

## Experiences in the therapeutic itineraries of mothers of children with intellectual disabilities

Mércia Mascarenhas Fernandes Cerqueira<sup>1</sup>  
Rafanielly de Oliveira Alves<sup>1</sup>  
Maria Geralda Gomes Aguiar<sup>1</sup>

**Abstract** *The scope of this study is to describe the experiences of mothers of children with intellectual disabilities who have been treated in a specialized institution in Feira de Santana, State of Bahia, during their therapeutic itineraries. The study adopted a qualitative approach and was conducted by means of semi-structured interviews. The results revealed that the discovery that their child has an intellectual disability is accepted by their mothers with emotions of shock, denial, anger, negotiation, depression and subsequent acceptance. The difficulties in therapeutic itineraries begin after the moment the child is diagnosed as having an intellectual disability, due to the lack of experience of health professionals in communicating the fact, which leads the mothers to search for other health services. Despite access to healthcare being one of the principles of the Unified Health System (SUS), therapeutic itineraries are fraught with difficulties at a geographical, economic and functional level. Intellectual disability is a health issue demanding constant care, and its impacts have repercussions in the family dynamics, identities and roles, requiring comprehensive attention to the children and their caretakers, especially in the type of support such that they may maintain their protective roles.*

**Key words** *Intellectual disability, Family, Access to healthcare services*

---

<sup>1</sup> Núcleo Integrado de Estudos e Pesquisa sobre o Cuidar/Cuidado, Universidade Estadual de Feira de Santana. Av. Transnordestina Km 03 s/n, Novo Horizonte. 44036-900 Feira de Santana BA Brasil. merciamfernandes@gmail.com

## Introduction

The scope of this study is the experiences of mothers of children with intellectual disabilities, leading to questions about the nature of the experience. A very brief incursion into the etymology of the word shows that word experience comes from the Latin *experiri* and means to prove or try something. The search for the understanding of experience, finds inspiration in Benjamin<sup>1</sup>, who perceives the experience as it touches us and marks us, often for life. It involves what happens to us as a private and individual experience (*erlebnisse*) recorded by memory, that can be communicated by reportable narrative, thereby becoming a shared experience (*erfarhung*); such as the experience of a mother caring for a child with intellectual disabilities.

This is based on the assumption that the process of listening to experiences lived by individuals, through their narrative echoes aspects that make them common, sometimes revealing their collective dimension (*erfarhung*). Thus, the idea that the narratives of mothers transmit the experience of their bodies in the relentless pursuit of health care for their children with intellectual disabilities, facing arduous and difficult therapeutic itineraries, seems very appropriate.

Intellectual disability refers to a psychopathological condition specifically related to the cognitive functions affecting the life of a child in various dimensions. It is characterized by discrepancies and changes in mental structures for knowledge, as well as significant limitations both in intellectual functions and in adaptive behavior expressed in conceptual, social and practical skills and is manifested mainly before 18 years of age. The most common causes for intellectual disabilities are factors of a genetic origin, complications during pregnancy, childbirth or the post-natal period<sup>2,3</sup>.

This study adopts the concept of intellectual disability proposed by the American Association of Mental Retardation (AAMR), referred to as:

*[...] substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: Communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work<sup>4</sup>.*

After the Montreal Declaration on Intellectual Disabilities adopted in 2004 by the World Health Organization (WHO), together with the

Pan American Health Organization (PAHO), the term “intellectual disability” came to be used in place of “mental disability”. Currently, there is a tendency to adopt the term “intellectual disability” in several countries, including Brazil<sup>5</sup>.

Brazil created the National Health Policy for People with Disabilities in 2008 with the purpose of rehabilitating disabled individuals in their functional capacity and their human performance, so as to contribute to their full inclusion in all spheres of social life, as well as protect their health and prevent diseases that determine the appearance of disabilities. To achieve the scope of this purpose it is essential to create environments favorable to the health of people with disabilities and the adoption of healthy habits and lifestyles, both of these people as those with whom they coexist<sup>6</sup>.

In line with this policy, disabled persons are citizens with health care needs that are specific to their own condition, which can be affected by diseases afflictions that are common to the rest of society, therefore requiring the support of other types of services<sup>6</sup>. The family then seeks to ensure comprehensive care that goes beyond the specialty.

Research conducted with mothers of children with intellectual disabilities, namely their primary caregivers, who experience a reality far removed from that called for by the National Health Policy for People with Disabilities, reveals the enormous obstacles they face in seeking health care for their children, traveling arduous and difficult therapeutic itineraries<sup>7,8</sup>.

