# Implementing a Program for Parents with Intellectual Disability in Sweden: A Feasibility Study

Elaine Mc Hugh

UNIVERSITY OF GOTHENBURG

Department of Psychology

*To my parents, for their love and support*

*&*

*to Erik, who I could not have done this without*

# Abstract

This thesis examines implementation of an evidence-informed parent education program for parents with intellectual disability, called Parenting Young Children (PYC), in the Swedish social services. The empirical studies on which the thesis is based aimed to evaluate how feasible and successful implementation of PYC has been to date, examining program fidelity, and the provision of program support. **Study I** explored perceptions of competence development and the training process for Swedish program users (support workers) who participated in monthly peer support groups. Focus groups discussed experiences of PYC and completed a competency questionnaire on two occasions. Perceived competence was high and increased over time. PYC peer support groups were thought to be beneficial for performance evaluation, exchange of information and coping with problems. However, many reported few opportunities to implement the program. **Study II** investigated peer group facilitators' (Area Coordinators) perceptions of working in peer support groups. Area Coordinators completed diaries each month after meetings, recording topics covered, difficulties experienced by the group and general reflections about peer support. Area Coordinators also attended a focus group. Several opportunities and barriers to program implementation were perceived within the groups. Interaction between the peer support groups and the organization/managers was thought to be particularly important, but difficult to achieve. In **Study III** fidelity was examined by tracking frequency of implementation of program activities and teaching approaches in support workers. Feasibility was explored through questionnaires addressing perceived program complexity and compatibility in support workers and their managers. Implementation of PYC was reported to be highly feasible, with overall positive attitudes to Evidence-Based Practice, good program compatibility and low perceived program complexity, as well as high satisfaction with implementation support. However, some behavioural aspects of PYC were rarely reported to be used in practice. Low implementation intensity was also reported. **Study IV** aimed to develop a PYC fidelity measure that included the perspective of program recipients. Two questionnaires were developed; one measured parents' perceptions of support workers' fidelity, the other was a self-report questionnaire for support workers. Items from the support worker and parent versions were compared for inter-rater reliability. Parents and support workers both reported very high fidelity. Scores were consistent over a three month period. Inter-rater reliability between parents and support workers was, however, only fair. Taken together, these results highlight enthusiasm and perceived need for PYC in the social services. Further work is needed in order to assist implementation of PYC and to develop both the program itself and program support.

*Keywords:* Evidence-Informed Programs, intellectual disability, implementation support, program fidelity, Parenting Young Children, feasibility

# Swedish summary

Under de senaste 50 åren har attityder till personer med intellektuella funktionsnedsättningar (IF) genomgått drastiska förändringar och idag blir personer med IF allt oftare föräldrar. Forskning visar att föräldrar med IF kan behöva ett stöd i sitt föräldraskap som är anpassat till deras behov. Parenting Young Children (PYC) är ett australienskt, evidensbaserat (evidence-informed) utbildningsprogram, som i första hand är utvecklat för målgruppen föräldrar med IF som har barn som är yngre än sju år. PYC översattes och lanserades bland svenska yrkesverksamma under 2010, och är det första föräldrautbildningsprogram inom den svenska socialtjänsten som tar hänsyn till föräldrars möjliga funktionsnedsättningar. Det finns flera potentiella hinder för implementering och användningen av PYC i detta sammanhang. Denna avhandling ägnas därför åt implementering av PYC inom den svenska socialtjänsten. De empiriska studierna syftar till att utvärdera hur genomförbar och framgångsrik implementeringen av PYC har varit hittills, med särskilt fokus på programtrohet och programstöd.

När PYC importerades och kontextualiserades i Sverige, fanns det inga särskilda rekommendationer eller riktlinjer för hur programmet skulle implementeras eller vilket stöd och vilken utbildning användarna behövde få. Därför utvecklades en modell, Swedish PYC Implementation Support Model (SweISM), specifikt riktad mot implementering av PYC i Sverige. En kombination av workshops, manualer och fortlöpande stöd i form av handledning eller coachning anses vanligen som den gyllene standarden för implementeringsstöd. Denna typ av stöd kräver stora resurser i form av pengar och kompetens. SweISM undersöker istället hur andra mer kostnadseffektiva och hållbara metoder fungerar i praktiken. Modellen innehåller både en inledande utbildning och ett kontinuerligt kollegialt metodstöd (peer support groups), med gruppträffar en gång per månad. Deltagarna i grupperna kan prata om PYC, öva PYC-färdigheter och hjälpa varandra att lära sig programmet. Varje grupp har en områdesansvarig (Area Coordinaror) som har erfarenhet av arbete med PYC, men inte förväntas besitta expertkunskap. De områdesansvariga fungerar som samordnare och samtalsledare för grupperna. Det finns begränsad kunskap om hur sådant stöd fungerar i implementeringsprocessen. De första två studierna undersökte PYC-handledarnas (de professionella inom socialtjänstem som använder PYC med föräldrar) och områdesansvarigas (samtalsledarna för PYC gruppbaserad kollegialt metodstöd) erfarenheter av SweISM.

**Studie I** undersökte uppfattningar om kompetensutveckling och utbildningsprocessen hos svenska PYC-handledare som deltog i PYC-utbildning under 2010 och som deltog i kollegialt metodstöd i grupper varje månad över ungefär ett år. Tio fokusgrupper genomfördes där erfarenheter av PYC diskuterades; fem direkt efter utbildningen, samt ytterligare fem ett år senare. Tolv PYC-handledare besvarade också en kompetensenkät efter utbildningen, och ett år senare. Resultaten från enkäter och fokusgrupper visade att PYC-handledarna rapporterade att de hade högre kompetens för att kunna arbeta med föräldrar med IF efter PYC-utbildning och efter delaktighet i kollegiala stödgrupper. Deltagarna var i allmänhet positiva till PYC-manualen och utbildningen. PYC-handledarna ansåg att stödgrupperna var till nytta för utvärdering av den egna prestationen, utbyte av information och för att diskutera problem med varandra. Det uppfattades som avgörande för kompetensutvecklingen att få tillfälle att använda

programmet med föräldrar med IF, men många PYC-handledare beskrev problem med att hitta föräldrar att använda programmet med. Överförande av kunskap från träning till praktik upplevdes som svår.

Studie II hade som mål att djupare undersöka användning av kollegiala stödgrupper från de områdesansvarigas perspektiv. Struktur och innehåll, områdesansvarigas uppfattningar av sin roll, samt utveckling av grupper över tiden undersöktes. Mellan 2012-2013, deltog PYC-handledare i kollegiala stödgrupper varje månad. Fem områdesansvariga fyllde i formulär efter varje möte, där de rapporterade vilket tema som valts för diskussion vid dagens möte, svårigheter i gruppen och allmänna reflektioner om mötena (15 kollegiala stödgrupper, 160 möten totalt). Fyra av dessa områdesansvariga deltog i en fokusgrupp om erfarenheter av att vara områdesansvarig och att interagera med verksamheter som använder PYC. Deltagarna uppfattade flera möjligheter och hinder för implementering av programmet och i deras arbete som områdesansvariga. Sammantaget, beskrev deltagarna både personliga och professionella utmaningar i sitt arbete, vilket tyder på ett behov av mer stöd och träning för områdesansvariga. Kommunikationen mellan kollegiala stödgrupper och verksamheter ansågs vara särskilt viktig, men svår att uppnå. Grupperna fokuserade främst på att sätta mål tillsammans med föräldern och att kommunicera och introducera PYC i familjer. Det fanns mindre fokus på särskilda undervisningsmetoder i PYC.

De sista två studierna fokuserade på begreppet programtrohet och praktikers uppfattningar om PYC som program. Programtrohet är centralt i evidensbaserat arbete: en hög grad av programtrohet innebär att praktiker utför metoden enligt instruktionerna i manualen. Detta är nödvändigt för att genomföra effektstudier och erhålla tillförlitliga resultatmått. Uppfattningar av programmet är också viktigt i och med att programmet måste vara genomförbart och praktiskt för praktiker i samband med deras arbetsmiljö, färdigheter och preferenser.

Studie III undersökte programtrohet genom implementeringsloggböcker. Efter PYC-sessioner med föräldrar, noterade PYC-handledarna de olika programkomponenter och undervisningsmetoder de använt sig av. Data insamlades under 14 månader från 27 PYC-handledare som jobbade med 46 föräldrar (588 PYC-träffar med föräldrar). Genomförbarhet undersöktes genom enkäter med frågor om uppfattningar om evidensbaserad praktik, programkomplexitet och programkompatibilitet hos 17 av PYC-handledarna och deras tolv chefer. Resultaten visade att PYC har hög genomförbarhet i praktiken: både cheferna och PYC-handledarna rapporterade positiva attityder till evidensbaserad praktik, hög programkompatibilitet och låg programkomplexitet. Frågan om programtrohet var dock mer problematisk. Till exempel rapporterade 59% av PYC-handledarna att det fanns vissa aspekter av PYC som de aldrig använde, till exempel att tydliggöra rollerna, observation eller uppföljning med föräldrar. Dessutom var det antal PYC-träffar som föräldrarna i genomsnitt erbjöds lägre än det antal som rekommenderas i programmet.

Studie IV hade som mål att utveckla ett frågeformulär för programtrohet med avseende på PYC, som också fångar de deltagande förädlarnas perspektiv och erfarenheter. Två frågeformulär utvecklades och användes i studien: ett självrapporterat frågeformulär för att mäta PYC-handledares uppfattning om sin egen programtrohet, och ett frågeformulär (ifyllt genom telefonintervju) som mätte föräldrars uppfattning om sin

PYC-handledares programtrohet. Både handledar- och föräldraformuläret innehöll frågor gällande innehållet i en specifik PYC-träff, vilket gör att handledarens och förälderns svar kan jämföras. Data insamlades från 22 föräldrar och 17 PYC-handledare för en genomsnittlig period på 3 månader. Femtio matchande förälder-PYC handledare versioner av frågeformulären insamlades. Både föräldrarna och PYC-handledarna rapporterade mycket hög programtrohet. Detta resultat höll sig oförändrat under tre månader. Samstämmigheten mellan föräldrarnas och handledarnas bedömningar var dock inte hög. Föräldern och handledaren var ofta oense om vilka frågor i formuläret som var tillämpliga för en viss träff. PYC är ett program som skall vara flexibelt och anpassas till föräldrars individuella förutsättningar, men kanske har denna flexibilitet också gjort det svårare att definiera och mäta programtrohet.

Sammanfattningsvis ger dessa resultat en bild av att svensk socialtjänst hyser entusiasm och upplever ett behov av PYC. PYC-handledare, chefer och områdesansvariga som deltog i studierna var nöjda med programstödet och uppfattade att PYC var relevant och viktigt för deras arbete. Dessutom rapporterade de att de införlivat flera aspekter av PYC i sitt arbete med föräldrar som har IF. Trots denna positiva inställning kunde vissa problem skönjas när det gällde PYC-handledares tillämpning av programmet, och i mätningen av programtrohet. Till syvende och sist, pekar resultaten på att implementeringen av PYC är ett komplext projekt. Det kan därför behövas en vidareutveckling av programmet, och ett intensifierat stöd både på ledningsnivå och ute i verksamheterna.

# Acknowledgments

There are many people who have played a part in this thesis, to whom I am deeply thankful. Thank you first and foremost to both of my supervisors, Associate Professor *Mikaela Starke* and Professor *Erland Hjelmquist* . Mikaela, you have been fundamental in my academic development. It has been a real pleasure to work with you in the last few years. Your support and generosity with your time have not gone unnoticed. Erland, thank you for your engagement and enthusiasm. Your deep knowledge and experience have given me the confidence to continue with my studies, even when I have doubted myself.

Thank you to everyone who provided feedback on versions of this thesis, especially Professor *Malin Broberg*, Associate Professor *Robert Holmberg*, Associate Professor *Henna Hasson*, Professor *Annika Dahlgren Sandberg*, and the members of the PIP group at the Department of Psychology and PROG group at the Department of Social Work.

A special thank you to all of the PYC Area Coordinators, without you this thesis would certainly not have been possible.

These two years have gone by far too quickly, in part due to my many brilliant PhD colleagues. Special thanks to my roommate *Py Eriksson* (for the daily chats and encouragement), *Hera Nowak* (for keeping me well fed and providing frequent doses of happiness), and *Renate Geurts* (who has become a fast but firm friend).

Thank you to *Peter Gill*, for proofreading this thesis and providing feedback on my Master's thesis. As probably the only person to have read both texts in their entirety, your help has been invaluable. To *Anna Wettergren,* who helped me enormously when I first moved to Gothenburg, and continues to be a wonderful presence in my Swedish and Irish life.

To my sister *Niamh*, and brother *James*, who both inspired me to keep studying. Thank you for continuing to be there, even when I am far away. Thank you to *Bernadette*, *Patricia* and *Stephen*, who I always look forward to visiting as a break from work life.

To my parents, *Ann* and *Gerry*. You have supported me unconditionally and lovingly. Your investment in your children's happiness and education is abundantly clear in everything that you do. Our academic careers are a testament to that. It is not often that I have the opportunity to clearly express how grateful I am, but I think of it often. Thank you.

*Erik*, you have the deepest insight into all of the ups and downs between the words written on these pages. Thank you for your kindness, openness and level headedness along the way. You have offered me everything from solid research advice, to a shoulder to cry on. It is a privilege to share this, and all other aspects of my life, with you.

*Elaine Mc Hugh*
Gothenburg, November 2016

# Preface

This thesis is based the following four papers, which are referred to in the thesis by their Roman numerals:

I.    Mc Hugh, E., & Starke, M. (2015). Understanding support workers' competence development in working with parents with intellectual disability. *Journal of Intellectual Disabilities, 19*(4), 326-341. doi: 10.1177/1744629515576045.

II.   Mc Hugh, E., & Starke, M. (2016). *Supporting implementation of an Evidence-Informed Program using peer support groups: Area Coordinators' perceptions and experiences*. Manuscript submitted for publication.

III.  Mc Hugh, E., & Starke, M. (2016). *Investigating feasibility and fidelity of the Parenting Young Children program in Sweden.* Manuscript submitted for publication.

IV.   Mc Hugh, E., & Starke, M. (2016). *Measuring program fidelity: Including the perspective of parents with intellectual disability*. Manuscript in preparation.

# Contents

# Introduction

Individuals with intellectual disability are frequently viewed as asexual, childish and dependent (Azzopardi-Lane & Callus, 2015). Therefore, this population has typically been actively prevented or discouraged from starting a family (Lennerhed, 1997). Only in the last 30 years have attitudes begun to change, and now there is agreement that appropriate support and education for parenthood is a basic human right (Article 23 of the UNCRPD, United Nations, 2006). Several researchers have developed and tested specialized educational interventions for parents with intellectual disability (e.g., Eyberg, Boggs, & Algina, 1995; Feldman & Case, 1997; McGaw, Ball, & Clark, 2002; Tymchuk, Hamada, Andron, & Anderson, 1990), with promising initial findings (Wade, Llewellyn, & Matthews, 2008). In order for such interventions to impact the lives of individuals with intellectual disability, however, successful implementation is fundamental.

The implementation process can be fraught with problems; as a result only a small number of research-developed practices are generally adopted by practitioners (e.g., Bellamy, Bledsoe, Mullen, Fang, & Manuel, 2008; Edholm, 2016; Murphy & McDonald, 2004). Implementation research attempts to overcome this by identifying the activities that are necessary to successfully put interventions into action (Fixsen, Naoom, Blase, & Friedman, 2005). The current thesis draws on both implementation research and theory in order to examine the implementation of an Evidence-Informed Program developed for parents with intellectual disability, implemented in the Swedish context. The program in focus, Parenting Young Children (PYC), is the first of its kind to be used by Swedish municipal social services, and thus provides a unique opportunity to examine various aspects of the provision of this specialized type of support.

The overall aim of the thesis is to critically evaluate how feasible and successful the implementation of PYC has been to date in Sweden. Two primary aspects of implementation are in focus: (i) program fidelity (i.e., the extent to which the program is used as intended by practitioners), and (ii) the provision of program support and education in the form of peer support. In addressing these issues the thesis is divided into three sections. The first section provides an introduction to current knowledge and research on parents with intellectual disability, as a precursor to describing the PYC program. The second section describes implementation research and theory in relation to program fidelity and peer support in PYC. The third section provides a summary of the four empirical studies on which the current thesis is based and includes a discussion of results in light of implementation research and theory.

# Section 1: Intellectual Disability and Parent Support

## Defining and Identifying Parents with Intellectual Disability

Before implementing the Parenting Young Children (PYC) program, it is necessary to consider who the program is developed for and how these individuals can be identified. Several terms which are synonymous or closely related to intellectual disability are commonly used, for example, cognitive or intellectual limitations, developmental disability, learning difficulty, intellectual impairments, or mental retardation (Collings & Llewellyn, 2012). Intellectual disability can furthermore encompass a wide span of different cognitive and intellectual difficulties. As a starting point, the concept may be better understood in the broader context of disability and human functioning. Three main models are typically used to provide a simplified understanding of how disability can be constructed; an *individual model*, a *social model* and a *relative model* (Pfeiffer, 2002).

The individual model (also known as the medical model, Grönvik, 2007) purports that people with disabilities have shortcomings which should be fixed. Disability is viewed as a functional or psychological limitation, and is therefore a "personal tragedy" (Oliver, 1986, p. 6). Within this model, appropriate treatments target the individual rather than their environment (Pfeiffer, 2002). Poor outcomes for children of parents with intellectual disability are attributed to the parent's inherent intellectual limitations. In contrast, the social model, instead, emphasizes social and environmental factors outside of an individual's intellectual capacity which are taken to explain negative outcomes. From this perspective, disability is constructed through interactions between people (Hedlund, 2009). Difficulties experienced by parents with intellectual disability may therefore be the result of a lack of resources and support, or childhood experiences of abuse and neglect (Neely-Barnes, Zanskas, Delavega, & Evans, 2014). The individual and social models have been criticized for attributing limitations entirely to either the environment or a specific diagnosis (Hedlund, 2009). Thus, the relative model strives to combine the influence of both individual and social phenomena. A range of possible approaches may then be appropriate to help people with disabilities, aimed at both the individual and their environment (Hedlund, 2009).

The relative model is particularly influential in guiding Swedish policies for disabled people (Berg, 2005), highlighting the influence of both individual characteristics and structural difficulties in society, such as oppression and discrimination (Tideman, 2015). For example, "From Patient to Citizen – The National Action Plan for Disability Policy" (Socialdepartementet, 2000) has the objective of ensuring that a disability perspective is adopted in all sectors of society; to create an accessible society; and to improve accommodations made for individuals with disabilities. The relative model is also evident in "The International Classification of Functioning, Disability and Health" (ICF) (Buntinx, 2016; World Health Organization, 2001), used within the social services. Briefly put, the ICF is a conceptual framework based on a biopsychosocial view of disability, including body functions, activities and participation. It provides a common language for practitioners, and can be used as a tool for enabling collaboration between interdisciplinary teams, or allowing international comparison of research studies (Buntinx, 2016).

While a relative model is clearly gaining popularity both in Sweden and internationally, diagnostic practices continue to focus on the individual/medical model. In other words, individual support and deficiencies are emphasized, rather than accessibility and participation in the social environment (Tideman, 2015). Primary diagnostic manuals include the "International Statistical Classification of Diseases" (ICD) (World Health Organization, 1992), the "AAIDD diagnostic manual" (Schalock et al., 2010), and the "Diagnostic and Statistical Manual of Mental Disorders" (DSM) (American Psychiatric Association, 2013). These three texts refer to broadly the same criteria: limitations in intellectual functioning; limitations in adaptive behaviour; and onset prior to 18 years of age (Schalock & Luckasson, 2015).

Standardized tests such as the Wechsler Intelligence Scale (Wechsler, 1949) are used to assess limitations in intellectual functioning using IQ scores. This is a measure of mental development in comparison to same-aged peers. A score of 70 is indicative of intellectual disability, and further categorizations can be made into mild (50-69), moderate (36-49), severe (20-35) and profound intellectual disability (<20) (American Psychiatric Association, 2013). Historically, these figures have fluctuated in an attempt to avoid over-representation of minority populations that may result from cultural biases present in IQ measures (Jenkinson, 1996). Such measures are furthermore based on a "normal" population, and are thus unreliable for assessing the intellectual functioning of individuals with intellectual disability. Thus, more recently there have been attempts to downplay the focus on IQ scores. For example, the DSM-5 no longer uses specific IQ ranges to categorize severity of intellectual disability, but continues to refer to an IQ of 70 as a diagnostic cut-off point. The notion of adaptive behaviour was introduced to provide a more comprehensive view of intellectual disability (Papazoglou, Jacobson, McCabe, Kaufmann, & Zabel, 2014).

