Support strategies that promote parenting skills for parents with intellectual disabilities

A systematic literature review

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Declaration of Authorship

Title of the work:

Support strategies that promote parenting skills for parents with intellectual disabilities: A systematic literature review

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"I hereby declare that the thesis submitted is my own unaided work. All direct or indirect sources used are acknowledged as references pursuant to APA-norm, as common for the *Master of Interventions in Childhood.*"

Jönköping, Date: June 4th, 2018

Signature:

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ABSTRACT

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Various studies address people with intellectual disabilities, but very few discuss parents with intellectual disabilities and support strategies to promote their parenting skills. The aim of this study is to describe different existing support strategies that parents with intellectual disabilities are offered regarding their parenting skills. A systematic literature review led to the analysis twelve articles with publication dates ranging from 2010 to 2018. The results demonstrated nine different support strategies within four categories of Dunst and Trivette's (1997) sources of support, inducing overall positive and successful outcomes. The implementation of support strategies on a holistic level, based on cooperation between the different bioecological systems, is promising. While a proactive approach proves to be more efficient, the reactive approach cannot be fully abolished in order to treat unanticipated child neglect. In the end, the foundation of trust, quality of implementation and the environmental proximity to the parent with intellectual disabilities, are essential for an accessible and successful support strategy. The limitations have been identified in the search strategy and lack of general research on parenting skills of parents with intellectual disabilities. These findings create the basis for transferring support strategies affecting parenting skills to other similar contexts. Further research is necessary in order to analyse the outcomes of the support strategies on family's life and children's development.

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List of Abbreviations

APA	American Psychological Association
COPE	Committee on Publication Ethics
CPS	Child Protection Services
CRPD	Convention on the Rights of Persons with Disabilities
ID	Intellectual Disability
IQ	Intelligence Quotient
PCIT	Parent-Child-Interaction Therapy
PID	Parents with Intellectual Disabilities
PYC	Parenting Young Children
SDT	Self-Determination Theory
TANF	Temporary Assistance for Needy Families
VIPP	Video-Feedback Intervention to promote Positive Parenting

1 Introduction

People with intellectual disabilities face multiple challenges throughout their lives. While their diagnosis is thoroughly discussed in educational and medical research, the impact of the disability on their everyday life and rights appears to be neglected. This becomes especially apparent in life-changing decisions such as the foundation of a family. People with intellectual disabilities are either completely left out or stigmatised and believed to have insufficient parenting skills (Mayes & Llewellyn, 2009).

At the same time, parenthood is a human right and people with intellectual disabilities deserve the exertion of autonomy and equal social support (Quinn, Degner, & Bruce, 2002). Therefore, the United Nations (1993, Rule 19.4) promote the training of professional support workers to assist parents with intellectual disabilities in the development of their parenting skills. However, there is often a discrepancy between policy and practice. Thus, the need to research the support strategies available to parents with intellectual disabilities regarding their parenting skills. In fact, parents with intellectual disabilities still face stigmatisation and discrimination within society, resulting in feelings of disempowerment and intimidation (Callow, Tahir, & Feldman, 2016). Additionally, parental intellectual disability constitutes the reasoning in one out of five child removal cases (Lightfoot & DeZelar, 2016), underlining once more the need for effective support strategies as a preventive measure.

This emphasises how crucial it is to develop a better understanding of the accessibility and success of the already existing support strategies that seek to improve the lives of those affected by intellectual disabilities and to evaluate whether they can be implemented across multiple cultures and contexts. Regarding support, it is also essential to note that good parenting skills benefit not only the family life but above all the children's developmental outcomes.

Support strategies can, in fact, improve parenting skills, yet each person reacts different depending on their upbringing, their personal beliefs, and their environment (Llewellyn, 2013). As such, this review is designed to respect the individuality of each human being and provide an overview of the different support strategies that facilitate necessary parenting skills within the current literature.

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2   Background

This chapter will introduce necessary information, which constitutes necessary information that will supplement the theoretical framework of the systematic literature review. It includes definitions of the core concepts and relevant findings of previous studies about parents with intellectual disabilities (PID) and the support extended to them regarding their parenting skills.

2.1   Intellectual disabilities

There is a lack of a unified definition of intellectual disabilities (ID) (Llewellyn & McConnell, 2002). The term itself has only been developed recently and is also known as mental retardation, learning difficulties, low Intelligence Quotient (IQ), or cognitive limitations (Collings & Llewellyn, 2012). The World Health Organisation defines intellectual disability as "significantly reduced ability to understand new or complex information and to learn and apply new skills" (WHO, 2018, para. 1). This can be translated into significant limitations within the intellectual functioning and adaptive behaviour. ID typically emerges before the age of 18 (Schallock, et al., 2010) and is classifiable into four degrees; mild, moderate, severe and profound (American Psychiatric Association, 2014).

The diagnosis differs between countries and the proportion of individuals affected by ID is most often not assessed. The lack of unified definition, differences in diagnosis and assessment make the research on ID more problematic around the world (Fujiura, Park, & Rutkowski-Kmitta, 2005). However, it is also a research topic that has developed drastically during the last decades, enabling more and more information flow (Burack, Russo, Flores, Iarocci, & Zigler, 2011). Social exclusion, bullying, and stigmatisation commonly accompany a diagnosis of ID (Collings & Llewellyn, 2012). Not only being responsible for oneself but for another human being - by becoming a parent - creates new obligations and obstacles, even more so for people with ID (Sigurjónsdóttir & Rice, 2016).

2.2   Parents with intellectual disabilities

Parenthood is a human right (United Nations, 1993). However, parents with intellectual disabilities (PID) are still a vulnerable and often stigmatised group. Therefore, there is the need for risk assessment and the creation of a well-adapted support practice (Meppelder, Hodes, Kef, & Schuengel, 2014). To obtain support, a person must be identified first, which is closely related to a referral to the service system (Tarleton, Ward, & Howarth, 2006). These issues of diagnosis and identification result in a vast number of individuals who are being left out of support programs and thereby reflect a general lack of information on PID (Coren, Thomae, & Hutchfield, 2011). Parents, in general, face more pressure, conflicts, and prejudices, by taking responsibility for other human beings, namely their children. Living with ID increases this pressure and stress levels significantly (Sigurjónsdóttir & Rice, 2016). Additionally, PID often come from a family background already involving cognitive impairments (Huus, Olsson, Andersson, Granlund, & Augustine, 2016), making it a vicious circle, which is hard for them to escape from. This fact

also makes accessing the appropriate supports difficult, as generations of a family often remain in common Child Protection Services (CPS) without reconsideration of support strategies once they grow up to be adults and become parents themselves (Mayes & Llewellyn, 2009).

2.3 Parenting skills

Parenting skills, also called basic childcare skills (Wilson, McKenzie, Quayle, & Murray, 2014) are a broad range of skills related to the caretaking and upbringing of a child (Knowles, Machalicek, & Van Norman, 2015). In general, parenting skills should protect the child from harm and neglect (Coren et al., 2011). Practical examples of those skills are nurturing, grocery shopping and meal planning, behaviour management, helping with homework, as well as supporting and guiding the child in his or her steadily developing social milieu (Knowles et al., 2015; Wilson et al., 2014).

Parenting consists of multiple tasks, including automatized responses, active cognitive engagement and the ability to adapt thinking and actions as new information is available (Azar, Stevenson, & Johnson, 2012). As compared to typically-functioning parents, PID are at higher risk of non-achievement of those skills. This is due to social deprivation related to the ID (Coren et al., 2011), financial problems (Pixa-Kettner, 1999) and lasting beliefs about their incapacity as a parent (McConnell & Llewellyn, 2002). Thus, they must constantly prove their parenting abilities to others (Llewellyn, 2013). Additionally, it has been shown that warm, involved, supportive and responsive parenting is related to positive child functioning. While antagonistic or irritable parenting is linked to poorer developmental outcomes of the child (Wade, Llewellyn, & Matthews, 2015). As mentioned-above, PID are often associated with those negative and poor parenting skills (Collings & Llewellyn, 2012), leading to stigmatisation.

2.4 Risks and consequences

The stigmatisation of PID exists both on a social and on a legal level (United Nations, 1993; Lightfoot & DeZelar, 2016). PID still provoke a certain anxiety within society (Callow et al., 2016). The United Nations (1993) state "ignorance, neglect, superstition, and fear are social factors that throughout the history of disability have isolated persons with disabilities and delayed their development" (p.3f). The prejudicial views of PID are widely spread, stigmatising them as hostile and irritable parents who are overstrained by their responsibility (Mayes & Llewellyn, 2009). They regularly become more insecure through this stigmatisation and are afraid to ask for support (McConnell & Llewellyn, 2002). Hence, they develop a lack of confidence in their parenting ability. Furthermore, they develop a negative feeling regarding the constant oversight by service workers, as they feel misinterpreted and judged (Mayes & Llewellyn, 2009).

The stigmatisation continues on a legal level. Recent studies show that children of PID are under high risk of removal from parental care (Collings & Llewellyn, 2012; Lightfoot & DeZelar, 2016). In fact, in 19% of the cases of child removal in the USA, parental intellectual disability is one of the multiple reasons

of removal and in 5,18% it is the sole reason, without a further screening of the situation (Lightfoot & DeZelar, 2016). Those numbers are proof of the ongoing stigmatisation and discrimination PID still face up until today. To identify parenting ability in PID, child custody evaluators use assessments based on intelligence and personality tests. This does an injustice to the social elements of parenting, as well as other important factors in child care (Callow et al., 2016; Llewellyn, 2013). Judges rarely, if ever, point out support services and the chance to change or improve. Most of the North American judges affected within the law system see parenting as a static variable, that cannot be changed in any way through support or treatment (Callow et al., 2016).

Although this study does not focus on the children specifically, the support strategies their parents get are above all aiming to protect the children and offering them the best possible developmental outcomes (Sigurjónsdóttir & Rice, 2016). Hence, it is crucial to note that the child removal not only renders negative outcomes for the parents handling the loss of their child but above all it puts the removed children in deprivation (Mayes & Llewellyn, 2009). Keeping this in mind, beneficial support for parenting skills for PID entails beneficial outcomes for their children and family life (McConnell & Llewellyn, 2002).