The promotion of accessibility and social inclusion requires that the health and education services should have physical access and environmental adaptations appropriate for the disabled individual, as well as trained professionals to care for them.

This study focuses on the therapeutic route of mothers of children with disabilities, whose narratives reveal dissatisfaction with the results obtained in the search for health care for their children, particularly with respect to the initial difficulties of access to therapies and services, and the inadequate care to which the children were submitted<sup>7</sup>. Mothers criticize the lack of ability of the health professionals, as witnessed in the meetings established with the latter, and also point out that care by a multidisciplinary team does not exist which is indispensable in view of the development of the potential of the individual with intellectual disabilities.

The narratives of the mothers about their experiences are important in order to know the

treatment given to children with intellectual disabilities, especially because, culturally, the care of children is the women's role, particularly for those with an illness or disability. In this respect, it is relevant to investigate the paths taken by mothers of children with intellectual disabilities looking for care, with a focus on the experiences they have had. A study with parents of newborns with intellectual disabilities revealed that their therapeutic itineraries in search of decent, humane and sensitive health care is a veritable *via crucis*<sup>8</sup>. The study of the topic presents an important ethical dimension related to the role of each service responsible for providing care to both children with intellectual disabilities and their families, as well as the agents who work there.

It should be emphasized that studies on the itineraries covered by the families seeking health care of the child contribute to identifying the difficulties faced by these families when making their journeys in search of care and highlight the functional barriers that thwart care to children in the primary care services<sup>9</sup>. They also offer tips when it comes to fostering skills of health care and care for the child.

In this article, the concept of a therapeutic itinerary is taken to be a set of plans, strategies and projects for a preconceived object: the treatment of an affliction. When faced with a situation involving an illness, people tend to set out on their journey in search of resolutions to the problem, there by embarking on their therapeutic itinerary<sup>10</sup>. It is also similar to the concept of a succession of events and decision making to deal with a situation of illness, which end up in the construction of a trajectory<sup>11</sup>.

In this respect, the experiences of mothers of children with intellectual disabilities treated in a specialized institution in the city of Feira de Santana, in the State of Bahia in their therapeutic itineraries was defined as the scope of research. Investigating the path taken by these mothers seeking health care for their children is relevant, given the difficulty of access to quality care, especially since the policy implemented to govern health sector actions aimed at this population segment only occurred belatedly in 2008<sup>6</sup>.

Given these considerations, this study sought to answer the following question: What are the experiences of mothers of children with intellectual disabilities in the therapeutic itineraries traveled in search of health care for their children? The aim was to describe the experiences of mothers of children with intellectual disabilities in their therapeutic itineraries.

## Methodology

The research is exploratory using a qualitative approach, since it sought to study a phenomenon and understand its individual and collective significance, consisting of the experiences of mothers in itineraries traveled in their quest to seek help for their children, as well as the feelings and emotions experienced in this process.

The survey was conducted in 2012, after approval of Protocol No. 73506/2012 by the Human Research Ethics Committee, due heed being paid to the recommendations of Resolution No. 466/12 of the National Health Council<sup>12</sup>.

The empirical field of the study was a civil philanthropic institution focused on the health and education of individuals with intellectual disabilities, which offers a multidisciplinary approach, covering the monitoring of families and the provision of outpatient services, such as diagnostic evaluation, pediatric neurology, psychology, educational psychology, social work, occupational therapy, physiotherapy, speech therapy, EEG and brain mapping.

Mothers of children with intellectual disabilities were invited to participate in the study. At that moment, they were informed about the theme and its objectives, and were asked to read the Informed Consent Form, explaining the risks and benefits, their voluntary participation and assuring them of confidentiality and anonymity.

Study participants were ten mothers of children with intellectual disabilities who met the following inclusion criteria: being the mother of a child treated by the institution; having a child who has been monitored since the time of diagnosis of the disability.

For this study, primary data collected through semi-structured interviews were used, following a script containing questions regarding socio-demographic data and the experiences and feelings of mothers of children with intellectual disabilities in the illness trajectory of their children. The data were recorded, transcribed and faithfully registered in the report.

