosokean kommunikointi, 1991; Pohjoismainen kuurosokeuden määritelmä, 2011). Tällöinkin puhetta on usein hidastettava, jotta kuurosokea henkilö kuulee selvästi, koska näkövamma vuoksi hän ei voi aina käyttää huuliolukua apuna puheen selventämisessä (Kuurosokean kommunikointi, 1991). Kuulo ja näkö voivat myös olla alentuneet niin paljon, että on käytettävä muita kommunikointitapoja. Henkilö voi viestiä vastaanottaessaan tarvita kirjoittamista (paperilla tai koneella), tikkukirjainten tekoa kämmenelle, pistekirjoitusta, sormiaakkosia, viittomia tai usean eri tavan yhdistelmää. Sormiaakkoset tai viittomat voidaan myös tehdä taktiilisti, jos henkilö ei näe enää riittävästi niiden lukemiseksi. Muilla menetelmillä kuin puheella kommunikoiminen hidastaa vuorovaikutusta. Sormiaakkosten käytön yhteydessä on havaittu, että sekä visuaalisesti että taktiilisti sormitettaessa kommunikointi on neljä-viisi kertaa hitaampaa kuin puheella kommunikoitaessa (Fuglesang & Mortensen, 1997). Puhuttua kieltä käyttävä kuurosokea vastaa usein itse puhumalla, vaikka puhe aikaa myöten saattaa muuttua, kun kuulovamma etenee. Tutut ihmiset saavat yleensä puheesta selvää, mutta vieraille se voi olla vaikeaa (Kuurosokean kommunikointi, 1991).

Kuurosokeiden henkilöiden kommunikaatiomahdollisuuksia voidaan lisätä sisäkorvaistutteilla (Möller, 2003), jotka yleistyivät Suomessa vuodesta 1997 alkaen niin kuulovammaisten lasten kuin aikuistenkin kuntoutuksessa (Kuuloliitto.fi). Sisäkorvaistute eli sisäkorvaimplantti on leikkauksessa asetettava kuulopuväline henkilöille, joille akustinen kuulokoje ei enää riitä kuulemiseen tai puheen erottamiseen. Istutejärjestelmä koostuu ulkoisista osista sekä leikkauksessa asetettavista sisäisistä osista (Kuuloliitto.fi). Istutteella voidaan saavuttaa hyvä puheentunnistuskyky vaikea-asteisessa kuulovauriossa (Dietz ym., 2018). Sisäkorvaistutetta on käytetty myös kuurosokeiden henkilöiden kuntoutuksessa. Kuurosokeana syntyneiden lasten osalta istute voi avata uuden kommunikaatiokanavan, mikä voi mahdollistaa myös puheen ja kielen oppimisen. Kuurosokeutuneilla istute voi vähentää eristäytyneisyyttä helpottamalla kommunikaatiolanteita (Möller, 2003).

Äidinkieleltään viittomakieliset henkilöt ovat oppineet kielen lapsuudessaan tai viimeistään koulussa ja olleet mukana kuurojen yhteisössä. Näön hiljalleen heiketessä henkilön tiedonsaanti rajoittuu ja kapeutuu. Putkinäön vuoksi kuurosokea ei enää seurata, kuka viittoo ja mitä viitotaan. Eri valaistusolosuhteet vaikeuttavat myös viittomisen näkemistä. Viittomakieleen olennaisesti liittyvien ilmeiden näkeminen hankaloituu. Tällöin ei esimerkiksi saa selvää kysymysilmaisuuksiin olennaisesti liittyvästä ilmeestä. Kun kuurosokeus on edennyt niin pitkälle, että siirrytään taktiiliin viittomiseen, on kuurosokea henkilö sosiaalisissa tilanteissa tiedon saannissa toisen ihmisen varassa. Tieto tulee hänelle aina toisen ihmisen, esimerkiksi tulkin kautta. Tällöin kuurosokea henkilö tarvitsee paitsi tietoa siitä, mistä puhutaan, myös siitä, kuka puhuu, miten, millaisella äänenpainolla hän puhuu, minkä näköinen puhuja on kyseessä, keitä muita on paikalla, mitä tapahtuu ja millaisessa tilassa ollaan (Hassinen, 1998; Miner, 2002).

## **1.2 Kuurosokeiden ja kuurojen henkilöiden psykologinen hyvinvointi**

Kuurosokeiden henkilöiden psykologisia ongelmia on tutkittu vain vähän. Espanjassa tehtiin vuoden 2017 aikana laaja hyvinvointikartoitus (Pardhan ym., 2017), jossa analysoitiin 23089 vastausta 15–103-vuotiailta henkilöiltä ja tutkittiin erikseen kuulo- ja näkövamman tai yhdistetyn kuulonäkövamman vaikutuksia mielialaan. Kaikilla tutkimukseen osallistuneilla havaittiin sekä ahdistuksen että masennuksen kohonneita arvoja. Henkilöillä, joilla oli yhdistetty kuulo- ja näkövamma, vakavampiasteisen ahdistus- ja masennusoireilun todennäköisyys oli suurempi. Näiden henkilöiden elämässä oli lisäksi tekijöitä, jotka vaikuttivat mielialaan, kuten vaikeuksia ihmissuhteissa, jokapäiväisen elämän askareissa, riittämätöntä ravinnon saantia sekä fyysisen aktiivisuuden vähenemistä. Pardhan ym. (2017) korostivat, että on tärkeä havaita ajoissa masennukseen vaikuttavia tekijöitä, ehkäistä mielenterveyden häiriöitä ja käyttää sopivia hoitokeinoja.

Kuurojen hyvinvoinnista ja psykologisista ongelmista on sekä kotimaisia että kansainvälisiä tutkimuksia. Osa näistä tutkimuksista on tehty koko viittomakielisestä väestöstä (esim. Lindfors, 2005) ja osa tiedosta on hankittu psykiatrisista yksiköistä tai psykoterapioista (esim. Glickman, 2009). Suomessa kartoitettiin kuurojen viittomakieltä käyttävien henkilöiden psykologisia oireita vuosien 2002–2004 välisenä aikana (Lindfors, 2005) ja havaittiin hieman kohonneita arvoja verrattuna väestöön yleensä. Yleisimmät psykologiset ongelmat kuuroilla olivat yksinäisyys sekä masennus- ja ahdistusoireet, joita havaittiin joka neljänellä vastaajalla. Tämä luku on hieman suurempi kuin keskimäärin Suomen väestössä.

Kansainvälisesti on usein viitattu Vernon & Daigle-Kingin (1999) tutkimukseen, jossa tarkasteltiin psykiatrisessa sairaalahoidossa olevien kuurojen mielen-terveysongelmia eri maissa ennen vuotta 1994. Yhteenvetona todettiin, että kuurojen mielen-terveysongelmat olivat yleisempiä kuin kuulevilla, mutta ero oli kohtalaisen pieni. Ohre ym., (2011) kokosivat katsauksen vuosina 1995–2011 julkaistuista tutkimuksista, joissa tarkasteltiin syntymästä saakka kuurojen aikuisten ryhmää. Tutkimuksista viisi koski kuurojen ryhmää yleisesti (mm. opiskelijat, kuurot aikuiset, kuurojen yhdistyksen jäsenet) ja kuusi psykiatrisessa avohoidossa tai sairaalahoidossa olleiden kuurojen henkilöiden ryhmää. Tulokset eivät tukeneet aikaisempia havaintoja kuurojen henkilöiden ja kuulevien mielen-terveysongelmien eroista. Toisin sanoen kuurot henkilöt eivät olleet haavoittuvampia ja eikä heillä ollut enemmän psykiatrisia diagnooseja verrattuna kuuleviin. Avohoidossa tai sairaalahoidossa olevilla kuuroilla sen sijaan ahdistus ja masennus vaikuttivat olevan yleisempiä kuin kuulevilla henkilöillä. Tutkitut ryhmät edustivat kuitenkin tiettyä alaryhmää tai maantieteellistä aluetta. Ohre ym. (2011) toteavat, että tutkimusten perusteella johtopäätösten tekeminen psykiatrisista oireista ja sairauksista sekä niiden esiintyvyydestä kuurojen ryhmässä on vaikeaa. Tähän vaikuttavat tutkimukseen valittujen valintakriteerit sekä tutkimusryhmien ja vertailuryhmien edustavuus ja sopivuus. Ajan myötä tutkimukset ovat parantuneet menetelmien ja erityisesti arvioinnin ja niihin liittyvien mittareiden osalta. Tulosten yleistettävyys koko kuurojen ryhmään on kuitenkin kyseenalaista.

Lindforsin (2005) tekemässä suomalaisessa tutkimuksessa havaittiin, että tarve saada keskusteluapua ongelmiin oli selvästi korkeampi henkilöillä, jotka käyttivät viittomakieltä verrattuna väestöön yleensä. Apua haluttiin erityisesti työhön liittyviin asioihin sekä ihmissuhdeongelmiin ja muihin psyykkisiin ongelmiin. Kokemukset kuurojen psykiatriselta poliklinikalta Helsingin ja Uudenmaan (HUS) sairaanhoitopiiristä osoittivat, että vuosina 1996-1998 hoidettujen viittomakielisten kuurojen tai vaikeasti kuulovammaisten henkilöiden (n = 44) yleisimmät ongelmat olivat masennus, ahdistuneisuus, persoonallisuushäiriöt, päihteiden liikakäyttö, skitsofrenia, kaksisuuntainen mielialahäiriö ja psykoottiset oireet. Muita diagnooseja olivat epilepsia, kehitysvammaisuus tai dysfasia ja muut kielelliset häiriöt (Ryynänen & Kostamo, 1998). Syömishäiriöt eivät osoittautuneet suureksi ongelmaksi kuurojen ryhmässä (ks. myös Glickman, 2009).

Osalla kuurosokeista tai viittomakielisistä henkilöistä voi olla ennen kaikkea palvelujen ja tuen tarvetta jokapäiväisessä elämässä, kodin hoidossa, asioimisessa tai työllistymisessä (Hassinen, 2009). Saman suuntainen huomio tuli esille myös Bodsworth ym. (2011) tekemässä kartoituksessa henkilöillä, joilla oli kaksoisvamma ja jotka kommunikoivat eri tavoin puhekielen avulla. Mukana ei siis ollut viittomakielisiä henkilöitä. Toiveena oli saada jokapäiväisen elämän toimintoja helpottavia yhteiskunnan tarjoamia palveluja, kuten kotiapua, sosiaalityöntekijän apua ja vapaaehtoistyöntekijöitä. Viittomakieliset henkilöt kaipaavat asumisympäristöä, jossa on kommunikaatiotaitoista henkilökuntaa, mikä vähentäisi yksinäisyyttä ja siitä aiheutuvia psykologisia ongelmia, kuten masentuneisuutta ja ahdistuneisuutta (Hassinen, 2009). Työttömillä henkilöillä, joilla oli Usher 1 (perinnöllinen oireyhtymä, johon liittyy kuurous ja näkövamma retinitis pigmentosa) ja jotka olivat viittomakielisiä, havaittiin samanlainen kohonnut riski liittyen huonoon terveyteen, epäluottamukseen toisiin ja taloudellisiin vaikeuksiin verrattuna työttömiin yleisesti (Ehn ym., 2018). Ongelmat olivat kuitenkin suhteessa suuremmat verrattaessa työssä käyviin Usher 1 -henkilöihin kuin työssä käyvien ja työttömien välillä yleensä.

### **1.2.1 Kuurosokeiden ja kuurojen henkilöiden hyvinvoinnin arviointi**

Ohre ym., (2011) kuvasivat tutkimuksessaan aineistoa, jossa hyvinvointia koskevat tulokset oli saatu retrospektiivisillä analyyseilla valmiista aineistoista, kuten potilaiden diagnooseista tai kysely- ja haastatteluaineistoista. Viidessä tutkimuksessa, joissa tarkasteltiin psykiatrisessa hoidossa olleiden kuurojen henkilöiden ryhmää, oli käytetty useita erilaisia mittareita. Näitä olivat yleinen terveystarkastus (General Health Questionnaire, GHQ-12; Goldberg & Williams, 1988), oirekysely (Symptom Checklist 8 ja 5; Fink ym. 1995) sekä masennuskysely (The Beck Depression Inventory II, BDI-II; Beck ym., 1961). Arvioinnit tehtiin henkilöiden itsensä valitsemalla kommunikaatitavalla joko kirjoitetussa muodossa tai viittomakielellä kasvatusten tai videolta.

Suomessa on viittomakielisten kuurojen ryhmässä käytetty myös yleistä terveystarkastusta (GHQ-12; Holi ym., 1998) sekä tekstimuodossa että viittomakielisenä käännöksenä (Lindfors, 2005). Lisäksi Lindforsin (2005) tutkimuksessa käytettiin Kohdeoirekyselyä (Target Complaints; Battle ym., 1966) osana hyvinvointikyselylomaketta sekä kirjallisena että viittomakielisenä käännöksenä. Viittomakielinen käännös oli saatavissa videoversioina niitä tarvitseville.

Yleisesti käytettyjen psykologisia oireita kuvaavien mittareiden käyttö viittomakielisillä kuuroilla tai kuurosokeilla henkilöillä vaatii mittareiden kääntämistä viittomakielelle (Ohre ym., 2011; Moore ym., 2013). Moore ym. (2013) kuvaavat Britanniassa lasten ja nuorten mielialaa ja epäsosiaalista käyttäytymistä kuvaavan mittarin käännösprosessia englanninkielestä brittiläiselle viittomakielelle kolmivaiheisena prosessina, johon kuuluu (1) itsenäisten kaksikielisten käännösryhmien valitseminen (viittomakielelle kääntämisen ryhmä ja takaisin alkuperäiselle kielelle kääntämisen ryhmä), (2) itse käännösprosessi ja (3) ns. takaisinkäännös menetelmä (viittomakielisen käännöksen kääntäminen takaisin alkuperäiselle kielelle).

Viittomakielisten psykologisten mittareiden vertailuryhmänä ovat yleensä ei-viittomakielisten ryhmät. Mittareiden kääntämisen lisäksi tarvittaisiin nimenomaan viittomakieliselle ryhmälle standardoituja mittareita. Tällaisesta on esimerkki Australian viittomakielisille validoitu hoidon tuloksellisuutta kuvaava mittari Outcome Rating Scale (ORS; Munro & Rodwell, 2009). Tätä menetelmää kehitettäessä, mittarin luotettavuuden testaamisessa oli mukana 44 mielenterveyspalveluja hakenutta viittomakielistä henkilöä sekä 55 kuurojen yhteisön jäsentä.

Aina pelkkä mittareiden kääntäminen ei ole riittävää, koska osalla tutkittavista henkilöistä on myös kielellisiä ongelmia tai muita vammoja, jolloin myös viittomakielisen materiaalin ymmärtäminen voi olla vaikeaa (Hassinen ym., 2014). Ymmärtämistä vaikeuttaa myös alkuperäisten mittareiden käsitteiden vaikeus sekä kysymysten tai ohjeiden liiallinen pituus. Usein tämä on ratkaistu niin, että käytetään lyhennettyjä versioita, kuten esimerkiksi oirekysely SCL:n eri versiot (Ohre ym., 2011). Kuurosokeiden puhuttua kieltä käyttävien henkilöiden kohdalla mittareiden käyttö saattaa vaatia materiaalin muuttamista henkilön käyttämän kommunikaation vaatimaan muotoon, kuten isokirjoitukselle tai pistekirjoitukselle (Hassinen, 2009).

Dammeyerin (2014) tekemän haun mukaan löytyi useita satoja tutkimuksia termillä kuurosokea (deafblind). Tutkimuksista suurin osa oli tehty aikuisena kuurosokeutuneiden ikääntyneiden ihmisten psyykkisestä hyvinvoinnista ja erilaisista elämän tapahtumista. Tutkimuksissa havaittiin, että kuurosokeutumiseen liittyi selkeästi kohonnut masennuksen esiintyvyys, kognitiivisten toimintojen heikentyminen ja vaikeudet jokapäiväisen elämän toimissa. Syntymästä saakka kuurosokeiden tutkimus oli keskittynyt kielellisiin ja kommunikaatiokysymyksiin liittyen erityisesti taktiilikommunikaation kautta tapahtuvaan vuorovaikutukseen. Tutkimukset olivat pääsääntöisesti tapaustutkimuksia. Yleisesti kuurosokeiden ryhmään liittyvissä tutkimuksissa Dammeyer (2014) nostaa esille vaikeuden saada edes pientä tutkimusryhmää kuurosokeita henkilöitä kuulo- ja näkövammaisuutta käsittelevään tutkimukseen, koska henkilöitä on niin vähän. Yleisestikin alue ei kiinnosta tutkijoita. Tutkimushaasteita tuovat myös erilaiset kuurosokeuden määritelmät, ryhmän heterogeenisuus, vaikeudet käyttää perinteisiä arviointimenetelmiä, kommunikaatioesteet sekä vaikeudet tulkita kuurosokean henkilön käyttäytymistä.

Glickman ja Pollard (2015) ovat puolestaan tarkastelleet kuurojen henkilöiden parissa tehtyä mielenterveyden tutkimuksen historiaa ja tulevaisuutta. He toteavat, että ennen 1970-lukua ja sen aikana tutkimus oli kuulevien tutkijoiden tekemää tutkimusta. Heidän viittomakielen taitonsa ei yleensä ollut hyvä eikä heillä ollut henkilökohtaista kosketusta kuurojen kulttuuriin. Tällöin oletuksena oli usein, että kuurouteen liittyy älyllistä vajavuutta sekä tunne-elämän ja käyttäytymisen ongelmia. Tästä seurannutta patologista kuvaa kuuroudesta ja siitä seuranneita virheellisiä tutkimustuloksia tutkijat ovat pyrkineet purkamaan seuraavat neljäkymmentä vuotta.

Edellä mainituista syistä voidaan myös sanoa, että kuurojen henkilöiden mielenterveyteen ja psykologiseen hyvinvointiin liittyvä tutkimus on

neljäkymmentä vuotta jäljessä kuulevien parissa tehdystä tutkimuksesta (Glickman ja Pollard, 2015). Tilanteen korjaamiseksi vaaditaan ennen kaikkea tutkijoita, 1) joilla on hyvä viittomakielen taito, 2) jotka tuntevat sekä psyykkisesti terveitä että sairaita kuuroja henkilöitä, 3) joihin luotetaan kuurojen yhteisössä ja 4) jotka saavat tutkimuksiin mukaan henkilöitä sekä 5) hallitsevat tutkimusmenetelmät. Silti nykyinen kuurojen mielenterveyteen liittyvä tutkimus kärsii edelleen ”sairaustaakasta”. Taakan keventämistä ei helpota se, että erityistä tukea tarvitsevien kuurojen on vaikea päästä mielenterveyspalveluihin.

### 1.3 Tapauskuvausmalli hyvinvoinnin arvioinnin välineenä

Psykiatriset diagnoosit määrittelevät tai nimeävät lääketieteellisen mallin mukaisesti asiakkaan ongelmat eri luokkiin. Psykologisen hoidon näkökulmasta diagnoosin antama tieto henkilön tilanteesta on kuitenkin varsin rajallinen tai puutteellinen (Lappalainen ym., 2007). Tästä syystä diagnoosit eivät yleensä kuulu kognitiivisen käyttäytymisterapian analyysimalliin tai tapauskuvaukseen (Persons & Davidson, 2001; Käypä hoito), mutta ne voivat kuitenkin olla hyödyksi hoidon suuntaamisessa ja päähoitomenetelmien valinnassa. Diagnoosien ongelmana on se, että niissä ei oteta huomioon riittävästi yksilöllisiä eroja samalla tavalla kuin yksilöllisessä tapauskuvauksessa (Haynes & Williams, 2003). Erityisesti silloin, kun asiakkaalla on monenlaisia ongelmia psykiatriset diagnoosit eivät ole riittäviä asiakkaan tilanteen hahmottamiseksi ja sopivan hoidon löytämiseksi (Sturmey, 1996; Sturmey, 2009). Diagnoosi ei myöskään selitä häiriön ilmaantumista, sen kehittymistä ja pysyvyyttä silloin kun ongelmien ymmärtämisessä ja kuvaamisessa hyödynnetään oppimispsykologian näkökulmaa (Bruch, 1999). Lisäksi eri kategorioiden, luokkien, välillä on diagnooseja, jotka menevät päällekkäin. Diagnoosit myös leimaavat ihmistä, vaikka ero psyykkisen sairauden ja terveyden välillä perustuu sopimukseen ja tilastolliseen keskijakaumaan.

Turkat (1985) toi asiakastapausten arviointiin ja hoitoon termin tapauskuvaus (case formulation). Turkat (1990) ja Eells (2007) määrittelevät tapauskuvauksen hypoteesiksi asiakkaan ongelmiin vaikuttavista ja niitä ylläpitävistä tekijöistä. Tapauskuvaus auttaa ammattihenkilöstöä hahmottamaan asiakkaan tilannetta yksilöllisesti ja tekemään sen pohjalta hoitoa koskevia päätöksiä. Tapauskuvausten avulla voidaan hoito suunnitella vastaamaan juuri kunkin asiakkaan yksilöllistä tilannetta, kuten ottamalla huomioon käyttäytymisongelmiin vaikuttavia eri tilannetekijöitä ja ongelmien voimakkuutta. Persons & Davidson (2001) toteavatkin tästä aiheutuvan tietyn jännitteen standardoitujen hoitojen ja tapauskuvauksen perusteella tehtyjen hoitojen välillä. Tämä liittyy ennen kaikkea siihen, ettei diagnoosiluokitukseen perustuvissa standardoiduissa hoidoissa vaadita yksilöllistä analyysiä. Taito tehdä tapauskuvaus katsotaankin olevan tärkeä ammatillinen kompetenssi ja perustaito, joka tulisi olla jokaisella terveydenhuollon ammattilaisella (British Psychological Society Division of Clinical Psychology, 2001; American Psychological Association (2005). Tätä tukee Abelin ym. (2016) tutkimus, jossa havaittiin yhteys terapeutin hyvien

tapaustutkimustaitojen sekä parempien ja pysyvämpien hoitotulosten välillä henkilöillä, joilla oli vaikeahoitoinen masennus.

Tapauskuvauksien hyödyt hoidossa ovat Persons & Davidsonin (2001) mukaan seuraavat: ongelmaluettelon laatiminen auttaa tekemään työskentelyhypoteeseja ja selventää näin hoidon tavoitteita. Tapauskuvauksen esittäminen auttaa terapeuttia säilyttämään selkeän fokuksen myös työskennellessään moninaisten ongelmien parissa. Tämän lisäksi asiakkaan ongelmien kuvaaminen tapauskuvauksen kautta auttaa asiakasta toimimaan aktiivisesti ja yhteistyössä terapeutin kanssa. Tapauskuvauksella voi auttaa myös terapeuttia ymmärtämään ja käsittelemään omia negatiivisia tunteitaan asiakasta kohtaan. Hän voi palata aina uudelleen tarkistamaan tapauskuvauksen, josta voi löytyä selittäviä tekijöitä siihen, mitä terapiassa tapahtuu. Toisaalta Follette ym. (2001) tuovat esille sen, että funktionaalinen, tapauskuvaukseen perustuva arviointi ei hoitotyössä ole kustannustehokasta. On myös epäselvää, miten arvioinnin tiedot kootaan yhteen luotettavaksi tapauskuvaukseksi ja miten siirrytään arvioinnista hoitosuunnitelmaan.

Käyttäytymisanalyysissä voidaan myös tarkastella ongelmakäyttäytymistä tietyssä tilanteessa, josta yksi esimerkki on Linehanin (1993) hyödyntämä dialektisen käyttäytymisterapian ketjuanalyysi (Kåver & Nilsson, 2004). Ketjuanalyysin avulla kartoitetaan ongelmakäyttäytymistä edeltäviä ja seuraavia vaiheita sekä käyttäytymistä laukaisevia ja ylläpitäviä tekijöitä. Ketjuanalyysiin liittyy myös analyysin eri vaiheissa keskustelu asiakkaan kanssa siitä, millaisia taitoja ja ongelmanratkaisumenetelmiä asiakas voisi jatkossa käyttää samankaltaisissa tilanteissa. Lopuksi kartoitetaan myös lyhyen ja pitkän aikavälin seuraukset (Lappalainen ym., 2007).

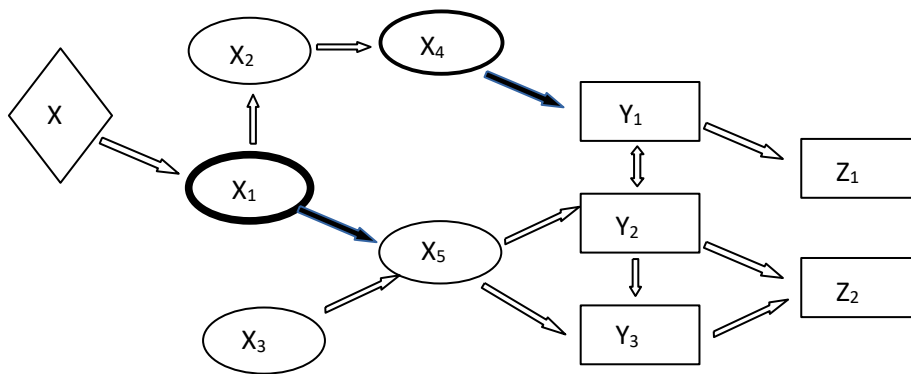
Haynesin ym. (2011, s. 26) mukaan tapauskuvaukseen perustuvissa analyysimalleissa on seuraavia yhteisiä piirteitä: 1. tapauskuvauksen validiteetti ja hyödyllisyys ovat riippuvaisia alkuarvioinnin laadusta, 2. tapauskuvauksen perusteella löydetään kullekin asiakkaalle mahdollisimman tehokas hoito, 3. asiakkaiden käyttäytymisongelmat ovat luonteeltaan erilaiset, 4. ongelmiin vaikuttavat syytekijät ovat erilaiset, 5. ongelmat ja niihin vaikuttavat tekijät voivat olla luonteeltaan multimodaalisia sisältäen ajatukset, tunteet, fysiologian ja toiminnan, 6. käyttäytymisongelmien tarkka kuvaus on olennaista tapauskuvauksessa, 7. terapeutin suhtautuminen ja uskomukset arvioinnista ennen hoitoa saattavat vaikuttaa arviointistrategioihin ja kerättävään aineistoon, ja 8. on hyödyllistä koota tapauskuvaus kirjoitettuun tai visuaaliseen muotoon.

### **1.3.1 Laaja funktionaalinen tapauskuvaus**

Yksi funktionaalinen tapauskuvaus ja tässä tutkimuksessa sovellettu malli on Stephen Haynesin kollegoineen kehittämä laaja funktionaalinen tapauskuvaus (Functional Analytic Clinical Case Diagrams, FACCD; Haynes ym., 2011; Haynes & O'Brien, 2000; Lappalainen ym., 2007).

Laajassa funktionaalisisessa tapauskuvauksessa (Kuvio 1) kaikki analyysin osat esitetään kuvina: käyttäytymisongelmat ja niiden vaikutukset, ongelmien väliset funktionaaliset suhteet, ongelmien suhteellinen vahvuus, kausaalisten ja ei-kausaalisten ongelmiin vaikuttavien suhteiden voimakkuus ja muoto sekä

kausalisuhteiden muutettavuus (Haynes, ym., 2011; Lappalainen ym., 2007). Laaja tapauskuvausmalli on kaikkein hyödyllisin (1) niiden asiakkaiden tilanteen arvioimisessa, joilla on monenlaisia ongelmia, (2) tilanteissa, joissa standardoidut hoidot eivät toimi, ja (3) hoitoyhteisöissä, joissa keskustellaan asiakkaan hoidon tavoitteista. Tapauskuvauksessa kausalisuhteet (merkitty nuolilla kuviossa 1) osoittavat asiakkaan ongelmakäyttäytymiselle olennaiset selittävät tekijät ja hoitokohteet sekä auttavat asiakasta hahmottamaan hoidon tavoitteet (Haynes ym., 2011; Haynes & O'Brien, 1990; Haynes & O'Brien, 2000; Haynes & Williams, 2003; Peterman & Muller, 2001).



KUVIO 1 Laajan funktionaalisen tapauskuvauksen malli (alkuperäinen FACCD, Haynes, O'Brien & Kaholokua, 2011). Kaaviossa X = alkuperäinen muuttuja, jota ei voi muuttaa, X<sub>1-5</sub> vaikuttavia tekijöitä, Y<sub>1-3</sub> käyttäytymisongelmia ja Z<sub>1-2</sub> ongelmien seurauksia. Nuolilla osoitetaan eri tekijöiden väliset kausalisuhteet ja eri symbolien viivan paksuudella niiden vaikuttavuuden vahvuus.

Laajan funktionaalisen tapauskuvauksen yhteyteen sopivat monet muut erilaiset arviointimenetelmät (Haynes & O'Brien, 2000). Analyysimallissa kuvatut muuttujat voivat edustaa erilaisia käyttäytymisluokkia (fysiologisia, kognitiivisia, persoonallisuuteen liittyviä) ja analyysin tarkkuustaso voi vaihdella. Tämä antaa väljyyttä analyysin tekoon silloin, kun funktionaalista tapauskuvausta käyttävät esimerkiksi kuurojen ja kuurosokeiden lähityöntekijät, joilla on tähän vain lyhyt koulutus. Tapauskuvausmallin etu on se, että ilman analyysia interventioista tai hoidosta saattaa puuttua kokonaiskuva ja se suuntautuu "väärille urille". Malli auttaa myös ammattilaisia näkemään paremmin henkilön kokonaistilanteen yksilöllisesti. Funktionaalisen tapauskuvausmallin (Haynes ym., 2011; Haynes & O'Brien, 1990 ja 2000; Haynes & Williams, 2003) katsotaan olevan laaja-alainen, yleinen käyttäytymisanalyysi. Sitä voidaan käyttää asiakkaan kanssa tai henkilökunnan yhteisessä työryhmässä käyttäytymisongelmien ja niihin vaikuttavien tekijöiden kuvaamiseksi visuaalisesti ja toisaalta myös terapiatyön raameina. Analyysi voi olla myös yksityiskohtaisempi ns. A-B-C -malli (Tuomisto ym., 1998), jossa yksittäisiä ongelmia tarkastellaan niitä edeltävien tekijöiden ja seurausten avulla. Edellä mainittujen käyttäytymisanalyysien väliin sijoittuu ketjuanalyysi, jota käytetään esimerkiksi dialektisessa



käyttäytymisterapiassa (Kåver & Nilsonne, 2004; Linehan, 1993). Hyvin tehty funktionaalinen analyysi voi jo itsessään olla interventio, mutta yleensä sen avulla haetaan intervention kohteita ja menetelmiä hyvinvoinnin lisäämiseksi ja oireiden vähentämiseksi.

### **1.3.2 Kuurosokeiden ja kuurojen henkilöiden hyvinvoinnin edistäminen psykologisilla interventioilla**

Suomessa oli vuonna 1996–1998 seitsemän psykoterapeuttia, jotka tarjosivat psykoterapiapalveluita kuurosokeille ja kuuroille henkilöille (Ryynänen & Kostamo, 1998). Kelan Palveluntuottajien luettelosta löytyi 12 terapeuttia, joilla oli maininta viittomakielestä vuonna 2021 ([www.kela.fi](http://www.kela.fi)). Kaikki eivät kuitenkaan toimi aktiivisesti. Psykoterapiapalvelujen tarjoajia viittomakielisille tai kuurosokeille henkilöille on näin ollen vähän. Kuitenkaan kaikki psykologisen avun tarvitsejoista eivät tarvitse pitkää intensiivistä psykoterapiaa, vaan tukea hyvinvoinnin lisäämiseen ja elämän haasteiden käsittelyyn. Tarve lyhyiden ja helposti saatavien psykologisten interventioiden kehittämiseksi onkin siksi ilmeinen. Seuraavassa esitellään kansainvälisiä interventiotutkimuksia, joissa on kuvattu erilaisia lyhyitä interventioita kuurosokeille ja kuuroille henkilöille. Näiden tutkimuskuvausten yhteydessä annetaan esimerkkejä siitä, miten interventioita on toteutettu käytännössä sekä pohditaan kuurosokeiden ja kuurojen henkilöiden psykologisiin hoitoihin liittyviä erityiskysymyksiä.

Buskermolen ym. (2013) kuvailivat ongelmallisen tai haasteellisen käyttäytymisen havainnoimista ja kirjaamista henkilöillä, joilla oli sekä kuulovamma että vakava-asteinen kehitysvammaisuus. Koska valmista menetelmää ongelmakäyttäytymisten kuvaamiseksi ei ollut, tutkijat kehittivät kyseiselle ryhmälle ja kullekin yksilölle soveltuvan haasteellisen käyttäytymisen arviointimittarin. Mittari perustui kahdeksaan käyttäytymisloukkaan ja viiteen vaikeustasoon. Esimerkiksi kommunikoinnin vastaanottamisessa ensimmäinen taso tarkoittaa viittomiseen, kuvakommunikaatioon reagoimista ja kykyä rauhoittua tilanteessa ja taso viisi sitä, ettei ota vastaan kommunikaatiota lainkaan. Tutkijat totesivat, että yksilöllisten käyttäytymistottumusten kuvaaminen ja arviointi vaatii usean asiakasta tunnevan ihmisen panosta. Tämä tutkimus esitteli erityisesti monivammaisten henkilöiden analyysi- ja arviointimenetelmiin liittyviä ongelmia. Usein arviointimenetelmiä ei ole tai niitä on tarjolla hyvin vähän.

Garnefski ja Kraaij (2012) kuvasivat satunnaistetulla kontrolloidulla tutkimuksella kognitiivisen itsehoito-ohjelman vaikutuksia emotionaalisiin ongelmiin. Kohderyhmänä oli aikuisena kuuroutuneet henkilöt, joilla oli masennusta ja ahdistusta. Tällä ryhmällä on omat kommunikaatiohaasteensa, koska monet joutuvat opettelemaan uuden kommunikaatiotavan (esim. viittomakielen tai huulioluvun), kun kuulolaite ei enää riitä. Kun aiemmin käytetty kieli on ollut puhuttu kieli, niin täysin uuden kielen opettelu vie aikaa. Useimmat kuuroutuneet henkilöt vastaanottavat viestiä huulioluvun avulla ja käyttävät hyödyksi jäljellä olevaa kuuloa. Ympäristö on näin ollen saatava sellaiseksi, että siinä sekä näkee että kuulee hyvin. Tällöin on huomioitava mm. valaistus, istumajärjestys, hälyäänet ja toisaalta puheäänien kuuluvuus, mitä terapeutit eivät välttämättä

osaa ottaa huomioon. Apua tarvitsevat jäävät usein näiden seikkojen vuoksi ilman tarvitsemaansa hoitoa. Itsehoito-ohjelma koostui kolmesta pääalueesta: rentoutuksesta, vääristyneiden ajatusten muuttamisesta ja henkilökohtaisten elämäntavoitteiden asettamisesta. Materiaaleina olivat työkirja ja -ohjeet sekä tallennettu materiaali (CD-ROM). Osanottajia (n = 28) pyydettiin tekemään tehtäviä tunti päivässä neljänä päivänä viikossa yhteensä neljä viikkoa. Tulokset osoittivat, että muutos oli suurempi ahdistuksessa kuin masennuksessa verrattuna vertailuryhmään. Johtopäätöksenä oli, että ohjelma oli toimiva ja helpotti henkilöiden tarvetta saada psykologista apua tai korvasi psykoterapian, kun sitä ei ollut saatavilla. Tulosten osalta oli kuitenkin otettava huomioon, että tutkimushenkilöiden määrä oli pieni ja tutkimuksessa käytettiin oireiden mittaamiseen pelkästään itsearviointia. Garnefski ja Kraaij (2012) pohtivat sitä, että tämän tyyppinen ohjelma saattoi toisaalta lisätä jo entuudestaan vahvaa yksinäisyyden tunnetta, koska ohjelmaan ei kuulunut henkilökontaktia. Pelkkä itsehoito-ohjelma ei sovellu kaikille, sillä itsehoito-ohjelman käyttö vaatii motivaatiota ja itsekuria. Jatkossa itsehoito-ohjelmiin olisikin hyvä lisätä henkilökohtaista ohjausta.

Anderson ym. (2016) puolestaan kuvasivat samanaikaisista traumaista ja riippuvuuksista toipuvien kuurojen henkilöiden parissa tehtyä terveystyöskäytännönsä. Posttraumaattisen stressioireyhtymän ja päihteiden käytön yhdistelmästä ja hoidosta tiedetään tämän ryhmän osalta vähän. Joitakin suuntaviivoja on kuitenkin esitetty hoitaville tahoille. Kysymykseen voi ensinnäkin tulla ennen hoitoa tapahtuva tiedon jakaminen oireista ja hyvistä selviytymiskeinoista sekä yhteisen kielen löytäminen. Viimeksi mainittu tulee kyseeseen erityisesti niillä henkilöillä, joilla viittomakielen taito ei ole kehittynyt riittävästi, jolloin käydään läpi hoidossa käytettävää terminologiaa. Toiseksi rakennetaan luottamusta, mikä perustuu erityisesti kuurouden ja kuurojen kulttuurin kunnioittamiseen, sillä monilla kuuroilla on kokemuksia alistettuna olemisesta. Kolmanneksi opetetaan taitoja, kuten selviytymiskeinoja, kommunikaatiota ja ongelmanratkaisua. Apuna voidaan käyttää myös visuaalisia ilmaisutapoja, kuten selviytymiskeinojen arvioinnissa liikennevalojen tapaan punaista ja vihreää lippua.

Viittomakielisillä kuuroilla on kokeiltu kognitiivisen käyttäytymisterapiaan kuuluvaa, Linehanin (1993) lähinnä persoonallisuushäiriöiden hoitoon kehittämän dialektisen käyttäytymisterapian (Davidson ym. 2012) soveltamista. Pilottitutkimukseen osallistui neljä psykiatrisessa avohoidossa olevaa henkilöä. He olivat eläneet ympäristössä, jossa eivät olleet saaneet riittävästi palautetta omasta käyttäytymisestään. Ohjelma oli kestoltaan yhdeksän kuukautta sisältäen 23 ryhmäistuntoa, jotka oli tulkattu viittomakielelle. Jokainen osanottaja sai myös yksilöllistä ohjausta sähköpostitse viikoittain. Henkilöistä kolme osallistui koko ohjelmaan. Yksityiskohtaisia tuloksia ei tästä pilottitutkimuksesta julkaistu, mikä oli sovittu etukäteen. Yksi osallistujista kuvaili kuitenkin sanallisesti oppineensa säätelämään tunteitaan ja toimimaan tilanteissa rauhallisesti ja järkevästi, vaikka kokisikin vihan tunteita. Lisäksi hän kuvasi oppineensa muita keinoja ja taitoja, kuten tietoisien läsnäolon taitoja.

Wakeland ym., (2013) puolestaan kuvasivat kognitiivisen käyttäytymisterapian ryhmässä toteutettavaa sovellusta sosiaalisesta ongelmanratkaisusta

(Social Problem Solving, SPS; Long ym., 2011) vankimielisairaalassa. Kokeiluun osallistui kolme syntymästään saakka kuuroa miestä. Yhteys puutteellisten ongelmanratkaisutaitojen sekä tunne-elämän (ahdistus ja masennus) ja käyttäytymisen ongelmien (päihteiden väärinkäyttö ja aggressiivisuus) välillä voivat osaltaan selittää kuurojen yliedustusta mielenterveysyksiköissä. Hyviin ongelmanratkaisutaitoihin kuuluu ongelman tunnistaminen ja määrittely, tavoitteiden asettaminen, erilaisten mahdollisten ratkaisujen ja toimintasuunnitelman määrittely sekä suunnitelman toteuttaminen. Ongelmanratkaisutaitojen opettaminen kuuluu myös kognitiivisen käyttäytymisterapian perusmenetelmiin (Lehtonen & Lappalainen, 2005). Interventio toteutettiin opettamalla henkilöille taitoja Stop and Think (SAT; McMurrin, 2008) -menetelmän mukaisesti. Ohjelma toteutettiin tunnin pituisina tapaamisina kerran viikossa viidentoista viikon ajan. Mukana oli ohjaajan lisäksi viittomakielen tulkki, joka oli perehtynyt työskentelyyn suljetuissa vankilaympäristöissä ja tunsikin myös kognitiivisen käyttäytymisterapian hoitomenetelmät. Ennen ohjelman aloittamista käsiteltiin osanottajien kanssa ajatusten, tunteiden ja käyttäytymisen käsitteiden välisiä eroja. Lisäksi ohjelmaa muokattiin viittomakieleen sopivaksi ja käytettiin visuaalista materiaalia ja rooliharjoituksia. Osanottajille tehdyt mittaukset osoittivat, että ongelmat vähenivät ja yleinen hyvinvointi kohosi. Mittarina käytettiin Suomessakin käytettävää CORE-OM-kyselyä (Evans ym., 2002), mikä mittaa subjektiivista hyvinvointia, oireita ja ongelmia, toimintakykyä ja sosiaalista vuorovaikutusta. Mittaria ei kuitenkaan ole validoitu kuurojen ryhmälle.

Syntymästä saakka kuurosokeiden (aikuisten) parissa tehdyt tutkimukset perustuvat pääsääntöisesti johtopäätöksiin, jotka on tehty havaintojen perusteella. Avustava henkilöstö on usein mukana intervention toteuttamisessa ja vaikutusten arvioinnissa, koska monet tähän kuurosokeitten ryhmään kuuluvista henkilöistä tarvitsevat asumispalvelua. Prain ym. (2010) tutkivat yhdeksän kuurosokean asukkaan ja yhdeksän heitä avustavan henkilön välistä vuorovaikutusta kahdessa asumispalveluyksikössä. Tutkimuksessa kerättiin kahdeksana päivänä 34 x 30 minuutin pituinen videomateriaali. Asukkaiden kommunikointotavat perustuivat pääasiallisesti eleisiin, ilmeisiin ja ääntelyyn. Avustavasta henkilöstöstä kahdeksan oli suorittanut vaadittavan ammatillisen pätevyyden ja yksi oli parhaillaan sitä suorittamassa. Henkilöt olivat työskennelleet syntymästä saakka kuurosokeiden asiakkaiden parissa keskimäärin lähes kuusi vuotta. Talenteet analysoitiin kahden ulkopuolisen havainnoijan avulla. Havainnoijat oli koulutettu käyttämään koodausjärjestelmää, jota oli aiemmin käytetty kehitysvammaisten asukkaiden yksiköissä. Johtopäätöksissä kiinnitettiin huomiota asukkaiden ja henkilökunnan väliseen vähäiseen aktiivisuuteen sekä vuorovaikutukseen. Ehdotuksena olikin, että asumispalveluyksiköissä pitäisi kiinnittää enemmän huomiota vuorovaikutuksen määrään ja keston sekä asukkaiden ja henkilöstön vuorovaikutuksen laatuun.

### 1.3.3 Viittomakielisten hoitoon liittyviä erityispiirteitä

Viittomakielisestä psykoterapiasta on amerikkalainen perheterapeutti Michael Harvey (1989) tuonut esille terapeuttien kokemuksia ja mahdollisia turhaumia kuurojen terapiatyössä. Terapeuteille erityisongelmia nimenomaan viittomakielisessä terapiassa ovat olleet kokemus kommunikaation vaikeudesta, kyvyttömyyden tunne kuurojen kanssa toimimisessa, edistymisen hitaus sekä fyysinen ja emotionaalinen väsymys, koska terapeutti joutuu olemaan jatkuvasti katsekontaktissa asiakkaaseen ja käyttämään paljon ilmeitä ja eleitä. Lisäksi terapeutti voi kokea ongelmallisena syyllisyyden tunteista nousevan avuttomuuden sekä haastavien tai itsetuhoisten potilaiden kohtaamisen.

Suomessa viittomakielisestä terapiasta ovat dokumentoineet Raija Pihavainio ja Pirjo Leino (1998). He ovat kuvanneet myös eroja puhekielisten ja viittomakielisten asiakkaiden välillä, kuten on tehnyt myös Harvey (1989). Terapeuteille on tuttua se, että asiakas ei ymmärrä terapeutin kysymystä, koska se on liian abstrakti eikä kiinnity mihinkään kyseisen henkilön elämässä. Tällöin terapeutti alkaa muotoilla kysymystä uudestaan ja voi yliohtaa asiakasta oman oletuksensa mukaisesti, jolloin ammattilaisen neutraalisuus saattaa vaarantua.

Kuurojen viittomakielisten ja huonokuuloisten henkilöiden kokemuksia psykoterapiasuhteesta on selvitetty laadullisella metasynteisillä, johon kuului kymmenen artikkelia (Gill & Fox, 2012). Kommunikaatio-ongelmat tulivat esille useassa artikkelissa. Kommunikaatio-ongelmia esiintyi myös ennen terapian alkua, jolloin asiakkailla oli vaikeuksia löytää terapeutti ja toisaalta kommunikoida muiden työntekijöiden, kuten palveluja välittävien henkilöiden kanssa. Sopiva terapeutti saattoi myös olla maantieteellisesti kaukana, jolloin matkoihin kului huomattava määrä aikaa. Suomessa Lintukangas-Alanderin (2013) opinnäytetyön kyselyyn vastanneiden 56 viittomakielisen henkilön mukaan mielenterveyspalveluihin hakeutumisessa suurin hankaluudet olivat leimautumisen pelko (30 %), tiedon puute (16 %) ja kokemus siitä, ettei saanut tarvitsemaansa apua (11 %). Myös palvelujen saatavuus (9 %) ja huonot kulkuyhteydet (4 %) hankaloittivat hakeutumista mielenterveyspalveluihin. Gill & Foxin (2011) mukaan terapiasuhteen aikana esille nousivat myös kommunikaatiovaikeudet terapeutin ja asiakkaan välillä sekä silloin, kun terapeutti viittoi itse tai silloin, kun hän käytti tulkkia. Terapeutin puutteelliset tiedot kuurojen kulttuurista aiheuttivat asiakkaassa epävarmuutta samoin kuin asiakkaan kokemat terapeutin negatiiviset tunnetilat asiakasta tai yleisesti kuuroutta kohtaan. Tulkkia käytettäessä saattoi esiintyä epäilyjä tämän luotettavuudesta ja pätevyydestä, kuten myös silloin, kun perheenjäsenet tai ystävät toimivat tulkkina.

Henkilöstön kouluttaminen on tärkeää, kun järjestetään kuntoutus- ja mielenterveyspalveluja vähemmistöille ja erityisryhmille (Glickman, 2009a ja 2009b; Gutman, 2002; Peoples, 2002). Yksi tärkeimmistä asioista kuntoutuspalvelujen järjestämisessä erityisryhmille on yhteisen kielen ja kommunikaatitavan löytäminen (Glickman, 2009a ja 2009b; Pohjoismainen kuurosokeuden määritelmä, 2011). Tämä on haaste niin kuurosokeiden kuin kuurojen viittomakielisten parissa toimiville ammattilaisille, koska asiakkaiden kielelliset ja kognitiiviset

taidot voivat vaihdella paljon. Lisäksi ammattilaisten lähtökohdat ovat erilaiset, mikä vaikuttaa viittomakielen taidon tasoon. Osa kuurosokeista ja kuuroista on kasvanut viittomakielisessä perheessä, kun taas osa on opiskellut kielen vasta myöhemmin.

