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How children of parents with intellectual disabilities experience their everyday life

A systematic literature review from 1985 to 2017

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ABSTRACT

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Various findings indicate that children of parents with intellectual disabilities have a higher risk for various difficulties, but only few studies interview children for an account of their experiences. This study aimed at assessing how children of parents with intellectual disabilities reflected their upbringing and their everyday life regarding their parent's disability. Eight studies were identified through a systematic literature review, with publication ranging from 1985 to 2017. Results show that the accounts contain both positive and negative experiences and reflect an ambivalent relationship towards the parents. The small population of the analyzed studies, as well as differences in the context and the method of the studies, allowed no general conclusions to be drawn. Further research is required to allow an evaluation of the experiences of children of parents with intellectual disabilities in a bigger context.

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I. Introduction

“Initially, it was very natural for me. I grew up with my mom, I learned the world through her eyes. The first painful moment that I experienced happened at school, when the children began to tease me and their parents looked at me strangely” (Wolowicz-Ruszkowska & McConnell, 2017, p. 4)

This citation was provided by a participant in a study that interviewed adult children that grew up with a mother who had an intellectual disability, when asked how they realized their mothers were different from others. Personal accounts of children who grow up with a parent with an intellectual disability have rarely been investigated by research so far, but existing study on the topic is the main content of this systematic literature review. A short introduction into the topic of parents with intellectual disabilities and their children, will be presented in the following paragraphs, ending with an overview over the continuing content of this study.

Parenthood for people with intellectual disabilities is a topic that has been studied in different contexts and across different countries for decades (International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), 2008). But while current scientific studies increasingly take the viewpoint of parents, especially mothers, with intellectual disabilities into consideration, the perspective of the children who grow up with parents who have an intellectual disability appears to be a neglected aspect in this field of research (Starke, 2013). By way of example, Faureholm (2010) highlighted how research has neglected to assess the life experiences of children who live with parents who have an intellectual disability, even though they are considered to have a higher risk for developing “intellectual, academic, and behavioral problems” (p. 64) and as grown-ups have more difficulties to lead an independent life. Up till date only few published studies were conducted with the aim to assess how children of parents with an intellectual disability experience their everyday life and how their parent’s disability affects their daily routine. And only a small portion of those studies interviewed the children directly.

To shed a light on the gap in this aspect of research and to compare available research findings, a systematic literature review was conducted. It was the main goal of this thesis is to systematically examine peer-reviewed articles that assessed the everyday life of children whose parents have an intellectual disability, based on the children’s personal account of their experiences.

This systematic literature review is structured in the following way: chapter two will first provide the theoretical framework of this thesis, before the aim and the related research question are presented in chapter three. Chapter four describes the method and the different steps of

conducting a systematic literature review, as it was adapted and used for the methodology of this paper. Chapter five will then summarize the findings of this systematic literature review, before a detailed discussion follows in chapter six. In the discussion section, relevant findings of this systematic literature review, as well as limitations of this study and its methodology and indications for future research will be presented, followed by a summarizing conclusion in the final chapter.

2. Background

In this chapter necessary information, that makes up the theoretical framework of this systematic literature review, will be stated, including definitions of core concepts and relevant findings of previous studies about the experiences of parents with intellectual disabilities and the everyday life of their children.

2.1. Intellectual Disabilities

A unified and overall accepted definition of intellectual disability has not been provided yet (IASSIDD, 2008; McConnell & Llewellyn, 2002), but there are some widely accepted definitions, for example provided by internationally respected manuals. The current and fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published by the American Psychiatric Association (APA; 2013) considers Intellectual Disabilities as part of the group of Neurodevelopmental Disorders and differs the disability by four levels of severity (mild, moderate, severe, and profound). The onset and manifestation of the disabilities combined under the term Neurodevelopmental Disorders is generally considered to occur during the early developmental period (APA, 2013).

Accounts of the prevalence of intellectual disabilities vary between different countries and different forms of intellectual disabilities, for example Seltzer et al. (2005) estimated that 15% of the population in the United States have a mild intellectual deficit.

While talking about intellectual disabilities as a diagnostic criterion Rapley (2004) also discussed intellectual disability as a “social-moral category” (p. 68) and reflected the stigmatization that often comes with being diagnosed with an intellectual disability. This aspect was reflected in various studies about parents with an intellectual disability and their children, as will be illustrated in the content of the following section.

2.2. Parents with intellectual disabilities

There is a long history of prejudice and discrimination against parents with intellectual disabilities (LaLiberte, Piescher, Mickelson, & Hwa Lee, 2016) and while a lot has changed, parents with intellectual disabilities still face various struggles.

There is no clear statement about the prevalence of parents with intellectual disabilities (Powell & Parish, 2017), due to various problems in identifying parents with intellectual disabilities as a population (IASSIDD, 2008). But a rising number of articles and studies centers around parents with intellectual disabilities and the assessment of their parenting skills. Many studies focus only on mother's with intellectual disabilities though (e.g. Powell & Parish, 2017;

Sheerin, Keenan, & Lawler, 2013), while some generally address parents with intellectual disabilities (e.g. Booth & Booth, 2004; Wade, Llewellyn, & Matthews, 2008), but only few are specifically about fathers with intellectual difficulties (e.g. Strike & McConnell, 2002). This results on more data being available on mothers with intellectual disabilities and their children.

While old prejudices about parents with disabilities are getting slowly reformed, there is often still a gap between parents with intellectual disabilities and their families and service providers and other professionals. Parents report feelings of not being taken seriously by service providers and experiencing a lot of prejudice against them, based on the label of their disability (Sheerin, Keenan, & Lawler, 2013; Strike & McConnell, 2002). There are also reports of difficulties getting formal support for themselves and their children (Sheerin, Keenan, & Lawler, 2013). Many parents with intellectual disabilities also fear that their children could get taken away from them (Sheerin et al., 2013). Different studies, for example Powell, Parish, and Akobirshoev (2016) found that mothers with intellectual disabilities experience different disadvantages, for example a lacking support network and a low socioeconomic status.

Llewellyn, McConnell, and Ferronato (2003) found that parents with intellectual disabilities were over-represented in a sample population of custody-hearings in Australia and that nearly half of them lost their cases and had their children removed from their care. Booth and Booth (2004) compared different studies concerned with the same research question and came to a similar conclusion: for more than one out of six children in the studied court cases either one or both parents had an intellectual disability and those children were the group most likely to be placed in a different care setting, instead of being released back into their parent's care. In the cases Booth and Booth (2004) analyzed neglect was the most commonly stated concern of professionals, providing an assumption that 60% of the children had already been subjected to a form of neglect, when the court proceedings took place, while another 30% were considered to be at risk for future neglect. Abuse, sexual or physical, was only reported in a minority of the cases and in most of these cases it was not the parent abusing the child (Booth & Booth, 2004). Booth & Booth (2004) further concluded that the reasons those cases were referred to custody proceedings were in most cases directly related to the parent's disability, but they also found indications that the parents did not receive adequate support. Another concern that was raised in the context of these studies was that the decision to remove the child from the parent's care was not always solely based on an endangerment of the child, but also partly due to the stereotypes that still exist about intellectual disabilities and parenting (Booth & Booth, 2004; McConnell & Llewellyn, 2002).

LaLiberte and colleagues (2016) also found that parents with intellectual disabilities are overrepresented in the child protection services (CPS) and discussed whether this was due to the CPS not being adequately prepared to provide parents with intellectual disabilities with the support they need or due to prejudice of the CPS workers against parents with intellectual disabilities. Azar, Robinson, and Proctor (2012) summarized findings that indicated that parents with intellectual disabilities are more often referred to CPS due to an accusation of abuse than parents without disabilities and discussed different possible causes for those findings. Azar, Stevenson, and Johnson (2012) also warned against using a lower IQ as the sole reason to explain a higher parenting risk for parents with intellectual disabilities.