Those stigmatising views are most often solely about capabilities of people with ID rather than actual evidence of maltreatment or even child neglect. It is in fact proven that with appropriate support strategies most PID can provide sufficiently good parenting (Llewellyn, 2013; Mayes & Llewellyn, 2009).

2.5   Support strategies

Based on the ongoing stigmatisation and discrimination of PID, there is a clear need for well-developed parenting support strategies (Meppelder et al., 2014). First, this will raise awareness in society and help PID overcome mistrust. Secondly, it will enable PID to develop their full potential and exercise their human right of parenthood without judgement based on their condition (Azar et al., 2012; Darbyshire & Kroese, 2012; Mayes & Llewellyn, 2009). The goal to create beneficial outcomes for their children needs to be kept in mind during the process. As Coren et al. (2011) state parenting skills can be improved just like any other skill with the appropriate support.

Social support is defined as people who provide help or people that one can consult for help (Meppelder et al., 2014). It also refers to any type of support given to or accessed by a PID from any professional, organisation, family, friends or even the participation in a group intervention (Darbyshire & Kroese, 2012). There is a difference being made between formal and informal support. Formal support being offered and searched by professionals, while informal support is given by sources such as family and friends (Darbyshire & Kroese, 2015; McGaw, Scully, & Pritchard, 2010). The phenomenon of PID preferring informal support to professional support, due to trust and accessibility benefits, remains high (Starke, 2013). However, informal support can seldom offer the multifaceted support needed and offers lower professional resources overall. Therefore, although the benefits of informal support should be used

and transferred into formal support, it is substantial for PID to also turn to formal support (Meppelder et al., 2014; Starke, 2013).

2.5.1 Accessibility

In order to guarantee beneficial outcomes of a support strategy, the accessibility and success rate are important factors. It is not enough to make a change through an intervention; one should always consider the accessibility of the support strategy and success of the outcomes (Donabedian, 1997). Especially important are support strategies focusing on the environment, as available resources promote accessibility (Imms et al., 2016).

Accessibility refers to the proximity of the support within the environment, the affordability (related costs) and the capacity of support strategy (number of participants admitted) (Karou & Hull, 2012). This is crucial, since support can only be used once it is made accessible to the affected population within their environment (Stewart, Barnfather, Neufeld, Warren, Letourneau, & Liu, 2006).

At the same time, the accessibility and its implementation influence the success of a support strategy (Smart & Conrad, 2017), thereby linking the two factors.

2.5.2 Success

The success rate is directly related, and measured through the improvement of the targeted skill; in this case parenting skills (Llewellyn & McConnell, 2002; Starke, 2013). An improvement can be systematically measured in a quantitative study or observed in a qualitative one. Success refers to a positive increase between the initial state and the outcome after an applied support (Donabedian, 1997). Moreover, an improvement can be subtle or significant (Bernard, 1979), meaning the outcome can develop moderately or substantially in comparison with the initial state.

Furthermore, the quality and nature of parent and professional are important during the implementation of a support strategy (McConnell & Llewellyn, 2005). Promoting a proactive approach leads to a higher success rate (Llewellyn & McConnell, 2002). However, the most used support, namely Child Protection Services, focuses on the risk and adapts a reactive approach instead of focusing on the capacity to change and develop (McConnell & Llewellyn, 2005). A proactive approach aims to offer early support in order to prevent negative outcomes, while a reactive approach acts after neglect or harm have been reported (Llewellyn & McConnell, 2002).

In general, there is a lack of suitable services for PID and identification or explanation of their accessibility and success. This lack of information on appropriate parenting support strategies for PID points out the need to only identify the strategies. This includes describing their accessibility and success for PID's parenting skills (Mayes & Llewellyn, 2009).

2.6 Theoretical framework

A theoretical framework is constituted by the Human Rights (United Nations, 1993 & 2015) and Bronfenbrenner's bioecological systems theory (Bronfenbrenner & Ceci, 1994), together with Dunst and Trivette's Resource-Based Approach Model (Trivette, Dunst, & Deal, 1997).

2.6.1 Human Rights

Human Rights describe the privileges that each person has, regardless of nationality, location, gender, origin, colour, religious believes, language or any other status (United Nations, 2015). The Office of the United Nations High Commissioner for Human Rights defines the values, which determine the human rights, to comprehend the origin and importance of a switch to a human rights perspective on disability (Quinn et al., 2002).

The United Nations (1993) identify disability as a world-wide fact with a growing number of concerned people, whose causes and consequences vary depending on their socio-economic status and governmental support.

Human Rights on Disability include the preservation of dignity, the exertion of autonomy, the valuation of differences and right of equality, as well as solidarity with free and equal social support (Quinn et al., 2002). Several paragraphs pertain especially to PID, these are the involvement of parents and persons with ID in all levels of the education process (Rule 6.3), the experience of parenthood and raising children autonomously (Rule 9.2), the promotion of ending stigmatisation and discrimination against parenthood of people with ID (Rule 9.3) and the training of professional support workers to assist PID in their own and their children's development (Rule 19.4) (United Nations, 1993).

Furthermore, the Convention on the Rights of Persons with Disabilities (CRPD), introduced in 2006 and operationalised in 2008, is a great achievement in protecting the rights of persons with disabilities (Freeman et al., 2015). Since its establishment, 177 countries have ratified it and 161 have signed it, making it an important legal document. Its principles are respectful interaction on all levels, non-discrimination, full participation and inclusion in everyday life, equal opportunities and accessibility (United Nations, 2006). However, there is a discrepancy between the policies and their implementation (Callow et al., 2016).

2.6.2 Bronfenbrenner's bioecological theory

Bronfenbrenner's (1994) theory can improve the understanding of the influences of different aspects on development, such as cultural, environmental, social, physical and psychic factors on a person's development by looking at the individual in multiple contexts. Hence, the bioecological background of the theory creates a relation between the different systems by interconnecting them and establishing a holistic approach. The individual is in the centre surrounded by the micro-, meso-, exo- and macrosystem, all under the influence of the chronosystem.
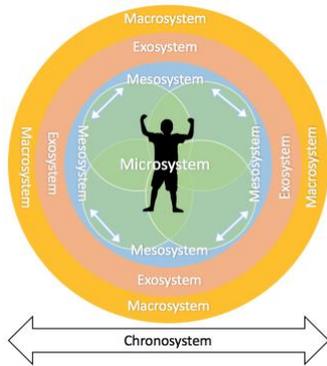
Figure 2.1 Adapted by the author, based on Bronfenbrenner & Morris (2006), The Bioecological Model of Human Development.

The microsystem regroups the immediate environment of the person, in this case, the PID and their family or friends. The mesosystem focuses on the interaction of the different actors within the microsystem and their influence on the person. For the PID the mesosystem becomes important when support workers are involved in their daily interaction such as parent-teacher meetings. The exosystem evolves around the indirect environment, involving service provision for PID. The macrosystem implies cultural values and regulations, but also the political and economic systems, an example of this are specific laws on ID and parenthood. The chronosystem crosses the other systems, by inducing changes through life transitions or special events (Bronfenbrenner, & Morris, 2006). An example of the chronosystem could be the support throughout a lifespan, which starts with the diagnosis of ID and accompanies the person when facing parenthood and other important changes.

2.6.3   Dunst & Trivette's resource-based approach to early intervention

Dunst and Trivette's (1997) research led to the resource-based approach to early intervention. The model identifies the interactions and influences of different ecological systems similar to Bronfenbrenner's (1994) bioecological theory (McBride, 1998). Early Intervention is defined as "the provision of support to families of infants and young children from members of informal and formal social support networks that impact both directly and indirectly upon parental, family, and child functioning" (Dunst, 1985, p. 179). The socio-economic environment surrounds a family, involving a variety of social actors and support possibilities, which can positively influence their outcomes. The model seeks to focus on the strengths and assets while supporting positive development over time through the collaboration of the different surrounding systems (Wolery, 2000). Thereby the model includes a broad range of societal and informal support, as well as the official and special service provision (McBride, 1998).

Figure 2.2 Dunst & Trivette's (1997) Resource-Based Model. In Wolery, M. (2000, p.194).

This thesis focuses on support strategies, which are related to the sources of support in the resource-based approach model. The sources of support are divided into four categories, namely personal social network, associational groups, community programs and professionals, as well as specialised services (Trivette et al., 1997). The four categories are also embedded within Bronfenbrenner's bioecological theory (1994). The personal social network (microsystem) involves persons the PID has regular contact with, such as its family, friends or co-workers. The associational groups (mesosystem) are embedded within the close community, such as

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support groups and service clubs provided to PID. The community programs and professionals (exosystem) go one step further, by offering planned support programs such as care programs and medical services. If offered in a country, they are offered nationwide and for everyone. There are several care programs that are directed towards parenting skills or people with intellectual disabilities, in a few cases even a combination of both (Llewellyn, 2013). The specialised services (exosystem and macrosystem) are designed for specific types of special needs, in this case PID, and include specialists, such as support workers and referral services (Wolery, 2000). All of them remain constantly influenced by the values and norms of the macrosystem and the changes throughout the chronosystem (Bronfenbrenner & Ceci, 1994).

2.7 Previous reviews

The background search demonstrated that similar reviews on the topics of parent education or training for PID already exist. However, those reviews only include quantitative studies, while the current review will allude to qualitative and quantitative studies. Wade et al. (2008) reviewed seven quantitative studies from 1994 to 2008, while Coren et al. (2011) established a Cochrane systematic review on three trials from 1992, 1994 and 2003. Moreover, Wilson et al. (2012) treated seven quantitative studies from 1999 to 2010 and Knowles et al. (2015) analysed thirteen quantitative articles from 1994 to 2012.

This review treats research from a more current time range than the above-mentioned reviews and includes qualitative articles. This enables the author to analyse the subject with greater detail and to include human experiences and observations.

Additionally, it gives new insights by using an analytic framework of Dunst and Trivette's (1997) resource-based approach. It promotes sustainability by using the sources of support within the model as main categories and including informal support. In fact, the resource-based framework is concerned with the source and nature of the support strategies (Trivette et al., 1997). It enables the author to explain sources of advantages of support strategies while also establishing more sustainable and comparable outcomes. It can lead to a more unified direction for others studying the same topic. In relation to this, the accessibility and success are also analysed, which has not been included in the other reviews.