### 1.3.4 Uuden aallon interventiot

Yksi uusimmista kognitiiviseen käyttäytymisterapiaan kuuluvista menetelmistä on hyväksymis- ja omistautumisterapia (HOT; Hayes ym., 1999; Hayes & Smith, 2008). Hyväksymis- ja omistautumisterapia tarjoaa useita etuja verrattuna perinteisiin kognitiivisen käyttäytymisterapian menetelmiin. Hyväksymis- ja omistautumisterapiassa pyritään ensisijaisesti psykologisten joustavuustaitojen lisäämiseen ja tätä kautta hyvinvoinnin lisäämiseen sekä oireiden vähentämiseen. Tavoitteena on lisätä tekoja, jotka edistävät hyvinvointia ja toisaalta lisätä taitoja käsitellä tunteita ja erityisesti negatiivisten ajatusten vaikutuksia. Menetelmän mukaan psykologista kärsimystä ei voi estää, mikä tarkoittaa sitä, että kaikilla, niin kuuroilla, kuurosokeilla kuin myös normaalisti kuulevilla ja näkeville, on samanlaisia ongelmia, kuten ajoittaisia ahdistuneisuuden tunteita ja epämiellyttäviä ajatuksia sekä murehtimista. Olemme siis kaikki "samassa veneessä" ja näin ollen hoitosuhteesta tulee automaattisesti tasa-arvoinen. Tällöin esimerkiksi leimautumisen pelko vähenee, koska hyvinvointi nähdään taitoina, joita kaikki voivat kehittää.

Hyväksymis- ja omistautumisterapian voidaan katsoa edustavan arvo-, hyväksyntä ja tietoisuustaitopohjaista näkökulmaa ja edistävän elämänlaatua ja hyvinvoinnin eri osa-alueita (Lappalainen ym., 2014). Hyväksymis- ja omistautumisterapiassa pyritään yksilöllisesti arvoja kartoittamalla tekemään asioita, jotka vievät kohti hyvinvointia (mm. Harris, 2012; Hayes ym., 1999; Pietikäinen, 2009). Tämä tapahtuu harjoittelemalla tietoista läsnäoloa, havainnointitaitoja, ajatusten eriyttämistä sekä ajatusten ja tunteiden hyväksymistä. Harrisin (2019) mukaan "mindfulness" hyväksymis- ja omistautumisterapian yhteydessä tarkoittaa kaikkia edellä mainittuja prosesseja: tietoisien läsnäolon avulla opitaan keskittymään tähän hetkeen ja samalla huomaamaan itsessä ja ympäristössä tapahtuvia asioita aistien kautta. Ajatusten eriyttämisellä saadaan etäisyyttä ajatuksiin, mielikuviin ja muistoihin. Hyväksynnän avulla opitaan tekemään tilaa erilaisille ajatuksille, tunteille, kehon tuntemuksille ja mielihaluille ja muille sisäisille kokemuksille. Arvojen tarkastelu puolestaan antaa suuntaa sille, mihin elämässä haluaa mennä. Arvojen perusteella tehdään valintoja teoista, jotka vievät hyvän elämän suuntaan (Pietikäinen, 2014). Hyväksymis- ja omistautumisterapiaan pohjautuvia interventioita kuuroille ja kuurosokeille on tehty ja tutkittu hyvin vähän.

## 1.4 Väitöstutkimuksen tavoitteet

Väitöstutkimuksen tavoitteena oli ymmärtää kuurosokeiden ja kuurojen elämäntilannetta hyödyntämällä yksilöllisiä analyysimalleja sekä välineitä ja menetelmiä hyvinvointipalveluiden kehittämiseksi. Tavoitteena oli soveltaa Haynesin ym. (2000, 2011) kehittämää funktionaaliseen tapauskuvausmallia (Functional Analytic Clinical Case Diagrams, FACCD) kuurosokeiden ja kuurojen henkilöiden käyttäytymisongelmien ja niihin vaikuttavien tekijöiden ymmärtämiseksi sekä toimivien psykologisten interventioiden löytämiseksi. Tavoitteena oli myös kehittää menetelmiä kuurosokeiden henkilöiden hyvinvoinnin edistämiseksi ja tutkia interventioiden vaikuttavuutta (katso myös Taulukko 1).

Väitöstutkimus koostui seuraavasta neljästä osatutkimuksesta:

1. *Millainen on kuurosokeuden vaikutus elämänlaatuun ja hyvinvointiin? Miten psykologisia interventioita voidaan hyödyntää kuurosokeiden elämänlaadun parantamiseksi?* (Osatutkimus I) Lähtökohtana oli koota perustietoa kuurosokeudesta sekä sen vaikutuksesta elämään. Aineistoa koottiin kirjallisista lähteistä niin ryhmätasolla yleisesti kuin visuaalisilla ryhmäkuvauksilla ja funktionaalisilla yksilötapauskuvauksilla.
2. *Millaisia psykologisia ongelmia kuurosokeilla on? Miten funktionaalista tapauskuvausmallia pystytään hyödyntämään niiden asiakkaiden psykologisissa interventioissa, joilla on monenlaisia ongelmia?* (Osatutkimus II) Tavoitteena oli kokeilla tapaus tutkimusmallin käyttöä kuurosokeusalan henkilöstön ja kuurojen kuntoutusalalla työskentelevän henkilöstön koulutuksessa ja selvittää mallin vaikutuksia asiakastyöhön.
3. *Miten funktionaalista tapauskuvausmallia voidaan soveltaa kuulo- ja näkövammaisen asiakkaan terapiassa, kun henkilöllä on myös monenlaisia fyysisiä sairauksia? Miten psykologisia, erityisesti kognitiivisen käyttäytymisterapian menetelmiä voidaan käyttää hoidossa?* (Osatutkimus III) Tavoitteena oli kuvata yhden asiakasesimerkin kautta psykoterapeuttisia työskentelytapoja, jotka pohjautuivat tapauskuvaukseen ja asiakkaan tilanteeseen.
4. *Voidaanko viittomakielisten kuurojen elämänlaatua parantaa kouluttamalla viittomakielellä työskenteleviä ohjaajia käyttämään tapauskuvausmallia ja kognitiivisen käyttäytymisterapian menetelmiä, erityisesti hyväksymis- ja omistautumisterapian (HOT) menetelmiä?* (Osatutkimus IV) Tavoitteena oli selvittää, oliko Tampereen ja Jyväskylän yliopistoissa toteutettu lyhyt HOT-koulutus (mm. Lappalainen ym., 2007; Lappalainen ym., 2014; Lappalainen ym., 2015) mahdollista siirtää myös viittomakieliseen työyhteisöön ja mitkä vaikutukset sillä olisivat.

TAULUKKO 2 Yhteenveto osatutkimusten tavoitteista.

<p><b>Osatutkimus I</b> Koonti kuurosokeiden asiakkaiden elämänpiiristä ja ongelmista</p>	<p><b>Osatutkimus II</b> Henkilöstön koulutus tapauskuvausmallin hyödyntämiseksi</p>	<p><b>Osatutkimus III</b> Yhden asiakkaan tilanteen analyysi ja hoito</p>	<p><b>Osatutkimus IV</b> Kokeilu kuurojen asumisyhteisössä hyväksymis- ja omistautumisterapian menetelmillä</p>
<p><b>Osatutkimuksen tarkoitus</b> Teoreettinen katsaus, jonka tarkoituksena oli kuvata kuurosokeiden henkilöiden elämäntilannetta ja mahdollisia psykologisia ongelmia sekä erilaisia tuen muotoja</p>	<p><b>Osatutkimuksen tarkoitus</b> Kuvaus henkilökunnan tapaustutkimusmallin oppimisprosessista sekä sen soveltamisesta käytäntöön</p>	<p><b>Osatutkimuksen tarkoitus</b> Kuvaus yhden asiakkaan terapiaprosessista ja arvio hoidon vaikuttavuudesta</p>	<p><b>Osatutkimuksen tarkoitus</b> Kuvaus ryhmäinterventiosta hyväksymis- ja omistautumisterapian menetelmillä ja arvio intervention vaikuttavuudesta</p>

## 2 YHTEENVETO TUTKIMUSTULOKSISTA

### 2.1 Osatutkimus I: Elämän mieli. Kuurosokeiden asiakkaiden elämänpiiri ja psykologiset ongelmat sekä psykososiaalinen ja psykoterapeuttinen kuntoutus

Osatutkimuksen I tarkoituksena oli kuvata kuurosokeiden ryhmää psykologisesta näkökulmasta kokoamalla sekä tietoa että käytännön kokemuksia henkilöistä, joilla on kuulo- ja näkövamma. Kuurosokeiden ryhmä on hyvin heterogeeninen, koska siihen kuuluvien henkilöiden vammautumisajankohta ja heidän vammojensa vakavuus vaihtelevat. Tämä näkyy myös kielessä ja kulttuurissa: noin kaksi kolmasosaa käyttää puhuttua kieltä ja yksi kolmasosa viittomakieltä (Kuurosokean kommunikointi, 1991; Miner, 2002; Rouvinen, 2001). Kuurosokeiden kulttuurissa korostuvat kaikkien aistien tietoinen hyväksikäyttö ja yhteistoiminta. Vaikka kaikkien aistien käyttöä harjoittelee ja tehostaa, on ympäristöstä saatu tieto kuitenkin usein pirstaleista ja kokonaisuus täytyy rakentaa pienistä palasista (Kontaktiryhmä, 2002; Rouvinen, 2001)

#### 2.1.1 Kuurosokeiden asiakkaiden psykologiset ongelmat ja niihin vaikuttavat tekijät

Kuurosokeuteen mahdollisesti liittyvien vammojen eteneminen, kuten esim. Usherin syndromassa, vaikuttaa siihen, että henkilöt joutuvat elämänsä aikana käymään vammautumisprosessia useaan kertaan läpi (Miner, 2002; Olesen & Jansbøl, 2005; Tully, 1988). Kuntoutusjärjestelmä auttaa selviämään uusista tilanteista kuntoutusohjauksella, erilaisilla apuvälineillä sekä ohjauksella uuteen tilanteeseen (Hassinen, 2004; Miner, 2002). Käytännössä tämä tarkoittaa jokapäiväisten elämän taitojen harjoittelua, kuten kodin hoitoa, liikkumistaitoja ja uusien kommunikaatiotaitojen opiskelua. Arjessa tarvittavat palvelut, kuten kodinhoito-, opas- ja tulkkauspalvelut eivät kuitenkaan ole aina riittävät, joten monilla



kuurosokeilla henkilöillä arki ei suju toivotusti. Suurin syy tähän ovat ongelmat palvelujen rahoittamisessa sekä tarvittavien henkilöiden puute. Toisaalta monet kuurosokeat henkilöt selviävät arjesta hyvin huolimatta monista käytännön ongelmista (Olesen & Jansbøl, 2005; Tully, 1988).

Koska kuurosokeiden psykologisesta hyvinvoinnista on verrattain vähän tietoa, on vertailukohteena tarkasteltu kuurojen ryhmässä tehtyjä tutkimuksia ja selvityksiä. Tavallisimpia psykologisia ongelmia kuuroilla ovat masennus, ahdistuneisuus, persoonallisuushäiriö, päihteen väärinkäyttö, skitsofrenia, kaksisuuntainen mielialahäiriö sekä psykoottisuus. Lisädiagnoosina on tavallisimmin ollut epilepsia, heikkolahjaisuus, kehitysvammaisuus, dysfasia tai muut kielelliset häiriöt (Ryynänen & Kostamo, 1998). Lindforsin (2005) tekemän kartoituksen mukaan yleisimpiä psyykkisiä oireita olivat yksinäisyys, masentuneisuus ja ahdistuneisuusoireet, joita arvioitiin olevan noin neljäsosalla vastaajista. Tämä on hieman enemmän kuin suomalaisessa väestössä keskimäärin. Keskusteluavun tarvetta sen sijaan oli merkittävästi enemmän kuin väestössä yleensä (Lindfors, 2005; Olesen & Jansbøl, 2005).

Vaikka kuurosokeiden henkilöiden psykologiset ongelmat eivät poikkea valtaväestön ongelmista, heidän joukossaan ilmenee joitakin erityispiirteitä, jotka koulutus- ja palvelujärjestelmät pyrkivät ottamaan huomioon. Kuulonäkövamman liittyy usein fyysinen jännittyneisyys ja stressi. Henkilöt joutuvat pinnistelemaan jatkuvasti kuullakseen ja nähdäkseen erilaisissa arjen tilanteissa (Ehrenbåge & Samuelsson, 1998; Hassinen, 2004; Lahtinen, 2004). Paitsi liikkuminen, niin yleensä arjen sujuminen turvallisesti aiheuttaa monelle pelkoja ja ahdistuneisuutta. Elämän eri vaiheissa on myös monia ratkaisuja, joihin kuulo- ja näkövamman vaikuttavat. Tällaisia ovat mm. ammatinvalinta, asuinpaikan valinta ja perheen perustaminen. Yksinäisyyden tunne on monen kuurosokean henkilön esille tuoma tunne, sillä läheisiä ihmisiä ei välttämättä ole riittävästi (Hassinen, 2004; Miner, 2002). Ihmiskontaktit saattavat olla kuurosokeiden kanssa työtä tekevien varassa, millä ei tunnetasolla ole samanlaista merkitystä kuin läheisillä ihmisuhteilla.

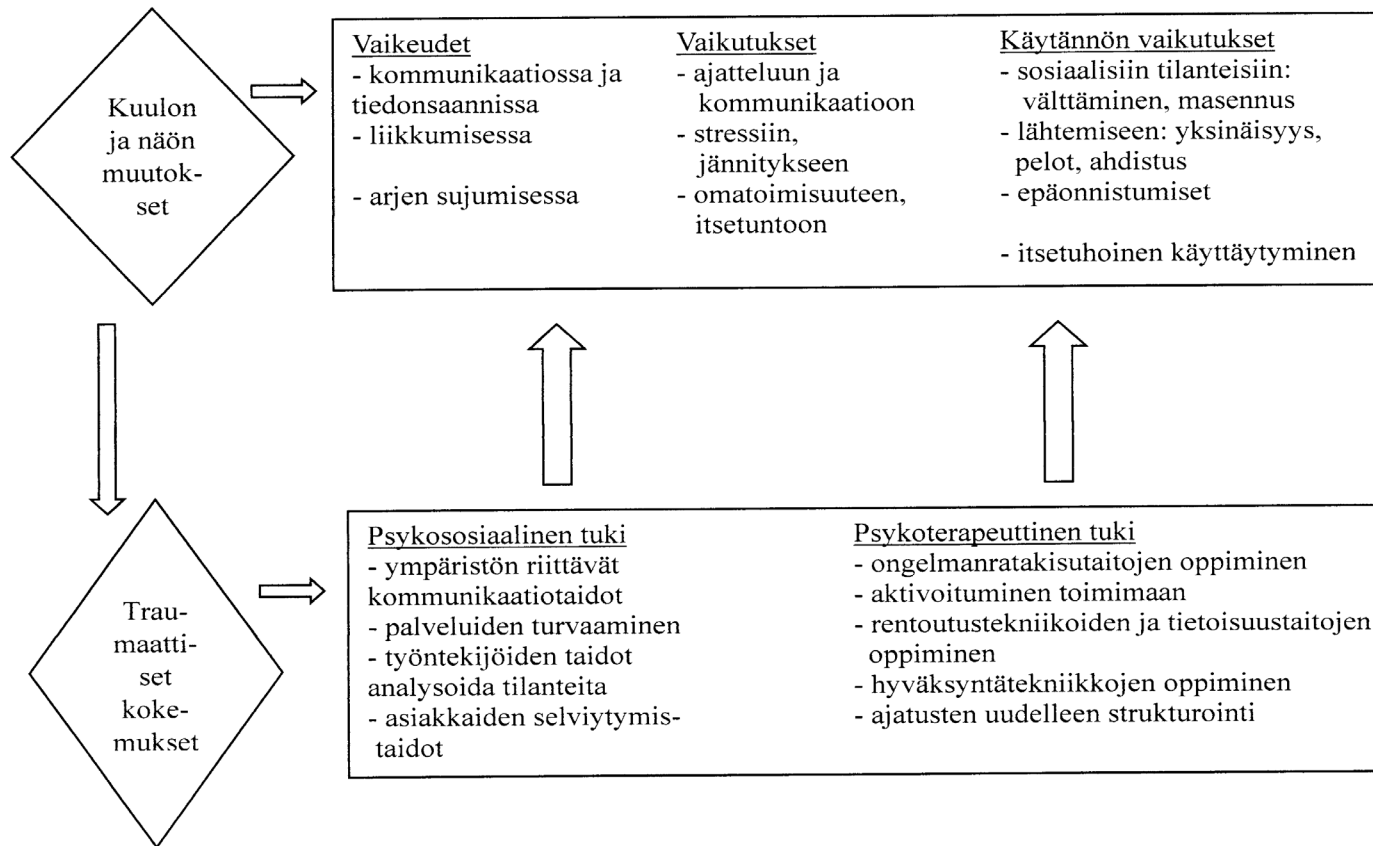
Yksinäisyyden tunne, eristäytyminen pelkojen takia ja ahdistuneisuus voivat johtaa masennukseen. Masennuksen taustalla ovat myös kuulonäkövammanautumiseen liittyvät prosessit sekä erilaiset traumaattiset tilanteet. Masennukseen voi liittyä myös itsetunto-ongelmia. Ahdistuneisuus ja masennus johtavat pahimmassa tapauksessa itsetuhoiseen käyttäytymiseen. Tämä voi näkyä välinpitämättömyytenä omasta itsestä huolehtimiseen, itsemurha-ajatuksina ja itsemurhayrityksinä (Ehrenbåge & Samuelsson, 1998; Hassinen, 2004; Miner, 2002). Joillakin kuurosokeilla henkilöillä on myös kuulo- ja näköharhoja, erityisesti vammojen muutosvaiheessa (Coker, 1995).

Arjesta selviytymisessä auttavat erilaiset psykososiaalisen tuen muodot. Näistä tärkein on kommunikoinnin turvaaminen kuurosokean henkilön ja ympäristön välillä, niin läheisten ihmisten kuin ammattihenkilöstönkin kanssa (Brennan, 1997). Avun tarvetta voi olla esimerkiksi sosiaalisissa tilanteissa selviytymisessä ja talousasioiden hoidossa (Olesen & Jansbol, 2005), jolloin tarvitaan erilaisia palveluja, kuten tulkkaus- ja kuntoutuspalveluja. Ympäristön näkemys

vaikuttaa siihen, miten kuurosokean henkilön omia voimavaroja ja elämänhallintakeinoja tuetaan (Brennan, 1997, Rouvinen, 2001). Tällöin ammattihenkilöstön hyvät vahvuuksien hyödyntämismenetelmät ja ongelmatilanteiden analysointitaidot tukevat kuurosokean henkilön itsenäisyyden tunteen vahvistumisessa ja elämän kokemista mielekkäänä.

Psykoterapeuttisessa kuntoutuksessa ovat esillä myös arjen tilanteet, kuten sosiaaliset tilanteet (Hassinen, 2004). Tällöin niitä voidaan lähestyä erilaisilla ongelmanratkaisukeinoilla ja toisaalta aktivoitumisena oman hyvinvoinnin edistämiseen, välttämisen sijaan (Lehtonen & Lappalainen, 2005). Rentoutustekniikat, kuten sovellettu rentoutus (Tuomisto, 1997) ja tietoisuustaidot (Hayes, 1995) ovat avuksi jännityksessä ja ahdistuksessa, joka voi liittyä niin liikkumisen kuin kommunikaation vaikeuksiin ja erilaisiin pelkoihin (Bourne, 1999). Myös erilaisia tilanteisiin liittyviä ennakko-odotuksia ja -uskomuksia voidaan tarkastella uudelleen ja muokata näitä uudennlaisiksi (Bourne, 1999). Koska osalla kuurosokeus on etenevä, ovat hyväksyntäteknikat (Hayes, 1995) hyviä menetelmiä tilanteiden muuttuessa. Tärkeimpänä on omien ajatusten ja tunteiden läpikäyminen ja hyväksyminen.

Kuviossa 2 on esitetty yhteenveto ja esimerkki kuurosokeiden asiakkaiden mahdollisista ongelmista (kuvion yläosa) sekä psykososiaalisesta ja psykoterapeuttisesta tuesta (kuvion alaosa).



KUVIO 2 Yhteenvedo kuurosokeiden asiakkaiden mahdollisista ongelmista sekä psykososiaalisesta ja psykoterapeuttisesta tuesta.

## **2.2 Osatutkimus II: A case formulation model for the assessment of psychological problems among deafblind persons (Tapauskuvausmalli arvioinnin välineenä)**

Useiden selvitysten perusteella vaikuttaa siltä, että kuurosokeilla henkilöillä voi olla kuulo- ja näkövammaan liittyviä kommunikaatio-ongelmia sekä emotionaalisia ongelmia, kuten, ahdistuneisuutta ja mielialaongelmia sekä käyttäytymisongelmia (Miner, 1995, 2002; Olesen & Jansbol, 2005). Ongelmat vaihtelevat, kuten niiden syytkin, koska henkilöt eroavat esimerkiksi vammautumisen ajankohdan, sosiaalisen ympäristön, aikaisempien traumaattisten kokemusten ja psykologisten oireiden suhteen. Siksi on tarve hyödyntää analyysimalleja, jotka mahdollisimman hyvin huomioivat yksilölliset erot. Osatutkimuksessa II kuvataan tapauskuvausmallia ammattihenkilöstön työvälineenä.

### **2.2.1 Menetelmä**

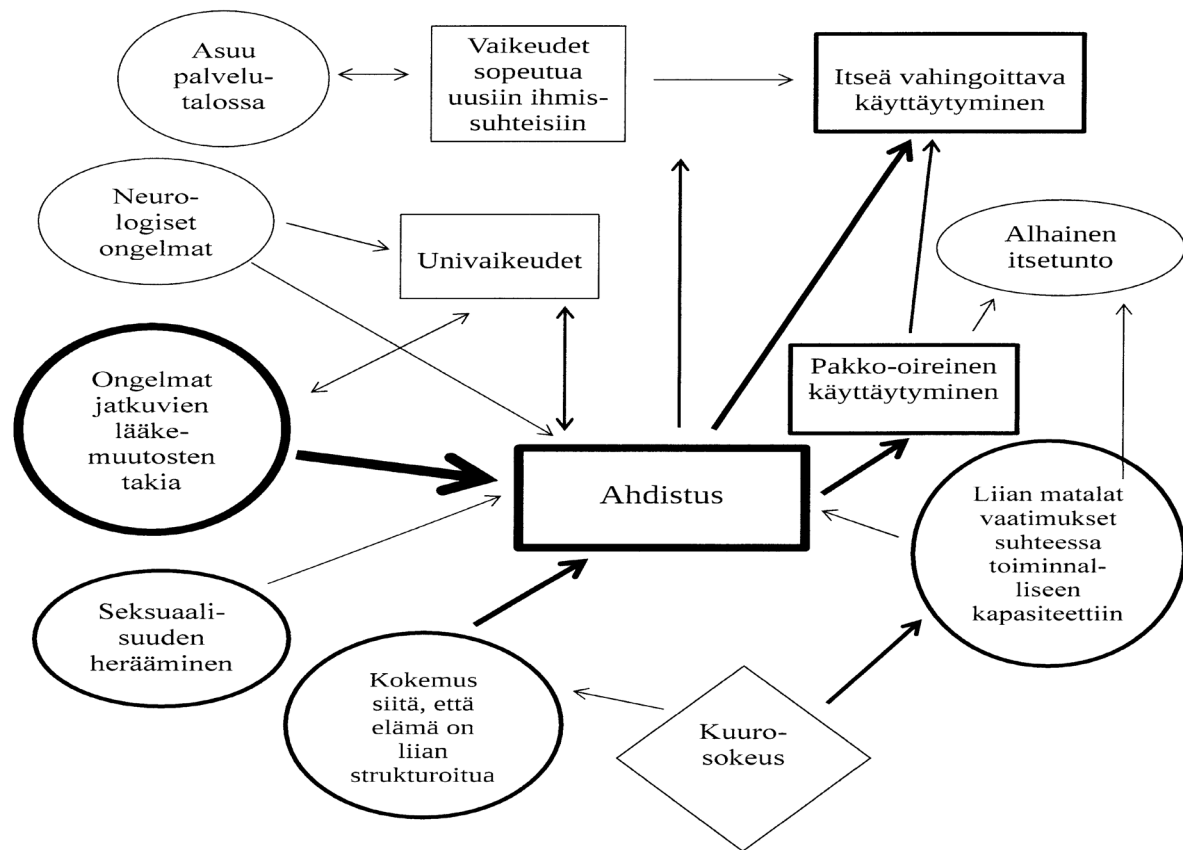
Aineisto kerättiin kuurosokeusalan henkilöstöltä koulutuksessa, jossa heitä opastettiin käyttäytymisanalyysin ja funktionaalisen tapauskuvauksen käyttöön. Koulutus koostui kolmesta kahden päivän lähijaksosta ja kotitehtävistä. Koulutettavia pyydettiin keräämään eri lähteistä tietoja asiakkaasta, jolla oli monenlaisia käytännön, käyttäytymisen tai mielialan ongelmia. Tietolähteitä olivat mm. asiakirjat asiakkaan elämänhistoriasta ja nykytilanteesta, asiakkaan haastattelu tai tarkkailu sekä työntekijöiden yhdessä keräämä tieto. Lähijaksolla käytiin läpi yleisesti käyttäytymisanalyysiä, kuurosokeuteen liittyviä neurokognitiivisia näkökulmia, hyvinvoinnin fysiologiaa ja psykologiaa tekijöitä sekä lyhyen ja pitkän aikavälin interventioita. Koulutettavat koostivat jaksojen välillä asiakkaastaan tapauskuvauksen, joka perustui Haynes & O'Brienin (2000) visuaaliseen malliin. Tämä tapahtui viisivaiheisen mallin mukaisesti, jossa 1. kerätään asiakkaasta taustatietoa, 2. tehdään tietojen perusteella lista ongelmista ja vahvuuksista, 3. luokitellaan ongelmat eri käyttäytymisen muotojen mukaan (kuten fysiologiset ja emotionaaliset reaktiot, ajatukset ja verbaalinen kommunikaatio, toiminta tai tekeminen), 4. esitetään tapauskuvaus visuaalisella mallilla, jossa kuvataan ongelmat ja näihin vaikuttavat tekijät sekä eri tekijöiden väliset vaikutussuhteet sekä 5. tehdään tämän pohjalta johtopäätökset ja hoitosuunnitelma.

Tutkimukseen koko aineistosta ( $n = 38$  kuurosokeaa tai kuuroa henkilöä) valikoitui 26 henkilökunnan tekemää tapauskuvausta, koska näissä tapauksissa oli käytetty kaikkia viittä vaihetta aineiston kokoamisessa. Valitut tapaukset jaettiin kolmeen ryhmään, joista tutkimukseen mukaan valittiin henkilöt, joilla oli sekä kuulo- että näkövamma. Nämä ryhmät olivat 1) kuurosokeutuneet henkilöt eli 4 miestä ja 10 naista ( $n = 14$ ) ja 2) syntymästä saakka kuurosokeat henkilöt eli 4 miestä ja 3 naista ( $n = 7$ ). Kolmas ryhmä, kuurojen ryhmä, jätettiin tämän tutkimuksen ulkopuolelle.

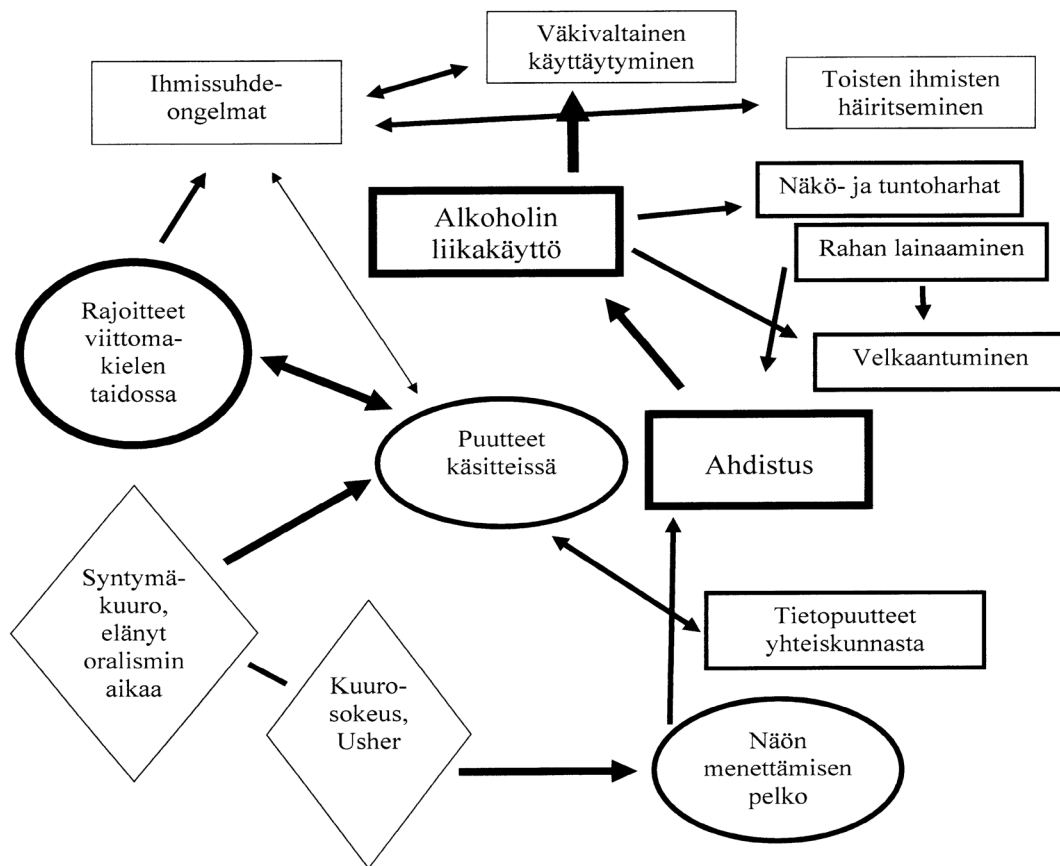
Kuurosokeutuneiden ryhmän keski-ikä oli 54,8 vuotta ja syntymästään saakka kuurosokeiden 29,3 vuotta. Ensimmäisessä ryhmässä oli enemmän naisia (n = 10) kuin miehiä (n = 4). Toisessa ryhmässä oli puolestaan lähes sama määrä naisia (n = 4) ja miehiä (n = 3). Kuurosokeutuneiden ryhmästä puolet käytti ensisijaisena kielenään viittomakieltä ja puolet suomen kieltä. Syntymästään kuurosokeiden ryhmästä useimmat henkilöt käyttivät monenlaisia kommunikaatiotapoja, jotka perustuivat viittomakieleen, eleisiin, esineisiin ja kuviin.

### **2.2.2 Tulokset**

Molemmissa ryhmissä suurimmat ongelmat ilmenivät kommunikaatiossa, mikä on yhtenevä aikaisempien tutkimustulosten kanssa (Miner, 1995, 2002 ja Olesen & Jansboel, 2005). Raportoituja ja havaittuja ongelmia molemmissa ryhmissä oli henkilöä kohden keskimäärin seitsemän, vaihdellen 3–11 ongelman välillä. Kuurosokeutuneiden ryhmässä pääongelmat olivat kommunikaatio-ongelmat, traumaattiset tai ahdistavat kokemukset, epäluottamus ja epäluulo, univaikeudet sekä yksinäisyys ja eristäytyneisyys. Syntymästään saakka kuurosokeilla yleisimmät ongelmat olivat kommunikaatio-ongelmat, aggressiivinen tai itseä vahingoittava käyttäytyminen sekä kärsimättömyys ja levottomuus. Funktionaalisen tapaustutkimuksen käyttöä kompleksissa tapauksissa kuvattiin kahdella asiakasesimerkillä (Kuvio 3 ja Kuvio 4).



KUVIO 3 Nuoren syntymästä saakka kuurosokean naisen tilanteen analyysi.



KUVIO 4 Keski-ikäisen kuurosokean miehen tilanteen analyysi.

### 2.2.3 Pohdinta

Avustavan henkilöstön tekemien arviointien ja tapauskuvausten perusteella voitiin havaita, että osalla kuurosokeista henkilöistä oli useita psykologisia ongelmia, jotka vaikuttivat elämänlaatuun. Ongelmiin vaikuttavat tekijät vaihtelivat kuitenkin henkilöiden välillä. Kuten aikaisempien tutkimusten perusteella oli odotettavissa (Miner, 1995, 2002 ja Olesen & Jansboel, 2005), kommunikaatio-ongelmat olivat yleisiä sekä kuurosokeutuneilla henkilöillä että syntymästä saakka kuurosokeilla.

Tutkimus osoitti, että käytetty tapauskuvausmalli voi olla henkilöstölle hyvä työväline, jonka avulla asiakkaan tilannetta ja interventioiden toimivuutta voidaan arvioida. Visuaalisen mallin avulla on mahdollista nähdä yhteyksiä ongelmien ja niihin vaikuttavien tekijöiden välillä, mitä ei aiemmin välttämättä ole huomattu. Usein visuaalinen kuvaus tehdään yhdessä asiakkaan kanssa, jolloin se auttaa myös asiakasta ymmärtämään ja kuvaamaan omaa sen hetkistä tilannetta. Samalla voidaan nähdä, mihin interventio kannattaa suunnata. Asiakkaalle tilanne voi näyttäytyä myös uudesta näkökulmasta, joka voi edistää välimatkan ottamista omaan tilanteeseen ja ongelmiin (Hayes ym., 1999). Uudenlaisen näkökulman löytyminen on erityisesti psykoterapiatyöskentelyssä yksi sen tärkeimmistä prosesseista.

## 2.3 Osatutkimus III: A case formulation: Psychological assessment and treatment of a person with a Prader-Willi syndrome and hearing and visual difficulties (Prader-Willi syndrooman tapauskuvaus ja hoito)

Osatutkimuksessa III on kuvattu yhden kuulo- ja näkövammaisen asiakkaan psykoterapiaprosessia. Kun henkilöllä on monenlaisia vaikeuksia erilaisten oireyhtymien tai sairauksien vuoksi, on tilanteen ymmärtäminen ja sen perusteella tehtävä psykologinen hoito haasteellista. Moniongelmaisten asiakkaiden psykologisia ongelmia on vaikea ymmärtää elämänhistorian ja nykyisten ongelmien kompleksisuuden vuoksi. Tilannetta on kuvattu funktionaalisella tapauskuvausella (FACCD, Haynes & O'Brien, 2000; Haynes ym., 2011), joka voi olla tällaisissa tapauksissa hyödyllinen työväline hoidon kohdentamiseksi ja hoitomuotojen löytämiseksi. Tässä esimerkissä hoidossa on käytetty kognitiivisen käyttäytymisterapian menetelmiä, koska niiden on todettu olevan tehokkaita hoitomuotoja kuvatun Prader-Willin oireyhtymän hoidossa (Singh ym., 2008). Tuloksia kuvataan sekä tehdyillä psykologisilla mittauksilla että asiakkaan ja terapeutin kokemuksilla.

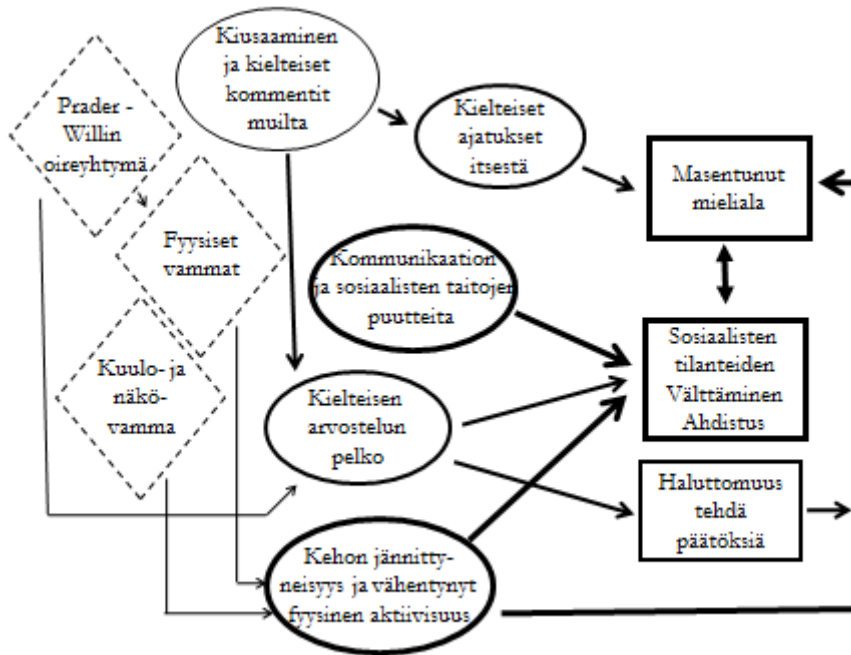
Asiakkaalla oli Prader-Willin oireyhtymä sekä kuulo- ja näkövamma. Suomessa on noin 150 henkilöä, joilla on Prader-Willin oireyhtymä ([www.pws-yhdistys.fi](http://www.pws-yhdistys.fi)). Se on harvinainen geneettinen sairaus, joka on aiheutunut 15. kromosomin virheestä. Oireyhtymässä on ominaista tietynlainen fyysinen ruumiinrakenne, kuten lyhytkasvuisuus sekä pienet kädet ja jalat, heikosti kehittyneet sukupuolielimet, epätavallisen suuri ruokahalu, ylipaino, diabetes, uniongelmat, käyttäytymisongelmat (esim. vihanpurkaukset ja pakko-oireisuus) ja lievä kehitysvammaisuus. Henkilöiden motorinen ja kielellinen kehitys ovat myös viivästyneet (Cassidy & Driscoll, 2009; Dykens, ym. 1992; Goldstone ym., 2008; Sinnema ym., 2011a). Oireyhtymän ja psykiatristen sairauksien välillä on myös havaittu yhteys, erityisesti kaksisuuntaisen mielialahäiriön ja masennuksen välillä (Sinnema ym. 2011b). Kehitys on yksilöllistä, mutta useimmilla puberteetti viivästyy. Nuoruusiässä korostuvat käyttäytymis- ja syömisongelmat, kun taas aikuisiän haasteena on itsenäistyminen (Singh et al., 2008). Prader-Williin ei ole varsinaista hoitoa, vaikka joitakin hormoni- ja leikkaushoitoja on käytetty (mm. Goldstone ym., 2008). Oireyhtymän vaikutuksia voidaan helpottaa hyvällä ruokavaliolla, terveydenhoidolla ja käyttäytymisen hallinnan opettamisella. Tässä kognitiivisen käyttäytymisterapian menetelmät voivat olla tehokkaita (Singh ym. 2008).

### 2.3.1 Menetelmä

Asiakas oli noin 35-vuotias nainen, jolla oli Prader-Willin oireyhtymä, lievä kuulo- ja näkövamma, lievä kehitysvamma, diabetes, krooninen selkäkipu, ylipaino ja masennus. Hänellä oli myös ollut psykoosioireita, joiden vuoksi hänellä oli ollut kaksi hoitajaksoa. Asiakkaalla oli näin ollen monenlaisia fyysisiä ja



psykologisia ongelmia. Hänellä oli sekä kuulon että näön jäänteitä jäljellä ja hyvässä olosuhteissa hän kuuli puheen ja pystyi liikkumaan itsenäisesti tutussa ympäristössä. Hän asui yksin ja selvisi jokapäiväisestä elämästä erilaisten palvelujen avulla sekä osallistui kuurosokeiden yhteisiin toimintoihin. Asiakkaan diagnoosina olivat toistuvat masennusjaksot. Tilanteen arvioinnissa käytettiin funktionaalista tapauskuvausta (Kuvio 5), joka laadittiin haastattelun ja ongelmaluettelon perusteella. Kuvauksesta näkyi, että masennuksen lisäksi asiakkaan pääasiallinen ongelma liittyi kiusaamiseen.



KUVIO 5 Funktionaalinen tapauskuvaus 35-vuotiaasta naisesta, jolla on ollut toistuvaa masennusta.

### 2.3.2 Hoito

Intensiivinen psykoterapia kesti kolme vuotta. Hoidon päätavoitteena oli asiakkaan mielialaan vaikuttaminen ja hänen elämänlaatunsa parantaminen, niin että hän pystyisi jatkamaan itsenäisesti asumista eikä tarvitsisi sairaalahoitoa mielialaongelmien vuoksi. Aluksi hoidossa keskityttiin asiakkaan kommunikaatiotaitojen parantamiseen. Tämä oli tärkeää, jotta terapeutti sai tietoa asiakkaan ajatuksista ja emotionaalisista reaktioista eri tilanteissa sekä tiettyihin oireisiin liittyen. Samalla lisättiin asiakkaan kehotietoisuustaitoja ja tietoisuutta kontekstuaalisista periaatteista ja menetelmistä käymällä läpi analyyseja eri elämäntilanteista. Taulukossa 3 on esitetty yhteenveto eri ongelmiin käytetyistä hoitomenetelmistä.

TAULUKKO 3 Yhteenveto hoitomenetelmistä.

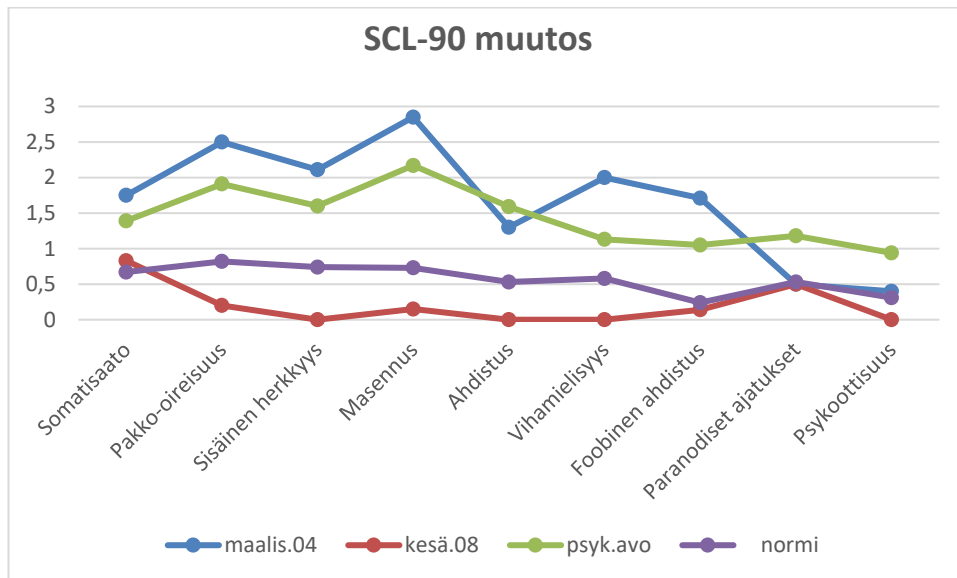
Psykologinen ongelma	Hoitomenetelmä
Kommunikaation ja sosiaalisten taitojen harjaannuttaminen	1. Rooliharjoitukset
Yhteyksien ymmärtämiseksi toiminnan, ajatusten, tunteiden ja fyysisten reaktioiden sekä kontekstuaalisten vihjeiden ja näiden seurausten välillä	2. Tarkennettu funktionaalinen analyysi ja ketjuanalyysit
Jännityksen helpottaminen sosiaalisissa tilanteissa ja matkustaessa	3. Kehotietoisuustaitojen harjaannuttaminen, Käyttäytymisen aktivointi tekemällä viikko-ohjelmaa, ongelmaratkaisu
Masennuksen ja traumaattisten kokemusten ymmärtäminen	4. Psykoedukaatio
Epämiellyttävien muistojen, ajatusten ja tunteiden hyväksyminen, jotka liittyivät elämänsisällönsä sekä vammaisuuden ja sairauksien aiheuttamiin rajoituksiin sekä motivaation ja halukkuuden lisääminen uusiin tekoihin	5. Arvotyöskentely, hyväksymistekniikat
Vastakkaiseen sukupuoleen ja parisuhteeseen liittyvän ujouden ja pelkojen kohtaaminen	6. Altistustekniikat
Tiedon saaminen asiakkaan tilanteesta ja elinympäristöstä	7. Asiakkaan rohkaiseminen käyttämään oppimiaan menetelmiä myös kotona. Terapeutin kaksi kotikäyntiä

Hoidossa käytetty kommunikaatiotaitojen harjoittelu ja yhdistäminen interventiomenetelmiin näytti olevan tärkeä tekijä hoidon edistymiselle, koska asiakkaalla ei aiemmin ollut mahdollisuutta käydä läpi psykologisia ongelmia ja niihin vaikuttavia tekijöitä. Näin oli mahdollista saada tietoa asiakkaan ajatuksista ja emotionaalisista reaktioista, jotka liittyivät tiettyihin tilanteisiin tai oireisiin. Hoidon aikana asiakas oppi kommunikoimaan tehokkaammin ja sai taitoja selvittää psykologisten ongelmien kanssa. Hän pystyi myös ottamaan entistä paremmin vastaan tietoa, mikä auttoi häntä jäsentämään tilannettaan.

### 2.3.3 Tulokset

Oirekysely SCL-90:n (Holi ym., 1998; Holi, 2003) ja masennuskysely BDI:n (Beck ym., 1961) mukaan asiakkaan psykologiset oireet vähenivät hoidon aikana (Kuvio 6). Seurannassa puoli vuotta hoidon loppumisen jälkeen ei masennusoireita enää ollut ja oireet kokonaisuudessaan olivat samalla tasolla kuin normiarvoja kuvaavassa vertailuaineistossa (Holi ym., 1998). Somaattiset oireet (kipu) vähenivät kuitenkin vähemmän kuin muut oireet, mikä selittynee Prader-Willin oireyhtymän aiheuttamista fyysisistä muutoksista. Asiakkaan mielestä kipua ei kuitenkaan ollut niin häiritsevää kuin aiemmin. Hän koki myös sosiaalisten

suhteittensa parantuneen. Terapeutin arvion mukaan asiakkaan kognitiiviset taidot kehittyivät hämmästyttävän paljon hoidon aikana. Kuviossa 6 voidaan havaita, että hoidon alussa maaliskuussa 2004 oireiden taso oli lähellä psykiatrisessa avohoidossa (psyk.avo) todettujen oireiden määrää. Hoidon lopussa kesäkuussa 2008 oireet olivat lähellä normiarvoja.



KUVIO 6 Oireiden muutos (SCL-90) hoidon aikana.

### 2.3.4 Pohdinta

Asiakkaalla oli Prader-Willin oireyhtymään ja kuulo- ja näkövammaan liittyviä fyysisiä ja psykologisia ongelmia sekä kommunikaatio-ongelmia. Hoidossa yhdistettiin kommunikaatiotaitojen harjaannuttaminen, syy-seuraussuhteiden havainnoiminen funktionaalisen ketjuanalyysin avulla, kehotietoisuustaitojen harjaannuttaminen, altistusmenetelmien sekä hyväksyntä- sekä arvotyöskentelyn käyttö.

Psykologisella interventiolla, jossa yhdistettiin erilaisia analyysimenetelmiä kognitiivisen käyttäytymisterapian sekä hyväksymis- ja omistautumisterapian menetelmiin näytti olevan myönteinen vaikutus asiakkaan hyvinvointiin ja elämänlaatuun. Samalla hänen taitonsa toimia yhteiskunnassa lisääntyivät lievästä kehitysvammasta huolimatta. Tutkimus osoitti, että kuulo- ja näkövammasta sekä geneettisesti määrittyneestä oireyhtymästä huolimatta henkilön elämäntilanteeseen ja hyvinvointiin pystyttiin vaikuttamaan kolme vuotta kestäneen hoitojakson aikana.

## **2.4 Osatutkimus IV: Acceptance and commitment therapy using Finnish sign language: training counselors in signed ACT for the deaf - a pilot study (Hyväksymis- ja omistautumisterapiaa viittomakielellä)**

Osatutkimuksessa IV kuvataan hyväksymis- ja omistautumisterapiaan pohjautuvaa kokeilua suomalaisella viittomakielellä. Kokeilu tehtiin kouluttamalla ohjaajia käyttämään tapauskuvausmallia ja hyödyntämään hyväksymis- ja omistautumisterapian periaatteita ja menetelmiä. Toteutettu malli oli ensimmäinen laatuaan Suomessa ja kansainvälisestäikin hyvin harvinainen. Taustana kokeilulle oli se, että viittomakielisiä terapeutteja on Suomessa alle kymmenen, joten viittomakielisiä psykologisia palveluja on tarjolla hyvin vähän. Oli tarpeen löytää uusia tapoja ja keinoja edistää viittomakielisten henkilöiden hyvinvointia.

