# The book as a medium for parents with a disabled child as part of an early caregiving process

(overview essay)

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**Abstract:** The paper presents the theoretical background related to book work as an integral part of supporting children with disabilities. Primarily, the book support described can be implemented in a family setting or a counselling setting as part of early care for families with children with disabilities. The authors of the paper describe the book as a medium between the adults (professional, parent) and the child with a disability. It is the latter that they see as instrumental in developing the child's overall personality, with an emphasis on gradually achieving as much independence as possible and improving quality of life.

**Keywords:** book, child with disabilities, early bibliotherapy, bibliotherapists, advantages of working with a book, disadvantages of working with a book

# 1 Insight to the book

According to Kováčová (2020), from the child's earliest years, the book has an essential and irreplaceable place in education and therapy. Overall, the book can also be compared to a play, for example, which is perceived as a natural part of a child's life, regardless of disability. A book has several uses in the hands of a child, it can simply be a toy (a plastic book when bathing), a medium (a dramatically commented book by a parent), a tool (an educational book with interactive elements), but also a friend or companion. Primarily, it becomes a mediator of information through illustrations, letters, and text, but also the relationship that is formed with the disabled child. According to Jan Amos Komenský (1956, p. 25), books are like the most loyal friends; they like to talk to you. They talk to us honestly, openly and without pretence about everything we want. They instruct us, they guide us, they encourage us, they comfort us, and they present to us things distant from our sight as if they were present. It is

for this reason, too, that we argue that the book plays a rather significant role in early bibliotherapy, where it is the medium between the adult and the child with a disability (Svoboda, 2014; Kováčová, 2020, Biarincová, 2022).

# 2 Getting acquainted with the book

The origins of a child's getting to know a book can usually be observed in the family. The child is encouraged to read during the early interactions. The environment in which the child exists can be enriched with a book in the form of a mantle attached to a crib, a playpen, or a crib. Later in reading, it is recommended to use a book consisting of a single hardcover. This type of book is quite exceptional (it is a handmade book made by an adult). It is characterised by having a picture (shape, symbol, pattern) on both sides on a distinctive monochrome background. When handling it, the child can see how the book is handled. In the early years, the most common book is a fabric book with interactive elements. The book is intended to be part of the strengthening of the relational bond between child and adult, while at the same time, it is a medium that allows for non-directive stimulation of the child's interest in the environment and the world of sounds, light and colours.

In the context of early bibliotherapy, the following functions can be identified (Figure 1), which were primarily elaborated by Křivohlavý (1987, pp. 472–477). In addition to the above-mentioned functions of the book by the mentioned author, we have added other functions from other sources (Smetáček, 1973; Pilarčíková-Hýblová, 1997; Remeš, Halamová, 2004; Molicka, 2002; Svoboda, 2014; Štubňa, 2016, Kováčová, 2020).

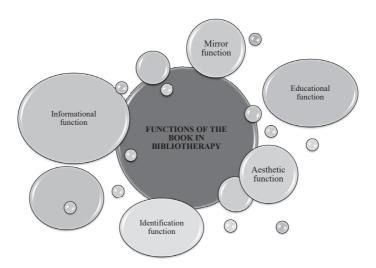


Figure 1: Functions of the book in bibliotherapy

The following functions can be attributed to the book:

- Informational function, which delivers information of various kinds to children for their further development and pushes them to increase their level of cognition. This may result, for example, in a potential reduction of fear of an unknown factor or situation in which they find themselves, etc. (Křivohlavý, 1987).
- Educational function when reading presents certain views on a particular problem, of course in a simpler form compared to a school-age child. It can provide the child with a role model for his or her future actions (Křivohlavý, 1987).
- A mirror function, where the child has the opportunity, with the help of an adult, to compare the views expressed by a particular person in the story (he/she may agree or disagree with it). Křivohlavý (1987) argues that comparing views can lead a child (who is discussing with an adult, communicating within a group, etc.) to re-evaluate or rebuild this-or-that view.
  - It happens that children in early and preschool age are righteously angry about injustice, or they "whisper" to the hero how to behave "... Run away," Anka shouts from her crib, while reading a story about a little boy who was chased by a bad bear. "Under here, hide here" (and pointing under his pillow..., Kováčová, 2020).
- The **identification function** which Křivohlavý (1987) perceives is that through it the child finds a character in the fairy tale to identify with (e.g. "I am as strong as a bear," shouts a three-year-old boy of a distinctly rachitic figure ). Štubňa (2016) argues that it is identification with one of the characters of a work that can be therapeutically or philosophically very effective for a child.
- **Aesthetic function**, working through the artistic text, is primarily associated with the human desire for beauty and harmony (Křivohlavý, 1987; Štubňa 2016).
- Relaxation function, bringing a feeling of relaxation, relaxation and peace (Křivohlavý, 1987). In this context, Smetáček (1973) also mentions the recreational function of the book, the description of which is similar to the relaxation function. Štubňa (2016) describes the relaxation function of the book from a general perspective, which we consider particularly interesting for the period of the child from preschool age up. The author (ibidem, pp. 35-36) argues that the relaxation function of literature is mainly realized through fiction works.

They are differentiated into two basic groups. The first group is fiction in the true sense of the word (literary fiction with symbolic meaning) and the second represents biographical or autobiographical works. According to the author (ibidem), the most common interpretation of a work of fiction for bibliotherapy is from a psychoanalytic point of view, because the patient (client) usually substitutes some kind of deficiency (compensates for a deficit) by reading, seeking support, help, a role model, and so on. The therapeutic intention is not necessarily to discover the symbolic meaning of the

work, but mainly to activate psychodynamic processes in the client and to enable him to discover and understand the unconscious parts of his ego. The second basic group is biographical or autobiographical work (stories inspired by real events), which already goes beyond the developmental period of the pre-school age. "Biographical and autobiographical works are primarily intended to provide readers emotional support, to point out different points of view in the perception of a certain situation, to be an example worth following, to show a way out (of a seemingly unsolvable situation) and to indicate a perspective of the successful overcoming of a problematic situation" (Štubňa, 2016, pp. 34–36).

- **Stimulating and supportive function**, because in the early years of a child's life, stimulation is one of the main priorities, which can be achieved, for example, through a book (Valešová Malecová, 2018).
- Socialization function, which Molicka (2002) describes by the example of a child who learns from the heroes in fairy tales to face and overcome difficulties arising in different social groups. Through the familiar/unknown story in which the characters figure, the child learns to be resilient. At first, the child is protected by the adult – parent, later he/she works in a group and is supported in the group so that the competence to be accepted and to succeed in the social group is strengthened.
- Spiritual function, where it can be debated whether it is an infiltration of the cultivating function. We justify its special mention by the fact that already in the history of book therapy a spiritual dimension has been used, especially in the sense of reading and interpreting the Holy Scriptures. Remeš and Halamová (2004, p. 47) argue that "biblical interpretation, so-called exegesis, is not meant to be a search for a once established and single meaning, but rather an active search for new and different meanings that are personally relevant to the person. This mode of interpretation is referred to as recipient-centred hermeneutics and is deeply rooted in the ancient Christian tradition." Štubňa (2016) mentions, in the use of the Bible, the «desert fathers» (Irish hermits living in the 4th-5th centuries AD) who developed an effective strategy to protect themselves from negative emotional states. In times of unwanted emotions, they immersed themselves in reading selected passages from the Bible that evoked joyful and optimistic attitudes.

The stated functions also consider the need for parent reinforcement and resilience during the delivery of early bibliotherapeutic intervention. We do not claim that the above hierarchy of listed book functions is complete (e.g., in terms of number, or individual characteristics, etc.), but we believe that the functions of the book itself in the context of early bibliotherapy are going to increase with the expansion of this support.

# 3 Principles of working with books in early bibliotherapy

The principles of working with books and the choice of the book in therapy are influenced by the current needs of the disabled child. Kováčová (2010) recommends following several principles where the primary setting and facilitator is the family/parent or another person who provides education and care for the child with a disability.

The principles of book selection in early bibliotherapy are presented and described in more detail in the following paragraphs. The author draws mainly on her experience in counselling practice concerning the developmental profile of the child with handicaps, threats, etc.