Adaptive behaviour refers to normal functioning within a peer group, in a community setting, and is more behaviourally focused than intelligence tests. Not only is the construct validity of adaptive behaviour problematic, but similarly to IQ scores, standardized measurements are used and normed in comparison to the general population. These tests only provide information on how an individual differs from what is typical for their peer group. Such measures do not indicate the functioning of individuals with intellectual disability in specific contexts, nor do they account for compensatory coping strategies (Jenkinson, 1996).

These categorizations of disability contrast with that of researchers such as Gunnar Kylèn (1983), who emphasized a more complete view of individuals with intellectual disability, taking into consideration contextual factors and existing abilities. By drawing on an individual perspective of disability, diagnostic systems ignore structural oppression, discrimination and disadvantages faced by people with intellectual disability (Gillman, Heyman, & Swain, 2000). Thus, these individuals are labelled as "deviant" from an ideal, normative state of intellectual and adaptive functioning. A further potential downfall resulting from this standardization is the possibility that practitioners will be less sensitive to individual differences (Söder, 1989). These factors have consequences for the provision of support for individuals with intellectual disability, given that a formal diagnosis is often necessary in order to access services. If diagnosis focuses on rigid cut-off points, while ignoring capacity to function in the environment, there is a risk that

individuals in need of support will be overlooked. The term *parents with intellectual disability* is used throughout this thesis. The reader should be aware, however, that this is a category to which people are assigned based on imprecise criteria.

## Prevalence of Parents with Intellectual Disability

Despite diagnostic and conceptual debates, several attempts have been made to estimate prevalence rates of intellectual disability internationally. The general prevalence of intellectual disability is estimated to be approximately 1% of the population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Intellectual disability is typically identified in school-aged children, probably due to intellectual and academic demands during this period  (Arvidsson, 2013). Mild intellectual disability accounts for about 85% of these cases (Maulik et al., 2011).  Parents with intellectual disability are likely to be part of this mild-to-borderline majority of individuals with intellectual disability, and may therefore be difficult to distinguish (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Those with mild intellectual disability may have little contact with disability services, or may never receive a formal diagnosis (Coren, Hutchfield, Thomae, & Gustafsson, 2010). Even if intellectual disability is diagnosed initially, this label can disappear in the post school years when academic demands decrease (Arvidsson, Widén, & Tideman, 2015; Tideman, 2015). Difficulties may not become apparent again until the responsibilities of parenthood arise. At this stage, however, parents' disability may be overlooked or remain unnoticed (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008).

Researchers in the field often make reference to indirect and anecdotal indications that numbers of parents with intellectual disability are on the rise (Guinea, 2001; McConnell, Llewellyn, & Ferronato, 2002).  While several formal attempts at estimating prevalence of parents with intellectual disability have also been made, estimates fluctuate depending on the inclusion criteria used. These studies are often based on mothers registered with healthcare or social service agencies (Man, Wade, & Llewellyn, 2016). In Norway, for example, 0,2% of all children (113 of approximately 60000 births per year) are estimated to have a parent with a formal diagnosis of intellectual disability, or closer to 1%, if parents with mild-to-borderline intellectual disability are included (525 of approximately 60000 births per year) (Tøssebro, Midjo, Paulsen, & Berg, 2014).

According to the Swedish National Board of Health and Welfare, there are no official records of parents with intellectual disability in Sweden (C. Gustafsson, personal communication, May 4, 2015). Research studies that have focused on prevalence rates in Sweden show similar variation to research results found elsewhere. In 1995, a survey was conducted in Skaraborg County. It found a prevalence of children born to mothers with intellectual disability of 1.4 children per 1000 based on children born between 1986-1995 (i.e., 0.13% of children born) (Bager, 2003). Another study looked at the five year incidence (1975-1989) of children born to mothers with intellectual disability in Blekinge County, resulting in an estimate of about 2.12 per 1000 children (i.e., 0.21 % of children born) (Weiber, Berglund, Tengland, & Eklund, 2011). More recently, attempts have been made to conduct similar surveys in Västra Götaland County. However, methodological

problems and issues in accessing information in regard to diagnosis have hindered the completion of these attempts.

Despite these difficulties, it seems reasonable to assume that, with increased integration and acknowledgment of the legal rights of people with intellectual disability, greater numbers from this population are likely to have children (Woodhouse, Green, & Davies, 2001). It can also be argued that, regardless of the presence or absence of any formal diagnosis, there is a need for parent education that is sensitive to varied learning styles and needs, and a need for practitioners to be sensitive to and educated in such differences. Support and education for parenthood can be beneficial for all parents across society, and several types of support are currently available for Swedish parents (Regeringskansliet, 2009). Recent research on the lives of parents with intellectual disability and their children provides a better understanding of the specific kinds of support that can be beneficial to parents with intellectual disability.

## Research on Parents with Intellectual Disability and their Children

While research on *parents* with intellectual disability is commonly referred to in the extant research, as well as throughout this thesis. There has, nevertheless, been a strong emphasis on mothers with intellectual disability rather than fathers. While a few qualitative studies have focused specifically on fathers with intellectual disability (Åhlund, 2010; Sigurjonsdottir, 2004), research on how gender may affect both experiences of parenthood and outcomes for children in this population is meagre. Before going on to describe the state of current knowledge of parents with intellectual disability, this underrepresentation of fathers ought to be noted.

The first published scientific work regarding parents with intellectual disability, titled "The Feebleminded Parent: A Study of 90 Family Cases", was published in 1947 (Mickelson, 1947). The article concluded that approximately one quarter of individuals with intellectual disability gave their children inadequate care, and pointed to intellectual disability alongside factors such as mental health and income as influencing adequacy of childcare. Notably, the author focused on sterilization, community supervision and institutionalization as ways to reduce and control the number of pregnancies in this population. Understanding of parents with intellectual disability and their lives has advanced drastically since then, with researchers around the world turning attention to this subject. The International Association for the Scientific Study of Intellectual and Developmental Disabilities has a special interest group of researchers focusing specifically on parents with intellectual disability, that includes researchers from a range of countries worldwide (e.g., United States, Canada, United Kingdom, Germany). Much of this research has, instead, focused on the capabilities of parents with intellectual disability, on educational approaches, and on the lives of children of parents with intellectual disability (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008; Llewellyn, 2013).

Mothers with intellectual disability are thought to have increased risks of poverty, childhood trauma, mental health problems and isolation (e.g., Aunos, Feldman, & Goupil, 2008; McConnell, Feldman, Aunos, & Prasad, 2011; Meppelder, Hodes, Kef, & Schuengel, 2015). However, research concerning children of parents with intellectual disability has made contradictory findings. Research from Sweden, for example, has

shown that these children are more likely to be stillborn, have low birth weight or die in the perinatal period (Höglund, 2012; Höglund, Lindgren, & Larsson, 2012). Research from the UK, in contrast, has shown that there are no differences in health or birth outcomes for these children, in comparison to the general population (Hindmarsh, Llewellyn, & Emerson, 2015). These contradictory results could be due to small sample sizes, lack of comparison groups, or differences in data collection procedures (Hindmarsh et al., 2015). Other research indicates that these children face social difficulties such as isolation and bullying (Collings & Llewellyn, 2012 ; Collings, 2014; Lindblad, Billstedt, Gillberg, & Fernell, 2013).

Overall, there has been a move away from the individualistic view that parental intellectual disability, in itself, automatically leads to poorer outcomes for children. Instead, increasing attention is now given to influential contextual factors. Feldman's interactional model (2002), for example, includes social factors, parental history, life crises, social support and services, and physical and psychological health as influences on parenting. These factors also impact on parenting in the general population (Wade, Llewellyn, & Matthews, 2011). Research by Emerson & Brigham (2014), using a representative population-based sample in England, supports the application of such interactional models to parents with intellectual disability. In line with previous research (Collings & Llewellyn, 2012), results showed that parental intellectual disability was associated with an increased risk for poverty, poor housing and social isolation. When these environmental adversities were controlled for, risks for poor child outcomes decreased by over 50%. These results point to the necessity of comprehensive and varied support services for parents with intellectual disability. Typically, this might include vocational training, mental health counselling, financial support and parent education for example (e.g., Booth & Booth, 2003; McGaw et al., 2002).

## Support for Parents with Intellectual Disability

Increased social isolation and a history of abuse and neglect in their own childhood (Granqvist, Forslund, Fransson, Springer, & Lindberg, 2014) means that individuals with intellectual disability may lack access to the informal learning opportunities and positive role models that are important for new parents  (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Formal education consequently plays a vital role, and must be appropriately tailored for the cognitive abilities and lives of people with intellectual disability. The focus and approach of such educational interventions has included the use of attachment theory and video-feedback (Hodes, Meppelder, Schuengel, & Kef, 2014), instruments for designing individual injury prevention education (Tymchuk, Lang, Sewards, Lieberman, & Koo, 2003), and more general models for good practice  (McGaw et al., 2002). Earlier interventions typically targeted practical skills such as shopping, planning meals and changing nappies (Feldman, Case, & Sparks, 1992; Sarber, Halasz, Messmer, Bickett, & Lutzker, 1983). Contemporary interventions also address relationship and interactional skills between the parent and child (Wade et al., 2008; Hodes et al., 2014).

In 1994, Feldman did the first comprehensive review of parent intervention studies. In 2008, Wade, Llewellyn and Matthews updated this with a systematic review of studies since 1994. Both reviews concluded that parents with intellectual disability can

learn adequate parenting skills using specific teaching approaches. Feldman (1994) recommended the use of behavioural techniques as part of interventions provided in the home environment. However, there has been a lack of high quality research in this area, with only three Randomized Control Trial studies to date, and indications that only some parents improve their parenting skills and knowledge (Coren et al., 2010). Wade and colleagues (2008) concluded that the research has given little attention to generalization of skills and contextual factors, and so conclusions about the success of interventions are somewhat limited. More recently, another systematic review (Wilson, McKenzie, Quayle & Murray, 2014) has supported earlier recommendations and called for more large-scale, controlled studies to provide stronger evidence of the efficacy of such interventions (Wilson et al., 2014). While much work clearly remains, overall, the findings are encouraging, and suggest that continued investment in specialized educational interventions is worthwhile. Since the Parenting Young Children (PYC) program is the intervention in focus in this thesis, the components and approaches included in the program are described in detail in the following section.

## Parenting Young Children (PYC)

PYC, originally developed in Australia, is a home-based, educational intervention for parents with intellectual disability who have children less than seven years of age. Previous to the introduction of PYC, no such program aimed at parents with intellectual disability was in use in Sweden. In PYC, collaboration with parents, individualized interventions, and empirically supported teaching strategies are emphasized (Mildon, Wade, & Matthews, 2008). The program is summarized in a manual containing advice about teaching parents with intellectual disability, and outlining appropriate teaching strategies. Two core modules, that may be taught to parents, are then described, followed by tips for ensuring program fidelity for practitioners and for maintenance of the parents' newly acquired skills over time. The manual has four sections, all of which follow a similar structure, detailing what is involved in specific program tasks, step-by-step instructions for how to approach the tasks, and a list of necessary teaching/program materials. Examples are used throughout and, in some instances, problem solving is also addressed (i.e., specific examples of what to do if something goes wrong during sessions).

**Section 1: Developing the intervention.** The first section describes generalizable considerations in work with individuals with intellectual disability, centring on continuous awareness of the individual's level of understanding and efforts to motivate the parent to actively participate in the intervention. Practitioners are instructed to always clarify their role and the parents' role at the beginning of the education, and to explicitly define clear, concrete goals together with the parent. These goals should be positively phrased, reflect what the parent wants, be based on perceived individual strengths, and be realistic. Following this, broad guidelines for developing the intervention are given, such as how to choose a focus for the intervention, and developing and preparing the teaching material.

**Section 2: Teaching strategies.** Four teaching strategies are described along with step-by-step instructions. These teaching strategies have been extensively researched and are commonly used in behavioural and social learning interventions (Bandura, 1971; Fuqua & Shook, 1983; Lovaas, 1987). These strategies include: discrimination training, role play, and coaching (described in Table 1). The importance of swift corrective

feedback, prompting and reinforcement in the form of specific praise are also emphasized (Stokes & Baer, 1977). Practitioners use task analysis to structure their teaching of skills and assess baseline performance. This involves breaking down complex childcare behaviours (e.g., bathing a child, holding a new-born baby) into chains of simple behaviours that can be taught step-by-step. Observation and recording of behaviour over time is used to track when behaviour change occurs.

**Section 3: Parent-Child Interaction and Child Care Skills (the two core program modules).** PYC comprises two modules that can be taught to the parent; Parent-Child Interaction and Child Care Skills. The parent and support worker together choose a module to be focused on, depending on goals and problems experienced by the parent.

*Module 1: (Child Care Skills)* is based on Maurice Feldman's Step-by-Step parenting program for parents with intellectual disability (e.g., Feldman & Case, 1997). Both Step-by-Step and the Child Care Skills module of PYC teach parents basic childcare skills (e.g., nappy changing, holding a baby and breastfeeding) based on the use of task analysis checklists to break down tasks into simple steps. Due to the large number of childcare skills associated with parenting, in PYC there is no specific curriculum outlined for which skills to teach the parent. The practitioner and the parent must decide together which skills are most important, based on their goals and the child's needs. The focus of this module is therefore on a general approach for teaching child care skills.

The practitioner uses task analyses to evaluate the parent's performance and as a basis for teaching the skill. When teaching child care skills the practitioner should describe the meeting for the parent, introduce the checklist (i.e., the completed task analysis), make an observation of how the parent currently performs the task, and then teach the skill using appropriate teaching strategies from Section 2.

*Module 2 (Parent-Child Interaction)* is based on Sheila Eyberg's Parent-Child Interaction Therapy (Eyberg, Boggs, & Algina, 1995). Parent-Child Interaction Therapy is an evidence-based behavioural intervention that draws on attachment and social learning theories. It has been empirically supported for reducing problem behaviours in children with conduct disorders and special needs, as well as reducing parent stress and depression (see Sheperis, Sheperis, Monceaux, Davis, & Lopez, 2015). It has also been implemented with parents who may face different challenges, including foster parents (Mersky, Topitzes, Grant-Savela, Brondino, & McNeil, 2014) and depressed mothers (Timmer et al., 2011). Similarly to Eyberg's intervention, in PYC the Parent-Child Interaction module aims to increase the parent's awareness and use of developmentally appropriate interaction and discipline with their child. The parent is firstly taught to set up an appropriate and safe play environment, and then taught important interactional skills in a specific order: attention, describing, repeating words, praise, modelling and ignoring. Each of these interactional skills is described in simple language in the manual. The reasons why these skills are important are also outlined in simple language, as an example of how the practitioner can introduce and explain these concepts for the parent. Examples and step-by-step instructions for teaching each of these skills are provided. Skills in this module should be taught firstly without the child present, using roleplay; following this the practitioner can coach the parent in the presence of the child.

**Section 4: The path to successful intervention.** The final section outlines pedagogical techniques that help successful implementation. The importance of

implementation fidelity, generalization of acquired skills and maintenance of the parent's new skills is emphasized. Tips for how this can be achieved are outlined.

        **Additional program materials.** The manual includes extra materials, some of which are compulsory in order to follow the program, and others which are provided as learning assistance for practitioners. The majority of this additional material includes task analysis checklists. These checklists are based on research and best clinical practice, but are not exhaustive. Therefore, advice for how practitioners can construct their own task analysis is also included. A compulsory *goal form* is also provided. This document is central to the intervention. Goals should be written down, using the form, including details of who should complete the goal, and how well, where and when it should be executed. Finally, checklists are also provided that list the core program principles. Practitioners are encouraged to use these checklists for self-evaluation of implementation fidelity.

Table 1

*Components of the PYC Program*

| PYC activities | Description |
| --- | --- |
| Clarifying roles and expectations | Outlining responsibilities and expectations |
| Goal setting | Setting goals that are positively phrased and reflect the parent's wishes. |
| Develop an individualized intervention | Decide what skills are needed, what parts of the manual are relevant, necessary resources and appropriate teaching approaches |
| Teach the parent | Teach skills using relevant PYC teaching approaches |
| Follow up | Check for maintenance and generalization of skills |
| Observation/task analysis | Checklists used to structure learning and track the parent's development. |
| PYC teaching approaches | |
| Discrimination training | Used to teach knowledge-based skills that cannot easily be demonstrated through action. The parent is taught to discriminate between correct and incorrect choices or behaviours. |
| Role play | Support worker and parent act out the skill together; one plays the role of the child, while the other plays the role of the parent. |
| Coaching | Used in situations when the parent is required to use the skill in a real-life situation. The support worker gives feedback to the parent as they perform the task |

**Establishing evidence for PYC.** While the earlier sections outlined research on available supports for parents with intellectual disability, issues surrounding how to define and evaluate what counts as "sufficient" research evidence were not addressed. Approaches to working with parents with intellectual disability can draw on knowledge from different sources, such as advice from peers and supervisors, personal experiences, theory and/or research evidence. This refers to a distinction between: theoretical knowing (i.e., based on frameworks for viewing problems, which may or may not be based in research), empirical knowing (i.e., based on qualitative/quantitative data-based research inquiry) and experiential knowing (i.e., based on tacit knowledge gained from experience). These types of knowledge overlap. For example, research which contributes to empirical knowing is also likely to contribute to theoretical knowing, and empirical knowledge is likely to be viewed through a lens of experiential knowing (Nutley, Walter, & Davies, 2007). The promotion of the Evidence-Based Practice movement has been part of Swedish social policy for more than 10 years (Sundell, Soydan, Tengvald, & Anttila, 2009). Thus, particular emphasis has been placed on generating and using empirically-based knowledge.

Evidence-Based Practice can be narrowly defined as "a particular methodology for producing a specific form of evidence: systematic reviews and meta-analyses of robust…research studies aimed at assessing the effectiveness of health and social policy interventions" (Nutley et al., 2007, p. 12-13). This definition gives precedence to empirically-based knowledge and the Randomized Control Trial. Earlier research on Evidence-Based Practice was particularly criticized for promoting this simplified view that researchers generate sound evidence, which practitioners apply in a straightforward fashion. A broader definition, on the other hand, views Evidence-Based Practice as a way to help people to make informed decisions based on the *best available* evidence (Davies, 2004). This softer approach to Evidence-Based Practice makes room for a variety of types of research studies (e.g., quasi-experimental designs, single case studies and research based on qualitative data), and also considers the role of experiential and theoretical knowledge. This broader view of Evidence-Based Practice is the approach adopted in this thesis, particularly since this perspective acknowledges that controlled research can be difficult to achieve in some cases, especially in small and difficult to identify populations such as parents with intellectual disability.

PYC is based on empirically supported approaches for teaching individuals with intellectual disability (e.g., modelling, role playing, discrimination training). As outlined above, elements of the program are inspired by a variety of more established approaches for teaching parents with intellectual disability. However, to date, there have been no rigorous, controlled studies of PYC that purport to establish exactly how the program affects both child and parent outcomes. Therefore, PYC is classified here as an Evidence-*Informed* Program. While Evidence-Informed Programs have an evidence base, such programs have not yet been rigorously tested in their entirety (Metz, Espiritu, & Moore, 2007). Strict proponents of Evidence-Based Practice would be inclined to criticize support of such program-use within social services without solid research evidence of efficacy. However, given the difficulty in conducting controlled research on this group of parents, Evidence-Informed Practice represents some of the best available evidence to date, particularly in Sweden, where no other such programs are currently in use.

**Existing research on the PYC program.** Some research has been conducted on PYC in Australia and Sweden. This research has shown that, post intervention, Australian parents perceived lower stress, reduced problematic behaviour in the child, and reported more confidence in their parenthood. Furthermore, parents perceived the program to be a good fit with their lives, goals and values  (Mildon et al., 2008). Starke (2015) conducted research on 9 Swedish parents using both interview and questionnaire methods in a repeated measures design over 12 months of PYC intervention. This study found that parents perceived more positive relationships with their PYC support workers, expressed satisfaction with the program, and perceived increased clarity about the demands of parenthood.