### **2.4.1 Menetelmä**

Kokeilu tehtiin Kuurojen Palvelusäätiön toimipisteessä Sampolassa Hämeenlinnassa. Säätiössä oli kokeilun ajankohtana kaiken kaikkiaan 250 asumis- tai työpalvelujen käyttäjää ([www.kuurojenpalvelusaatio.fi](http://www.kuurojenpalvelusaatio.fi)), joista tähän kokeiluun osallistui 16 vapaaehtoista asiakasta sekä yhdeksän ohjaajaa. Ohjaajat valitsivat asiakkaat sen perusteella, miten he katsoivat heidän soveltuvan kokeiluun viittomakielen taitonsa perusteella ja miten paljon he todennäköisesti tarvitsisivat ja hyötyisivät kokeilusta.

Kuten muissa vastaavissa intervention vaikuttavuutta mittaavissa tutkimuksissa, käytettiin arvioinnissa mittareina Suomen väestöön validoitua SCL-90-oirekyselyä (Derogatis & Cleary, 1977; Holi ym., 1998; Holi, 2003), BDI-massensuskyselyä (Beck ym., 1961) sekä psykologista joustavuutta arvioivaa AAQ-2-mittaria (The Acceptance and Action Questionnaire; Bond ym., 2011). Ennen kokeilua mittarit käännettiin suomalaiselle viittomakielelle. Käännöstyöhön osallistuivat viittomakielinen psykoterapeutti, viittomakielen tulkki sekä ryhmä kuuroja, jotka olivat äidinkieleltään viittomakielisiä henkilöitä. Yhteisten keskustelujen jälkeen yksi ryhmän kuuroista jäsenistä viittoi käännökset videolle.

Kokeilun lopuksi sekä asiakkaat että ohjaajat arvioivat kokeilua puolistrukturoidulla kyselyllä. Asiakkaita pyydettiin kommentoimaan käytettyjä materiaaleja ja menetelmiä, muun muassa sitä, olivatko nämä ymmärrettäviä, mitä harjoituksia he olivat tehneet ja mitkä näistä olivat edelleen käytössä. Ohjaajia puolestaan pyydettiin arvioimaan koulutusta, työnohjausta sekä käytössä olleita materiaaleja.

Kokeilun alussa ohjaajat osallistuivat kaksipäiväiseen koulutukseen, jossa käytiin läpi hyväksymis- ja omistautumisterapian taustaa, mallia sekä menetelmiä. Lisäksi ohjaajia ohjattiin käyttämään funktionaalista tapauskuvausta (Haynes ym., 2011; Haynes & O'Brien, 1990; Haynes & O'Brien, 2000; Haynes & Williams, 2003; Petermann & Mueller, 2001). Tapauskuvauksen avulla ohjaajilla oli mahdollista saada yleiskuva asiakasta vaivaavista asioista ja ongelmista sekä

tehdä näiden mukaan asiakkaalle räätälöity interventio. Tapauskuvauksen käyttö oli osalle ohjaajista tuttu aikaisemmista koulutuksista. Aiemmat kokeilut ovat osoittaneet, että lyhyelläkin koulutuksella on mahdollista soveltaa hyväksymis- ja omistautumisterapian menetelmiä käytäntöön (mm. Lappalainen ym., 2007; Lappalainen ym., 2014; Lappalainen ym., 2015; Räsänen ym., 2016).

Kokeilun aikana ohjaajat käyttivät koulutusmateriaalina ja ohjauksen tukena suomenkielisiä HOT-kirjoja kuten Hyväksymis- ja omistautumisterapia käytännön terapiatyössä (Lappalainen, ym., 2004) ja Vapaudu mielesi vallasta ja ala elää (Hayes & Smith, 2008) ja perustivat oma-aloitteisesti opintoryhmän käytäntöön läpi kirjallisuutta yhdessä. Materiaaleissa on kuvattu tarkemmin hyväksymis- ja omistautumisterapian prosessit sekä useita kymmeniä harjoituksia ja metaforia. Lisäksi kaikki ohjaajat osallistuivat ryhmätyönohjaukseen joka toinen viikko.

Ennen kokeilun alkua käännettiin kaksi hyväksymis- ja omistautumisterapian harjoitusta (Tarkkailija ja Laita tunteet eteesi) ja seitsemän metaforaa (mm. Talo, Köyden veto hirviön kanssa) suomalaiselle viittomakielelle ja nauhoitettiin DVD-materiaalina. Ohjaaja käytti videomateriaalia asiakkaiden kanssa kirjallisten materiaalien lisäksi. Asiakkailla oli myös mahdollisuus katsoa viittomakielistä materiaalia itsenäisesti. Kokeilu kesti yhteensä kolme kuukautta. Ohjaajia ohjeistettiin tapaamaan asiakkaita viikoittain 60 minuuttia kerrallaan. Heitä pyydettiin laatimaan asiakkaasta aluksi funktionaalinen tapauskuvaus ja sen jälkeen käymään asiakkaan kanssa hyväksymis- ja omistautumisterapian mukaista arvotyöskentelyä. Arvotyöskentelyssä asiakkaita pyydettiin arvioimaan henkilökohtaisesti tärkeitä asioita eri elämänalueilla (mm. perhe, työ, koulutus) ja valitsemaan tekoja, jotka vievät näiden arvojen suuntaan. Omaan hyvinvointiin vaikuttaminen tekojen ja toiminnan avulla suunniteltiin yhdessä ohjaajan kanssa ja asiakas toteutti niihin liittyviä tekoja tapaamisten välillä. Arvotyöskentelyn lisäksi ohjaajia tuettiin käyttämään hyväksymis- ja omistautumisterapian periaatteita sekä muita menetelmiä tapaamisten aikana. Tapaamisten määrä vaihteli 7-11 välillä ja tapaamisten kesto oli 20-90 minuuttia (ka = 65 min). Keskimäärin ohjelma sisälsi 10 noin tunnin pituisia tapaamista, mutta tapaamisten pituus vaihteli.

Ohjaajien käyttämiä hyväksymis- ja omistautumisterapian menetelmiä kuvattiin harjoitusten määrällä ja sillä, minkälainen harjoitus oli kyseessä. Tulokset liittyen masennukseen (BDI), oireiluun (SCL-90 alaluokkineen) ja psykologiseen joustavuuteen (AAQ-2) analysoitiin SPSS-tilasto-ohjelman t-testillä (keskiarvo ja keskihajonta) sekä sisäisillä efektikokoarvoilla. Mittaukset tehtiin kokeilun alussa ja lopussa sekä puolen vuoden kuluttua (seurantamittaukset).

## 2.4.2 Tulokset

Kokeilun alussa kaikilla asiakkailla (94 %, n = 15) yhtä lukuun ottamatta oli masennuskyselyn (BDI) mukaan vähintään lieväasteinen masennus (masennusoireiden määrä korkeampi kuin 9) ja 69 %:lla (n = 11) oli vähintään kohtalaista masennusoireilua. Oirekysely SCL-90:n keskiarvo ja hajonta (ka 1,37, hajonta 0,57) olivat tässä tutkimuksessa lähellä tasoa, joka oli suomalaisilla psykiatrisessa

avohoidossa olevilla asiakkailla (ka 1,56, hajonta 0,61; Holi ym., 1998). Näin ollen tutkituilla asiakkailla oli suhteellisen paljon psykologisia ja fyysisiä oireita.

Kokeilun aikana ohjaajat tekivät arvotyöskentelyä kaikkien asiakkaiden kanssa. Asiakkaat tekivät keskimäärin kuusi erilaista harjoitusta (min = 3, max = 10) ohjelman aikana. Puolet asiakkaista (n = 8) teki enemmän kuin viisi harjoitusta. Noin puolet asiakkaista oli tehnyt videoavusteisia Tarkkailija ja Laita tunteet eteesi -harjoituksia. Muita käytettyjä harjoituksia olivat mm. Matkustajat bussissa ja Mielen juna. Metaforista käytetyimpiä olivat Talo (n = 13), Linnunpönttö (n = 9) ja Köydenveto hirviön kanssa (n = 11).

Ohjaajien yleisen arvion mukaan yhtä lukuun ottamatta kaikkien asiakkaiden (n = 15) hyvinvointi kohentui kokeilun aikana. Ohjaajat kokivat myös oman työtyytyväisyytensä parantuneen, minkä vuoksi he toivoivat samanlaisia kokeiluja jatkossa. Opintopiiri koettiin erittäin hyödylliseksi sekä uuden oppimisen näkökulmasta että mahdollisuudesta kokeilla erilaisia harjoituksia. Puolet ohjaajista koki kokeilun erittäin haastavaksi, erityisesti siksi, että käsitteet olivat uusia ja niiden selittäminen asiakkailla oli vaikeaa. Tämän vuoksi toivottiin lisää video-materiaalia. Mittaukset veivät joidenkin asiakkaiden kohdalla pitkän ajan, minkä ohjaajat kokivat hankalaksi.

Kokeilun lopuksi kaikki asiakkaat halusivat suositella vastaavaa työskentelyä muille. Suurin osa heistä (94 %, n = 15) ilmaisi, että oli aiempaa helpompaa keskittyä elämän tärkeisiin asioihin ja että kokeilu oli lisännyt heidän kykyään tunnistaa tunnereaktiot (100 %, n = 16). Kyselyjen mukaisilla tuloksilla näkyi merkittävä muutos oirekysely SCL-90:n alaluokissa somatisaatiossa, sisäisessä herkkyydessä ja ahdistuksessa alkumittauksesta puolen vuoden seurantaan. Vastaava trendi näkyi depressio-oireissa sekä SCL-90:n yleisessä GSI-arvossa. Yksilötasolla vaihtelut olivat kuitenkin suuret. BDI-masennuskyselyn mukaan yhdeksällä asiakkaalla (56 %) 16:sta masennuspisteet laskivat (vähintään 5 yksikköä) alkumittauksesta loppumittaukseen ja noin kolmasosalla lasku jatkui vielä seurantajaksolla. Oirekysely SCL-90 tulosten mukaan puolella (50 %, 8/16) kokeiluun osallistuneista asiakkaista psykologiset ja fyysiset oireet vähenivät vähintään 0,20 yksikköä loppumittauksessa. Kahdella asiakkaalla oireet lisääntyivät loppumittauksen ja seurannan välillä. Psykologinen joustavuus koheni kokeilun aikana yhdeksällä asiakkaalla (56 %), mutta heikkeni seurannassa neljän asiakkaan kohdalla.

### **2.4.3 Pohdinta**

Tässä työssä on esitelty yksi kansainvälisestikin harvoista kokeiluista, jossa hyväksymis- ja omistautumisterapiaa (HOT) on tehty viittomakielellä. Koska viittomakielen taitoisten terapeuttien määrä Suomessa on vähäinen, päätimme kouluttaa ohjaajia soveltamaan hyväksymis- ja omistautumisterapian mukaisia menetelmiä suomalaisella viittomakielellä. On kuitenkin huomattava, että kokeiluun osallistunut asiakasjoukko ei edustanut koko viittomakielistä väestöä Suomessa. Ryhmään kuului henkilöitä, joilla oli tarvetta ympärivuorokautiseen viittomakieliseen asumisympäristöön ja tuettuun työtoimintaan.

Tässä tutkimuksessa ohjaajia pyydettiin valitsemaan kokeiluun asiakkaita, joilla oli kohtuullinen suomalaisen viittomakielen taito ja joilla näytti olevan tarve psykologisten ongelmien käsittelyyn. Enemmistöllä asiakkaista oli useita psykologisia ongelmia. Ongelmien käsittelyyn ei ole riittävästi viittomakielen taitoisia henkilöitä, joten kokeiltiin, voivatko lähityöntekijät oppia lyhyen koulutuksen avulla soveltamaan HOT-menetelmiä. Tutkimus osoitti samalla, kuinka psykologisia hoitoja voi toteuttaa erityisryhmillä. Lisäksi se osoitti, millaisia ongelmia vastaaviin kokeiluihin voi liittyä ja kuinka HOT-menetelmiä voidaan soveltaa viittomakielelle.

Tutkimuksen tulokset osoittivat, että on mahdollista kouluttaa viittomakielentaitoisia ohjaajia käyttämään HOT-menetelmiä. Tulokset osoittivat myös sen, että ohjaajia voidaan opastaa käyttämään HOT-menetelmiä suhteellisen vähäisellä koulutuksella, johon sisältyy oppimateriaalia, DVD-materiaalia ja työnohjausta. Kokeilu osoitti myös sen, että asiakkaiden kanssa pystyttiin toteuttamaan kohtuullisen vaativia HOT-pohjaisia harjoituksia ja metaforia. Näin siitäkin huolimatta, että sekä asiakkaat että ohjaajat kokivat uudet käsitteet haastaviksi. Tähän saattoi olla syynä niin asiakkaiden kuin ohjaajienkin vaihteleva viittomakielen taito sekä toisaalta mahdollinen DVD-materiaalin käännosten epätarkkuus.

Kokeilun tuloksista vedettävissä johtopäätöksissä on oltava varovainen. Tämä johtuu mittareiden käytön vaikeuksista sekä kontrolliryhmän puuttumisesta. On myös huomattava, että tapahtuneet muutokset asiakkailla olivat suhteellisen pieniä. Vertasimme tässä tutkimuksessa saatuja tuloksia kahteen tutkimukseen, joissa oli käytetty ei-hoitoa saaneita henkilöitä vertailuryhmänä (Lappalainen ym., 2014; Lappalainen ym., 2015; Räsänen, ym., 2015). Muutokset tässä tutkimuksessa masennuksessa, psykologisissa ja fyysisissä oireissa sekä psykologisessa joustavuudessa olivat hieman suuremmat verrattuna ryhmään, jolle ei annettu mitään hoitoa.

Suuret yksilölliset erot tulivat selvästi esille erityisesti loppumittauksissa. Yleisesti asiakkaat olivat kokeneet arvojensa täsmentyneen sekä saaneensa muita hyötyjä. Ohjaajat toivat esille ongelmat mittausten tarkkuudessa, mikä nostaa esille kysymyksen mittausten luotettavuudesta ja tarkkuudesta. Tutkimuksessa havaittiin, että viittomakielisten mittareiden kehittäminen on jo itsessään tärkeä osa-alue. Kontrolliryhmän puute oli merkittävä ongelma johtopäätöksiä vedettäessä. Myöskään ohjaajien taitoja käyttäen oppimateriaalia HOT-menetelmiä ei tutkimuksessa arvioitu.

Tutkimus osoitti, että arvioitaessa vastaavien interventioiden vaikuttavuutta kannattaa pyrkiä arvioimaan ja kuvaamaan asiakkaiden yksilöllisiä muutoksia. Ryhmätasoinen arviointi ei tuo esille intervention vaikutuksissa havaittuja yksilöllisiä eroja. Kokeilun pituutta on myös tarkasteltava sen valossa, että vaihtelut kielitaidossa asettavat haasteita mittausten tekemiselle sekä menetelmien soveltamiselle. Kaiken kaikkiaan kokeilu vaikutti positiivisesti niin asiakkaiden hyvinvointiin kuin ohjaajien työtyytyväisyyteen. Kuurojen Palvelusäätiö päättikin siksi toteuttaa vastaavanlaista koulutusta muissa palvelukeskuksissa.

## 3 POHDINTA

### 3.1 Keskeiset havainnot ja johtopäätökset

Osatutkimuksessa I (Hassinen, 2010) kuvattiin kuurosokeita henkilöitä, heidän elämänpiiriään, mahdollisia ongelmiaan sekä psykososiaalista ja psykoterapeuttista kuntoutusta. Kuurosokeutta tarkastellaan Pohjoismaisen kuurosokeuden määritelmän (2011) mukaisesti. Tämä pohjautuu WHO:n (2001) julkaisemaan toimintakyvyn, toimintarajoitteiden ja terveyden kansainväliseen ICF-luokitukseen, International Classification of Functioning, Disability and Health (Paltamaa & Anttila, 2015, s. 15). Tässä luokituksessa toimintakyky kuvaa sitä, miten sairauden ja vamman sekä kontekstuaalisten tekijöiden yhteisvaikutukset näkyvät ihmisen arjessa ja elämässä. Toimintakyvyllä tarkoitetaan myös kykyä selviytyä tärkeistä arjen toiminnoista siinä ympäristössä, jossa ihminen toimii. Kuurosokeiden henkilöiden kohdalla – pohjoismaisen kuurosokeuden määritelmän mukaan – tarkastellaan sitä, miten kaksoisvamman vaikutus osallisuuteen ja suoriutumiseen yhteiskunnassa, jolloin otetaan huomioon kaksoisvamman vaikutukset kommunikaatioon, tiedon saamiseen ja ympäristöön orientoitumiseen. Arjessa ja jokapäiväisessä elämässä selviytymisessä voidaan tarvita erityisiä ympäristö- ja palvelujärjestelyjä. ICF-luokitus yhdistää sekä lääketieteellisen että yhteiskunnallisen näkökulman toimintakykyyn toisin kuin aiempi malli, joka lähti sairauksien seurauksista (ICIDH, International Classification of Impairments, Disabilities and Handicaps; WHO, 2001).

Osatutkimuksessa I (Hassinen, 2010) kuvattiin aluksi kuurosokeutta vammautumisasajankohdan mukaan eli onko kuurosokeus synnynnäistä vai kehittynyt tai aiheutunut myöhemmin sekä tätä kautta kaksoisvamman vaikutuksia kieleen ja kulttuuriin (NUD, 1986). Kuurosokeiden ryhmän heterogeenisuus tulee esille erityisesti kommunikaatiossa. Eri kommunikaatiotavat perustuvat joko viittomakieleen tai puhuttuun kieleen, mikä vaikuttaa myös tiedon saamisessa ja ympäristöön orientoitumisessa. Yhdistävä kulttuurinen tekijä on kaikkien aistien



tietoinen hyväksikäyttö, jolloin kuulo- ja näköaistin lisäksi käytetään tunto-, haju- ja makuaistia lisäämään heikentyneiden kaukostaitein informaatiota tai korvaamaan puuttuvia aisteja. (Kontaktiryhmä 2002; Rouvinen, 2001)

Arjen toiminnoissa selviytymisessä on tarkasteltu erityisesti asumista sekä itsenäistä toimimista ja tämän mahdollistavia palveluja. Kuurosokeiden henkilöiden elämänlaadun ja hyvinvoinnin kokemista laadukkaana edesauttavat elämänhallinta, mielekkyys ja sosiaaliset suhteet (Rouvinen, 2001). Tämän toteutumisessa ovat merkittävinä kuurosokeiden kulttuuriin liittyvät tärkeät arvot, kuten itsemääräämisoikeus ja omista asioista päättäminen, jotka edellyttävät sekä sisäistä että ulkoista elämänhallintaa (Rouvinen, 2001). Sisäisiä keinoja ovat esim. liikkumistekniikan taidot, pistekirjoitus ja toimiva kommunikaatitapa. Ulkoisia keinoja ovat yhteiskunnan järjestämät tulkki- ja kuljetuspalvelut, avustajajärjestelyt, tiedonsaanti, turvaverkoston rakentaminen ja mielekkään tekemisen mahdollistaminen. Näitä ovat mm. palveluasuminen, kotiin tarvittavat muutostyöt ja tekniset apuvälineet sekä tiedonsaantia helpottavat apuvälineet, joissa usein hyödynnetään tietotekniikkaa. Näiden yhteensovittaminen ja palvelujen saaminen vaatii paitsi kuurosokealta henkilöltä itseltään aktiivisuutta ja taitoa tuoda esille omia tarpeitaan, niin usein myös kuntoutustyöntekijän tukea (Kuurosokeiden elinolot Pohjolassa vuonna 2000; Sosiaalhallitus 1987 ja 1990).

Palveluja saadakseen kuurosokeiden henkilöiden on usein pitänyt perustella yhä uudestaan palvelujen tarvetta, vaikka vammoissa ei olisikaan tapahtunut muutoksia. Tämä on voinut olla nöyryyttävää ja kuluttavaa ja korostaa jo vanhentunutta näkökulmaa vamman aiheuttamasta seurauksesta (Hassinen, 2010). Palvelujen saatavuus tai riittävyys vaikuttavat toimintakykyyn arjessa. Näitä psykososiaalisia vaikutuksia on julkaisussa tarkasteltu eri kielellisissä ryhmissä eri ikäkausina. Psykososiaalista tukea tarvitaan jokapäiväisestä elämästä selviytymiseen ja toimivien kommunikaatiokeinojen löytämiseen vertaistuen avulla tai erilaisia palveluja järjestämällä. Kuurosokeat henkilöt tarvitsevatkin usein yksilöllisesti kohdennettua tukea ja kuntoutusta tilanteen helpottamiseksi (Olesen & Jansbol, 2005).

Kuurosokeuden vaikutukset toimintakykyyn ovat erilaisia ja yksilöllisiä eri kuurosokeiden ryhmissä. Osatutkimuksessa I kuvattiin laajemmin psykososiaalisia vaikutuksia viittomakielisten ja puhekielisten kuurosokeiden ryhmissä. Viittomakielisillä kuurosokeilla, joista suurimpana ryhmänä Usher, nousi esille kielen merkitys. Ympärillä olevien ihmisten, kuten esimerkiksi vanhempien kanssa ei ole välttämättä yhteistä sujuvaa kieltä. Siksi vanhempien voi esimerkiksi olla vaikea kertoa lapselleen näköongelmista. Tasapaino-ongelmat ja kömpelyys altistavat myös koulukiusaamiselle. Myöhemmässä vaiheessa elämää on pohdittava kotoa lähtemistä, ammatinvalintaa ja työnsaantimahdollisuuksia erityisesti näkövamman takia. Näön heikkeneminen vaikuttaa myös kommunikaatioon. Siirtyessään taktiiliin viittomiseen ja opastustarpeen lisääntyessä osa kuurosokeista henkilöistä kokee menettävänsä vapauttaan. Samalla he saattavat kokea masennusta, tulevaisuuden pelkoa ja katkeruutta niitä ihmisiä kohtaan, jotka näkevät. Puhekielistet kuurosokeat henkilöt ovat kasvaneet kuulevassa ympäristössä, jolloin kieli ei ole yleensä ongelma, vaan pikemminkin aistien

muuttuminen. Tällöin kommunikaatio vaikeutuu sen takia, ettei kuule hyvin eikä heikentyneen näön takia pysty lukemaan huulilta. Tiedon saaminen ja ryhmässä toimiminen vaikeutuvat, mikä on merkittävä elämänlaatua heikentävä tekijä. Kuulon heikentymiseen liittyvää prosessia analysoitaessa (Stone, 1987) on tullut esille, että ainoa yleismaailmallinen stressitekijä on kommunikaation häiriintyminen.

Psykologisista ongelmista nousevat esille fyysinen jännittyneisyys ja stressi, pelot ja ahdistuneisuus, masentuneisuus ja traumaattisten kokemusten muistot sekä aistivammojen vaikutus persoonallisuuteen. Osatutkimuksessa I kuurosokeiden henkilöiden tilanteiden moninaisuutta on kuvattu myös kahdella asiakasesimerkillä, joissa on käytetty tapauskuvausmallia (Haynes & O'Brien, 2000). Tapauskuvausmallien avulla myös osoitettiin, miten yksilöllistä tapauskuvasta voidaan hyödyntää suunniteltaessa psykoterapeuttista kuntoutusta.

Osatutkimuksessa II osoitettiin, millä tavalla käyttäytymisanalyysiin pohjautuvaa tapauskuvausmallia voidaan soveltaa asiakkaan tilanteen kartoittamiseksi. Laajassa funktionaalisessa tapauskuvauksessa kaikki analyysin osat esitetään kuvina: käyttäytymisongelmat ja niiden vaikutukset, ongelmien väliset funktionaaliset suhteet, ongelmien suhteellinen merkittävyys, kausaalisten ja eikausaalisten ongelmiin vaikuttavien suhteiden voimakkuus sekä kausaalisuhteiden muutettavuus (Haynes & O'Brien, 2000; Lappalainen ym., 2007). Osatutkimuksessa II osoitetaan lisäksi, että henkilöstöä voidaan ohjata suhteellisen lyhyellä koulutuksella käyttämään analyysimallia, joka voi toimia yhteisenä työvälineenä asiakkaan tilanteen kartoittamiseksi. Osatutkimuksessa kuvattu koulutus muodostui kolmesta kahden päivän jaksosta, joiden välissä oli Haynesin & O'Brienin (2000) tapauskuvausmallin mukaisia kotitehtäviä. Ohjaajien tuottamat tapauskuvaukset osoittivat kuurosokeiden henkilöiden kokemia keskeisiä ongelmia. Sekä kuurosokeutuneilla että syntymästä saakka kuurosokeilla henkilöillä osoittautuivat kommunikaatio-ongelmat yleisimmiksi elämänlaatua heikentäviksi tekijöiksi. Lisäksi kuurosokeutuneiden ryhmässä raportoitiin mm. muistoja traumaattisista kokemuksista, epäluuloisuutta ja epäluottamusta, uni-ongelmia, yksinäisyyttä ja eristäytyneisyyttä. Syntymästä saakka kuurosokeilla henkilöillä esiintyi enemmän näkyvän käyttäytymisen ongelmia, kuten aggressiivista käyttäytymistä, kärsimättömyyttä ja levottomuutta. Nämä ongelmat nousivat useasti esille työntekijöiden havaintojen kautta, koska asiakkaan kielelliset taidot eivät välttämättä riittäneet kuvaamaan ongelmia kielellisesti. Molempien ryhmien kohdalla voidaan tapauskuvauksen avulla havaita interventioden mahdollisuudet vaikuttaa myönteisesti elämänlaatuun. Intervention ja toimenpiteiden vaikuttavuutta voi myös seurata palaamalla ajoittain takaisin tapauskuvausmalliin.

Osatutkimuksessa III on kuvattu yhden asiakkaan psykoterapiaprosessi. Asiakkaalla oli lievä kuulo- ja näkövamma sekä Prader-Willin oireyhtymä, johon liittyy lievä kehitysvamma, diabetes, krooninen selkäkipu, ylipainoa ja masennus. Osatutkimuksessa III esiteltiin esimerkki siitä, miten tapauskuvausmallia voidaan hyödyntää silloin kun asiakkaalla on useita toimintakyvyn rajoitteita. Terapiaprosessin aikana havaittiin myös, että laaja tapauskuvausmalli auttaa

kehittämään asiakkaan taitoja havaita asioiden välisiä yhteyksiä ja lisää tätä kautta ymmärrystä elämän varrella tapahtuneista asioista ja niiden merkityksestä nykyisyyteen. Taitoa syvennettiin vielä useilla graafisesti kuvatuilla ketjuanalyysillä eli ns. A - B - C-malleilla, jossa A = käyttäytymistä edeltävät tekijät, B = itse käyttäytyminen ja C = käyttäytymisen seuraukset (mm. Lappalainen ym., 2007). Näiden mallien avulla käytiin läpi asiakkaan elämänhistorian traumaattisia kokemuksia mm. kiusaamisesta. Julkaisussa III osoitettiin, miten asiakkaan hoidossa voidaan käyttää monenlaisia ja monipuolisia menetelmiä. Työssä osoitettiin myös, miten psykologisilla hoidoilla voidaan auttaa asiakkaita myös tilanteissa, joissa heillä on harvinaisia synnynnäisiä tai geneettisiä poikkeavuuksia, kuten tässä tapauksessa Prader-Willin oireyhtymä kuulo- ja näkövamman lisäksi. Tapauskuvausmallin ja ketjuanalyysien avulla asiakasta opetettiin näkemään erilaisia ratkaisutapoja ongelmiin. Näin asiakkaan kognitiiviset taidot, erityisesti syy-seuraussuhteiden näkeminen ja ongelmanratkaisutaidot kehittyivät terapia-prosessissa analyysitaitojen avulla.

Oirekysely SCL-90:n ja masennuskysely BDI:n mukaan asiakkaan psykologiset oireet vähenivät hoidon aikana. Seurannassa puoli vuotta hoidon loppumisen jälkeen ei masennusoireita enää havaittu ja oireilu kokonaisuudessaan oli samalla tasolla kuin työssäkäyvillä henkilöillä vertailuaineistossa (Holi, 1998). Somaattiset oireet (mm. kipu) kuitenkin vähenivät vähemmän kuin muut oireet, mikä selittynee Prader-Willin oireyhtymän aiheuttamilla fyysisillä muutoksilla. Asiakas korosti kuitenkin sitä, että kipu ei ollut niin häiritsevää kuin aiemmin ja sosiaaliset suhteet olivat parantuneet.

Osatutkimuksessa IV kuvattiin sitä, kuinka henkilöstöä voidaan kouluttaa käyttämään tapauskuvausmallia ja lyhyitä interventioita, vaikka heillä ei ole psykologisiin hoitoihin liittyvää ammatillista koulutusta. Interventiot pohjautuivat hyväksymis- ja omistautumisterapiaan, johon henkilöstö sai ammattilaisten tarjoamaa koulutusta ja työnohjausta. Ohjaajat perustivat myös keskinäisen luku-piirin käydäkseen yhdessä läpi opittua teoriaa ja menetelmiä. Kokeilu kesti kaikkiaan kolme kuukautta, jolloin ohjaajat tapasivat asiakasta noin kerran viikossa. Kokeilu osoitti, että ohjaajat pystyivät ilman psykoterapiakoulutusta toteuttamaan psykologisen intervention viittomakielellä. Käytännön vaikeutena oli se, että asiakkaan kanssa käytetyt mittarit ja harjoitukset olivat hyvinkin haasteellisia. Kokeilun edetessä työ helpottui, mutta samalla tuli esille interventioon käytetyn ajan lyhyys. Aikaa intervention toteuttamiseen oli varattu 10 viikkoa, mikä osoittautui asiakkaiden palautteen ja ohjaajien kokemuksen mukaan liian lyhyeksi. Yhteinen toive olikin, että vastaavissa kokeiluissa interventioihin käytetään tulevaisuudessa pitempi ajanjakso. Jo lyhyessäkin ajassa tuli kuitenkin esille se, että interventioilla voi olla vaikutusta sekä asiakkaiden että henkilöstön hyvinvointiin. Yhtä lukuun ottamatta kaikkien asiakkaiden (n = 15) hyvinvointi kohteni kokeilun aikana. Lisäksi ohjaajat kokivat oman työtyytyväisyytensä parantuneen. Asiakkaiden osalta vaikutukset olivat hyvin yksilölliset, mikä teki tulosten esittämisen ryhmätasolla haasteelliseksi. Työntekijöiden hyvinvoinnin lisääntyminen sen sijaan näkyi selvästi Palvelusäätiön säännöllisesti tekemässä

henkilöstön hyvinvoinnin kartoituksessa (Luukkainen, 2010). Kuurojen Palvelusäätiössä ryhdyttiinkin käyttämään mallia myös muissa toimipisteissä.

### **3.2 Kuurosokeiden ja kuurojen henkilöiden psykologista hyvinvointia lisääviä tekijöitä**

Psykologisen hyvinvoinnin osatekijöitä voidaan tarkastella ICF-luokituksen mukaan (Paltamaa & Anttila, 2015), jossa kuurosokeiden henkilöiden kohdalla korostuu kaksoisvamman vaikutus yhteiskunnassa osallistumiseen ja suoriutumiseen. Tällöin ympäristössä ja palveluissa on tehtävä erilaisia järjestelyjä, jotta mahdolliset kommunikaatio-, tiedonsaanti- ja liikkumisongelmat helpottuisivat. Tässä tutkimuksessa korostui kommunikaation merkitys, niin kuin monissa muissa kuurosokeiden tai kuurojen ryhmissä tehdyissä tutkimuksissa (mm. Koskinen, 2000). Tutkittujen ryhmien yhtenä tärkeimmistä perusteista psykologiselle hyvinvoinnille oli kommunikaatio läheisten kanssa ja tässä tutkimuksessa erityisesti asiakassuhteissa. Esille nousi molemminpuolinen kommunikaatiotaitojen tärkeys: sekä asiakkaan taidot ilmaista itseään ja omia tarpeitaan että vastaanottajan taidot ymmärtää asiakasta ja kommunikoida niin, että asiakas tulee ymmärretyksi. Kommunikaatiovaikeuksien seuraukset voivat olla myös psykologisia, kuten yksinäisyyttä ja mielialaongelmia, joista puolestaan seurauksena on usein välttämiskäyttäytymistä ja lisääntyvää sosiaalista eristäytymistä. Tätä vahvistaa myös mahdollinen palvelujen puute, esimerkiksi opas- tai tulkkauspalveluissa. Osa tutkimukseen osallistuneista henkilöistä ilmoitti liikkumisen esteenä myös sosiaalisten tilanteiden pelot ja jännityksen, joista seurauksena voi olla kotiin jääminen ja eristäytyminen. Tutkimusten mukaan erityisesti epämiellyttävien tunteiden välttämisen on havaittu olevan yhteydessä psykologisiin ongelmiin (mm. Kotsou et al., 2018; Spinhoven et al., 2014).

Kuurosokeiden ja kuurojen henkilöiden arjen ongelmat ovat yksilöllisiä ja erilaisia ja näin ollen psykologiset ongelmatkin ovat erilaisia. Psykologiset ongelmat voivat ”hukkaa” käytännön ongelmien alle, kuten arjen kommunikaation tai liikkumisen ongelmiin. Arjessa toimimista ja selviytymistä voidaan edesauttaa psykososiaalisella tuella, kuten mahdollisuudella löytää vertaistukea ja hyviä sosiaalisia suhteita sekä mielekäästä tekemistä. Tapauskuvausmallin avulla on mahdollista tuoda esille henkilön arjen ongelmien moninaisuus sekä myös mahdolliset psykologiset ongelmat, niiden seuraukset ja se, että kuurosokeat henkilöt on otettava palvelujärjestelmässä yksilöllisesti huomioon.

### **3.3 Tutkimukseen liittyvät ongelmat ja rajoitukset**

Psykologisiin tekijöihin keskittyvää tutkimusta kuurosokeiden tai kuurojen viittomakielisten henkilöiden tilanteesta on sekä kansainvälisesti että erityisesti

Suomessa vain vähäisessä määrin. Tutkimukset ovat lähinnä kartoituksia psykologisista tai yhteiskunnallisista ongelmista ja palvelutarpeista (mm. Koskinen, 2001; Lindfors, 2005). Psykologisia interventiotutkimuksia on tehty kansainvälisesti jonkin verran, kuten johdannossa on kuvattu. Näistä osa on kognitiivisen käyttäytymisterapian menetelmiin perustuvia kokeiluja, joissa tutkijat kohtasivat samanlaisia haasteita kuten tässä tutkimuksessa. Näitä olivat ryhmien ja tutkimusjoukon pienuus, sopivien mittareiden löytämisen hankaluus, kommunikaatio-ongelmat sekä viittomakielisten tutkijoiden tai terapeuttien vähäisyys. Ongelmana on myös se, että kuurosokeitten tai kuurojen viittomakielisten ryhmien tutkiminen ei kiinnosta tutkijoita.

Tässäkin työssä tutkittavien henkilöiden määrä oli pieni. Osatutkimuksessa I oli mukana kaksi henkilöä, osatutkimuksessa II oli 21 henkilöä, osatutkimuksessa III yksi ja osatutkimuksen IV henkilömäärä oli 16. Kun on kyse erityisryhmistä, aineistot eivät voi olla suuria. Lisäksi erityisryhmien sisällä on monenlaisia erillisiä ryhmiä. Tuloksien yleistettävyyden suhteen pitää näin ollen olla varovainen. Yksi tulosten luotettavuuteen vaikuttava tekijä on käytettyjen mittareiden (mm. osatutkimuksessa IV käytettyjen SCL-90, BDI ja AAQ-2) soveltuvuus tutkituille henkilöille. Koska kyseisiä mittareita ei ole laadittu näitä ryhmiä varten, mittarit eivät välttämättä sovellu suoraan kuurosokeiden ja kuurojen henkilöiden arviointiin. Mittaaminen on ongelmallista ja haasteellista, koska mittarit on laadittu ja niiden luotettavuus on tutkittu eri kielellä. Tarvitaan erityisesti erityisryhmille soveltuvia arviointimenetelmiä, joissa eri tavalla kommunikoivat henkilöt otetaan huomioon. Käytännön työssä arvioinnin olisi hyvä kohdistua esimerkiksi elämänlaatuun. Hyvinvoinnin arvioimiseksi tarvitaan mittareita, jotka mittaavat psykologista hyvinvointia niin, että löydetään myös tietoa taidoista, joiden avulla hyvinvointia voisi edistää.

Tapauskuvausmallin käyttämisessä on myös omat rajoituksensa (Haynes ym, 2011). Ensinnäkin pitää huomata, että tapauskuvausmalli on oletus asiakkaan tilanteeseen liittyvistä tekijöistä tai suhteista ja muuttuu tekohetken ja kontekstin muuttuessa. Tapauskuvausmalli on myös työläs tehdä eikä sitä kannata käyttää silloin, kun asiakkaalla on vain vähän ongelmia. Interventioita suunniteltaessa pitää myös ottaa huomioon se, että kaikki vaikuttavat tekijät eivät näy mallissa. Tällaisia voivat olla mm. käytettävissä oleva aika, motivaatio muutokseen ja taloudellinen tilanne sekä työntekijän taidot.

### **3.4 Tutkimushaasteita tulevaisuudessa**

Tulevien vuosien haasteena on ensinnäkin kehittää kuurosokeiden ja viittomakielisten henkilöiden hyvinvoinnin arviointiin sopivia mittareita ja arviointivälineitä. Kuten aiemmin on tullut esille, sopivia mittareita on vaikea löytää. Tässä tutkimuksessa käytetyn arvolähtöisen työskentelyn (Hayes ym. 1999; Hayes & Smith, 2008) havaittiin tuovan hyvinvointia elämään. Tutkittavat kokivat ehkä ensimmäisen kerran elämässään, että heistä oltiin kiinnostuneita ja heidän mieliteilloillaan oli merkitystä, ja he pystyivät omilla valinnoillaan vaikuttamaan

elämäänsä. Olisi tärkeää selvittää tarkemmin ja perusteellisemmin, mitä vaikutuksia arvo- ja hyväksyntäpohjaisilla menetelmillä on kuurosokeiden ja viittomakielisten henkilöiden hyvinvointiin ja ihmissuhteisiin.

Toisena haasteena ovat interventioissa käytettävät harjoitteet. Osatutkimuksissa III ja IV käytettiin erilaisia kognitiivisen käyttäytymisterapian ja hyväksymis- ja omistautumisterapian harjoitteita. Ennen kokeilun alkua käännettiin kaksi hyväksymis- ja omistautumisterapian harjoitusta (Tarkkailija ja Tunteet eteesi) ja seitsemän metaforaa (mm. Talo, Köyden veto hirviön kanssa) suomalaiselle viittomakielelle ja harjoitukset videoitiin DVD:lle. Ohjaaja käytti videomateriaalia asiakkaiden kanssa kirjallisten materiaalien lisäksi. Tämän kokeilun lisäksi tarvittaisiin laajempaa tutkimusta tai käytännön kokeilua, jonka puitteissa kehitettäisiin lisää erityisryhmille sopivia harjoitteita ja interventiomenetelmiä. Myös teknologisten ratkaisujen kuten verkko- ja mobiilisovellusten hyödyntämisestä interventioissa ja palveluissa tulisi selvittää lisää.

Haasteena on lisäksi se, miten henkilöstö voidaan kouluttaa käyttämään arviointimenetelmiä ja erilaisia interventioita tämän asiakasryhmän hyvinvoinnin edistämiseksi. Tässä työssä tehdyn tutkimuksen perusteella ei vielä voida vetää johtopäätöksiä siitä, miten pitkäkestoinen koulutus ja työnohjaus tarvitaan, jotta henkilöstöllä olisi riittävästi tietotaitoa psykologisten interventioiden käytännön toteutukseen. On myös pohdittava, pitäisikö opittuja taitoja, kuten esim. hyväksyntään ja tietoiseen läsnäoloon liittyviä taitoja arvioida. Mielenkiintoista on myös se, mitkä tekijät vaikuttavat siihen, että henkilökunta hyväksyy ja alkaa käyttää uusia menetelmiä omassa työssään. Joka tapauksessa osaavaa henkilöstöä tarvitaan toteuttamaan erilaisia asiakkaiden hyvinvointia lisääviä interventioita tai hoitoja. Lisää tutkimusta tarvitaan koulutusten vaikuttavuudesta ja niiden vaikutuksista myös henkilökunnan työhyvinvointiin ja -viihtyvyyteen.

Uusin lähestymistapa ongelmien käsitteellistämiseen ja sopivien interventioiden löytämiseen on prosessipohjainen kognitiivinen käyttäytymisterapia (Hayes & Hofmann, 2018). Prosessipohjaisissa hoidoissa etuna on se, että ne eivät ole ongelma- tai diagnoosilähtöisiä. Näin ollen henkilöiden on helpompi ottaa tietoa vastaan ja tarkastella omaa tilannettaan eri näkökulmista sekä löytää tapoja lisätä hyvinvointiaan. Koska prosessipohjaisessa näkemyksessä hyvinvoinnin nähdään koostuvan taidoista, tarvitaan lisää tutkimusta olennaisista taidoista, jotka tuovat hyvinvointia. Tässä työssä tutkittujen ryhmien osalta tämä tarkoittaisi nimenomaan kuurosokeiden tai kuurojen henkilöiden hyvinvointitaitojen tarkempaa selvittämistä. Esille ovat nousseet lähes kaikissa esitetyissä tutkimuksissa kommunikaatioon liittyvien taitojen merkitys. Tästä syystä tarvitaan lisää tietoa kommunikaatio-ongelmien vaikutuksesta elämänlaatuun.

### **3.5 Johtopäätökset käytännön työhön**

Tutkimuksessa käytetty funktionaalinen tapauskuvausmalli on soveltuva kuurosokeilla ja viittomakielisillä henkilöillä sekä yksilölliseen asiakastyöhön että henkilöstön työvälineeksi, kun tarvitaan arviointia asiakkaan ongelmista ja

niihin vaikuttavista tekijöistä sekä päätöksiä siitä, mihin interventiot kohdenneetaan. Kun tehdään päätöksiä tarvittavista interventioista, tapauskuvausmalliin kuvatuista ongelmien seurauksista voidaan arvioida, miten suuri vaikutus tiettyyn muuttujaan kohdistetulla interventiolla voi olla. Visuaalisen mallin avulla on helpompi saada käsitys siitä, mitä tekijöitä asiakkaan elämäntilanteeseen liittyy ja mihin voidaan vaikuttaa. Asiakkaan on myös usein helpompi nähdä oma tilanteensa visuaalisen mallin kautta. Yhtenä käyttäytymisanalyysin tai yksilöllisen tapauskuvauksen hyötynä Kohlenberg ym. (2002) tuovat esille sen, että se voisi toimia taustateorianana, joka auttaa terapeuttia tai muita ammattilaisia sopivan menetelmän valinnassa ammattilaisen koulukunnasta riippumatta. Yksilöllistä tapauskuvausta tehtäessä aineistoa voidaan myös kerätä monista eri lähteistä ja käyttää erilaisia arviointimenetelmiä (Haynes & O'Brien, 2000). Tämä voisi olla arvokas menettelytapa kuurojen ja kuurosokeiden alalla toimiville työntekijöille, jotka työssään saavat monenlaista informaatiota asiakkaistaan.

Kuten osatutkimuksessa IV kuvattu lyhyt interventio osoitti, henkilökuntaa voidaan lyhyelläkin koulutuksella opettaa käyttämään tapaustutkimusmallia työvälineenä, samoin kuin arvo- ja hyväksyntäpohjaista työskentelyä. Kokeilun seurauksena Kuurojen Palvelusäätiössä toteutettiin koko organisaation läpi kulkeva asiakaslähtöisen arvotyöskentelyn malli (Hassinen ym., 2014). Menetelmät ovat jääneet elämään, koska koko organisaatio on lähtenyt arvolähtöiseen työskentelyyn päättäjät ja johto mukaan lukien. Menetelmien käyttämisen on myös havaittu lisäävän työntekijöiden hyvinvointia (Luukkainen, 2010). Toteutetulla kokeilulla osoitettiin, että henkilökuntaa voidaan kouluttaa lyhyellä koulutuksella edistämään asiakkaiden psykologista hyvinvointia silloinkin, kun työntekijöillä ei ole terapiakoulutusta. Jos viittomakielistä ammattihenkilöstöä terapeuttiin työhön ei ole tarjolla, ei-ammattilaisia voidaan kouluttaa toteuttamaan lyhyitä interventioita, kuten esimerkiksi tässä työssä käytettyä arvo- ja hyväksyntälähtöistä työskentelyä. Kaikki asiakkaat eivät myöskään tarvitse pitkää terapiaa, vaan psykososiaalista tukea. Aikaisemmalla puuttumisella ja interventioilla voidaan ennaltaehkäistä psykologisten ongelmien syntymistä ja vähentää olemassa olevia ongelmia sekä lisätä elämänlaatua kuurojen ja kuurosokeiden sekä myös muiden erityisryhmien keskuudessa.

Tulevaisuutta ajatellen nousee esille erityisesti kysymys siitä, millaisia tarpeita kuurosokeilla tai kuuroilla henkilöillä on psykologisten interventioiden tai psykoterapian suhteen. Näitä tarpeita tulisi kartoittaa tarkemmin. Tämän työn ja aikaisempien tutkimusten perusteella voidaan olettaa, että tarvitaan sekä pitkiä psykoterapioita että lyhyempiä terapeutteja interventioita. Etäterapiat mahdollistavat viittomakielisten terapiapalvelujen saamisen, vaikka terapeutti olisikin fyysisesti pitkän välimatkan päässä. Netin kautta olisi mahdollista tehdä myös erilaisia lyhytterapeutteja interventioita tai tarjota muita psykologisia ohjelmia viittomakielellä. Palveluiden kehittäminen vaatii kuitenkin varoja ja panostusta sekä asiasta innostuneita henkilöitä. On tärkeää, ettei erityisryhmiä unohdeta kehitettäessä hyvinvointipalveluja. Tämä työ antaa esimerkkejä siitä, mihin suuntaan palveluiden kehittämisessä voitaisiin edetä.

## SUMMARY

### **A case formulation model for the assessment and promotion of psychological wellbeing in deafblind and deaf persons**

Psychological assessment and treatment of a deafblind or deaf person with multiple difficulties due to syndromes or disabilities and potential additional diseases can be challenging because of the complexity of the problems. Therefore, it is important to identify individual factors contributing to distress and to offer assessment methods and appropriate treatment to promote the psychological well-being of this group.

The present work aimed to apply the functional case formulation strategy and analytic case formulation model known as the functional analytic clinical case diagram (FACCD, Haynes et al. 2000, 2011). In the current work, the FACCD was used to describe and understand behavioral problems and causal relationships associated with problems in the population with hearing and vision impairment. The aim was to find out how case formulation models can be combined with psychological interventions and thereby how these assessment models can facilitate psychological interventions for persons with hearing and vision problems. A further purpose was to demonstrate different ways to apply case formulation models such as the FACCD.

The aim of Study I was to describe a group of deafblind people from a psychological perspective by gathering both knowledge and practical examples of individuals with hearing and visual impairments. The study indicated that the group of deafblind people was heterogeneous, suggesting that the psychological problems they experienced would vary greatly between them and various other deafblind groups. The current research suggested that loneliness and symptoms of depression and anxiety are among the most common problems reported by people with hearing and vision problems. Study 1 gave an overview of psychosocial and psychotherapeutic rehabilitation and illustrated psychological interventions for people with hearing and visual impairments using two imaginary examples.