Studies about interventions for parents with intellectual disabilities found that the parents can very well parent their own children successfully, when given the right support (e.g. Wade, Llewellyn, & Matthews, 2008). The IASSIDD (2008) discussed different factors that can influence whether or not parents with intellectual disabilities succeed in their parenting responsibilities, for example naming the presence and helpfulness of formal and informal support and the presence or absence of co-morbidity as influencing factors.

Especially the role of formal and informal support was found to be a crucial factor and will be discussed further in the content of this study.

2.3. Children's rights and needs

There is no clear definition on what makes a good parent, but one of the basic responsibilities of a parent is to take care of his child's needs and protect his child's rights.

In 1989, the General Assembly of the United Nations (UN) passed a convention on the rights of children, that has been signed and ratified by nearly every country around the world, with the exception of the United States and Somalia (Santos Pais & Bissell, 2006). Included in the convention are, among others, the right for children to grow up with their parents, to have their opinions heard and respected, and to receive protection from any kind of abuse (Santos Pais & Bissell, 2006; UN, 1989). The countries that signed the convention committed themselves to protecting children's rights, which for example include respecting and preserving a parent's responsibilities and to always act in the child's best interest (Santos Pais & Bissell, 2006). Different articles of the convention also guarantee various aspects related towards participation, for example the freedom of expression (article 13) and the right to access to information (article 17) (UN, 1989). In the International Classification of Functioning, Disability and Health, the Children and Youth Version (ICF-CY) the World Health Organization (WHO; 2007) broadly defined participation as a child's involvement in any

situation or action that is occurring in the child's environment. Falkmer, Oehlers, Granlund, and Falkmer (2015) highlighted that participation is "crucial in order to feel included" (p. 365), thereby naming one aspect why participation is both a crucial need and a right each child has.

Foremost it is the duty of the respective countries' authorities (UN, 1989) to protect children's rights. But it is also the parent's duty to ensure that their children's rights are guaranteed and to support their children's development to the best of their own abilities. The convention guarantees a child the right to grow up with his parents (UN, 1989), but also states that the respective state parties always must protect the child's best interest, which in some cases might not be staying in the parent's care. As indicated in the studies about court proceedings involving parents with intellectual disabilities (e.g. Booth & Booth, 2004; McConnell & Llewellyn, 2002) as they were presented in the previous section of this paper, this is a conflict that can play a big role in the lives of children of parents with intellectual disabilities.

Shonkoff and Phillips (2000) also highlighted how a child's development is dependent on "the health and well-being" (p. 7) of the child's parents, as well as on other factors like cultural influences, risk factors, and resilience that make up the dynamic and interrelated relations of "biology and experience" (p. 23), which influence a child's development on different levels. When one or both parents of a child live with an intellectual disability it might affect various aspects of the child's life. The dynamics of risk factors and resilience are another aspect that will be looked at in the content of this study and the concepts themselves will be explained in the following section.

2.4. Parents disability as a risk factor and reason of stigmatization or a possible source of resilience

Since the interaction between risk and resilience in relation to the parent's difficulties is a crucial aspect in this field of research, the concepts as well as closely related terms will be defined in the following paragraphs.

For Osofsky and Thompson resilience is "the ability to recover from or adjust easily to misfortune or sustained life stress" (Osofsky & Thompson, 2000, p. 67). Resilience means that a child develops well despite the presence of risk factors and function well under stressful conditions (Werner, 2000). When assessing resilience, risk factors and protective factors are taken into consideration (Opp, 2011). As by the general definition of the WHO (2009) risk factors increase the likeliness of negative developmental or health outcomes. Garbarino and Ganzel (2000) differ between different categories of risk factors, for example biological,

sociocultural, or environmental risks and stress that a higher number of risk factors equals an overall greater risk. Contrary to risk factors there are protective factors (Ellenbogen, Klein, & Wekerle, 2014) that can increase a person's resilience towards risk factors and possibly compensate for risk factors, at least to a certain degree (Dunst, Trivette, & Hamby, 2014). Sameroff and Fiese (2000) preferred to use the term promotive factors instead of protective factors, since in their opinion those supporting factors do more than just protect a person from risk factors, and can actively enhance development.

Newman (2002) found that different forms of impairment in a child's parents or siblings can be a risk factor for the child having to grow into the role of a young carer, which is defined as a minor "whose life is in some way restricted because of the need to take responsibility for a person who is ill, has a disability, is elderly, is experiencing mental distress or is affected by substance misuse" (p. 616). The term young carer can in this context be considered as a synonym to the phenomenon parentification, which is also defined as children having to take on "roles and responsibilities that are typically considered the responsibility of adults, but which parents have relinquished" (Harrison & Albanese, 2012, p. 12).

The stigmatizing effect of having a disability has lessened compared to previous times (Perkins, Holburn, Deaux, Flory, & Vietze, 2002), one reason lying in different conventions like the UN convention protecting the rights of persons with disabilities and protecting them against discrimination (UN, 2006). Starke (2013) defined stigmatization as the integration of the identity as it is defined by the environment into a person's self-concept, which in this context means that a person's identity is reduced to the characteristics of his disability. Perkins and colleagues (2002) highlighted how children can feel stigmatized "by certain characteristics and behaviors of their parents" (p. 299), for example when they significantly differ from what is perceived to be typical behavior for other parents in the respective cultural and societal context. This can provide another risk factor for the children's social and emotional development.

Many studies that researched the influence a parent's intellectual disability can have on their child considered the parent's difficulties to more likely be a risk factor for the child's development, but there are also some studies that suggest that children of parents with intellectual disabilities can do well in spite of or maybe even due to the experiences and challenges they face due to their parent's difficulties, which could make their parent's disability a source of resilience in some aspects (Newman, 2002).

2.5. Formal and informal support

The concepts explained above all play into the theoretical framework that is the basis of this systematic literature review. Another concept that is part of the theoretical framework of this study is the concept of formal and informal support. All forms of support provided by relatives or friends were considered as informal support, while support from official institutions, like schools or churches, and professionals was counted as formal support.

Various findings like Faureholm (2010) presented in his study indicate that children who grow up with at least one parent with an intellectual disability have a higher risk for various problems and difficulties. But most of those studies did not ask the respective children for direct recounts of their experiences, which is a crucial aspect when trying to answer the question how intellectual disabilities may affect parenting skills and in consequence the upbringing and everyday life of children of parents with intellectual disabilities. This systematic literature review will search for and analyze studies that interviewed children and adult children of parents with intellectual disabilities, with the goal of giving an authentic account of their experiences. The aim and research questions that were formulated in this context, will be presented in the following chapter.

3. Aim and research questions

The aim of this systematic literature review is to assess how children and adult children of parents with intellectual disabilities experience their everyday life and reflect on their upbringing regarding their parent's disability.

The following two research questions were formulated as a basis to fulfill the aim of this systematic literature review:

- How does their parent's disability influence the upbringing and daily life of children when at least one parent has an intellectual disability?
- How do children of parents with intellectual disabilities reflect their relationship with their parents?

To answer the research questions and to further focus the analyzed data three sub-questions were formulated:

- How do children of parents with intellectual disabilities evaluate the role of formal and informal support for their daily life?
- Looking back on their childhood do (adult) children consider their parent's disability as a risk factor for their own development or as a source of resilience?
- How are accounts of perceived stigmatization and bullying related to the diagnosis of intellectual disability of the children's parents?