The transformation of the data collected in its raw state into research results involves procedures to systematize, categorize and make analysis possible. The content analysis technique was used, which correspond to three phases: pre-analysis, which was carried out on the initial readings, which resulted in a first impression of the *corpus*, followed by its organization, moving forward to the definition of the registration units, context units and empirical category; anal-

ysis or exploration of the material, which consisted of successive readings of the *corpus* in order to codify it by aggregating it into units that allow the description of the relevant characteristics of the content; processing of the results, in which an attempt was made to understand the underlying content, by inference and interpretation<sup>13</sup>.

The process of analysis and interpretation of the data made it possible to construct the empirical category of therapeutic itineraries of mothers of children with intellectual disabilities: discovery, sentiments and difficulties.

## Results and discussion

The participants of the study were mothers between 23 and 53 years of age. Three stated that they were of African-Brazilian descent, three were Caucasians and four were non-white. They were from Feira de Santana (BA) and other surrounding towns. A variation in the level of education was clear: five reported having completed high school, one had not completed high school and four had not completed primary school. With regard to occupation, all the mothers reported being housewives; two of them mentioned occupations as artisan and daily help. With regard to religion, six of them declared themselves to be Catholic, three Protestant and one Christian. The number of children ranged between one and four.

The category studied revealed details of the experiences of the mothers, their feelings about the discovery and the fact of living with their child's disabilities and the difficulties encountered in the trajectory in search of care.

### **Therapeutic itineraries of mothers of children with intellectual disabilities: discovery, sentiments and difficulties**

The paths taken by the mothers of children with intellectual disabilities in the search for answers to questions regarding doubts about diagnosis and treatment for the problem of their children represent their therapeutic itineraries, showing the trajectories that they have traversed because of their life circumstances.

The need that mothers have to acquire knowledge about the health status of their children spurs their search for health services, which is often elicited upon the child's birth, since the parents inherently tackle the fact that the child has an intellectual disability with a sense of shock

and denial, anger, negotiation, depression and, finally, acceptance<sup>14</sup>. At this point they feel apprehensive about facing a new, disturbing and often threatening situation, so they then demand information about the status of their child, with questions and doubts that often go unanswered.

Thus, the difficulties encountered in the therapeutic itineraries already begin at the moment of diagnosis of a child with intellectual disabilities. The reports of mothers reveal the concern felt when they saw changes in their children, the answers for which took a very long time to obtain: *As from 6 months I started to notice. I began to see that when she lay down, she could not sit up again on her own. I gradually became aware of it, right? And it was a neurologist in Salvador [who diagnosed it], when I lived for a while in Salvador, but by then she was already 5 years old.* (Carolina).

The provision of skilled care to children with disabilities and to their families is the responsibility of the health services, so it is up to these professionals to provide guidance on the conditions of a child with disabilities, as well as propose the necessary care required to deal with the situation. However, a study points out that parents receive little information from the professionals in relation to their doubts regarding cerebral palsy and Down Syndrome, which prejudices the application of adequate treatment of children and interferes with educational practices and decision-making<sup>15</sup>. Correct and pertinent information afford the family, particularly mothers, more certainty as to understanding of the child's condition and allow objectivity in the search for specialized care and professionals.

The diagnosis of intellectual disability in itself is a painstaking process, because it involves the understanding of genetic, social and environmental factors. For this reason, it must be done by health professionals who are part of a multidisciplinary team; it can be performed in clinics, hospitals, rehabilitation centers and specialized clinics and by interdisciplinary teams of educational institutions<sup>16</sup>. This diagnosis sometimes involves a lengthy process, as intellectual deficiency results in substantial limitations in the functioning of the individual, and these may not appear during the neonatal period, as in the case of Carolina, who discovered the intellectual disability when her daughter was 5 years old. This process may be hampered by the family's lack of knowledge about which health institutions offer treatment to children with intellectual disabilities and which professionals are the best choice for monitoring their children.

A thorough and sometimes amazingly lengthy process, the diagnosis is hampered by several other factors, such as the aforementioned lack of information on the family's part. It is an aspect often aggravated by the failure of the health professionals to provide information during child consultations, as well as offering superficial information in an atmosphere that is closed for dialogue, which obliges mothers to seek consultations with other professionals, to answer their questions and ease their anguish and anxieties<sup>17</sup>.

The lack of clarification and guidance on the health of the child by the professionals at the institution where the child was born, was reported by all the mothers interviewed. *In the ward no pediatrician told me anything. No pediatrician talked to me at any time [...]. I left the hospital without a pediatrician coming to talk to me, to say 'Listen mother, your daughter may have a slight problem; I will issue a referral for you to take nothing'*. (Natália). It is clear that the absence of information, guidance and possible referrals, causes the family to remain in doubt as to the child's real health condition, and insecure as they do not know who to turn to.