The aim of Study II was to investigate how deafblind persons experiencing multiple psychological problems were assessed by healthcare professionals who were trained in functional analyses and in applying the case formulation model (FACCD). Based on the clinical assessment data, the investigated 21 deafblind persons were reported to have between 3 to 11 psychological problems each. These problems build a complex network since the problems interacted with each other. Two case examples were given to illustrate the complexity of a deafblind person's life situation and the functional relations among problems and possible causal variables. Study 2 showed that it is possible to train staff members – with no previous experience with psychological interventions – to apply psychological assessment methods such as the FACCD.

Study III presented a case example of the behavioral assessment and treatment of a person with Prader-Willi syndrome, hearing and vision difficulties,



mild learning disability, diabetes, depression, chronic pain problem, and an overweight BMI. The treatment incorporated a case formulation model, functional analysis of specific behavioral problems, communication skills training, body awareness training, and contextual principles and techniques. The treatment was provided over a period of three years. This case example showed that although chronic and inherited disorders cannot be cured, psychological interventions can significantly increase wellbeing and quality of life. Further, the case demonstrated how a client can be involved in the treatment by applying the functional analyses models. Overall, the study showed the usefulness of individual behavioral assessment methods among individuals with multiple syndromes and psychological problems.

Study IV investigated the effectiveness of the treatments delivered by staff members in a rehabilitation center for deaf clients. Staff members received brief training in how to apply the functional case formulation strategy and analytic case formulation model (FACCD) and how to use the principles of acceptance and commitment therapy (ACT). The training consisted of 16 hours of lectures, 15 hours of supervision, and studying ACT manuals. A total of 16 clients and 9 staff members attended the trial, which included 8-10 treatment sessions for each client. The intervention was conducted using Finnish Sign Language. In addition, psychological questionnaires and ACT metaphors and exercises were translated to Finnish Sign Language. The results indicated that there was a large variation in how the deaf clients who experienced several psychological problems responded to the treatment. However, the results showed decreases in psychological symptoms and increases in skills of psychological flexibility. The trial demonstrated that it is possible to train staff members – with no previous experience with psychological interventions – to apply psychological intervention methods in their daily work.

In conclusion, the results of the current research showed that a clinical case formulation model such as the functional analytic clinical case diagram can be a useful tool when selecting targets for the treatment of persons with vision, hearing, and communication problems and when making further treatment decisions. The findings of the current research showed that, in addition to hearing, vision, and communication problems, deafblindness and deafness can be associated with psychological problems that may benefit from more precise psychological assessment and treatment. Thus, cognitive behavioral assessment and intervention procedures should be applied more in assessment and treatment in order to increase the quality of life of minority groups such as persons with hearing and vision difficulties.

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#### WWW-lähteet

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# **ALKUPERÄISARTIKKELIT**

## **I**

### **SENSE OF LIFE. THE LIFE WORLD, PSYCHOLOGICAL PROBLEMS, PSYCHOSOCIAL AND PSYCHOTHERAPEUTIC REHABILITATION OF DEAFBLIND CLIENTS.**

by

Leena Hassinen 2010  
The MIELI Project, the Service Foudation for the Deaf

Helsinki: Kuurojen Palvelusäätiö.

Uudelleenjulkaistu Kuurojen Palvelusäätiön luvalla.



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The MIELI Project, the Service Foundation for the Deaf  
2010

ISBN 978-951-98990-6-0

Printed by: Offsetkolmio, Hämeenlinna

Illustration: Clients who have participated in events  
held by the Activity Centre for the Deafblind.

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# PREFACE

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A book about the life, psychological problems and rehabilitation of deafblind clients provides a remarkable opportunity to understand the problems of deafblind clients and develop rehabilitation and treatment methods. This book provides an understanding of the possible problems linked with deafblindness and gives examples of how these problems can be described, analysed and dealt with. It is crucial that existing psychotherapeutic research data is applied to the groups that need it the most. The methods and their applications presented in the book can be considered as cutting edge, even from an international perspective. Very little literature in the world deals with the corresponding applications for the development of therapy with the deafblind. Accordingly, this book serves both as a textbook for various fields and as a handbook for people who work with the deafblind or face similar challenges.

One of the strengths of the book is the enlightening examples and hands-on descriptions of ways to conduct analysis and rehabilitation measures. We hope that the book will promote the development of rehabilitation and treatment methods for other groups with special needs and that it will be used diligently in various communities and training events. We sincerely believe that applying the message of the book will promote and enhance the quality of life of the deafblind.

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# INTRODUCTION

From 2005 to 2009 the Service Foundation for the Deaf conducted the MIELI project to develop psychotherapy with the deafblind. The goal of the project was to help deafblind persons towards a better life by developing methods that are applicable in individual and in group psychotherapy and to offer people working in the field the means to support the psychological well being of deafblind clients.

One of the projects early tasks was to gather data on deafblind clients, their life world and their psychological problems. The material was compiled from both Finnish and international sources, mostly from articles. While literature about deafblindness does exist, there is very little on the connection between deafblindness and psychological problems.

The purpose of this book is to provide general knowledge, both to people working in the field and to those who are interested in the subject of deafblind persons but have no prior experience in this area. Accordingly, some general facts about deafblind persons and their life world, such as housing, education and available services, has been attached in the opening section.

The latter part of the book describes the psychological problems that deafblind clients face and how these can be alleviated with psychosocial or psychotherapeutic support. The focus is primarily on the clientele of the kind of rehabilitation services in which psychological problems arise, particularly in reference to various rehabilitation services. At the same time, it is important to note that being deafblind does not necessarily mean having problems as much as it means facing challenges, in functioning in a society made for people who can hear and see. For example, deafblind persons are more susceptible to stress than the average population. Some deafblind persons, however, have better physical and psychological means of coping with stressful situations than other deafblind people, as well as a better social support system.

The latter part of the report deliberately takes a problem-oriented approach. This is partly grounded on the theoretical background of the project, which is behavioural analysis that uses the description of a problem as a starting point. One partial justification for this is the fact that the psychological and mental health problems of minority groups are still difficult topics to talk about. Despite this, addressing the problems head-on can help the clients, their families and personnel working in the field to seek help if they need it.

The author would like to warmly thank the numerous people who shared their valuable comments and critiques at various stages of the writing process.

# KEY CONCEPTS

The following pages present the key concepts in this book as they are used in this particular context.

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## **Deafblindness, visual and hearing disability**

According to the revised Nordic definition, "Deafblindness is a specific limitation of function. Deafblindness, the combination of hearing and visual impairment (dual disability), complicates sharing and performing to such an extent that it demands specific planning of environment and services from society".

## **Congenital deafblindness**

Persons with congenital deafblindness have been deafblind since birth or early childhood. They often also have other disabilities or illnesses such as heart diseases, cerebral palsy and developmental disabilities.

## **Acquired deafblindness**

Persons with acquired deafblindness are born with the ability to hear and/or see and have become disabled later in life. The majority of these people learn their native language through their sense of hearing. Nevertheless, this category also includes deaf persons using sign language who later develop visual problems. In most of these cases, the major reason for developing visual and hearing impairment is Usher syndrome.

## **Usher syndrome**

Usher syndrome is a covertly inherited syndrome in which the hearing disability can vary from deafness to difficulty hearing. Visual impairment is caused by *retinitis pigmentosa*, which typically causes a limited visual field, also referred to as tunnel vision, night blindness, hemeralopia, glare-induced vision problems and weakening of contrast sensitivity. Some sufferers also experience balance problems.

## **Communication**

The communication of deafblind persons is based either on spoken or sign language, depending on the degree of the hearing impairment. Persons who use sign language sign and are signed to in free space or through tactile sign language. Deafblind persons who use spoken language usually use speech to communicate. They can also be communicated to using speech or, if their hearing is significantly

reduced, by writing, tracing, using finger-spelling or signs. A combination of several different means is often used.

## Psychosocial support

Psychosocial support can generally refer to the total degree of support a person needs in order to cope in their everyday life. However, certain issues arise for deafblind persons, such as the efficiency of communication between a deafblind person and their environment. These issues also include access to peer support and the opportunity to live among the deafblind culture in an environment that is suitable for the person, as well as the physical and psychological services they require.

## Psychotherapeutic rehabilitation

In addition to psychotherapy services, psychotherapeutic rehabilitation refers to the forms of professional support that aim to increase psychological well-being.

**Artist:** Rauli Jalo. **Name:** *Foxes and Hens.* A fox is lurking behind the henhouse. Inside the henhouse is a hen hatching an egg. On the other side of the henhouse is a corral with hens and chicks.  
**Technique:** Mixed technique.



# 1 BACKGROUND

## 1.1 Deafblindness

The term 'deafblind' is easily interpreted as referring to a person who is completely deaf and completely blind. However, this definition applies to only a small proportion of the 850 deafblind people who use the services of the Finnish Deafblind Association. According to the definition agreed on by the Nordic countries, a person is considered deafblind if "he or she has a critical combination of a visual and a hearing disability" (Finland's Ministry of Social Affairs and Health, 1979). Therefore, in addition to persons who are completely deaf and blind, the definition of deafblindness also includes persons who retain residual vision and/or hearing. The diagnosis of a person as deafblind starts with a unique, interdisciplinary evaluation based on the person's ability to function and factors that hinder this ability. Deafblindness has been shown to have a particular effect on a person's communication, moving and information acquisition (Kaitalo, 1990).

The definition of deafblindness has been revised in the Nordic countries in order to account for the international classification of Functioning, Disability, and Health ICF (2005) issued by the World Health Organisation (WHO). According to the definition in preparation, "Deafblindness is a specific limitation to functioning. Deafblindness, the combination of hearing and visual disability (dual disability), makes sharing and performing difficult to such an extent that it requires specific environmental and service arrangements from society ... Thus, multiprofessionalism and special knowledge in the field of deafblindness are emphasised."

The term 'deafblindness' can also be used to describe a culture and a group identity. A distinction is made in English literature between the terms 'deaf', which is used as a medical term, and 'Deaf', which is a social and cultural term. A similar distinction exists in sign language, including Finnish sign language. The signs differ according to the viewpoint from which deafness is being discussed. The deafblind, on the other hand, wish to use the term 'deafblind' when referring to a group, even though, on an individual level, the terms 'deafblind person' or 'deaf person with a severe visual disability' can be used (McNamara, 1997; Olesen & Jansbøl, 2005). Culture also manifests itself among the deafblind in such a way that they have two clearly separate cultures: the culture of the deafblind using sign language and the culture of those using spoken language (Miner, 2002; Rouvinen, 2001).

The group of deafblind includes persons with widely varying degrees of deafblindness. In addition, the unique point in time at which the disabilities occur makes the group heterogeneous. The deafblind can be divided into four different categories according to the point in time at which their disability appeared. The percentages in each category are fairly congruent across the Nordic countries (NUD, 1986).

**Table 1.** Grouping the deafblind.

I	1.	Persons with congenital deafblindness	20%
II	Persons with acquired deafblindness or progressive deafblindness; this group can be further divided according to their primary disability into:		
	2.	Persons with congenital visual disability whose hearing has declined later in life	10%
	3.	Persons with congenital hearing disability whose vision has declined later in life (the majority are deafblind persons with Usher syndrome)	30%
	4.	Persons that have acquired deafblindness in adulthood or old age	40%

Usher syndrome is the largest single cause of deafblindness. It is covertly inherited, which means that it can appear suddenly from across several generations. Most Finnish cases of Usher syndrome have occurred in the Eastern and Northern parts of the country. According to a 1990 study by Kaitalo, the occurrence of Usher syndrome in the province of Lapland was 27.9 per 100,000 habitants, compared to only 7.1 per 100,000 habitants in Uusimaa. The number of deafblind persons in the study with Usher syndrome was 348.

The forms of Usher syndrome also vary remarkably. Usher Type 1 includes persons with severe hearing impairment, often deafness, who communicate using sign language. Usher Types 2 and 3 have varying degrees of hearing impairment, to the extent that some persons have been able to learn the spoken language used in their environment through their auditory sense. In all of the groups, the visual disability is caused by retinitis pigmentosa, or Rp, also known as retinal degeneration. It causes narrowing of the visual field, which creates so-called tunnel vision, increases night blindness and weakens contrast sensitivity. Rp also hinders the eyes' ability to adjust to different lighting and might affect the perception of colours. It also increases the chance of develop cataracts. Research regularly provides new information about, for example, new types of Usher syndrome (Kaitalo, 1990; Lahtinen & Miettinen, 1991; Pakarinen, 1997; Olesen & Jansbøl 1, 2005).

It is not possible to predict the development of a visual or hearing impairment for sufferers of Usher syndrome, which makes it especially stressful. As an individual experience, the hearing or visual disability can feel more severe than tests indicate it is. For example, as the ability to see deteriorates, a person can also experience a change in hearing as lip reading becomes more difficult (Olesen & Jansbøl, 2005).

**Table 2.** Summary of the differences between the most common types of Usher syndrome according to the degree of hearing disability.

Type	Hearing disability	Balance	Language, communication
Usher 1	Congenital and severe, often deafness	Balance problems	Sign language in free space or tactile sign language
Usher 2	Congenital ranging from mild to severe. Often remains relatively stable.	No Usher-related balance problems	Spoken language supported by lip-reading, signs
Usher 3	Develops gradually with stable periods. May lead to deafness.	No Usher-related balance problems	Spoken and written language, sign language if the person is deafened

People who work with deafblind persons must have knowledge of deafblindness as well as the ability to convey this knowledge to their clients. Swedish psychiatrist Ann Gardner (1991 a and b) suggested that people who work with deafblind persons with Usher syndrome should at least have knowledge of the following issues:

1. All three Usher deafblindness types, including how the syndrome originates and some knowledge of genetics
2. The effects of sensory disabilities, such as the effect that night blindness has on everyday life
3. Practical measures for reducing the effects of sensory disabilities, such as information on special equipment and the effects of different environments
4. The behaviour caused by sensory disabilities as well as understanding psychological and mental reactions
5. The phases of life of Usher persons across different age groups, even if the person only works with a certain age group
6. The practical risks to oneself caused by sensory disabilities. Entry into different risky situations can be discussed with the deafblind person
7. How to answer questions an Usher client may have about the possibility of becoming blind
8. Different means of communication
9. Different organisations that work in the field of deafblindness

Gardner emphasised that deafblindness is a special field, so knowledge about hearing or visual disabilities does not necessarily qualify someone to work in the field of deafblindness.

Other causes of congenital deafblindness have, particularly in earlier times, including the mother's pre natal rubella (German measles) and the consequences of various infections. Vaccines and the development of healthcare have helped reduce these factors considerably. Acquired deafblindness in adulthood can be caused by an accident or by violence. Deafblindness can also be related to aging, even though persons who develop hearing or visual disabilities in old age have not usually been within the compass of services provided for the deafblind. Lately, however, greater attention has been paid to this specific group and services have been developed (Kaitalo, 1990; Kun kuulo ja näkö ovat heikentyneet, 1999; Sosiaali- ja terveystieteiden ministeriö, 1979).

## **1.2 The effects of deafblindness on communication, information acquisition and environmental orientation**

The heterogeneity of the Finnish deafblind community is reflected in language, with the group including both Finnish and Swedish speaking persons as well as users of sign language. The latter are especially dominant in the Usher group. Although one-third of deafblind persons in Finland are sign language users (The Finnish Deafblind Association, 1996), most deafblind persons use spoken language. In these cases the speech must often be slowed down in order to help the deafblind person hear clearly since, due to their visual disabilities, they cannot lip-read (Kuurosokean kommunikointi, 1991).

A deafblind person's hearing and vision can often deteriorate to such an extent that alternative means of communication must be used. In order to receive a message a deafblind person may require writing (typing or by hand), tracing, Braille, finger-spelling, signing or a combination of several different methods. Finger-spelling and signs can also be conducted in a tactile manner if a person is no longer capable of seeing them. Communicating using methods other than speech slows down the interaction. Researchers have discovered that using visual or tactile finger-spelling takes four to five times longer than communicating through spoken language (Fuglesang & Mortensen, 1997). A deafblind person who uses spoken language often replies through speech, although their speech may alter as time passes and the hearing disability progresses. People who are familiar to the deafblind person can usually comprehend, but outsiders may find it difficult to understand (Kuurosokean kommunikointi, 1991).

Persons for whom sign language is their mother tongue have learnt the language in early childhood, or at school at the latest, and have been part of the deafblind community. As eyesight gradually deteriorates, a person is often left lacking information in many situations. Their narrowing vision makes it increasingly difficult to follow who is signing and what is being signed. Changes in lighting can also make it difficult to follow sign language. It is common at this stage for a deafblind person



to isolate themselves from other deaf people, and they may shut out a person who is not able to keep track with the communication. When it becomes difficult to distinguish the facial expressions essential to sign language, a deafblind person will be unable to recognise the expression linked specifically with interrogative sentences, for example. When deafblindness has progressed to such extent that tactile signing is required, a deafblind person's information acquisition in social situations is completely dependent upon other people. He or she will only acquire information through another person, such as an interpreter. As a result, a deafblind person not only requires information about what is being said, but also about who is saying it, the tone of voice being used, what the speaker looks like, who the other people present are, what is happening, and the space in which the communication is taking place (Hassinen, 1999; Miner, 2002).

Sign language is a visual language and it contains many non-linear features. Both of these factors make it difficult for a non-native speaker, such as an employee, to understand their client. The non-linear way of thinking especially affects the way in which a person using sign language expresses different matters and the links between them, which is different from people who use spoken languages. Among other things, this manifests itself in practical situations where, even though the signs themselves are understandable, it is difficult to comprehend the connections between them. Only once a sufficient number of signs are available is it possible to form the "core of the message" as well as the idea that the person using sign language wants to convey. On the other hand, a person who uses sign language might find it hard to understand an issue that is presented, for example, as a relationship between two different matters, without sufficient background knowledge of the other things related to it. This reflects the different methods of expression in visual and spoken languages as well as the differences in ways of thinking (Hall 1976; Harvey, 1989).

Overall, the deafblind culture emphasises the conscious utilisation and cooperation of all senses. When forming a view of the world, vision and hearing are used as much as possible, but sense, taste and smell become more important and meaningful as their sensitivity evolves. Touch is important for communication and information acquisition but it can also be used to enjoy art and experience beauty. Even when the use of all senses is practised and made more efficient, the knowledge acquired from the environment is often fragmented and the overall picture must be constructed from small pieces (Kontaktiryhmä, 2002; Rouvinen, 2001).



**Table 3.** Summary of the means of communication for the deafblind (Hassinen, 1998; Lahtinen, 2004)

<b>Sign language users</b>	<b>Spoken language users</b>
<b>Receiving messages</b>	<b>Receiving messages</b>
Through vision <ul style="list-style-type: none"> <li>• Using sign language in free space</li> <li>• Signing close up</li> <li>• Signing “in the tunnel”</li> </ul> Vision not sufficient for receiving messages: <ul style="list-style-type: none"> <li>• Tactile signing</li> </ul>	Through hearing and vision <ul style="list-style-type: none"> <li>• Speech</li> <li>• Lip reading</li> </ul> Hearing not sufficient for receiving messages: <ul style="list-style-type: none"> <li>• Lip reading</li> <li>• Signed speech</li> <li>• Finger-spelling</li> <li>• Writing on paper or on a computer</li> </ul> Vision not sufficient for receiving messages: <ul style="list-style-type: none"> <li>• Speech</li> </ul> Hearing and vision not sufficient for receiving messages: <ul style="list-style-type: none"> <li>• Tactile signing</li> <li>• Tactile finger-spelling</li> <li>• Braille</li> </ul>
<b>Producing messages</b>	<b>Producing messages</b>
<ul style="list-style-type: none"> <li>• Signing in free space</li> </ul>	<ul style="list-style-type: none"> <li>• Speech</li> </ul>
<ul style="list-style-type: none"> <li>• Tactile signing</li> </ul>	

Many deafblind persons use a combination of several means of communication, especially during the transformation of their visual or hearing disability.



**Artist:** Rauli Jalo  
**Name:** A horse  
**Technique:** Clay

## 1.3 The life world of a deafblind person

### LIVING AND OPERATING INDEPENDENTLY - COORDINATING SERVICE DEMANDS

According to the general Nordic policy on the disabled, Finland and other Nordic countries aim to provide deafblind persons with a chance to have control over their everyday lives, autonomy on matters concerning themselves and the option to participate in society. The opportunity to choose one's housing, live independently and have control over one's own life are considered central factors in life. Habitation can also provide contacts with other people and is important for the development of a person's identity and self esteem (Kuurosokeiden elinolot pohjolassa vuonna, 2000).

The 2005–2014 target programme of the Finnish Deafblind Association (Tavoiteohjelma 2005–2014) sets out the rights that can provide deafblind persons with a productive, autonomous life in an equal society:

1. The right to be deafblind
2. The right to lead a full life as a member of society
3. The right to have their own language, culture and teaching
4. The right to move about independently and autonomously
5. The right to life-long rehabilitation that is unique and of good quality
6. The right to life-long learning and self-education
7. The right to choose the environment for habitation and life

Most deafblind persons live alone or with their families. However, independent living can lead to loneliness and a lack of contact for the deafblind person, whether they live alone or surrounded by family. Deafblind persons require outside contacts and help, in and out of the home. Outside help is needed at home in practical matters and information acquisition and outside the home in tasks such as shopping, going to the bank or the post office, etc. In order to cope in everyday life without being patronised, it is essential to arrange suitable habitation and services (Kuurosokeiden elinolot pohjolassa vuonna, 2000).

The law concerning the services provided for the disabled in Finland offers deafblind persons the opportunity for supported living, if needed. However, the interpretation of the law can cause problems in terms of how communication affects the choice of supported living (Karinen, 1994). Deafblind persons are often offered supported living in their own municipalities rather than in the residence units designed for the deaf and the deafblind founded by the Service Foundation for the Deaf and the Finnish Deafblind Association. The expenses of supported living are met by rent collected from the residents and from municipal service fees.

The law concerning the services provided for the disabled entitles deafblind persons living in their own homes to alterations and necessary special technical equipment. The same principles also apply in supported living. The colouring and the facilities must be planned so that it is possible for a deafblind person to move about safely. For example, adequate contrast in the colour of the door jamb in relation to the wall and the removal of sharp corners can make it significantly easier to move about. In addition, alterations can be made to areas such as the washing room and lavatory, as well as to the lighting. Fixed alarm systems (such as a doorbell or a fire alarm) can be installed, as well as induction loops, which make it possible to listen to the radio and television without having to turn the volume up too loud (Karinen, 1994).

Technological developments over the last few years have led to remarkable advances in special equipment that has assisted in the information acquisition of the deafblind. Special utility programmes are available for Windows-based systems to facilitate the use of this equipment. In addition, different kinds of programmes help make reading easier. Depending on the person's vision or hearing, magnifying programs, speech synthesisers or additional programmes that enable the use of a Braille monitor can be used. Web cameras and visual phones are helpful, especially for persons who use sign language. Other possible sources of sign language information include video bulletins from the Finnish Association for the Deaf, While other visual aids include magnifying glasses and desktop video magnifiers. This special equipment is granted in Finland mainly by central hospitals and the Social Insurance Institute of Finland (Karinen, 1994; Tero, K. 2005).

However, alterations and special equipment are not always sufficient and cannot replace human contact. Many deafblind persons require home help to take care of their home and do the shopping. It is often the case, however, that home help personnel cannot use sign language or are not capable of using their client's means of communication. As a result, the human contact that a deafblind person seeks can remain quite superficial and might even cancel out other work (Kuurosokeiden elinolot pohjolassa vuonna 2000).

In 1997, the Service Foundation for the Deaf began working on a project called Kotiväylä to help meet the special needs of deaf and deafblind persons. This operation has now been established in Finland's larger cities. The basic idea is that personnel should have adequate communication skills and that clients should be served holistically. Services include home help, healthcare and hospital care, helping out in daily activities and other services that might be required. At the same time, an overview of the person's ability to manage in everyday life can be formed. One part of the operation is day groups where deafblind persons can meet (the Service Foundation for the Deaf, 2004).

A deafblind person can also acquire the contacts and help they needed for everyday tasks through voluntary work. The Finnish Deafblind Association, the Service Foundation for the Deaf and the Viva Project of the Finnish Association of the Deaf have been training support persons, but the number of support persons still does not meet demand. A support person's job is to visit the deafblind client, read their mail, provide guidance outdoors, etc. Accompanied by a support person, a deafblind person can feel more secure about going to new places and trying out new activities. In return, during their meetings the deafblind person can educate the support person on deafblindness and, for example, teach the use of sign language or other means of communication. It is essential that the support person masters the means of communication used by the deafblind person. Deafblind persons have also been trained as support persons. The Viva Project focuses on the training of support persons who use sign language. Meeting a peer can be very meaningful to a person who has recently acquired deafblindness (Kuurosokeiden elinolot pohjolassa vuonna, 2000; Kärpänen, 2006).

Instead of, or in addition to a support person, a personal assistant can help a deafblind person in their daily activities. This service is defined in the law concerning the services provided for the disabled, but has so far been seldom used. This is due to a lack of education of the personal assistants as well as the attitudes of the municipalities regarding the need for a personal assistant. Providing a personal assistant is obligated from the beginning of 2009. Municipalities reimburse a person with disabilities for wages paid to a personal assistant. Sign language instructors have been trained to help and guide deafblind persons in their daily activities. Their employment has so far been insecure due to a lack of sponsorship. However, demand for their professional services clearly exists. In some Finnish municipalities, deafblind persons have been able to use the services of both sign language instructors and interpreting services.

One of the key requirements that enables independent functioning and participation of a deafblind person is a functioning interpretation service. Article 6 of the Manifestation of the Rights of Deafblind People states, "deafblind persons must have the right to a cost-free interpretation service that enables them to communicate efficiently and maintain their connection with other people and the environment." The deafblind have been active users of the service from the very beginning. The service originally only included sign language interpretation for the deaf, but when it came to deafblind persons, other forms of interpretation were also required. The need for other means of communication had already been clearly stated in the law concerning the services provided for the disabled (Ahola, 1991; The Social Government of Finland, 1987 and 1990).

Interpreting services can be used in various daily activities, social situations, functions of society and hobbies. According to the law on services provided for

the disabled, an interpreting service is a subjective right and a minimum of 360 hours per year is allowed by law (the Ministry of Social Affairs and Health, 1979). There has been debate over the years regarding whether the number of hours is sufficient and there may be a change in the future. There are many aspects to consider besides the adequacy of hours and interpreters. Interpreting for the deafblind consists of lingual translation, description of the environment and guidance.

It is possible for a deafblind person to use a transportation service, either in support of the interpreting service or separately. The service primarily includes local transportation and transportation to nearby municipalities, which may cause problems in attending clubs or other activities targeted at the deafblind (the Social Government of Finland, 1987).

In order to receive the services that provide help in daily activities, a deafblind person must be active and aware and have the skills they require in to communicate their needs. Even though deafblindness is a permanent disability in most cases, some deafblind persons are constantly required to justify their need for services. This can be a humiliating reminder of a person's disability and weakness rather than of their strengths and ability to cope in complex, modern society. Many deafblind persons do have rehabilitation workers and other experts in the field to whom they can turn for guidance and advice in seeking services. When applying for services, one should keep in mind that they are provided by the municipality in which the deafblind person resides, so using supported living services does not affect the municipality of residence. This may change in the future. The granting of medical rehabilitation and rehabilitation services for people with severe disabilities usually requires a rehabilitation plan put together in conjunction with the client, as well as statements from experts articulating the requirement.

### **BASIC EDUCATION, VOCATIONAL TRAINING AND PROFESSIONAL REHABILITATION**

Deafblind children and children with visual and hearing disabilities have received their basic education either in a special school for children with visual or hearing disabilities, such as the Haukkaranta School in Jyväskylä, or in a regular school. Deafblind pupils with developmental disabilities have usually been placed under the schooling of care services for people with developmental disabilities. The growing trend is to integrate children and young people with visual and hearing disabilities in regular schools.

After completing their basic education, young deafblind persons must start to plan their professional careers and vocational training. They can choose to

**Table 4. A summary of the services available for deafblind persons**

(A service guide for the deafblind and for persons with visual and hearing disabilities 2003.)

Service	Granted by/grounds for granting	Amount	Providing
Supported living	Social services/the law concerning services provided for the disabled		Obligatory
Alterations made to apartments including tools and other equipment	Social services/the law concerning services provided for the disabled		Obligatory
Special equipment to ease information acquisition	Healthcare centres, central hospitals, The Social Insurance Institution of Finland/medical rehabilitation		Discretionary
Special equipment that help hearing, seeing, moving	Healthcare centers, Central hospitals/ Medical rehabilitation		Discretionary
Home help service	Social service/the law concerning services provided for the disabled		Discretionary
Personal assistant	Social services/the law concerning services provided for the disabled		Obligatory
Interpretation service	Social services/the law concerning services provided for the disabled	Minimum of 360 hours per year	Obligatory
Transportation service	Social services/the law concerning services provided for the disabled	18 one-way transports a month in addition to transports to school and work	Obligatory. Usually includes only local transport and transport in nearby municipalities
Psychotherapy	The social insurance institution of Finland/ The Medical rehabilitation of persons with severe disabilities	Generally 40 to 80 times a year	Must be applied for once a year
Adjustment training, e.g. sign language tutoring	Social services / the law concerning services provided for the disabled		Discretionary



either study in regular schools or schools designed for people with visual or hearing disabilities. In Finland, the professional rehabilitation of young people with congenital deafblindness can be carried out in Bovallius Vocational college (formerly known as the Nikkarila School of Home Economics) or as teaching provided by the Arla Institute at the agencies of the Service Foundation for the Deaf. The majority of deafblind persons of working age in Finland have been trained at the Arla Institute (formerly known as the Vocational College for People with Visual Disabilities), which is a unit that specialises in professional rehabilitation and training of the deafblind. Since the 1980s, the Arla Institute has provided preparatory training for approximately 15 deafblind persons a year as well as training at vocational departments. Deafblind persons using sign language have also been able to study at the Turku Vocational School for People with Hearing Disabilities, known as the Aura Institute (Kuurosokeiden elinolot pohjolassa vuonna, 2000; Turunen, 2003).

Expanding vocational training for the deafblind and adding versatility to the selection of professions is a major challenge for the future. Due to the small size of the group, solutions tailored to specific groups are also applicable to the deafblind. A basic survey conducted in the Frans Leijon project (see next chapter) indicated that 52 persons (24% of Finland's deafblind) were in need of professional rehabilitation. There was a need for further education, situation-bound or other evaluation, professional retraining and marketing training (Kuurosokeiden elinolot pohjolassa vuonna, 2000; Lehtola, 2000).

### **MEANINGFUL ACTIVITIES AND WORK**

The challenges related to providing work and meaningful activities for deafblind persons were mapped out between 1997 and 2001 in the Frans Leijon project by the Finnish Deafblind Association. In the basic survey, regional secretaries and rehabilitation managers were asked questions concerning regional recreational possibilities and their use. Almost half of the 220 deafblind persons included in the survey had daily hobbies and meaningful activities; one-fifth of the group participated in these activities two or three times a week, and less than one-fifth did so once a week. The rest of the group had hobbies and meaningful activities that they participated in less frequently or occasionally. Recreational options were utilised by persons of working age, pensioners, the unemployed and students. The most popular recreational activities were sports, attending clubs and associations for people with visual and hearing disabilities and for the deafblind, and crafts (knitting and weaving for women and woodwork and basket weaving for men). Similar recreational activities were also found in a Scandinavia-wide survey. On the other hand, recreational activity was significantly less among the employed, there was very little energy left for other things after work and chores (Olesen & Jansbøl, 2005).



According to certain assessments, the rate of deafblind persons who are employed is lower than for people with other disabilities. For example, in Great Britain the percentage of deafblind persons employed is five percent, compared to 68 percent of persons with developmental disabilities. The figure does not indicate the percentage of people who are willing to work but are not employed. In order to be employed, deafblind persons require more support than usual and the employer must be informed of the effects of deafblindness, for example, in terms of communication. For a deafblind person to be employed, more choices are needed in terms of working hours as well as in the work place. Not all deafblind persons have the chance to work full time, but a part-time job might be uneconomical for the person. Employing a deafblind person also involves certain costs, such as special equipment. On the other hand, it should be noted that a person can experience being a part of society through other things than just productive work (Ellis, 1998; Guest, 1998).

In Finland, deafblind persons work as masseurs and fitness workers, brush and body workers and upholsterers. Some work as entrepreneurs or independent professionals, for example, in the Resource Centre for the Deafblind in Tampere, which is owned by the Finnish Deafblind Association. Some work for different job centres, such as the Sampola Work Centre, which is owned by the Service Foundation for the Deaf. There have been attempts to broaden the job opportunities for the deafblind by setting up workshops, like the Kajatupa-workshop in Kajaani. Industrial job opportunities include production line work and packing. In addition, individual deafblind persons work as computer programmers, care assistants, school assistants, office workers, kitchen maids, shop assistants and newspaper carriers. New areas in the employment of deafblind persons including gardening, computer technology, musical therapy, translating and interpreting foreign languages, law, PR, arts, and museum work (Katinen, 1994; Kuurosokeiden elinolot pohjolassa vuonna, 2000; Rossinen, 2005).

The employment of deafblind persons has received Europe-wide attention. At least two projects have been supported by the EU; one including Italy, Portugal and Denmark and the other one involving Italy, Portugal, Sweden and England. The national goals for most of the projects have been to discover the abilities and skills of deafblind persons and to find structures that support employment. Creating a network and increasing public knowledge of deafblindness have also been raised as important goals in many countries. Deafblind persons have been employed through the projects as well, which enables them to become role models for others. The projects also often include research (Hawkes & Green, 1997). When it comes to the deafblind, work can be even more valuable than it is for the general population because it prevents isolation. Tasks are not always necessarily interesting, but work raises the quality of life for the individuals and increases their chances for independent living. Many of the employed deafblind people work in tasks in which they cannot use their capabilities efficiently or advance their careers. Many also wish to retire early when eyesight and hearing start

to cause problems (Karinen, 1994; Guest, 1998; Kuurosokeiden elinolot pohjolassa vuonna, 2000).

Research conducted in Denmark (Clausen et al., 2004) showed that, among all disability groups, psychological factors are an essential part of staying in the job market. Work motivation is generally high among disabled people since work gives them independence and provides social contacts. On the other hand, the alterations required in the working environment may stand in the way of employment. The disabled person's professional and social skills, as well as their low level of independence may also prevent them from being employed. Low self-esteem can also cause people to underrate their capabilities. However, these barriers can often be removed by good basic rehabilitation and guidance.

### REHABILITATION

In Finland, the Rehabilitation Centre for people with Visual and Hearing Disabilities in Jyväskylä, owned by the Finnish Deafblind Association, and the Rehabilitation Home for Children and Young people with Multiple Hearing Disabilities, owned by the Finnish Federation of the Hard of Hearing, are in charge of rehabilitation services for young people and adults with congenital deafblindness, as well as their families. Both arrange rehabilitation courses and adjustment training, which is primarily funded by the Social Insurance Institute of Finland and the Finnish Slot Machine Association. In addition to young people with visual and hearing disabilities and their families, friends and workers are also involved in the operation. Rehabilitation

**Artist:** Marja-Leena Karjalainen. **Name:** A fox. **Technique:** Clay.



services also include municipal guidance and counselling of families and people working in close contact with people with visual or hearing disabilities, and staff training (Turunen, 2003; Siksi Projekti, 2005).

The most important organisers of services for adults with acquired deafblindness are the 10 regional secretaries of the Finnish Deafblind Association. Together they form the core of the nationwide network of resources and expertise in the field of deafblindness. Besides client work, the rehabilitation services also include cooperation with government officials and service systems, as well as training, course activities, and support person activities. In addition to traditional supported living services, unique rehabilitation and adjustment group courses are held in the Resource Centre for the Deafblind in Tampere. The deafblind have shown greater interest recently in studying IT (information technology) as well as everyday skills and communication. Deafblind persons can also receive rehabilitation in their own homes in the form of Braille lessons and means of communication or mobility skills. The group courses are funded by the Social Insurance Institute and the Finnish Slot Machine Association. Individual rehabilitation is also funded by healthcare and social services as obligated by the law concerning the provision of services for the disabled (Aluesihteerin kuurosokean asialla; Suomen Kuurosokeat ry).

Rehabilitation of the deafblind is also provided by rehabilitation instructors at central hospitals, lay workers working with people with hearing disabilities in congregations, and municipal social workers working among people with hearing disabilities.

**Artist:** Rauli Jalo. **Name:** A crane sitting on a rock, preying on frogs. **Technique:** Chicken wire, newspaper-paste.



## 1.4 The Psychosocial effects of Deafblindness

For most deafblind persons, the deterioration of senses is a gradual process. Before losing their sight and hearing, they have already been able to accumulate a great amount of experiential data through their vision and/or hearing. After their senses have been disabled, they have to restructure their environment through their sense of touch. This means that the world is literally “at their fingertips”, and additional information is acquired, for example, through olfaction. When reorganising their surrounding reality, a deafblind person goes through a process of change. At the same time, the people around the deafblind person create new ways of connecting with that person, which also requires adjustment and change on their behalf (Alvarez, 1993; Rouvinen, 2001).

The changing visual and hearing disabilities often also require alterations to the home, school and workplace environment to better suit the current situation. In particular, lighting, adequate space, colour contrasts, the placement of objects and the tranquility of the environment need special attention. Difficulty moving about in the dark can also hinder independent mobility. However, deafblind persons often feel that decision-makers do not pay sufficient attention to experts when planning new solutions (Ehrenbåge & Samuelsson, 1998, Möller, 1999). Sharing information so that the environment can truly understand the deafblind person’s situation is a challenge to the person as well as to people working in the field.

In addition, when the deafblind persons are considered, it often seems that the operational effects of the disability lead to so many problems coping in everyday life that the persons are unable to show their abilities. For example, the deafblind person’s intellectual or other mental capacity may be under-used, which can manifest itself in demands that they set for the environment. It is also common for surrounding people to be unable to truly understand the situation of the deafblind person and offer them the right kind of assistance in the right matters. A study based on interviews with deafblind persons in the Nordic countries between 1999 and 2003 provided experience-based knowledge and understanding of living with a progressive hearing disability (Olesen & Jansbøl, 2005).

Knowledge of the effects that deafblindness has on the psychological and social state of a person has only been available relatively recently. In most cases the material has been biographical, such as books and films on the life of Helen Keller or a Finnish deafblind man called Frans Leijon. The life stories of deafblind Finns have been compiled in books such as *Kuurosokeilla on puheenvuoro* (Ahola, 1991) and *Miten pagisemattomia auttaa tahdottiin* (Ojala, 1986). The most recent publication about deafblind people and their families in Finland is entitled *Haasteena kuurosokeus* (Vartio, 2006).

### **1.4.1 PERSONS WITH CONGENITAL DEAFBLINDNESS**

In Finland, persons whose visual and hearing disabilities have been manifested in early childhood are classified as congenitally deafblind. Deafblindness is often related to a developmental disability that can form as early as in the fetal stage. According to the Rehabilitation Centre of the Finnish Deafblind Association, there are currently about 130 deafblind children and adolescents in Finland. In addition, 150 persons are classified as deafblind who are receiving special care in three units that specialise in deafblindness. The development of communication is especially problematic for the deafblind and it also has far-reaching effects on a person's life. Many behavioural problems such as disorderly conduct and symptoms associated with autism are consequences of a lack of communication. Families must be knowledgeable about the deafblind adolescent, as must the people who work with them, in order to establish communication (Turunen, 2003).

### **1.4.2 DEAFBLIND PERSONS USING SIGN LANGUAGE**

Reports of the lives of deafblind persons using sign language have been written in Scandinavia and in the USA. Descriptions of the lives of Usher 1 deafblind (persons using sign language) at stages from childhood to old age have been collected at the Helen Keller Center in the United States (Miner, 1995, 2002). The data was gathered through interviews with 39 deafblind persons aged between 16 and 67 and people close to them in group discussions. In Scandinavia, 20 Usher persons (eight Usher 1 and 12 Usher 2) were interviewed between 1999 and 2001. The interviews were conducted twice during the first year and once every subsequent year. The goal was to produce experience-based information on life with a progressing disability and the results of the project were published at the end of 2005 (Olesen & Jansbøl, 2005).

### **CHILDHOOD AND ADOLESCENCE**

In the American survey, the interviewees said that they had usually become aware that there was something wrong with their eyesight during adolescence. Confirmation had usually come from friends rather than parents. Even though they knew about it, many parents had difficulty telling their child about their disability. Because the visual symptoms of the Usher syndrome become more apparent during puberty, that particular stage in life has been especially difficult for many sufferers. Visual problems clearly increased in conjunction with the other changes that are generally linked with puberty. For many, this has led to isolation from peers at this particular stage, due to difficulties discussing their vision problems. Deafblind adolescents have been bullied because of their clumsiness and poor mobility. Deafblindness can thus be considered as a risk factor in susceptibility to bullying in schools (Miner, 1995, 2002).

Visual problems and the inability to communicate with loved ones can cause feelings of sadness and grief. In addition, leaving home, choosing a profession, and being

employed can cause worry, as can the fear of being dependent on others. The interviewees also shared their worries regarding forming romantic relationships and being rejected by loved ones for being a burden. Because of this, it is important for adolescents with Usher syndrome to be able to meet each other to exchange thoughts and become familiar with the use of tactile sign language. Depression and suicidal thoughts and attempts are common among deafblind adolescents. However, the ability to identify depression in a deafblind person requires experience with the deaf and the deafblind as well as sufficient communication skills (Miner 1995, 2002).

In four of the adolescents studied through the Scandinavian interviews no knowledge had been available about Usher syndrome, either for themselves or their families. On the other hand, discussing the effects of the visual disability had been taboo in some of the families. Even greater challenges were faced in terms of choosing a profession and education, especially if the visual disability had manifested itself at an early stage. In these cases, vocational guidance had been insufficient and many deafblind persons had stopped their studies when practical problems had become too great. Examples of these problems included special equipment not arriving on time, or constant changes in the study environment, which caused great difficulties in seeing and hearing (Olesen & Jansbøl, 2005; Niskanen, 1999).

### **ADULTHOOD**

The challenges that a deafblind person faces in adulthood include starting a family and, as the visual disability progresses, redefining their roles as mothers, fathers, spouses, employees or caregivers. Deafblind persons have indicated that one of their major causes of anger is the loss of personal space when they have to start communicating through tactile signing. A deafblind person is touched even when he or she does not want to be in contact with other people. Besides anger, the emotions described by deafblind persons include depression, fear of the future, a lack of hope and pleasure, suicidal thoughts, resentment towards the seeing, fear of losing the love and respect of family members and a tremendous feeling of isolation when friends stop keeping in touch. Some have also attempted suicide. Many feel guilty for being looked after and dependent on others. It is often hard for family members and friends to understand what the person is going through and he or she may not get enough support to solve the unbalanced situation (Miner, 1995, 2002).

### **OLD AGE**

Older deafblind persons often worry about their remaining years and what will happen if their spouse passes away and their children have moved out. Accordingly, families should be encouraged to discuss and plan their future. Worrying might partly be caused by a lack of knowledge about aging, especially if they have not had sign language interpreting when visiting a doctor. A deafblind person who uses

sign language often loses contact with and support from the deaf community, so there should be a careful analysis of his or her needs and the possible means of support provided (Miner, 1995).

A deafblind person's visual problems can receive too little attention in the deaf community. A study conducted in the Netherlands (Fritschy et al., 1996) clearly showed that there insufficient attention had been paid to the needs of the deafblind persons using sign language in supported living services. There had been shortcomings in both the communication skills of the deafblind persons as well as the staff and other residents. Very little effort had been made to alter the environment to better suit the needs of deafblind persons and ensure that deafblind persons had the opportunity to participate in activities in and outside the house. In other words, the number of staff and one-on-one time with each deafblind resident was inadequate. Of course, this is also a question of funding. However, it should be kept in mind that the people who participated in the study were elderly and some of them had severe symptoms of dementia, so the barriers were not only external but also caused by the human aging process.

### **1.4.3 DEAFBLIND PERSONS USING SPOKEN LANGUAGE**

Because there has been less material on deafblind persons who are hard of hearing than about sign language users, material about the hard of hearing has been used to describe their psychological problems. The visual problems are usually the same, since the group includes a large number of people diagnosed with Usher syndrome. The Scandinavian survey has also provided material from deafblind persons who use spoken language.

#### **CHILDHOOD AND ADOLESCENCE**

Most deafblind persons who use spoken language have been educated in regular schools. The symptoms of Usher syndrome may have appeared in adolescence, when attention was drawn to the adolescent's sight and hearing problems. According to the Nordic survey (Olesen & Jansbøl, 2005), a large number of deafblind adults had reached the same level of education as their siblings. This result, which is surprising to some extent, is due to the fact that the vision of the people included in the account had started to deteriorate significantly as late as in their adulthood. However, their choice of profession had already been affected by their eyesight at an earlier stage. Many had dreamed of a different profession than the one for which they had trained, as they had to consider the limitations set by their visual disability.

#### **ADULTHOOD**

Stone (1987) described the effects of a hearing disability in adulthood as follows: A hearing disability has far-reaching effects. It does not just affect the person alone, but the whole family, workplace and surrounding community. It causes irritation,



creates tension and increases stress. The only universal stress factor known is the disturbance of communication, which results if hearing is lost or if it deteriorates. In these cases the stress works both ways as it is transferred to the surrounding people in various degrees depending on how close the relationship is.

The communication of a person with a hearing disability changes as the disability progresses. It becomes less linear because some of the elements in the speech are not heard. The person also often tries to fill in the missing information by guessing. The interaction included more pauses and becomes slower, which can cause frustration and rejection on both sides. According to some studies, it seems that a hearing disability not only changes the quantity of information but also the way the brain processes it. There is a transfer from processing auditory information to processing visual information. This might be explained by the fact that eyes are utilised in lip reading as well as in following sign language (Harvey, 1998).

Besides linearity, the communication of a deafblind person can be described through high and low context (Hall, 1976). In high context communication the words contain almost all the information that a person wants to produce, which is not the case in low context communication. Because the majority of people, that is, the hearing, are used to high context communication, the skill of using intuition and body language as a means of communication has been lost. This is one reason why interaction between a hearing person and a person with a hearing disability is difficult.

A hearing disability not only hinders communication but also functioning and participation in activities because it restricts social interaction. A person with a hearing disability may isolate themselves, suffer from low self-esteem and the loss of autonomy and even lose the will to live. In particular, the constant stress in communication situations becomes chronic and creates anxiety and exhaustion. Listening and lip reading demand a great amount of physical and mental energy. The feeling of loneliness can be very powerful, even when the person is surrounded by others. Feelings of anger and of being threatened can also surface. However, the symptoms caused by stress do not necessarily become overwhelming if the person is able to find good ways to cope with the hearing disability (Burfield & Casey, 1987; Stone, 1987).

The ability to adjust to a hearing disability is affected by the person's earlier experiences and psychological problems in figuring out the personal effects of the hearing disability and the support of the environment. The rehabilitative training programmes formulated by Burfield and Casey (1987) raised the most important factors in adjusting to a hearing disability. These factors are taught to people with hearing disabilities as well as their families. The following viewpoints also fit the frame of reference of cognitive behavioural therapy.



1. Physical and psychological tension
  - How the hearing disability increases nervous tension
  - How nervous tension affects a person who is hard of hearing
  - The importance of decreasing nervous tension
  - Ways of decreasing nervous tension
2. The connection between thoughts, feelings and behaviour
  - Malfunctioning thought processes that are often found among persons who are hard of hearing
  - The effect of these thoughts on emotions and sensations
  - The effect of emotions and sensations on behaviour
  - How to turn thinking in a more productive direction
3. The principles of efficient interaction
  - Perceiving our actions. What turns people 'on' or 'off'
  - Linking actions with the hearing disability
  - Practising the skills of efficient interaction
4. Special rules of communication for the hearing and the hard of hearing
  - Forming concrete rules
  - Displaying the use of these rules
  - Practising behaviour that reinforces the rules

In the process of adaptation, Burfield and Casey (1987) emphasised the process that precedes denial, anger, guilt and depression, in which a person decides to operate in ways that help them reconnect with the environment. As self-acceptance is recovered, a connection with surrounding people is re-established and the will to face the challenges of everyday life increases, the person's mental health also improves. A peer support group is often a good way of advancing the adaptation process.