**A stage model of program/manual development.** As a consequence of the fact that PYC is to be regarded as an Evidence-Informed Program, it is both under development and being implemented by practitioners in the field. However, even interventions with a strong evidence-base will not necessarily be implemented unless they are practically feasible and acceptable. For this reason, some researchers have proposed a stage model of program/manual development, within which program development is viewed as a process rather than a final product (Onken, Blaine, & Battjes, 1997). This involves gradual development of a program, with attention being paid to both the efficacy of the intervention and acceptability or suitability for the environment in which it is being implemented. An initial stage, Stage I, involves early pilot studies, alongside manual writing, development of program training and fidelity measurement for untested interventions. This is followed by Stage II, involving the refinement of highly defined guidelines to be used in efficacy studies.  Development of Stage III manuals involves consideration of issues of transferability, such as investigation of interventions across diverse populations, and cost effectiveness. In the current thesis, PYC is examined as a Stage I manual, implemented on a project or trial basis. Relevant questions, therefore, involve issues such as how best to develop fidelity measures and program training, as well as integrating existing research evidence in a manner feasible for practice settings. By making consideration of such factors at this early stage, the program can be tailored to its context throughout its development and testing.

# Section 2: Implementing Parenting Young Children in Sweden

## The Swedish context

The majority of the research on interventions for parents with intellectual disability has taken place in clinic-like settings, with implementation, presumably, being closely monitored by the intervention developers. Less is known about the use of such interventions by practitioners working in the field (Starke, Wade, Feldman, & Mildon, 2013). This section, therefore, focuses on implementation issues and the Swedish context for the Parenting Young Children (PYC) program. Contextual information about the background to the introduction and implementation of PYC in Sweden is outlined below. Following this, implementation research and theory that has been influential in guiding efforts to implement PYC in Sweden is discussed.

## The Path to Parenthood and Legal Rights to Support

In 1934, a Sterilization Act was passed for individuals with intellectual disability and mental health issues, resulting in the sterilization of 63,000 people from 1934-1975 (Lennerhed, 1997). Approximately 20,000 of these sterilizations are estimated to have taken place under conditions of coercion or persuasion. In 1976, a new sterilization legislation was amended, and an earlier marriage ban for people with intellectual disability was lifted. As part of what social services referred to as the Normalization Principle (Normaliseringsprincipen), throughout the 1970s and 1980s, people with disabilities gained greater freedom in making decisions about their lives and in becoming active members of the community (Bruno, 2012). Today, sterilization may only be performed, if directly requested by the individual (Areschoug, 2005). With the introduction of the Care Law (Omsorgslagen), in 1968, people categorised as intellectual disabled became legally entitled to health care, housing and employment. This shift from segregation to integration meant that individuals who previously lived in mental hospitals and institutions began to live in the community (Bruno, 2012).

Increased integration, the possibility of being able to marry and the ban on forced sterilization meant that individuals with intellectual disability had a greater possibility of having children. A further development has been the introduction of laws intended, specifically, to protect the legal rights of individuals with disabilities to have families. In 2000, the Swedish parliament introduced a national action plan ("From Patient to Citizen – The National Action Plan for Disability Policy") outlining goals and future directions for disability policy (Socialdepartementet, 2000). This action plan aimed to increase integration and accessibility across all sectors of society, including: "the possibility for people with disabilities to live family lives…to ensure that laws do not discriminate against people with disabilities in relation to sexual relationships, marriage and parenthood" (Socialdepartementet, 2000, p. 160). The UN Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations, 2006) contains similar sentiments and was ratified by Sweden in 2008. Article 23, in particular, states that the signatories: "shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships,

on an equal basis with others" (United Nations, 2006). The Swedish Agency for Participation (Myndigheten för delaktighet; MFD) is now responsible for following and promoting the implementation of the convention in disability policy. However, to date, MFD has not focused on access to parenthood for individuals with intellectual disability (H. von Axelson, personal communication, July 19, 2016).

The Social Services Act (Socialtjänstlag**,** Swedish abbreviation SOL, 2001) and The Act Concerning Support and Service for Persons with Certain Functional Impairments  (Lag om Stöd och Service till vissa Funktionshindrade, Swedish abbreviation LSS, 1993) are laws responsible for the provision of support for people with intellectual disability in Sweden. Enforcement of SOL is aimed at overseeing how social services function and is applicable to all citizens, including those with disabilities. It states that individuals have the right to support, if their needs cannot be met through other means.  However, the type of support that ought to be provided is not specified (Trydegård & Szebehely, 2008).  The LSS law, on the other hand, is aimed specifically at children and adults younger than 65 years of age, with developmental disability, autism or permanent intellectual disability resulting from brain injury, and those with other physical or mental impairments not associated with normal aging. Support, therefore, is linked to a medical diagnosis (see individual model of disability in Section 1). Ten different kinds of possible support are outlined.  These relate to basic needs, such as, assistance at work, at school, with household tasks and leisure activities. Equality, self-determination and the right to live a normal life are emphasized. However, the meaning of these terms is open to interpretation (Bergstrand, 2011) and, notably, support for and during parenthood is not mentioned. From a legal perspective, neither SOL nor LSS outline the kinds of additional supports parents with intellectual disability are entitled to or ought to receive.  In 2009, the Swedish government introduced a national plan that aimed to make parental support available to all parents in Sweden, providing "knowledge about children's health, emotional, cognitive and social development and/or strengthen the parent's social network" (Regeringskansliet, 2009, p. 4). However, while some attention is given to the need for targeted support for parents facing specific difficulties, little has been done to address how parents with intellectual disability can be provided with adequate and appropriate assistance.

## Swedish Municipality Based Social Services

Given the lack of appropriate support for parents with intellectual disability in Sweden, PYC was introduced in the Swedish social services on a project basis in 2010. This was intended as a step towards increasing knowledge of parents with intellectual disability and to provide more appropriate approaches for working with this population within the social services. PYC in particular was chosen because its social pedagogical approach and ethical values were thought to be a good fit for Swedish law and regulations. To date, PYC has been implemented within  municipality based social services in 26 different municipalities, some of which have participated for the full duration of the project, and others which have participated for a shorter period (Mensas, 2014).

Sweden is divided into 290 different municipalities and 21 counties (Government Offices of Sweden, 2004). Municipalities and county councils are bound by the Local

Governance Act (Kommunallagen). Municipalities are responsible for the provision of social care, and can have elaborate and different arrangements for coordinating their activities at a local level. Some larger Swedish municipalities, such as Gothenburg, are further divided into municipal districts (Hayward, 2007) . This means that the system within which PYC is implemented may vary greatly from one municipality to another. As a consequence, PYC is used in a variety of contexts by a span of workers with different roles and educational backgrounds. Generally speaking, PYC is used by individuals who are referred to as support workers, employed by the social services in home-based family work in the municipalities that are included in this project.  Bergman and Johansson (2015) have reported how home-based family work typically includes a mix of practical help, talk-based support and counselling, and educational interventions. However, what is included in home-based family services varies across different municipalities and is therefore difficult to define.

One example from a municipal district in the Gothenburg municipality is used here to illustrate how and where PYC has been used. There are 10 municipal districts in Gothenburg, organized in different ways, but which, overall, resemble the structure outlined in Figure 1.   Within each municipal district, the district authority has a geographical area of responsibility, rather than any specialized area of concern. In some municipalities services are divided into four sectors; education (utbildning); culture and leisure (kultur och fritid); elderly care (äldreomsorg hälso- och sjukvård); and, individual, family and disability care (individ- och familjeomsorg funktionshinder). In the municipal district chosen for this example, the implementation of PYC takes place within the individual, family and disability care sector. Individual, family and disability care is overseen by a sector manager, below who are managers responsible for various units or individuals. The units that are marked in bold in Figure 2 contain support workers who use the PYC program. Figure 2 was made in collaboration with a member of the PYC project, working within the municipality, and is not to be regarded as an official organization map.
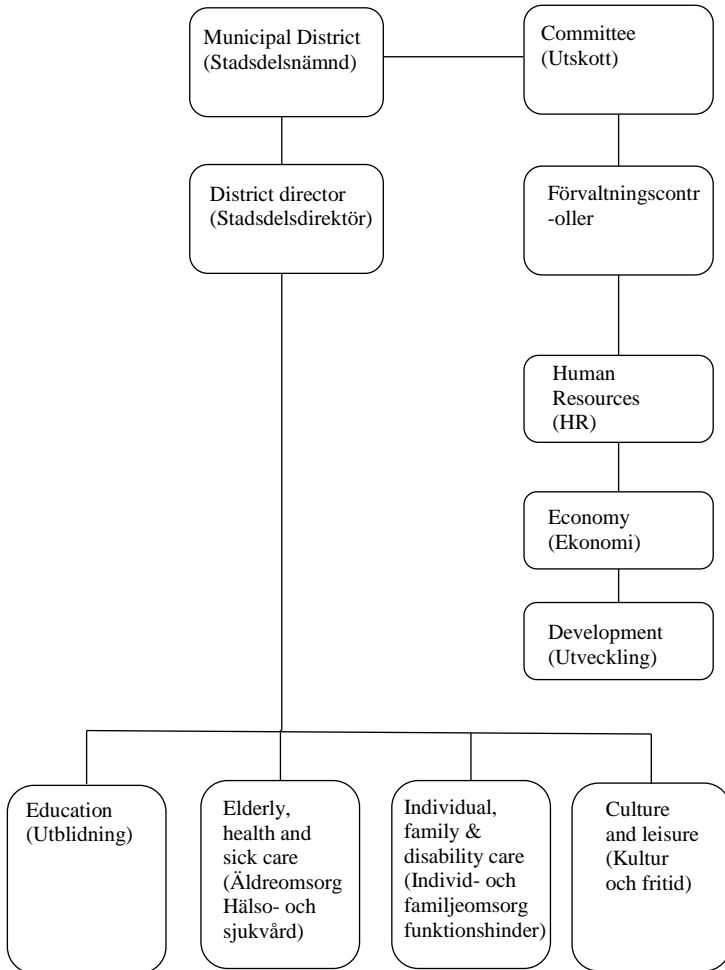
*Figure 1.* Organizational map of municipal districts in Gothenburg. Adapted from *Göteborgs Stad webpage. Stadsdelsförvaltning.* Retrieved from
http://goteborg.se/wps/portal/enheter/stadsdelsforvaltning/vastra-hisingens-stadsdelsforvaltning/

```
                    ┌─────────────────────┐
                    │   Sector manager    │
                    │   (Sektorschef)     │
                    └─────────────────────┘
                                    │
                        ┌───────────────────────────┐
                        │  Operations developer     │
                        │ (Verksamhetsutvecklare)   │
                        └───────────────────────────┘
```

Manager: support and service (Områdeschef : Bistånd och service)

Manager: work market and employment (Områdeschef: Arbetsmarknad, sysselsättning)

Manager: Home and personal support (Områdeschef : Boende, personligt stöd)

Manager: common/general manager (Gemensamma chef)

**Unit for children, youths and families (Enheten för Barn, unga och familj)**
**Unit for adults including:Adult resources and child resources units  (Enheten för Vuxna inkl resurs vuxna, resursenheten Barn)**
**Support unit phys (Biståndsenheten Fys)**
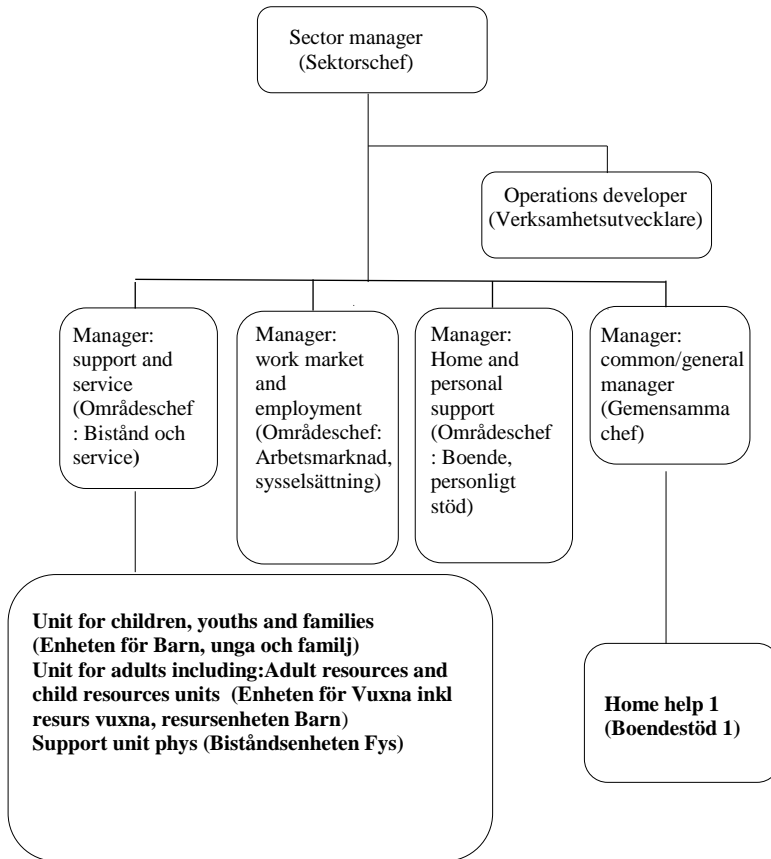
**Home help 1 (Boendestöd 1)**

*Figure 2*. Map of use of PYC in the individual, family and disability care sector in one municipal district in Gothenburg.

## Translation and Adaptation of Parenting Young Children

In order to enable the implementation of PYC in Sweden, the program has been translated from English to Swedish. This is relevant because interventions suitable for one group may not be applicable across different populations or communities (Guerra & Knox, 2008). Apart from the issue of accurate language translation, cultural-fit can be important from the perspective of the client and the agency, depending on political, religious and economic factors, as well as on cultural norms for family life (Kumpfer, Pinyuchon, Melo, & Whiteside, 2008). Some authors (Castro, Barrera, & Martinez, 2004) propose that both surface and deeper changes to programs may be acceptable, provided that program structure and key components are not affected. PYC has therefore been contextualized and translated in close collaboration with the program developers, taking care to avoid dilution of key program components. However, given that the program is still under development and has not been subjected to rigorous evaluation, possibilities to improve and accommodate the contents of the manual have also arisen.

Thus, a number of changes were made to the PYC manual as part of its translation. To date there have been three main versions. In Version I, PYC was translated from English to Swedish for the first time. This was completed by a professional translator. The initial translation was then further developed by a reference group from different agencies who worked as experts and consultants for the PYC project (e.g., representatives from Rädda Barnen (Save the Children) and the coordinating psychologist from Barnhälsovården (Child Care Unit), Södra Älvsborg County) (Mensas, 2014). Experts outside of the reference group were consulted where necessary, as well as practitioners who had used the original program translation in practice. This process highlighted a number of necessary changes. For example, some checklists in the original Australian manual described how children should be protected from the sun. For the Swedish version it was also necessary to develop checklists for protecting children from cold weather conditions.

Following this, in Version II, the text was again expert-reviewed by the PYC research group and other consultants, and consideration was given to feedback from the professionals who took part in the first training sessions, as well as from focus groups. Local rules and regulations, and the UN convention on the rights of the child were consulted (Mensas, 2014). One of the largest changes was made to the manual in Version III. In the previous versions, as part of the parent-child interaction module, parents were taught to ignore the child's bad behaviour, such as tantrums or whining (a component of Eyberg's Parent-Child Interaction therapy; Eyberg, Boggs, & Algina, 1995). Instead, due to concerns that parents may misuse the ignoring strategy, a section on training and setting boundaries on negative behaviours was inserted. Finally, a back-translation from Swedish to English was completed for Version III. This has been reviewed and approved by the program developers in Australia.

## Developing an Implementation Strategy for Parenting Young Children

When PYC was imported and contextualized for Swedish circumstances, there were no specific recommendations or outlines for implementation support and training of program users and agencies. Implementation research and theory have therefore played a vital role in setting up a system for assisting support workers in learning to use PYC, and also, in developing ways to examine program fidelity.

## An Introduction to Implementation Research

Investigation of how interventions are implemented first began appearing in the 1980s (Meyers, Durlak, & Wandersman, 2012). As this area grew, the complexity of the implementation process became increasingly apparent. For example, eight aspects of implementation have been identified, as well as at least 23 personal, organizational, or community factors that are influential (Dane & Schneider, 1998; Durlak & DuPre, 2008). Because implementation happens in complex, applied contexts, experimental designs that account for all of these variables are difficult to conduct, and rigor and generalizability can suffer as a result (Meyers et al., 2012). Today there is a better basis of both qualitative and quantitative studies that investigate this process in a more systematic manner (e.g., Domitrovich, Gest, Jones, Gill, & DeRousie, 2010; Fagan, Hanson, Hawkins, & Arthur,

2008; Walker & Koroloff, 2007). Researchers have made extensive attempts to describe implementation, from description of different steps in the implementation process (e.g., Fixsen et al., 2005; Fixsen, Blase, Naoom, Van Dyke, & Wallace, 2009), to conceptual frameworks based on research and practical experiences (see Nilsen, 2015, for an overview).

Implementation frameworks summarize "ideas and practices that shape the complex implementation process and can help researchers and practitioners use the ideas of others who have implemented similar projects" (Meyers et al., 2012, p. 465). They are therefore useful in helping to understand the implementation context and how implementation can be aided. Frameworks may be based on process models, determinant frameworks, classic theories, implementation theories or evaluative approaches (Nilsen, 2015). As a result, accumulating of a coherent research base is difficult. Efforts have been made to design comprehensive implementation frameworks, which consider a number of different theoretical perspectives simultaneously, for example, Meyers and colleagues' Quality Implementation Framework (2012), and Fixen and colleagues' (2005) frameworks for implementation. The National Implementation Research Network (NIRN) has developed five overarching frameworks of implementation referred to as the Active Implementation Frameworks (Fixsen et al., 2005). NIRN's model of *Implementation Drivers* was used in order to build a support system for support workers implementing PYC in Sweden.

## The Swedish PYC Implementation Support Model

**Implementation drivers.** According to Fixsen and colleagues' (2005) model of implementation drivers, the factors which lie behind an organization's ability to adopt interventions can be categorized into *competency drivers*, *organization drivers* and *leadership drivers*. Briefly put, leadership drivers include the need for leadership that can help to cope with technical issues, such as time or funding, and adaptive issues, such as deciding on how best to approach problems. Organization drivers include facilitative administrators, systems interventions and staff performance assessments. Facilitative administrators are individuals who help to change organizational practices and provide a good environment for the implementation of interventions. Systems intervention includes the provision of adequate financial, organizational, and human resources to support those who use the program (e.g., Klingner, Ahwee, Pilonieta, & Menendez, 2003). Staff performance assessment involves feedback on performance, for example program fidelity, which can help the practitioner to continue to improve his/her performance. Competency drivers include staff selection, preservice and in-service training, and ongoing coaching and consultation. This means that individuals with the appropriate education/experience must be chosen to implement the program. These individuals must also be provided with appropriate education and training, and furthermore, must receive direct feedback about how the program is used in practice in order to achieve high fidelity.

In reality, when implementing interventions, it is difficult to account for and support each of these different implementation drivers to the full extent that might be desirable. However, these components are integrated and compensatory, in that they influence each other and can replace each other if necessary. In implementing PYC in Sweden, competency drivers and organizational drivers, in particular, have been in focus.

**Components of the Swedish PYC Implementation Support Model (SweISM).**
The Swedish PYC Implementation Support Model (SweISM) provided competency
drivers in the form of initial training and ongoing support. The model aimed to ensure that
program users retained knowledge about PYC after initial training, to offer the
opportunity to discuss problems encountered and to provide feedback about program
implementation. It did not include more intensive, structured and evidenced-based
methods of supporting practitioners or agencies, such as on-site coaching (Reinke,
Stormont, Herman, & Newcomer, 2013). Instead, it aimed to provide support that was
cost-effective and sustainable over the long term, by investigating the use of peer support
as an alternative support method. Peer support is not included as a potential competency
driver in the implementation drivers model (Fixsen et al, 2005). To date, there is little
research that investigates the potential of this kind of support in the implementation
process. The SweISM included three main elements; workshops, monthly peer support
groups and peer support group facilitators, known as Area Coordinators (see Figure 3).

*Workshops.* Workshops, with the PYC program creators, incorporated both
lecturing and active learning techniques, such as role play. Introductory workshops were
aimed at program users with no previous experience or training in the program and
provided basic knowledge about goal setting, teaching methods and approaches to
teaching child care and parent-child interaction according to PYC. Booster workshops
included more in-depth training for program users who had already received introductory
training. These workshops focused more closely on program fidelity and problem solving
related to actual experiences of using PYC in practice.