4. Method

The chosen method for this study was a systematic literature review. Cook, Sackett, and Spitzer (1995) defined this method as “the application of scientific strategies that limit bias to the systematic assembly, critical appraisal, and synthesis of all relevant studies on a specific topic” (p. 167). Petticrew and Roberts (2006) named a systematic review as a suitable method to summarize a large amount of information presented in numerous different studies and articles and Jesson, Matheson, and Lacey (2011) said the word systematic indicates that you work in a scientific and methodological way.

As indicated the most common use of a systematic literature review is to give an overview over existing research and this was also why this method was chosen for this study. While it was indicated by other studies that there were few existing articles that interviewed children of parents with intellectual disabilities about their experiences and their everyday life, the goal of this systematic review was to provide an overview over the existing literature and to highlight resulting indications for future research in this field.

In the content of this systematic literature review articles that give a voice to the experiences of children that grew up with at least one parent with an intellectual disability will be analyzed and compared looking for similarities and differences in the lived experiences of these children.

The process of the systematic literature review that was performed for this study will be explained in detail in this section. The search procedure, the selection criteria, the data extraction and analysis, as well as the quality assessment of the found articles will be described respectively in the following sections.

4.1. Search procedure

Varying combinations of the following search terms were used in the databases ERIC, MEDLINE, PsychINFO, PubMed, SAGE journals, and Wiley using both thesaurus and free term search in combination, depending on the respective database: (intellectual disability OR mental retardation OR cognitive impairment) AND (parents with disabilities) AND (child* OR young adults OR adolescent* OR youth) AND (parent* OR mothers OR fathers). The searches were performed on the 25th of February 2017.

The search procedure was adapted for each database to identify a maximum of articles related to the aim of this study. Therefore, the use of truncations (*) and the combination of thesaurus and free terms varied depending on what combination of search terms led to the finding of the highest number of related articles. The exact combination of search terms for

database as well as a flowchart of the search procedure can be found in the appendix (Appendix A; Appendix B).

4.2. Selection criteria

Various inclusion and exclusion criteria was formulated to select articles that fit the aim and research question of this thesis. Both formal criteria (e.g. published in English and in a peer-reviewed journal) and content-related selection criteria (e.g. asking children who have lived with at least one parents with an intellectual disability for a certain time for their experiences directly) were used to select suitable articles. A complete list of the inclusion and exclusion criteria that was used for the selection process can be found in table 4.1.

Table 4.1

Inclusion and exclusion criteria for the selection of articles

Inclusion criteria	Exclusion criteria
Publication type - Article - Published in a peer-reviewed journal - In English	Publication type - Book chapters, literature review, doctoral thesis, other literature - Not published in a peer-reviewed journal - Any other language than English
Participants children and adult children - with at least one parent with a diagnosed intellectual disability - who lived with their parents for at least a certain time of their childhood - with or without a diagnosed impairment	Participants parents with learning disabilities
Method - interview - questionnaire (single) case study	Method - observation - testing
Focus how parent's disability affects: - children's everyday life - family dynamics - risk factors and resilience - education - integration in society - social life	Focus - Interventions - Court decisions

Study design	Study design
• Empirical studies ○ Qualitative ○ Quantitative ○ Mixed	• Systematic literature review

A time range for the publication date of the articles was not included as an inclusion criteria, since it was suspected beforehand that only a small number of articles would fit the rest of the inclusion criteria and the goal was to include all the articles available, that directly interviewed children that grew up with at least one parent with an intellectual disability.

4.3. Selection Process

A total of 321 articles was found searching the six databases. 46 of those articles were identified as duplicates using the tool Zotero, a research tool created by the Roy Rosenzweig Center for History and New Media. A flowchart displaying the selection process is included in the appendix (Appendix A).

4.3.1. Title and abstract screening

For the 275 articles that were left after the exclusion of all the identified duplicates, the title and abstract were screened using the inclusion and exclusion criteria (table 5.1) to identify articles that related to the aim and research question of this study. During this process 265 more articles were excluded from this study since they were found to not meet either formal or content-related criteria or a combination of both. Most of the articles were excluded because they did not meet the method or the participants inclusion criteria.

4.3.2. Full text screening

Full text screening was performed on the ten articles that remained after administering the inclusion and exclusion criteria during the screening of the title and abstract. Four more articles were excluded during this procedure, because while meeting most of the inclusion criteria they did not meet the method inclusion criteria (using a questionnaire, an interview, or a case study to directly convey children's experiences).

At the same time, two articles that were referred to in the articles included in the full text screening process, were hand-searched and the full text was also screened.

In the end, eight articles remained to be further assessed in regards of their quality, two of them the result of referrals and hand-search. Seven of those articles (Wolowicz-Ruszkowska &

McConnell, 2017; Lindblad, Billstedt, Gillberg, & Fernell, 2013; Starke, 2011; O'Neill, 2011; O'Neill, 1985; Ronai, 1997) were qualitative using interviews to collect information from the participants. Some studies additionally used questionnaires (Starke, 2013) or tests (O'Neill, 1985) and therefore used mixed methods. One of the seven articles was a single case-study (Ronai, 1997). The instrument of the eighth study was a questionnaire (Perkins et al., 2002). Even though this was the only study mainly using a quantitative instrument that after the process of full-text screening was still considered for this study, it was decided to include the study. As established before there is not much research available that is directly asking for the experiences of children who grew up with a parent with an intellectual disability. Also, the study design was found to be similar enough to the other studies to allow a comparison, especially since some of the other studies used both qualitative and quantitative methods (O'Neill, 1985; Perkins et al., 2002).

4.3.3. Quality assessment tool

To evaluate the quality of the eight articles that were left after the full text screening a quality assessment tool was designed based on the assessment tools for qualitative and quantitative research provided by the Child Care and Early Education Research Connection (CCEERC; 2013) and the Critical Review Form for Qualitative Studies (Letts, Wilkins, Law, Stewart, Bosch, & Westmorland, 2007). Questions for both qualitative and quantitative articles were combined to fit the assessment of the different methods of the eight studies. The full version of the quality assessment tool can be found in Appendix E.

The designed assessment tool resulted in a scale from 0-25 points. 25 to 18 points were considered high, 17 to 9 points medium, and 8-0 points low quality. Not all the studies could reach a maximum of 25 points: for most of the studies the maximum points were 24 because one of the items of the quality assessment tool asked for the way drop-outs were handled, but since most studies did not have any drop-outs this question was only applicable to one study (O'Neill, 2011). The other studies had a maximum of 24 points except the study of Ronai (1997) only had a maximum of 22 points since it was the only single-case study included in this systematic literature review. Even if the maximum score was less than 25 points the cut-off scores to distinguish between high, medium, and low quality remained the same.

Item 10 of the quality assessment tool inquired about the degree of trustworthiness the respective researcher provided for his study: hardly any of the articles addressed this part specifically, therefore the amount of points was set depending on the amount of information provided in relation to trustworthiness.

All eight articles received a high or medium quality: Five articles were rated high with 18 out of 24 possible points (Lindblad et al., 2013; Wolowicz-Ruszkowska & McConnell, 2017), 19 out of 24 (Starke, 2011; Starke, 2013), and 19 out of 25 points (O'Neill, 2011). The other three articles were of medium quality according to the used quality assessment tool, with 17 out of 24 (Perkins et al., 2002), 14 out of 24 (O'Neill, 1985), and 14 out of 22 points (Ronai, 1997).

4.4. Data extraction

A protocol was designed to unify the data extraction for all eight articles. The whole protocol can be found in Appendix C under the extraction section of the protocol.

One of the results of the data extraction process provided demographic information on the participants that were summarized in table 4.2.