For persons with acquired deafness, the key question is how to balance between two worlds. They identify themselves as belonging to the hearing community but, because of their acquired deafness, face challenges functioning within it. At this point, some discover the deaf community and seek the company of persons who use sign language. This is not a simple process, however. Early on, the person with acquired deafness can be excited by the new community and eager to become a part of it. Later on comes frustration, anger and denial, because understanding sign language is difficult and the deaf perceive the person with acquired deafness more as a member of the hearing community. The use of sign language can also start to seem like a factor that isolates the person from the majority of the population. A person with acquired deafness can thus feel as though they belong to a marginal group that is stuck between the two communities (Harvey, 1998).

## OLD AGE

Because the basic needs of deafblind persons do not change as they age, needs such as communication possibilities, the acquisition of information and unobstructed moving must be secured. Various illnesses can increase the obstacles created by hearing and vision, for example in daily chores and moving about. Because of this, it is crucial to update the services on a regular basis to better suit the person's situation. The learning of new skills and information acquisition in a changing situation demand constant learning and adaptation. The goal is to provide the person with the chance to participate in the functions of society according to his or her own capabilities (Saarinen, 1998).

**Artist:** Rauli Jalo

**Name:** A cow, a rhino and a giraffe

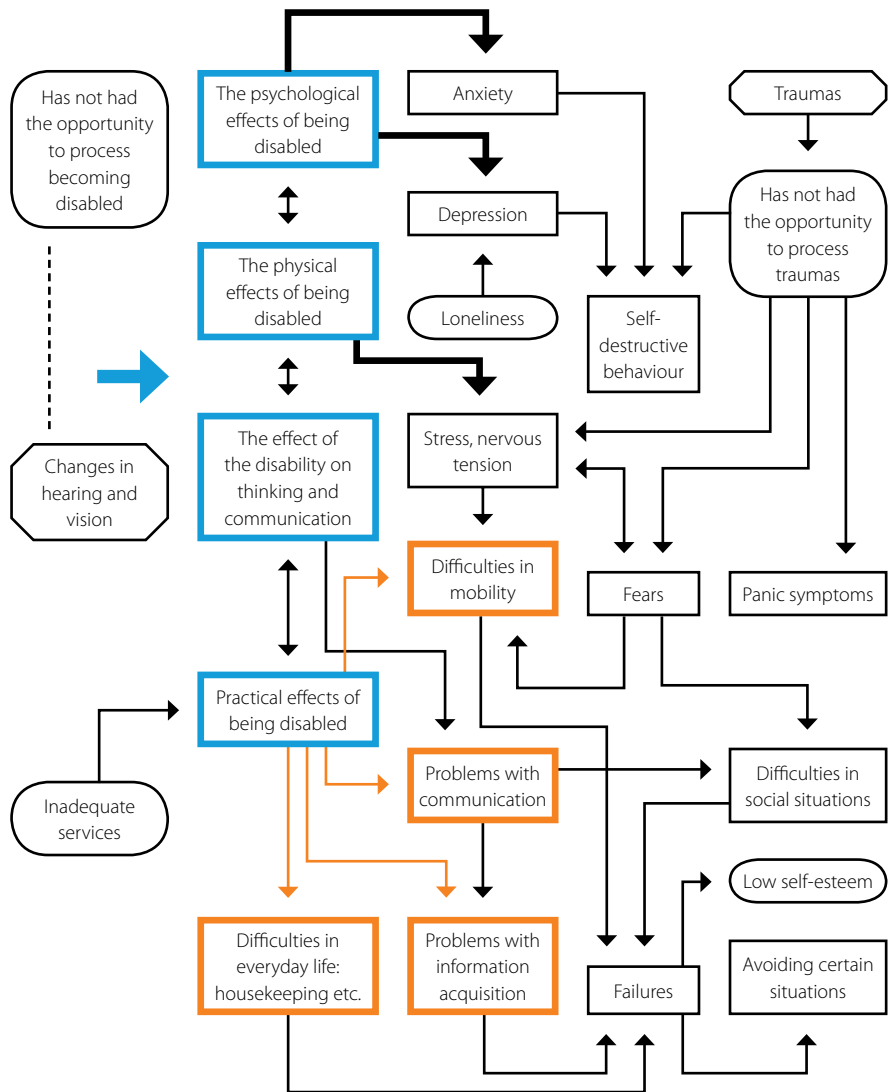
**Technique:** Mixed technique



## 2 THE PSYCHOLOGICAL PROBLEMS OF DEAFBLIND CLIENTS

At the end of the material is a visual graph based on behavioural analysis, which is used to summarise the problems of the deafblind as a group as well as the problems of individual clients. The process of analysis is described together with examples of clients. Attachment 1 provides instructions on how to read the graph.

**Table 1.** The Psychological problems of deafblind clients and the factors affecting them.



There is no precise information available on the psychological effects or problems of deafblindness. However, it is fair to assume that there are similarities between the deafblind and the deaf. Experiences in the psychiatric clinic of the Hospital District of Helsinki and Uusimaa (Hus) in Finland indicate that diagnoses of the deafblind do not differ from those of the deaf. The most common illnesses among the deaf are depression, anxiety, personality disorders, substance abuse, schizophrenia, bipolar disorder and psychotic behaviour. On the other hand, eating disorders are not a major problem among the deaf. Additional diagnoses generally include epilepsy, intellectual disability, developmental disability or dysphasia or other linguistic disorders (Ryynänen & Kostamo, 1998).

A study that mapped the psychic symptoms of a deafblind person or a deaf person using sign language, conducted between 2002 and 2004 (Lindfors, 2005), gave slightly increased evaluations. The most common psychological symptoms were loneliness, depression and anxiety symptoms, which were estimated to be found in one in four respondents. This number is slightly higher than in the average Finnish population. The need for help discussing problems was significantly higher among persons who use sign language than among the population in general. Help was especially necessary with relationship, work-related and other psychological problems. In a Nordic mapping (Olesen & Jansbøl, 2005) over one-third of the 20 people interviewed reported having used the services of psychologist in order to cope with the emotional or other difficult reactions related to a crisis.

As a result of their progressive disabilities, many deafblind persons must go through the process of becoming disabled more than once. Both hearing and visual disability can progress quickly or plateau for a period of time. Usher syndrome is especially difficult because its progression cannot be predicted. The rehabilitation system helps sufferers cope with new situations through rehabilitation guidance, different kinds of special equipment and training. In practice this means training the necessary everyday skills, such as taking care of the home, moving about and studying new communication skills. However, some people have been traumatised by being disabled and have not always been capable of processing the situation. The services needed in everyday life, such as domestic care, guidance and interpretation services, are also insufficient at the moment, so for many deafblind persons everyday life is not working as smoothly as it should. The main reasons for this are the problems in funding the services and the lack of persons offering the services (Hassinen, 2004; Miner, 2002).

On the other hand, many deafblind persons are able to cope well in everyday life despite their many practical difficulties. A positive attitude towards the situation and traits assist in the adaptation process. These include self-confidence, patience, flexibility, objectivity, persistence, willingness to take risks, the ability to accept oneself and others despite their flaws and, most importantly, a sense of humour.

Other helpful factors include established techniques for reacting to surprising situations or the ability to solve problems, as well as the ability to understand the variety of life and accept the facts (Tully, 1988; Olesen & Jansbøl, 2005).

Even though the psychological problems of deafblind persons do not deviate from the problems of the majority, there are some distinguishing features. The problem areas described below have arisen both in the literature and in the author's own therapy work.

### **PHYSICAL TENSION AND STRESS**

Physical tension and stress are often linked with deafblindness. The deafblind must struggle constantly in order to hear and see in different situations. Familiar situations are usually handled well, but unfamiliar situations and people increase tension. It takes a lot of energy to orientate to new places and new people and their way of communicating. The same goes for working with new interpreters, even though interaction with an interpreter is usually easier. Familiar places can also create surprises. For example, moving about in winter time is not easy when snow covers familiar landmarks. Physical tension and stress are common among nearly all deafblind persons. They can manifest in physical symptoms such as headaches, tension in the neck and shoulder area, aches caused by poor posture, tiredness and problems with sleep. Stress also affects hearing and sight (Ehrenbåge & Samuelsson, 1998; Hassinen, 2004; Lahtinen, 2004).

*In therapy situations, physical tension can be perceived, for example, in the way the client is sitting; he or she may be in a position that makes breathing difficult. This can also happen when the client is standing or walking. Also, the contact with the therapist and with other people can remain only partial. The message conveyed by body language conflicts with the spoken message. As a result, the position of the body is also important in the communication situation.*

### **FEARS AND ANXIETY**

In addition to moving about, everyday life can cause fear and anxiety. Basic activities such as going to the store, cooking, cleaning and doing the laundry require a lot of energy, and often outside help. There are also many life decisions that are affected by hearing and visual disabilities. These include career choices, choosing a place of residence and starting a family. Raising children is a major challenge for many deafblind parents. Loneliness is a feeling that many deafblind people recognise since they are not necessarily close with many people. Human contact may be restricted to employees and not very emotionally meaningful (Hassinen, 2004; Miner, 2002).

*Situations that cause fear are usually processed in the beginning of psychotherapy with a deafblind person. For example, riding on a bus alone may be a constant*

*source of fear and panic symptoms. Strange and even familiar situations and places and social contacts can cause anxiety for many. The easiest solution perhaps is not to leave the house, which again increases isolation.*

### **DEPRESSION**

Feelings of loneliness, isolation caused by fear, and anxiety can easily lead to depression. Depression can also be caused by the processes related to becoming deafblind, as well as traumatising situations. Deafblind persons often enter psychotherapy with diagnosed depression, which can also be related to self-esteem issues. At worst, anxiety and depression can lead to self destructive behaviour, which can manifest itself as neglect of oneself and suicidal behaviour (Ehrenbåge & Samuelsson, 1998; Hassinen, 200; Miner, 2002).

*Psychotherapy regularly brings up the depression periods in a client's life during which they may have had suicidal thoughts and attempts. The environment has usually reacted to them in some way, but after-care has not been provided. With many clients, depression has been prolonged and requires both medication and longitudinal therapy.*

### **TRAUMAS IN THE LIFESPAN OF A DEAFBLIND PERSON**

Hearing and vision problems can cause dangerous 'close calls', for example in traffic, which can increase cautiousness and fear of moving about. Many deafblind persons have also been bullied at school or in the workplace because of their disability. In addition, some have experienced other traumatic situations in their life such as sexual abuse and emotional and financial exploitation. In particular, the traumas of clients in psychotherapy arise when discussing their personal histories and they usually do not have the opportunity to process these situations with anyone (Hassinen, 2004).

*When working with deafblind clients, the traumas that they have experienced surface constantly. So far I have not met a client who was not bullied at school. This alone has been very traumatic for many clients and they have not been able to process the issue. The Nordic survey shows similar results. Violations against bodily integrity are also common. These can include molestation or even rape. Deafblind persons are also sometimes taken advantage of emotionally and financially.*

### **DEAFBLINDNESS AND PERSONALITY**

The deterioration or complete lack of eyesight and hearing also has an impact on a person's personality. However, it is difficult to understand the process and grasp the factors that are directly caused by the double disability. Some clients are also diagnosed with a personality disorder and it is difficult to determine whether this is caused by the disability or other factors. However, it is fairly clear that

dependency problems linked with personality are severe among some deafblind persons. Dependency on the help of other people is so significant that it becomes psychological. This can be manifested in, for example, constant seeking of human contact because loneliness and anxiety are otherwise unbearable.

Some deafblind persons also experience hallucinations, especially during the transformation of their disability. These hallucinations are also experienced by people who are completely deafblind. The rare descriptions of these visual and auditory hallucinations have been documented by Jackie Coker (1995). In their mildest form the hallucinations appear as lights, colours or different sounds. The sounds can be voices, music or noise, while the visual images can include clear images of people or places and stories in a visual form. These images often appear before falling asleep but can also be consciously activated and produced during the day, especially if the images are positive. The images offer an easy escape from reality and people do not necessarily want to give them up, which other people might find hard to understand.

I have also come across people who experience visual and auditory hallucinations, most of which are unpleasant. They can take the form of voices that criticise, give orders or punish. The visual images can be very violent, such as killing, detached limbs and blood. Such hallucinations are extremely frightening.

It is also important to remember that in some syndromes and illnesses, such as Charles Bonnet syndrome, it is common to experience visual hallucinations at certain stages. In these cases the visual hallucinations are actually images recorded by the brain that usually surface when a person is resting or in a calm situation. These images occur with persons of all ages but usually cease after a year or a year and a half after they begin (Royal National Institute of the Blind, 2006).

### **EXAMPLES OF CLIENTS**

Deafblind clients must deal with a wide range of psychological problems. Besides the problems with their vision and hearing, they face difficulties in many practical issues that increase the effects of the disability. The following sections use behavioural analysis to describe the situations of two deafblind persons. The progression is based on a model of Functional Behavioural Analysis, which I have developed for my doctoral thesis in special pedagogics. Because the group of deafblind people in Finland is small and the people are easily recognisable, I have compiled the examples from the situations and the progress in therapy from several clients.

This chapter includes a description of the clients' problems. Methods for treatment are described in Chapter 5.

**EXAMPLE 1.** Short description of a client and her situation.

The client is a 30-year-old deafblind woman who still has some residual vision and hearing and has been diagnosed with Usher 2. There have been changes in her level of vision and hearing. The client lives alone and is familiar with using different services such as interpreting and transportation and home care services to help her cope with everyday tasks. She is able to move about in familiar surroundings using a white cane. Unfamiliar situations and people cause her anxiety.

The client has been diagnosed with depression that sometimes becomes manic behaviour. Both the depression and the manic activities make her tired and unable to leave the house. She has some friends and relatives but most of her human contact is with employees. She wants to be as independent as possible and rarely asks for help. At times she participates in clubs and activities for the deafblind but she sometimes suffers from feelings of loneliness. In the past she has experienced bullying and frightening molestation attempts by men.

**2. A list of the client's problems and strengths.**

<b>Problems</b>	<b>Strengths in relation to problems and in general: means for solving the problems</b>
1. Nervous tension: especially in situations in which it is difficult to hear or see	1. Willingness to participate in familiar situations
2. Too hard on herself -negative thoughts	2. Can laugh at herself sometimes - good sense of humour
3. Difficulty in expressing emotions, especially anger and sadness; also has strong outbursts of emotion	3. Medication has improved the situation; the goal is to reduce the medication in order to make recognition of the processing of feelings easier
4. Problems with sleep: in the beginning of a manic period	4. Has learned to stop insomnia through medication
5. Feelings of guilt when she feels that she is not doing well enough	5. Can reason her own limits
6. Problems with eating: binge eating at times, at times suffers from lack of appetite	6. Understands the importance of nutrition, eating is sometimes unproblematic
7. Difficulty expressing her emotions	7. Persistent, tries to manage on her own as long as possible
	8. Intelligent, expresses herself well verbally



### 3. Problems according to the different forms of behavior.

Organic, physiological reactions	Emotional reactions	Cognitions	Behavior
<p>Bad positioning of the body due to a constant need for surveillance of the environment.</p> <p>Nervous tension in new situations, manifests itself as sweating, trembling and palpitations.</p> <p>Rapid changes in weight.</p>	<p>Fear of arising emotions:</p> <ul style="list-style-type: none"> <li>• Crying fits</li> <li>• Anxiety</li> </ul> <p>Binge eating to repress emotions</p>	<p>Demands on herself, self-blame:</p> <p>"I should have been more clear at the meeting".</p> <p>"I'm a no-good, stupid failure".</p> <p>Does not articulate her needs because of the fear of bothering other people and being a burden.</p>	<p>Struggles to cope with difficult situations for too long and wears herself out</p>

When discussing this list of issues it was agreed that there are several issues that can, at times, vary in importance. However, nervous tension, trouble sleeping and emotional problems are the most problematic issues that the client experiences.

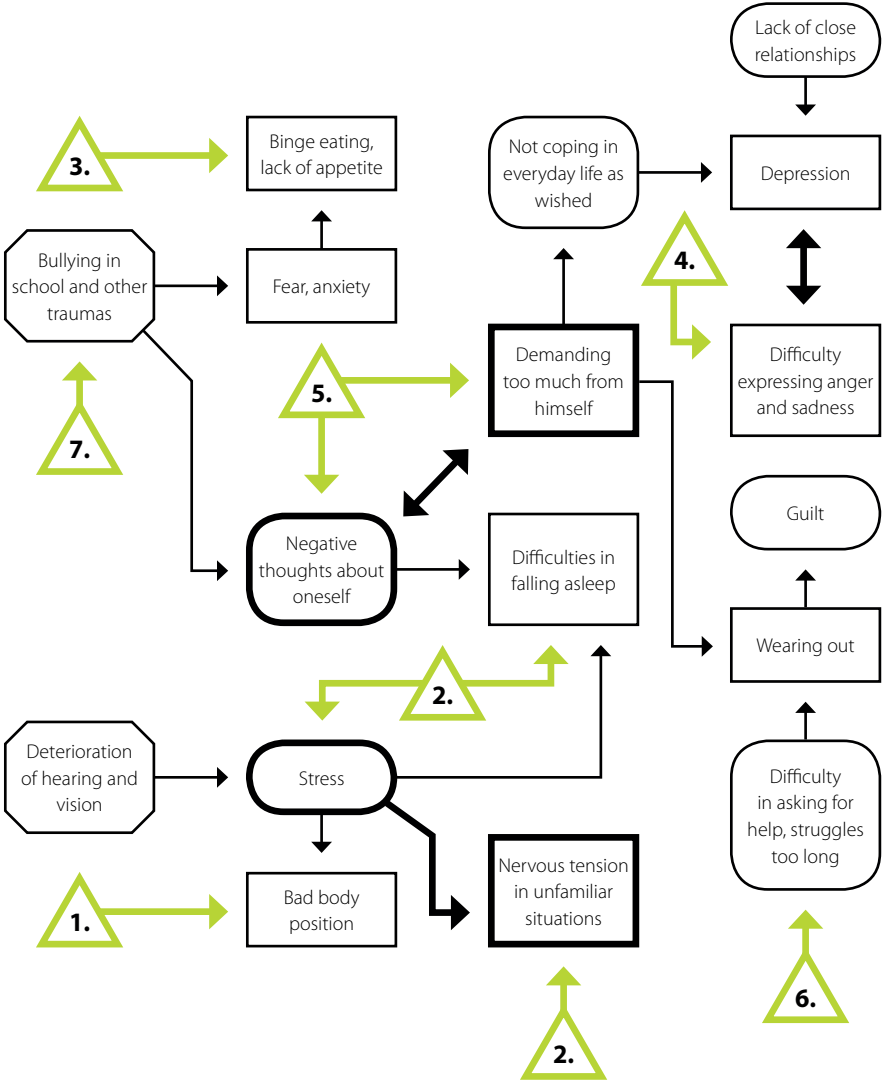
On the other hand, the client has various means to solve the problems but she is still strongly reliant on instructions given to her by other people. She lacks the ability to rely on her own skills and experience. In order to go deeper into her problems, we must specify them according to different forms of behaviour.

### 4. ANALYSIS GRAPH

As in this particular case, it is common for a client to suffer from a diverse list of problems and it can be difficult to determine the issues that need to be worked on. In order to obtain a general view of the problems in conjunction with the client, different factors are placed on a graph. At the same time it is possible to add the underlying factors that are known but not expressed in the actual list of problems. The graph also offers a framework for therapy and it can be brought up again and repeated as the therapy progresses.

The treatment methods are marked on the graph with numbered triangles. These are presented more thoroughly in Chapter 5.3.

**Graph 2.** The functional behavior analysis of a 30-year-old deafblind woman.



**EXAMPLE 2.** A short description of a client and his situation

The client is a 60-year-old deafblind man with Usher syndrome 1. He was born deaf and attended a special school for the deaf. His parents did not use sign language but he learned it at school. Problems in vision surfaced in puberty. The client wanted to become an auto mechanic and began his studies at a vocational school for the deaf. However, his visual problems became an obstacle and he did not finish his studies. He stayed at home for a couple of years but then enrolled in a vocational school for people with visual disabilities in order to become a coachwork mechanic. During this period he also married a deaf woman when both were just over 30. They do not have children.

The client found a job as a coachwork mechanic but had to quit 10 years ago, largely due to his health as a result of high blood pressure and asthma. Both conditions are being treated with continuous medication. At the time he quit his job, the client had become completely blind. His wife has been his guide and takes care of most of the chores. She has also worked as his communicator by tactilely signing stories from newspapers and other information. The sudden hospitalisation of his wife due to her heart problems caused the client a lot of worry about how his life would be organised. The client has been diagnosed with depression and anxiety, which manifests itself in various fears. His depression has been treated with medication but at the time he began therapy the medication was not in use. Employees of a home care service visit the client on weekdays to take care of issues related to health and housekeeping such as taking care of medical dosages, cooking, cleaning, laundry and shopping. The client uses interpreter services when working with the employees and attending events for the deafblind.

The client's problems appear to be quite clear, as can be seen in the list below. Early on in the therapy we had to sometimes go through signs that were unfamiliar to me. I was using a different sign when referring to the word in question. As we continued, I tried to keep in mind the signs that the client was using. I did not always succeed but he usually understood if I used a sign that was different from his. The client was a very competent sign language user and understanding each other was relatively easy. At first the conversation revolved around concrete matters, but as the therapy progressed we were able to attach different issues to new situations and find cause-effect relationships, etc.

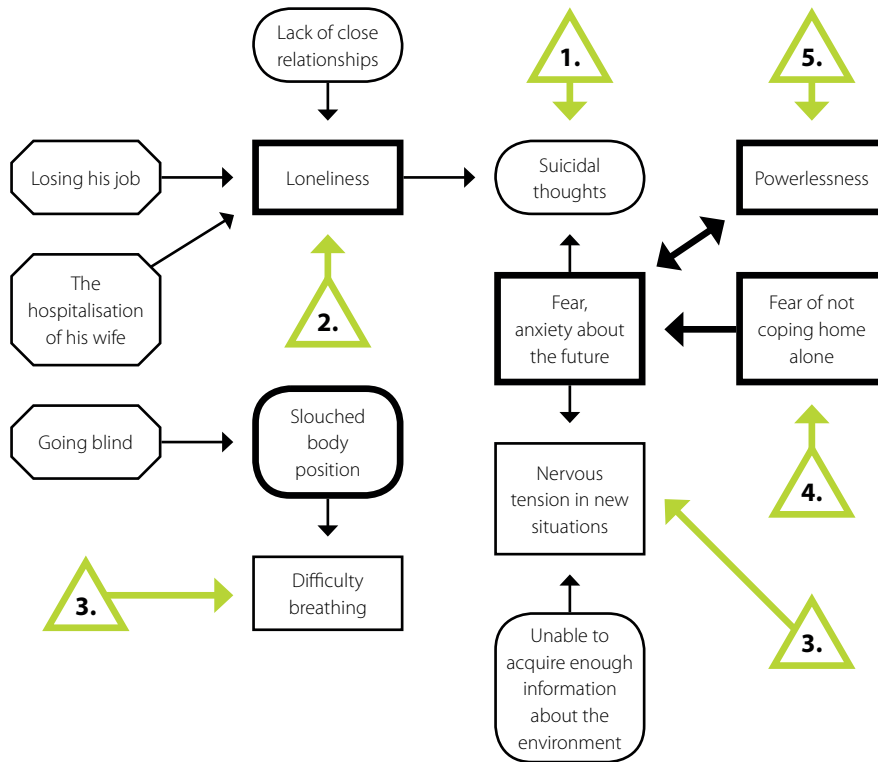
## 2. A list of the clients problems and strengths.

Problems	Strengths in relation to problems and in general: means for solving the problems
1. Nervous tension: especially in new situations	1. Throws himself into new situations if accompanied by a familiar caregiver or interpreter
2. Fear of not coping at home alone	2. Has learned to handle chores, can manage the weekends on his own
3. Loneliness	3. In addition to employees, an old friend visits once in a while
4. Powerlessness: sometimes unable to get out of the bed in the morning	4. Always active when caregivers are around
5. Powerful depression at times, suicidal thoughts	5. No clear plans for committing suicide

## 3. The problems arranged according to the different forms of behaviour.

Organic, physiological reactions	Emotional reactions	Cognition	Actions
<p>Upper body slouched forward, using the upper part of the lungs. This makes his asthma worse.</p> <p>Nervous tension in new situations manifests as sweating, trembling and palpitations.</p>	<p>Fear of managing at home alone.</p> <p>Feelings of loneliness.</p> <p>Mood is mainly dispirited.</p>	<p>Often feels: "I can't manage" "I'll be institutionalized" "I want to die"</p> <p>Recollecting going blind and the hospitalisation of his wife.</p>	<p>Often suffers from powerlessness, difficulties of getting out of the bed in the morning.</p> <p>Activities also require effort.</p>

**Graph 3.** The functional behavior analysis of a 60 year old deafblind man.





**Artist:** Rauli Jalo  
**Name:** A peacock  
**Technique:** Mixed technique

# 3 THE PSYCHOSOCIAL SUPPORT AND REHABILITATION OF DEAFBLIND CLIENTS

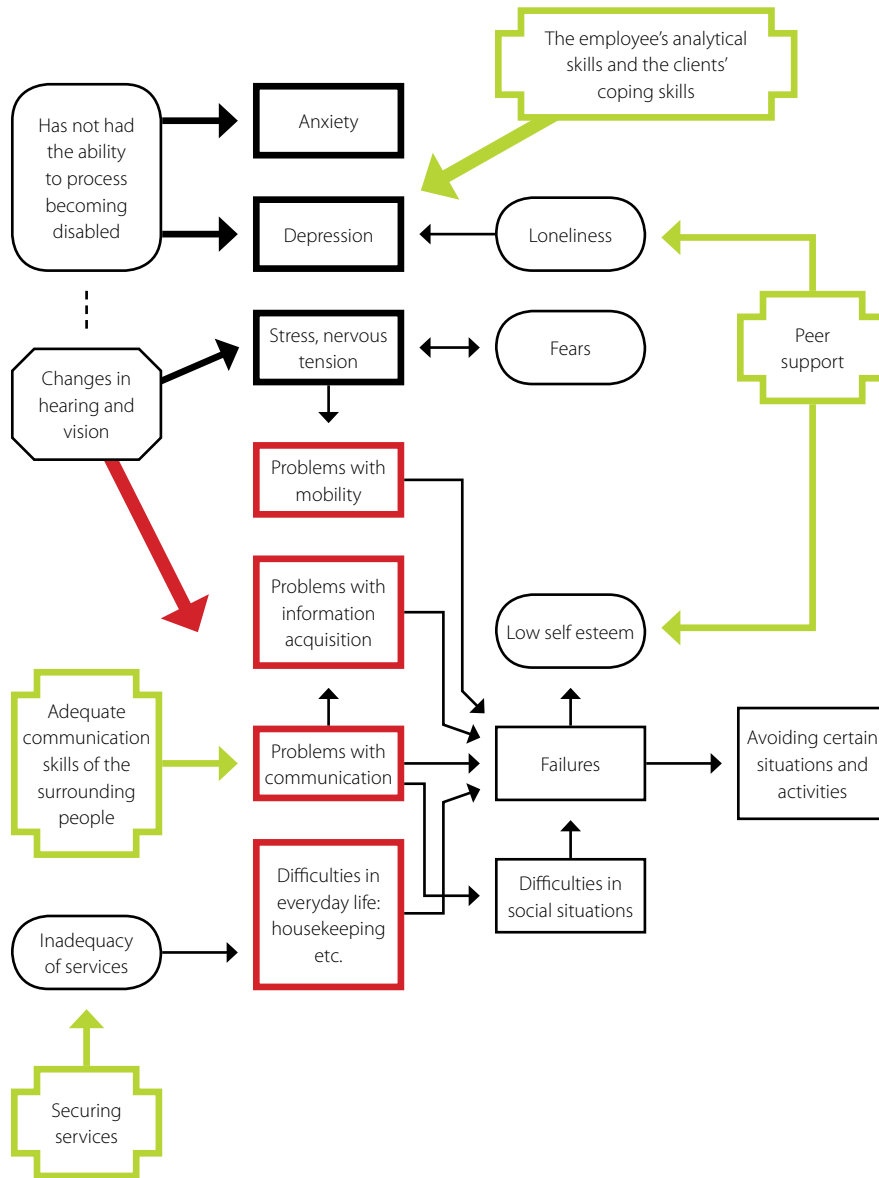
## 3.1 Forms of psychosocial support and rehabilitation

Psychosocial support can be interpreted to cover all the support a person needs in order to cope in everyday life. However, when deafblind persons are considered, certain special issues arise (Brennan 1997). The basic starting point is the ability of the deafblind person to communicate efficiently with their environment, which is also the most common obstacle between an employee, such as a therapist, and a client. In particular, the communication of persons with congenital deafblindness is usually linguistically restricted and requires other forms such as drawing, picture or object communication or role play exercises. People with acquired deafblindness may also face problems in areas such as understanding vocabulary or meanings. Good language skills can also remain unutilised because of the slow pace of such forms of communication as writing or lip reading. Nevertheless, it is important to keep in mind that the ability to use spoken language is not linked with intelligence but with the point in time at which deafblindness occurred, the degree and development of the disability, childhood interaction in the family and experiences in school.

In the Nordic survey (Olesen & Jansbøl, 2005) the interviewees required various forms of help and support. One important area was receiving information and practical help in order to cope in their everyday lives. For example, they required support in financial issues and managing social situations. Family members also needed help supporting the deafblind person. Deafblind persons also appreciated peer support to help deal with their emotions and to evaluate their situations.

Deafblindness alone does not necessarily create developmental problems or problems adapting. The question lies more in the way in which the environment perceives deafblindness as an obstacle, robbing a deafblind person of an essential part of being human. What follows is that a deafblind person is neither offered the same opportunities for education or employment or similar services as other people, nor given enough challenges. This increases the isolating effect of deafblindness and reduces the opportunities to acquire information and learn to lead an independent life. Furthermore, the behaviour and possible psychological problems of a deafblind person cause misinterpretations. Therefore, people working in the field should be very familiar with deafblindness as well as with different means of communication and the deafblind culture in order to understand the deafblind person's situation (Brennan, 1997).

**Graph 4.** Psychosocial means with deafblind clients.





The existence of a deafblind culture has been a topic of discussion and a certain degree of homogeneity has been discovered among the deafblind. Similarities include the effects that deafblindness has on basic daily activities such as communication, information acquisition and mobility. Positive self-esteem and a realistic view of the self help to cope in everyday life. The identity, or consciousness of the self and one's opportunities and place in society, enable wellbeing and the experience of meaningfulness of life. The image of the self is always created in a social context, so finding the right reference group enables a positive self image to be formed. However, a deafblind person must often reconstruct his or her identity several times due to the progression of the disability (Brennan, 1997; Rouvinen, 2001; Kontaktiryhmä, 2002).

Being in control of one's own life, meaningfulness and social relationships increases well being and enhances the quality of life. In the deafblind culture, autonomy and the ability to make decisions are important values that require both inner and outer abilities. Inner abilities include mobility skills, Braille and an efficient means of communicating. Outer abilities are provided by society: interpreting and transportation services, assistant services, means for information acquisition, the building of a safety network and enabling meaningful activities. Work or other meaningful activities and hobbies enrich life. Because of the lack of interpreters and assistants, hobbies must often be selected so that they can be attended alone. Social contacts are important, although finding voluntary, equal relationships can be difficult. Measuring the quality of life on different scales can enhance it and help find a suitable form of psychosocial and rehabilitational support. Taking a holistic approach is crucial when evaluating the situation (Brennan, 1997; Rouvinen, 2001; Kontaktiryhmä, 2002).

Apart from the issues related to communication and culture, the need for psychosocial support for the deafblind is apparent in the grief process and in questions on independence. Going through a grief process is essential for further adaptation. The grief process has often been described as progressing in stages, including denial, anger, depression, bargaining (turning to different experts) and acceptance. However, the process should be seen more as a spiral where the early stages are lengthier and more powerful, but then shorten and lighten as time goes by. It is also important for employees to acknowledge this (Brennan, 1997).

In rehabilitation work, as in a deafblind person's everyday life, the balance between independence and dependence arises. A deafblind person's ability to cope with everyday life enables independence. On the other hand, interdependence between people is necessary in some aspects of life, especially to prevent isolation. It is therefore relevant to enable the deafblind person to acquire the skills and information they need. At the same time, it is also sometimes healthy to depend

on other people, such as requiring the services of an interpreter. However, being close to another person can also bring about a dependence problem. Life changes, such as losing a driver's licence or the role of the family provider can be painful experiences and weaken independence and autonomy (Brennan, 1997).

Psychosocial rehabilitation has been used particularly in the treatment of persons who have suffered trauma. However, the model is also applicable in situations where the client's life needs to be eased on a wider scale. The services can be targeted at the following sectors (Penk & Flannery, 2000):

- Everyday life skills
- Social interaction with family and friends
- Avoiding destructive behaviour and advancing health-promoting behaviour, including the treatment of substance abuse
- Supported living
- Educational and professional needs

In practice, psychosocial rehabilitation has been formed into a seven-section model (Penk & Flannery, 2000):

1. The health and psychoeducation of the patient (guidance and counselling)
2. Self help/practising the skills needed in independent life
3. Supported living
4. Practising the skills needed in a family
5. Practising social skills
6. Vocational rehabilitation
7. Coordinating different sections of the model to suit each client.

### **3.2 A project for the psychosocial support of the deafblind**

The issue of enhancing the psychosocial support of deafblind persons arose in Finland some years ago, when several different sources discovered problems in coping in everyday life. In 2002 a three-year project for Psychosocial support for the Deafblind was launched. The Honkalampi Foundation, the Service Foundation for the Deaf and the Finnish Deafblind Association all participated in the project. When the foundations of the project were laid out, psychosocial support for the deafblind was determined to be:

1. Peer support and its use to build a deafblind identity.
2. Support from a group through which a deafblind person can feel that he or she belongs to a specific community in school, place of residence, and work.
3. Diminishing the feelings of physical and psychological loneliness and insecurity by increasing information and means for contacting the necessary quarters.

The most important working methods in the project have been its various groups for the deafblind as well as staff training. Peer group functions have included groups for deafblind women, men and for controlling stress and anxiety. The women's group was a sign language group, meaning that the group leader heard and used sign language. Some of the participants brought a personal interpreter if they needed one. In other groups the leaders used Finnish, which was translated into sign language. All of the groups also included persons who were deaf but whose vision was intact, which indicates the strength of the sign language identity. Mutual interaction and the exchange of thoughts have played an important role in the groups, and communication without interpreters has also been consciously encouraged in the groups, for example through pair discussions. The men's group has been active and has visited different places and tried new relaxation techniques. The group for controlling stress and anxiety has been an educational group that applies a British model (White, 2000; Hassinen, 2002; Kontaktiryhmä, 2002).

Peer support is one of the individual methods of coping with problems used by deafblind persons, where the culture of the group and their way of thinking and acting are quite distinct. The group shares the multiple means of communication, taking advantage of all senses and the forming of a shared identity. Humour and stories of various mishaps are typical in the group. Different forms of art also introduce deafblind culture (Rouvinen, 2001).

At a personal level, however, is the tough side of being deafblind, and the personnel working in the field of deafblindness come face to face with the hardships in their clients' lives. Accordingly, we started the personnel training by covering the psychological and practical factors that affect the everyday activities of deafblind clients. The training was conducted in three two-day sessions of contact work and additional homework. Case study clients were used as the core of the training and were analysed using the functional behaviour analysis presented earlier. The presentation of problems in a visual form is based on a model by Haynes and O'Brien (2000), which was completed by adding means from a German model (Petermann & Muller, 2001). In the training, the examples of clients were supported by relevant theoretical background knowledge, gained particularly from the fields of neurocognition and psychiatry.

The model for analysis has been in use since 2001. So far this tool has been used by approximately 70 employees working in the field of deafblindness. This method of analysis has been described as laborious and the constant use of it in daily work is not necessarily possible due to a lack of time. On the other hand, in some working units it has been used as a mutual tool for the working group when planning rehabilitation. Using the model enables information to be gathered and mutual ways of thinking to be found. The tool, especially the visual model of analysis, has

been praised for its clear way of giving an overview of the client's situation. This is partially impacted by the fact that people who work using sign language find it easy to grasp due to the visual nature of sign language. Adopting a behavioural analysis way of thinking has, above all, facilitated the discovery of problems and the factors that cause them, and has therefore provided information on means applicable in relieving the situations of each client. The situation of a deafblind client is often so complex that it is not always possible to grasp it in daily work.

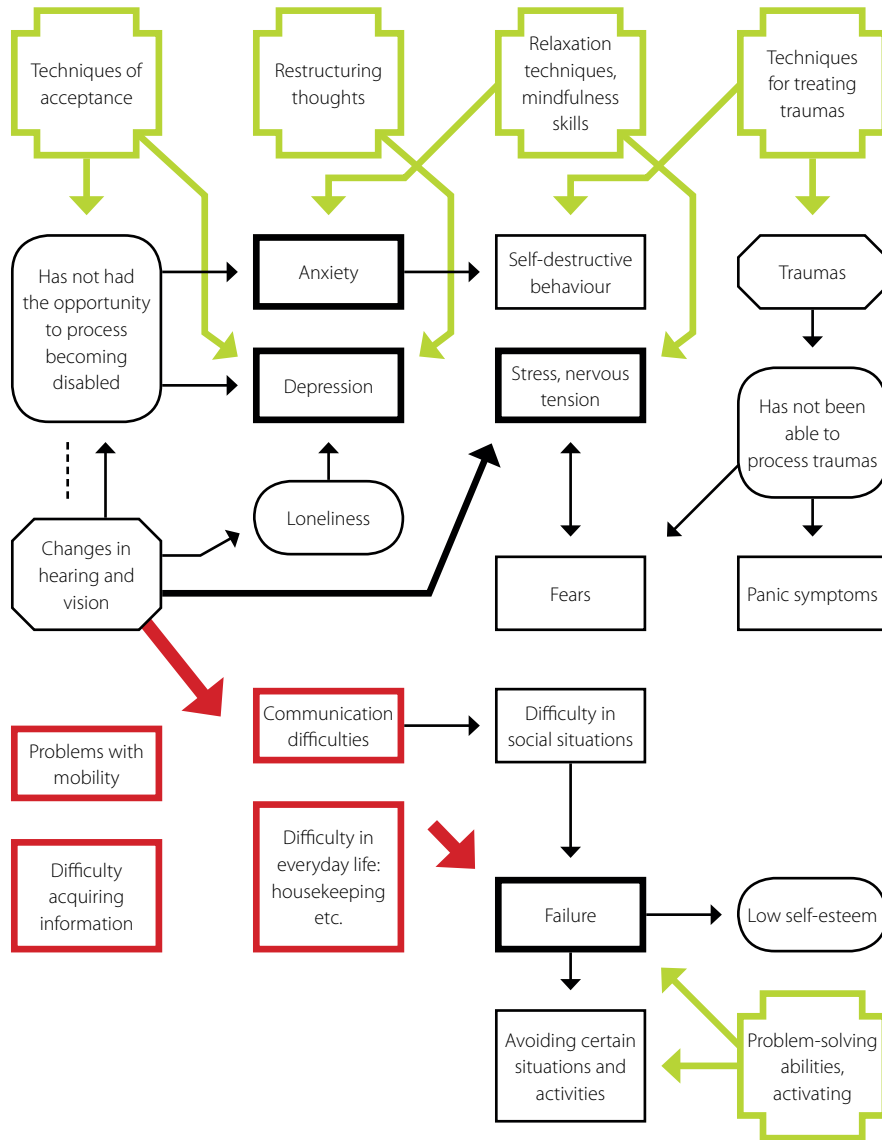
# 4 THE PSYCHOTHERAPEUTIC REHABILITATION OF DEAFBLIND CLIENTS

## **4.1 Practical matters to be taken into consideration in psychotherapy**

In the early stages of psychotherapy with a deafblind person, certain special issues arise that must be taken into consideration. The first is communication and the second is questions on the history of deafblindness related to the early mapping.

If a deafblind person uses sign language, the therapist must either be able to use it as well or use an interpreter. Because there are very few therapists who use sign language in Finland, as in other countries, the most common choice is to use an interpreter when working with a client who uses sign language. However, in Finland it is also common not to use therapy services because of the unwanted presence of a third party. The studies on the use of a sign language interpreter in therapy situations with deaf clients conducted by Hoyt, Siegelman and Schlesinger (Porter, 1999), found that, to some extent, therapists work differently with deaf persons than they do with other clients. According to the studies, therapists who work with deaf clients are more active and straightforward, they do not make as many interpretations on abstract levels, they use more different communication techniques, such as drawing and mimicking and they provide more information and practical support. In addition, a lot more cooperation and consultation with different quarters is required. Most of these factors are considered to be the characteristics of good therapy anyway.

**Graph 5.** Psychotherapeutic treatment methods of deafblind clients



In addition to the practical issues in seeing and hearing, the use of an interpreter in the therapy of a deafblind client raises several questions, including the following (Hassinen, 1999):

1. The kind of emotional bond that is established between the client and the therapist when the client constantly follows the expressions and gestures of the interpreter or receives them through tactile signing. Although the task of the interpreter is to convey the tone of voice and the appearance of the therapist, direct contact between the client and the therapist might only be established when greeting and parting.
2. How deep into the thoughts and experiences of a deafblind person the therapist can penetrate when they are bound to another language and culture. An interpreter is an expert in different languages and cultures but only uses this expertise in the process of interpreting. Occasionally, if necessary, the interpreter may also convey cultural factors, such as the status of a person in the culture in question. Language and culture, however, carry a number of hidden meanings, which may be completely ignored and thus affect the interaction.
3. How confidential the client perceives the therapy as being. Considering therapy conducted in sign language, American family therapist Michael Harvey (1989) brought up the experiences of therapists and their possible frustrations in therapy work with the deafblind. Particularly common problems among therapists in sign language therapy are caused by: shock caused by the difficulty in communication, feelings of incapability when working with the deaf, slow progression and physical and emotional fatigue, which are caused by the need for constant eye contact with the client and the abundant use of facial expressions and gestures, an overwhelming feeling of helplessness that arises from feelings of guilt and rescue fantasies, and dealing with difficult or self-destructive patients.

In Finland, a family therapist named Pirjo Leino (Pihavainio & Leino, 1998), who works with patients using sign language, has reflected on the impact that language and culture have on the development of a deaf person as well as on a therapy situation. Many middle-aged deaf people (or deafblind persons using sign language) have not had the opportunity to sufficiently absorb either their native language or the deaf culture. The hearing have defined the proper ways for them to function and the deaf person expects the therapist to do so as well. Previous experiences of the hearing being smarter and knowing what to do also come across in therapy. The deaf or deafblind person conforms to the therapist's views and no progress is made. The therapy usually ends at this point and is considered useless. The problem, however, is the fact that the client and the therapist have not been able to establish a good interaction, a so-called good therapy relationship.

Whether communicating directly with a deafblind client or through an interpreter, it is crucial to consider problems in hearing and vision. If the client has residual vision or hearing, the following issues should be planned beforehand (Hassinen, 1999):

1. Accessing the place of therapy; can the client come alone, or does he or she need a guide?
2. Is the space adequately lit and are there sufficient contrasts? For example, is there a good contrast between the doorway and the wall? Is the seating arranged so that the client will not be dazzled? How is the seating arranged in relation to the windows? Is movement unobstructed and, if necessary, is there a one-colour wall behind the therapist to prevent visual clutter.
3. The therapist or the interpreter should also pay attention to what he or she is wearing: single-coloured dark clothing, no shiny jewellery, good facial contrast such as lipstick or a headband if she has fair hair and skin, etc.
4. When the client uses his or her hearing, it should be ensured that there is no unnecessary noise or echoes in the room. Distance should also be planned according to the client's hearing ability.
5. It should be noted that therapy, particularly lip reading, is physically and psychically strenuous and there should be breaks if needed.

The client's ability to use their hearing and vision can vary as the situations change, as well as if they are going through personal changes. Usher syndrome, for example, causes visual and hearing disabilities to progress and situations may change quite quickly. Also, a person's physiological and psychological state affects hearing and vision. The state of the client's hearing and vision should be kept in mind when moving from the place of therapy into another space or outside. Moving into bright daylight may shock the client and time is needed for the eyes to adjust. Even the slightest change can cause quite serious problems. Also, when assigning homework, the therapist should consider whether the client can manage it on their own or whether they need someone to read and write the homework, for example. Some clients might be able to read fluently using a magnifying glass or a desktop video magnifier but others may require help. Clients who use sign language may need help translating their homework into sign language, in which case interpreting services should be available (Hassinen, 1999; Lahtinen, 2004).

Working with deafblind clients requires creative thinking in coming up with different means for actualising exercises during therapy sessions. For example, in relaxation exercises it is a good idea to first go through the exercise in small portions and consider the signs that can be drawn on the client's skin while performing the exercise. In particular when communicating with the client in a tactile manner, the hands are constantly tied to the communication, and the client is likely to be tense in anticipation of receiving a message. Therefore, relaxation exercise can progress



without using words to explain, by using touching the body, or agreeing on signs that communicate the progressing of the exercise (Hassinen, 1999).

Visualisation exercises can also be difficult for some clients. I have found in other contexts that both deafblind and deaf persons can find it hard to move away from the concrete world and think about what could be or might have been. Therefore, the use of images, objects, sounds, smells, or tastes can be used to spark the visualisation exercise (Hassinen, 1999).

*In my own therapy work I have increasingly experimented with the use of bodily exercises, such as Tai Chi and relaxation through mindfulness exercises. Progressive relaxation, or tense-and-release relaxation, appears to be difficult since it may cause pain and actually increase tension. Trying out new exercises can actually open up new ways for the client to perceive their situation. For example, this can include putting feelings first when the primary feeling can change drastically when another feeling is raised as primary. This can bring up feelings of anger related to a certain situation or person.*

**Artist:** Rauli Jalo. **Name:** Windmill. Two friends are sitting inside the windmill talking. There is a garden outside where among the trees and flowers you can find a cat, a bird and a mouse. **Technique:** Mixed technique.



## 4.2 Ethical questions in psychotherapy

No literature is available regarding the ethical aspects of mental health work among deafblind clients. There is, however, material on deaf clients that can be applied when working with the deafblind. It is important nevertheless to keep in mind that the deafblind community is even smaller than the deaf community, and holds within it both representatives of cultural majority and minorities.

In their discussions, mental health care workers working with the deaf have raised the following ethical questions (Gutman, 2002):

- Encountering clients outside therapy sessions, for example, in town or in events for the deaf.
- Cooperation with other professionals and facilities that employ them.
- Fighting against rumors and becoming marked. Therapists are often well known among the deaf community.
- Facing the financial, educational and professional problems in the lives of deafblind clients in therapy situations.
- The attempt to secure high quality, although there are too few mental health care professionals to begin with.
- Serving clients without being educated in working with the clients in question.
- Keeping your private life “self-fostering”

There is no literature that describes clinical therapy work in the field of deafness, so many issues remain problematic. Gutman (2002) described the transformation of the ethical view in rehabilitation from medical paternalistic practice and models, to a view that respects autonomy and cooperation in decision-making. The latter is especially difficult in mental health work among the deaf because it raises the issue of discrimination against minorities and the issue of deaf people being perceived as disabled instead of as a linguistic minority. Hearing professionals therefore determine the methods of treatment and the goals as well as evaluate the results of the treatment and the possibility of using generally available, inexpensive treatments or rare, expensive treatments. There is a movement towards clients having power over their own treatment. In these cases, plans for treatment are negotiated mutually. The treatment can include an educational segment that encourages the client to participate in the treatment, as well as creates a mutual understanding of the treatment process. This not only requires sensitivity towards ethical questions but also clinical skills and “professional virtues”.