*Monthly peer support groups.* The peer support groups were intended to provide
continued support for skills development in working with parents with intellectual
disability and to support the implementation of PYC, by offering the opportunity to
discuss problems encountered in implementation and to receive feedback about program
implementation. Meetings were semi-structured and involved interacting with colleagues
to discuss problems faced in implementation, to reflect on experiences of using the
program and to practice key program skills. The location and size of peer support groups
was based on the spread of workplaces in participating municipalities. In most cases, a
number of geographically close support workers, from different municipalities, would
attend the same peer support group together. This meant that, in many cases, individuals
from different workplaces met to discuss PYC.

*Area Coordinators.* Area Coordinators facilitated peer support group discussion,
organized times and venues and acted as a connection between the Swedish research
team, the Australian program developers, and the Swedish organizations within which
PYC was being implemented. They were supported by the research team and program
developers, as well as having regular meetings with other Area Coordinators. Area
Coordinators were not PYC experts. However, over the course of the 3 year project, they
accumulated considerable experience of the program, and knowledge of problems in
implementation from the different implementation sites where they worked. They also
received additional support from the program developers and the research team in the
form of meetings where they could ask questions and raise issues. In addition to their role
in assisting competence development, Area Coordinators were also considered to be

organization drivers, facilitating good environmental and organizational conditions for program implementation through their contacts with managers.
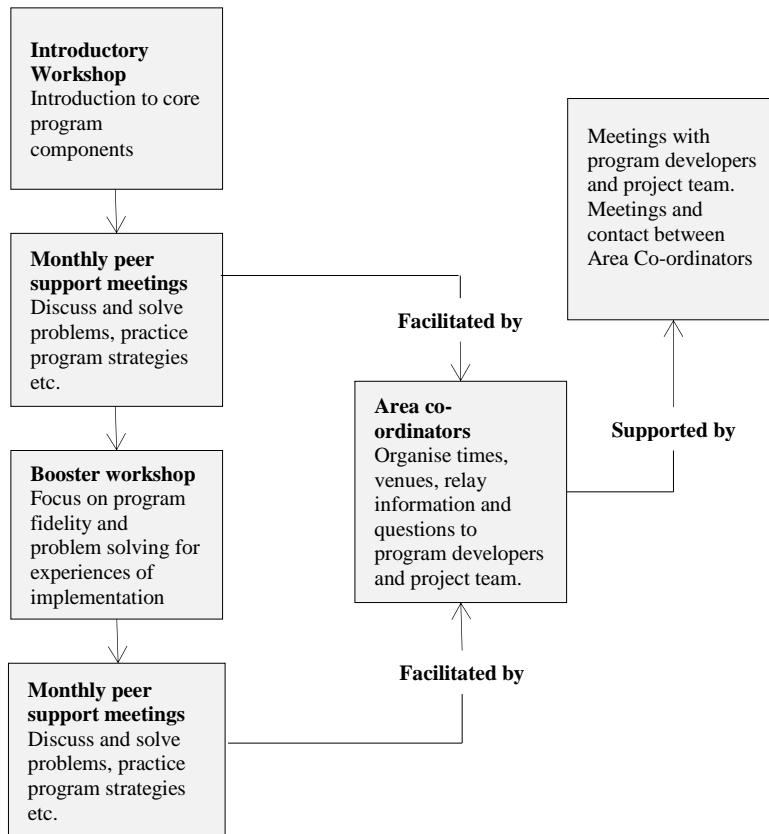


*Figure 3.* The Swedish PYC Implementation Support Model (SweISM)

## Research Support for the SweISM

A combination of workshops, manuals and ongoing support in the form of supervision or coaching is considered to be a gold standard of implementation support (Beidas & Kendall, 2010). The importance of training and on-going technical assistance has the most empirical support of all approaches which are understood to assist implementation (Meyers et al., 2012). For example, one study (Miller, Yahne, Moyers, Martinez, & Pirritano, 2004) showed, in a randomized control trial, that the use of performance feedback and expert coaching increased post-training proficiency. Fixsen and colleagues (2005) suggest that immediate feedback in the context in which the program will be applied is most effective for program fidelity. Research suggests that this training should furthermore be provided by an official coach (Miller et al., 2004).

However, as in the case of PYC in Sweden, this is not always an option when the necessary resources are not available (Ramanadhan, Wiecha, Gortmaker, Emmons, & Viswanath, 2010). For this reason, it is important to find and test more accessible and sustainable methods of easing the implementation process for practitioners and organizations. In the implementation of PYC in Sweden, peer support has, therefore, been used as a replacement for on-site coaching, in order to assist both program learning and organizational adoption.

   **Peer support.** The peer support referred to in this thesis is based on research relating to peer teaching and learning. Peers refers to individuals who are equal in abilities, social status or qualifications. People commonly learn from their peers in an informal fashion, whether it be at work, in their personal life or in a school setting. In one sense, any attempt to study peer learning processes formalizes this type of learning, by making it more explicit and using it in a purposeful manner. Moving towards formalization of peer learning may have a positive impact on students by taking advantage of processes that cannot be utilised by teachers or supervisors (Boud, 1992). In contrast, supervision involves a student or less experienced individual observing, being helped or receiving feedback from a more experienced and established member within the field (Smith, 2009). Thus, the distinguishing feature, differentiating between peer learning and supervision, is the presence or absence of a hierarchy between two or more individuals, based on knowledge, competence or social status.

   Formal supervision, in contrast to peer learning, emphasises training and competency in supervisory skills. Therefore, mastery of the skills that the supervisor oversees is not enough in itself to lead to good supervision (Smith, 2009). As such, supervision is a clearly defined role in many fields, which requires specific qualifications. Clinical supervision for mental health professionals, for example, has been divided into a number of different models or approaches (e.g., psychotherapy based supervision or developmental based models; Näslund & Ögren, 2010). Supervision may be provided for students, or qualified professionals, and may be either group or individual based

   However, the concepts of peer learning and supervision are not necessarily mutually exclusive, as learning interventions may place peers and supervisors at different status levels. Recently, there has been increasing interest in the use of helpers or facilitators (essentially taking on supervisory roles) who have more similar capabilities to the people that they teach (Topping, 2005; Secomb, 2008). The helper may be a more appropriate model for the student. This type of teaching is collaborative and learners are self-directed (Topping, 2005; Secomb, 2008).

   A variety of peer learning strategies have been investigated, including peer tutoring, peer teaching, peer group learning and peer consultation, amongst others (Lincoln & McAllister, 1993). In this thesis, the term *peer support* is used to differentiate the approach from other methods used in the field. Peer support refers to semi-structured, peer-lead groups that are intended to assist program implementation by providing mutual support and feedback for individuals trained in the PYC program. The Area Coordinator acts as a kind of inexpert supervisor. In the PYC project, the Area Coordinators had a similar, or slightly higher, level of training to other members of the peer support groups. They also gained experience and knowledge, over time, from working with several peer support groups. Furthermore, they received greater program support from the research

team and the program developers. They did not receive formal training in their role as a peer group facilitator, learning instead from continued practice. They also helped with organizational issues which arose in discussions in the peer support groups. Research relating specifically to the use of this kind of inexpert support in the implementation process is difficult to find. However, there are many relevant published studies on the effects of peer teaching and learning.

Research has suggested that peer learning and support can result in increased confidence, enthusiasm and feelings of competency, as well as decreased isolation (Secomb, 2008; Zins, Maher, Murphy, & Wess, 1988). It has also been argued that peer learning helps students and professionals to learn how to learn, by actively encouraging them to take responsibility for their own learning process (Boud, Cohen, & Sampson, 1999; Boud & Middleton, 2003). The use of peers is thought, potentially, to overcome difficulties that might be associated with using hierarchical structures that involve discussion leaders, in that having an authoritarian presence may hinder the free exchange of ideas. A valid concern, on the other hand, is that peer leaders might lack adequate knowledge, thereby providing advice that may be inappropriate or of poor quality. Poor learning may also be an outcome, if learning styles are not compatible (Secomb, 2008).

Comparatively little is known about the role of peer group facilitators and their perspectives. The extant research, largely from studies that examine approaches to health promotion, suggests that peer facilitators can be empowered to act as change agents (Booker, Robinson, Kay, Najera, & Stewart, 1997), as well as feeling satisfaction and personal benefits (Norr, McElmurry, & Misner, 1999).

## Use of Evidence and Fidelity to Parenting Young Children

Evidence produced from research studies can be used in different ways in practice settings. Instrumental use of evidence involves "the direct impact of research on policy and practice decisions" (Nutley et al., 2007, p.36). Conceptual use, on the other hand, is less direct, and, instead, raises consciousness of issues and influences understanding and attitudes. Instrumental use is most relevant in this thesis, since PYC aims to do more than raise practitioners' awareness about parents with intellectual disability, but to also influence how practitioners behave. Within Fixsen and colleagues' *Usable Interventions Framework* (2005) it is argued that the instrumental use of evidence should involve faithfully reproducing the same behaviour in different contexts. In other words, practitioners should have fidelity to the original research, and thus, presumably, should produce the same results. According to this framework, in order for an intervention to be practically usable it must fulfil four specific criteria. Firstly, there must be a clear description of the intervention: the intervention must have distinct values and principles, and the target population who will benefit most must be clearly defined. Secondly, information about essential functions must be available, meaning that the specific functional aspects of the intervention must be known. Unless these core components of the intervention are identified, it is difficult to establish whether or not it is actually used as intended. Thirdly, operational definitions of core program components must be available. The core components must therefore be adequately described so that they are reproducible in practice and can be used in a consistent manner. Finally, performance assessments or fidelity measures should be available to provide evidence that the

intervention is used as intended. The section below discusses PYC as a manualized program, in light of these characteristics of usable interventions, with particular emphasis on establishing and defining program fidelity.

## Establishing Fidelity using Manualized Programs

Detailed intervention descriptions are used in efficacy research in order to control for extraneous variables and type III error, allowing researchers to distinguish between intervention failure and implementation failure (Nelson, Cordray, Hulleman, Darrow, & Sommer, 2012). Variations in dosage, program use and following an intended protocol all have an effect on outcomes (Dobson & Cook, 1980), with many research studies showing that high fidelity is related to better program outcomes (e.g., Abbott et al., 1998; Becker, 2001; Keith, Hopp, Subramanian, Wiitala, & Lowery, 2010). Fidelity is not a simple concept, however, and there are varied uses and conceptualizations in the research literature (Carroll et al., 2007; Dusenbury, Brannigan, Falco, & Hansen, 2003 ; Kilbourne, Neumann, Pincus, Bauer, & Stall, 2007). O'Donnell (as cited by Nelson, Cordray, Hulleman, Darrow, & Sommer, 2012), for example, outlines seven different definitions used in health and educational research. One frequently referenced example (Dane & Schneider, 1998) breaks fidelity down into five components; (i) Adherence - the extent to which practitioners implement aspects of the program as intended; (ii) Exposure - dosage or amount of treatment the client receives; (iii) Quality of delivery- whether practitioners preform the tasks to a sufficiently high standard; (iv) Participant responsiveness – the extent to which the participant/client engages with the program and whether they react as expected and 5) Program differentiation - whether or not the program differed from a control condition. Furthermore, fidelity has been said to be moderated by factors such as intervention complexity and facilitation strategies (Carroll et al., 2007)

The desire to achieve consistency in how practitioners use research evidence has influenced how research is communicated and disseminated. Given that academic research can be difficult for practitioners to both access and interpret (Crosswaite & Curtice, 1994; Williams & Coles, 2007), guidelines and detailed manuals are often used (Fraser, 2003) as an alternative to requiring practitioners to independently seek out and evaluate available evidence. Guidelines can include broad recommendations for best practice in applied fields, and are *"systematically developed statements to assist practitioner and patient decisions about appropriate care for specific clinical circumstances"* (Field & Lohr, 1990, p.8). Programs, in contrast, such as PYC, are more specific and comprehensive. Programs, therefore, target a particular issue or type of approach. In such cases manuals are often used in tandem with training in order to act as a resource and complete guide for following a program. Some manuals might also go further, acting as educational tools in themselves and include literature reviews, detailed descriptions of techniques, case examples, and suggestions for how to structure and sequence an intervention from start to finish (Fraser, 2003).

## Establishing Fidelity in Parenting Young Children

**Considering program flexibility versus structure.** One might assume that manuals are consistently rigid and prescriptive. However, manuals can have several different forms (Addis, 1997). It has been postulated that manuals limit creativity and

flexibility of practice, causing practitioners to behave in a standardized manner (Forbat, Black, & Dulgar, 2014). However, manuals do not necessarily clearly address every potential aspect of fidelity, and, may therefore come to rely, to varying extents, on the practitioner's own judgement. For example, key program components and methods for tracking quality might be specified, while guidance on length of treatment, or how the client should react and engage over time might be excluded. It is difficult, and some suggest undesirable, for an intervention to encompass every potential eventuality. As a consequence, several studies have highlighted the importance of program adaptation. For example, the Rand Report (Berman & McLaughlin, 1976) identified three outcomes of efforts to implement programs: mutual adaptation, non-adaptation (also referred to as non-implementation) and cooptation. Mutual adaptation includes changes that take place both in the intervention and the setting/organization (Berman & McLaughlin, 1976), and has been found to be most desirable option in leading to behaviour change.

While all manuals may be classified as standardized, the degree of standardization can vary. A highly standardized manual may be most appropriate for clients with clearly defined and recognizable problems (Buck & Dent-Brown, 2014; Gaston & Gagnon, 1996). Flexible standardized manuals (Gaston & Gagnon, 1996) may be necessary for less well defined problems. The first manual therapies in psychology were behavioural manuals in the 1960s. These kinds of interventions are relatively easy to communicate in manual format because they involve highly specific and generalizable procedures, such as, tracking behaviour, reinforcement and prompting (Buck & Dent-Brown, 2014). In contrast, flexible standardized interventions allow for individualization, depending on the client (Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 2009). Thus, interventions might look substantially different from one person to the next, depending on their specific needs. PYC represents the latter form of program, where a large number of decisions are left to the support worker's judgement. The support worker develops an individualized intervention within the PYC framework and, based on the parent's goals and needs, chooses how many goals to set, what pace to work at, and which teaching approaches to use.

Program fidelity is emphasised within the PYC manual and education. When PYC was first introduced in Sweden, practitioners received checklists of core program components and were encouraged to track fidelity over time. However, these aspects of PYC had not been evaluated and were found to require further development in order to track practitioners' performance. Therefore, two of the studies presented below examine the issue of program fidelity within PYC. Particular emphasis is placed on developing methods for assessing program fidelity.

# Section 3: Summary of Studies and General Discussion

The general aim of the thesis is to critically evaluate how feasible and successful the implementation of the Parenting Young Children (PYC) program has been to date in Sweden, in particular, in relation to program fidelity and the provision of program support and education in the form of peer support (as outlined in the Swedish PYC Implementation Support Model (SweISM) above). The empirical studies provide greater insight into experiences of implementing PYC in Sweden.

As proposed in Fixsen's framework of Implementation Drivers (2005), it is known that continued and varied forms of support, following initial training, are necessary for facilitating implementation, notwithstanding the fact that these kinds of support are costly and demand extensive resources. Study I and Study II, therefore, investigate the use of peer support, in conjunction with workshop training, manuals, and facilitation from Area Coordinators as a competency driver and organizational support for PYC. Study III and Study IV investigate how the program itself is used and perceived by support workers and managers who work with PYC, with a focus on establishing and measuring fidelity to PYC.

## The Parenting Young Children Project: A Timeline

PYC has been implemented in Sweden as part of a three year research and development project (2010-2013). Thus, this thesis forms part of a larger implementation study. While the current theses focuses on implementation supports, fidelity and characteristics of PYC, the larger research project also examines implementation outcomes, caregiver outcomes and potential moderators (see Figure A1 in the appendix for an overview of the PYC project model).

Due to the project status of the implementation of PYC, the focus has been on innovation and testing of new ideas and implementation solutions within a fixed timeline (see Figure 4). The first introductory program workshop was held in English by the program developers in October of 2010. The peer support structure began after soon after, on a pilot basis. It was during this period that Study I took place.

Further PYC workshops took place in March of 2012, and the booster and introductory format described in the previous section was introduced to meet the needs of support workers in the field. Following this, the monthly peer support structure continued. Peer support meetings became more distinct and structured, as more agencies took part and the project team gained more experience. While the content of these meetings was still being directed by the group members, Area Coordinators began to use checklists, developed as part of the project, to help in structuring meetings. The aims of the meetings also became more established. It was around this time that Study II took place.

In 2013, two more booster workshops were provided, the second of which, for the first time, was provided by a Swedish trainer. The peer support meetings also continued after this training. It was during this period of the PYC project that Study III and Study IV took place.
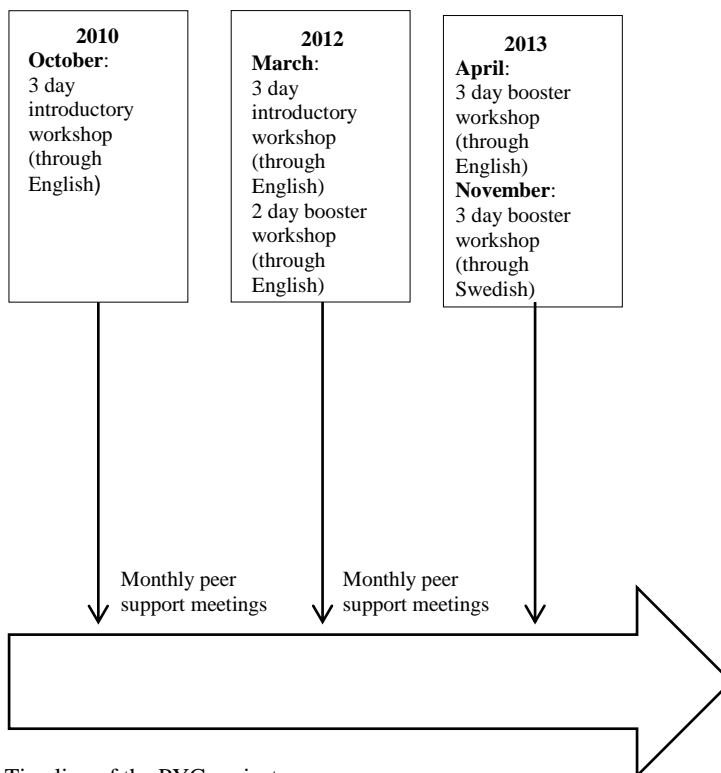
| **2010**<br>**October**:<br>3 day introductory workshop (through English) | **2012**<br>**March**:<br>3 day introductory workshop (through English)<br>2 day booster workshop (through English) | **2013**<br>**April**:<br>3 day booster workshop (through English)<br>**November**:<br>3 day booster workshop (through Swedish) |

Monthly peer support meetings

Monthly peer support meetings

*Figure 4.* Timeline of the PYC project

# Ethical Considerations

All four studies included in the thesis were approved by the Regional Ethical Review Board in Gothenburg, Sweden (Dnr 055-12(T180-13), "Att Pröva och Utvärdera Föräldrautbildningsprogrammet 'Parenting Young Children'" ("Testing and Evaluating the Parent Education Program 'Parenting Young Children'")). Stipulated ethical precautions were maintained through the safe storage and de-identification of all research data gathered as part of the project. Written informed consent was also obtained from all participants after they had been informed about the purpose of the studies and intended use of the data.

In general, standard ethical guidelines were strictly followed. However, it was vital to give extra consideration to the ethical inclusion of parents with intellectual disability in Study IV. Persons with intellectual disability are regarded as especially vulnerable and in need of particular attention and care (Pilnick, Clegg, Murphy, & Almack, 2011). Effective communication of the purpose of the research and ensuring that terms of participation are clearly understood can present a difficult task, especially for individuals with cognitive and reading difficulties (Dye, Hare, & Hendy, 2007). In such cases, consent forms and study information may be more appropriately presented verbally or accompanied by pictures. Furthermore, researchers need to be more sensitive and aware of signs of non-consent (Swaine, Parish, Luken, & Atkins, 2011). Extra care was

therefore taken in achieving informed consent from parents with intellectual disability in Study IV. They were provided with oral and written information and opportunities to end participation, at any stage, was emphasized throughout the research process.

# Study I

Study I was an investigation of how the Swedish PYC Implementation Support Model (SweISM) was received and perceived by support workers in the early stages of program introduction in Sweden in 2010. This study aimed to explore their perceptions of the training methods provided in the SweISM (i.e., the workshop, manual and peer support groups). It also investigated experiences of how these methods influenced perceived competence development. Since the SweISM was in the earlier stages of its development, it meant that roles and aims of different aspects of the model were less well defined.