The signature, but even more the official ratification of the CRPD by countries is also essential to this review, as the time range is chosen accordingly. Most countries that signed the CRPD, ratified it in 2008 and 2009 (United Nations, 2018), thus the chosen timeframe for this review starts after the ratification process. Moreover, the International Disability Alliance (IDA) established internationally accepted CRPD implementation guidelines (IDA, 2012) which started at the beginning of this review's timeframe, meaning 2010. This could have an influence on the research development and number of articles in the disability domain.

To summarise and justify the need for this study, the current review differs from the already published ones by (1) the inclusion of qualitative studies, (2) the methodological approach and (3) the timeframe covered.

2.8 Rationale

Intellectual disabilities have profound effects on those affected. While they have rights and obligations in the same way everyone does, people with ID are often stigmatised and discriminated against solely based on their condition. Parents with intellectual disabilities are a marginal group often neglected in research and especially in societal care, resulting in negative outcomes for their children and their parental rights in general. Studies show that the lack of support for parenting skills causes a high risk of removal from parental care for children of PID. Most often the identification of risk is based on IQ tests rather than social competences and the possibility to develop with appropriate support strategies.

To prevent child neglect and societal stigmatisation, as well as develop the quality of care, support strategies for their parenting skills are needed. Thus, the urge to identify not only the existing support strategies but also their accessibility and success. This study focuses on finding and describing support strategies for the parenting skills of PID tested and implemented in societal care systems.

3 Aim and research questions

The aim is to describe different existing support strategies that parents with intellectual disabilities are offered regarding their parenting skills.

The following research questions need to be answered:

RQ1. What support strategies exist for parents with intellectual disabilities regarding their parenting skills?

RQ2. How do the identified parenting support strategies for parents with intellectual disabilities map onto Dunst and Trivette´s sources of support (1997) within the resource-based framework?

RQ3. How accessible are the identified parenting support strategies for parents with intellectual disabilities regarding their parenting skills?

RQ4. How successful are the identified parenting support strategies for parents with intellectual disabilities regarding their parenting skills?

4 Method

A systematic literature review is used to identify, evaluate and integrate the findings of the different articles. This method is a comprehensive study of literature covering a particular area or topic (Aveyard, 2010). The goal is to identify, critically evaluate and integrate data of relevant studies regarding a specific aim as well as matching research questions (Baumeister & Leary, 1997; Cohen, Manion, & Morrison, 2011). The review is objective, transparent and replicable, hence a detailed description of the search procedure, data collection, and analysis in the following.

4.1 Search procedure

For the article collection, five databases related to education and health were selected. Those were ERIC, SAGE, ScienceDirect, Taylor & Francis and Wiley. The following search terms were used in varying combinations depending on the respective databases; (Intellectual Disability OR Mental Retardation) AND (Parents with Disabilities AND Parenting) AND (Support OR Therapy) AND (Child OR Children OR Youth). The searches were conducted on March 10th, 2018.

The search strategy was adapted to the different databases, using thesaurus terms and free term search strategies, as well as title, abstract or keyword searches. The table with exact search terms for each database can be found in the appendix (Appendix A, Table 9.1) and Figure 4.1 illustrates a flowchart of the selection process.

4.2 Selection criteria

A variety of inclusion and exclusion criteria was developed to select the articles in accordance with the aim and research questions of the thesis. Relevant articles were chosen based on formal criteria (i.e. type of publication, year of publication) and subject-related criteria (i.e. participants, focus). Table 4.1 illustrates the exact inclusion and exclusion criteria.

Table 4.1 Inclusion/Exclusion criteria

Inclusion	Exclusion
Publication Type:	**Publication Type:**
Scientific Article	Book chapters, literature review, doctoral thesis,
Peer-reviewed	protocols, conference papers and other literature
In English	
Year 2010-2018	
Free full-text access	
Participants:	**Participants:**
Parent with intellectual disability	Children with intellectual disabilities
European, North-American or Australian	Children to typically-functioning parents
Focus:	**Focus:**
Parenting Support strategies given/received regarding parenting skills	Court decisions, custody, child neglect

Study Design:	Study Design:
Empirical Studies	Literature review
Qualitative	
Quantitative	
Mixed	

The choice to only use English literature is justified by it being the common language of the author and the university, hence enabling higher transparency. The time range (2010 to 2018) is chosen to analyse the current situation and eliminate outdated facts, considering the ratification and the inception of the convention on the rights of persons with disabilities (CRPD) by most countries as the start of this review. The studies are from the western culture, so as to provide an insight and possibility to adapt the results in other countries with similar resources and general values (Huntington, 1996). The choice is also based on the author's context and possible future implications. The focus is implied in the aim and the study design is open as to find a maximum of eligible data.

4.3 Selection process

A total of 123 articles was found using different search terms and the publication date limitation in the five databases (Appendix A, Table 9.1). To facilitate the search process, the Covidence software was used as an online screening tool for systematic literature review (Babineau, 2014). It facilitated the identification of duplicates, as well as the screening of titles and abstracts. In this procedure, fourteen articles were eliminated as they were duplicates. A summarised overview of the selection process can be found in Figure 4.1.

Moreover, articles from previous reviews on this topic have already been identified for the background beforehand. They have then been hand searched for further articles, but none of those adhered to the inclusion criteria.

4.3.1 Title and abstract

The 109 remaining articles were screened for Title and Abstract to find articles related to the aim. This procedure enabled a disposition of 87 more articles due to the exclusion criteria (Table 4.1). Most articles were removed, as they did not involve parents with intellectual disabilities, but children or as they focused on child neglect by parents with intellectual disabilities instead of parenting support strategies.

4.3.2 Full-text

The remaining 22 articles underwent full-text screening. One article was added by hand searching as multiple articles referenced it. In this step, six articles were eliminated for not fully adhering to the inclusion criteria (i.e. Study Design, Country conducted in, Focus).

The 17 final articles were further assessed regarding their quality. Low-quality articles were removed, resulting in twelve articles to be analysed. Nine out of these are qualitative studies using direct implementation of support strategies as home-based interventions or interviews, and three are mixed studies, implementing questionnaires (see Table 4.2). In general, there is not a lot of recent research based on parenting support strategies for parents with intellectual disabilities, thus all methods were included in the data analysis to gain a broader insight.
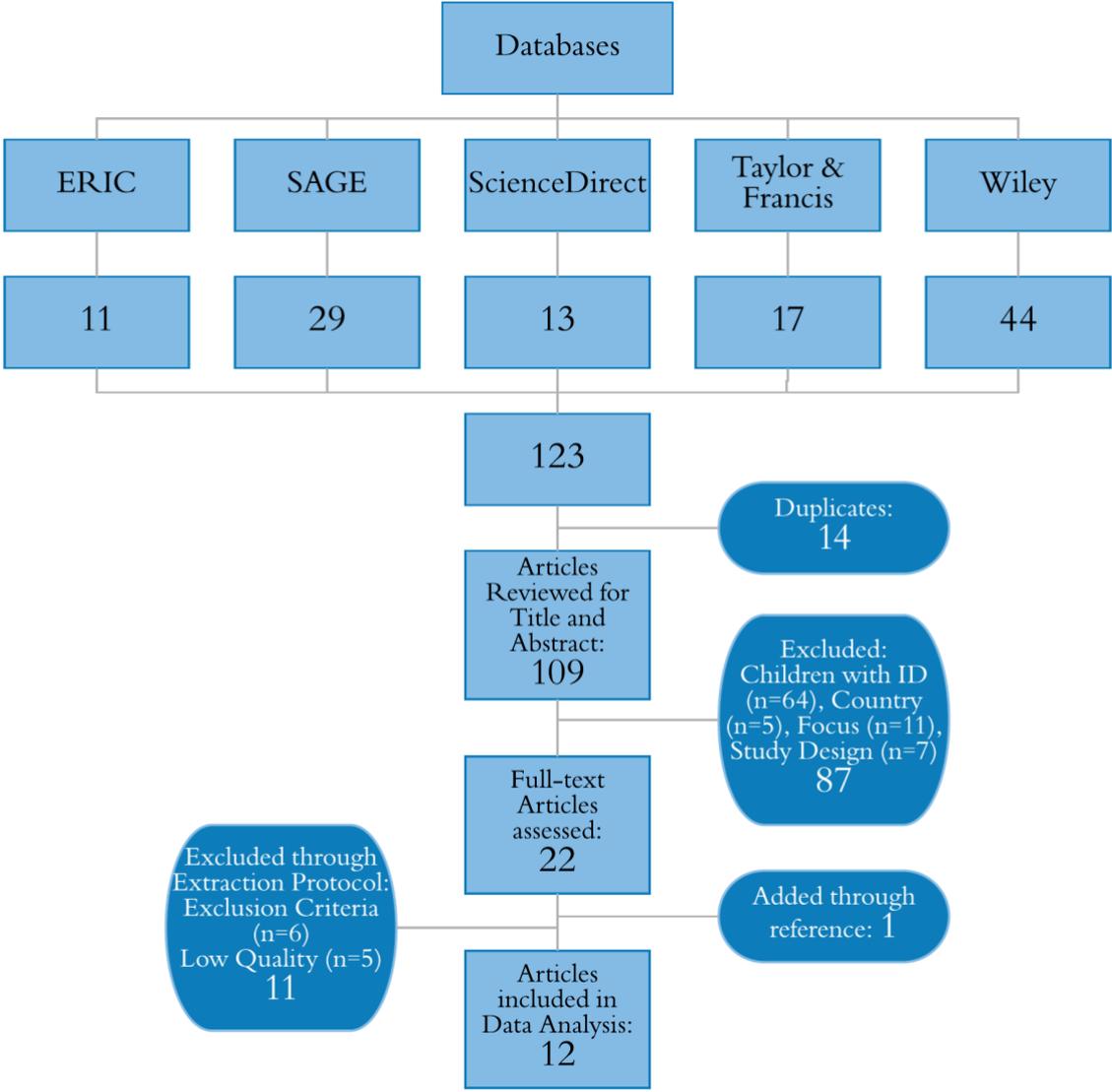

Figure 4.1 Flowchart of Selection Procedure (created by author)

4.4   Quality assessment

To evaluate the quality of the articles, a quality assessment tool was created based on the *Critical Review Form for Qualitative Studies* (Letts, Wilkins, Law, Stewart, Bosch, & Westmorland, 2007), the *CASP Qualitative Checklist* (Critical Appraisal Skills Programme, 2018) and the *Quantitative Research Assessment Tool* (Child Care and Early Education Research Connection, 2013) to address all three types of study design. The questions and ratings of the tools are not modified, solely combined into one quality assessment tool.