One of the most important ethical issues in mental health care work with the deaf is finding a mutual language so that the client can receive the information they need via their own language. As mentioned above, a sign language interpreter should be used in situations where the therapist’s language skills are not adequate. In addition to

language skills, there is a need for understanding of multiculturalism, which requires wider, long-term relations with deaf persons other than the clients. When working in such a small community, it is important to consider confidentiality, the competence of the therapist and other possible connections and attitudes towards the deaf community. Because there are no specific models of how to handle ethical questions,

methods such as problem solving can be applied in difficult situations. The starting point, therefore, is to recognise the problem, seek different ways to solve it, and weigh the possible effects of these methods. When seeking a final solution, general rules can be used as criteria, such as the golden rule of how you would want to be treated (Corbett, 2002; Gutman, 2002).

Ethical issues arise more frequently when the mental health care workers are deaf or deafblind because they are

a part of the same minority as their clients. This increases the probability of encountering clients in other situations, as well as the probability that the clients know each other. The therapist must also consider general attitudes in the deaf community, such as their attitude towards inner ear implants. Some clients may also idealise a deaf therapist and seek contact with him or her outside the therapy sessions. In these cases the therapists must protect themselves, for example by changing their phone number, which could cause problems in their private lives. The professionalism and reputation of a therapist is more visible in a small community than in a larger one (Leigh, 2002).

Staff training is essential when arranging mental health care services for minorities and different special groups (Gutman, 2002; Peoples, 2002). In addition to general professional competence, other basic issues relate to paying attention to other mutual relationships that may exist, different qualification standards and matters concerning confidentiality. Constant training, clinical supervision and consultation in problematic issues are the most important actions to prevent ethical problems. People who train new professionals in the field should take care that the future employees are academically, linguistically and culturally competent and motivated to offer care that is as ethical and high quality as possible.



**Artist:** Rauli Jalo. **Name:** An old car. **Technique:** Clay.

# 5 METHODS AND APPLICATIONS OF PSYCHOTHERAPY WITH THE DEAFBLIND

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## 5.1 Psychotherapy with persons with hearing disabilities

People with congenital hearing disability often have various beliefs about themselves that are linked to their disabilities. According to family therapist Michael Harvey (1989), one possible goal in psychotherapy involving the hard of hearing can be to challenge these beliefs. Through feedback received in different situations, a person may link himself or herself with various beliefs, assumptions and images, such as being disabled, helpless or stupid. Even the impact of a moderate hearing disability on a person's life can be an experience that causes the person to withdraw rather than face the constant demands and stress brought on by different situations. As a result, personal competence is tested constantly.

Links to the predominant ways of thinking are sought and re-modelled in therapy by experiencing various situations. It is also important to discover the effect that a person has on himself or herself, as well as the effects that people have on each other. One of the practised techniques is the skill of assertiveness or self-defence. The situation is similar with deafblind persons. Active participation in social situations, seeing the bright side of humiliating situations ("I'm glad I'm not completely deaf"), trying out the worst case scenario (for example, taking out the batteries of the hearing aid on a public beach) and seeking the company of agreeable people, can be possible exercises to change behaviour. At the same time, it offers an opportunity to test ideas about being a burden to others. Sadness and worry are also a part of the process and should not be confused with clinical depression. Feelings of anger often surface as well (Harvey, 1989).

In psychotherapy for the hard of hearing, similar focal points have come up in the process. According to Harvey (1989), these points are:

1. Increasing biological and audiological understanding of the hearing disability by discussing it with experts such as doctors and audiologists
2. Reading about hearing disabilities
3. Acquiring a hearing aid
4. Using a hearing aid
5. Acquiring other special equipment, such as a light alarm on the doorbell or a telephone sound amplifier, if necessary
6. Being alert in social situations so that it is possible to deduce the topic of conversation and thus make lip reading easier
7. Admitting the inability to hear others
8. Recognising and labelling emotions linked with hearing disabilities, such as worrying
9. Discussing emotions with other people with hearing disabilities
10. Understanding that you should not automatically burden all family members and friends but learn to choose the people with whom you can discuss your personal feelings
11. Discussing the hearing disability with people who do not have hearing disabilities
12. Reducing the spread of the effects of the hearing disability – changing the phrase “being disabled” from a noun to an adjective and thus redefining oneself
13. Increasing assertiveness or self-defence and understanding the need to educate many hearing people to react properly during discussions. This way, the person with a hearing disability is neither left out of the conversation nor required to wait around and hope for the hearing people to change.

In Finland the basic rehabilitation of deafblind clients is usually conducted before they start psychotherapy. The hearing aid and other special equipment have already been acquired and it is possible to begin the above-mentioned process from stage six.

## 5.2 Psychotherapy with deafblind persons

The goals for psychotherapy with deafblind persons are similar to those for clients who are deaf or hard of hearing. However, there are some special issues that must be taken into consideration (Brennan, 1997):

1. Efficient communication between a therapist and a deafblind client is essential
2. The therapist must be able to create a warm, accepting and non-condemning attitude towards the deafblind client
3. The therapist must be genuine and consistent in their relationship with the deafblind client. The therapist must be especially alert when giving out information so that it does not increase dependency problems
4. The therapist's positive attitude must be expressed, in one way or another, so that the deafblind client does not miss factors essential to growth. Attention must be drawn to matters such as the possible withdrawal of the client, raised level of egocentricity and the breaking off of existing relationships.

Miner (2002) lists five different issues that must be taken into consideration in the early stage of psychotherapy of an Usher client. These issues are:

1. The age at which the client became aware of the diagnosis
2. Whether the parents received the information first and whether they withheld it from the client for some time
3. Whether the client received wrong information from friends and family members
4. Since the diagnosis, whether the client has been in contact with other Usher persons
5. Whether the client is able to sufficiently communicate with family members

In the Nordic survey (Olesen & Jansbøl, 2005) clients were affected differently when they received the diagnosis according to:

1. The stage of life at which the diagnosis was made
2. The situation in which it occurred and whether both the situation and the environment are safe
3. The kind of support that is available after the diagnosis is made.

### **5.3 Experiences of the use of cognitive behaviour therapy in psychotherapy with the deafblind**

I have worked as a psychotherapist since 1999 using a variety of cognitive behaviour therapy methods. This chapter will describe some of the special features I have noticed in psychotherapy with the deafblind, as well as methods that I or other therapists have used that are applicable in working with the deafblind. The methods and processes of both individual and group psychotherapy will be described in greater detail in later MIELI project publications.

As described above, one issue that is raised in psychotherapy with the deafblind is the complexity of the client's problems. Accordingly, the model for functional behaviour analysis, described in the client examples, suits individual therapy well. The fact that the problem areas processed are discussed with the client provides a good setting for cooperation. I sometimes repeat the analysis during therapy and, if necessary, pick a specific area for separate analysis. Accessing the factors that affect the problems requires deeper chain analysis or, in other words, delving into one problem area or factor (Hassinen, 2004).

As noted above, the key difference between psychotherapy in general and psychotherapy with the deafblind is communication. Some of my clients are hard of hearing, which means I have to communicate clearly and slowly. Some use sign language, which can either mean signing in a very small free space or in a tactile manner from hand to hand. In whatever form the communication is conducted, it is slower than spoken communication. Accordingly, in practice, I do therapy in two 45-minute sessions. This is also partly due to the fact that my clients live far away, up to 450 kilometres. Therefore, therapy sessions are held every fortnight. This is not very practical in acute cases but it is manageable otherwise. If necessary, I also keep in contact with clients between therapy sessions by phone or by e-mail. I have also conducted hour-long sessions on a weekly basis for which every other session has been held via videophone. With some of my clients, however, it has been possible to meet on a weekly basis (Hassinen, 2004).

When I began psychotherapy work with the deafblind I assumed that there would not be any other great challenges, apart from communication. When it comes to communication, the most important and time consuming challenge in the early stages of therapy is to find a mutual mean and a mutual language. In particular, establishing mutual terminology with clients who use sign language takes time. On the other hand, it is great to see the expansion of the client's way of thinking when he or she has the opportunity to sign about matters that are more complex and multidimensional than those related to everyday life. However, I have gradually discovered that psychotherapy with the deafblind, on the whole, requires a different kind of grip. Although the theoretical framework suits my clients, as do many

methods of cognitive behaviour therapy, I constantly have to create applications of my own (Hassinen, 2004).

The following sections include a short description of the use of cognitive behaviour therapy and its applications in psychotherapy with the deafblind. The methods are covered quite briefly, as they will be discussed in more depth in future publications of the project.

Some kind of reflection on the personal history of the person is always necessary with a deafblind client. It might not happen in the early stages of the therapy, when acute issues are foremost, but is relevant once these issues have been resolved. At this point it is usually discovered that the client has not had the chance to share their feelings related to the disability, such as sadness, anger, worry, fear or anxiety (Hassinen, 2004).

While discussing personal histories, we also come across questions of acceptance, such as how bearable it is to live as a deafblind person. At this stage, ACT (Acceptance and Commitment Therapy) and its exercises can be a good method. The basic principles of ACT are acceptance, commitment to living according to one's own values and acting according to these values. An analysis of good living can be conducted in the early stages of therapy. This makes it possible to examine the client's goals and what they have done in order to reach these goals. Deafblind persons are familiar with discussing their values given that they have been forced to readjust to new situations in their lives as their disabilities have progressed (Hayes, 1995; Miner, 2002).

A lot of information sharing takes place during therapy sessions, and the information should be delivered in such a way that is understandable to the client. In practice this means using clear language and, for example, simplifying exercises. The terminology used must be constantly made more understandable, whether using spoken language or sign language. This alone presents a challenge for the therapist, as does homework. In addition, the therapist must consider whether the client can manage the homework alone, or whether he or she needs assistance. In some cases I have made tape recordings of the homework, but there is usually insufficient time for that type of work. Assigning homework is therefore less common with deafblind clients than it is with other clients (Harvey, 1989; Hassinen, 2004).

With every deafblind client, one must pay attention to stress and tension, which relates to both physical tension and anxiety. Progressive relaxation, or relaxing different parts of the body by tensing and releasing (Tuomisto et al. 1997), has been shown to be a good method. However, this method might not suit deafblind clients. Progressive relaxation does not make all clients feel relaxed and some have



difficulty doing the homework. With some clients, good results can be achieved through mental picture exercises, especially if touch is involved.

It is always useful to discuss general relaxation methods that the clients can use. Many clients use physiotherapy and horseback riding therapy. Different kinds of baths, sauna and swimming can also be relaxing, as can listening to music, scents and physical exercise. Gym training, gymnastics or Tai Chi, performed in a small group, is good for increasing muscle strength, which improves balance. Taking walks is a popular basic exercise that also benefits deafblind persons since it helps them relax, alleviates depression and makes weight management easier. Most, however, cannot go for walks by themselves and require a guide (Hassinen, 2004).

In some situations, tension can turn into panic attacks; it is treated with panic treatment methods such as abdominal breathing, diverting attention and positive inner speech. Moving about independently, or even with a guide, causes symptoms similar to panic symptoms in some deafblind persons. In these cases, breathing exercises and diverting the attention away from oneself may be sufficient to ease the situations. Sometimes it is useful to go through the situations through problem-solving. This kind of situation might, for example, include a client getting lost in their own neighborhood (Bourne, 1999; Hassinen, 2004).

As mentioned in the section describing problems, many deafblind clients have traumatic situations in their personal history. Consequently, I have been increasingly exploring means for treating traumas in order to find additional tools to ease clients' situations. With some clients I have primarily used cognitive methods to treat trauma and with others I have added methods of relaxation and exposure. Exposure helps the client to confront thoughts, feelings, physiological reactions or situations that they have previously avoided through the use of mental picture exercises or in concrete situations with so called in vivo exercises. In this context I have also become familiar with EMDR (Eye Movement Desensitisation and reprocessing), which I have adapted by replacing eye movements with tapping on the thighs. With some clients, we have been able to access experiences and feelings at a whole different level using touch. Using touch will also be one of the most important areas for development in psychotherapy with the deafblind (Hassinen, 2004, Lehtonen & Lappalainen, 2005).

Various corporal methods have also been used more generally to treat traumas. The theoretical basis for this is the fact that traumatic experiences are preserved as original emotional and sensual experiences, as well as images for years. A person's nervous system is constantly wound up and the body is in a state of dissociation, which manifests itself as numbness and weakened senses. At this point, mere talking cannot necessarily access the experiences stored in the memory (Van der Kolk, 2002).

A client's body consciousness can be increased with different methods that, in addition to EMDR, include corporal therapies conducted by a psychotherapist or other professional. Especially when using methods that require touch, it is good to have help, for example, from a physiotherapist. In these cases, the key to therapy is teamwork. During the therapy session, the therapist observes changes in the client's body, such as breathing, skin colour, muscle tension or relaxation, movements, reflexes or positions in order to find the right level of activity. While overly strong activation can cause a state of panic or dissociation, a connection with painful feelings is necessary. The goal is for the client to learn to observe what is happening in their body and therefore acquire new means of self control and remain focused on the present situation. Notions made by the therapist help the client in this task (Munukka-Dahlqvist, 2002).

In addition to the treatment of anxiety and possible traumas, depression is one of the most common problems that require treatment. Loneliness often increases depression and negative thoughts about oneself. Methods for treating depression are basically similar than in general, with an emphasis on activating the clients and restructuring their thoughts. Problems activating a deafblind client often lie in the absence of another person; leaving the house would require a guide. When reshaping the client's thoughts, it is usually possible to process their deviations in thoughts and core beliefs to some extent. The linguistic skills of the client, however, have a powerful effect on how much progress it is possible to make. Working with thoughts is usually the most difficult and challenging part of psychotherapy with the deafblind and becomes possible only at the final stages of therapy (Hassinen, 2004).

The next section returns to the client examples presented earlier (Graph 2, page 38 and Graph 3, page 41).

### **CLIENT EXAMPLE 1 AND METHODS FOR TREATMENT**

At the analysis stage we go through the situation and, to some extent, the client's personal history. At an early stage of the treatment we chose to deal with those problem areas that troubled the client the most, with the goal of easing the effects of deafblindness on everyday life. The key points in the progress of the treatment are presented here.

#### **1. CORRECTING MALPOSITIONS OF THE BODY**

A malposition caused by constant stress can manifest particularly in the client's tendency to hunch forward. To correct the position we use mindfulness exercises as a starting point. As the client was sitting she was asked to pay attention to her body and its relation to the chair or sofa and the position in which she was sitting. In the therapy situation we paid constant attention to the position of the body and it gradually became corrected automatically.

At the same time, we performed abdominal breathing exercises in both a hunched and a straight position. This allowed the client to experience the difficulty or ease of breathing in different positions.

## **2. MEANS FOR MANAGING THE SYMPTOMS OF NERVOUS TENSION IN UNFAMILIAR SITUATIONS**

The client made a list at home about the situations she found caused nervous tension. We went through the list and rated the situations from the most difficult to the easiest, based on a scale of difficulty from zero to 100. At this point the client also received information about the origins of panic symptoms. During a therapy session we went through one situation evaluated as semi-difficult as an exposure exercise using visualisation. In this exercise the client applied the body consciousness and abdominal breathing techniques learnt earlier in order to ease panic symptoms.

Thoughts related to the situation causing nervous tension also surfaced during the exercise, including "I will surely faint" and "I will make a fool of myself." These thoughts were discussed and their relation to reality was reflected on. The client was assigned homework that required her to use her abilities in unfamiliar situations that she knew she would encounter.

The next stage focused on problems with eating and sleeping, because they were related to anxiety. At the same time we went through daily and weekly activities in order to discover stress factors.

## **3. STOPPING BINGING, STARVING AND PROBLEMS WITH FALLING ASLEEP**

At first, the client was asked to keep a diary of her eating and sleeping. She succeeded in both for a couple of days, after which she grew weary. The diaries were analysed in order to find out how bingeing, starving and problems with sleep develop. The goal was to discover warning signals early on so that behaviour could be corrected. At the same time we observed possible stress factors that may have contributed to triggering problematic behaviour.

During several therapy sessions, the client and I went through different situations in which she had tried to break off bingeing or problems with sleep. The observation was not easy and required revision of the chain analysis. Finding physical tension was the easiest and we already had means to manage it such as abdominal breathing, outdoor activities or a warm shower. At times the client experienced general restlessness and anxiety, which was difficult to grasp. In these cases, moving about calmly in her own room and talking to herself about what she saw and sensed proved to be a good method. Phoning a friend often diffused the situation, while organising things and cleaning were also good methods that were discovered earlier.

The next stages of therapy required longitudinal processing and they were covered in an overlapping manner.

#### **4. LABELLING AND RECOGNISING EMOTIONS**

Labelling began by going through a list of emotions. The client ticked off the emotions that she had experienced during the previous week and possible situations with which they were linked. The situation that raised the most emotions was processed in order to bring out the bodily sensations, thoughts and actions in that specific situation. The client had already learnt to observe her body, so it was easy to move on to linking the observations with other factors.

The client learned the connection between her body and thoughts and their effect on experiencing emotions. In the exercise we used different body positions and facial expressions while also emphasising the client's contribution to interaction. The client is not always able to see the faces of the people with whom she is talking, and is therefore unable to evaluate their possible emotional states. Also, the effects of her own actions were unclear. Therefore, communication situations were rehearsed as a role play by placing emphasis on the use of body and facial expressions.

An important part of the emotional work was the acceptance of the client's own feelings. For this we utilised ACT exercises in putting feelings first, and the observer exercise, which has a wider impact on acceptance.

#### **5. STOPPING NEGATIVE INNER SPEECH**

Negative inner speech and beliefs often surfaced during the therapy, especially in situations where daily activities did not go as well as the client had wished. Thoughts and beliefs were listed and examined by asking the client to evaluate their truthfulness on a scale from zero to 100 percent. At first the client found it difficult, but gradually she realised that her thoughts were merely thoughts. This was also helped by ACT exercises, such as the encouragement not to think, which leads to an opposite situation.

#### **6. EXPRESSING PERSONAL NEEDS, DEFENDING ONESELF**

Because it is important for the client to express their personal needs, we conducted role play exercises of different situations. In the role-play the client could rehearse the difficult situations she had experienced with different words and a different emphasis.

After the client's state was stabilised, it was possible to process traumatic experiences.

#### **7. PROCESSING BULLYING AND MOLESTATION ATTEMPTS**

In the beginning of the third year in therapy the client showed a willingness to process traumatic situations in her past. The processing began with experiences of

being bullied in school. Because the situation was stable and the client was used to visualisation exercises, we began with the most difficult experience. The client went through a situation of bullying on a school bus, where another pupil attacked her verbally and physically. In the visualisation exercise the narration was made in the present tense, as if it was happening at the moment. This raised powerful emotions but the client was capable of going through the situation. The speech was recorded and the client's homework was to listen to the tape on a daily basis. The same situation was repeated in several therapy sessions and the client gradually began to feel at peace with the issue of school bullying.

Processing the molestation attempts, on the other hand, was more difficult and we began it by rating the situations from the easiest to the most difficult. From these situations we chose a semi-difficult one to process in the therapy sessions. The situation had to be interrupted several times to ensure the client was relaxed enough to continue.

### **A SUMMARY OF THE TREATMENT METHODS AND RESULTS**

At the end of three years of therapy, the client felt content for having received the means to control her physical tension and bare various emotions. She also felt that she had more courage to express her needs, although it was still not easy. Stress and its effects still remain issues that she finds difficult to observe and the situations are too easily prolonged. She is, however, capable of constantly educating herself in this matter. The client's situation was followed up using the SCL 90 symptom checklist twice a year and the BDI depression inventory approximately every two months. A change was also perceived in these scales.

### **CLIENT EXAMPLE 2 AND TREATMENT METHODS**

#### **1. SUICIDAL THOUGHTS**

We started by going through the client's suicidal thoughts and whether he had plans to act on these thoughts. This was not the case, as the thoughts were linked with loneliness and fear of the future. At the same time we agreed that if these feelings became more powerful, he would immediately discuss them with home care workers and with me as we met. The home care workers could also call me if needed.

#### **2. LONELINESS**

The feeling of loneliness, related to the client's suicidal thoughts, came across as powerful. The matter was raised again several times during the therapy. Considering the suicidal thoughts, we went through situations and times when he felt particularly lonely to determine his thoughts and bodily sensations. Weekends and nights

proved to be the most difficult. On the other hand, we went through situations that he felt were easier, which included being around people and having activities.

The client himself had already noticed that certain activities relieved loneliness and together we came up with possible new methods. Actively leaving the house brought relief, although it was occasionally difficult. Sharing thoughts with other people, which had started in therapy, was selected as a wider goal. It was important, however, to list the persons with whom the client could share his thoughts, and interaction skills were practised with conversation exercises. An important part of sensations was the ability to recognise bodily tension and relieve it.

### **3. NERVOUS TENSION**

Relieving nervous tension began by describing bodily sensations in new situations. In these situations the most significant problem was shortness of breath. The client tried abdominal breathing, which he found difficult. Breathing exercises were combined with repositioning of the body by lifting the upper body and consciously keeping it in a better position. This also made abdominal breathing easier. The client was also instructed to practice these skills on a daily basis.

Different situations causing nervous tension were examined by seeking methods for tension relief. Besides breathing and finding a better position, the client's fear of embarrassing himself was also raised. Because he is unable to see his environment, he suspects that other people stare and talk about him whenever something unusual happens. We agreed that in such situations he would ask the person accompanying him to describe more accurately what is going on, what people are doing, who they are looking at, etc.

### **4. THE FEAR OF NOT BEING ABLE TO COPE AT HOME**

The client was occasionally very worried about not being able to cope on his own and having to be institutionalised. His wife's hospitalisation seemed to be prolonged. We focused on the weekends when he had to be alone and the things he is capable of doing. The major problem was the feeling of insecurity and the anxiety it caused rather than performing practical activities. This was the point of focus in the following sessions, when we conducted an exercise in which the client would go around his apartment and sign to me what was where. Through this exercise he learned to bear the feelings and develop a sense of what is around him.

### **5. POWERLESSNESS**

Because it was impossible to use BDI or SCL due to the complex language they involved, mood was measured on a scale from -5 to +5. This gave us an idea of the changes in the client's mood. In the beginning there was very little change and the mood was constantly on the negative side but there was a gradual change towards

the positive end of the scale. There were still occasional relapses during holidays and after visits to the hospital. These relapses were processed and the client agreed that he was able to bear the situations. He had already experienced that change was possible. The feeling of powerlessness was relieved by home care workers checking the client's meals and their frequency. The client also formed a habit of taking a short daily walk in a familiar environment in which he could cope on his own. Occasionally, accompanied by a friend, he was able to take longer walks. The client did not have any significant sleeping problems.

### **A SUMMARY OF THE CLIENT'S TREATMENT METHODS AND RESULTS**

The therapy of the client lasted for one year, which is a short time in sign language therapy. During therapy the client had other employees to help him in practical matters, which made the therapy process easier. We also went through some exercises with the employees in order to help them instruct and activate the client in performing them. We also discussed different housing choices, if he was left alone and was unable or grew tired of living in his current apartment. This information also gave him relief.

A decrease in tension and fear was the most significant change in the client's state. He also learned to demand more information about what is happening in the environment in order to increase his awareness. Feelings of loneliness and sadness still bother him at times but he is able to bear them. Occasionally the client spoke about being blinded and his wife's state but these issues no longer caused anxiety. Daily routines have gradually been established and the future does not seem as frightening as it used to.

## **5.4 A project for the development of psychotherapy with the deafblind - the MIELI Project**

In early 2005 the Service Foundation for the Deaf, in affiliation with Finland's Slot Machine Association, began working on the MIELI project for the development of psychotherapy with the deafblind. The project, which continued until the end of 2009, aimed to help deafblind persons achieve a better life by developing methods that are applicable both in individual and group psychotherapy and by providing personnel in the field with the means to support the psychological wellbeing of deafblind clients. Behavioural analysis and cognitive behaviour therapy were used as a framework for the project. Another goal was to create a multi-professional model for psychotherapy and therapeutic guidance for the deafblind, as well as, in general, a model for psychotherapeutic work with the deafblind. The MIELI project produced educational material related to psychotherapy as well as scientific data. International connections were also established during the project by becoming familiar with work related to the

field in different countries and distributing the results of the project via various publications and conferences (Hankesuunnitelma, 2005).

The upcoming publications of the MIELI project will present various methods that can be incorporated into cognitive behaviour therapy to improve the quality of the therapy with deafblind persons. These include particularly corporal methods and applications of mindfulness exercises and exercises related to ACT –therapy. The methods are tested both individually and in groups to learn about their effects. The goal is to modify the therapy process to better serve the special needs of the deafblind.

An essential part of the project is to share proven methods and practices through personnel training and to find new methods. This will allow the results of the project to be put to wider use. Personnel training began in the spring of 2007.



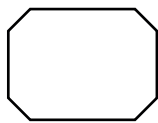


# APPENDIX 1.

## **Constructing a functional behaviour analysis of the client's problems and factors that possibly affect them.**

70

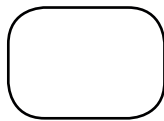
A graph was drawn based on the information gathered, in which the following symbols are used:



An original factor (e.g. deafblindness, a trauma) that cannot be changed.



A behavioural problem or its effect



A factor affecting the problem

The thickness of the line illustrates the problem and the importance of the factors affecting it. The thickness of the arrow illustrates the strength of the influence.

----- No influence

—————> One-way influence

←————→ Two-way influence

————— Weak

————— Average

————— Strong



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There is very little literature available on the connection between deafblindness and psychological problems. Sense of Life delves into the everyday life and psychological problems of deafblind clients and the ways of helping them through means of psychosocial and psychotherapeutical support. The book offers basic information for personnel working in the field as well as to those who share the interest, but do not have prior experience of deafblind persons. The publication is a part of the Mieli -project by The Service Foundation for the Deaf sponsored by The Finnish Slot Machine Association.



Even though the psychological problems of deafblind persons do not differ from those of the majority of population, deafblindness as a limitation of functioning brings about certain special features. According to a Nordic definition deafblindness is a combination of limitations of hearing and seeing. It restricts a person's performance and full participation in society to such extent that that it requires society's support in the form of special services, adjusting the environment and/or acquiring special equipment.

Special issues arise in psychotherapeutic rehabilitation and psychosocial guidance that need to be taken into consideration. Examples of deafblind clients are used in the book to describe these special issues, as well as how these persons have been helped using cognitive behavior therapy.

The book is applicable both as a textbook for various fields as well as a handbook for people working with the deafblind and those facing other similar problems. The author, Leena Hassinen, has nearly 30 years of multifaceted experience in working with deaf and deafblind persons.



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ISBN 978-951-98990-6-0



## II

# CASE FORMULATION MODEL FOR THE ASSESSMENT OF PSYCHOLOGICAL PROBLEMS AMONG DEAFBLIND PERSONS

by

Hassinen, L., Haynes, S. N., Timonen, T., & Lappalainen, R. 2012

Scandinavian Journal of Disability Research, 15(4), 325-341

DOI: 10.1080/15017419.2012.724444

Uudelleenjulkaistu Routledgen luvalla.

## A case formulation model for the assessment of psychological problems among deafblind persons

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In order to describe and understand possible problems associated with deafblindness we applied a functional analysis case formulation strategy and Functional Analytic Clinical Case Diagrams (FACCD). We collected clinical assessment data from deafblind persons who were experiencing multiple psychological problems as reported by their healthcare professionals. The data were collected after the healthcare professionals were trained in functional analyses and in applying FACCD. The 21 deafblind persons assessed by healthcare professionals were reported to have 3–11 psychological problems. Two case examples are given to illustrate the complexity of a deafblind person's life situation and the functional relations among problems and possible causal variables. Thus, in addition to vision, hearing and communication problems, deafblindness can be associated with other psychological problems that may benefit from more precise psychological assessment and treatment. We found that the functional analysis and FACCD were useful in helping assess and understand persons with visual and hearing difficulties, especially when there are indications of concomitant psychological problems.

**Keywords:** deafblindness; functional analysis; FACCD; staff training

### Introduction

In Finland there are approximately 800 individuals, who have dual sensory disability–deafblindness.<sup>1</sup> Although the term “deafblindness” refers to total deafness and blindness most of the individuals having these impairments still have residual hearing and/or vision (The Finnish Association of the Deafblind 1996; Kaitalo 1990). Within the group of the deafblind there are individuals with *acquired* deafblindness, in which hearing and/or vision problems initially occurred later in life (around 80% of the deafblind population, NUD 1986; 88%, Olesen and Jansbøl 2005) and *congenital* deafblindness, in which the sensory impairments initially occurred in early childhood (about 20%, NUD 1986). The percentages of each group among the deafblind population are fairly similar in all the Nordic countries. Due to varying degrees of hearing impairment, language use varies: approximately 2/3 use spoken language, Finnish or Swedish whilst 1/3 use Finnish Sign Language as their primary means of communication (Kuurosokean kommunikointi 1991). Most persons who are deafblind live alone or with their families. However, whether a person with deafblindness lives alone or with his or her family, independent living

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outside of a community in which there are no other deafblind or deaf members can lead to social isolation and feelings of loneliness. To facilitate daily living inside and outside the home, persons with deafblindness usually require outside contacts and help (e.g., information acquisition, shopping, going to the bank or the post office (Kuurosokeiden elinolot Pohjolassa vuonna 2000)).

Within the group of persons with acquired deafblindness, the largest single cause of deafblindness is Usher syndrome (Lahtinen and Miettinen 1991; Olesen and Jansbøl 2005; Pakarinen 1997). It is inherited and often latent, which means that it can appear suddenly after not being manifested for several generations. Usher syndrome includes persons with varying degrees of hearing impairment (from mild hearing loss to deafness), and the visual disability caused by *retinitis pigmentosa*. This causes narrowing of the visual field, which creates so-called tunnel vision, increases night blindness and weakens contrast sensitivity. The development of a visual or hearing impairment in Usher syndrome is unpredictable. The causes of congenital deafblindness include the mother's prenatal *rubella* (German measles) other diseases, and the consequences of various infections (Kaitalo 1990; Siksi-projekti 2005).

Thus, persons with deafblindness differ in the severity and time of onset of hearing and vision impairments, concurrent limitations, and strengths. Deafblindness often has a particularly strong effect on a person's communication, environmental orientation, and information acquisition (Kaitalo 1990). Deafblindness can also make it difficult for persons to show their special abilities (Hassinen 2004; Möller 1999; Tully 1988; Hassinen 2010). For many deafblind persons the stress of coping with their daily lives and the challenges associated with their communication limitations can lead to physical stress, tension, fear, and anxiety.

Most of the data on the psychological and social aspects of deafblindness derive from rehabilitation settings in the United States (Miner 1995, 2002). Recently, however, a large survey on the effects of deafblindness was done in Scandinavia (Olesen and Jansbøl 2005). This study indicated that people with hearing and vision problems are often underidentified and may lack proper diagnoses. Making diagnosis more difficult, some deafblind persons try to hide their problems. According to Miner (1995, 2002), the most common psychological problems with young persons who are deafblind are adverse reactions from peers at school, worrying and feelings of sadness associated with visual problems, and communication difficulties with family and friends. During adulthood typical psychological difficulties include anger, depression, fear for the future, lack of hope and pleasure, suicidal thoughts and attempts, anger against those who can see, fear of losing the love and respect of family members, and a feeling of extreme isolation, particularly when friends no longer initiate contact (see also Brennan 1997; Ehrenbåge and Samuelsson 1998). Some persons have also had traumatizing experiences in their lives. There is some data suggesting that deaf children are 2–3 times more likely to be sexually abused than their hearing peers (Kvam 2004).

Data from the psychiatric clinic of the Hospital District of Helsinki and Uusimaa (Hus) in Finland indicate that the behaviour problems of persons who are deafblind do not differ significantly from persons who are deaf only. The most common problems among the deaf were depression, anxiety, personality disorders, substance abuse, schizophrenia, bipolar disorder and psychotic behaviour. Additional diagnoses generally include epilepsy, intellectual disability, developmental disability or dysphasia or other linguistic disorders (Ryynänen and Kostamo 1998).

A study that evaluated the psychiatric symptoms of 213 deaf or deafblind persons using sign language was conducted in Finland between 2002 and 2004 (Lindfors 2005). The results indicated that the most common psychological symptoms reported by the respondents were loneliness (19%), depression (17%), and anxiety symptoms (16%). Altogether, psychiatric problems were present in 24% of the respondents. The number is slightly higher than in the average Finnish population (19%). Also the need for help in discussing problems was significantly higher among the respondents (14%) than among the population at large. Respondents were particularly interested in receiving help in dealing with relationships, work, and their psychological problems. These data are similar to those from a Nordic survey (Olesen and Jansbøl 2005), which found that over one-third of the 20 people interviewed reported having used the services of a psychologist in order to cope with the emotional or other difficult reactions related to a crisis.

Although there is overlap in behavioural and emotional problems between persons who are and are not deafblind, it is likely that the causes of these problems are different for the two groups, strengthening the potential benefits of careful psychological assessment and case formulation. It is important to collect more information on the psychological problems that deafblind persons face in order to develop the best treatment strategies. It seems that persons with deafblindness have problems related to their sensory impairments and they experience unpleasant emotional reactions associated with these impairments such as anxiety, communication difficulties, and mood problems associated with adverse and challenging life experiences (Miner 1995, 2002; Olesen and Jansbøl 2005). Because of these multiple problems and individual differences among persons in the problems they face, and differences in causal variables for their problems (e.g., inherited impairments, depression, social isolation, abuse, challenges to learning, etc.), there is a need for an individualized approach to clinical case formulation and treatment.

One case formulation model is Functional Analytic Clinical Case Diagrams (FACCD), (see Haynes and O'Brien 1990; Haynes and O'Brien 2000; Haynes and Williams 2003; Petermann and Müller 2001; Haynes, O'Brien, and Kaholokula 2011). In FACCD, the case formulation (functional analysis) is illustrated with a causal diagram that presents aspects of an individual client that are relevant to explaining and treating the client's behaviour problems and helping the client attain his or her treatment goals. These aspects include the client's behaviour problems and goals, functional relations among behaviour problems, the relative importance of behaviour problems, the strength and form of causal and non-causal relations for behaviour problems, and the modifiability of causal variables. The essential part of FACCD is the functional relations among variables—the functional analyses. The functional analysis and FACCD are most clinically useful in three contexts: (1) with complex clinical cases—especially with clients with multiple problems areas and multiple, interacting causal variables, (2) with cases in which standardized treatment is failing, and (3) in treatment team settings in which treatment goals for a client are discussed. Thus, it could be argued that the deafblind persons and professionals working with deafblind persons may benefit from a functional analysis and the FACCD.

The information depicted in the FACCD can be useful in several ways. It organizes the clinician's clinical judgments relating to a client's behaviour problems and their causes; it encourages a sequential, systematic, and specific clinical case formulation and decision making; it can point to areas where additional assessment

is needed; it facilitates clinical case presentation to other professionals; it presents clinical hypotheses about the client; it encourages research on clinical judgment process; it encourages the use of science-based clinical assessment strategies; it focuses attention on current more than historical causal variables; it reduces the emphasis on formal psychiatric diagnosis, and it can be used to illustrate variables and relations that affect treatment goals.

The functional analysis can be used to supplement or as an alternative to the American Psychiatric Association's DSM-system (APA 2000). The main difference between these approaches is that the functional analysis looks beyond the diagnoses and labelling of behaviour problems and emphasizes functional relations in order to make a client's problems and other behaviour problems understandable—the main goal of the functional analysis is to *explain* behaviour problems and suggest the best treatment focus.

Although diagnosis can be useful in case formulation, there are several limitations when using diagnoses in clinical practice (see review of the role of diagnosis in behavioural assessment in Nelson-Gray and Paulson 2004). A diagnosis is often helpful when communicating information between professionals within the healthcare system. However, because a particular diagnosis can reflect many different combinations of symptoms, a diagnosis is often insufficient for understanding and effectively treating a client's behaviour problems. The descriptions of a disorder, such as deafblindness, give little information on specific behaviours of a particular client, the unique aspects of a client's situation, his or her goals and strengths, or the variables that may be affecting them. When developing an individualized psychological intervention such as cognitive behavioural approaches, more specific information on specific problems, causal variables, and their functional relations is necessary. A diagnosis provides no information about how problematic behaviours vary across situations and contexts, and how different psychological problems and external events may interact with each other. Further, a diagnosis may not address psychological problems that can have significant impact on the quality of life of a deafblind person.

We were interested in understanding the psychological problems faced by many deafblind persons. The purpose of this article was to describe deafblind persons who have multiple psychological problems and apply the functional analysis and FACCD to better understand these problems. We give examples of how a functional analysis model and FACCD can aid the rehabilitation and treatment of persons who are deafblind.

## **Method**

### ***Procedure***

The cases were collected during behavioural assessment training provided for professionals working with persons who are deafblind. First, the professionals were trained to use the functional analysis and FACCD and instructed in how to apply the model for their own client cases. The data presented in this paper are based on the trainees' cases.

Behavioural assessment training was provided to 69 professionals (staff members, rehabilitation workers, nurses, psychologists, social workers, teachers, etc.) working with persons who were deafblind or deaf. The training was done during three



two-day workshops and using home assignments. During the training, client case examples were analyzed using the functional analysis model of case formulation. The staff members were instructed to bring information of one client case—with multiple problems—to the workshop. They were also instructed to gather information about their client from different sources, e.g., documents on the client's history, and current life situation, possible interview with the client about the current problems, observation of the client's behaviour, and case conferences dealing with the client. The staff members did not use any validated instruments for assessing psychological symptoms because that was not part of their profession. The first workshop included lectures on general issues of functional analysis and neurocognitive issues related to deafblindness. Between workshops the trainees were instructed to begin applying functional analysis with their clients. Workshop two dealt with physical and psychological issues in well-being. The trainees were instructed to finish the behavioural analysis cases after workshop 2. Workshop 3 concentrated on short and long term interventions. The functional analysis model learned during the workshop was as follows: (1) background information about the client is collected; (2) the problems and strengths of the client are listed; (3) problems are classified according to different forms of behaviour (i.e., response modes such as physiological reactions, emotional reactions, thoughts and verbal communication, acting and doing); (4) the case formulation is illustrated with a causal diagram that presents behaviour problems and functional relations among behaviour problems, the relative importance of behaviour problems, the strength and form of causal and non-causal relations for behaviour problems, and the modifiability of causal variables; (5) conclusions are made on the basis of the analysis, and treatment plans are made on how to best help the client. The different symbols used in the FACCD are described later in this paper in the Appendix. Briefly, the rectangle indicates a behaviour problem; a circle indicates a causal variable (an antecedent variable, consequence, moderator variable), and a diamond indicates a historical causal variable that cannot be modified. These symbols illustrate a client's problem areas as well as contextual and situational variables, moderator variables, and contingencies that affect them. The functional relations between the variables are depicted by arrows and lines that indicate the strength, direction, and form of functional relation. (Haynes and O'Brien 2000; Haynes, O'Brien, and Kaholokula 2011).

The overall goal of the functional analysis and the FACCD is to estimate the relative *magnitude of effect* of each causal variable. That is, the degree to which a treatment focus on the causal variable would be expected to result in benefits for the client. Although effects can be calculated mathematically, this estimate can often be done through visual inspection of the FACCD. Clinical judgments from the FACCD can be more precise by adding judgments of the importance of a problem by using numbers or, as in this model, graphic illustration. The strength of the connection between variables can be estimated by using different line thicknesses. (Haynes, O'Brien and Kaholokula 2011).

### ***Deafblind Subjects***

There were altogether 38 deafblind or deaf clients analyzed using the model by the trainees who attended the training. Some of the case formulations were made by one staff member whilst others were constructed by pairs or small groups of participants. Of those 38 analyses, 26 complete analyses were chosen for this article. These cases

selected included all the steps of the model as presented above (Haynes, O'Brien, and Kaholokula 2011 actually propose 21 steps in the functional analysis of clients). Twelve clients were omitted from this article as their case formulations were incomplete because of limited time during the workshops.

The 26 complete cases were divided into three groups according to hearing and vision impairment and time of onset. The number of men and women in each group was as follows: Group 1. Deafblind clients with acquired deafblindness: 4 men, 10 women (14); Group 2. Congenitally deafblind clients: 4 men, 3 women (7); Group 3. Deaf clients with or without additional impairments, no vision problems: 4 men, 1 woman (5). Because the main interest was on groups of individuals with deafblindness, groups 1 and 2 (persons with acquired deafblindness and congenitally deafblind persons) were chosen for more thorough data analysis.

The two groups of persons with acquired and congenital deafblindness were defined as follows. First, the group of clients with acquired deafblindness ( $n = 14$ ) consisted of those persons who had become or were becoming deafblind later in their lives. Within this group, persons could have (a) been born visually impaired and their hearing weakened later; (b) been born with hearing impairments and their vision weakened later, or (c) become deafblind as adults or as older adults. The group of congenitally deafblind clients ( $n = 7$ ) included persons who had been born with hearing and vision impairment. The mean age of the persons in the group with acquired deafblindness was 54.8 years (range 14 years to 86 years) and the group of congenitally deafblind persons was 29.3 (range 16 years to 50 years). There were more females ( $n = 10$ ) than males ( $n = 4$ ) in the first group, and the number of females ( $n = 3$ ) and males ( $n = 4$ ) was nearly equal in the second group. In the acquired deafblindness group half of the subjects used speech and half Finnish Sign Language as a primary communication method. Of sign language users approximately half used signing in free space and half used tactile signing. In the congenitally deafblind group most of the subjects had multiple means of communication based on sign language, gestures, objects, and pictures. In the acquired deafblindness group 12 subjects were unmarried. In the congenitally deafblind group all subjects were single. In both of the groups most subjects lived in residential housing facilities or with family members (the acquired deafblindness group  $n = 9$  and the congenitally deafblind group  $n = 7$ ). Five subjects with acquired deafblindness lived alone.

## Results

Consistent with the results of past research, and on the basis of assessments done by the staff members, the most common difficulties within the both groups were problems with communication. Both groups reported an average of about seven psychological problems per person (ranging from 3 to 11).

The main problems of the subjects with acquired deafblindness were communication difficulties, traumatic or distressing experiences (e.g., mocking at school, accidents in traffic due to limited hearing and vision, sexual harassment), mistrust and suspiciousness (e.g., somebody has been in a person's home and stolen money), sleeping problems (e.g., difficulties falling to sleep), loneliness, and social isolation. These problems were reported by more than 50% of the deafblind persons. In addition to the main problems, the subjects with acquired deafblindness reported having problems such as negative thinking, fear of losing control in life, problems

with nutrition (e.g., eating too few meals), socially unacceptable behaviour (e.g., ringing the doorbell of neighbours during the night), frequent changing of medication, eating problems (e.g., binge-eating), passiveness, shyness, and alcohol abuse.

Within the group of congenitally deafblind persons, the most common problems were communication problems, aggressive or self-injurious behaviours (e.g., hitting her/himself by banging her/his head on the wall, hitting and biting other persons), impatience, and restlessness (e.g., leaves table before finishing eating, does not wait for staff to help with putting clothes on). Also over 70% of these subjects had rapid mood changes, medical problems (e.g., epilepsy, congenital heart failures), and anxiety and fear problems (e.g., towards new staff members and new situations). Additional problems reported were as follows: life was too structured and restricted (because frequent changes in everyday life cause, for example, anxiety), problems associated with puberty and sexuality, problems associated with nutrition and health, constant changes in medication or neurological problems.

Since the literature (e.g., Kvam 2004) has suggested that the incidence of traumatic life experiences could be high among deafblind persons, we did additional analysis of these problems in our sample. Among those subjects with acquired deafblindness, 9 subjects out of 14 (64%) reported the traumatic life experiences mentioned above. Many of those having traumatic experiences reported sleeping difficulties, aggressive behaviour, and severe mental health problems (including psychotic behaviour, delusions, and personality disorders). Only one person with congenital deafblindness was reported as having had a traumatic life experience (14%). More specific analysis of trauma experiences would be needed in order to make appropriate treatment plans but because of the design of the study we were not able to collect these data. An important finding, with implications for individualized case formulations and treatment, is that there were important differences among persons in the types of problems experienced.

### **Functional Analysis and FACCD**

In order to illustrate both the complexity of the individual cases and the benefits of the functional analysis model two case examples are presented. These case examples were done during the workshops. The background information has been modified in order to protect the identity of the subjects.

#### ***Case 1***

##### ***Background***

The client was a deaf man of about 50 years with Usher Syndrome. He was born deaf and had gradually been losing sight so that he had only a narrow visual field left. His native tongue was Finnish Sign Language although Finnish had been the language of his childhood family. This and oral method at school had effected his mastering of sign language. The client used an old-fashioned type of sign language which caused some communication problems. Young staff members and interpreters in particular had difficulties understanding his signing. He used little Finnish, for example, and he fingerspelled words. He had stopped work because of his vision deterioration and was on a pension. He lived at a residential centre which provided housing facilities

and communication through sign language. He received help for his house chores and other domestic chores when needed. His main problems were difficulties in communication because of language deficits, lack of skill in managing his money and a severe drinking problem. Approximately twice a month, he had a heavy drinking period which would last for 4–5 days and which sometimes caused vision and sensory delusions with consequent anxiety. He also had difficulties with social relationships because of violent behaviour and bothering people with asking for money during drinking periods. This led to fear and avoidance among some of the other residents as well as frequent conflicts between him and other residents. Figure 1 shows the case formulation (FACCD) made by the staff members. It indicated the strong association between language deficits and drinking problems. Drinking, on the other hand, influenced several other problems like violent behaviour. Conversely, his deficits in communication and fear of losing his sight affected his drinking, so drinking would be used to reduce this anxiety and feelings of distress.

The case formulation suggested that there was a behavioural chain leading to violent behaviours and problems in relationships. As illustrated in Figure 1, deafblindness due to Usher Syndrome leads to a fear of losing vision (this fear probably includes specific thoughts and emotional reactions that we were not able to describe in this study). The fear of losing vision causes anxiety, and anxiety increases the probability of excessive drinking of alcohol. Excessive drinking increases the probability for violent behaviour (e.g., pushing people). Violence is associated with problems in relationships. Additionally, relationship problems are affected by problems or limitation of using sign language.

The functional analysis illustrated by the FACCD suggests several treatment possibilities. The treatment could address fear of losing vision and the associated anxiety. It might be possible to help him reduce his anxiety by discussing his fear and the possible consequences of the loss. In order to deal with these problems more information of specific thoughts and emotional reactions associated with the fear

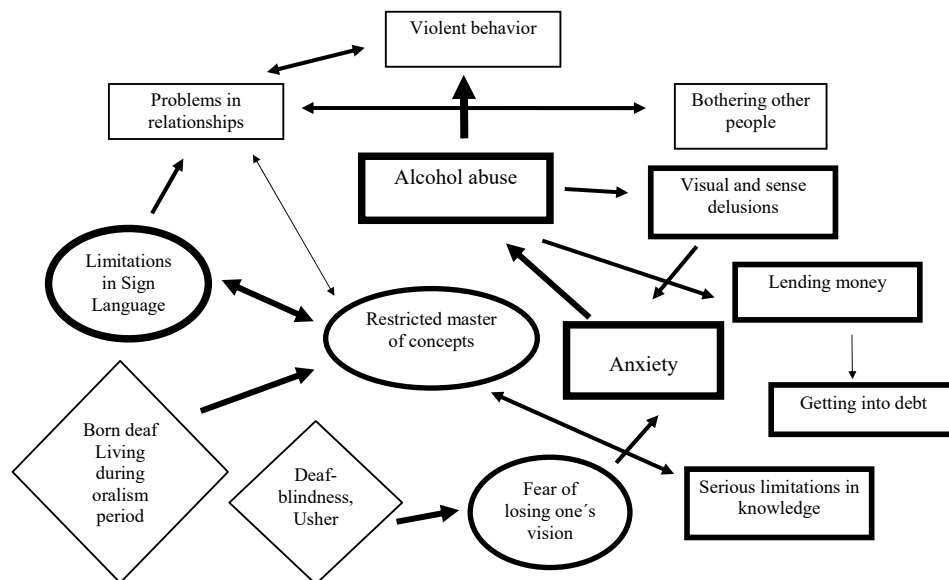


Figure 1.

would be helpful. Thus, one of the benefits of a functional analysis and FACCD is that they can help the clinician understand where additional assessment data would be helpful. For example, when using exposure procedures (Rothbaum, Foa, and Hembree 2007), it would be helpful for the therapist to know what contextual variables (e.g., situations) trigger specific emotional reactions, and what thoughts are associated with these reactions. Further, acceptance strategies (Eifert and Forsyth 2005) could be used for dealing with the anxiety. Thus, we could teach the client to be willing to have his own experiences related to deafblindness, fear of losing vision, and anxiety (Hayes and Smith 2005). Acceptance means opening up and making room for painful feelings, sensations, and emotions (Harris 2009). Specific knowledge of these emotions and knowledge of avoidance behaviours associated with them would be helpful in treatment. Another alternative would be to consider the role of staff members' responses to the client. Are they appropriate to his behaviours? Is it possible that the arrangement at the institution might contribute to the problems (e.g., activities, staff training). Thus, the FACCD points out both for the client and for the staff possible critical behaviours to be analyzed more closely.