## Method

Thirty one (31) support workers (i.e. program implementers, working in Swedish social services) from eight municipalities participated in focus groups. Twelve of these support workers also completed a competency questionnaire. A repeated measures design was used. Five separate focus groups met on two occasions (two to three months after the introductory workshop and almost 1 year after the workshop). Each meeting took place over approximately three hours. A focus group interview protocol was used, which included questions about perceptions of the PYC program, contextualization of the program for Sweden, and experiences of using the program with parents.

A shortened version of Clayton, Chester, Mildon and Matthew's (2008) training questionnaire was collected twice, after the PYC workshop and one year later. The questionnaire included ratings of both perceived importance and perceived skills in 9 different training areas relating to work with parents with intellectual disability. Participants rated their perceived skill in each area on a scale from 0 (*not relevant for my work*) to 5 (*advanced level of skill*). The total perceived skill score was obtained by calculating the mean score across the nine items. The data described here is a subset of a larger data set. The process and logic for reducing the original dataset is explained in Figure 5.

**Analysis.** Thematic analysis (Braun & Clarke, 2006) was used to analyse the focus group data. The analysis focused on experiences of the training methods, the training process and reflections about skills development. While reliability measures were not used in this study, both authors discussed and amended the themes together throughout the analysis. For the competency measure, descriptive statistics are reported and the data were analysed using an exact sign test.
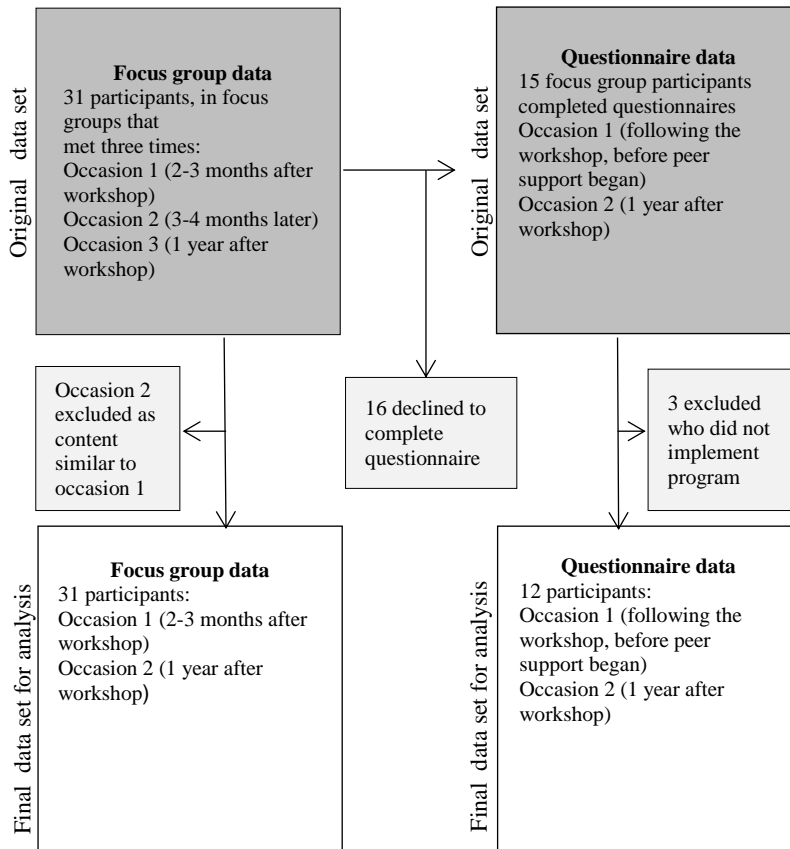
*Figure 5.* Process of reducing the original data set

## Results

      **Focus groups.** Three main themes were identified: (i) *initial challenges to learning*, (ii) *skills development* and (iii) *continued training needs*. The themes describe support workers' discussions about the training process and skills development over time. Under the theme initial challenges to learning, one of the most common discussions amongst support workers was difficulties in finding appropriate target parents to implement the program with. A high level of paperwork and disorganization of the PYC manual were also perceived to be problematic. Under the theme of skills development, participants were largely positive towards the program manual and workshop training. Application of the program in real-life settings was identified as an important step in the competence development deemed necessary for development of program-relevant skills. Some had difficulty in applying this knowledge in practice without on-site coaching or support. Conversations in the peer support groups were thought to offer a structured way

of practicing program skills and exchanging information and tips. This was thought to be particularly valuable in cases where support workers did not yet have a family to work with. Regarding continued training needs, a desire for further training and additional supports, such as coaching and increased contact with program developers, was expressed.

**Training questionnaire.** Perceived skills in all areas of concern were high on both occasions, with mean ratings over the midpoint of 2.5. The exact sign test revealed that total perceived skill scores were significantly higher at the end of data collection in comparison to when the study began ($p = .012$), suggesting perceived skill improvement in working with parents with intellectual disability over the period of data collection. Seven of the nine areas were perceived to have some improvement. However, these differences were not compared statistically due to the small sample size. Skills that were not perceived to improve were *notification of social services concerning maltreated children/children at risk of maltreatment*; *human relations/interactions* and; *questions about sexuality*.

# Study II

Study II investigated the perspectives of the peer support group facilitators (i.e., Area Coordinators). The aim was to examine more closely the perspectives of Area Coordinators on peer support groups who were active in the later phases of the implementation process of PYC in Sweden (2012-2013). A further aim was to generate a deeper understanding of PYC peer support groups, by investigating Area Coordinators experiences of: (i) the content of meetings; (ii) of how support groups were used and developed over time; and (iii) the Area Coordinators' reflections on their own work with support groups and with agencies.

## Method

Data for this study came from a focus group conducted with the Area Coordinators in early 2014, and from peer support group diaries, completed by Area Coordinators once a month, following peer support meetings. The diaries were collected over a period of between 4 to 18 months (mean = 11 months), starting with the first group meeting after the April 2013 PYC workshop. Five Area Coordinators participated (all women). Four of these were trained social workers and one had education in psychology. Data was collected on all 15 peer support groups, active in Sweden at the time.

**Peer support group diaries.** The diaries recorded information on duration of meetings, number of participants, and number of those participants who were currently using PYC actively with families. Additionally, the diaries contained a checklist of possible topics covered at the meeting. Area Coordinators indicated what topics they did and did not cover. Furthermore, the diaries included open ended questions, where Area Coordinators annotated additional topics, as well as their general reflections on the meeting.

**Focus group**. Four of the Area Coordinators took part in a focus group (1 hour 30 minutes in duration). A focus group interview protocol was used, covering perceived pros

and cons of peer support, problems faced, and the Area Coordinators' experiences of their own roles in the peer support groups.

**Analysis.** The focus group data were analysed using content analysis as described by Graneheim & Lundman (2004), assisted by NVivo software. Identified categories were subsequently tested for inter-rater reliability. Inter-rater reliability, ($\kappa=.85$, p $<.0005$), was deemed "almost perfect" according to Landis and Koch's guidelines (Landis & Koch, 1977).

The analysis of the peer support group diaries included an examination of descriptive statistics and content analysis, also assisted by NVivo software. All open ended responses were coded using the predetermined options provided as multiple choice questions in the checklist. New codes were also generated where necessary. These codes were checked for inter-rater reliability; there was substantial agreement between the two raters ($\kappa=.61$, *p* $<.0005$; see Landis & Koch, 1977). Finally, for the first eight meetings in each peer support group, codes were graphed over time. Because the data was collected on groups for different periods of time, it was not possible to graph and compare all of the collected data.

## Results

**Diary data.** Program implementation was low among most peer support groups, with 13 out of 15 groups having an average of less than 50% of members actively implementing the program. The most commonly discussed themes across all peer support groups were: setting goals, communicating and introducing PYC, recruiting families, and creating a working alliance.

When codes from the first eight meetings were graphed over time, results showed that meetings were largely used to discuss aspects of the PYC program which could be described as *the core ethos of PYC*. This included collaborative goal setting, role play and creating a working alliance. Little time was used to discuss or practice the technical skills which are part of the program, such as correct use of program materials, task analysis or specific teaching approaches.

**Focus group data.** Three main categories were identified*; organizational barriers to implementation, experiences of being an Area Coordinator*, and *functionality of the peer support groups*. The results showed that the Area Coordinators perceived several factors within the organization to be problematic for implementation of PYC, which, in turn, presented problems for the peer support groups. For example, Area Coordinators reflected that some organizations did not carefully select which employees to send to PYC training. Support workers were furthermore viewed, by the Area Coordinators, to have relatively low status within the organization and to have very poor access to resources. This was judged to make implementation difficult: because of a lack of time to practice skills; because of limited access to computers or other resources; and because of limited learning opportunities. Lack of knowledge in those managers and social workers that worked closely with the support workers was thought to be an important issue, which hindered referral of parents to PYC trained support workers. Perceived opportunities to overcome these challenges mostly involved including managers to a greater extent in the peer support meetings and establishing stronger ties

between the Area Coordinators and the organizations. However, inclusion of managers was seen as a difficult task.

While some Area Coordinators felt pressure to be an expert in the program, overall, they described their experiences as positive. They felt particularly well supported by other Area Coordinators in the personal challenges that they had encountered. On the other hand, they felt that they had little support for the professional challenges that they faced.

# Study III

Study III explored the concepts of feasibility and fidelity in delivering PYC. Feasibility, using the concept of program compatibility, in terms of: (i) support workers' and managers' general attitudes towards Evidence-Based Practice; (ii) support workers' perceptions of demands for the program, municipality based support from the social services, and past experience of parenting programs; and (iii) managers' perceptions of conditions for program implementation and support from staff. A second aim was to examine support workers' perceptions of program complexity in terms of their general experience of using PYC, including their views on program usability. Finally, fidelity was examined by investigating which aspects of PYC were used, in practice, by support workers.

## Method

Twenty seven (27) support workers (all women) from 15 municipalities participated in the study. While they had varied levels of training and work experience, all worked with parents with intellectual disability. Twelve line managers (9 women, 3 men), who worked closest to these support workers, also participated. The majority were employed as unit managers (*n*=5) at social service agencies implementing the PYC program.

Measures included the Evidence-Based Practice Attitudes Scale (EBPAS, Aarons, 2004), non-validated questionnaires developed specifically for assessing feasibility of PYC, and an implementation diary used to examine program fidelity. Both managers and support workers completed the feasibility measures in autumn 2013. Implementation diaries were collected over 14 months in total, from August 2013 to October 2014.

**EBPAS (Aarons, 2004).** The Evidence-Based Practice Attitudes Scale consists of 15 statements, rated on a scale from 0 (*not at all*) to 4 (*to a very great extent*), and contains four sub-scales, relating to different aspects of attitudes towards Evidence-Based Practice: appeal (4 items), requirements (3 items), openness (4 items), and divergence (4 items). The scale was translated from English to Swedish.

**Program compatibility (support workers).** Questions related to the perceived demand for PYC (*yes/no* response format) and perceptions of how appropriate the program is for their work (5 point scale from 1= *not at all appropriate* to 5=*very appropriate*). An open ended question asked participants to describe their work tasks. Support workers reported their experience with other parenting programs on a 5 point scale from 1 = *no experience* to 5 = *a lot of experience*. Support workers were also asked if they were satisfied with the support they received (*yes/no* response format).

**Program compatibility (managers).** This questionnaire addressed managers' perceptions of their staff's support for the program (5 point scale from 1=*yes, all*, to 5 = *none*) and the perceived conditions for implementing PYC within the agency (5 point scale from 1 = *very good,* to 5 = *very poor*).

**Program complexity.** Support workers were asked to report on their general experience of using PYC in their work (6 point scale, from 0 = *bad* to 5 = *excellent*), as well as how usable they perceived the program to be (5 point scale, from 0 = *unusable* to 4 = *unusable*).

**Implementation diary.** Fidelity was measured through an implementation diary, completed by support workers. In the implementation diary, support workers recorded the dates that meetings took place with parents, type of PYC activity (clarifying roles and expectations, goal setting, teaching the parent using PYC approaches, follow- up and observation) and PYC teaching approaches used (role play/coaching/discrimination training) (see Table 1 for an overview of PYC activities and teaching approaches). The type of PYC activity completed was reported via an open-ended question. Specific teaching approaches were reported via a multiple choice question.

**Analysis.** Due to the small sample size, cell counts were visually inspected in order to assess program feasibility, rather than using statistical analysis. Fidelity was analysed from the implementation diaries, based on support workers' reported use of different types of PYC activities and PYC teaching approaches in the sample as a whole. In order to complete this analysis, responses to the open ended question on teaching activities were firstly coded in vivo (i.e., codes were assigned using words or phrases taken  directly from the data). Activities that did not fit under the five types of PYC activities (i.e., clarifying roles and expectations, goal setting, teaching the parent using PYC approaches, follow- up and observation) were coded as *Non-PYC Activities*. Use of PYC activities was analysed by calculating the percentage of times each activity was mentioned out of the total number of activities for the whole sample (688 activities mentioned in a total of 588 PYC meetings). Use of teaching approaches was analysed by calculating the percentage of times each teaching strategy (role play/coaching/discrimination training) was mentioned out of the total number of reported teaching strategies for the whole sample (461 strategies mentioned).

Percentages for the reported PYC teaching approaches and activities used were also calculated, for each support worker, over the whole period when they were reporting implementation of the program with each parent. These percentages for individual support workers and mean percentages for the whole group are reported in line graphs and visually inspected. Participants who had reported less than 10 instances of performing PYC activities or less than 10 instances of using PYC teaching approaches were excluded from this analysis. The final sample for this analysis included 18 support workers working with 29 parents based on their reports of PYC activities performed, and 12 support workers implementing working with with 21 parents based on their reports of PYC teaching approaches used.

## Results

**Program feasibility.** Most managers reported very good conditions (58%) for implementing the PYC program. Managers furthermore reported that all (50%) or most

(42%) of their employees supported PYC and its implementation. From the support workers' perspective, the majority reported that there was a demand for PYC in their workplace (88%). They furthermore reported that PYC was either very appropriate, in general (47%), or appropriate to use as part of their usual work tasks (47%). Most of these support workers reported that they were satisfied with the support they received (82%) from the SweISM and from their agency. They did not indicate a desire to receive further support.

**Attitudes towards Evidence-Based Practices.** Both managers and support workers reported positive attitudes towards Evidence-Based Practices, with all subscale scores well above the midpoint of 2. Independent *t*-tests, using a Bonferroni adjusted alpha of .01 (.05/5), showed that the total sample of managers and support workers had significantly more positive attitudes towards Evidence-Based Practice compared to American population norms, as reported by Aarons and colleagues (2010). Swedish support workers and managers were significantly higher on the total score, ($t(34) = 3.46$, $p =.001$, $d = .52$), as well as the subscales: appeal ($t(34) = 5.16$, $p < .000$, $d = .75$); openness ($t(34) = 4.35$, $p = < .000$, $d = .55$); divergence ($t(34) = 12.9$, $p < .000$, $d = 1.99$); and requirements ($t(34) = 4.05$, $p < .001$, $d = .57$). In other words, on the dimensions appeal, openness, divergence and requirements, Swedish respondents were significantly *more positive* than comparable Americans

All of the support workers responded positively regarding PYC, with most reporting that their experiences were very good (47%). Similarly, support workers indicated that they thought PYC was either very usable (53%) or usable (41%) in their work.

**Program fidelity.** Over the period of data collection, support workers reported an average of 1.8 meetings per month (range 1-7) with individual parents. The reported PYC activities typically involved either directly teaching the parent skills using various PYC teaching techniques (70%), or goal setting with the parent (14%). Other PYC activities were reported much less frequently, and, furthermore, a number of other *Non-PYC activities* appeared to take place during PYC sessions (10%). *Non-PYC* activities included helping the parent with practical tasks, such as cleaning their apartment or child minding. A large variability in how PYC was implemented by individual support workers with individual parents was evident. Reporting of follow-up, clarification of roles and observation, was consistently low, with 59% of the sample never reporting any of these three activities.

The majority of teaching approaches recorded by support workers focused on discrimination training (47%), followed by coaching techniques (33%). Role play was reported least frequently (20%). Similarly to the results observed with PYC activities, there was a large amount of variation in the teaching approaches that individual support workers used with individual parents. For example, two support workers (implementing the program with 4 parents) reported using discrimination training alone, without reference to other teaching approaches.

# Study IV

Fidelity measures are a necessary component for the development of Evidence-Based Programs. Therefore, Study IV was aimed at developing, and assessing a fidelity

measure based on support worker (i.e., practitioner) and parent (i.e., client) ratings. Parents were included since they were considered to have valid and important insights into support workers' use of PYC. This also allowed for comparison between support workers' and parents' perceptions of PYC sessions. The goal of the study was to develop a PYC fidelity measure, establish perceived program fidelity for both parents and support workers, and examine agreement between support workers' self-reports and parents' perceptions of fidelity. Further aims included describing changes in fidelity over time and examining usability of the parent questionnaire.

## Method

Separate questionnaires for parents and support workers were developed to assess fidelity to PYC. The questionnaires were designed to enable comparison between support worker and parent perceptions of single PYC sessions. Therefore, the parent version included questions that are comparable to items in the support worker version, except that, in the parent version, straightforward language and a focus on concrete events was used (Ciemnecki & CyBulski, 2007). The questionnaires yield separate, but comparable, parent and support worker ratings of implementation fidelity. The items in both questionnaires were based on a core principles checklist, which is included in the PYC manual. Questions were developed in collaboration with the program developers. A repeated measures design was used, with data being collected once a month from autumn 2013 to autumn 2014.

**PYC Support worker fidelity measure.** The support worker version included 18 items relating to planning the intervention, goal setting, teaching skills, meeting atmosphere, evaluation of the intervention effectiveness, and generalization and maintenance of skills. Response options for each item included *yes*, *no* and *not-applicable*. The not-applicable response was included because PYC is an individualized program, meaning that not all aspects are relevant for each client or in every session.

**PYC Parent fidelity measure.** The parent version included 13 items regarding goal setting, teaching skills, and atmosphere of the meeting. All questions were phrased, using straightforward language and vocabulary, in order to be able to make comparisons with ratings for the support worker version. Some items were omitted from the parent version as they were deemed to either refer to concepts which were too abstract, or refer to aspects of fidelity which would be difficult for parents to assess, given their level of knowledge of how the program works. Response options for each item included *yes*, *no* and *not-applicable*. The parent version was completed by interviewers, via telephone, who read the question to parents and presented them with item responses.

**Interviewers' perceptions.** Questionnaires were also administered to the telephone interviewers' to ascertain their perceptions of both conducting the telephone interviews and of the parents' understanding of questionnaire items. This questionnaire included a question about interviewers' general experiences of conducting the interviews and their views on parents' level of understanding of questions posed.

The resulting data set was composed of fidelity questionnaires collected from pairs of support workers and parents over a mean period of 3.9 months (range: 1-9). It was not always possible to collect questionnaires from both the support worker and the parent regarding a specific meeting. In total, 60 fidelity measures were collected from support

workers, and 74 from parents, with 50 matching pairs. The interviewer perception questionnaire was administered to all five interviewers, after all fidelity measures had been collected.

Data was collected on 20 parents (8 men, 12 women) and 17 support workers (all women). There were 20 support worker-parent pairs in total. Support workers were from 15 municipalities in Sweden.

**Analysis.** Fidelity scores were calculated as ratios with *not applicable* responses being counted as missing data. For example, if responses to the 13 items from the parent version were: *yes* for 6 items, *no* for 5 items, and *not applicable* for two items: 6/11 = a fidelity score of .55. Fidelity scores could potentially range from 0 to 1, with 1 representing perfect fidelity. Cohen's kappa was used to establish inter-rater reliability, for the 13 comparable items, from the 50 matching support worker and parent versions of the questionnaire. In order to assess perceptions of fidelity over time, the first three months of parents and support workers questionnaires were analysed (i.e., 17 parents and 9 support workers) and examined graphically. Those who completed *less* than a three month quota of fidelity questionnaires were excluded. Because the data was collected in a naturalistic implementation context, intervention length (over a period of time) received by parents was not controlled for. Thus, data was collected, for a variation of time periods, from parent-support worker pairs. Examination of fidelity data, using a time period of three months, allowed for the inclusion of the most possible participants in this analysis.