The full version of the combined quality assessment tool can be found in the appendix (Appendix B, Table 9.2). The highest score on the quality assessment is 16 points or 100%. An article is assigned high quality when it is equal to or above 75% (≥12/16 points). An article is assigned medium quality when it is equal to or between 50 and 75% (8-11/16 points) and anything below 50% (<8/16 points) of the score is low quality. To guarantee quality awareness, the low-quality articles were not used in the results section.

Out of the 17 full-text approved articles, five are excluded due to low quality. This leads to 12 articles to be included in the results section; out of which, five are of medium quality and seven are of high quality.

To further ensure quality in this study, the verification, regrouping reliability, validity, and generalisability from the data of the literature review take place at all different stages of the research procedure. Hence, all the factors become intertwined (Cohen et al., 2011). Granheim and Lundman (2003) also include the importance of "credibility, dependability and transferability" (p.109). By choosing articles from different backgrounds and of different actors' perspectives, various insights on the aim are gained and a higher degree of credibility is ensured.

4.5   Description of included articles

Out of an initial number of 123 articles gathered through a systematic search on the five databases, 12 articles fit both the inclusion criteria and quality assessment. The articles were included if they met all the inclusion criteria and demonstrated high or medium quality. The list of included articles, referred to by numbers in the following, can be found in Table 4.2.

Seven high quality articles (2; 3; 4; 7; 10; 11; 12) and five medium quality articles (1; 5; 6; 8; 9) are referred to in this results section. Four articles and their respective studies are from the USA (1; 2; 3; 8), while the others are from Europe (Belgium [4], Netherlands [5; 6; 7] & Sweden [9; 10; 11; 12]). Chengappa, McNeil, Norman, Quetsch, and Travers (2017), together with McHugh and Starke (2015) and Glazemakers and Deboutte (2012) use mixed approaches. The remaining 9 articles all use qualitative methods. The review does not include any quantitative study.

The definition of parents with intellectual disabilities eligible for the parenting support was mostly a low IQ (in general at least below 80) (5; 1; 2), but also learning disabilities (1; 4), lower adaptive functioning (6; 9), and social barriers to inclusion (9; 10; 11) were used in the target group criteria.

Parenting skills, as seen in the articles, are related to internal capacities to learn from the environment and prior experiences, respecting their environmental and social resources (1). It is a complex, but also rewarding activity (6). Parenting is a dynamic responsibility with shifting demands and expectations of skills (10). Autonomy, flexibility, and reflexivity are modern attributes to it (8). PID are often depicted as lacking parenting skills and having low confidence regarding their parenting style, making them vulnerable to prejudices by society (11). This frequently results in the removal of the children instead of effective parenting support strategies (1).

A full description of the articles and their content is assembled in a data extraction protocol, the layout of which can be found in Appendix C, Table 9.3. The characteristics of the article, information on the method and data collection, as well as participants, are retrieved by this tool. Additionally, definitions of essential terms are collected. In this data extraction, the parenting support strategies are identified within a structured analysis matrix and mapped onto Dunst and Trivette's (1997) sources of support within the resource-based model. The support strategies for parenting skills are divided into their description, the accessibility (measured through proximity, affordability, and the number of admitted participants), the success (measured or observed improvement of the targeted parenting skills in the articles), as well as the perspectives and opinions of PID and support workers. The limitations, quality, and inclusion or exclusion criteria are mapped out in the end.

Table 4.2 List of included articles (created by author)

Identification number	Author (Year)	Article Title	Country	Method	Participants	Topic	Quality
1	Azar, S.T., Robinson, L.R. & Proctor, S.N. (2012)	Chronic Neglect and Services Without Borders: A Guiding Model for Social Service Enhancement to Address the Needs of Parents with Intellectual Disabilities	USA	Qualitative	273 (parents)	Adapt Parenting Support to PID	Medium
2	Chengappa, K., McNeil, C.B., Norman, M., Quetsch, L.B. & Travers, R.M. (2017)	Efficacy of Parent-Child Interaction Therapy with Parents with Intellectual Disability	USA	Qualitative and Quantitative	6 (3 parent-child dyads)	Parent-Child Interaction Therapy for PID	High
3	Gaskin, E.H., Lutzker, J.R., Crimmins, D.B. & Robinson, L. (2012)	Using a Digital Frame and Pictorial Information to Enhance the SafeCare® Parent-Infant Interactions Module with a Mother with Intellectual Disabilities: Results of a Pilot Study	USA	Qualitative	2 (1 mother & 1 support worker)	SafeCare PII module, and pictorial materials	High
4	Glazemakers, I. & Deboutte, D. (2012)	Modifying the 'Positive Parenting Program' for parents with intellectual disabilities	Belgium	Qualitative and Quantitative	30 (15 mothers & 15 fathers)	Adapt Positive Parenting Program (Triple P) to PID	High
5	Hodes, M.W., Meppelder, H.M., De Moor, M. Kef, S. & Schuengel, C. (2016)	Alleviating Parenting Stress in Parents with Intellectual Disabilities: A Randomized Controlled Trial of a Video-feedback Intervention to Promote Positive Parenting	The Netherlands	Qualitative	85 (83 mothers & 2 fathers)	Video-Feedback intervention for stress diminishment in PID	Medium
6	Hodes, M.W., Meppelder, H.M., De Moor, M. Kef, S. & Schuengel, C. (2017)	Effects of video‑feedback intervention on harmonious parent-child interaction and sensitive discipline of parents with intellectual disabilities: A randomized controlled trial	The Netherlands	Qualitative	85 (83 mothers & 2 fathers)	Effects of Video-Feedback intervention on parent-child interactions for PID	Medium
7	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	The Netherlands	Qualitative	36 parents & 17 support workers	Evaluate Video-Feedback intervention adapted to PID	High
8	Knowles, C., Blakely, A., Hansen, S. & Machalicek, W. (2016)	Parents with Intellectual Disabilities Experiencing Challenging Child Routines: A Pilot Study Using Embedded Self-Determination Practices	USA	Qualitative	4 (2 parent-child dyads)	Outcomes of self-determination practices in parenting interventions for PID	Medium
9	McHugh, E. & Starke, M. (2015)	Understanding support workers' competence development in working with parents with intellectual disability	Sweden	Qualitative and Quantitative	31 support workers	Support Workers' perception on "Parenting Young Children" (PYC)	Medium
10	Starke, M. (2011a)	Descriptions of children's needs and parenthood among mothers with intellectual disability	Sweden	Qualitative	7 mothers	Experiences of PID	High
11	Starke, M. (2011b)	Supporting Families with Parents with Intellectual Disability: Views and Experiences of Professionals in the Field	Sweden	Qualitative	19 support workers	Support Workers' attitudes towards their clients	High
12	Starke, M., Wade, C., Feldman, M.A. & Mildon, R. (2013)	Parenting with disabilities: Experiences from implementing a parenting support programme in Sweden	Sweden	Qualitative	31 support workers	Clinical utility of PYC in a Swedish context	High

4.6 Data analysis

The research aim guides the choice of contents and the whole process of the data analysis (Robson, 1993). The data analysis is processed through a deductive qualitative content analysis to delineate the units of general meaning relevant to the aim (Hycner, 1985). The units of general meaning are condensed into codes, which emerge from categories and sub-categories. The data analysis is manifest and not latent, as to not misinterpret meanings, but focus on the surface structure (Catanzaro, 1988).

A deductive content analysis is based on previous knowledge, such as a theoretical framework, moving from the general to the specific categorisation (Burns & Grove, 2005). The benefits of deductive versus inductive qualitative content analysis are higher reliability, higher trustworthiness, the possibility to explain causal relationships and generalise the findings to a higher extent (Catanzaro, 1988; Elo & Kyngäs, 2008). The analysis consists of a preparation phase involving the selection of the unit of analysis and making sense of the data as a whole. This leads to the organising phase, in which a categorisation matrix (structured analysis matrix) is developed. The structured analysis matrix implies only features, which correspond to the categories, unlike the unconstrained matrix. The next step is the review and coding of the data within all the included articles, meaning the data is coded in correspondence to the categorisation matrix. Finally, the results are reported within their categories and conceptual system (Elo & Kyngäs, 2008). The category list is thus elaborated before the analysing process, such that the data analysis can be based on the existing codes (Bengtsson, 2016).

The categories of this data analysis are based on Dunst and Trivette's (1997) sources of support in the resource-based approach model to answer the aim.

4.7 Ethical issues

The conduct of a literature review must be done with respect to ethical issues. The Committee on Publication Ethics (COPE, 2010) offers an appropriate guidance on this topic. The righteous referencing style is important to acknowledge the contributors of the articles. Moreover, accuracy must be ensured through meticulous data extraction. Finally, the review cannot be a duplicate of a similar review or involve plagiarism in any way (Higgins & Green, 2008; Wager & Wiffen, 2011).

The five ethical principles (American Psychological Association, 2002) were addressed in both the articles used and this literature review. They were assured through meticulous analysis. The beneficence and non-maleficence are guaranteed by protecting the rights and welfare of the participants, respectively the authors of the chosen articles. Fidelity and responsibility are enabled through upholding professional standards of conduct. The integrity is upheld by truthfulness and accuracy, which is meant to ensure there is no misrepresentation of facts. The explanation of limitations and potential biases enables justice within the paper. Finally, the respect for people's rights and dignity is found throughout the articles and literature

review. It is included in the selection of participants and through the elimination of prejudices to the author's best extent (Hanson & Kerkhoff, 2011).

The author has an individual pre-understanding of support strategies within educational settings through the background of being a teacher. The master course gives the author further access to knowledge regarding support, interventions and intellectual disabilities. At the same time, a previous knowledge of intellectual disabilities is provided through the bachelor thesis, which treated that topic within children. The concept of parenting or being a parent is scientifically seen new to the author and information was previously only available through informal connections, such as family and friends. The combined topic of parents with intellectual disabilities can hence be approached objectively.