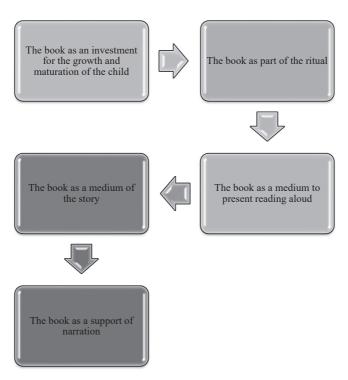


Figure 2: *Principles of working with books in early bibliotherapy* 

# 3.1 The book as an investment for the growth and maturation of the child

A book is meant to be part of a family, its life. The child needs to know where there is a place in the apartment/home, the so-called family library. It is a place where books are returned, re-selected for reading and are always available. The library is, symbolically speaking, a cot for books that can be put there to rest, each waiting to be returned for when and by whom. In this the books in the library are patient.

A bookcase may consist of a few pieces of books, whether cloth, paper, wooden, or self-made. A child as young as one and a half years old can be led to have a realistic idea about the concept of a library, at the same time positively influencing his relationship with books and thus teaching values through them.

**Branko, 20 months old**, communicates through his signs, he is hyperactive and he has regular problems with kidney inflammation (in the 3rd month he was diagnosed with an underdeveloped left kidney in a sonogram).

Branko likes books, especially books with animals. How does he read? "Well, I have to describe it to you", Branko's mother starts the conversation. "Branko first sits down, and puts the book in front of him. Usually with the back of the cover. He's fascinated by the barcode, to which he pays a lot of attention. He runs his finger along the lines, admiring the rails, the tiny bugs and the butterflies (That's how his parents named the lines and numbers in the bar code, B.K. note). He reads the cover of the book on his own, even though we often sit by him. He proceeds very systematically. After reading the back and front cover of the book, he starts flipping through it. My husband says he is probably imitating us. Opening a new double-page spread, he lies down on the book and pretends to think, ..." (Kováčová, 2020).<sup>1</sup>

#### 3.2 The book as part of the ritual

The process of reading consolidates the relationship between the child and the parent. A fixed time, a place to read, allows the parent to create a space for regular, ritual reading or working with a book.

The book does not have to be read in its entirety. Sometimes a particular passage or a few typical sounds to a particular character's depiction is enough. For better orientation in the text, it is advisable to use bookmarks or devise other ways of marking where the process with the book has been stopped for various reasons (fatigue, inappropriate selection, disinterest, etc.).

# Felicita, 3 and a half years old, has frequent lower respiratory tract illness.

Parents with three-and-a-half-year-old Felicita never forgot to go to the bookstore when visiting the shopping mall. Felicita always found a place in the children's book section. She took off her coat and made a ritual of reading. The serving staff already knew them well, they always came to tell her that they enjoyed such readers. Felicia carried her books and read them with full respect. Leaving the bookstore was usually not without screaming and crying. The parents decided to make a small library for their daughter as well. They bought her a smaller movable box that could fit a few books. The container

<sup>&</sup>lt;sup>1</sup> The described situation, which is given as an illustrative example, is taken from the counselling practice (note b.k.).

was called a bookstore (Felicita always insisted on it, she didn't want to admit that it should be a library, B.K's note). Felicita always pushed the box to one of her parents and put the books out. From that time forward, crying and screaming were no longer what accompanied Felicita and her parents out of the bookstore (Kováčová, 2020).<sup>2</sup>

#### 3.3 The book as a medium to present reading aloud

The importance of reading aloud should not be underestimated. Comprehension listening precedes comprehensive reading. The child perceives the tone of voice, the emotional colouring that gives a certain dramatic quality to the story. DeBaryshe and Binder (1994) examined parents' convictions about the goals and process of reading aloud to children. The results reflected convictions consistent with current theories of language acquisition and literacy building. Reading aloud to children may be among the most beneficial learning experiences at home that parents can provide to children. It contributes to the development of language competence, including vocabulary development, story comprehension, character recognition, etc. Early reading influences subsequent reading performance.