Table 4.2

Demographic data of the participants

	Age range	Gender	Diagnose of I. D.	One or both parents have I.D.	Education level	Employment
Wolowicz-Ruszkowska & McConnell (2017)	24-34	74% female 26% male	None	One parent (mother)	65% tertiary education 4% did not graduate	100%
Starke (2011)	18-32	45% female 55% male	100%*	One or both	n/s	n/s
Starke (2013)	18-32	n/s	100%*	One or both	n/s	n/s
Perkins et al. (2002)	9-17	50% female 50% male	None*	One parent (mother)	n/s	n/s
Lindblad et al. (2013)	19-23	40% female 60% male	60%	One parent (mother)	60% special education 40% mainstream school / 10% did not graduate	20% students 10% still in school 50% employed 10% unemployed 10% sick leave
O'Neill (1985)	n/s	n/s	None*	One or both	8% dropped out of school 92% still in school	-
O'Neill (2011)	n/s	n/s	None*	One or both	24% high school 54% earned GED° after dropping out of school 18% adult education courses	n/s
Ronai (1997) (single case)	n/s	female	no	One parent (mother)	University degree	Yes

Notes. Percentages were rounded, n/s stands for “not specified” indicating that the study either

did not address this aspect or did not provide the respective data for all the participants
*spending the majority of their childhood in their parent's care was an inclusion criteria
for the study

°GED stands for General Equivalency Diploma

An overview over relevant data of the articles, for example the country it was conducted in and what methods were used, can be found in Appendix D.

4.5. Data analysis

A qualitative content analysis was performed to analyze the content of the included articles. During the data extraction, important concepts of the articles were identified. The step of data analysis was meant to help the researcher scientifically interpret and compare the results of the analyzed studies (Bos & Tarnai, 1999).

For the purpose of this study inductive qualitative content analysis as described by Elo and Kyngäs (2008) was used combine the particular findings of the different studies to a more general statement and to support the drawing of specific conclusions. The method of inductive content analysis was chosen as a method, because it provides a systematic approach to support a researcher in the process of summarizing information, while still reaching a broad enough description of a phenomenon (Elo & Kyngäs, 2008).

To organize the collected data as part of the inductive content analysis (Elo & Kyngäs, 2008) open coding was used to find shared subcategories for the different articles. The process of open coding (Elo & Kyngäs, 2008) requires the creation of categories and subcategories to support the development of a model to “describe the phenomenon in a conceptual form” (p. 107).

After the process of open coding, the researcher aimed to group the headings collected for the individual articles into subcategories of a higher order (Elo & Kyngäs, 2008). But because of the differences in the contexts, methods, and overall focus of the analyzed articles the found subcategories would have been too small, providing not enough detail to be a basis for a following critical discussion. Instead the following generic categories were designed to fit main aspects most of the articles addressed respectively:

- Thoughts on the effect their parent's disability had on their upbringing
- The ambivalence in the relationship with their parents
- The difference in the value of informal and formal support
- Society's failures - experiences of bullying and feelings of stigmatization

To summarize the findings and the content of those generic categories an overall main category was also designed: “The ambiguous diversity in growing up with parents who have an intellectual disability - looking back on childhood experiences and reflecting current life satisfaction”.

The results of the data analysis will be presented in the following results section in the content of the composed generic categories.

5. Results

A search of the six databases Eric, PubMed, Medline, PsychINFO, SAGE journals, and Wiley using various combinations of different search terms led to 321 articles. 46 of those articles were duplicates. Title and abstract of the remaining 275 articles were screened using the stated inclusion and exclusion criteria, leaving ten articles that were screened at the full-text level.

Eight studies (Wolowicz-Ruszkowska & McConnell, 2017; Lindblad et al., 2013; Starke, 2013; Starke, 2011; O'Neill, 2011; O'Neill, 1985; Perkins et al., 2002; Ronai, 1997) remained for the process of data extraction and analysis. A list of the identified articles and detailed information about the studies can be found in Appendix D.

The aim of this study was to assess the everyday life experiences of children of parents with intellectual disabilities and how they reflect upon their upbringing in relation to their parent's difficulties. Two research questions were formulated based on the aim, asking how the children feel their parent's disability affected their upbringing and how they view their relationship with their parents. For specific aspects that were taken into consideration in the process of answering the two research questions three sub-questions were formulated, asking how the interviewed children evaluated formal and informal support systems, whether they considered their parents disability to be a risk factor for their own development or a possible source of resilience, and how they perceived the connection between experiences of bullying and stigmatization in relation to their parents' difficulties.

5.1. Thoughts on the effect their parent's disability had on their upbringing

The first and main research question asked in what way and to what extend the interviewed children felt that their parent's disability has affected their upbringing. The accounts of their upbringing varied between the participants of the studies and often displayed a similar ambivalence in the reflection of their overall relationship with their parents (Lindblad et al., 2013; O'Neill, 1985; O'Neill, 2011; Perkins et al., 2002; Ronai, 1997).

The young adults, when looking back at their childhood experiences, mostly described being aware that they and their families were different than others or were perceived as different by their peers (Perkins et al., 2002; Starke 2013). The degree to which they agreed with this perception of outsiders of their family or whether they felt like outsiders (Starke, 2013) varied between the accounts presented in the different studies. The experiences of stigmatization will be further discussed in the fourth section of this chapter.

There was no clear majority of positive or negative recounts about their own upbringing, when comparing the results of all eight studies. For some of the studies, a majority of the participants (Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017) reflected well on their upbringing and reported that their parents did a good job in caring for them. Participants also said their parents helped them in becoming more independent and named their family as a source of resilience (Starke, 2013). Ronai's (1997) account of her own upbringing reflected more negative experiences than most of the participants in the other studies. Apart from Ronai's single case (1997), the studies of Lindblad et al. (2013) and O'Neill (2011) reported a majority of negative accounts when asking about childhood experiences, with an overwhelming majority of 90% (Lindblad et al., 2013) and 60% (O'Neill, 2011). The one participant of the study done by Lindblad and colleagues (2013) who reflected positively on his childhood, grew up with other relatives and not his parents.

In the other studies, negative accounts were overall evened out by positive accounts, for example the participants of Wolowicz-Ruszkowska and McConnell's study (2017) reflected that their childhood experiences, while difficult in some aspects helped them develop a better resilience and supported their development into independent adults.

Quite common among the participants were cases of "parentification" where children had to take on responsibilities that were not according to their age because of their parents' difficulties (O'Neill, 1985; Ronai, 1997; Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017), for example in many of those cases the firstborn children were needed to care for their younger siblings (Starke, 2011). In those cases, the younger siblings often reflected on their upbringing more positively than the oldest sibling (Starke, 2011), who had to take on more responsibility to support the parents.

Experiences of perceived stigmatization and bullying due to their family's situation were reported in many studies (Lindblad et al., 2013; Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017). Wolowicz-Ruszkowska and McConnell (2017) even found that most participants in their study named the negative reactions of other people towards their parents as the biggest challenge they faced during their childhood. But on the positive side most of the interviewees did not let the judgement of others affect the way they perceived their parents (Wolowicz-Ruszkowska & McConnell, 2017).

Another positive aspect that was reflected by a participant in Starke's study (2013) was that he felt his parents were more supportive and understanding of his intellectual disability, due to their own experiences. Similar statements of other participants indicated that they considered

their family as a safe place, that at the same time supported their inclusion in society (Starke, 2013).

When asked to reflect the effects their parent's disability had on their upbringing, many participants stated their personal conclusion as knowing that their parents tried the best they could (e.g. Wolowicz-Ruszkowska & McConnell, 2017). The accounts of the participants also concluded that different factors like the presence of formal and informal support and the behavior of the environment influenced how severely they felt their parents' difficulties influenced their everyday life. Those aspects were included in the three sub-questions stated in chapter three and will be addressed after the following paragraph, which addresses the second main research question.