5 Results

The results unite the information on support strategies available to parents with intellectual disabilities regarding their parenting skills. They include their descriptions, the mapping onto Dunst and Trivette's (1997) resource-based framework, as well as their accessibility and success rate. The twelve articles included different support strategies that each adheres to a specific source of support. The main finding of this systematic literature review is that nine parenting support strategies for parenting skills of PID were identified within the chosen articles. Some are established strategies, but most haven't been implemented or researched extensively. Through the deductive data analysis, four support categories have been identified. The identified parenting support strategies for PID are presented briefly before connecting them to the analytic framework of sources of support by Dunst and Trivette (1997).

5.1 Identified support strategies

The following shortly illustrates the identified support strategies, to later explain them in depth while mapping them onto the sources of support in the resource-based model. The first support strategy is informal support, which consists of mentoring by relatives or friends (4; 8; 10). Second is the Positive Parenting Program (Triple P), a skill-focused intervention outside one's home, designed to improve the parenting skills through meetings and open talks with persons of similar background. It is offered to everyone but can be adapted to group meetings of only a specific target group (4). Self-Determination Theory (SDT) is also a skill-focused intervention, using behavioural teaching principles and focusing on the improvement of judgement through mastery of nine different parenting skill steps (8). Moreover, there are Child Protection Services (CPS), a reactive approach neglecting the personal background and existing worldwide (1; 10; 11). Additionally, support workers constitute a support strategy. They are professionals from the social, educational or health sector that complete special training to work with PID on their parenting skills (2; 5; 6; 9; 12). Ideally, support workers act as persons of trust (3; 10). Another support strategy is the Parenting Young Children Program, which is a home-based capacity-building program specifically designed for parents with intellectual disabilities (12). This program aims to improve the health and well-being of children to PID through working on parenting skills (9). Temporary Assistance for Needy Families (TANF) is also a capacity-building program, which is family-centred and focuses on the evaluation and assessment of parenting needs of PID (1). One more capacity-building program is the Parent-Child-Interaction Therapy (PCIT), focusing on improving parenting skills by using family strengths and interaction (2; 3; 6). The last identified support strategy is the Video-Feedback Intervention to promote Positive Parenting (VIPP) aiming to improve the sensitivity and parenting skills by the means of video observation and analysis during daily interactions (5; 6; 7). A more detailed overview of the above-mentioned support strategies can be found in Table 5.1. It alludes to the next results section, the mapping onto Dunst and Trivette's (1997) sources of support.

Table 5.1 Overview of support strategies within Dunst and Trivette's (1997) sources of support (adapted by the author, based on the included articles)

Sources of Support	Personal Social Network	Associational Groups		Community Programs and Professionals				Specialised Services	
Support Strategies	Informal Support	Triple P	SDT	CPS	Support Workers	PYC	VIPP	TANF	PCIT
Articles based on	4; 8; 10	4	8	1; 10; 11	All	9; 12	5; 6; 7	1	2; 3; 6
Characteristics	-sharing of experiences	-skill-focused -behavioural teaching principles -outside home -limited time	-skill-focused -behavioural teaching principles -home-based -unlimited	-same for everyone -worldwide existence -reactive	-complete special training -work with PID and their families -ideally person of trust	-home-based -cognitive disabilities -capacity-building -proactive	-home-based -attachment & coercion theory - behavioural teaching principles -visual aid	-family-centred -capacity-building -proactive	-home-based -family-centred -capacity-building -proactive
Short Description	Close environment of the PID providing non-specific support	Meeting people with similar issues regarding their parenting to consult	Improving ability of judgement through mastery of 9 steps	Reacting to cases of child abuse or neglect	Mediators between PID and government	Interventions to improve the health and well-being of PID's children	improve sensitivity and parenting skills through video observation during daily life interaction	Identification procedures for evaluation and assessment of the parenting needs of PID	Use family's strengths to improve parenting skills through interaction
Procedure	Through family and friends	Group sessions and follow-up phone calls	home visits with focus on mastery of one step at a time	support workers, legal actions and child removal	Meetings, home visits, active care	Training for professionals to feel more competent and confident in the work with PID	Recording and feedback sessions with one closing visit after 3 months	Screening and parenting assessment, followed by intervention and training	Separate interactions, then combined interactions to achieve mastery in defined skills

Note. Triple P = Positive Parenting Program; SDT = Self-Determination Theory; CPS = Child Protection Services; PYC = Parenting Young Children Program; VIPP-SD = Video-Feedback Intervention to promote Positive Parenting; TANF = Temporary Assistance for Needy Families; PCIT = Parent-Child-Interaction Therapy.

5.2 Mapping onto Dunst and Trivette's (1997) resource-based model

The identified support strategies mentioned-above are categorised into Dunst and Trivette's (1997) sources of support in the resource-based approach model (Table 5.1) to answer the second research question. The personal social support relates to the close environment such as family or friends and is informal. The associational groups are support groups of equals (i.e. groups of parents with intellectual disabilities) and function within the close community; they are mostly informal but if joined by a support worker become partially formal. The community programs and professionals are governmental support programs offered nationwide for everyone. While they are offered to PID, they are not specific to their case. The specialised services involve specialists and support programs specifically designed for PID (Wolery, 2000).

5.2.1 Personal social network

Three articles mentioned personal social network in form of informal support explicitly. Two of which also adhere to associational groups (4; 8) and one related to community programs and professionals (10).

The informal support is a universal parenting support strategy (8), available in the proximate environment without diagnosis and professionals (4). Informal support can be everyone within the environment of the PID. This includes the family, but also municipality, regulations and environmental settings in general, which provide non-specific support to the entirety (10). The personal social network relies on the mutual confidence and strong bond between the PID and people within their direct environment (4). A higher sensitivity of the support person, founded on the close relationship and insight into the PID's everyday life, leads to a more open-minded attitude of the PID based on trust (8; 10) and creates an open access to information for PID. The information flow is facilitated through the existent interpersonal connection (4). The personal social network does not provide the same quality of support as formal one, as those people are not trained in the interaction and treatment of PID and can only represent own experiences (4; 8; 10).

5.2.2 Associational groups

The support from associational groups is the use or adaptation of the resources already available in the close environment of the family (8). In general, associational groups and their therapy programs enable the parents to be involved and make decisions themselves. Those programs reassure PID's capability and prior knowledge, rather than stressing professionals' ideas (4). Hence, the focus lies on self-determination and the support of improving parenting skills already present within PID. At the same time, they don't impose a pre-established plan to follow (8). The associational groups benefit from the contact between like-minded people, in this case PID, by providing space and time to interact and learn from each other (4; 8).

Two articles included such groups in different ways. The Positive Parenting Program (Triple P) takes place in a group setting outside of the home (4), while the Self-Determination Theory (SDT) becomes an integral part of the participant's everyday life. Both are skill-focused and employ behavioural teaching principles (4; 8). Triple P is initially a program available to every parent, in which one gets the chance to meet people with similar or the same issues regarding their parenting. A few changes make it useful to PID. Adaptations include the diminishment of sessions and their duration. This is to keep up the participants' attention (4). In total, five group sessions of two hours each are planned, followed up by three 20 minutes' follow-up phone calls to the parents. In the same way, SDT is available to everyone. It focuses on the parental right of judgement and building upon this right. Their ability of judgement is being enhanced over time through the mastery of nine competencies; choice-making, decision making, problem-solving, goal-setting, independence, self-regulated behaviour, self-instruction, self-advocacy and internal locus of control (8). The time span of the two support strategies varies, as Triple P is limited in time and SDT is planned to continue after each achievement. It includes a follow-up even after the mastery of all steps is completed (4; 8).

5.2.3 Community programs and professionals

Common Child Protection Services (CPS) and the use of the Parenting Young Children (PYC) program are both community programs, offered to the public by the government (9; 11). They are completed through the work of support workers (10; 12). Professional support workers either get special training to indirectly educate the parents (9) or are the mediators and bearers of news between government and families (1). Three of the articles include CPS and two talk about PYC, while professional support workers are mentioned in all the articles.

Azar, Robinson, and Proctor (2012) described the typical CPS service provision, as not containing specific adaptations to PID, but being used widely as parenting support strategy for any parents. It is used with parents ranging from typically-functioning to chronically sick or special needs. PYC, on the other hand, is a specifically designed home-based parent support program for parents with cognitive disabilities (12). It is a capacity building program, of which the goal is to improve the health and well-being of zero to six-year-old children of PID through an intervention with their parents (10). This proactive program takes place during the early years of the children and uses pieces of adult learning theory, as well as a family-centred approach (10; 12). Both community programs consist of training for professional support workers. They will in return teach and work with PID and their families (12) or control child neglect (1). While CPS exists worldwide in different shapes (11), PYC is a support strategy established in English in Australia and now translated to the language and context of Sweden (12).

Both programs include support workers; additionally, the support through professional support workers, in general, is also a separate support strategy (9; 11). All the included articles incorporate the work of support workers, showing the importance of the professional dimension of support. The stress

level of the workers and their education become decisive in the work with PID (10; 11). The attitude of the support workers and their function as a person of trust can have a great influence on the outcome of the families with PID (2; 3; 5; 7; 8; 12). Equally, they can also provoke feelings of shame and reluctance when not trained properly or not showing the due respect towards PID (11).

5.2.4 Specialised services

Three support strategies, included in six articles are specialised services for PID. Those implicate the parent with ID and its family directly (1; 2; 3; 5; 6; 7). The Temporary Assistance for Needy Families (TANF) establishes improved identification procedures for evaluation and assessment of the parenting needs of PID (1). It uses a family-centred approach in three steps. First, the screening and parenting assessment take place. Next is the intervention with the PID. Last comes a down-to-reality and specifically adapted training to build capacities within the parents (1). TANF is like most specialised services proactive as opposed to reactive, as it is designed to prevent child maltreatment or neglect by PID (1).