In the communication of the diagnosis, it is up to the health professional to talk to the family firmly and forcefully, offering to listen patiently to the questions and report sincerely on the impact that the intellectual disability will have on the life of the child and of the family. Thus, the experiences of parents seen as being threatening to the integrity of the child, the family or their own peace of mind, may represent an important moment of change and learning for all concerned.

One should not expect that parents with little or no guidance, should suddenly be able to handle such a diversity of mixed feelings about their child. This is a delicate moment as the family is hoping to get a positive response in relation to the child, which will diminish their suffering and facilitate the process of acceptance. Thus, it is quite possible that the professionals will often have to deal with the anger that parents feel about the situation and, often at the bearer of bad news. Thus, it is essential that the professional knows and considers the psychological processes involved in the reactions of the parents<sup>18</sup>, being able to establish a relationship of partnership with the family of the child with disabilities, in order to make them better able to care for their children<sup>15</sup>.

For some families, the confirmation that the child has intellectual disabilities presents itself as a major psychological upheaval and becomes a

powerful source of constant conflict with repercussions on the parents, the other members of the family group and also, significantly, on the child him/herself<sup>9</sup>. This discovery is permeated by feelings such as despair, grief, sadness, disbelief, denial, among others. *This was a planned pregnancy. I always prayed to God to have a daughter. Then, when the child was born, I saw it was a girl. I was very happy, but then when I found out she had Down Syndrome, it left me very downhearted, because I thought she would not be a normal child, but even so, I kept asking God for strength to accept it.* (Gabriela).

The care provided to children with intellectual disabilities involves the entire scope of personal care and home life, both encompassed by the activities of daily life. Such care is intense, constant, continuous and complex, with the potential to turn into a source of stress and oppression for carers<sup>20</sup>. Acknowledging this reality highlights the importance of providing care to the entire family group in a comprehensive manner, however, as reported by the mothers, the care provided by health professionals is directed only to the child. *In my case, I do not have though I should have psychological support. I need a tranquilizer because it is difficult to endure.* (Érica).

From her statements, it is evident that the lack of spaces of care and forms of support to cope with the demands related to her child's illness led to the medicalization of Érica's psychic distress. The understanding that child care requires the inclusion of the family is essential for humane, comprehensive and effective care, which includes psychological and social support actions, guidelines for carrying out the activities of daily living and basic rehabilitation actions, and offering expert support in hospital or home confinement situations<sup>7</sup>.

Actions able to bolster caregivers and their (informal and formal) social support networks would potentially minimize the suffering and stress faced by the family, especially mothers, in the trajectory in search of care and resolution of the health needs of their children, since such paths are permeated by difficulties that act as barriers to access, which require them to make repeated visits to several institutions.

Although, guaranteed by law, the search for care by people with disabilities is permeated by overcoming many obstacles, especially regarding access to specialized services. Often the treatment the child needs is not offered in the city of residence, obliging the family to move to another city, which generates additional costs, as report-

ed by Gabriela: *She had difficulty speaking. So I came here looking for a speech therapist in Feira de Santana, but only managed to find a private speech therapist. It was made more difficult because there was no public transport to go there. I would have to pay transport costs and pay the speech therapist.*

The lack of specialized services in some cities, sometimes obliges families to move to locations where services capable of attending the needs of the children are offered. *It was when I asked for leave from work and came to Feira de Santana, to get a treatment here in APAE. I spent two years to get the treatment. I could not get all the appointments, but today she is attended here in APAE on Chromosomes 21 and CAPSi. (Gabriela).*

The routine of families with children with intellectual disabilities is affected by the need for attention that they require. Due to the new reality, many mothers are unable to reconcile the routine care of children with their employment, and eventually give up their jobs to devote themselves fully to their children, as in the story of Gabriela: *I went back to Capela [in Alto Alegre] to work, but as I had to work 40 hours (per week) I would be unable to take care of her and come here, I opted for dismissal.*

When seeking health care for their children, mothers face many problems that pervade negligence in the care of newborns, through to the difficulty of arranging for the hospitalization of the child, which show obstacles in functional access. *He had a fever, I took him to the Polyclinic, but they did not resolve anything ... so I picked up my son and I walked over to Hospital B [specialized hospital]. I was depressed because I felt a lot of humiliation. (Lorena).*

In the report of Lorena, whose son was diagnosed with innate metabolism error, her frustration is clear due to the same lack of resolution. However, she believes that the experience as the primary caregiver and child's companion in frequent hospitalizations led her to become a more focused and attentive person, who learned to deal with both the child and with other people with disabilities.