## Results

The mean fidelity score for the whole sample of support workers was very high (.93, range: .77-1). Perceived fidelity was similarly high for parents, with a mean score of .94 for the whole sample (range: .57-1). Over a three month period, mean fidelity scores were consistently high, on average, for both support workers and parents. Parents, when compared with support workers, reported more variability in their assessments of fidelity.

The number of observed agreements between support workers and parents was 66%, which is classified as fair, according to Landis and Koch's (1977) guidelines, κ =.234 (95% CI, .164 to .304, *p*< .0005). Observer disagreements were almost exclusively related to parent and support workers disagreeing on which items were not applicable for a given session. One rater, typically, would respond that the item was *not applicable*, while the other responded *yes*. This meant that overall fidelity scores remained high in both groups, while, simultaneously, only reaching a fair degree of agreement. Parents reported *not applicable* (30% of responses) more frequently than support workers (15% of responses).

## General Discussion

The overall aim of the thesis was to make a critical evaluation of how feasible and successful the implementation of the Parenting Young Children (PYC) program has been, to date, in Sweden. While several aspects of implementation are addressed in the empirical studies, two primary implementation issues were in focus: program fidelity and the provision of program support and education, especially in the form of peer support. The general discussion that follows below is divided into two sections that highlight these

issues, namely, Reflections on the Swedish PYC Implementation Support Model (SweISM), and Reflections on Program Fidelity.

However, a number of general conclusions may firstly be drawn about the success of these first attempts to implement PYC in a Swedish context. In Study I, results showed that support workers, in general, were positive toward the supports provided to them as part of the SweISM and as part of the PYC program. Peer support groups were thought to be beneficial for performance evaluation, exchange of information and coping with problems. Support workers perceived themselves to be quite highly skilled in areas related to working with parents with intellectual disability, and also perceived that these skills improved over the PYC training period. Area Coordinators, in Study II, were similarly positive towards peer support. Studies III and IV turned attention to the use of the program in practice and to program fidelity. In Study III support workers reported that they implemented several aspects of PYC in practice with parents with intellectual disability. Both managers and support workers reported that the program was easy to use and compatible with their workplace and work tasks. Study IV found that parents with intellectual disability, and support workers, reported high program fidelity. Despite these generally positive findings, several obstacles to implementation and fidelity measurement have been identified in this thesis.

## Reflections on the Swedish PYC Implementation Support Model

In Study I, obstacles were observed in the use of peer support groups as a competency driver (Fixsen et al, 2005). Difficulties were reported in coping with the structured, manualized nature of the program, as well as in the challenge of moving from program learning to program implementation. Similar findings were observed in Study II, where few support workers succeeded in implementing PYC with parents with intellectual disability. Area Coordinators believed that support for agencies in implementing PYC and including managers in program learning and implementation was important in overcoming these difficulties, but that this was difficult to achieve. Furthermore, Area Coordinators perceived that support groups spent most time discussing key aspects or initial steps of PYC, such as program goals, recruitment of parents and introduction of the program to new parents. Less time was spent discussing, or practicing, technical skills. Peer support may, therefore, be seen as most useful in assisting general program understanding and attitudinal changes within agencies, rather than increasing program fidelity and more specific skills development. Two main issues would appear to arise: the ability to transfer learning from peer support/training to the practice setting; and a need for greater collaboration from the organizations implementing PYC.

**Transfer of learning.** In Study I, many of the difficulties described by support workers related to transfer of learning. Transfer of learning involves the application of skills learned in one context to another context (Perkins & Salomon, 1992). Near transfer includes application of skills to contexts which are similar to the context in which the skill was learned. Conversely, far transfer involves application of skills in dissimilar contexts (Perkins & Salomon, 1992). Far transfer is common within education, as students or professionals often learn new skills in classrooms and then, later, must apply these skills in the workplace. Past research has suggested that transfer is often difficult in such circumstances (e.g., Walters, Matson, Baer, & Ziedonis, 2005). In line with these

findings, results from Study I suggest that using peer support groups, which are removed from the practice setting, can present problems for implementation (Fixsen et al., 2005).

**Using peer groups to assist task alignment.** The SweISM has focused largely on ways in which to increase support workers' competency, and less on organization drivers such as facilitative administrators, and systems interventions (Fixsen et al, 2005). Despite the reports from managers, in Study III, that they had good knowledge of and support for PYC, there would appear to be a need for greater collaboration, cooperation and communication between individuals working directly with PYC and other individuals in the organization. Based on the Area Coordinators' discussions in Study II, in particular, it was evident that participating agencies, more broadly, required more support in order to increase engagement and knowledge of issues relating to parents with intellectual disability. This appears to be particularly relevant for those individuals who were closely involved with support workers' implementation efforts (i.e., their closest managers, and social workers). Increasing knowledge of PYC and of the specific conditions necessary for its implementation among influential decision makers within the organization is one potential means of overcoming the implementation and referral problems indicated in this thesis.

Facilitative administration and technical support could be incorporated into peer support groups in a more structured manner, as a possible solution to organizational problems, such as referral of target parents and the need for greater program knowledge within the organization (Fixsen et al., 2005). Increasing contact between Area Coordinators and managers is another potential way forward in helping to alleviate these problems.

Overall, these issues illustrate how broader organizational changes do not seem to have taken place in the agencies which have adopted the PYC program. The findings also show how difficulties arise when practitioners are trained in a new program, and then try to implement it in a system that is not yet structured to accommodate it. The use of supports, external to the agency itself (i.e., peer support groups), is not sufficient as a means of coping with these problems, since individual practitioners are not expected to work in isolation. They are reliant on the resources available at the agency, on the skills and knowledge of other practitioners in their agencies and on their managers (Gjems, 1997).

Exploration of the possibility of using peer support as a way of encouraging and assisting task alignment may therefore be of relevance (Beer, Eisenstat, & Spector, 1990). Task alignment can be defined as change which begins at the periphery of an organization. Thus, change is often driven by what needs to be done, rather than being based on abstract concepts such as participation or culture. According to Beer and colleagues (1990), in contrast to task alignment, the implementation of programmatic change, which focuses on individual knowledge, attitudes and behaviour, may not be effective. According to a task alignment model, employees' roles and responsibilities should, instead, be changed in order to solve specific problems. This approach is more focused on finding solutions to problems experienced in practice. In such situations, if Area Coordinators were more familiar with each agency's situation and challenges, they could assist individual managers and agencies in finding solutions to referral and knowledge related problems (Beer et al., 1990).

The project status of the implementation of the PYC program is also of relevance in regard to the possibility of task alignment. PYC has been implemented on a project basis. Outcomes and conditions that arise within specific projects may be substantially different to where implementation is on a non-project basis, since projects may tend to be more contained and self-sufficient (Packendorff, 1995; Borum & Christiansen, 1993; Pinto & Prescott, 1990). Therefore, strengthening existing organizational resources becomes highly important for the continued implementation of PYC, on a non-project basis, thereby bridging boundaries between project- and more permanent organizational structures (e.g., Lehtonen, 2007).

**Area coordinators as peer supporters.** One barrier to the task alignment discussed above would seem to be the skills and training of Area Coordinators. In relation to Area Coordinators' experiences of being peer facilitators, many advantages and benefits of their role were discussed in Study II. The position allowed them to have greater personal development and involvement in a field which they believed to be both interesting and of importance. The Area Coordinators felt supported, on a personal level, by contact and meeting with other Area Coordinators. However, they perceived a need for greater support for the professional challenges they were facing. Difficulties related to their level of knowledge, and the conflicts between being a peer and feeling pressure to play the role of an expert. More training is necessary for Area Coordinators to be able to deal with these kinds of challenges.

Further difficulties were presented by the fact that Area Coordinators were external to the agency itself. This meant that they were relatively unfamiliar with the agencies which were implementing PYC, and that they had to build knowledge and rapport with managers and staff over time. Thus, questions may also be raised in regard to the extent to which they could be considered to be real peers to the others in the various groups. Area Coordinators were better educated than most of the other members of the groups and had a higher position within the social services. Coupled with Area Coordinators' accumulation of additional knowledge and experience from working with several support groups, as well as having contact with the program developers and the project team, their experiences and struggles with pressure to take on a more expert role may not be surprising. Making the roles and responsibilities of Area Coordinators and other group members clear from the beginning is important for assisting groups in working well together.

To date, use of the label of supervisor has been avoided, in relation to Area Coordinators, mostly due to their lack of expertise in the PYC program. However, consideration of supervising theories may be relevant in training Area Coordinators, since assistance in coping with different group dynamics and challenges was one of the main areas in which Area Coordinators desired additional support. Internal group relationships, typically, are the most important theme in supervision. However, the role of the supervisor also includes dealing with external factors, such as conditions in the organization as a whole (Gjems, 1997). The communicative link between program delivery and program support is, therefore, extremely important. In line with a social systems perspective, Hawkins and Shohet's (Hawkins et al., 2012) seven-eyed model for supervisors working in human resource professions may be of particular relevance. This model purports that a supervisor must have knowledge in several different areas.

Therefore, supervisors may view their world through several different eyes, in order to be attentive to the many different elements, parts and aspects that constitute the whole. This, for example, might include a supervisor's self-reflections, and the wider context, such as, ethical, organizational, social and cultural dimensions their work.

Examination of the use of the SweISM in the current thesis highlighted several difficulties and opportunities in the implementation process of the PYC program. These may also be of some relevance for implementation strategies in other contexts. Most pertinently, a common problem with program implementation is that programs are designed to be applied in a standardized manner. However, in reality, the organizations and individuals who use them face unique problems that cannot be addressed by simply attending program training without follow-up or support. For this reason, when one program is seen to fail, organizations are often inclined to implement an alternative program, rather than attempting to solve those problems, at an organizational level, that may have hampered or impeded the original program (Beer et al., 1990). Such generalizable programs may, unintentionally, take focus away from helping agencies to solve the actual problems they faced when trying to help, support and identify parents with intellectual disability. Ultimately, while support structures such as the SweISM may appear to be beneficial, increased efforts are needed to bridge the gap between Evidence-Informed Programs, such as PYC, and the organizations within which they are implemented. It is also necessary to encourage agencies to think critically about and engage with the issues that make implementation of Evidence-Based Practice difficult.

## Reflections on Program Fidelity

In line with more general research on parenting programs for parents with intellectual disability (Wade et al., 2008), it is recommended that parents receive weekly, one hour, PYC sessions (approximately four per month) (Mildon et al., 2008). However, in Study III, parents received, on average, slightly less than two meetings per month. Furthermore, approximately 10% of reported "PYC activities" were not in fact PYC activities at all. In these instances, time was spent on more practical aspects of support workers' interactions with parents, such as, assisting with paperwork or house cleaning. There may be several explanations for this low intensity implementation, such as, a simple lack of time or awareness of the recommended frequently of PYC sessions. Future research, therefore, may need to investigate causes of and conditions conducive to such low implementation intensity, and focus on finding solutions to this problem, either by changing the program itself, or through providing additional education and support within municipalities.

Despite the apparent low implementation intensity received by parents, results from Study IV reveal that both support workers and parents perceived support workers as having high fidelity to core components of PYC. Although past research has shown that practitioners tend to have inflated perceptions of their program adherence (Lillehoj, Griffin, & Spoth, 2004), other research has uncovered areas of both convergence and divergence in self-reported and observational measures of program fidelity (Gross, Hurley, Ross, & Thompson, 2016). Self-reports are likely, therefore, to be indicative of practitioners' program fidelity in a more general sense. In light of this, results from this

study are promising. And, furthermore, parents reported several positive interactions and experiences with support workers.

PYC was, however, implemented in widely different guises by different support workers. Some behavioural aspects of PYC, such as following up on generalization and maintenance of skills, as well as observation of parents' skills, were, apparently, not used by some support workers. In regard to teaching approaches, while approximately half the sample used a mix of all three approaches, others reported that they had focused, almost exclusively, on discrimination training with parents over a period of several months. These results may be explained by factors such as inadequate training or a belief that some teaching approaches are inappropriate or difficult to use in practice (Keenan et al., 2014). Alternatively, given the flexibility of PYC, support workers may have tailored program delivery appropriately, based on parent's needs. Regardless of the reasons for these variations, building in program flexibility has potential consequences for how measurement of program fidelity ought to be approached.

**Program flexibility.** Program flexibility, which is inherent to the PYC program, has many potential advantages, since parenting involves challenges that are changing continuously, as the child grows and develops. Furthermore, practitioners, typically, are required to implement even very rigid programs across diverse contexts and with variously differing clients, which, in turn, means that strict guidelines do not necessarily equate to ease of implementation (Galinsky et al., 2013). Some research has shown that strict program fidelity does not always have a positive impact on implementation effectiveness (Castonguay, Goldfried, Wiser, Raue, & Hayes, 1996 ; Barber et al., 2006), whereas, moderate fidelity, employed by skilled workers, has been known to show superior outcomes in some cases. However, this reliance on program flexibility, can result in higher demands being made on support workers' skills and training. All four studies included in this thesis point to the fact that the PYC is being implemented, in Sweden, by a wide variety of support workers, with varying experience and educational backgrounds. In this context, flexibility is potentially problematic, especially for practitioners with less practical experience and insufficient knowledge about working with parents with intellectual disability. Coaching, in the form of on-site expert feedback, could further assist learning by providing feedback in more complex contexts, where a need for differences in techniques and problem solving strategies may be necessary (Miller et al., 2004). As stated earlier, this type of feedback is not provided as part of PYC training, but may be necessary to assist support workers in appropriately adapting PYC to individual parents' needs.

The most prominent conundrum posed by program flexibility was particularly apparent in Study IV. Namely, if PYC is to be flexible, what benchmark, or marks, ought to be used to judge program fidelity? In other words, how can one distinguish between instances where PYC is, or is not, fully implemented? This became most evident in the use of the *not applicable* response option used in the fidelity measure. The disagreement between parents' and support workers' assessments, on which aspects of PYC were relevant to which sessions, highlights a weakness in the fidelity measure itself. This also points to problems with objectivity when judging which aspects of the program should, or should not be included in sessions. PYC is currently regarded as an Evidence-Informed Program. However, future efficacy trials will most likely be required to better establish

eventual parent and child outcomes. Unless the PYC program is further developed, it will be difficult to distinguish between intervention failure and implementation failure. Development of clearer guidelines for how many sessions should be dedicated to certain activities would, therefore, be beneficial. Modular programs allow for flexibility for practitioners in choosing between modules, and allow for intervention modification, based on clients' goals. Practitioners are provided with specific guidelines on which course of action ought to be taken, based on clients' presenting symptoms (McHugh, Murray, & Barlow, 2009). Integrating such attributes into the PYC Program might also prove beneficial.

Ultimately, identification of the active ingredients of the program (and the specific circumstances in which they ought to be used) is necessary in order to simplify PYC fidelity measurement and to provide clearer guidelines for practitioners and parents (Herschell, 2010). As a first consequence, more time should be invested in developing the program theory of PYC and in identifying causal relationships between program components and outcomes (von Thiele Schwarz, Hasson, & Lindfors, 2015). Fidelity studies, typically, focus almost exclusively on reports of program adherence (von Thiele Schwarz et al., 2015). Little research has assessed relationships between self-reports and behavioural observations (Schoenwald et al., 2010), even less research has looked at the relationship between client reports and behavioural observations. A combination of expert behavioural observations, parent reports and support worker reports of program fidelity could provide more insight into how best to meaningfully integrate client ratings of fidelity for programs such as PYC.

## Limitations and Future Research

The results reported in this thesis ought to be considered in light of a number of limitations. In working with qualitative data, transferability refers to the extent to which any results can be applied to other contexts (Koch, 2006). In the current thesis the researcher attempted to provide a detailed description of the context, design and participants involved in the research, to enable readers to make an informed decision about the generalizability of the findings. The studies which form the body of this thesis are all based on small sample sizes and are open to differences in interpretation, thus making generalization to other contexts or time periods more difficult. In Study I, for instance, perceived skills development may have been due to the peer support meetings, to practicing the program with a parent over time, or, to other factors that were not accounted for in the research design. Furthermore, while all individuals trained in PYC were invited to participate in the studies, many declined. It is possible that those who declined or dropped out of the research had very different experiences of program implementation than those represented here.

Both Study I and Study II included focus groups. Using focus groups is a matter for debate among researchers, and has been criticized for generating superficial discussions, and for generating data that are difficult to interpret because of the effect of group interactions (Powell & Single, 1996). Focus groups were chosen in the current thesis because they provided a possibility of stimulating different viewpoints among participants, thereby uncovering discussion topics and perspectives which might not have been highlighted in one-on-one interviews (Kitzinger, 1995). None of the studies included

in the current thesis involved direct observations. Observation of support workers using the program in practice or participating in peer support would provide a more detailed picture of peer support, and program fidelity.

Other methodological limitations include the use of a simple language version of the fidelity questionnaire in Study IV. Responses to questions in the parent and support worker versions may, therefore, not be directly comparable. In order to further develop the PYC fidelity measure, both practitioners and parents should probably respond to the same questionnaire, containing the same questions. A further limitation of the PYC fidelity measure was that parents and support workers were not interviewed about their experiences of completing the fidelity measures and their understanding of the questions involved. Time and resource constraints meant that interviewers were relied on as proxy assessors of parents' understanding.

Finally, there is a need to further evaluate PYC to ascertain program effectiveness. As has been highlighted throughout the thesis, there are two dimensions to supporting parents with intellectual disability; the interventions themselves, and the implementation of those same interventions. Both the intervention design and its implementation must be of high quality in order to achieve good outcomes. Findings from Study I, Study III, and from some earlier research on PYC, indicate that the program has been well received by practitioners, by parents and by managers. However, more research is needed to ascertain the effectiveness of PYC. Problems experienced in program implementation could, therefore, potentially be associated with issues relating to the program itself, rather than to the type of implementation support provided.

## Conclusions

This thesis has highlighted a strong interest in and reported need for programs such as PYC within Swedish social services. Several aspects of PYC and the training provided to practitioners have been met with enthusiasm, both by managers and support workers. The implementation of PYC appears to have increased knowledge and awareness amongst practitioners about a typically marginalized group of parents, namely, parents with intellectual disability. However, further work is needed in order to develop the program, and to assist in implementing PYC for parents with intellectual disability. While peer support appears to be beneficial in the context of implementation, evidence for some limitations has been provided in this thesis. Onsite coaching and broader engagement and education for organizations implementing the program are necessary. Further research is needed to develop guidelines for the appropriate use of the PYC, using flexible program delivery strategies. Such advances should assist in the development of fidelity measures, which, in turn, can assist future efficacy testing of PYC.

## References

Aarons, G. A. (2004). Mental health provider attitudes toward adoption of Evidence-Based Practice: The Evidence-Based Practice Attitude Scale (EBPAS). *Mental Health Services Research*, *6*(2), 61–74. https://doi.org/10.1023/B:MHSR.0000024351.12294.65

Aarons, G. A., Glisson, C., Hoagwood, K., Kelleher, K., Landsverk, J., & Cafri, G. (2010). Psychometric properties and United States national norms of the Evidence-Based Practice Attitude Scale (EBPAS). *Psychological Assessment*, *22*(2). https://doi.org/10.1037/a0019188

Abbott, R., O'Donnell, J., Hawkins, J. D., Hill, K. G., Kosterman, R., & Catalano, R. F. (1998). Changing teaching practices to promote achievement and bonding to school. *American Journal of Orthopsychiatry*, *68*(4), 542–552.

Addis, M. E. (1997). Evaluating the treatment manual as a means of disseminating empirically validated psychotherapies. *Clinical Psychology: Science and Practice*, *4*(1), 1–11. https://doi.org/10.1111/j.1468-2850.1997.tb00094.x

Åhlund, I. (2010). *Our father: On fathers with intellectual disabilities* (Master's thesis). Retrieved from http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Ahlund-Our-Father.pdf

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Areschoug, J. (2005). Parenthood and intellectual disability: Discourses on birth control and parents with intellectual disabilities 1967–2003. *Scandinavian Journal of Disability Research*, *7*(3-4), 155–175. https://doi.org/10.1080/15017410500246103

Arvidsson, J., Widén, S., & Tideman, M. (2015). Post-school options for young adults with intellectual disabilities in Sweden. *Research and Practice in Intellectual and Developmental Disabilities*, *2*(2), 180–193. https://doi.org/10.1080/23297018.2015.1028090

Arvidsson, P. (2013). *Assessment of participation in people with a mild intellectual disability* (Doctoral dissertation). Retrieved from http://www.avhandlingar.se/avhandling/c567cfc4ef/

Aunos, M., Feldman, M., & Goupil, G. (2008). Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 320–330. https://doi.org/10.1111/j.1468-3148.2008.00447.x

Azzopardi-Lane, C., & Callus, A.-M. (2015). Constructing sexual identities: People with intellectual disability talking about sexuality. *British Journal of Learning Disabilities*, *43*(1), 32–37. https://doi.org/10.1111/bld.12083

Bager, B. (2003). Barn till mödrar med utvecklingsstörning–en inventering. [Children to mothers with developmental disability –an inventory]. *Läkartidingen*, *100*(1-2), 22–25.