The Parent-Child-Interaction Therapy (PCIT) is also proactive and works with both the parent and the child. It uses parent-directed interaction and child-directed interaction to identify the weaknesses and combine the strengths of the family. This improves the bond and interaction and thereby indirectly parenting skills (2). PCIT exists in different forms, SafeCare® Parent-Infant Interactions Module being a very specific PCIT, focusing on physical and non-physical skills in a range of daily and play activities. The goal is for PID to achieve mastery in parenting skills previously identified (3). The same goal is identified in Video-Feedback Intervention to promote Positive Parenting (VIPP). It is based on insights from the attachment theory and the coercion theory. It works with the design of parenting interventions in their own home, focusing on concrete skill enhancement through behavioural teaching strategies (6). The goals are to increase the sensitivity of PID and prevent conflict, but also to improve positive parenting skills and diminish any form of escalation of conflict or defiant hostility within the family (7). The Intervention is structured into pre-intervention interviews at the family's home, followed by 15 home visits in total. Seven of these are recording sessions, each of which are followed by a feedback session and one closing visit at the end of the three-month period. During the recording sessions, the parents interact in their daily life and play with their children. The feedback sessions are then used to analyse the behaviour together with a professional; identifying personal strengths, addressing doubts and finding joint solutions to the issues. At the same time, a scrapbook, with stills taken from the video-recordings and short comments, is established as a visual reminder of the session (5).

5.3 Accessibility of identified support strategies

The accessibility is measured through proximity within the PID's environment, the affordability and the capacity of the program.

The accessibility of the personal social network varies between individuals, as each PID has a different network (8). It takes place in the close environment, making it the most proximal form of support (4). In

general, an intellectual disability includes a limited (small in numbers) but, at the same time, solid (reliable) personal social network (4; 10). As stated by Starke (2011a, p.292), "helpful relations are […] rather special in that one's own parents are usually more readily available than other sources of support".

The associational groups are not offered everywhere, but if offered, they are easily accessible to the people in the community (4). "Practitioners may create accessible learning opportunities for these parents by modifying the tools and behavioural methods they already have" (4, p.624), making the Positive Parenting Program (Triple P) and Self-Determination Theory (SDT) adaptable anywhere. The Triple P is more accessible as it consists of group meetings, allowing a large number of participants (4), while the SDT is less accessible by needing one support worker per case (8).

The accessibility of the community programs and professionals differ widely. The Child Protection Services (CPS) are accessible only in retrospect (reactive approach) after an event is reported (11). On the other hand, they are not exclusive to any group and can be accessed by anyone free of cost (1). The accessibility to the Parenting Young Children Program (PYC) is restricted, due to the prior need of translation and adaptation to the context (12), as well as the necessary training of the support workers (9). The support workers' accessibility vastly depends on the program, ranging from low accessibility due to the restricted number of participants (2; 3; 5; 7) to high accessibility in group meetings (4).

The accessibility to specialised services is generally more restricted. They are unavailable in most countries and PID must be given one of few spots within the program (1; 3; 5). The Temporary Assistance for Needy Families (TANF) is "cost-saving in constructing a system that is more effective and stops the revolving door of involvement with CPS" (1, p.146), making it more accessible. The Parent-Child-Interaction Therapy (PCIT) and Video-Feedback Intervention to promote Positive Parenting (VIPP) lie within the proximal environment as home-based models (2; 5), also influencing their accessibility positively. The time investment of one support worker per family (2; 7) and the cost of the device for a VIPP decrease the accessibility of these support strategies. It remains a societal issue to adopt a more universal approach towards the provision, maintenance, and accessibility of specialised services for PID (1).

5.4 Success of identified support strategies

The success is identified through the measured or observed difference between the initial state and the outcomes.

The success rate of the personal social network demonstrates a worthy complementary support strategy to enhance formal support (4; 8). The participants stated, "that having such contacts had strengthened them as parents, improving their parenting abilities" (10, p.291). At the same time, the informal support remains difficult to scientifically evaluate on its own due to the high individualism and contextuality, as well as low replicability (10).

The results section of support from the associational groups shows that adaptations of the Triple P, as well as the standard procedure of SDT, are successful support strategies to PID. In fact, "significant reduction in maladaptive parenting behaviours" (4, p.622) was identified. To underline these findings, "89 percent (of the participants) reported that Group Triple P had helped them […] to deal with parenting problems, if these occurred" (4, p.622). Moreover, the success is improved by occasionally implementing a professional support worker into the groups, thus slightly combining it with support strategies within community programs and professionals. In this matter, the participants "demonstrated immediate increases in correctly completed steps of the parenting routine in the first training session and reached the mastery criterion", meaning "80% or higher for three consecutive observational sessions" (8, p.441).

The success of community programs and professionals vastly depends on the respective program and professional (1; 5; 8; 12). CPS are not adapted to special needs, following a reactive approach and focusing on the negative facts instead of the provision of support. Participants indicated a "lack of clear communication from the social services or insufficient or inadequate information" (10, p.293), decreasing beneficial outcomes. This often results in negative feelings of PID towards support workers bearing the news of issues (1; 11). A proactive approach can prevent the negativity and focus on strengths, resulting in a successful intervention (1; 8). As a result, "perceived skill scores were significantly higher at time B (after support) than time A (before support), p = 0.012" (9, p.336). Additionally, PYC makes the professionals feel more competent and confident in their interaction with PID (11; 12). They stated that the program is well structured and flexible, "which allowed them to work with individual parents and to draw on and improve their existing skills" (9, p.334). The community programs and professionals are paving the way for a successful collaboration, but still lack further research on their outcomes, as well as lingual and contextual adaptations (10; 11; 12).

Evidence-based interventions and systematic change activities within the specialised services improve parenting skills (1; 2; 6; 7). The VIPP initiated an increase in the support workers influence on the parent and one mother stated, "she was now better able to understand Rose's (her daughter) needs" (7, p.397). Moreover, it was observed that "the feedback reinforced positive interactions between the primary caregiver and the child" (6, p. 306). As for the PCIT the parenting "skill demonstration increased to 91.6% after training was completed" (5, p.196) and all the "participants showed an increase in the positive parenting composite and decrease in negative parenting composites" (4, p.263), indicating improved parenting skills after the implementation of the support strategy. Equally, TANF is reported as observably "successful in increasing parenting skills and improving child outcomes" (1, p.140).

6 Discussion

This systematic literature review focuses on describing support strategies extended to PID in general and within Dunst and Trivette's sources of support. Furthermore, it questions their overall accessibility and success. By searching various databases, twelve articles containing nine different support strategies for parenting skills were found adhering to the aim and research questions. Accordingly, there are vast possibilities in the support for PID. The strategies were categorised into the four sources of support during the process of a deductive content analysis, leading to the results to discuss.

6.1 Discussion of results

Parenting skills are connected to the caretaking and upbringing of the child (6; 8; Knowles, Machalicek, & Van Norman, 2015) that protect the child from harm and neglect (1; Coren et al., 2011). Moreover, free and equal social support for people with a disability is a human right (United Nations, 1993; Quinn et al., 2002), which needs to be complied. The available support strategies all included parents with intellectual disabilities and perceived parenting skills as essential influencers in the parent-child-interaction. Additionally, those strategies impact the child's developmental outcomes. This common background is important to enable a deeper understanding when discussing the studies, and their outcomes.

6.1.1 Available support strategies and the sources of support

Nine existing support strategies for parenting skills of PID have been identified within four sources of support. The personal social network was represented as informal support in three articles (4; 8; 10). It is building up essential trust and confidence within PID. The informal support strategy has the most personal and immediate influence by being embedded in the microsystem (Bronfenbrenner & Ceci, 1994) of the PID. The other six articles are thus neglecting the role of trust and accessibility benefits, in favour of professionally led intervention programs. The informal support is however important regarding the improvement of parenting skills as it offers a more personal contact (Meppelder et al., 2014; 4). While the programs with trained support workers are important in the adult education aspect, the focus on individuality can derive to a more norm-based idea of society (1; 11). PID are expected to adapt accordingly. This often leads to a scared, defensive, and uncooperative approach by the PID (Callow et al., 2016; Mayes & Llewellyn, 2009). In turn, this limits the information flow enabled through confidential cooperation (8) and neglects the high availability of informal support strategies in the personal social environment (Starke, 2013). The informal support and its undeniable benefits should be considered as an asset alongside formal support strategies.

The active use of available resources is especially encouraged in support strategies involving the personal social network or associational groups (8). Thereby extra expenses are reduced and social, financial and political benefits enabled to everyone involved. The complexity consists of identifying and

activating the appropriate resources according to the desired outcomes of parenting skills. A professional's distinctive perspective on essential parenting skills facilitates this procedure (Meppelder et al., 2014; 4; 8). Leading up to community programs and professionals, as well as specialised services, which operate in the meso-, exo- and macrosystem (Bronfenbrenner & Ceci, 1994). They involve support workers and service provision in the PID's everyday life, as well as interactions with others. Moreover, they are most often based on constitutional regulations.

Referring to community programs and professionals as a source of support, three support strategies were identified; standardised Child Protection Services (CPS), the Parenting Young Children Program (PYC) and support workers (1; 9; 11). This category was the most varied, as it provided information on one reactive (CPS) and one proactive (PYC) approach at the same time. The reactive approach is overall regarded as critical (McConnell & Llewellyn, 2005; 1; 9) as it focuses on remedying an abuse after it has been identified. Instead, programs should focus on developing parenting skills beforehand and prevent negative outbreaks. The proactive approach already considers the outcomes for the children of PID and their overall family life beforehand (McConnell & Llewellyn, 2002). Based on the results, Child Protection Services should be revised and adapted to a more proactive approach, enabling the support workers to help sustain a fruitful and mostly positive atmosphere when working with PID. Of course, this is rather a utopic illusion if speaking of it to a full extent, since child neglect is still happening. Since it is not predictable all the time, there remains the need to interrupt and treat abuse in hindsight. Nevertheless, the results show that PID should already be offered support strategies regarding their parenting skills beforehand. In fact, the proactive approach offers a more effective way and neglect can be prevented ahead of time. CPS should thus not be the priority action.

PYC for example has shown to be a favourable alternative, firstly as it is planned for the training of parenting skills of people with cognitive disabilities, thus professionals are specifically trained in this domain and secondly it still offers the freedom of adaption to tailor it to specific needs and goals (9; 12). This family-centred approach puts the focus on the support for the parents with the goal to incite beneficial outcomes for their children, demonstrating a broader perspective on the topic and early intervention strategies (McConnell & Llewellyn, 2002; 12).