According to the FACCD made by the staff members, there could be additional targets for the treatment. The staff members could also address alcohol abuse, violent behaviours, and communication problems (problems in using sign language). Violent behaviours are probably a function of communication problems, social skills deficits, alcohol use, etc. Several options exist for dealing with these difficulties. For example, staff members could increase self-knowledge of the client by describing more closely in co-operation with the client each of these problems (e.g., what usually happens in these situations, and what the triggers are for his behaviour). Also it might be helpful to teach him better communication strategies so that the client could learn better ways to communicate with others, to communicate his wishes, to have more social contact and express himself, and increase enjoyable activities. Training the client's social skills would help reduce violent behaviours (Bourne 2005). He also needs other ways to reduce anxiety other than drinking, such as meditation, relaxation, physical activity. Furthermore, motivation for making changes with these problematic behaviours could be increased by value analyses (Dahl et al. 2009). Description of values could be used to help the client select direction for his life that is congruent with what is deeply important to him. This may help to establish goals supporting movement in a direction that increases the quality of life of the client. Thus, by helping the client define what matters to him, it may provide a context in which he may be more willing to experience difficult thoughts and feelings and anxiety associated with excessive drinking, violent acts, and communication difficulties. This may increase the possibility that the client is more willing to make changes with the problems pointed out by the visual diagram. These examples illustrate how the case formulation with persons who are deafblind can help staff members or a therapist understand factors that are helpful in making treatment decisions.

## ***Case 2***

### ***Background***

The client was a 20 year-old woman born deaf and with slight visual impairment. She had also been diagnosed as having a learning disability and mild mental retardation.

She communicated using signs, gestures, pictures, and objects. She lived in a residential housing facility that offered sign language services. She worked every day at the sheltered work facilities with a personal assistant. In her every day practical activities she was relatively independent.

According to the members of staff, her main problems were anxiety and mood changes. Anxiety affected many aspects of her daily living. It was suggested by the staff that her anxiety was connected in some way to sexuality (such as physiological reactions in her body). This hypotheses made by the staff is problematic. "Sexuality" would probably not account for a variation in feelings of anxiety. "Sexuality" is a trait and anxiety level usually varies across hours and days. Thus, here the FACCD points out that more specific analysis is needed in order to understand this relationship. However, because the client was using only a limited amount of signs and communicated mainly via pictures, gestures and objects, the staff was not able to specify thoughts and feelings connected to these physiological reactions. It seemed that anxiety had increased during puberty. The staff had been hypothesizing that one possible cause for anxiety could be some neurological impairment. (It is important to notice that these kinds of hypotheses are not useful causal analysis. They would lead the staff to conclude that there was nothing they could do to help her because it was neurological.) They described that she had periods when her actions stopped without any clear reason. During this kind of "attack" she seemed to have an epileptic type of seizure and she seemed to "be absent", but there was no formal diagnosis of epilepsy. Before or during the attack she seemed to hold her breath, her face turned red and her body was tense. The staff pointed out that "the attacks" could also produce or increase anxiety. However, they did not have enough information about the situations like, for example, where and when the attacks were most likely to occur. Most behaviour problems are not random. Identifying situations in which these problems occur can help identify factors that trigger or maintain them.

The staff also reported sleeping difficulties and problems in social situations, like refusing to be in contact with some staff members. She seemed to be emotionally unstable (e.g., she reacted instantly to changes in her environment) and it was thought that this was related to her difficulties in handling anxious moods. It was also hypothesized that anxiety increased when she was experiencing difficulties communicating, but there was no clear evidence that the anxiety level was different between situations where she was using sign communication or not. Still, difficulties could arise because of, for example, different reactions to men versus women, older versus younger people or staff versus other patients. The functional analysis can indicate where additional information is needed.

Figure 2 shows the case formulation made by the members of staff. The formulation points out several rather complicated interactions between different problems and possible causal variables. This case description is an example of the advantages of a visual functional case formulation. It is easier to summarize complicated information if it is presented diagrammatically. The case formulation illustrated in Figure 2 suggests that there were several variables affecting anxiety. There were sleeping difficulties, possible neurological problems or impairments (shown as a diamond shape), constant changes in medication, experiencing her life to be too structured or her environment too limited, and experiencing demands that were too low in relation to her functional capacity (note that it was not clear how this would be mediated). The anxiety produced was associated with compulsive behaviours (e.g., constantly moving her legs while sitting), self-harming behaviours

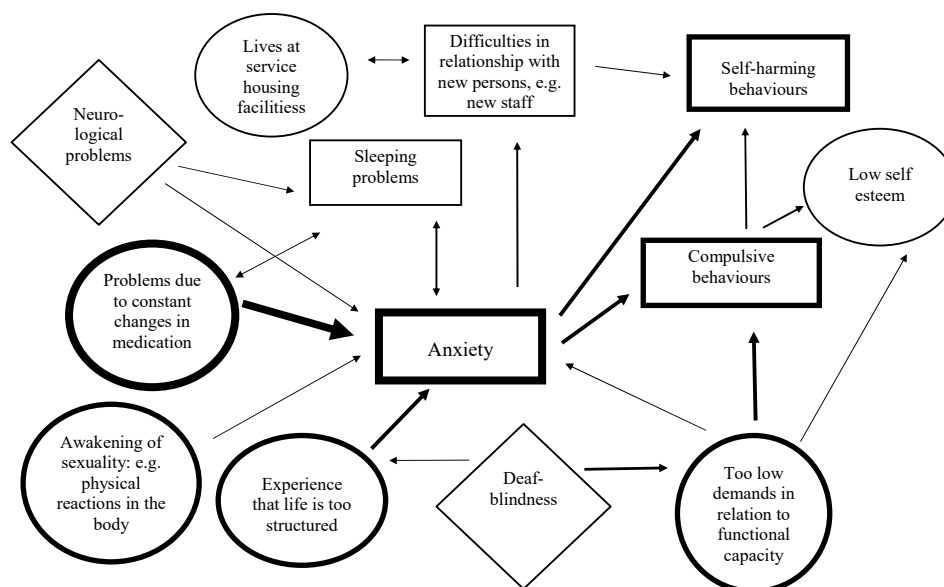


Figure 2.

(e.g., banging her head against a wall), sleeping problems, and withdrawal in social settings, especially when she had to meet new people. The analysis pointed out that self-harming and other compulsive behaviours were possibly used to reduce anxiety. Compulsive behaviours were associated with low self-esteem that was at least partly caused by demands being too low and a lack of actions related to limited demands. Difficulties experienced in social situations kept her living at home and limited her learning new social skills.

The Functional Analytic Clinical Case Diagram suggests that by reducing her levels of anxiety or the number of anxiety episodes she experienced could lead to a reduction in several other problems. In other words, the functional analysis pointed out the possibility that by targeting the treatment to deal with one central problem, several other problems could be altered. The analysis indicated that the client made attempts to control or alter anxiety by harming herself and through compulsive behaviours. On the basis of this, it could be hypothesized that she probably also used other behaviours to regulate or control anxiety. Thus, the case formulation indicated that there might be other problematic behaviours not yet named by the staff member (or by the client). One of the main targets for the treatment could be teaching the client to deal with her anxiety in ways that do not have negative consequences for her quality of life. The diagram points out several variables that affect anxiety and which could be used in the treatment. For example, teaching the client to reduce her anxiety levels and teaching her new ways to cope when she feels anxious so that other behaviour problems don't occur may require that the clinician produce (in a controlled manner) anxiety during the sessions. Thus, the functional relationships presented in the case formulation may help the staff members anticipate the reactions and behaviours of a client. This might be especially useful with clients who have limited communication skills. Furthermore, on the bases of the case formulation, the staff members or the therapist would know that the client may need new skills to deal with her anxiety (for example, relaxation or acceptance skills).

These few examples show how the FACCD could be applied in rehabilitation or in treatment. Several other possibilities exist for applying the diagram in the treatment of case number 2. One of the advantages of the case formulation model is that it usually points out several treatment alternatives.

#### **Feedback from the staff members regarding clinical utility of the functional analysis and FACCD**

According to the members of staff who took part in the training of functional analysis and the FACCD the use of the case formulation model was helpful but also challenging. Participants reported that the FACCD helps staff to present the information about a client in a compact form, and it helps them to more clearly understand clients' current problems and factors affecting them. It was, however, pointed out that it was challenging to estimate the types of functional relations and their strength between different variables. According to the participants, the diagram also helped them to observe their own impact on their client's problems. It was also mentioned that the case formulation helps the clients to understand their own situation and to more specifically describe the goals and rationale for the rehabilitation efforts. One of the disadvantages stated was that the FACCD takes a lot of time to establish and cannot therefore be done with all clients.

#### **Discussion**

The purpose of this article was to illustrate the application of functional analysis and Functional Analytic Clinical Case Diagrams (FACCD) (Haynes, O'Brien, and Kaholokula 2011) to describe possible psychological problems among deafblind persons having multiple problems, and to give examples of how a functional analysis approach to case formulation and FACCDs could assist in the rehabilitation and treatment of persons who are deafblind. The assessments and functional analyses made by the staff members indicated that some deafblind persons may have a relatively large number of psychological problems significantly affecting their quality of life and that the array of problems and their causal relations differed among deafblind persons. The group of deafblind persons analyzed in this study reported 3–11 psychological problems in addition to hearing and vision difficulties. These problems, along with their communication problems, may require more precise and individualized analyses and treatment. The interaction between different problems can be complex.

As to be expected, communication (both receptive and expressive communication) problems were very common among persons who had been born with hearing and vision impairment and among persons who had acquired deafblindness as adults. Earlier studies by Miner (1995, 2002) and Olesen and Jansbøl (2005) support this observation. They noticed that the most common psychological problems with young deafblind people seem to be experiences of mocking at school, worrying and feelings of sorrow associated with visual problems, and communication difficulties with family and friends. The observation that almost all subjects in this study reported communication difficulties is not surprising. However, the fact that communication difficulties were stated as a problem by so many subjects points out that communication difficulties, and especially their effects on psychological wellbeing, should not be underestimated. This is also challenging to the assessment



and treatment process as well as a difficult challenge for counsellors. The fact that communication problems were reported so often raises the possibility that there are communication difficulties between the staff members and deafblind clients and that intervention at the level of the institution may be warranted. This points out the importance of communication training as well as the possible need for supervision. It is also important to keep in mind that communication difficulties can also lead to other psychological problems of the clients. Thus, there is probably an interaction between the client's psychological problems and communication difficulties. The FACCD or other case formulation models can be used to describe and highlight individual interactions between communication difficulties and other psychological problems.

In addition to communication difficulties several other psychological problems were reported by the deafblind persons included in this study. Most of the subjects who had acquired deafblindness as adults reported traumatic experiences, mistrust and suspiciousness, sleeping problems, and loneliness and isolation. In addition to these commonly reported problems several other psychological difficulties were observed such as negative thinking, fear of losing control in life, problems with nutrition, socially unacceptable behaviours, eating problems, passiveness, shyness, and alcohol abuse. These observations are in accordance to earlier studies (Brennan 1997; Ehrenbåge and Samuelsson 1998; Miner 1995, 2002) reporting that typical psychological difficulties among deafblind persons have included, for example, anger, depression, fear for the future, lack of hope and pleasure, suicidal thoughts and attempts, fear for losing the love and respect of family members, and a feeling of isolation. Within the group who had born with deafblindness, the most common problems in addition to communication difficulties were aggressive behaviours, impatience, and restlessness. Furthermore, the majority of these subjects reported rapid mood changes, medical problems, and anxiety and fear problems.

It is important to note that the problems described above were collected from a selective group of clients who were chosen because the staff members expected them to have multiple problems. Thus, the data presented in the study do not suggest that all persons with visual and hearing impairments have psychological problems. This paper only points out the fact that clinicians should be aware that deafblind persons may have other difficulties and indicates the types of problems a deafblind person may experience. It is also important to remember that psychological problems vary from individual to individual. This can be seen in the cases presented in this paper. The fact that deafblind persons may have several psychological problems in addition to communication difficulties, and the fact that the combination and the consequences of the problems are always very individual gives many challenges to the staff members.

The case formulation model and FACCD presented here can be a useful tool which staff members could use in order to understand persons with visual and hearing difficulties especially when there are indications of multiple psychological problems or a client has not been responsive to treatment. The case formulation model can be used and applied by professionals other than psychologists or psychiatrists. One of the great advantages of the FACCD model is that it may give very useful hypotheses of complex interactions between different problems and variables that may not otherwise be noticed. The model makes it easier to see the complexity and diversity of a client's situation. Without the model it would be difficult to see the interaction between variables that are crucial for change. Therefore

the FACCD model can be a useful tool in case conferences. Although it is time-consuming in the beginning, it can ultimately be time-efficient. Further, it is possible that a broader formulation may result when a group of clinicians interact with the client in different ways and in different contexts, and collect different data (see, for example, Horowitz et al. 1989).

The visual case model formulation can also help clients describe and understand their present life situation. If the client is not able to see, the staff members can go through the case diagram verbally. It is possible that case formulation increases clients' self-knowledge. It may even change the concept of self. When case formulation is done in close co-operation with the client, it may give distance to her/his situation. That is to say, the client is viewing her/his situation from another perspective. In fact, it has been suggested that this phenomena, called also "the observing self", is one of the key processes in psychotherapy (Hayes, Strosahl, and Wilson 1999). Furthermore, case formulation may function as a motivational tool in counselling and in the treatment. Since the model is usually done in close co-operation with the client, the client is automatically involved in the counselling or in the treatment process from the beginning of the treatment. To make a relevant case formulation, good assessment is crucially important. However, staff members are not usually trained to use formalized behavioural observations, staff-rating forms, and structured interviews. Training staff members to use these assessment tools may increase the accuracy of the case formulations models.

The model helps also to specify treatment goals, and possibly the order in which the interventions methods will be used. The case formation model can also be used as a tool for assessing intervention effects. The intervention may include functional analysis, psycho-education, communication and social skills training, exposure procedures, behavioural activation, body awareness training, value work (including individual motivation assessment), acceptance, and mindfulness exercises (see, for example, Glickman 2009; Hayes, Strosahl, and Wilson 1999). The staff members can go back to the case formulation model during the treatment process in order to evaluate whether there are changes in the model done at the beginning of the treatment. Re-evaluation of the model is crucial, because the model is based mostly on a hypothesis made on the basis of limited information, and some of the hypotheses might be wrong. In fact, case formulation and intervention are closely connected. Intervention is needed in order to verify the hypotheses.

The validity of the clinical inferences that are made on the bases of the FACCD depends on the validity of the assessment data upon which it is based. It must be remembered that the case formulation model describes hypotheses on the basis of available data. Since in clinical practice the data are often limited or missing, any hypothesis made during the assessment process may be too limited or even wrong. Ideally data should be acquired through multiple methods and sources. The validity of the FACCD is tested via the effects of the treatment based on it. It is important to monitor the effects of the treatment and frequently evaluate and refine the pretreatment model. The model made at the beginning of the treatment may be misleading. Thus, it is important to evaluate and to follow whether the treatment has those effects as expected. If expected changes in the behaviour problems do not occur, some elements of the case formulation are invalid and require modification. Important causal variables may have been missed, there may be moderator variables operating that were not identified, or the importance of, or relations among, behaviour problems, or the strength of relations may have been misestimated.

The clinician should remember, and communicate to others, that functional analysis and the Functional Analytic Clinical Case Diagram are only a summary of the clinician's clinical judgments—or clinicians if there is more than one FACCD—at the time the assessment was conducted and in that assessment context. The elements of a Functional Analytic Clinical Case Diagram are likely to change over time, differ across contexts, and reflect measurement errors and clinical judgment errors.

### Acknowledgements

This study was part of a project called “Psycho-social support for Deafblind People”. The project was supported by the Finnish Slot Machine Association and conducted by the Honkalampi Foundation, the Service Foundation for the Deaf, and the Finnish Association of the Deafblind.

### Note

1. For more information, please see [www.kuurosokeat.fi](http://www.kuurosokeat.fi).

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Appendix

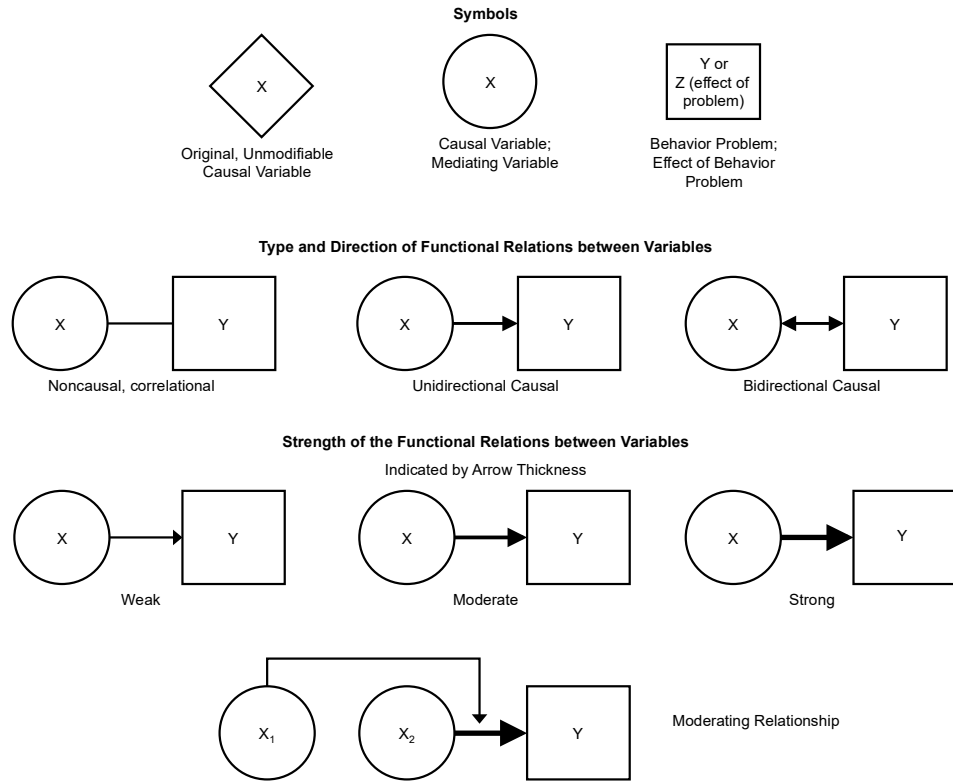


Figure 3.



### III

## **A CASE FORMULATION: PSYCHOLOGICAL ASSESSMENT AND TREATMENT OF A PERSON WITH A PRADER-WILLI SYNDROME AND HEARING AND VISUAL DIFFICULTIES**

by

Hassinen, L., Lappalainen, R., & Timonen, T. 2012

International Journal of Mental Health and Deafness, 2(1)

Uudelleenjulkaistu ESMHD:n luvalla.

CASE REPORT

## A case formulation: Psychological assessment and treatment of a person with a Prader-Willi syndrome and hearing and visual difficulties

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### ABSTRACT

Psychological treatment of a person with multiple difficulties due to syndromes or disabilities and possible additional diseases can be challenging because of the complexity of the problems. This case example presents a behavioural assessment and treatment of a client having Prader-Willi syndrome, hearing and vision difficulties, mild learning disability, diabetes, depression, chronic pain problem, and overweight problem. The case formulation showed that mood problems among multi problem clients are difficult to understand because of the complexity of the history and present problems. Clinical case formulation model such as the Functional Analytic Clinical Case Diagram can be a useful tool when selecting targets for the treatment, and when making other treatment decisions. This paper presents a long-term treatment of a multi-problem client. The treatment incorporated communication skills training, functional analysis, body awareness training and contextual principles and techniques. This case example shows that although there is no "cure" for some chronic and inherited disorders, psychological interventions can significantly increase wellbeing and quality of life of these clients. Thus, cognitive behavioural assessment and intervention procedures should be applied more in order to increase the quality of life of minority groups.

### Introduction

### KEYWORDS

Prader-Willi syndrome,  
deafblindness, behaviour  
analysis, cognitive  
behaviour therapy

There are approximately 150 persons who have Prader-Willi syndrome (PWS) in Finland.<sup>1</sup> Prader-Willi syndrome is a rare genetic disorder in which seven genes (or some subset thereof) on chromosome 15 are deleted or unexpressed on the paternal chromosome. Prader-Willi syndrome is traditionally characterized by ambiguous genitals, short stature, characteristic facial appearance, small hands and feet, abnormally increased appetite and obesity, diabetes, sleeping problems, behavioural problems (eg temper tantrums and compulsive traits), decreased functional activity of the gonads and mild mental retardation. Gross motor and language development are delayed.<sup>2-5</sup>

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Most people with Prader-Willi are mildly mentally retarded the average IQ being around 70 or

slightly lower. Some people have recorded IQs of 85 or above, while a minority have severe learning

difficulties. However, studies made by Cassidy<sup>6</sup> and Curfs & Fryns<sup>7</sup> suggest that 50-65% of persons with PSW fall within the mild/borderline/low average intellectual range (IQ more than 70). Individuals may sometimes find it difficult to perform at their IQ level, as emotional and social skills are often less developed. Regardless of measured IQ, most people with PWS have multiple severe learning disabilities and poor academic performance.<sup>3,8</sup> It has also been suggested that there is an association between PWS and comorbid psychiatric illness. In a recent study 63 out of one hundred and two individuals were screened positively on psychopathology. This included bipolar disorder with psychotic symptoms, psychotic illness, depressive illness with psychotic symptoms and depressive illness without psychotic symptoms.<sup>9</sup>

People with PWS are individual in their growth pattern, and there is no set way in which they all develop. A minority start to develop sexually at a young age, but in the majority, puberty is delayed until the late teens. Prader-Willi syndrome is also frequently associated with an extreme and insatiable appetite, often resulting in morbid obesity. Behavioural and eating problems may become more challenging during the teens and early twenties. As adults, people with PWS have varying abilities in attaining independence, although all will need some form of support or monitoring to help with controlling their food intake, and thus their weight.<sup>10</sup> Despite the fact that many individuals have the intellectual and physical ability to work, they are usually ill-equipped on an emotional and social level to deal with the stresses and demands of the ordinary workplace.<sup>11</sup> However, they can make a positive contribution to society in many ways and may be involved in voluntary work, craft work, or have a part-time job. Many people live with their families, but an increasing number are living in residential homes, or being supported to live in the community. In the past, life expectancy was short because of health problems associated with massive obesity, but nowadays life expectancy is increasing because of better dietary management or mindfulness-based health wellness programs

and better understanding of the problems associated with Prader-Willi syndrome.<sup>2,9,10,12</sup>

Apart from various hormone treatments and some surgical intervention (eg. to bring down undescended testes), there is no "cure" for Prader-Willi syndrome.<sup>2,4,5,13</sup> There have been many advances in the fields of genetics, but it will take several years before the genes that are involved in PWS are fully identified. To date no drug treatment has proved to be of lasting help with regard to suppressing appetite. Severe challenging behaviour and some mental health problems have responded relatively successfully to drug treatment, but dosages need to be carefully monitored. Many of the adverse effects of the syndrome can be lessened by good dietary management, exercise programmes, good general health care, and by good general management of behaviour and education. Use of cognitive behavioural approaches seems to be effective psychological treatment for challenging and mental health problems for persons with Prader-Willi syndrome.<sup>10</sup>

Persons with Prader-Willi syndrome may have other severe problems such as hearing and vision difficulties, learning disability or CP. In Finland there are approximately 800 individuals, who have dual sensory handicap- deafblindness.<sup>14</sup> Although the term deafblindness refers to total deafness and blindness most individuals having these impairments still have residual hearing and/or vision. Deafblindness has been shown to have a particular effect on a person's communication, moving and information acquisition.<sup>14</sup> According to the revised Nordic definition<sup>15</sup> hearing and visual disability (dual disability), limits activities of a person and restricts full participation in society to such an extent that it requires specific environmental and service arrangements from society. According to Hassinen<sup>16</sup> and Olesen & Jansbøl<sup>17</sup> it often seems that the operational effects of the disability lead to so many problems in everyday life that the persons are unable to show their abilities. For example, the deafblind person's intellectual or other mental capacity may be under-used, which can manifest itself in demands that persons with dual impairment set for the



environment. It is also common for surrounding people to be unable to truly understand the situation of the deafblind person and offer them the right kind of assistance in the right matters.

The changing visual and hearing disabilities often also require alterations the environment at home, at school and at workplace to better suit the current situation. In particular, lighting, adequate space, colour contrasts, the placement of objects and the tranquillity of the environment need special attention. Difficulties moving in the dark can also hinder independent mobility. As Burfield & Casey<sup>18</sup> and Stone<sup>19</sup> point out hearing disability alone not only hinder communication but also functioning and participation in activities because it restricts social interaction. Persons with a hearing disability may isolate themselves, suffer from low self-esteem and the loss of autonomy and even lose the will to live. In particular, the constant stress in communication becomes chronic and creates anxiety and exhaustion. Listening and lip reading demand a great amount of physical and mental energy. The feeling of loneliness can be very powerful, even when the person is living in a social context. However, the symptoms caused by stress do not necessarily become overwhelming if the person is able to find constructive ways to cope with the hearing disability.

There is no precise information available on the psychological effects or problems of deafblindness. However, it is fair to assume that there are similarities. The psychiatric clinic of the Hospital District of Helsinki and Uusimaa (Hus) in Finland<sup>20</sup> indicate that diagnoses and behaviour problems of deafblind do not differ from those of the deaf. The most common illnesses among the 44 deaf and deafblind individuals or persons with severe hearing impairment who were treated in the clinic between March 1996 and December 1998 were depression, anxiety, personality disorders, substance abuse, schizophrenia, bipolar disorder and psychotic behaviour. Additional diagnoses generally included epilepsy, intellectual disability, developmental disability or dysphasia or other linguistic disorders. On the other hand, eating disorders were not a major problem among the deaf.

The survey that described the psychic symptoms of Finnish deaf-blind or deaf persons using sign language was conducted between 2002 and 2004 using the following questionnaires<sup>21</sup>: The Well-being Questionnaire, Life Situation Questionnaire<sup>22</sup> (Pokkinen, 2001), The Target Complaint Method<sup>23</sup> (Battle, 1996), and the GHQ-2 (General Health Questionnaire,<sup>24</sup> Goldberg, 1972). About half of those the questionnaires were posted, attended the survey. The data suggested that most common psychological symptoms among the 213 participants were loneliness, depression and anxiety symptoms, which were estimated to be found in one in four respondents. This number is slightly higher than in the average Finnish population not having sensory disabilities. The need for therapeutic help associated with problems was significantly higher among persons who use sign language than among the population in general. Help was especially necessary with relationship, and work-related problems.<sup>21</sup> In a Nordic study<sup>17</sup> over one-third of the 20 people interviewed reported having used the psychological services in order to cope with the emotional or other difficult reactions related to crisis.

Even though the psychological problems of deaf-blind persons do not differ from the problems of persons without sensory disabilities, there are some distinguishing features.<sup>16</sup> Body tension and stress are often linked with deaf-blindness, because sensory disabilities require the person to be more aware of the surroundings. In addition, everyday life can cause fear and anxiety because of not fully being able to be aware of what is happening around you or how to cope with domestic duties, such as cooking, and shopping. Feelings of loneliness, and isolation caused by fear, and anxiety can easily lead to depression. Depression can also be caused by the deterioration of senses, as well as traumatising situations. Hearing and vision problems can cause dangerous 'close calls', for example in traffic, which can increase cautiousness and fear of moving about. Many deaf-blind persons have also been mocked at school or in the workplace because of their disability. This may lead to feelings of failure and

low self-esteem, and thereafter persons start to avoid certain situations.

Due to their psychological problems, some deaf-blind persons may require professional help. The goals for psychotherapy with deaf-blind persons are similar to those for clients who are deaf or hard of hearing. However, there are some special issues that must be taken into consideration.<sup>25</sup> For example efficient communication between a therapist and a deaf-blind client is essential, and the therapist must be able to create a warm, accepting and non-condemning attitude towards the deaf-blind client.

Psychological treatment of a person with multiple difficulties due to syndromes or disabilities and possible additional diseases can be challenging because of the complexity of the problems. Case formulation models might be useful when professionals working with individuals who have multimodal problems try to understand person's situation. One of the case formulation models is the Functional Analytic Clinical Case Diagrams FACCD.<sup>26,27,28</sup>

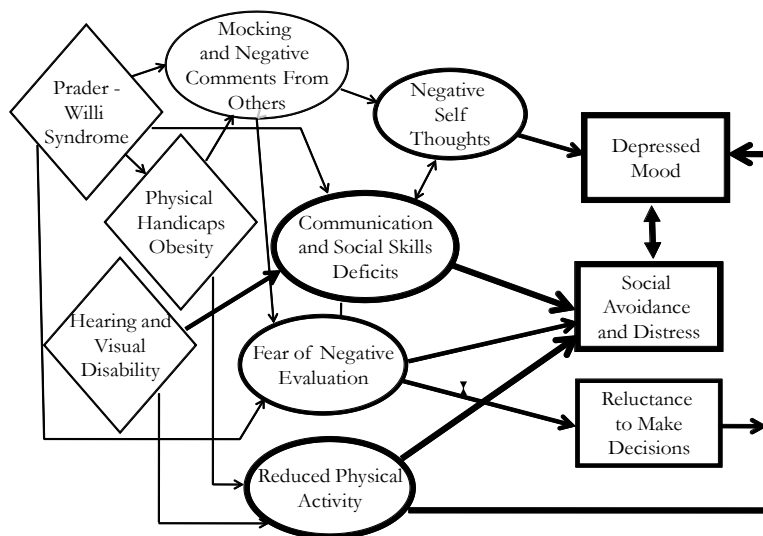
In FACCD the case formulation is illustrated with a vector diagram that presents behaviour problems and goals, functional relations among behaviour problems, the relative importance of behaviour problems, the strength and form of causal and non-causal relations for behaviour problems, and the modifiability of causal variables. The functional analysis and FACCD are most useful in three contexts: (1) with complex clinical cases - especially with clients with multiple problems areas and multiple, interacting causal variables, (2) with cases in which standardized treatment is failing, and (3) in treatment team settings in which treatment goals for a client are discussed. Thus, it could be argued that persons with multiple severe problems and professionals working with these problems may benefit of the FACCD. The aim of this paper was to describe how a behavioural case formulation model, and a psychological intervention based on cognitive behavioural methods could be applied to a client with several syndromes and psychological difficulties. The purpose is to present a case with a very rare

combination of problems including hearing and vision problems, a Prader-Willi syndrome, and some other severe health difficulties. The case is presented with the permission of the client, but some of the background information having less scientific importance has been modified in order to protect identity of the client. Furthermore, the aim of this work is to illustrate how behavioural science can increase the quality of life of the persons suffering with multiple handicaps when other treatments or interventions have a limited or no effect.

## Method

### *Participant*

The client was a 35-year old woman. She had poor vision and hearing, but could function with both senses. She could see in good lighting situations and move independently in familiar places. She used a white cane outside, and when travelling. She could also hear in quiet surroundings and when interacting in one-to-one basis. She had difficulties in noisy environment and group discussions. She lived alone, but had domestic help four times a week. She needed help especially for cleaning, shopping and cooking. She attended activities for deaf-blind people a few times a week. She had experienced several periods of depression during the last ten years, and during the last two years she had had periods when she had experienced psychotic symptoms, and she had been hospitalized twice for few weeks. She had suffered from overweight problem since her childhood, clumsiness as well as difficulties in moving because of pain problems in knees and back. The pain was sometimes very intensive. She was also diagnosed having mild learning disability. These difficulties were linked to Prader-Willi syndrome diagnosed during her adolescence. During the treatment she was diagnosed to have diabetes. She was referred to the treatment due to depression. However, it became evident that Prader-Willi syndrome had more impact on her problems than sensory disabilities. In summary, this case example presents as assessment and treatment of a client having hearing and vision difficulties, Prader-



Note. Physical handicaps due to PWS: short stature, short extremities, frail knees and back

Figure 1. A Functional Analytic Clinical Case Diagram of the client

Willi syndrome, mild learning disability, diabetes, depression, psychotic symptoms, chronic pain problem, and overweight problem. A more precise description of client's problems is presented below.

*Assessment*

The client had been diagnosed having repeated depression periods. Diagnose of depression was done by a licensed psychiatrist before the treatment in order to get financial support for psychotherapy from the Government organized insurance system. At the beginning of the treatment the client's situation was described using Functional Analytic Clinical Case Diagram FACCD<sup>26,27</sup> On the basis of the interview a problem list was made, and a case model was formulated. This case formulation is presented in Figure 1<sup>26</sup>. The problem list was made applying the behaviour analytic, and cognitive behavioural therapy –principles. Thus, the therapist made first a general description of the problems or issues as presented by the client. After the general problem listing, a more precise problem description was made in co-operation with the client. The therapist described with the client what emotional reactions, physiological reactions, thoughts and overt behaviours were associated with the presented problems. Because of the

communication difficulties at the beginning of the treatment, the therapist and the client used approximately six months (10 sessions) to formulate the case model presented in Figure 1.

The case formulation presented in Figure 1 indicated that in addition to depression, the main problem of the client was the experiences associated with mocking and negative comments from others. According to the client

mocking had been going on over several years. In fact, it seemed that mocking and the consequences of mocking had been present most of her life. The client reported that the worst mocking experiences had been at school, but she had experienced mocking also later in life. This seemed to be due to looking and behaving differently than others due to Prader-Willi syndrome (obesity, clumsiness, difficulties with studying due to mild mental retardation). On the basis of the case formulation mocking experiences and problems associated with mocking became the main theme for the treatment. The analysis indicated an association between mocking, negative self-thought, fear of negative evaluation and depressed mood. A closer description of the mild learning disability showed that the client had difficulties to understand some words and terms, she had some deficiencies of common knowledge and communication skills (for example, she had difficulties to have conversations). Because of her obesity she had been called "fatty". She had been left out of groups and group activities, and she had been treated badly by others (for example, her classmates had stolen, hidden and damaged her belongings). The case formulation indicated that because of these earlier experiences the client reported during the treatment experiences of shame because of looking different, feelings and thoughts of being worse than others, and feelings

of anger because not knowing Prader-Willi diagnosis earlier. She reported thoughts such as “Why I was treated so badly? Did I do something wrong? Could I have done something differently?” She reported fear of being mocked when participating in group-activities for deaf-blind people. She reported that she experienced difficulties when having contact with the opposite sex. She described herself of being very shy, she did not know what and how to start and keep a conversation going. She experienced also feelings of disappointment and guilt for not being able to be as active as she would like to be, and fear in new situations and in situations where she had to meet new people.

The case formulation suggested that in addition to these difficulties or experiences, depression was also affected by social avoidance and distress as well as minimal physical activity. The reduced physical activity, on the other hand, was probably associated with or affected by several factors such as sleeping too many hours, medication for pain problems and overweight. It was hypothesized that social avoidance was affected by her communication difficulties and social skills deficits, and these difficulties were associated with her learning disabilities. Thus, the case formulation suggested that there were several factors associated with depression, and these factors interacted with each other.

During the treatment depression was assessed with BDI and overall symptoms with SCL-90. Beck Depression Inventory (BDI) is a widely used self-report questionnaire with 21 items measuring the severity of depression.<sup>29</sup> The BDI has good reliability and validity in both nonclinical and clinical populations. The Symptom Checklist-90 (SCL-90) is a broad self-report checklist of psychopathological symptoms.<sup>30</sup> SCL-90 has been validated for the Finnish population.<sup>31,32</sup> In this study the scores from SCL-90 are reported as General Severity Index (GSI) describing the amount of the symptoms. The GSI index (SCL-90-GSI) is calculated by dividing the client's scores (from 0 none to 4 extreme) by the number of questions (90). The SCL-90 consists of the following primary symptom dimensions:

somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Each of the nine symptoms dimensions comprises 6-13 items. The scores on each dimension are means of the scores of all items of the dimensions. According to Holi<sup>32</sup> SCL-90 is useful in clinical settings, as it performs well as screening instrument and is sensitive to change over time. However, subscales scores should be used as a basis for discussions about a patient's symptoms, not for diagnostics and interpretations.

### **Treatment**

The intensive psychotherapy lasted for three years. The treatment was done every other week (20 sessions per year, altogether about 60 sessions), and each session lasted 90 minutes. The goals for the treatment were formulated after the assessment phase. The main goal of the treatment was to affect the client's mood problem, and to increase her quality of life meaning that she could be able to continue independent living, and avoid treatments in psychiatric hospital, that she could be able to do her household duties as well as leave home and go out shopping, attend activities for deaf-blind persons, take a walk etc. The case formulation in Figure 1 suggested that there were several treatment alternatives. The treatment below describes the alternatives that were used in this case.

#### *Communication and social skills training*

The first year of the treatment concentrated mainly on increasing client's communication skills.<sup>25</sup> The combination of Prader-Willi syndrome, poor vision and hearing, and mocking experiences had probably affected her ways to communicate with other people. For example, she had a tendency to answer questions with yes and no answers, and it was difficult for the therapist to obtain information of her thoughts and emotional reactions. Thus, one of the aims of the treatment was to increase her communication skills in order to have an effect on her mood problems, and it was also hypothesized that better communication skills were needed for successful treatment

process. During the treatment she was practiced to have a dialogue and to speak more than just answer the therapist 's questions.<sup>33</sup> The therapist used verbal prompts such as "Tell more about it. When did this happen? How did you feel?" during the sessions. During the discussions the therapist encouraged the client to tell her needs in a way that she was being understood (e.g. what she wanted home-help people to do and what not). The therapist validated the client's experiences as being a handicap person with certain strengths, such as being able to live independently and moving outside without a guide. Naming ("tacting") feelings (such as shame, guilt and sorrow) was practiced when mocking experiences were discussed. For example, the therapist asked what feeling the client was experiencing when they were discussing of a specific mocking experience or alternatively the therapist suggested a feeling or emotional experience to the client who either verified or denied it. Client's assertiveness skills were increased using both instructions and direct skills training. During the assertive training difficult situations were first identified and described.<sup>34</sup> Then, skills to express own opinions were trained using role plays during which the client was instructed to change her non-verbal communication style, and try out different ways how to express opinions verbally.<sup>33,34</sup> For example, the therapist trained client to express her opinions to home assistants.

#### *Specific functional behaviour analysis*

During the treatment several specific functional analysis or descriptions of behavioural chains (describing 6-7 specific situations) were done in co-operation with the client. Interactions between specific actions, thoughts, emotional and physiological reactions, contextual cues as well as their consequences were presented to the client and they were discussed with her using a white board. The therapist presented behavioural chains on the board on the basis of client's descriptions. The purpose of these descriptions was to help the client to understand the causal relationships associated with her problems and wellbeing (for example, to understand the effect of Prader-Willi syndrome). These descriptions were primary used

to describe her mocking experiences. These descriptions offered also a possibility to deal with emotions and thoughts associated with past mocking experiences and current situations. For example, the therapist asked the client to describe a situation where she had recently experienced emotional reactions similar to earlier mocking experiences. An example of these situations with a behavioural chain is described below. With others, somebody laughed at her □ remembered the past experiences □ anxious □ thoughts: "I am not as good as others" □ withdrew from the conversation. This mocking experience as well as other experiences were analysed several times during the treatment.

#### *Body awareness training and behavioural activation*

The case formulation indicated that the client's physical activity level was associated with physical handicaps due to Prader-Willi syndrome as well as with difficulties of hearing and vision. The client also reported body tension, which she especially experienced during social situations and while travelling. Body tension increased also the likelihood for panic symptoms. Several exercises were done in purpose to affect her body tension. The client practiced deep breathing and taiji, and she was instructed to mindfully observe her body postures while she was doing the exercises.<sup>35</sup> These practises were also used during a break within the 90 minutes sessions, because especially at the beginning of the treatment, the client was too tired to work the whole 90 min session without a break. In order to help her to deal with social situations she was instructed to use deep breathing and attention focusing skills learned during the body awareness training exercises in social situations, for example when travelling by bus. The client and the therapist made also weekly plans (e.g. they went through client's schedule of doing household duties with domestic help and by herself, and made plans attending activities outside home such as deafblind meetings) as well as identified past and coming events causing tension. Problem solving strategies were also used in order to find alternative ways of behaving in situations associated with high tension. She was

also informed how panic symptoms develop and how she could cope with them.<sup>34</sup>

#### *Psychoeducation*

The therapist educated the client about different symptoms associated with depression and traumatizing experiences, such as mocking. Psychoeducation was used in some form during every session. As a consequence of communication training, the client became verbally more active during the treatment, and started to ask more questions when she noticed that she did not understand something.

#### *Value work and acceptance exercises*

Value work<sup>36,37</sup> (Hayes, Strosahl & Wilson, 1999; Hayes & Smith, 2005) indicated that safe home environment and good relations with her childhood family members as well as attending events for deaf-blind people were especially important to the client. During the sessions several experiential exercises and metaphors based on Acceptance and Commitment Therapy were done such as the observer exercise, and the physicalization exercise.<sup>36,37</sup> The aim of these exercises was to increase client's skills to accept her thoughts and emotional reactions associated with her life history and limitations caused by her handicaps and diseases. The purpose of experiential exercises and value work was to increase motivation and willingness to take new actions.

#### *Exposure procedures*

The client was very shy with opposite sex and in intimate relationships. This was due to lack of communication skills, lack of information of intimate relationships, and because of her mocking experiences. During the third year of the treatment the therapist applied exposure procedures that included for example imaginary and in vivo exposure procedures.<sup>38</sup> The exposure was done with pictures during therapy sessions and TV-programmes at home presenting couples hugging or kissing and evaluate her anxiety level between 0 – 100. The anxiety level of the first pictures presented during the session was 80. As

the exposure procedure continued the anxiety level decreased to 0-5. The client was also instructed to observe and notice couples when walking in the city.

#### *Home visits*

The therapist made two home visits. The purpose of the visits was to collect information of the context where the client was living, and to encourage the client to use methods used during the sessions at home. During the second visit the rehabilitation counsellor and home help advisor were present.

### **Results**

On the basis of BDI and SCL-90 the client's psychological symptoms decreased during the treatment. According to the SCL-90 the client reported relatively large number of psychological symptoms before the treatment started (Figure 2). The SCL-90 measured 10 months before the treatment started showed GSI = 1,82. Thus, the client's symptoms were at the same level as reported by a Finnish psychiatric outpatient sample (mean GSI = 1.56, sd = 0.61, n = 249<sup>32</sup>). At the beginning of the treatment the GSI value was 1,22 and 10 months later GSI was 1,16. Figure 2 shows that psychological symptoms had decreased after about one and a half year from the beginning of the treatment. At this point (Figure 2), the level of symptoms was equal to or at lower level as compared to a Finnish community sample (mean GSI = 0.60, sd = 0.44, n = 337<sup>32</sup>). However, at the end of the treatment the client reported very few symptoms (GSI = 0.18, Figure 2). At the beginning the measures of the SCL-90 subscales were at the same or higher level than psychiatric outpatient subscale measures except paranoid ideation and psychoticism (Figure 3). During the treatment client's somatic symptoms decreased less as compared to the other scales (Figure 3). This was probably due to Prader-Willi syndrome. The client was able to complete the BDI questionnaire for the first time after 14 months from the start of the treatment. At this time, the client reported mild depressive symptoms (BDI = 17) according to the BDI

(Figure 4). As we can observe from the figure, at the end of the treatment she reported very few depressive symptoms (BDI = 1). During the follow-up measurement six months after the treatment had ended (about 3 years and 6 months after the treatment started) the client did not report any depressive symptoms (BDI= 0) and she had very few psychological symptoms (SCL/GSI = 0.24). Both measurements showed some increase during the first year of the treatment, when the client's grandfather died.

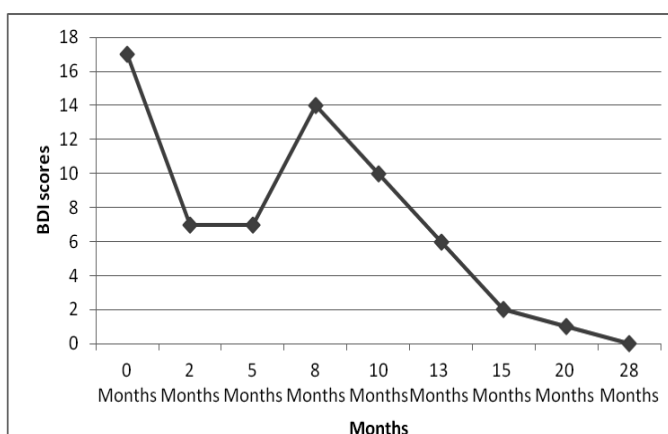


Figure 3. Depression symptoms as measured by BDI scores during the treatment. The client was able to complete the questionnaire for the first time after 14 months from the start of the treatment.

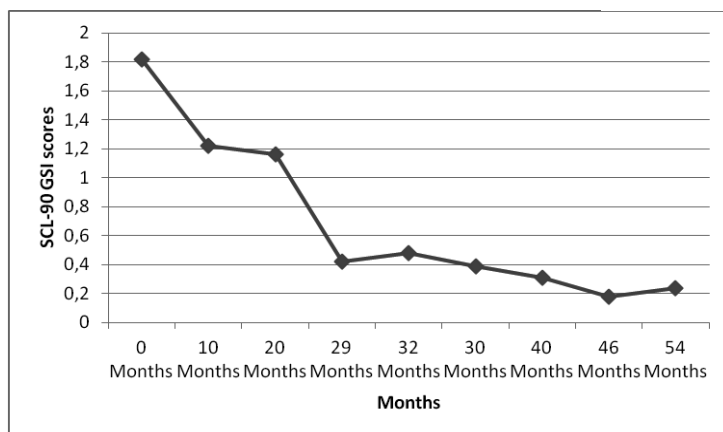


Figure 2. Psychological symptoms as measured by SCL-90, GSI scores during the treatment

After the treatment chronic pain problems were still present but the client reported that the effect of pain was different. According to her the pain was less disturbing and she did not experience the pain as strongly as previously. The client reported improvement in social skills and social relationships. She actively took more initiative in social relationships, for example she contacted deaf-blind friends by phone. She had learned to defend herself and present her opinion, even a different one. She was also satisfied with her increased activity level. For example, she started to attend tailored excursions for deaf-blind persons, and she attended rehabilitation courses for deaf-blind persons at the end of the treatment. The client also paid more attention to her home environment. She was actively involved in home making, for example she bought new furniture.