5.2. The ambivalence in the relationship with their parents

The second research question of this study asked how the interviewed (adult) children reflect the relationship they currently have with their parents. In this context the same ambivalence the children displayed in the recollection their upbringing was also reflected: Most participants of the analyzed studies described having an overall satisfactory relationship with their parents, but at the same time the majority recapitulated ambivalent memories of their childhoods (Lindblad et al., 2013; O'Neill, 1985; Ronai, 1997; Wolowicz-Ruszkowska & McConnell, 2017) that they felt still affected their current relationship with their parents. In the two studies of Starke (2011; 2013) the majority of the participants described their relationship with their parents as positive, but at the same time there were also accounts of very negative connotations in the relationships with their parents (Starke, 2013). This goes for some of the other studies as well: For example, only 10 percent of the participants in the study of Lindblad and colleagues (2013) reported to have regular contact with both parents.

O'Neill (1985) hypothesized that the fact that children without intellectual disabilities were at some point likely to surpass their parents intellectual level, might have affected the parent-child relationship. While the participants themselves gave no direct account of viewing this factor as an influence on their relationship with their parents, indications of viewing their parents' difficulties as strenuous were indirectly reported in some cases (e.g. Ronai, 1997).

Descriptions of different forms of abuse and neglect were overall only reported in a minority of cases (e.g. O'Neill, 2011; Starke, 2011), but because of the different numbers of participants no general percentage could be established. Ronai (1997), as the only single-case study included in this systematic literature review, reported both severe physical and sexual

abuse by both parents. Apart from Ronai's (1997) single case, only the study of Lindblad et al. (2013) found accounts of abuse and/or neglect in a majority of the participants (60%).

Participants also reflected that they were dissatisfied with the contact they had with their parents, without providing further detail (Starke, 2013).

5.3. The difference in the value of informal and formal support

Informal support, mostly provided by grandparents, was found to be one of the most important supportive factors, especially when formal support was absent or lacking (O'Neill, 1985; Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017). Siblings were also named as an important source of support (Starke, 2011). No informal support for example often meant that the children had to take on more responsibilities to support their parents compared to families where the grandparents or other family members provided a lot of informal support (Wolowicz-Ruszkowska & McConnell, 2017). The value of grandparents or other close relatives lay not just in the additional support they often provided, but also in the consistency the close relationship with other adults gave the children (Starke, 2011).

While informal support was overall named to have a lot of positive effects on the children and their families, some participants of the study conducted by Wolowicz-Ruszkowska and McConnell (2017), reported that they sometimes felt that the support of their grandparents or other family members was undermining their parents' parenting in a way. Wolowicz-Ruszkowska and McConnell (2017) also found that a lot of children whose family did not have a lot of informal support spoke very positively about their parents' efforts in raising them.

The provision or lack of informal support also had a lot of indirect effects: Wolowicz-Ruszkowska and McConnell (2017) for example found that if children had no informal support, learning that their parents were different than other parents was more likely to negatively affect the children's biography.

Formal support on the other hand was often lacking or even perceived as completely absent in the children's life and their parent's life (Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017). If present formal support was both perceived positively or negatively (Starke, 2011). Some participants in the study conducted by Starke (2011) reported their teachers as a source of support, but most of the accounts about the perception of their relationship with their teachers was negative.

5.4. Society's failures – Experiences of bullying and feelings of stigmatization and social exclusion

According to the accounts of the participants their parent's disability often resulted in stigmatization through other people, both peers and adults, that affected the whole family and also resulted in feelings of social exclusion (Lindblad et al., 2013; Perkins et al., 2002; Starke, 2013).

Most participants described being aware that their family was different, with varying reports about whether or to what extent this was perceived as burdening (Perkins et al., 2002; Starke, 2013). Wolowicz-Ruszkowska & McConnell (2017) reported in their findings that the way they realized or were told about their mothers' difficulties was perceived as humiliating by a majority of the participants. Perkins and colleagues (2002) concluded that perceived stigmatization could also have a negative effect on the relationship between the child and its mother, but that a positive caregiving style of the mothers lessened the negative effects of stigmatization. So, while some children reported that they started to perceive their family's differences negatively at some point and tried to hide parts of their living circumstances from outsiders many also reported positive experiences that were rooted in their families' special features (Wolowicz-Ruszkowska & McConnell, 2017).

Some of the studies reported a majority of participants who experienced bullying, especially in the school context (Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017): Both females and males, children with and without intellectual disabilities, whether they attended a mainstream classroom or a special education setting. In the study of Starke (2011) all participants reported experiences of bullying from peers at school. The bullying ranged from verbal bullying to physical abuse (Starke, 2011) and was mostly committed through peers but also by adults, for example parents of peers who would not allow their children to play with the participants of the study (Wolowicz-Ruszkowska & McConnell, 2017). Teachers usually failed to notice the bullying and the children also did not want to tell their parents or teachers either out of fear of the bullies or to protect their parents (Starke, 2011). Starke (2011) also reported accounts of children, mostly male participants, admitting to having used violence to protect themselves against the bullying of their peers.

An experience that was only reported in the study of Wolowicz-Ruszkowska and McConnell (2017) was that some children reported that they started to avoid other children that also had a parent with an intellectual disability, because they feared that contact to them would only increase the risk of stigmatization.

Reports of depression, self-destructive behavior, and even suicide-attempts were also named in relation to experiences of being bullied (Starke, 2011). Perkins and colleagues (2002) further found that experiences of stigmatization also negatively affected the relationship between the child and its mother.

5.5. The ambiguous diversity in growing up with parents with an intellectual disability – looking back on childhood experiences and reflecting current life satisfaction

The main finding of this systematic literature review was that the experiences the participants reflected about their childhood and their relationship with their parents displayed a broad diversity, ranging from very positive to very negative experiences, not just between the different studies and the participants, but in most cases also for one individual participant.

When asked how they would evaluate their standing in life at the time, most of the interviewed children being adults at the time rated their overall health and well-being as satisfactory (Lindblad et al., 2013; Starke, 2013), but participants from different studies also reported previous and/or current phases of depression, suicide-attempts, and self-injurious behavior in a varying percentage of the participants (Lindblad et al., 2013; Starke, 2011; Starke, 2013).

While often having few friends outside the family during childhood (Starke, 2011), adult children mostly reported a satisfactory social network, including peers and professionals next to relatives (Starke, 2013).

As a summary of the findings that were presented in this systematic literature review, the main point seemed to be that the participants recounted very ambivalent experiences, recalling both good and bad memories about their upbringing and the contact they currently have with their parents, ranging from regular to none, with every connotation between positive and negative feelings. A percental overview over the main findings of this chapter is presented in table 5.1.

A detailed discussion of the main findings of this section, as well as implications for future research, and some of the limitations of this paper will ensue in the following chapter of this paper.

Table 5.1

Overview over main findings in percentages

	Spend majority of childhood in parent`s care	Accounts of abuse/neglect	Presence of formal/informal support	Experiences of bullying/stigmatization	Regular contact to parents	Cases of Parentification
Wolowicz-Ruszkowska & McConnell (2017)	100%*	n/s	n/s	n/s	n/s	at least 13%
Starke (2011)	100%*	Abuse: 18% Neglect: 9%	27% formal	100%	n/s	n/s
Starke (2013)	n/s	n/s	n/s	n/s	n/s	n/s
Perkins et al. (2002)	100%*	n/s	n/s	n/s	100% (still lived in parent`s care)	n/s
Lindblad et al. (2013)	30%	60%	30% formal, 30% informal	30%	10%	n/s
O`Neill (1985)	84%	n/s	n/s	n/s	84% (still lived in parent`s care)	25%
O`Neill (2011)	46%	Abuse: 35% Neglect: 18%	n/s	n/s	76%	n/s
Ronai (1997)	Yes	Yes	Informal (Yes) Formal (No)	Yes	Yes	Yes

Notes. Percentages were rounded, n/s stands for “not specified” indicating that the study either did not address this aspect or, in most cases, did not provide data on this topic for all the participants

*spending the majority of their childhood in their parent`s care was an inclusion criteria for the study

6. Discussion

The aim of this systematic literature review was to assess how (adult) children of parents with intellectual disabilities experience their everyday life and reflect their upbringing in relation to their parent's disability. In this chapter, first a reflection of relevant findings will be presented, followed by a discussion of limitations of this literature review and its methodology. The last section of this chapter will then present indications for future research.