The fact that support workers are mentioned in every article proves a unanimous understanding of them as adequate - and above all necessary - support for PID in the development of their parenting skills. The support workers hence constitute the only unanimity in the results, meaning their influence and thereby training needs to be considered to its full extent (Llewellyn & McConnell, 2002; 11; 12). Dunst (1985) also alluded to the direct and indirect impact of social relationships on specific outcomes regarding support. Since the diagnosis of ID is usually detected before the age of 18 (Schallock, et al., 2010), the professional support worker assigned to a case should remain the same over an extended period of time. This would enable a foundation of trust and mutual respect (Llewellyn & McConnell, 2002; 4) before the

question of parenthood even arises. In that way, the professional and social bond can grow and lead to beneficial outcomes for the PID, their family, and their children's development.

Further, half of the articles mentioned three kinds of specialised services, which are immediately directed towards PID, thus illustrating an exclusively adapted version of support strategies. Temporary Assistance for Needy Families (TANF), Video-Feedback Intervention to promote Positive Parenting (VIPP) and Parent-Child-Interaction Therapy (PCIT) are all proactive. They create parenting skills learning situations for the parents to be involved in and thereby actively prevent unfavourable situations (Llewellyn & McConnell, 2002; 1; 3; 6). On one hand, they are still disabling inclusive information gathering during the time of support, due to their specifically adapted program. Thus, opening it up to more people could create more sources of knowledge sharing. On the other hand, those support strategies are very promising and need to be further developed and spread throughout different countries and contexts as to be able to generalise their findings and gain a more meaningful insight.

In the end, it is inevitable to notice that the support strategies are intertwined and often only divided by a fine line of bureaucratic interpretation and classification. Hence, encouraging a discussion about their accessibility and success.

6.1.2   Accessibility of support strategies

The articles do not specifically address the accessibility question; however, it is an important factor in the practical implementation of support strategies for PID as the Convention on the Rights of Persons with Disabilities underlines (United Nations, 2006). A person can only benefit from a support strategy if it is, in fact, accessible in its environment (Bronfenbrenner & Ceci, 1994; Trivette et al., 1997). Furthermore, a support worker can only be trained in a support strategy if the necessary resources are provided, thus accessible. In fact, most of the articles did not address accessibility thoroughly. The information gathered is an overview of proximity, affordability and capacity aspects.

The personal social network is the most accessible and sustainable of the four sources of support, as it is embedded in the microsystem (Bronfenbrenner & Ceci, 1994) and thereby closest to the PID. Nonetheless, this informal support differs tremendously from every individual, as some have a steady circle of family and friends and others are more secluded (Starke, 2013; 4 & 8). In terms of affordability, it does not involve any costs. Furthermore, it can implement as many persons as desired, thereby enabling high capacity of participants.

At the same time, associational groups being enclosed in the mesosystem (Bronfenbrenner & Ceci, 1994) can remedy if there is a lack of personal social network. They offer semi-formal support and still lie within the close environment of the PID. They are not available everywhere in the western countries, thus not everyone can benefit from them. However, if they are integrated into a municipality, the accessibility is guaranteed to all the citizens without restraint (4). Moreover, practitioners can modify the resources

available to adapt them to their context. This makes it the responsibility of the municipalities and their citizens to establish associational groups for support. The macrosystem can enhance the situation through educating society about ID and other special needs.

The accessibility to community programs and professionals was discussed the least in the articles. In general, it seems inferior to the previous support strategies, as it lies within the exosystem (Bronfenbrenner & Ceci, 1994) and is more remote to the PID. Child Protection Services are only accessible once a situation occurred and not previously (1). At the same time, the Parenting Young Children Program is, as of now, only limitedly available in two countries (9) and therefore related to low accessibility regarding proximity. The support workers, being important in every article, are accessible more easily. However, the PID must often take the initiative themselves or risk being denounced for child neglect before gaining access to support (4; 8 & 10). Accessibility to support strategies within community programs and professionals is thus relying on the individual, his confidence and often his personal social network.

Last stands the accessibility to specialised services within the exo- and macrosystem. These are restricted and mostly in their early stage. This means they are still working with tests rather than being established programs (1; 3 & 7). The PID need to be assigned a spot within those programs to get the support. In the future, this support strategy should be made more easily accessible through training support workers, as they are curical for PID. Additionally, the cost-saving aspect of proactive versus reactive approaches influences the accessibility positively (1) and should be considered in the planning.

The articles included in this review originate from western countries with similar resources and global values, making the support strategies more easily transferable to comparable nations (Huntington, 1996; 9 & 12). The previously discussed support strategies can hence be slightly adapted to the context or resources available. This would increase their accessibility throughout the western world and other countries that can provide the necessary conditions. It is also essential to note the importance of a holistic implication of the different systems of Bronfenbrenner's (1997) bioecological theory to enable a higher accessibility through the cooperation of the systems and resulting in a multidimensional perspective. This could help improve the accessibility on all levels and make it less dependent on the surrounding conditions, such as legislative obstacles.

6.1.3 Success of support strategies

The focus of the articles was not on the success rate itself, but rather on the concept of the strategies and their implementation in a context of PID. Nevertheless, the results and conclusions were a decisive factor in determining the success rate of the learning process and internalisation of behavioural techniques regarding the parenting skills of PID. The abstract factor of success was identified through the measured or observed improvement of parenting skills between the initial state and the state after the support.

The success of the personal social network, with its informal support, depends on the individual and its surrounding. However, building trust towards others and confidence in oneself is enhanced, which in return facilitates the success in learning parenting skills (Llewellyn & McConnell, 2002; 4; 8 & 10). Trust and confidence are essential in any successful intervention, making the informal support a vital complementary support strategy (Starke, 2013). However, the scientific evaluation of informal support remains challenging, due to the individualism and contextuality.

The support strategies within associational groups provide a successful outcome if adapted to the specific context. Hence, the Positive Parenting Program and Self-Determination Theory are successful only when handled appropriately by the group and support workers (4 & 8). This highlights the importance of a thought-out program and training for professionals to guide and support the PID in their own development. Those support strategies can then result in a reduction of maladaptive parenting behaviours and an increase of positive parenting skills (4; Mayes & Llewellyn, 2009).

The community programs and professionals proved to be most successful when adopting a proactive approach (1; 10 & 12). These findings demonstrate the importance of the consideration of PID and the valorisation of the individual over theories. A reactive approach results in insufficient information (10), while proactive approaches lead to higher perceived skill scores within the participants (9).

The specialised services, such as temporary assistance for needy families, Parent-Child-Interaction Therapy and Video-Feedback Intervention to promote Positive Parenting have demonstrated an improvement in parenting skills (1; 2; 6 & 7). They indicated a significant increase in positive parenting composites and decrease in negative parenting composites in three studies. However, there is still a lack of generalizable data on success in specific studies and research in general (Bernard, 1979; McConnell & Llewellyn, 2005).

In conclusion, a combination of informal and formal support seems crucial to beneficial outcomes. The combined professionalism, involving well-trained support workers providing specifically planned support regarding parenting skills, with the help of relationships within a personal social network provide the ideal basis for successful support strategies.

In the end, a remarkable finding is the lack of research on the actual success rate of the different support strategies. While this was part of the rationale, the findings are even more telling, and demonstrate the low extent to which success is evaluated. The articles discuss this lack on a lingual and contextual basis (10; 12), however, the importance of beneficial outcomes is rarely discussed regarding the quality of those support strategies. These findings justify once more the corresponding research question and need for further research on the actual outcomes of support strategies for parenting skills of PID.

6.2 Discussion related to previous reviews

Similar reviews have been established in the past. As mentioned in the background, this review differs by (1) the inclusion of qualitative studies, (2) the methodological approach and (3) the timeframe covered. Thus, the need to discuss the similarities and differences of the findings of the reviews.

6.2.1 Similarities

All reviews underline the lack of research and bias of small sample sizes, emphasising the need for further research. In this way, the current review tries to add to the previous findings in a qualitative way.

Wilson et al. (2012) determined encouraging results regarding social childcare skills of PID. They highlighted home-based methods as the most effective intervention. The current review also discovered that specialised services with home-based and family-centred strategies are the most effective. However, there still remains a need for combined strategies. Furthermore, Wade et al. (2008), Coren et al. (2011) and Knowles et al. (2015) all accentuate home-based and behavioural parent training for PID and the advantages of those to acquire parenting skills. This type of support strategies alongside others are identified and discussed equally in the current review. In the end, the shared results demonstrate the effectiveness of support strategies implementing behavioural teaching strategies and new understanding is added through the implementation of qualitative studies and non-specialised services.

6.2.2 Differences

The main difference between the current review and the previous ones is the inclusion of qualitative studies to gain a new insight. Consequently, the adoption of a qualitative deductive content analysis based on a resource-based model differs from the previous studies, which employed a quantitative methodology. Moreover, the current review analyses articles from a later timeframe than the earlier reviews.

Some difference can also be found in terms of findings. The reviews only included specialised services, neglecting the presence and possible adaptation of other established programs. Wilson et al. (2012) did not evaluate the parenting skills measured within homework activities, while Knowles et al. (2015) solely focused on home-based support strategies adapted. The current review adds to the field by looking for support strategies on every level and implementing informal support, which suggests higher sustainability. Moreover, Wade et al. (2008) acknowledge the neglect of contextual factors in their research. Those are meanwhile being approached in the current review by the resource-based model as the deductive framework.

Wade et al. (2008, p.351) suggest the need "to determine the influence of immediate or more distal contextual factors" in future research, which this review included with Dunst and Trivette's (1997) sources of support in relation to Bronfenbrenner's (1994) bioecological theory.

6.3 Discussion of methodology

The systematic review has benefits and weaknesses. It gives an overview of current research; however, it is limited to available resources. In general, it establishes a good starting point to gain an insight into the development of a topic over time, but will not give away the same information on a topic as a specifically designed study. Different authors might thus find various findings, depending on their search procedure. On the other hand, the detailed explanation of the search procedure within a systematic literature review guarantees a replicable and trustworthy research.