Bandura, A. (1971). *Social learning theory*. New York: General Learning Press.

Barber, J. P., Gallop, R., Crits-Christoph, P., Frank, A., Thase, M. E., Weiss, R. D., & Gibbons, M. B. C. (2006). The role of therapist adherence, therapist competence, and alliance in predicting outcome of individual drug counselling: Results from the National Institute Drug Abuse Collaborative Cocaine Treatment Study. *Psychotherapy Research*, *16*(2), 229–240. https://doi.org/10.1080/10503300500288951

Becker, D. R. (2001). Fidelity of supported employment programs and employment outcomes. *Psychiatric Services*, *52*(6), 834–836.

Beer, M., Eisenstat, R., & Spector, B. (1990). Why change programs don't produce change. *Harvard Business Review*, *68*(6), 158–166.

Beidas, R. S., & Kendall, P. C. (2010). Training therapists in Evidence-Based Practice: A critical review of studies from a systems-contextual perspective. *Clinical Psychology: Science and Practice*, *17*(1), 1–30. https://doi.org/10.1111/j.1468-2850.2009.01187.x

Bellamy, J. L., Bledsoe, S. E., Mullen, E. J., Fang, L., & Manuel, J. I. (2008). Agency–university partnership for Evidence-Based Practice in social work. *Journal of Social Work Education*, *44*(3), 55–76. https://doi.org/10.5175/JSWE.2008.200700027

Bergman, A., & Johansson, M. (2015). Hemma-hos-insats för barnfamiljer. Förekomst, variation, innebörd [Home-based services for families with children. Prevelance, variation and meaning]. (Report series in social work No. 2). Retrieved from http://www.diva-portal.org/smash/record.jsf?pid=diva2%3A850863&dswid=4135

Berg, S. (2005). Personal assistance reforms in Sweden: Breaking the assumption of dependency. In C. Barnes & G. Mercer (Eds.), *The social model of disability: Europe and the majority world* (pp. 32–48). Leeds: University Press.

Bergstrand, B. O. (2011). *LSS: Stöd och service till vissa funktionshindrade. [LSS: support and service for people with disabilities]*. Höganäs: Komlitt.

Berman, P., & McLaughlin, M. W. (1976). Implementation of educational innovation. *Educational Forum*, *40*(3), 345-370.

Booker, V. K., Robinson, J. G., Kay, B. J., Najera, L. G., & Stewart, G. (1997). Changes in empowerment: Effects of participation in a lay health promotion program. *Health Education & Behavior*, *24*(4), 452–464. https://doi.org/10.1177/109019819702400405

Booth, T., & Booth, W. (2003). Self-advocacy and supported learning for mothers with learning difficulties. *Journal of Learning Disabilities*, *7*(2), 165–193. https://doi.org/10.1177/1469004703007002006

Borum, F., & Christiansen, J. K. (1993). Actors and structure in IS projects: What makes implementation happen? *Scandinavian Journal of Management*, *9*(1), 5–28. https://doi.org/10.1016/0956-5221(93)90032-N

Boud, D. (1992). The use of self-assessment schedules in negotiated learning. *Studies in Higher Education*, *17*(2), 185–200. https://doi.org/10.1080/03075079212331382657

Boud, D., Cohen, R., & Sampson, J. (1999). Peer learning and assessment. *Assessment & Evaluation in Higher Education*, *24*(4), 413–426. https://doi.org/10.1080/0260293990240405

Boud, D., & Middleton, H. (2003). Learning from others at work: Communities of practice and informal learning. *Journal of Workplace Learning*, *15*(5), 194–202. https://doi.org/10.1108/13665620310483895

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bruno, L. (2012). Föräldrar med kognitiva svårigheter – att bryta ny mark. Erfarenheter från Uppsala län. [Parents with cognitive difficulties – breaking new ground. Experiences from Uppsala county]. Retrieved from http://www.regionuppsala.se/upload/Dokumentation/Rapporter/2012/Foraldrar_med_kognitiva_svarigheter_2012.pdf

Buck, E. T., & Dent-Brown, K. (2014). Creative manuals. *International Journal of Art Therapy*, *19*(2), 82–87. https://doi.org/10.1080/17454832.2014.906475

Buntinx, W. (2016). Adaptive behaviour and support needs. In A. Carr, C. Linehan, G. O'Reilly, P. Noonan Walsh, & J. McEvoy (Eds.), *The handbook of intellectual disability and psychology practice* (pp. 107–135). London: Routledge.

Carroll, C., Patterson, M., Wood, S., Booth, A., Rick, J., & Balain, S. (2007). A conceptual framework for implementation fidelity. *Implementation Science*, *2*, 1-9. https://doi.org/10.1186/1748-5908-2-40

Castonguay, L. G., Goldfried, M. R., Wiser, S., Raue, P. J., & Hayes, A. M. (1996). Predicting the effect of cognitive therapy for depression: A study of unique and common factors. *Journal of Consulting and Clinical Psychology*, *64*(3), 497–504. https://doi.org/10.1037/0022-006X.64.3.497

Castro, F. G., Barrera, M., & Martinez, C. (2004). The cultural adaptation of prevention interventions: Resolving tensions between fidelity and fit. *Prevention Science*, *5*(1), 41–45. https://doi.org/10.1023/B:PREV.0000013980.12412.cd

Ciemnecki, A. B., & CyBulski, K. A. (2007). Response among people with disabilities. In T. Kroll, D. Keer, P. Placek, J. Cyril, & G. Hendershot (Eds.), *Towards best practices for surveying people with disabilities*. New York: Nova Science Publishers Inc.

Clayton, O., Chester, A., Mildon, R., & Matthews, J. (2008). Practitioners who work with parents with intellectual disability: Stress, coping and training needs. *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 367–376. https://doi.org/10.1111/j.1468-3148.2008.00444.x

Collings, S. (2014). *Influences in the social worlds of children of mothers with intellectual disability* (Doctoral dissertation). Retrieved from http://hdl.handle.net/2123/12033

Collings, S., & Llewellyn, G. (2012). Children of parents with intellectual disability: Facing poor outcomes or faring okay? *Journal of Intellectual and Developmental Disability*, *37*(1), 65–82. https://doi.org/10.3109/13668250.2011.648610

Coren, E., Hutchfield, J., Thomae, M., & Gustafsson, C. (2010). Parent training support for intellectually disabled parents. *The Cochrane Database of Systematic Reviews*, (6), 1–60. https://doi.org/10.1002/14651858.CD007987.pub2

Crosswaite, C., & Curtice, L. (1994). Disseminating research results-the challenge of bridging the gap between health research and health action. *Health Promotion International*, *9*(4), 289–296. https://doi.org/10.1093/heapro/9.4.289

Dane, A. V., & Schneider, B. H. (1998). Program integrity in primary and early secondary prevention: Are implementation effects out of control? *Clinical Psychology Review*, *18*(1), 23–45. https://doi.org/10.1016/S0272-7358(97)00043-3

Davies, P. (2004, February). *Is evidence-based government possible?* Paper presented at the 4th Annual Campbell Collaboration Colloquium, Washington, DC. Retrieved from http://www.sandy-campbell.com/sc/KTC_Module_1_files/KTC%20Module%201%20-%202.3b%20-%20Davies%202004.pdf

Dobson, D., & Cook, T. J. (1980). Avoiding type III error in program evaluation: Results from a field experiment. *Evaluation and Program Planning*, *3*(4), 269–276. https://doi.org/10.1016/0149-7189(80)90042-7

Domitrovich, C. E., Gest, S. D., Jones, D., Gill, S., & DeRousie, R. M. S. (2010). Implementation quality: Lessons learned in the context of the Head Start REDI trial. *Early Childhood Research Quarterly*, *25*(3), 284–298. https://doi.org/10.1016/j.ecresq.2010.04.001

Durlak, J. A., & DuPre, E. P. (2008). Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. *American Journal of Community Psychology*, *41*(3-4), 327–350. https://doi.org/10.1007/s10464-008-9165-0

Dusenbury, L., Brannigan, R., Falco, M., & Hansen, W. B. (2003). A review of research on fidelity of implementation: implications for drug abuse prevention in school settings. *Health Education Research*, *18*(2), 237–256. https://doi.org/10.1093/her/18.2.237

Dye, L., Hare, D. J., & Hendy, S. (2007). Capacity of people with intellectual disabilities to consent to take part in a research study. *Journal of Applied Research in Intellectual Disabilities*, *20*(2), 168–174. https://doi.org/10.1111/j.1468-3148.2006.00310.x

Edholm, L. (2016, August 6). Socialtjänsten måste bli mer vetenskaplig [Social services must become more scientific]. *Svenska Dagbladet*. Retrieved from http://www.svd.se/socialtjansten-maste-anvanda-seriosa-metoder

Emerson, E., & Brigham, P. (2014). The developmental health of children of parents with intellectual disabilities: Cross sectional study. *Research in Developmental Disabilities*, *35*(4), 917–921. https://doi.org/10.1016/j.ridd.2014.01.006

Eyberg, S. M., Boggs, S. R., & Algina, J. (1995). Parent-child interaction therapy: A psychosocial model for the treatment of young children with conduct problem behavior and their families. *Psychopharmacology Bulletin*, *31*(1), 83–91.

Fagan, A. A., Hanson, K., Hawkins, J. D., & Arthur, M. W. (2008). Bridging science to practice: Achieving prevention program implementation fidelity in the community youth development study. *American Journal of Community Psychology*, *41*(3-4), 235–249. https://doi.org/10.1007/s10464-008-9176-x

Feldman, M. A. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities*, *15*(4), 299–332. https://doi.org/10.1016/0891-4222(94)90009-4

Feldman, M. A. (2002). Parents with intellectual disabilities: Impediments and supports. In D. Griffiths & P. Federoff (Eds.), *Ethical dilemmas: Sexuality and developmental disability* (pp. 255–292). Kingston, NT: NADD Press.

Feldman, M. A., & Case, L. (1997). The effectiveness of audiovisual self-instructional materials in teaching child-care skills to parents with intellectual disabilities.

*Journal of Behavioral Education*, *7*(2), 235–257.
https://doi.org/10.1023/A:1022897226255

Feldman, M. A., Case, L., & Sparks, B. (1992). Effectiveness of a child-care training program for parents at-risk for child neglect. *Canadian Journal of Behavioural Science/Revue Canadienne Des Sciences Du Comportement*, *24*(1), 14–28. https://doi.org/10.1037/h0078698

Field, M., & Lohr, K. (1990). *Clinical practice guidelines: Directions for a new program*. Washington, DC: National Academies Press.

Fixsen, D. L., Blase, K. A., Naoom, S. F., Van Dyke, M., & Wallace, F. (2009). *Implementation: The missing link between research and practice*. Tampa, FL: National Implementation Research Network: University of South Florida.

Fixsen, D. L., Naoom, S. F., Blase, K. A., & Friedman, R. M. (2005). *Implementation research: A synthesis of the literature.* Florida: The National Implementation Research Network.

Forbat, L., Black, L., & Dulgar, K. (2014). What clinicians think of manualized psychotherapy interventions: Findings from a systematic review. *Journal of Family Therapy*, *37*(4), 408-428. https://doi.org/10.1111/1467-6427.12036

Fraser, M. W. (2003). Intervention research in social work: A basis for evidence-based practice and practice guidelines. In A. Rosen & E. K. Proctor (Eds.), *Developing practice guidelines for social work Intervention: Issues, methods, and research agenda* (pp. 17–36). New York: Columbia University Press.

Fuqua, R. W., & Shook, G. L. (1983). Behavioral procedures in community survival skills training. *Australia and New Zealand Journal of Developmental Disabilities*, *9*(4), 177–184. https://doi.org/10.3109/13668258309016155

Galinsky, M. J., Fraser, M. W., Day, S. H., & Richman, J. M. (2013). A primer for the design of practice manuals: Four stages of development. *Research on Social Work Practice*, *23*(2), 219–228. https://doi.org/10.1177/1049731512468957

Gaston, L., & Gagnon, R. (1996). The role of process research in manual development. *Clinical Psychology: Science and Practice*, *3*(1), 13–24. https://doi.org/10.1111/j.1468-2850.1996.tb00055.x

Gillman, M., Heyman, B., & Swain, J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability & Society*, *15*(3), 389–409. https://doi.org/10.1080/713661959

Gjems, L. (1997). *Handledning i professionsgrupper. [Supervision in profession groups]*. Lund: Studentlitteratur.

Governmnet Offices of Sweden. (2004). Kommunallagen, på engelska. [The Local Government Act, in English]. Retrieved from http://www.regeringen.se/contentassets/af7654d2c0bf469f9a62a58d473369c7/kommunallagen-pa-engelska

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Granqvist, P., Forslund, T., Fransson, M., Springer, L., & Lindberg, L. (2014). Mothers with intellectual disability, their experiences of maltreatment, and their children's attachment representations: A small-group matched comparison

study. *Attachment & Human Development*, *16*(5), 417–436. https://doi.org/10.1080/14616734.2014.926946

Grönvik, L. (2007). The fuzzy buzz word: Conceptualisations of disability in disability research classics. *Sociology of Health & Illness*, *29*(5), 750–766. https://doi.org/10.1111/j.1467-9566.2007.01014.x

Gross, T. J., Hurley, K. D., Ross, J., & Thompson, R. (2016). Comparing self-report and observations to assess the implementation of an in-home program serving at-risk families. *Journal of Public Child Welfare*, *10*(1), 96–116. https://doi.org/10.1080/15548732.2015.1114061

Guerra, N. G., & Knox, L. (2008). How culture impacts the dissemination and implementation of innovation: A case study of the Families and Schools Together Program (FAST) for preventing violence with immigrant Latino youth. *American Journal of Community Psychology*, *41*(3-4), 304–313. https://doi.org/10.1007/s10464-008-9161-4

Guinea, S. M. (2001). Parents with a learning disability and their views on support received: A preliminary study. *Journal of Intellectual Disabilities*, *5*(1), 43–56. https://doi.org/10.1177/146900470100500106

Hawkins, P., Shohet, R., Ryde, J., & Wilmot, J. (2012). *Supervision in the Helping Professions*. UK: McGraw-Hill Education.

Hayward, R. (2007). Deinstitutionalisation and community living–outcomes and costs: Report of a European Study. County report, Sweden. In J. Mansell, M. Knapp, J. Beadle-Brown, & J. Beecham (Eds.), *Deinstitutionalisation and community living–outcomes and costs. Volume 2: Main Report.* (pp. 524–542). Canterbury: Tizard Centre, University of Kent.

Hedlund, M. (2009). Understandings of the disability concept: A complex and diverse concept. In C. A. Marshall, E. Kendall, M. E. Banks, & R. M. S. Gover (Eds.), *Disabilities: Insights from across fields and around the world* (pp. 5–18). Westport, CA: Praeger.

Henggeler, S. W., Schoenwald, S. K., Borduin, C. M., Rowland, M. D., & Cunningham, P. B. (2009). *Multisystemic therapy for antisocial behavior in children and adolescents*. New York: Guilford Press.

Herschell, A. D. (2010). Fidelity in the field: Developing infrastructure and fine-tuning measurement. *Clinical Psychology: Science and Practice*, *17*(3), 253–257. https://doi.org/10.1111/j.1468-2850.2010.01216.x

Hindmarsh, G., Llewellyn, G., & Emerson, E. (2015). Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research: JIDR*, *59*(6), 541–550. https://doi.org/10.1111/jir.12159

Hodes, M. W., Meppelder, H. M., Schuengel, C., & Kef, S. (2014). Tailoring a video-feedback intervention for sensitive discipline to parents with intellectual disabilities: A process evaluation. *Attachment & Human Development*, *16*(4), 387–401. https://doi.org/10.1080/14616734.2014.912490

Höglund, B. (2012). *Pregnancy, childbirth and midwifery care among women with intellectual disability in Sweden* (Doctoral dissertation). Retrieved from http://swepub.kb.se/bib/swepub:oai:DiVA.org:uu-183388?tab2=abs&language=en

Höglund, B., Lindgren, P., & Larsson, M. (2012). Pregnancy and birth outcomes of women with intellectual disability in Sweden: A national register study. *Acta Obstetricia et Gynecologica Scandinavica*, *91*(12), 1381–1387. https://doi.org/10.1111/j.1600-0412.2012.01509.x

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities. (2008). Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 296–307. https://doi.org/10.1111/j.1468-3148.2008.00435.x

Jenkinson, J. C. (1996). Identifying intellectual disability: Some problems in the measurement of intelligence and adaptive behaviour. *Australian Psychologist*, *31*(2), 97–102. https://doi.org/10.1080/00050069608260187

Keenan, M., Dillenburger, K., Röttgers, H. R., Dounavi, K., Jónsdóttir, S. L., Moderato, P., … Martin, N. (2014). Autism and ABA: The gulf between North America and Europe. *Review Journal of Autism and Developmental Disorders*, *2*(2), 167–183. https://doi.org/10.1007/s40489-014-0045-2

Keith, R. E., Hopp, F. P., Subramanian, U., Wiitala, W., & Lowery, J. C. (2010). Fidelity of implementation: Development and testing of a measure. *Implementation Science*, *5*(99). https://doi.org/10.1186/1748-5908-5-99

Kilbourne, A. M., Neumann, M. S., Pincus, H. A., Bauer, M. S., & Stall, R. (2007). Implementing evidence-based interventions in health care: Application of the replicating effective programs framework. *Implementation Science*, *2*(42). https://doi.org/10.1186/1748-5908-2-42

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *BMJ : British Medical Journal*, *311*(7000), 299–302.

Klingner, J. K., Ahwee, S., Pilonieta, P., & Menendez, R. (2003). Barriers and facilitators in scaling up research-based practices. *Exceptional Children*, *69*(4), 411–429. https://doi.org/10.1177/001440290306900402

Koch, T. (2006). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, *53*(1), 91–100.

Kumpfer, K. L., Pinyuchon, M., Melo, A. T. de, & Whiteside, H. O. (2008). Cultural adaptation process for international dissemination of the Strengthening Families Program. *Evaluation & the Health Professions*, *31*(2), 226–239. https://doi.org/10.1177/0163278708315926

Kylén, G. (1983). *The intellect and intellectual handicaps.* Stockholm , Sweden: Stiftelsen ALA.

Lag om stöd och service till vissa funktionshindrade [The act concerning support and service for persons with certain functional impairments ]. (1993). Retrieved from https://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Lag-1993387-om-stod-och-ser_sfs-1993-387/

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*, 159–174.

Lehtonen, P. (2007, August). *The emergence of a temporary organization: Boundary activities at the program-parent organization interface.* Paper presented at the

9th Nordic Academy of Management Conference (NFF), Bergen, Norway. Retrieved from http://www.nhh.no/Files/Filer/institutter/for/conferences/nff/papers/lehtonen-p.pdf

Lennerhed, L. (1997). Sterilisation on eugenic grounds in Europe in the 1930s: News in 1997 but why? *Reproductive Health Matters*, *5*(10), 156–161.