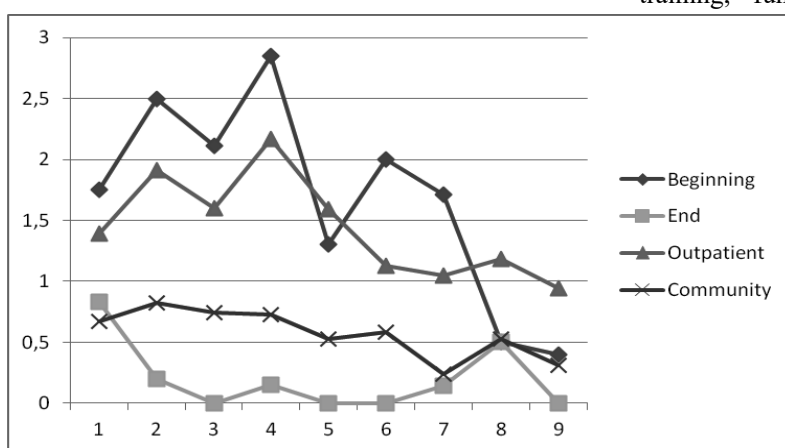
According to the client many people around her commented the positive changes in her behaviour.

As observed by the therapist client's cognitive skills e.g. ability to notice relationships between different variables, making conclusions, comparing events during her life history and ability to see their impact in her present situation increased during the treatment. It was hypothesized that the increase of these skills was mainly a result of repeated use of the situation specific chain analysis.

### Discussions

Cognitive behavioural assessment and intervention procedures can be applied in order to increase the quality of life of minority groups. The aim of this paper was to describe how behavioural case formulation and cognitive behavioural therapy approaches could be applied to a client with multiple problem areas including Prader-Willi syndrome, hearing and vision problems, mild learning disability, depression, diabetes, overweight problems, and traumatic experiences. Psychological problems among multi problem clients having communication difficulties or limitations are challenging to treat because of the complexity of the problems and problem history. This case example shows that a psychological intervention including behavioural case formulation and several cognitive behavioural

procedures can have a positive impact to client's mood, quality of life and psychological wellbeing although the client has several handicaps including an inherited Prader-Willi syndrome (PWS), and poor vision and hearing. Although there is no "cure" for PWS neither for the hearing and vision difficulties, this study shows that psychological interventions can significantly increase wellbeing and quality of life of these clients and possibly of clients having other handicaps. There are a few other case studies indicating that cognitive behavioural methods similar as applied in this study showed positive changes in health habits with Prader-Willi Syndrome.<sup>10</sup>



SCL-90 dimensions: 1 somatization, 2 obsessive-compulsive, 3 interpersonal sensitivity, 4 depression, 5 anxiety, 6 hostility, 7 phobic anxiety, 8 paranoid ideation, 9 psychoticism

**Figure 4. SCL-90 dimensions in the beginning and at the end of the treatment compared to Finnish psychiatric outpatient sample and community sample (Holi 2003)**

This case example showed how the intervention process of a person with communication difficulties and large number of additional problems could proceed. Behavioural case formulation model was applied as a tool in order to understand and summarize client's complex situation. Case formulation is a practical way to summarize the assessment information both for the therapist and for the client. Functional Analytic Clinical Case Diagram (FACCD) used in this study, is especially useful when a client has large number of problems and when they interact with each other. Also, a more specific behavioural functional analysis was integrated to the other

intervention procedures throughout the whole treatment process.

In this case example the target of the treatment at the beginning was to increase client's communication skills. On the bases of this case it could be argued that integrating communication skills training with intervention procedures from the beginning of the treatment could be important for clients with sensory disabilities. Increased communication skills may be crucial for example in order to get knowledge of client's thoughts and emotional reaction associated with specific situations and symptoms. In fact, in this case the treatment incorporated communication skills training, functional analysis, body awareness

training and contextual principles and techniques to help the client both to increase effective communication and to increase skills to manage with psychological symptoms.

On the bases of this case it could be hypothesized that during client's life history the impact of a person's problems may in some cases increase in a cumulative

way. This may be a consequence of not been able to receive psychological treatment for her difficulties early enough. Thus, one personal problem increases probability for another problem.

For example, difficulties and limitations in communication skills and cognitive functioning may increase probability that the person has not possibilities to discuss and share her life experiences with others. "Being different" because of the handicaps may increase probability of negative comments from others. All these experiences may increase avoidance of social situations, and may affect negatively person's ability to use her or his cognitive skills effectively. This view is supported by general knowledge about Prader-Willi syndrome. Individuals with the PSW may sometimes find it difficult to perform at their IQ level, as emotional and social skills are



often less developed.<sup>3</sup> This case example suggests, that psychological interventions can have a positive impact also to cognitive skills as well as communication skills.

The data of the number and the type of psychological problems among persons with sensory disabilities is relatively limited. However, it is possible that the number of problems is slightly higher than in the average population not having sensory disabilities.<sup>21</sup> Furthermore, this case example indicates that persons with multiple disabilities may need support when they experience emotionally challenging events. In this case the client's grandfather's death caused her emotional distress. In a Nordic study<sup>17</sup> over one-third of the 20 people interviewed reported having used the psychological services in order to cope with the emotional or other difficult reactions related to crisis. Possible increased vulnerability for life stressors could be associated with limited social interaction and limited communication skills. As Burfield & Casey<sup>18</sup> and Stone<sup>19</sup> have pointed out, hearing disability alone not only hinder communication but also functioning and participation in activities because it restricts social interaction. Thus, it could be hypothesised that if a person has visual problems and possible other physical restrictions, social avoidance and distress are more likely to occur.<sup>39</sup>

Lack of professionals, who have communication skills needed for working with sensory disabilities or knowledge of sensory and other handicaps as well as knowledge of psychological interventions methods, prevents clients with special needs to get proper psychological interventions. As observed in this study, these interventions can have large impact to these individuals' quality of life, wellbeing and significant skills needed to be adapted to the society. This is also true for individuals having learning disabilities.<sup>10</sup>

We will argue that a combination of a clinical case formulation model and cognitive behavioural intervention methods are useful tools for increasing the quality of life of minority groups with multiple disabilities when no other methods available. We need more knowledge of methods

that are effective for these groups. One of the challenges is that it is very difficult and in some cases impossible to run controlled clinical trials with these populations. We need other methodological approaches.

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## IV

### **ACCEPTANCE AND COMMITMENT THERAPY USING FINNISH SIGN LANGUAGE: TRAINING COUNSELORS IN SIGNED ACT FOR THE DEAF. A PILOT STUDY**

by

Hassinen, L. & Lappalainen, R. 2018

*Journal of Contextual Behavioral Science*, 8, 74-81

DOI:10.1016/j.jcbs.2018.02.005

Uudelleenjulkaistu Elsevierin luvalla.



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## Brief Empirical Reports

## Acceptance and commitment therapy using Finnish sign language: Training counselors in signed ACT for the deaf – A pilot study



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## ARTICLE INFO

## Keywords:

Acceptance and Commitment Therapy (ACT)  
Deaf  
Finnish Sign Language  
Training

## ABSTRACT

This study evaluated the implementation of Acceptance and Commitment Therapy in Finnish Sign Language in a rehabilitation center for deaf people. Sixteen (16) clients and nine (9) staff members participated in this pilot study. Staff members received a brief training in Acceptance and Commitment Therapy (ACT) including 16 h lectures, 15 h supervision, and studying material. Each staff member treated 1–2 clients during 8–10 sessions. As part of the study, several ACT metaphors and exercises were translated into Finnish Sign Language. The study indicated that counselors with limited knowledge of psychological interventions were able to deliver an ACT intervention using Finnish Sign Language after a relatively brief training. The intervention was well accepted by both the clients and the counselors, and showed encouraging effects on clients' wellbeing. The study highlighted a need of valid assessment methods for clients who use sign language. This study provides an example how ACT-based interventions could be provided to minority groups.

## 1. Introduction

In Finland, there are approximately 4000–5000 people who are deaf and use Finnish Sign Language (FinSL) as a means to communicate (The Finnish Association of the Deaf, 2017). It has been shown that the sign language deaf people use is a natural language (e.g., Padden & Humphries, 1988; Stokoe, 1960). It has a unique structure and vocabulary (signs) and takes a visual and gestural approach. Since 1960, there has been a growing interest in understanding sign languages and deaf culture, all over the world. In fact, every country has one or several sign languages (see, e.g., Sacks, 1989; Pfau, Steinbach, & Woll, 2012). There are also variations of certain sign languages. For example, a person who has become deaf later in life might develop his/her own version of a spoken language or just use some signs to support spoken language (Lauren, 2006).

Most deaf children (95%) are born to hearing parents (Mitchell & Karchmer, 2005; Spencer & Marschark, 2010). As a result, in many cases parents of deaf children have first learned a sign language themselves to then mediate these skills to their child. Especially in recent decades, skills in sign language have been increasingly supported by practices in kindergartens and schools (Stredler-Brown, 2010). Several decades ago in Finland, for example, FinSL was forbidden at schools and only allowed to support the spoken language of the majority of the population (in this case, Finnish or Swedish; Rainó, 2000; Salmi & Laakso, 2005). Likewise in other languages, context affects a

child's ability to gain good language skills (e.g., family and school). There is some evidence suggesting that although the sign language of deaf children fostered by hearing parents may not be as rich as that fostered by deaf parents, deaf children of hearing parents communicate quite fluently by the age of five (Takala & Lehtomäki, 2002; Takkinen, Jokinen, & Sandholm, 1999) and this is especially true for deaf children who have also communicated with deaf adults. However, some deaf children may have additional handicaps, such as dysphasia, cerebral palsy (CP) or visual problems, and these handicaps can have an effect on learning language skills (Lindfors, 2005; Sinkkonen, 1994).

In Finland, a study by Lindfors (2005) reported a slightly higher number of psychological symptoms among a deaf population in comparison to the general population. The most common psychological symptoms were loneliness, depression and anxiety symptoms, which were estimated to be found in one out of four respondents (Lindfors, 2005). Also, the need for conversation regarding personal concerns was significantly higher among people who used FinSL than among the general population (Lindfors, 2005). Depression, anxiety, personality disorders, substance abuse, schizophrenia, bipolar disorder and psychotic behavior were reportedly the most common problems among deaf and deaf-blind individuals or people with severe hearing impairment of those treated at, for example, a psychiatric clinic in Southern Finland, according to Ryyänänen and Kostamo (1998). Additional diagnoses usually included epilepsy, intellectual disability, developmental disability, dysphasia and other linguistic disorders (Ryyänänen &

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Kostamo, 1998).

Staff training is essential when arranging rehabilitation and mental health care services for different special groups (Glickman, 2009; Gutman, 2002; Peoples, 2002). One of the challenges for service providers working with deaf people is to find a mutual language. It is important that clients can receive the information they need through a language that they can understand. This poses a challenge for health care professionals who provide psychological interventions. As far as we know, only a limited number of psychologists and psychotherapists use sign language or some kind of sign mode. For example, in Finland, less than ten psychologists or psychotherapists use FinSL in their practice (The Association for Sign Language Psychotherapists, 2017). These have all passed an intermediate-level FinSL test or have grown up in a signing environment with deaf parents. In addition, there is a large variation in sign language skills among clients, who range from fluent sign language users to those who use a limited version of sign language or modes. These variations are probably a result of exposure to various modes of communication practices at an early age, especially at home or in school. According to Lindfors (2005), some clients may have further difficulties, such as dysphasia, and other disabilities including poor eyesight, cerebral palsy (CP), or mental retardation. According to Glickman (2009), a major problem for deaf people with communication difficulties is a lack of access to fluent models of fully accessible language. He refers to this particular group as the traditionally underserved.

According to Long, Long, and Oulette (1993), this term refers to a person who cannot communicate effectively through speech, speech reading or sign language, and whose English language skills are at or below the third-grade level. In addition, they need assistance to maintain their employment, housing or friendships due to inabilities in taking another person's perspective or actively initiate relationships (Duffy, 1999). As outlined by Glickman (2009), clients with language and learning difficulties require more extensive treatment as they are prone to have associated neurological, emotional and behavioral challenges. Further, they are vulnerable to misdiagnosis and inappropriate treatments. It is a challenge for professional caregivers for the deaf, but they are academically and linguistically competent as well as motivated to provide ethical and high-quality care (Gutman, 2002; Peoples, 2002). For example, in discussing the history of mental health care, Glickman (2009) highlights that deaf people with language difficulties are classed as "low functioning" in that regard. However, Gutman (2002) describes a transformation of ethics from medical paternalistic practices to respecting autonomy and engaging in cooperative decision making, in the recent years.

Acceptance and Commitment Therapy (ACT) emphasizes personal values and acts, while respecting autonomy and cooperation in accordance with one's values (Hayes et al., 2004; Hayes, Luoma, Bond, Masuda & Lillis, 2006; Hayes, Strosahl & Wilson, 1999). A unique feature of ACT is that it does not view human suffering as an abnormality, thereby making it a less stigmatizing approach (Strosahl & Robinson, 2009). Therefore, ACT can be a suitable intervention model with deaf people as well as with other special groups. In addition to values and value-based actions, ACT uses metaphors and experiential exercises aimed at teaching people psychologically flexible behavioral strategies. Yet, there is little knowledge on using ACT with deaf people as well as in regard to teaching acceptance-, mindfulness- and value-based skills to deaf people using sign language.

The ACT literature has grown rapidly in recent times and several studies have shown the effectiveness of ACT procedures (e.g., Bluett, Homan, Morrison, Levin, & Twohig, 2014; Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Ruiz, 2010). For example, evidence has supported the effectiveness of ACT for the treatment of work-related stress (Bond & Bunce, 2003), psychoses (Bach & Hayes, 2002; Gaudiano & Herbert, 2006), depression (Zettle & Haynes, 1986; Zettle & Rains, 1989), trichotillomania (Woods, Wetterneck, & Flessner, 2006), epilepsy (Lundgren, Dahl, Melin, & Kies, 2006), obsessive-compulsive

disorder (Twohig, Hayes, & Masuda, 2006), and social anxiety disorder (Dalrymple & Herbert, 2007). Also, research indicates that stress management interventions based on ACT strategies have a positive impact on employees' psychological health, well-being and stress management skills (Bond & Bunce, 2000; Bond & Bunce, 2003; Bond & Hayes, 2002; Donaldson-Feilder & Bond, 2004).

Strosahl and Robinson (2009) state that the reason to share ACT with service providers is to empower their efforts in order to deliver beneficial services and share common values. Exposure to ACT principles can assist them in developing and maintaining patience, acceptance, flexibility and an egalitarian stance needed to explore, encourage, educate, and promote healing. This way, they are more likely to be effective, experience satisfaction in their work, and be more resilient to fatigue (Strosahl & Robinson, 2009). It has therefore been recommended that counseling and guidance professionals should consider including acceptance-based methods in their interventions (Donaldson-Feilder & Bond, 2004). If professional health care providers have stigmatizing beliefs about their clients, acceptance-based methods could also help the providers to better manage their feelings and thoughts (Hayes et al., 2004). We were interested in applying an ACT-oriented intervention for persons using FinSL and to investigate whether this approach could be successfully applied by counselors.

The overall aim of the study was to provide a brief value- and acceptance-based intervention with the intention of improving the well-being of deaf and deaf-blind clients. We set out to investigate: (1) whether it was possible for the staff of a rehabilitation center with no prior ACT experience to provide an ACT-based intervention in Finnish Sign Language; (2) whether the clients and the staff would approve of the ACT-based intervention approach; and (3) whether counselors with no prior ACT experience could successfully improve the well-being of the deaf and/or deaf-blind clients in the rehabilitation center using the brief ACT-based intervention in Finnish Sign Language. In order to examine the acceptability, usefulness and effectiveness of this approach, we trained staff of a housing service center in the ACT-based methods and strategies.

## 2. Method

### 2.1. Procedure

At the time of our research, about 250 persons attended the housing and sheltered work services of the Service Foundation for the Deaf (see [www.kuurojenpalvelusaatio.fi](http://www.kuurojenpalvelusaatio.fi)). These clients wanted to live and work in a community where Finnish Sign Language (FinSL) is used. The reason for seeking these services can be to overcome communication problems, loneliness and isolation, or a lack of other appropriate service providers. Clients might have additional disabilities, such as poor vision, physical incapacities or psychological limitations. Service providers in the service centers use FinSL and are trained to understand deaf people. Some of the staff members are deaf FinSL users themselves.

The study was conducted at the Sampola Service Center, which is owned by the Finnish Service Foundation for the Deaf. The center provides supported housing services, workshops and other work activities using FSL for deaf and deaf-blind people. The staff members attended a lecture presenting and describing the ACT model. After this introductory lecture, upon their request, we decided to test the ACT intervention model (Hayes et al., 1999, 2006) at the center. The procedure is described in detail as follows.

### 2.2. Participants

At the time of our research, about 50 people attended the housing and sheltered work services at the Sampola Service Center. Staff members selected 20 clients for potential participation in the research study. The criteria for the selection were (1) satisfactory FinSL skills and (2) a need for psychological intervention as evaluated by the

counselors. The selection was determined by the counselors, who were in contact with the participants on a daily basis. At the time of the study, no reliable measures were available at the center to determine the selection otherwise. Of the twenty clients originally selected, four refused to participate. Three of these clients had practical reasons, since they were living outside the center. One participant was not able to take part because of his poor mental condition. Consequently, 16 clients (men,  $n = 9$ , 56%; women,  $n = 7$ , 44%) attended the trial. All the participants were FinSL users. Their mean age was 43.8 years ( $SD = 9.13$ ; min. 22 to max. 60). All except two were working at the Sampola Service Center (88%), and about half were living at the center ( $n = 9$ , 56%). Ten (63%) of the participants were single. Seven (44%) participants had previous psychiatric diagnoses (Schizophrenia,  $n = 3$ ; Psychotic Disorder,  $n = 2$ ; Bipolar Disorder,  $n = 1$ ; Delusional Disorder,  $n = 1$ ) and were on medication, but none were receiving psychotherapy or psychological treatment at the time. However, we could not evaluate whether or not the diagnoses were still appropriate. There were no changes in the clients' medication during the study. All of the clients had the equivalent of an elementary school education. Out of the 16 clients, 6 used FinSL as their primary means of communication, and 10 used written Finnish to some extent.

Overall, 9 voluntary counselors participated in the study (8 females, 1 male). All of the counselors were working at the Service Foundation for the Deaf. Their duties were to guide clients in household duties and work assignments as well as in social security and financial issues. The mean age of the counselors was 43.9 years ( $SD = 9.12$ ; min. 27 to max. 58), and they had been working with deaf or deaf-blind clients for an average of 10.8 years ( $SD = 6.67$ ; min. 3 to max. 20). The education level of the counselors ranged from elementary school ( $n = 1$ ) and college ( $n = 5$ ) to university degree ( $n = 3$ ). None had prior psychotherapy training. The staff who attended the trial had passed the same test as used for FinSL interpreters.

### 2.3. Measurements

The participants were assessed before and after the intervention, and again after a 6-month follow-up period. The time span between pre- and post-intervention measurements was four months, and between post-intervention and follow-up measurements six months. At the time of the study, there were no assessment tools available at the center to measure the psychological well-being of the clients. We decided to measure depression using the Beck Depression Inventory (BDI), because depression was reported by Lindfors (2005) to be a common psychological symptom among the Finnish deaf population. In addition, we were interested in describing the overall psychological symptoms of the clients and used the Symptom Checklist-90 (SCL-90) for this purpose. The number of assessment measures had to be limited because they were presented to the clients using video recordings (see below).

#### 2.3.1. Symptom measures

Depression was assessed with the Beck Depression Inventory (BDI) and overall symptoms with the Symptom Checklist-90 (SCL-90), lower scores indicating fewer symptoms. The BDI is a widely used self-report questionnaire with 21 items measuring the severity of depression (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Scores between 0 and 9 indicate minimal depression, between 10 and 18 mild depression, between 19 and 29 moderate depression, and between 30 and 63 severe depression. SCL-90 is a broad self-report checklist of psychopathological symptoms and has been validated in regard to the Finnish population (Derogatis & Cleary, 1977; Holi, 2003; Holi, Sammallahti, & Aalberg, 1998). In this study, the scores from the SCL-90 are reported using the General Severity Index (GSI). The GSI (SCL-90-GSI) is calculated by dividing a client's scores (from 0 as 'none' to 4 as 'extreme') by the number of questions (90). The SCL-90 consists of the following primary symptom dimensions: somatization, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety,

paranoia ideation, and psychoticism. Each of the nine symptom dimensions is comprised of 6–13 items. The score of each dimension is the mean of the scores of all its items. However, according to Holi (2003), SCL-90 subscale scores should not be used as a basis for a patient's diagnostic description.

#### 2.3.2. Process measures

Psychological flexibility and experiential avoidance were measured using the Acceptance and Action Questionnaire – II (AAQ-II), a 10-item questionnaire that involves both the ability to accept difficult thoughts and feelings as well as to engage in valued activity in their presence. The questionnaire uses a 7-point Likert-type scale, where high scores indicate high psychological flexibility (range 0–70; Hayes et al., 2006). The AAQ-II started out as a 10-item scale, but was reduced to a 7-item scale in 2011 with the Cronbach alpha  $\alpha = 0.84$  (Bond et al., 2011). The 7- and 10-item versions correlated at  $r = 0.96$ , and consequently the version of the AAQ-II used earlier in this study should be valid for research purposes (Bond et al., 2011).

#### 2.3.3. Translation of the measures

The measures (SCL-90, BDI, and AAQ-II) were translated into Finnish Sign Language in cooperation with a licensed psychotherapist with thirty years experience in using FinSL and a group of native deaf signers, as well as a professional interpreter. The final translations were discussed and evaluated by this expert group before they were recorded on video. A deaf native signer signing the final translation was recorded on video. The SCL-90, BDI and AAQ-II were presented to the clients using these video recordings. The clients filled out the questionnaires while watching the recordings, and the counselors helped them when necessary.

#### 2.3.4. Other measures

At the end of the intervention, both the clients and counselors were asked to report their experiences in the intervention using a semi-structured questionnaire. Most questions presented to the clients were open-ended. The clients were asked to comment on the materials and methods used (e.g., if the material was understandable), what exercises they engaged in during the session and whether they were still using them, what they found to be difficult or easy, what their general learning experience was ("What have you learned?"), whether they would be willing to participate in similar interventions in the future (yes/no), whether they would recommend the intervention to others (yes/no), as well as leaving room for open-ended comments about the overall experience. The questionnaire given to the staff included both Likert-type questions and open-ended questions. The counselors were asked to give their feedback regarding the training, supervision and materials provided ("Was the provision of training/supervision/materials sufficient?"), and were asked how many times they had participated in the study group, what was easy or difficult, whether they see a need for similar interventions in the future (yes/no), whether they acquired any skills, whether they had developed new exercises that were congruent with the ACT model, whether the intervention had an impact on their clients (none/small/moderate/large or very large impact), whether they had experienced some negative or positive emotional reactions during the project (e.g., tension, anxiety, excitement, satisfaction); and they were given open-ended questions (e.g., "Do you think this project is useful for you? If so, how?"). Further, the counselors were asked to report the number and type of exercises they had used with each of their clients.

### 2.4. Intervention

The counselors attended a two-day (16 h) workshop presenting the background, model and methods of ACT. The trainer had more than 10 years experience in ACT. Most counselors had previous training in the formulation of the Functional Analytic Clinical Case Model (FACCM).

The researchers had used similar brief training procedures earlier. These earlier experiences have shown that students have been able to apply the ACT model successfully after receiving an equivalent training (e.g., Lappalainen, Lehtonen et al., 2007; Lappalainen et al., 2014; Lappalainen, Langrial, Oinas-Kukkonen, Tolvanen, & Lappalainen, 2015; Räsänen, Lappalainen, Muotka, Tolvanen, & Lappalainen, 2016). Thus, we repeated the training procedure that had worked successfully earlier. In our equivalent study (Kyllönen., Muotka, Puolakanaho, Astikainen & Lappalainen, 2018, under review), we investigated the adherence to the ACT protocol after a comparable training in accordance with the coding manual authored by Plumb and Vilaradaga (2010). In these studies, the competence in ACT was at a satisfying level (on a scale from 1 to 5,  $M = 3.29$ ,  $SD = 0.94$ ). The workshop was interpreted in Finnish Sign Language. This was done because several of the counselors used FinSL as their main language. The presentation of a Functional Analytic Clinical Case Diagram (FACCD) or model and the practice of constructing it by using imaginary cases were also included in the training workshop (see Haynes and O'Brien, 1990; Haynes and O'Brien, 2000; Haynes and Williams, 2003; Peterman and Müller, 2001; Haynes, O'Brien, and Kaholokula, 2011). The case formulation model was used to help the counselors obtain an overview of the clients' concerns and problems, and to tailor the intervention individually for the clients. The model was already being used in the center for the purpose of rehabilitation documentation. FACCD (Haynes & O'Brien, 2000; Lappalainen & Miettinen, 2007) is a graphic approach for describing problematic behaviors of clients, the relations between behavioral problems, and the importance of those relations. FACCD helps describe a given client's current problems in a graphical form. Further, the workshop included lectures on general principles and core processes of ACT, as well as experiential exercises. Counselors used the Finnish Acceptance and Commitment Therapy manual (Lappalainen et al., 2004), and the Finnish translation of the ACT self-help manual (Hayes & Smith, 2008) throughout the intervention trial. The Finnish ACT manual describes the main assumptions underlying ACT, outlines the core processes involved, and gives examples of how they can be applied during the intervention. It includes 32 metaphors and 18 exercises that could be used during the intervention. Counselors received group supervision every second week during the treatment, and each session lasted for approximately 3 h. The supervisor was an experienced psychotherapist familiar with the ACT procedures. All counselors took part in the supervision sessions. In addition, the counselors organized a weekly study group in order to acquire more competence in applying the ACT model. The Finnish ACT book (Lappalainen et al., 2004) and ACT self-help book (Hayes & Smith, 2008) served as study material.

At the start of the project, the following two ACT exercises were translated into Finnish Sign Language and recorded as such on video for presentation purposes: "The Observer" and "Putting Emotions in Front of You." Correspondingly, seven metaphors were also translated and recorded in the same way: "The House," "The Bird House (a variant of 'The House' metaphor)," "The Tug-of-War with a Monster," "The Man in the Hole," "The Quicksand," "The Hungry Tiger," and "The Jelly Donuts." The same FinSL experts who translated the measurements and DVD also produced the translations of the exercises and metaphors. The exercises and metaphors were presented to the clients using both the video recordings and the material provided by the trainers (the Finnish Acceptance and Commitment Therapy manuals, Lappalainen et al., 2004; and the Finnish translation of the ACT self-help manual, Hayes & Smith, 2008). The clients also had the possibility of using the ACT-based DVD at a time of their own convenience.

The intervention lasted three months. The counselors were instructed to have one 60-min weekly session with the clients. The counselors were first instructed to make a case formulation model for the clients (FACCD; Haynes et al., 2011), followed by a value analysis of ACT. The value work was done as follows. First, examples of different domains or areas usually included in the value analysis were presented to the clients (e.g., family members, work, education). Second, the

clients were asked to select the domains that might be of importance to them, and to describe their own values in these domains. Third, they were asked or prompted to define actions related to personally important values. Fourth, these actions, specified in cooperation with the counselors, were used when homework assignments were given to the clients. In addition to the work with values, the counselors were instructed to apply and support different ACT principles and methods presented in the manuals (see Results). The number of sessions with the clients varied from 7 to 11. Each session lasted from 20 to 90 min ( $m = 65$  min), depending on the clients' ability to work with the intervention procedures. The counselors also ran an ACT study group during the intervention. The study group held five meetings and the members were instructed to study the ACT manuals (described above) and to discuss the material with other counselors taking part in the project.

#### 2.4.1. Procedures for data analysis

The actual use of the ACT methods by the counselors was reported by describing the number and types of exercises used during the intervention. The total scores of the BDI, SCL-90 and AAQ-II, as well as the SCL-90 subscales (somatization, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism), were calculated using the SPSS software program (mean and standard deviation). We used a repeated measure design (SPSS: General Linear Model) to study whether within-group changes were statistically significant. Of the 16 clients who agreed to participate in the study, two refused to participate in the follow-up measurement. The follow-up values of these clients were replaced by their post-intervention values. The correlations between the total number of exercises/metaphors with the changes in BDI, SCL-90 and AAQ during the intervention were calculated using Pearson correlation coefficients. The magnitude of the treatment effects was studied using within-group effect sizes at post-intervention and 6-month follow-up measurement points (ES; Cohen's  $d$ ). They were calculated as follows. The within-group ES was calculated for both the post-intervention and follow-up measurements by dividing the mean change by the combined (pooled) standard deviation ( $SD$ ) (Feske & Chambless, 1995; Morris & DeShon, 2002). Because of a relatively small sample size, the possible bias of Cohen's  $d$  was corrected by an unbiased estimate of Hedges'  $g$  (Hedges & Olkin, 1985; Hedges, 1981). A within-group ES of 0.5 was considered small, 0.8 medium, and 1.1 large (Öst, 2006; Roth & Fonagy, 1996)

### 3. Results

According to the BDI, at the beginning of the intervention all clients except one (94%,  $n = 15$ ) reported at least mild depression symptoms (BDI higher than 9), and 69% ( $n = 11$ ) reported at least a moderate level of depression symptoms. The mean of the SCL-90 GSI score observed in this study ( $m = 1.37$ ,  $SD = 0.57$ , Table 1) was close to the level observed in the Finnish psychiatric outpatient population ( $m = 1.56$ ,  $SD = 0.61$ ; Holi et al., 1998). This suggests that the investigated clients reported a proportionately high number of psychological symptoms.

#### 3.1. Application of the ACT procedures

During the sessions, the counselors practiced value-oriented development with all clients at the beginning of the intervention. On average, the participants completed six different exercises (min. 3 and max. 10 different exercises per client) during the intervention. Half of the clients ( $n = 8$ ) received more than five different ACT experiential exercises or metaphors. The two most frequently used exercises were the video-recorded exercises "The Observer," practiced with eight clients (50%), and the "Putting Emotions in Front of You" exercise, practiced with seven clients (44%). Other exercises included "The Mind Train," "The Passengers on the Bus," "Naming Objects," as well as



**Table 1**

Mean values (standard deviations) at Pre-, Post- and 6-month Follow-up, and F- and p-values and effect sizes (Pre-Post/Pre-Follow-up). \* = Statistically significant change over time (Pre, Post, F-up,  $p < 0.05$ ).

Measures	Pre	Post	6-mo Follow-Up	F (2,30)	p	ES (g)
BDI	21.19 (7.55)	16.25 (6.77)	18.13 (6.32)	2.95	0.068	0.67/0.43
SCL-90 GSI	1.37 (0.57)	1.27 (0.63)	1.08 (0.57)	3.15	0.057	0.16/0.50
SCL-90 dimensions						
Somatization	1.31 (0.63)	1.25 (0.75)	1.01 (0.71)	3.34	0.049*	0.08/0.44
Obsessive-compulsive	1.66 (0.75)	1.43 (0.56)	1.29 (0.67)	2.57	0.094	0.34/0.51
Interpersonal sensitivity	1.47 (0.68)	1.27 (0.83)	1.06 (0.64)	3.35	0.049*	0.26/0.61
Depression	1.34 (0.65)	1.28 (0.70)	1.22 (0.67)	0.42	0.660	0.09/0.18
Anxiety	1.34 (0.70)	1.26 (0.76)	1.03 (0.65)	3.56	0.041*	0.11/0.45
Hostility	1.00 (0.71)	0.92 (0.58)	0.82 (0.63)	0.49	0.619	0.12/0.26
Phobic anxiety	1.06 (0.88)	1.06 (1.05)	0.99 (0.88)	0.27	0.765	0.00/0.08
Paranoid ideation	1.66 (0.77)	1.61 (0.72)	1.23 (0.74)	2.27	0.121	0.07/0.56
Psychoticism	1.28 (0.71)	1.28 (0.50)	1.18 (0.68)	0.31	0.738	0.00/0.14
AAQ-2	42.63 (10.44)	46.13 (9.22)	46.31 (6.12)	2.20	0.128	0.35/0.42

different kinds of mindfulness exercises (for example, the “Follow your Breathing” exercise), and describing an emotion on paper and putting it in one’s pocket. Moreover, additional value-oriented work was applied with some clients (such as “Six months time to live”, and “What kind of a person would you like to be in ten years”). The following metaphors were the most frequently used: “The House” ( $n = 13$ ), “The Bird House” ( $n = 9$ ), “The Tug-of-War with a Monster” ( $n = 11$ ), “The Hungry Tiger” ( $n = 7$ ), “The Man in the Hole” ( $n = 6$ ), and “The Jelly Donuts” ( $n = 3$ ).

### 3.2. Experiences of the counselors

According to the counselors’ evaluation of the clients’ well-being, all except one of the participants ( $n = 15$ ) had benefitted from the intervention. Several counselors expressed their wish for similar interventions to be undertaken in the future (reflected in the following comment, “We were lucky when we got this opportunity”). All counselors reported that the intervention had a positive impact on their practices. Most of them reported that the intervention also had a positive influence on their level of satisfaction at work. They further reported that they had acquired new tools and changed their work habits, and that their relationships with the clients had improved. The study group organized by the counselors was reportedly very useful. However, about half of the counselors also reported that the intervention was very demanding (5 of 9). According to the counselors, the ACT concepts were rather hard to explain and communicate to the clients, because the concepts were new to both. Hence, they requested more DVD material in Finnish Sign Language. Some of the clients also perceived the assessment procedure to be time-consuming as well as challenging (for some clients, the BDI and SCL-90 assessments required more than two hours, and in some cases necessitated a separate session). Further, some of the clients found it difficult to understand the rating scales, such as the BDI scale for the four-level classification.

### 3.3. Clients’ experiences with the intervention

At the end of the intervention, all of the 16 participants wanted to recommend the intervention to others. A high majority of the participants (94%,  $n = 15$ ) reported that it was easier for them to focus on what was important in their personal lives, and that the intervention had improved their ability to recognize emotional reactions (100%,  $n = 16$ ). They further reported that after the intervention, they were able to influence their lives, think differently, focus on their well-being, and think positively about themselves. It was also reported that even when they had negative feelings, they could continue to be active (described by one client as follows, “I can take a walk despite feeling depressed and though it’s raining”). Some clients stated that after the intervention, they applied the metaphors (such as The Tug-of-War with

a Monster, The House, The Quicksand) and mindfulness exercises to handle any unpleasant feelings or thoughts (described by one client as follows: “I try to do mindfulness exercises when I feel that I begin to get nervous”). Overall, 14 out of 16 (88%) clients were willing to continue applying what was learned in the ACT-based intervention in the future. Those who expressed their intention to continue applying what was learned in the intervention ( $n = 14$ ) reported that the intervention had helped them to reflect on their personal issues; it had increased their coping skills and they felt that life was better.

Two clients, who did not continue with the intervention, stated that “thinking is hard,” and “this was enough for me” (meaning “I do not need more”). The clients’ experiences with the ACT exercises and metaphors (signed on DVD) were largely positive. On the other hand, new terms and concepts caused some problems. For example, some of the clients reported that sometimes they had to watch the signed ACT-DVD several times before they understood the meaning of the exercise. Likewise, some of them experienced the assessment methods as challenging and needed individual support when completing the questionnaires. As a consequence, extra time was needed for the assessments.

### 3.4. Effects of the interventions as measured by the inventories

A significant effect for time was found in the SCL-90 subscales for somatization, interpersonal sensitivity, and anxiety (see Table 1). The pairwise comparison showed that the clients reported significantly reduced symptoms from the pre-intervention to 6-month follow-up measurements. A trend in the main effect was observed both for depressive symptoms (BDI;  $p = 0.068$ ) and the total score of psychological symptoms (SCL-90/GSI;  $p = 0.057$ ). There was a slight, nonsignificant increase in psychological flexibility from a score of 42–46. Table 1 shows that the pre to post and pre to follow-up within-group effect sizes were relatively small and varied from pre to post from 0.00 (phobic anxiety) to 0.67 (BDI), and from pre to follow-up from 0.08 (phobic anxiety) to 0.61 (interpersonal sensitivity). Although there were slight trends of larger changes among the clients with no severe diagnoses, no statistically significant differences were found. Further, the correlations of the total number of reported exercises and metaphors with changes in the BDI, SCL-90 and AAQ (BDI change,  $r = -0.10$ ; SCL-90 change,  $r = 0.30$ ; AAQ change,  $r = 0.09$ ) were low.

Individual change scores from the pre- to post-intervention measurements ( $n = 16$ ) and from the pre-intervention to the 6-month follow-up measurement ( $n = 14$ ) in the BDI, SCL-90-GSI and AAQ are presented in Figs. 1–3. Individual scores indicated that there was a large variation between participants at the beginning of the intervention. Also, there was a large variation in how the intervention impacted the clients. In the BDI, 9 out of 16 participants (56%) showed a decrease in depression scores from pre to post (at least a score of 5), and about a

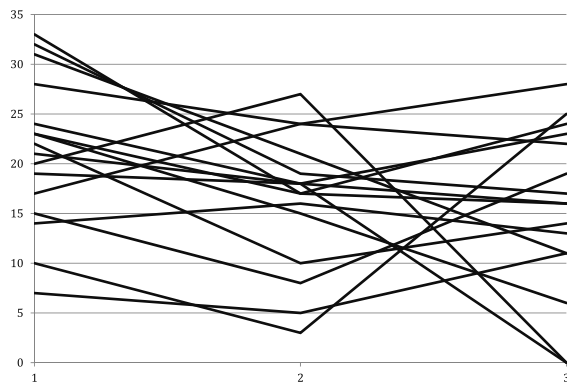


Fig. 1. Overall symptoms with the SCL-90 (GSI). Individual changes during the intervention (1–2,  $n = 16$ ), and during the follow-up (2–3,  $n = 14$ ).

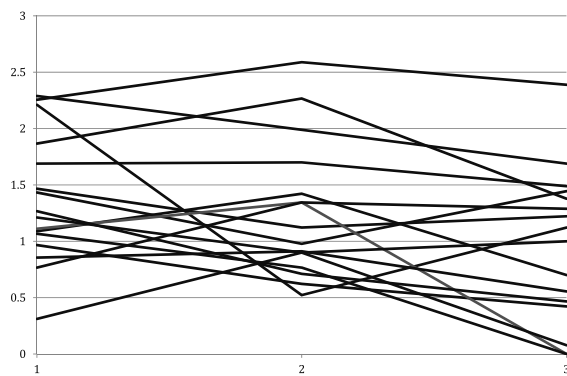


Fig. 2. Symptoms of depression (BDI). Individual changes during the intervention (1–2,  $n = 16$ ), and during the follow-up (2–3,  $n = 14$ ).

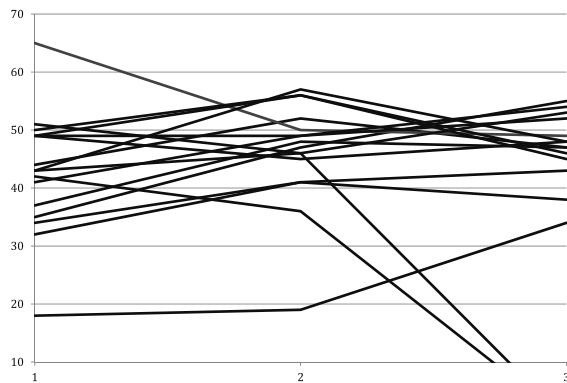


Fig. 3. Psychological flexibility (AAQ-2). Individual changes during the intervention (1–2,  $n = 16$ ), and during the follow-up (2–3,  $n = 14$ ).

third of them ( $n = 3$ ) reported an increase in symptoms during the follow-up period. In the SCL-90, 50% (8 of 16) showed a decrease in symptoms (at least a score of 0,20) from pre to post, and 2 of them showed an increase during the follow-up. Further, 9 out of 16 (9 of 16, 56%) showed an increase in psychological flexibility during the intervention (scored higher than 5), and 4 of them ( $n = 4$ ) a decrease in flexibility skills during the follow-up. Thus, roughly half of the participants demonstrated positive changes during the active intervention

period, but some of them were not able to maintain the changes after the intervention, during the follow-up period.

It should be noted that there were low correlations at the baseline between the BDI and SCL-90 ( $r = -0.19$ ,  $p = 0.487$ ,  $n = 16$ ) as well as between the BDI and AAQ-II ( $r = -0.13$ ,  $p = 0.64$ ,  $n = 16$ ) measurements at the beginning of the study. However, the correlation between the SCL-90 and AAQ-II was high ( $r = -0.73$ ,  $p = 0.001$ ,  $n = 16$ ). These low correlations between the BDI and SCL-90/AAQ-II are exceptional seen in relation to the correlations reported in other Finnish studies featuring clients with similar levels of depression symptoms. For example, in a study by Kohtala, Lappalainen, Savonen, Timo, and Tolvanen (2013), the pre-intervention correlation between the BDI and SCL-90 was 0.70 and between the BDI and AAQ it was  $-0.55$ .

#### 4. Discussion

To the best of our knowledge, this is one of only a few acceptance-, mindfulness-, and value-based interventions conducted in sign language. The number of professional therapists able to provide psychological interventions in sign language is very limited. Therefore, we decided to train counselors in applying ACT procedures with the clients using Finnish Sign Language (FinSL). It is important to note that the study sample does not represent FinSL users as a whole, but a subgroup of persons experiencing some psychological concerns.

In this study, the counselors were instructed to select those clients from the center who had satisfactory FinSL skills and seemed to need psychological intervention. The majority of the selected clients experienced a significant number of personal problems. In practice, because of the limited services available in Finnish Sign Language, the only way to provide psychological interventions to the selected clients was to train the counselors, who could then apply the intervention methods. Therefore, we believe that this study provides a good example of how psychological interventions can be provided to special groups. Moreover, it describes possible difficulties associated with such interventions, especially when applying ACT in sign language. We hope that this study will encourage clinicians and researchers to provide psychological interventions for underserved populations and special groups.

Our findings suggest that it is possible to train counselors who use Finnish Sign Language to provide their clients with acceptance- and value-based interventions. The findings further indicate that such treatment can be provided with relatively few workshops that include written study and DVD material as well as supervision. All clients practiced several metaphors and experiential exercises during the intervention, demonstrating that rather complicated and challenging mindfulness- and acceptance-based exercises can be applied to Finnish Sign Language. Overall, the clients reported positive changes related to their quality of life as well as their skills to handle emotional reactions and thoughts even after the intervention. However, some counselors and clients reported that the new terms and concepts were challenging. These experiences could be due to the variation in Finnish Sign Language skills both among the counselors and clients. Thus, participants' and counselors' skill levels in sign language could have impacted the results. As pointed out by Glickman (2009), a characteristic feature for the traditionally underserved deaf population is language dysfluency in sign language. This problem is related to language deprivation linked to growing up in a nonsigning or inadequately signing environment. On the other hand, it is also possible that the reported difficulties were due to counselors' possible inability to appropriately communicate conceptually accurate concepts, and/or due to some of the signed ACT-DVD materials not having been accurately translated, and/or due to the fact that some individuals facing language problems may suffer from commonly associated neurological, emotional and behavioral difficulties (Glickman, 2009). Nevertheless, it was interesting to observe that the ACT intervention improved clients' self-knowledge. As stated by one client, "It influenced my thinking, making

it broader.”

We propose that the conclusions drawn regarding the effects of the intervention should be considered with caution, and the results need to be repeated in other studies for greater reliability. This is due to some difficulties reported while using the assessment tools, and due to the fact that no control condition was included in the study design. We also acknowledge that the observed changes were relatively small. Based on the symptom measures, the results indicate that the ACT-based intervention had an effect on the following SCL-90 subscales: (1) symptoms of somatization reflecting distress arising from bodily perceptions; (2) interpersonal sensitivity including feelings of personal inadequacy in comparisons with others, as well as uneasiness and discomfort during interpersonal interactions; and (3) anxiety composed of symptoms such as nervousness and tension. Further, a trend of diminished depressive symptoms during the intervention was observed. We compared our study with two studies using a waiting list control group (with equivalent levels of symptoms at the beginning of the study) in order to see whether the changes in the present study bore more significance compared to when no treatment was offered. The within-group effect sizes (ES) from pre- to post-intervention measurements were used to compare the changes (using the three studies' pooled standard deviation in their pre-intervention measurements in order to make the comparisons comparable). The observed improvements in depression, psychological and physiological symptoms, as well as in psychological flexibility were slightly greater in the present study than typically seen in waiting list groups. In the present study, the within-group effect size for the BDI was moderate ( $d = 0.64$ ), while these effect sizes were small regarding the waiting list group ( $d = 0.11$ , Kohtala et al., 2015;  $d = 0.36$ , Lappalainen et al., 2015). For the SCL-90 the ES from pre to post was  $d = 0.43$  compared to  $d = 0.25$  and  $d = 0.08$  in the studies by Kohtala et al. (2015) and also Lappalainen et al. (2015). Psychological flexibility (AAQ) has typically remained at the same level in the waiting list group ( $d = 0.08$ , Kohtala et al., 2015;  $d = 0.03$ , Lappalainen et al., 2015), while a small effect was observed ( $d = 0.29$ ) in the study group of the present study. These comparisons suggest that the ACT intervention provided by the counselors had a positive impact on clients' general well-being, but the changes were relatively small.

At the end of the intervention, a majority of the clients reported that the intervention had clarified their values, and the intervention also had several other beneficial effects. Yet, there was also a large individual variation in the effects of the intervention as measured by the questionnaires (BDI, SCL-90, and AAQ). Based on individual descriptions of the changes in the symptoms and process measures, it could be seen that roughly half of the participants demonstrated positive changes during the active intervention period. However, some of these clients showing beneficial changes were not able to maintain these changes after the intervention. Thus, an intervention including 7–11 sessions over a period of three months might be too short in order to produce favorable long-term changes among the majority of clients.

According to the feedback provided by the counselors as well as the clients, some of the assessment methods were experienced as difficult to comprehend. This observation raises questions about the validity and accuracy of the measurements. The correlations between the BDI and SCL-90 as well as between the BDI and the AAQ scales were exceptionally low. On the other hand, the correlation between the SCL-90 and AAQ was high, and comparable to other studies (e.g., Kohtala et al., 2015; Lappalainen et al., 2015). Furthermore, in general, it is a challenge in itself to find appropriate measurement instruments for the deaf. Measurement instruments reflecting the well-being and quality of life of deaf people using sign language are extremely important. These instruments are needed in order to assess the well-being of such clients, and in order to accurately evaluate the effects of interventions aimed at increasing their well-being.

In addition to measurement problems, there are several other issues that need to be observed when drawing conclusions from the present study. In this study, we did not include a control group. Hence, it is

possible that the observed effects were caused by other factors that are not related to the intervention or attention received during the study. Further, there was no assessment of the competence of the counselors regarding their application of the ACT procedures. Therefore, we suggest that these methodological limitations be considered in further research.

Instead of using a group comparison model, single case approaches might be more suitable for analyzing the effects of interventions aimed at similar populations. In line with this, assessment tools that provide a possibility for obtaining data over a longer period of time might be very useful. It should be noted that interventions that are focused on the use of sign language are time-consuming, especially when the clients represent various levels of language skills. It would therefore be logical to assume that perhaps the time frame of the current intervention was too short. This assumption is supported by the clients' responses. Also, web- and mobile-based interventions could be used to promote the dissemination of psychological interventions for special groups and underserved populations. We propose that further research is necessary in this specific direction.

To conclude, the present study provides an example of developing an intervention for special groups and for underserved populations. We have observed promising results that indicate that the acceptance- and value-based intervention was well accepted by both the clients and the counselors. We observed indications of positive effects of the intervention on the well-being of approximately half of the clients. Furthermore, many counselors reported that the intervention had positively impacted their level of satisfaction at work. Based on the feedback obtained from the clients and counselors, the Finnish Service Foundation for the Deaf decided to provide similar training throughout all the centers that are owned by the foundation within Finland.

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