Therapeutic itineraries traveled by mothers show that the care of their children required great effort, dedication and abdication of personal life to ensure access to services offered by health institutions and public and private education, as well as civil organizations. Mothers reported that they made efforts to tackle the obstacles related to the geographical, functional and affordable access to health services, far beyond their capabilities.

Although access to healthcare is a constitutional right and one of the principles of the Unified Health System (SUS), the reports of mothers point to obstacles, particularly with regard to the geographical, functional and economic dimensions. In the social dimension, access is considered a fundamental category. Acquiring it is the first step to be overcome by the users when they set out on the quest for health<sup>21</sup>.

The geographical access is evaluated on the basis of time spent in the form of displacement and the distance between the user's residence and the health service, while economic access considers the costs and benefits that the users expend in their search for health care<sup>21</sup>. Even though there may be health services near the user's home, the decision to use them is influenced by how the patient is received in the unit, confidence in the experience of the employees, the type of service offered, the capacity and competence of the staff and the problem-solving ability of these services. As can be seen in the comments made by Iara, who had to move from the city where she lived to find service in the state capital: *The service was good here in APAE and in Salvador. It is only there where I live that the service is bad.*

To deal with the health problems of their children, some mothers resorted to private health services due to the alleged lack of some resources they needed and/or space available in public institutions. These reports reveal difficulties in terms of functional access, involving access per se to the services needed by the user, including the types of services offered, the available hours and the quality of care<sup>21</sup>.

Another problem faced by mothers seeking access to services is the financial limitation, since the removal to specialized institutions, often in other cities, generates additional costs: *Sometimes I did not have the fare. I would walk because that is the way it is there. He was in the early stage and could not miss a day. If he missed a day, he lost his slot. So, I went on foot. (Renata).*

The difficulties in access to health services, in some situations, are minimized through an agreement with a private company to purchase health services, as Tatiana says: *I imagine that if it was not for the plan it would have been very difficult, because in the beginning when we needed to find a speech therapist, my God, it was a real problem!* For her part Patricia warns that getting service only occurs when it is intermediated by influential people, even in public services. *It all depends on you knowing someone with influence to get care, even in public service.*

It is recommended that the Primary Care should receive, attend to the complaints, advise on further examination, offer basic medication, monitor the progress of each case and, where necessary, make the referral of children with intellectual disabilities, to specialized care units<sup>22</sup>. The performance of the Basic Health Units (BHU) and the Family Health Units (USF) is essential in the process of care and monitoring of people with disabilities, but such services were only mentioned by Amanda, Carolina, Gabriela and Renata. The latter said: [...] *the doctor [from the USF] gave me a referral. So I took the referral and I came here [APAE] and scheduled an appointment.* The mothers waited to get medical care for their children and, instead of this, were sent to other institutions. It is understood that Primary Care must tackle the challenge of being more than just a place of passage and referral to other health institutions.

The services offered by USF are divergent from the reality and the needs of children and families, which have their rights restricted by the incoherence of the system, revealing the inaccessibility to health care at all levels of care, including those of referral and counter-referral<sup>23,24</sup>.

Above all, the narratives of mothers indicate that attending the health needs presented by children with intellectual disabilities involves their sociocultural context, namely the user as a subject, and is not limited to the performance of a single professional or even only the health area<sup>25</sup>. The actions of health and multidisciplinary team services should provide social support for families, particularly mothers, demonstrating that there is the involvement of a group of professionals who provide the aid and assistance needed.

In this respect, it is the duty of the multi-professional team offering social support of the emotional type, characterized by showing care and willingness to listen; information support, because it represents a source of knowledge and enlightenment; support material, by providing resources necessary for the monitoring of children with intellectual disabilities; and evaluation of support, giving feedback to mothers on how they should act, offering suggestions, compliments, claims, and provide the incentive necessary to maintain their attitude<sup>23</sup>. *The psychologist talked to me and to him [son]. There is also the school teacher, who offers special tutoring for him. And there is the physician, who is a neurological specialist, because he's nervous and has learning difficulties.* (Amanda).