6.1. Discussion of substantial findings – the heterogeneity in children's experiences and the need for more formal support

In the first section of this chapter the substantial findings of the results section will be discussed in relation to the theoretical framework of this paper and relevant findings will be reflected.

As the theoretical framework of this study indicated, growing up with a parent who has an intellectual disability is likely to affect a child's life in a way, that is directly related to the parents' difficulties. For example, only a minority of the participants (30%) in the study of Lindblad and colleagues (2013) spend their whole childhood in their parent's care, supporting the findings of other studies (e.g. Booth & Booth, 2004; LaLiberte et al., 2016) that found an overrepresentation of parents with intellectual disabilities and their families in custody hearings and child protection services.

Despite predominant accounts of ambivalent feelings about their relationship with their parents many of the interviewed adult children reflected their upbringing and the challenges they faced as something positive that enhanced their resilience and was crucial for them to become competent and independent adults (e.g. Wolowicz-Ruszkowska & McConnell, 2017). The accounts of the participants of the different studies overall supported the fact that most of them did not perceive their parent's disability as the single cause for risks and difficulties they struggled with during their upbringing. The interviewees reflected that many factors, like the presence or lack of formal and informal support had an enormous influence on the quality of their parent's parenting skills and in turn their upbringing. As Starke (2013) summarized the difficulties children of parents with intellectual disabilities were found to generally have a higher risk for, are only partly related to a lack of parenting skills but also to an unsupportive environment. The summarized accounts of the analyzed articles support this statement. Participants reflected very positively on the influence of informal support they received, while lack of support was found to have negative consequences for the children's experiences (O'Neill, 1985; Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017).

It can be argued that contextual factors, like which country the participants grew up in and in what time, might have significantly influenced their experiences. 32 years lie between the oldest (O'Neill, 1985) and the newest study (Wolowicz-Ruszkowska & McConnell, 2017) that were analyzed in this review. A lot has changed in those 32 years, not just in the terminology but important laws and conventions have been passed (e.g. UN, 1989; UN, 2006) with the goal to improve the life of individuals with disabilities and their families.

A term that seems quite fitting to summarize how the experiences of the interviewed (adult) children of parents with intellectual disabilities differed from possible stereotypes and prejudices, is that most of the participants of Wolowicz-Ruszkowska and McConnell's study reflected their childhood as "different yet ordinary" (2017, p. 5). The negative assumptions and findings some studies reported (e.g. Faureholm, 2010) were only partially supported by the accounts of the articles that were analyzed in the context of this literature review. There were negative accounts, for example reports about abuse (e.g. Lindblad et al., 2013; O'Neill, 2011), that supported findings that suspected that their parent's disability could be considered as a risk factor for the children's development. But some of the analyzed studies also reported that a majority of the interviewees overall reflected their upbringing positively (Starke, 2011; Wolowicz-Ruszkowska & McConnell, 2017).

Overall, the findings of this systematic literature review showed that a parent's disability was not the only possible source of risk factors for the children, but other's perceptions of and reactions towards the parent's diagnosis could be a risk factor for the children's social and emotional development, self-esteem, and inclusion in society (e.g. O'Neill, 2011). Some participants even named their childhood experiences as a source of resilience (Wolowicz-Ruszkowska & McConnell, 2017), but those were exceptions.

In summary, the findings of this systematic literature review were as heterogenous as the participants and their experiences. This and the small sample size did not allow any general conclusions to be drawn.

6.2. Quality and limitations of analyzed articles

As explained in the quality assessment portion of the method section all the analyzed articles were found to be of at least medium quality, with five articles of high quality. One enormous difference in the quality of the articles was their year of the publication: the oldest articles was published 32 years ago (O'Neill, 1985), the newest in 2017 (Wolowicz-Ruszkowska & McConnell, 2017). This was one of the aspects that impeded the content analysis that included the comparison of the articles findings, for example because of the now outdated terminology

that was used by O'Neill (1985), as it was common in that time. Also, only few of the articles specifically addressed ethical aspects (Perkins et al., 2002; O'Neill, 2011; Wolowicz-Ruszkowska & McConnell, 2017), like obtaining informed consent from the participants, or were approved by an ethical board (Lindblad et al., 2013; Starke, 2011; Starke, 2013). Both aspects were included in the quality assessment tool (Appendix E) and affected the level of quality that was assigned to the articles.

As indicated in the background section many of the published articles in this field focus only on mothers with intellectual disabilities (e.g. Powell & Parish, 2017). This was reflected in the fact that 50 % of the articles that were analyzed in this systematic literature review only interviewed children whose mothers had an intellectual disability (Lindblad et al., 2013; Perkins et al., 2002; Ronai, 1997; Wolowicz-Ruszkowska & McConnell, 2017). This made up another limitation of this systematic review. Also, most of the studies interviewed adult children of parents with intellectual disabilities, making this a mostly retrospective study. Only the participants of the studies of Perkins and colleagues (2002) and O'Neill (1985) were all underage.

Another limitation is that the analyzed studies were conducted in three different countries: one in Poland, four in the United States, and three in Sweden. Those three countries have different policies and support systems in place that affect the amount and type of support children of parents with intellectual disabilities and their families can get. For example, as Wolowicz-Ruszkowska and McConnell (2017) stressed in their study only informal support is available for families where at least one parent has an intellectual disability in Poland and there is also no official register gathering information on this population. With nearly all studies highlighting how important formal and informal support is for families with at least one parent with an intellectual disability the lack of formal support is likely to affect the lives of the and in turn, affect the results of the respective study.

The method of the studies also varied to some degrees, even though most of them used semi-structured interviews to gain knowledge of the everyday life experiences of the participants. For example, the way the participants were recruited varied between most of the studies: some used official registers to find their participants (e.g. Perkins et al., 2002), while others used more informal ways to recruit participants, for example by using service providers as intermediaries (Wolowicz-Ruszkowska & McConnell, 2017).

Another significant difference was the level of involvement the parents had in their children's upbringing, for example not all participants lived with their parents for their whole

childhood. The level of parent's involvement already varied between the participants of the studies themselves and even more so when comparing the studies.

Also, the number of participants was small for all the studies, which is another thing highlighting how underrepresented studies interviewing children of parents with intellectual disabilities are in general.

Those differences made it difficult on many levels to compare the eight articles. One of the biggest differences between the articles was that some articles only interviewed children of parents with intellectual disabilities who did not have an intellectual disability themselves (e.g. O'Neill, 1985; 2011) and some where all participants had an intellectual disability (e.g. Starke 2011; 2013), while others interviewed both (adult) children that were free of diagnosis and children who had an intellectual disability as well (e.g. Lindblad et al., 2013).

The limitations of the analyzed articles as well as of this study in general need to be considered when interpreting the found results, but could also be used as a starting point for future research.

6.3. Methodological limitations

There are some methodological limitations this study was influenced by, that will be discussed in the following paragraphs.

Even though a thorough search of six databases was performed, using various combinations of search words that were established after numerous trial runs in different data bases (Jesson et al., 2011), it can in no way be guaranteed that all studies that interviewed children of parents with intellectual disability, that were published in English were found.