# 3.4 The book as a medium of the story

The choice of the story that forms the main content of the book is significant for the process of early bibliotherapy itself. In the beginning, these are isolated pictures that adults link together, combining them into a simple content line, or bringing the pictures closer to situations already experienced and familiar to the children's perceivers. The story should be chosen to be primarily age-appropriate, consider the specific needs of the individual child (client), and correspond with the therapeutic intent of the bibliotherapeutic intervention. Stories can be real, fantasy or original. It is advisable to choose stories in which the child can identify with a particular character (such stories are suitable for children as early as the end of the third year of life).

Each story used in early (biblio) therapeutic intervention should have a simple structure, a central idea and a charge through which the child understands the ongoing plot (Kováčová, 2010). These can be stories that are supportive for the child, in the sense of pointing out situations that the child with disabilities finds problematic (e.g. when the child is afraid; when the child cannot fall asleep; when the child is crying; when the child is aggressive while eating meals, etc., for more see Molicka, 2002).

<sup>&</sup>lt;sup>2</sup> The described situation, which is given as an illustrative example, is taken from the counselling practice (note b.k.).

**Bruno, is 4 years old**, with communication impairment (since the age of three in regular speech therapy and special education care).

Bruno laughs. Mom enters Bruno's playroom but sees no one. "Bruno, what are you laughing at?" "But, Shisho tells me how it was at the monkeys." The mother looks at Bruno and puts her hand on his forehead to see if her son has a fever. Bruno shakes his head and begins a dialogue with his mother. Mom wonders, "Who is Shisho? Where does he live? Is he a friend from kindergarten? "She is getting more and more restless.

Bruno's mother comments on her reaction regarding Shisho: "I had the impression that my son was going to develop a psychiatric illness, which my grandfather had, and then my grandfather had to be hospitalised and he died after a while there. The next day I checked the situation at the kindergarten. I called the classroom teacher and asked if they had a new child in the class. She listened to me with a serious face and smiled at the end. Yes, we know about Shisho. He is a very funny boy. He likes to read books about animals. And your Bruno has told us some of the stories too. And I, as a mom who is supposed to know everything, walked away in a confused manner. On the one hand, I was relieved, but I couldn't understand what was going on. What kind of friend? Does everyone know about him? After coming home from kindergarten, I sat down with Bruno. Are we going to read? Bruno nodded his head in approval and showed me a place where I could sit down. And you wouldn't guess who I was sitting next to! Next to Shisho, of course!" (Kováčová, 2020).3

# 3.5 The book as comsupport of narration

By reading the book(s), the child's narrative activity is stimulated in the presence of the parent. This is to support the development of the narrative competencies of the child with disabilities, which are gradually developed in the process of working with the book (Svoboda, 2014; Kováčová, 2020).

It is about structuring the story, dividing it into a certain number of phases (or points).

Each phase of the story can be with the child:

- role-played (e.g. using everyday objects, toys, puppets, ...),
- retold (e.g. using questions, unfinished sentences, ...),
- re-sung, etc.

The possibilities of story transfer are many and diverse in the way they can be conveyed (Kováčová, 2020), and their simplification is often the primary task in the early stages of bibliotherapy.

<sup>&</sup>lt;sup>3</sup> The described situation, which is given as an illustrative example, is taken from the counselling practice (note b.k.).

# 4 Advantages and disadvantages of working with books in the early bibliotherapy

There are both advantages (Table 1) and disadvantages (Table 2) in working with books (whether they are bibliopedagogical or bibliotherapeutic processes) (modified according to Machkova, 1998). We present a more detailed description of them in the following table elaboration.

**Table 1:** *Advantages of working with a book* 

The advantages of working with a book include	Selection of literature	Literature selection is the first factor described by Machkova (1998) as taking into account needs, age and possible disadvantages – when working with well- selected literature where the plot is well developed and the characters, setting and ideas are appropriately characterised, the work is comfortable in terms of time.
	Development of personality	Working with literature contributes to the overall sophistication of the individual, offering insight into a multitude of plots and situations, and empathy with the character and attitude of persons, while also leading him/her to tolerance.
	Problem-solving	A literary image can function as an "intellectual mask" of the current problem when a literary theme is combined with a non-literary theme, e.g. a situation of animosity between two members of a group can be represented by music, colour, environment, etc.
	Development of knowledge	Working with a literary theme fulfils the life experience and the life philosophy of the humanity (group) and leads to better awareness and knowledge of the differences and correspondences of different cultures and their values.
	Self-knowledge	Through the character, it can be a matter of looking at one's own attitude from a new point of view. In this way, working with a literary theme enriches the spiritual side of a person.
	Developing the imagination	It allows one to go beyond the every day, i.e., the ordinary banalities of life.