Lillehoj, C. J., Griffin, K. W., & Spoth, R. (2004). Program provider and observer ratings of school-based preventive intervention implementation: Agreement and relation to youth outcomes. *Health Education & Behavior*, *31*(2), 242–257. https://doi.org/10.1177/1090198103260514

Lincoln, M. A., & McAllister, L. L. (1993). Peer learning in clinical education. *Medical Teacher*, *15*(1), 17–26. https://doi.org/10.3109/01421599309029007

Lindblad, I., Billstedt, E., Gillberg, C., & Fernell, E. (2013). An interview study of young adults born to mothers with mild intellectual disability. *Journal of Intellectual Disabilities*, *17*(4), 329-338. https://doi.org/10.1177/1744629513508366

Llewellyn, G. (2013). Parents with intellectual disability and their children: Advances in policy and practice. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(2), 82–85. https://doi.org/10.1111/jppi.12033

Lovaas, I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, *55*(1), 3–9. https://doi.org/10.1037/0022-006X.55.1.3

Man, N. W., Wade, C., & Llewellyn, G. (2016). Prevalence of parents with intellectual disability in Australia. *Journal of Intellectual & Developmental Disability*, 1–7. https://doi.org/10.3109/13668250.2016.1218448

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. *Research in Developmental Disabilities*, *32*(2), 419–436. https://doi.org/10.1016/j.ridd.2010.12.018

McConnell, D., Feldman, M., Aunos, M., & Prasad, N. (2011). Parental cognitive impairment and child maltreatment in Canada. *Child Abuse & Neglect*, *35*(8), 621–632. https://doi.org/10.1016/j.chiabu.2011.04.005

McConnell, D., Llewellyn, G., & Ferronato, L. (2002). Disability and decision making in Australian care proceedings. *International Journal of Law, Policy and the Family*, *16*(2), 270–299. https://doi.org/10.1093/lawfam/16.2.270

McGaw, S., Ball, K., & Clark, A. (2002). The effect of group intervention on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities,* 15(4), 354-366. https://doi.org/10.1046/j.1468-3148.2002.00143.x

McHugh, R. K., Murray, H. W., & Barlow, D. H. (2009). Balancing fidelity and adaptation in the dissemination of empirically-supported treatments: The promise of transdiagnostic interventions. *Behaviour Research and Therapy*, *47*(11), 946–953. https://doi.org/10.1016/j.brat.2009.07.005

Mensas, L. (2014). Parenting Young Children – PYC: Rapport från tre års utvecklings- och implementeringsarbete [Parenting Young Children- PYC: Report from three

years development and implementation work].Retrieved from http://hb.diva-portal.org/smash/get/diva2:884039/FULLTEXT01

Meppelder, M., Hodes, M., Kef, S., & Schuengel, C. (2015). Parenting stress and child behaviour problems among parents with intellectual disabilities: The buffering role of resources. *Journal of Intellectual Disability Research*, *59*(7), 664–677. https://doi.org/10.1111/jir.12170

Mersky, J. P., Topitzes, J., Grant-Savela, S. D., Brondino, M. J., & McNeil, C. B. (2014). Adapting Parent–Child Interaction Therapy to foster care outcomes from a randomized trial. *Research on Social Work Practice*, *26*(2), 157-167. https://doi.org/10.1177/1049731514543023

Metz, A. J., Espiritu, R., & Moore, K. A. (2007). What is evidence-based practice? (Research-to-results brief). Retrieved from http://www.childtrends.org/wp-content/uploads/2007/06/2007-14WhatIsEBP.pdf

Meyers, D. C., Durlak, J. A., & Wandersman, A. (2012). The quality implementation framework: A synthesis of critical steps in the implementation process. *American Journal of Community Psychology*, *50*(3-4), 462–480. https://doi.org/10.1007/s10464-012-9522-x

Mickelson, P. (1947). The feebleminded parent: A study of 90 family cases. *American Journal of Mental Deficiency*, *51*(4), 644–653.

Mildon, R., Wade, C., & Matthews, J. (2008). Considering the contextual fit of an intervention for families headed by parents with an intellectual disability: An exploratory study. *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 377–387. https://doi.org/10.1111/j.1468-3148.2008.00451.x

Miller, W. R., Yahne, C. E., Moyers, T. B., Martinez, J., & Pirritano, M. (2004). A randomized trial of methods to help clinicians learn motivational interviewing. *Journal of Consulting and Clinical Psychology*, *72*(6), 1050–1062. https://doi.org/http://dx.doi.org.ezproxy.ub.gu.se/10.1037/0022-006X.72.6.1050

Murphy, A., & McDonald, J. (2004). Power, status and marginalisation: Rural social workers and evidence-based practice in multidisciplinary teams. *Australian Social Work*, *57*(2), 127–136. https://doi.org/10.1111/j.1447-0748.2004.00127.x

Näslund, J., & Ögren, M. (2010). Handledningskartan. [Map of supervision]. In J., Näslund, & M. Ögren. In J. Näslund & M. Ögren (Eds.), *Grupphandledning: Forskning och erfarenheter från olika verksamhetsområden* (pp. 15-24). Lund: Författarna och Studentliteratur.

Neely-Barnes, S., Zanskas, S., Delavega, M. E., & Evans, T. K. (2014). Parenting with a disability and child mental health: A propensity score analysis. *Journal of Social Work in Disability & Rehabilitation*, *13*(3), 226–246.

Nelson, M. C., Cordray, D. S., Hulleman, C. S., Darrow, C. L., & Sommer, E. C. (2012). A procedure for assessing intervention fidelity in experiments testing educational and behavioral interventions. *The Journal of Behavioral Health Services & Research*, *39*(4), 374–396. https://doi.org/10.1007/s11414-012-9295-x

Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science*, *10*, 53. https://doi.org/10.1186/s13012-015-0242-0
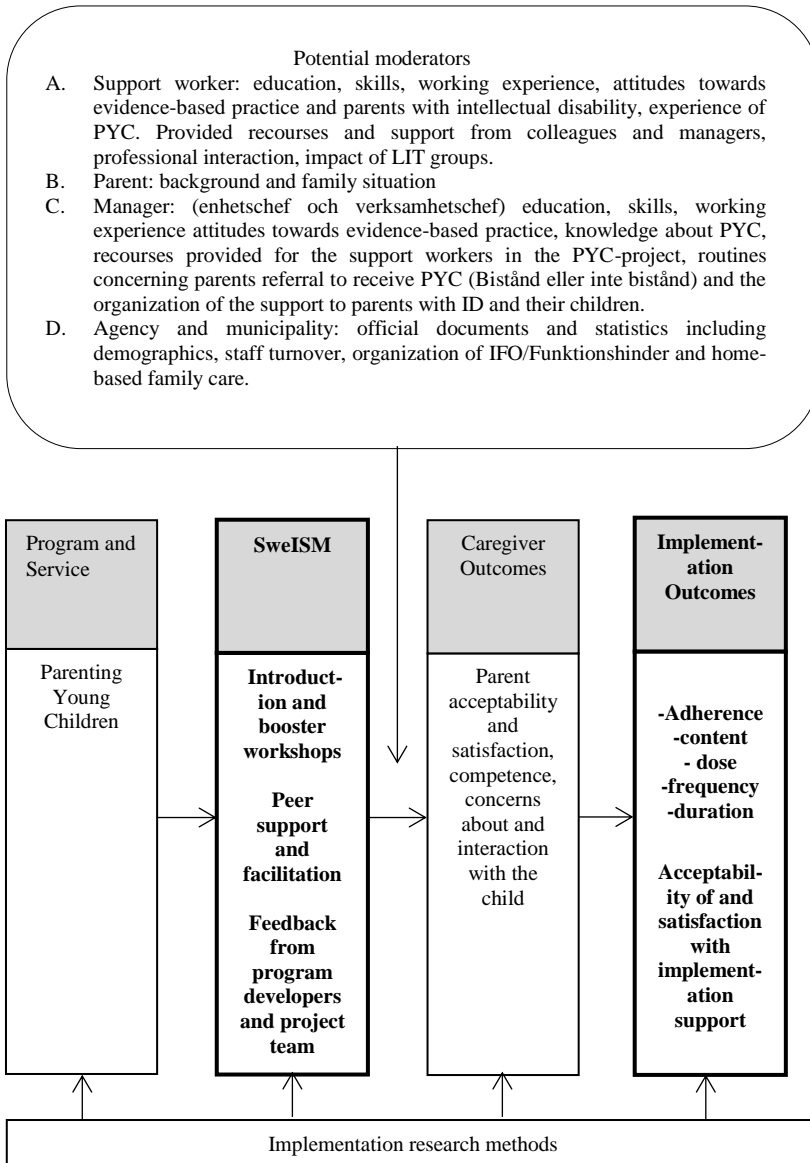
Norr, K. F., McElmurry, B. J., & Misner, S. J. (1999). The community health advocate's point of view. In B. Mc Elmurry, C. Tyska, & R. S. Parker (Eds.), *Primary health care in urban communities* (pp. 55–78). Boston: Jones and Bartlett Publishers.

Nutley, S. M., Walter, I., & Davies, H. T. O. (2007). *Using evidence: How research can inform public services*. Bristol: Policy Press.

Oliver, M. (1986). Social policy and disability: Some theoretical issues. *Disability, Handicap & Society*, *1*(1), 5–17. https://doi.org/10.1080/02674648666780021

Onken, L. S., Blaine, J. D., & Battjes, R. J. (1997). Behavioral therapy research: A conceptualization of a process. In S. W. Henggeler & A. B. Santos (Eds.), *Innovative approaches for difficult-to-treat populations* (pp. 477–485). Arlington, VA, US: American Psychiatric Association.

Packendorff, J. (1995). Inquiring into the temporary organization: New directions for project management research. *Scandinavian Journal of Management*, *11*(4), 319–333.

Papazoglou, A., Jacobson, L. A., McCabe, M., Kaufmann, W., & Zabel, T. A. (2014). To ID or not to ID? Changes in classification rates of intellectual disability using DSM-5. *Intellectual and Developmental Disabilities*, *52*(3), 165–174. https://doi.org/10.1352/1934-9556-52.3.165

Perkins, D. N., Salomon, G., & Press, P. (1992). Transfer of learning. In T. N. Husen & T. N. Postlethwaite (Eds.), *International encyclopedia of education* (pp. 6652–6657). Oxford: Pergamon Press.

Pfeiffer, D. (2002). The philosophical foundations of disability studies. *Disability Studies Quarterly*, *22*(2), 3-23 http://dx.doi.org/10.18061/dsq.v22i2.341

Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). "Just being selfish for my own sake . . .": Balancing the views of young adults with intellectual disabilities and their carers in transition planning. *The Sociological Review*, *59*(2), 303–323. https://doi.org/10.1111/j.1467-954X.2011.02006.x

Pinto, J. K., & Prescott, J. E. (1990). Planning and tactical factors in the project implementation process. *Journal of Management Studies*, *27*(3), 305–327.

Powell, R. A., & Single, H. M. (1996). Focus groups. *International Journal for Quality in Health Care*, *8*(5), 499–504. https://doi.org/10.1093/intqhc/8.5.499

Ramanadhan, S., Wiecha, J. L., Gortmaker, S. L., Emmons, K. M., & Viswanath, K. (2010). Informal training in staff networks to support dissemination of health promotion programs. *American Journal of Health Promotion : AJHP*, *25*(1), 12–18. https://doi.org/10.4278/ajhp.080826-QUAN-163

Regeringskansliet. (2009). Nationell strategi för ett utvecklat föräldrastöd. En vinst för alla. [National strategy for a developed parent support. A benefit for everyone.]. Retrieved from http://www.regeringen.se/content/1/c6/22/28/46/26d1a9d7.pdf

Reinke, W. M., Stormont, M., Herman, K. C., & Newcomer, L. (2013). Using coaching to support teacher implementation of classroom-based interventions. *Journal of Behavioral Education*, *23*(1), 150–167. https://doi.org/10.1007/s10864-013-9186-0

Rosen, A., & Proctor, E. K. (2003). *Developing practice guidelines for social work intervention: Issues, methods, and research agenda*. New York: Columbia University Press.

Sarber, R. E., Halasz, M. M., Messmer, M. C., Bickett, A. D., & Lutzker, J. R. (1983). Teaching menu planning and grocery shopping skills to a mentally retarded mother. *Mental Retardation*, *21*(3), 101–106.

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., … Yeager, M. H. (201AD). *Intellectual disability: Definition, classification, and systems of supports.* Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., & Luckasson, R. (2015). A systematic approach to subgroup classification in intellectual disability. *Intellectual and Developmental Disabilities*, *53*(5), 358–366. https://doi.org/10.1352/1934-9556-53.5.358

Schoenwald, S. K., Garland, A. F., Chapman, J. E., Frazier, S. L., Sheidow, A. J., & Southam-Gerow, M. A. (2010). Toward the effective and efficient measurement of implementation fidelity. *Administration and Policy in Mental Health and Mental Health Services Research*, *38*(1), 32–43. https://doi.org/10.1007/s10488-010-0321-0

Secomb, J. (2008). A systematic review of peer teaching and learning in clinical education. *Journal of Clinical Nursing*, *17*(6), 703–716. https://doi.org/10.1111/j.1365-2702.2007.01954.x

Sheperis, C., Sheperis, D., Monceaux, A., Davis, R. J., & Lopez, B. (2015). Parent-child interaction therapy for children with special needs. *The Professional Counselor*, *5*(2), 248–260. https://doi.org/10.15241/efh.5.2.195

Sigurjonsdottir, H. B. (2004). Intellectually limited fathers, their families and formal support services. In K. Kristiansen & R. Traustadottir (Eds.), *Gender and disability: Research in the Nordic countries.* (pp. 239–254). Lund: Studentlitteratur.

Smith, K. L. (2009). A brief summary of supervision models. Retrieved from http://www.marquette.edu/education/grad/documents/Brief-Summary-of-Supervision-Models.pdf

Socialdepartementet. (2000). Från patient till medborgare – en nationell handlingsplan för handikappolitiken. [From patient to citizen – a national action plan for disability policy]. Retrieved from http://www.regeringen.se/rattsdokument/proposition/2000/03/prop.-1999200079/

Socialtjänstlag [The Social Services Act]. (2001). Retrieved from http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Socialtjanstlag-2001453_sfs-2001-453/

Söder, M. (1989). Disability as a social construct: The labelling approach revisited. *European Journal of Special Needs Education*, *4*(2), 117–129. https://doi.org/10.1080/0885625890040204

Starke, M. (2015). *Parents' and support workers' experiences of a parenting education program*. Manuscript in preparation.

Starke, M., Wade, C., Feldman, M. A., & Mildon, R. (2013). Parenting with disabilities: Experiences from implementing a parenting support programme in Sweden. *Journal of Intellectual Disabilities*, *17*(2), 145–156. https://doi.org/10.1177/1744629513483523

Stokes, T. F., & Baer, D. M. (1977). An implicit technology of generalization. *Journal of Applied Behavior Analysis*, *10*(2), 349–367. https://doi.org/10.1901/jaba.1977.10-349

Sundell, K., Soydan, H., Tengvald, K., & Anttila, S. (2009). From opinion-based to Evidence-Based social work: The Swedish case. *Research on Social Work Practice*, *20*(6), 714-722. https://doi.org/10.1177/1049731509347887

Swaine, J., Parish, S. L., Luken, K., & Atkins, L. (2011). Recruitment and consent of women with intellectual disabilities in a randomised control trial of a health promotion intervention. *Journal of Intellectual Disability Research*, *55*(5), 474–483. https://doi.org/10.1111/j.1365-2788.2011.01399.x

Tideman, M. (2015). Education and support for people with intellectual disabilities in Sweden: Policy and practice. *Research and Practice in Intellectual and Developmental Disabilities*, *2*(2), 116–125. https://doi.org/10.1080/23297018.2015.1067868

Timmer, S. G., Ho, L. K. L., Urquiza, A. J., Zebell, N. M., Fernandez Y Garcia, E., & Boys, D. (2011). The effectiveness of parent-child interaction therapy with depressive mothers: The changing relationship as the agent of individual change. *Child Psychiatry and Human Development*, *42*(4), 406–423. https://doi.org/10.1007/s10578-011-0226-5

Topping, K. J. (2005). Trends in peer learning. *Educational Psychology*, *25*(6), 631–645. https://doi.org/10.1080/01443410500345172

Tøssebro, J., Midjo, T., Paulsen, V., & Berg, B. (2014). *Foreldre med kognitive vansker i møte med barnevernet [Parents with cognitive difficulties meeting with child welfare]*. Retrieved from https://brage.bibsys.no/xmlui/handle/11250/2365794

Trydegård, G. B., & Szebehely, M. (2008, June). *Care services for older and disabled persons in Sweden. A comparison from the perspectives of care recipients, families and care workers*. Paper presented at the Transforming elderly care at local, national and transnational levels conference, Copenhagen. Retrieved from http://www.sfi.dk

Tymchuk, A. J. (1999). Moving towards integration of services for parents with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, *24*(1), 59–74. https://doi.org/10.1080/13668259900033881

Tymchuk, A. J., Hamada, D., Andron, L., & Anderson, S. (1990). Home safety training with mothers who are mentally retarded. *Education and Training in Mental Retardation*, *25*(2), 142–149.

Tymchuk, A. J., Lang, C. M., Sewards, S. E., Lieberman, S., & Koo, S. (2003). Development and validation of the illustrated version of The Home Inventory for Dangers and Safety Precautions: Continuing to address learning needs of parents in injury prevention. *Journal of Family Violence*, *18*(4), 241–252. https://doi.org/10.1023/A:1024020431801

United Nations. (2006). Convention on the rights of persons with disabilities. Retrieved from http://www.un.org/disabilities/convention/conventionfull.shtml

von Thiele Schwarz, U., Hasson, H., & Lindfors, P. (2015). Applying a fidelity framework to understand adaptations in an occupational health intervention. *Work*, *51*(2), 195–203. https://doi.org/10.3233/WOR-141840

Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 351–366. https://doi.org/10.1111/j.1468-3148.2008.00449.x

Wade, C., Llewellyn, G., & Matthews, J. (2011). Modelling contextual influences on parents with intellectual disability and their children. *American Journal on Intellectual and Developmental Disabilities*, *116*(6), 419–437. https://doi.org/10.1352/1944-7558-116.6.419

Walker, J. S., & Koroloff, N. (2007). Grounded theory and backward mapping: Exploring the implementation context for wraparound. *The Journal of Behavioral Health Services & Research*, *34*(4), 443–458. https://doi.org/10.1007/s11414-007-9054-6

Walters, S. T., Matson, S. A., Baer, J. S., & Ziedonis, D. M. (2005). Effectiveness of workshop training for psychosocial addiction treatments: A systematic review. *Journal of Substance Abuse Treatment*, *29*(4), 283–293. https://doi.org/10.1016/j.jsat.2005.08.006

Wechsler, D. (1949). *Wechsler intelligence scale for children*. San Antonio, TX, US: Psychological Corporation.

Weiber, I., Berglund, J., Tengland, P.-A., & Eklund, M. (2011). Children born to women with intellectual disabilities – 5-year incidence in a Swedish county. *Journal of Intellectual Disability Research*, *55*(11), 1078–1085. https://doi.org/10.1111/j.1365-2788.2011.01441.x

Williams, D., & Coles, L. (2007). Teachers' approaches to finding and using research evidence: An information literacy perspective. *Educational Research*, *49*(2), 185–206. http://dx.doi.org/10.1080/00131880701369719

Wilson, S., McKenzie, K., Quayle, E., & Murray, G. (2014). A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability. *Child: Care, Health and Development*, *40*(1), 7–19. https://doi.org/10.1111/cch.12023

Woodhouse, A. E., Green, G., & Davies, S. (2001). Parents with learning disabilities: Service audit and development. *British Journal of Learning Disabilities*, *29*(4), 128–132. https://doi.org/10.1046/j.1468-3156.2001.00059.x

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

Zins, J. E., Maher, C. A., Murphy, J. J., & Wess, B. P. (1988). The peer support group: A means to facilitate professional development. *School Psychology Review*, *7*, 138–146.

# Appendix

Potential moderators
A. Support worker: education, skills, working experience, attitudes towards evidence-based practice and parents with intellectual disability, experience of PYC. Provided recourses and support from colleagues and managers, professional interaction, impact of LIT groups.
B. Parent: background and family situation
C. Manager: (enhetschef och verksamhetschef) education, skills, working experience attitudes towards evidence-based practice, knowledge about PYC, recourses provided for the support workers in the PYC-project, routines concerning parents referral to receive PYC (Bistånd eller inte bistånd) and the organization of the support to parents with ID and their children.
D. Agency and municipality: official documents and statistics including demographics, staff turnover, organization of IFO/Funktionshinder and home-based family care.

| Program and Service | SweISM | Caregiver Outcomes | **Implement-ation Outcomes** |
|---|---|---|---|
| Parenting Young Children | **Introduct-ion and booster workshops**<br><br>**Peer support and facilitation**<br><br>**Feedback from program developers and project team** | Parent acceptability and satisfaction, competence, concerns about and interaction with the child | **-Adherence**<br>**-content**<br>**- dose**<br>**-frequency**<br>**-duration**<br><br>**Acceptabil-ity of and satisfaction with implement-ation support** |

Implementation research methods

*Figure A1.* The PYC project model. The current thesis examines implementation support strategies, used to support implementation of the PYC program in Sweden, and implementation outcomes (highlighted in bold). This research forms part of a larger implementation study which also examines caregiver outcomes and potential moderators.