While a systematic literature review aims to reduce bias, this literature review was not peer-reviewed, so it might reflect the researcher's personal bias in some aspects. For example, the tool for the quality assessment was adapted by the researcher. Also, the chosen method for the data analysis, inductive content analysis after Elo and Kyngäs (2008) is likely to reflect the researcher's personal bias in some aspects, since the process of coding is never completely objective.

6.4. Implications for future research

Most of the analyzed articles reflected negatively on the limited research about children of parents with intellectual disabilities, especially regarding the small number of articles that

directly asked children of parents with intellectual disabilities for direct accounts of their experiences.

The fact that the extensive search of different databases that was part of the method section of this literature review only resulted in eight suitable articles for this review, supports the claim for the necessity of more research being done in this specific field. A high amount of future research is necessary to have more studies conducted in similar contexts (e.g. in the same country, with a similar method and population etc.) to make the findings more comparable and allow a few more general conclusions to be drawn about the experiences of children that grow up with at least one parent that has an intellectual disability. What is further needed are follow-up studies like the one performed by O'Neill (2011) to see how the children's situation and their perception of their own experiences change with age.

Another possibility for future studies would be to also interview children of parents with intellectual disabilities about how formal support could be improved to support them and their families better.

Overall, the discussion section of this study shows that to include the individual and very heterogeneous experiences of children that grow up with at least one parent with an intellectual disability into a bigger framework significantly more research is needed. Also, future research should not just observe the development of children of parents with intellectual disabilities, but also interview them to get a more authentic account of how they perceive their childhood experiences.

7. Conclusion

“I both love and hate my mentally retarded mother.” (Ronai, 1997, p. 431)

This honest quote of Ronai (1997) was chosen to introduce the conclusion of this paper, because it mirrors the ambivalence many children of parents with intellectual disabilities recount when asked about their childhood experiences and their relationship with their parents. This ambivalence was also found to be the red thread in the findings of this systematic literature review.

As indicated in the limitations of this study the sample size that was analyzed in this literature review is too limited to allow for general conclusions to be drawn. While children that grew up with at least one parent with an intellectual disability reflected different difficulties that were related to their parent’s disability, it cannot be said that an intellectual disability automatically negatively affects parenting skills. Mothers and fathers with intellectual disabilities can be great parents to their children, but at the same time they likely need additional support to fulfill their children’s needs and guarantee their rights.

It is the final conclusion of this paper, that more research needs to be done on the experiences of children who grow up with a parent that has an intellectual disability. The question how their parent’s disability affects their parenting skills and therefore the child’s upbringing will always remain too individual and personal to be generalized. While there might be black and white in deciding what makes a good parent, there is also a huge grey area in between. As Newman (2002) so fittingly put it, it is time to leave old prejudices behind and acknowledge that the majority of parents with intellectual disabilities just as much as parents without a disability only want what is best for their children, even though they might need additional support to develop their full potential as parents. Also, a parent’s disability does not automatically pose a risk towards their children’s development – it might not affect their life too much or it could even promote their resilience (Newman, 2002). It is the job of service providers and society in general to provide at risk populations like parents with disabilities and their children with adequate support. Because, as Azar, Robinson, and Proctor (2012) stressed, intellectual disability itself “is not an indicator of parenting quality” (p. 131).

It was the purpose of this paper to highlight articles that give a voice to the children of parents with intellectual disabilities, to make the world hear their experiences and to shed a light on the fact that more research in this field is needed to create a new, informed, and prejudice-free basis for service providers, parents with intellectual disabilities, and their children to work together.

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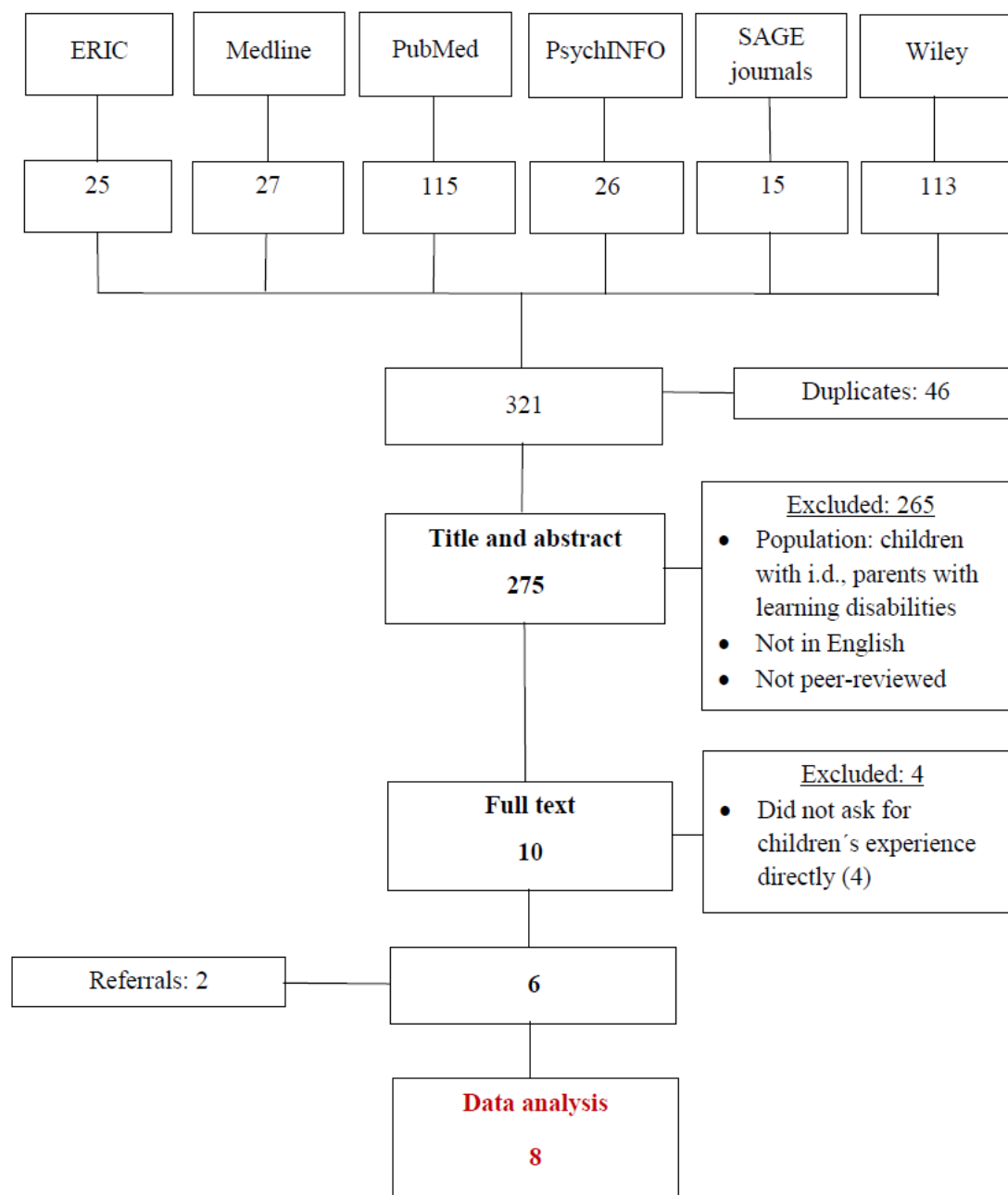
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9. Appendix