According to Rutter (1985, p. 610), the undeniable advantage of bibliotherapy is "its potential to develop in the client creativity, imagination, communication skills, selfconfidence and resilience".

**Table 2:** *Disadvantages of working with a book* 

with a book	Difficulty of choice	The difficulty of choice requires the therapist (educator) to take the time and effort to obtain the material. This means that when working with children he/she must routinely read children's books to make the right choice for the specific situations and conditions of the work. Very difficult is the search for a literary motif linked to the formulated theme.
f working lude	Continuous work	This is the need for constant tracking and monitoring of the literature that is relevant to a given age and social group while focusing on a specific theme.
advantages of wo we can include	Difficulty of preparation	Working with a literary theme is very demanding in terms of preparation, dramaturgical knowledge, and dramatic skills, as it is necessary to consider in advance the necessary organisational arrangements, not only within the group but when working with an individual.
Among the disadvantages of working with a book we can include	The possibility of error	When choosing a literary theme, a mistake is possible, and this is the case if one is working with an original theme. It may happen that the therapist (educator) does not reflect the interests and needs of the group.  A common mistake is to try to present to the group what interests (inspires) the teacher, regardless of the age and social composition of the group.

The actual form of the book (or its format and content) used by the therapist in early intervention or the parent in early education is difficult to describe in a way that could be seen as universal. The book must be specifically chosen (not arbitrary) and clearly must meet the individual and specific needs of the child for his/her state of health.

#### 5 Conclusion

In the very beginning of early childhood education, specific ideas for different variations in the use of the book arise when a parent seeks to stimulate his or her child. Later, if development is not considered optimal and the parent seeks help, it is the (biblio)therapist who offers concrete ideas for working with the child considering the child's current state of health and needs (Müller, Svoboda, 2021).

(Biblio) Therapists gradually leave more space for the parents to their accomplishments and approve their actions, thus moving the early care through the book ahead and supporting the quality of family life as a system.

Nowadays, the therapist is expected to adopt an interdisciplinary approach, which requires, in addition to philosophy, knowledge of such disciplines as ethics, psychology, and literary science, which examines literary works with a content orientation towards physically disabled children. Parents and professionals are to work together to educate and develop the child in the spirit of socially accepted and beneficial values that present calls for harmonious behaviour in interpersonal relationships and calls for fair decision-making and just action (Hajduk, 2014, p. 95). We live in an era that pays increasing attention to persons who require special care. Critically, since 1955, when the Australian writer and humanist Alan Marshall wrote the bestseller "I Can Jump Puddles", which became known on several continents, there are not enough children's books translated from the originals to help parents and children understand the various health issues that lie in the knowledge of the physical and neurological differences of disabled children in the current era of globalization.

At present, the most inspiring authors are, for example Laurie Ann Thompson, an American writer, winner of the "Schneider Family Book Awards" for her book American Emmanuel's Dream. It is the true story of Emmanuel Ofosu Yeboah, a young man from Ghana who was born with a disability and went to school with the support of his family, became a cyclist, and gained international fame for his achievements. The Dolly Grey Prize for Children's Literature was awarded to Shaila Abdullah's younger daughter Aanyah Abdullah. They bring the story of a little girl who forms a close bond with a child with cerebral palsy. The Dolly Gray Prize for Children's Literature is awarded to authors, illustrators and publishers of quality fiction and biographical books for children and young adults that authentically portray individuals with developmental disabilities such as autism spectrum disorders, intellectual disabilities, and Down syndrome. The specific needs of parents, and caregivers during the process of caring for a child with a disability also require specific literature that will, to the greatest extent possible, assist the development of children in the sense outlined earlier in this article. This is a common challenge for all.

However, the above-mentioned literature is for older children. Children in early childhood care ought also to be of interest to special-purpose bookmakers.

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