The choice of a deductive qualitative content analysis helped generalise the findings and make them comparable to other studies. While Dunst and Trivette's (1997) Resource-Based Approach to Early Intervention has already been used as a basis for a deductive content analysis in at least one other study (Dunst, Trivette, & Raab, 2013), this specific theoretical background of only their sources of support has not yet been used. Nevertheless, it enabled a specific view and categorisation of the topic and is appropriate to use in future research.

The methods in the different articles and studies were different, ranging from qualitative methodology to mixed methods, enabling a more holistic approach to the topic. The medium and high-quality articles, as determined by the composed quality assessment tool, proved to be containing a lot of resourceful information on the topic. Hence, the tool is adapted to this literature review and its intended outcomes. Furthermore, the countries studied in the selected articles and justified by the similarities of the western world, demonstrated connections and allow a future transferability of support strategies. The developed quality assessment and data extraction tools, together with the general benefits of the deductive qualitative content analysis, amplify a high trustworthiness and high reliability of this systematic literature review (Elo & Kyngäs, 2008). Moreover, internal validity was reached through the adaptation of the identified support strategies and appropriate procedure. While external validity is given to a smaller extent, as the findings are in fact out of authentic situations but the number of participants was too small to fully generalise (Cohen et al., 2011).

Lastly, the pre-understanding of the author was helpful in the comprehension of specialist terms but did not interfere with the newly acquired knowledge, as the author was not previously familiar with this specific topic. Thus, the topic was treated objectively.

6.4 Limitations

A limitation of this literature review is the lack of data on support strategies specifically designed for PID. Only a third of the strategies are established for and adapted to PID, while the remaining 6 are parent or family support strategies in general. Another limitation is the shortcoming of participants in the studies, making general statements about their success rate difficult. On this specific topic, the articles of

good enough quality were often by the same authors or contributors, challenging an objective point of view. Not much research has been conducted in the specific field up until today. The participant number within the studies was low, with most of them ranging from 2 to 30 participants. Only two studies had a sample size of 85 and one had a size of 273. This makes it impossible to establish qualified generalisations and thereby diminishes the degree of external validity.

The search strategy demonstrates an additional limitation, as the used search words limit the number and quality of articles retrieved. Hence the search could be more exhaustive by implying more search words coherent to the topic. The search words for support strategies in a further research should be elaborated and include "parenting support" and "parenting skills", while the wording of ID can be elaborated with terms such as "learning difficulties", "mental disability" and "cognitive impairment". Moreover, the search words for the target population can be extended by terms such as "mother", "father" and "caregiver". More search words can be added according to these examples.

The search for only English articles is also a limitation, since articles from other countries might be in different languages and could further address the topic. In the same way, only full-text articles, that were freely available, peer-reviewed and published between 2010 and 2018 were considered, excluding all other articles. Even if trial runs of the search procedure have been fulfilled and different databases have been used, it cannot be guaranteed that all studies concerning support strategies for parents with intellectual disabilities that were published in English after 2010 have been identified. In addition, having only one researcher in the selection process has an influence on the reliability, as the bias is being increased during the search procedure and selection process. Moreover, the data analysis is deductive, it was restricted to Dunst and Trivette's (1997) model. Another researcher might find a different appropriate framework or constitute its own inductive approach.

Another limitation is the non-universal interpretation of ID in each country, which influences the choice of participants for the studies and thereby the outcome. This is not only an issue for this thesis but in general for the research in the field of special needs. This definition should enhance specific research on the topic, while still enabling the freedom of elaborating on a basic definition.

6.5 Future research

The fact that during the search within five databases, such few articles matched the criteria, demonstrates the need for future research in the domain of support strategies in parenting for PID, but also the implementation of more search words matching the criteria. Thus, future research needs to include a broader use of adapted search words.

Furthermore, most support strategies are rather upcoming than well established, making further research on them inevitable. Research needs to be conducted in similar contexts (i.e. countries, cultural or

societal values, affected population) to offer a higher amount of comparable, as well as generalizable results.

Regarding the Human Rights and country-specific legal constitutions, a universal or at least unified western world definition of ID should be established as mentioned above. A unified definition needs to include a basic understanding, which can be further elaborated case-specifically. A good start would be the World Health Organisation's definition (WHO, 2018) considering intellectual disability as significant limitations within the intellectual functioning and adaptive behaviour, while still leaving open niches within these categories for individual cases to expand.

The future research in this domain should focus on the training of support workers on one hand and include the perspective of PID on the other hand. This would enable giving PID a voice and develop a well-elaborated training for professionals resulting in the foundation of trust and a successful intervention basis. In relation to the support strategies offered, follow-up studies on children's developmental outcomes need to be conducted in a second step. The impact of the support strategies on the children's development is essential in order to determine the quality of the support offered. Questioning older children or adolescents and their opinions, on the quality of support and how it could be improved, should be included in future research. Those studies would result in authentic perceptions of PID's children and family everyday life and how the implication of support strategies influences it.

7   Conclusion

There is a general lack of research on support strategies offered to parents with intellectual disabilities, which needs to be thoroughly researched in the future. By including qualitative studies, this gap indicated by previous reviews is partially filled. The identification of nine different strategies implemented within four sources of support, however, demonstrated the upcoming rise of support for parents with intellectual disabilities and their families. Furthermore, it is positive that only one of those strategies, namely Child Protection Services, was based on a reactive approach. All the others are focusing on the beneficial outcomes of early intervention through a proactive approach. The results have shown that none of the identified support strategies is really complete on its own, but a combination of informal and formal support is most promising. Regarding the implementation of support strategies, cooperation between different systems (Bronfenbrenner & Ceci, 1994; Trivette et al., 1997) is crucial for the best results in both, accessibility and success. At the same time, the closer the support is taking place to the person himself (Bronfenbrenner & Ceci, 1994) the more accessible the support strategy becomes. Additionally, the better the quality of the relationship between the support worker and the PID, the more successful any strategy becomes. Those statements imply that resources are not the most essential for an accessible and successful support strategy, but rather the proximity and quality of implementation within the PID's environment. A profound training in the corresponding domain should meanwhile ensure the quality of personal characteristics that build further trust and mutual respect between support worker and PID. Moreover, the results prove a high transferability in between the different countries included in this study, since they share similar values and resources. This makes it possible to initiate support strategies in other countries by translating and slightly adapting them to the nation-specific context. Hence, this research can lead to a promotion of diversity within support strategies, offering more options and higher chances of appropriate support to PID.

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9 Appendices

9.1 Appendix A: Search words and used databases

Table 9.1 Search words and used databases

Database	Search Words			
	Intellectual Disabilities	**Parenting with disabilities**	**Support Strategies**	**Children**
ERIC	Thesaurus Term "Intellectual Disability" OR "Mental Retardation"	Thesaurus Term "Parents with Disabilities"	Support OR Therapy	Child OR Children OR Youth
SAGE	ti(Intellectual Disabilities)	ti(Parents with Disabilities) AND Parenting	Support OR Therapy	Child OR Children OR Youth
ScienceDirect	tak(Intellectual Disabilities)	tak(Parents with Disabilities) AND Parenting	Support OR Therapy	Child OR Children OR Youth
Taylor and Francis Online	ti(Intellectual Disabilities)	ti(Parents with Disabilities) AND Parenting	Support OR Therapy	Child OR Children OR Youth
WILEY	ti(Intellectual Disabilities)	ti(Parents with Disabilities) AND key(Parenting)	Support OR Therapy	Child OR Children OR Youth

Note. ti = following keyword had to be included in the title of the searched articles; tak = means the keyword has to be listed within the title, abstract or keywords in the article; key = the keyword has to be included in the keyword section of the article.

9.2 Appendix B: Quality assessment tool

Table 9.2 Quality assessment tool

Quality Assessment Criteria

Method	Answer	Comments:
1. Purpose/Aim Was the purpose/aim stated clearly?	(1) Yes (0) No	
2. Terminology Was the used terminology defined explicitly?	(2) Defined explicitly (including possible referrals) (1) Defined indirectly in the context of the study (0) Not sufficiently defined	
3. Theoretical Approach Was a theoretical perspective identified?	(1) Yes (0) No	
4. Design Was the study design appropriate to the aim of the study?	(1) Yes (0) No	
5. Data Collection and Analysis Was the data collected and analysed in a scientific way?	(1) Yes (0) No	
6. Descriptive Clarity Was descriptive clarity used appropriately by the researchers?	(1) Yes (0) No	
7. Trustworthiness Was trustworthiness specified?	(1) Yes (0) No	
8. Limitations Were limitations addressed?	(1) Yes (0) No	
9. Conclusion Did the article provide a conclusion drawn from the previous content?	(1) Yes (0) No	
10. Implications Are the findings valuable for future research?	(1) Yes (0) No	
11. Literature Was relevant background literature reviewed?	(1) Yes (0) No	
Ethical Approach		
12. Ethical Approval Was the study approved by an ethical board?	(1) Yes (0) No	
13. Consent Was an informed consent obtained?	(1) Yes (0) No	
Participants		
14. Description Were the participants described in adequate detail?	(1) Yes (0) No	
15. Sample Size Was the sample size sufficient for the research purpose?	(1) Yes (0) No	
Total Points	/16	*Total in percentage:* %

Note: ≥75% = High Quality ; 75% > & ≥ 50% = Medium Quality ; <50% = Low Quality

9.3 Appendix C: Data extraction tool

Table 9.3 Data extraction tool

Data Extraction Protocol			
Article	Author Title Journal published in Year published in Country conducted in Study Focus Keywords Aim and Research Questions		
Method	Quantitative Qualitative Mixed Other		
Data Collection	Interview Questionnaire Mixed Other		
Participants	Parents with intellectual disabilities Number of participants		
Definitions	Intellectual disabilities Parents with intellectual disabilities Parenting Skills		
Support Strategies (Structured Analysis Matrix)	Personal Social Network Associational Group Community Programs and Professionals Specialised Services	Description Accessibility (2) Success (3) Perspectives of PID and professionals	(2) proximity, affordability, admitted number of participants (3) measured (quantitative), observed (qualitative, i.e. direct citation) improvement
Limitations	Methodology Other		
Quality	High Medium Low		
Inclusion/Exclusion Criteria	Included Excluded → Reason:		