Appendix A. Flowchart displaying search procedure



Appendix B. Search words and used databases in relation

Databases	Search words				
	<u>Intellectual Disabilities</u>	<u>Children</u>	<u>Caretakers</u>	<u>Parents with Disabilities</u>	
ERIC	Thesaurus term "Mental Retardation"	child* OR youth adolescent OR adult*	-	Thesaurus term "Parents with Disabilities"	
MEDLINE	Thesaurus term "Intellectual Disability"	child* OR youth adolescent OR young adults	parent* OR mother OR father	Impaired parents	
PsychINFO	ti(intellectual disabilities OR cognitive* OR mental retardation)	ti(child* OR adult* OR adolescent youth)	ti(parent* OR mother OR father)	if(Parents with disabilities)	
PubMed	ti(intellectual disabilities OR cognitive impairment OR mental retardation)	ti(child* OR adult* OR adolescent youth)	parent* OR mother OR father	Parents with disabilities	
SAGE journals	ti(intellectual disabilities)	ti (children OR young adults)	-	Parents with disabilities	
Wiley	ti(intellectual disabilit* OR cognitive* OR mental retardation)	ti(child* OR adult* OR adolescent youth)	-	ti(parents with intellectual disabilities OR mothers with intellectual disabilities OR fathers with intellectual disabilities)	

Note. ti = following keyword had to be included in the title of the searched articles; if = means the keyword also had to be listed as a keyword in the article

Appendix C. Protocol of selection process and data extraction

Protocol for selection of articles and data extraction		
General information	Title:	
	Authors:	
	Year:	
	Journal study was published in	
	Country study was conducted in:	
Inclusion/Exclusion criteria	Included if	Excluded if
	Peer-reviewed article	Any other form of publication
	In English	Any other language
	(adult) children with at least one parent who has a diagnosed intellectual disability are asked how they experienced their everyday life in regard to their parent's disability	(adult) children are only observed or assessed or only parents or professionals get interviewed
	Aim was stated clearly	Aim was not stated clearly
	Limitations were named	Limitations were not addressed
	Study design was qualitative, quantitative, or a mixture of both	Study design was a literature review
Data extraction		
<u>Population</u>		
How many participants were included in the study?		
How old were the participants?		
Did the participants have a diagnosed special need as well?		

Method

How were the participants recruited?

What was the aim/purpose of the study?

What kind of terminology was used (e.g. intellectual disability versus cognitive impairment)?

What kind of study design was used?

- ☐ qualitative
- ☐ quantitative
- ☐ mixed methods

Was the study approved by an ethical board?

Was informed consent obtained?

Results

Short description of results:

Discussion

What kind of limitations were named (if any)?

What were the indications for future research?

Conclusion

Short description of the conclusion:

Appendix D. Overview over selected articles

No.	Title	Author(s)	Year	Journal	Country	Type of Study	Target group	Number of participants
1	The experience of adult children of mothers with intellectual disability: a qualitative retrospective study from Poland	Wolowicz-Ruszkowska, A. & McConnell, D.	2017	Journal of Applied Research in Intellectual Disabilities	Poland	Qualitative (interview)	Adult children of mothers with moderate or severe intellectual disability, that were brought up in the family home	23
2	An interview study of young adults born to mothers with mild intellectual disability	Lindblad, I., Billstedt, E., Gillberg, C., Fernell, E.	2013	Journal of Intellectual Disabilities	Sweden	Qualitative (interview)	Adult children of mothers with mild intellectual disability	10
3	Everyday Life of Young Adults with Intellectual Disabilities: Inclusionary and Exclusionary Processes Among Young Adults of Parents with Intellectual Disability	Starke, M.	2013	Intellectual and Developmental Disabilities	Sweden	Qualitative (interview and questionnaire)	Adult children with intellectual disabilities with at least one parent with an intellectual disability	10
4	Young adults with intellectual disability recall their childhood	Starke, M.	2011	Journal of Intellectual Disabilities	Sweden	Qualitative (interview)	Adult children with intellectual disabilities who lived most of their live with at least one parent with a similar diagnosis	11
5	Average and Bright Adults with Parents with Mild Cognitive Difficulties: The Huck Finn Syndrome 20 Years Later	O'Neill, A. M.	2011	Journal of Applied Research in Intellectual Disabilities	United States (New England)	Qualitative (interview)	Adult children who had no intellectual disability but grew up with at least one parent with an intellectual disability	17
6	Normal and Bright Children of Mentally Retarded Parents: The Huck Finn Syndrome	O'Neill, A. M.	1985	Child Psychiatry and Human Development	United States (N. E.)	Qualitative (interview)	Children without i.d. with at least one parent with an i.d.	23
7	Children of Mothers with Intellectual Disability: Stigma, Mother-Child Relationship and Self-esteem	Perkins, T. S., Holburn, S., Deaux, K., Flory, M. J., & Vietze, P. M.	2002	Journal of Applied Research in Intellectual Disabilities	United States (New York)	Questionnaire	Children without intellectual disabilities living with mothers with intellectual disabilities	36
8	On Loving and Hating My Mentally Retarded Mother	Ronai, C. R.	1997	Mental Retardation	United States	Case study	Report of one adult child about growing up with a mother with an intellectual disability	1

Appendix E. Quality assessment tool

Criteria for the assessment of reviewed articles
Population
1. Population. Does the population that was eligible to be selected for the study include the entire population of interest or just a selective subgroup of the population of interest? [2] Eligible population includes entire population of interest or a substantial portion [1] Population represents a limited or selective subgroup of the population of interest [0] No description of the population
2. Was the used sampling method and selection of participants appropriate for the study purpose? [1] Yes [0] No
3. Sample Size. How many participants were selected for the study? [2] Sample size larger than similar studies [1] Sample size the same as similar studies [0] Sample size smaller than similar study or sample size not given
Method
4. Aim. Was the aim/purpose of the study stated clearly? [1] Yes [0] No
5. Terminology. Was the used terminology defined explicitly? [2] Used terminology was defined explicitly or by referring to an official manual like the DSM 5 [1] Terminology was explained indirectly in the context of the study [0] Terminology was not clearly defined
6. Theoretical perspective. Was a theoretical perspective /background for the study clearly identified? [1] Yes [0] No
7. Design. Was the study design appropriate for the purpose of the study? [1] Yes [0] No
8. Data collection and recording. Was the data collected and recorded in a scientifically appropriate way? [1] Yes [0] No
9. Directness. Did the researchers ask directly for children's and adult children's opinions and experiences (e.g. in an interview or through a questionnaire)? [2] Children were interviewed directly or given a questionnaire or gave their opinion freely [1] Reflection of children's opinion only made up one part of the article [0] Children's opinion was not the main content of the article
10. Trustworthiness. Was evidence provided for the fulfillment of the four aspects of trustworthiness? Credibility [1] Yes [0] No Transferability [1] Yes

☐ [0] No Dependability ☐ [1] Yes ☐ [0] No Confirmability ☐ [1] Yes ☐ [0] No
11. Descriptive clarity. Did the researcher(s) provide descriptive clarity, e.g. by giving appropriate descriptions of the circumstances and the participants and by clearly identifying their own role and their relationship with the participants? ☐ [1] Yes ☐ [0] No
12. Drop-outs. Were eventual drop-outs handled and reported appropriately? ☐ [1] Yes ☐ [0] No
13. Conclusion. Was a conclusion provided and did it match the findings of the study? ☐ [1] Yes ☐ [0] No
14. Limitations. Were limitations of the method addressed in the article? ☐ [1] Yes ☐ [0] No
15. Implications. Are the findings valuable for future research? ☐ [1] Yes ☐ [0] No
Ethics
16. Ethical approval. Was the study approved by an ethical board? ☐ [1] Yes ☐ [0] No
17. Consent. Was informed consent obtained? ☐ [1] Yes ☐ [0] No
Publication
18. Peer review. Was the article published in a peer-reviewed journal? ☐ [1] Yes ☐ [0] No

Note. Adapted from the Quantitative and Qualitative Research Assessment Tools of the CCEERC (2013) and the Critical Review Form for Qualitative Studies (Letts et al., 2007)