It is common knowledge that a relationship based on dialogue between the professionals in-

involved in the care of children with intellectual disabilities and their parents, provides the encouragement of the latter to participate more actively in care and in decision-making for their children

The impact of a health problem that requires constant care, such as an intellectual disability, and that will extend over a lifetime, affects the family dynamics, identities and roles. Moreover, it is a challenge for public health because, often in the organization of services, the supply is reduced and there is low coverage, difficult access and discontinuance of care<sup>7</sup>.

This challenge can undermine the sense of promoting comprehensive care, which is a constitutional right enshrined in the National Health Policy for People with Disabilities, since the children require intersectoral care and their caregivers also need support and care so that they can sustain their protective role.

Reports revealed the struggle of mothers for the social inclusion of their children to ensure that they receive care and treatment consistent with their real needs. So they accessed the professional subsystem of health care without revealing preference for public or private service, indicating that the geographical, economic and functional dimensions of access are relevant factors in determining the configuration of the itinerary.

It is an arduous and constant search for these women who devote a major part of their lives to care for their children with intellectual disabilities. This task is challenging, since caring for the emotional and physical needs of the latter requires dedication, time and effort, in addition to providing financial, social and emotional distress for the family, which calls upon the support of its closest relationship network<sup>26</sup>.

It is understood that the care of these families is key to their empowerment in order to deal with the adversities relating to the situation of disability of the children as well as maintain the healthy family functions and interactions<sup>27</sup>. Families need attention, respect, care, information, guidelines and the support of the health team. It is up to nurses and other members of the health-care team to meet the needs of families and be willing to listen and understand their fears, their problems and concerns, seeking ways to facilitate the adaptation and coexistence with the disabled child.

The care process assumes a commitment to the families, helping them to understand each phase experienced by them, so that they can feel empowered in the process of taking care of the

child. It must also be grounded on an inter-subjective relationship, which fosters the creation of bonding and trust, so that the family can provide the conditions for the growth, development and social inclusion of the child<sup>23</sup>.

### Final considerations

In the therapeutic itineraries traveled in search of health care for their children, the mothers experienced the discovery of intellectual disability with feelings of shock, denial, anger, negotiation, depression and, eventually, acceptance. Confirmation of the diagnosis of disability is a lengthy process, which affects the family dynamics, manifesting itself as a major psychological upheaval for the family. At this point, mothers seek the support of institutions and health professionals, because they feel unprepared to deal with the intellectual disability and care of their child.

Mothers face difficulties related to the diagnosis of their children, as they lack clear and objective guidance on the health status of their child as well as how to look after them from the moment of birth. All this in a context of failures in communication in the reception and care provided by health institutions. The search of mothers for health care for their children is permeated by going back and forth to various health institutions, which becomes averitable ordeal for them.

It is evident in the narratives of mothers in their itineraries, that their bodies seem to be tireless, however, these same bodies are sorely tested by the difficulties encountered in gaining access to health services. The mothers admit that they are marked by the suffering in their struggle, yet they still need to redouble their efforts and main-

tain constant dedication to their children in seeking to ensure they get the health care they need.

The narratives of mothers of children with intellectual disabilities lead us to believe that they are always ready and willing to provide care. Their bodies take constant care of another being, while they neglect themselves. For this reason, the implication is that their bodies are tirelessly active in search of resources that can ensure their child's needs in terms of care. These are bodies that are always alert and vigilant, that get little or no rest.

It is suggested that health services should provide comprehensive care that attend the needs of these children and their families, which requires the enhancement of the capabilities and skills of health professionals, in line with the policies geared for the disabled. Care for children with disabilities requires multidisciplinary, interdisciplinary and intersectoral actions, in order to produce more effective responses to the demands of the children with intellectual disabilities and their families.

Health care for children with intellectual disabilities is a challenge, especially because it requires comprehensive care provided by an interdisciplinary team, whereby it is necessary that the institutions are prepared to receive them, from the moment of admission to referrals and guidance. Therefore, it is necessary to invest in ongoing education for professionals, such that they are able to attend and care for this group that have daily health care, education and social interaction needs. It is also important to monitor the families of these children, ensuring that they receive more humanized and comprehensive care and uphold the rights of individuals with disabilities duly guaranteed by law and enforced in public health policies.



## Collaborations

MMF Cerqueira worked in the research design and in the analysis and interpretation of the data. RO Alves worked in the analysis and drafting of the article and approval of the version to be published. MGG Aguiar worked in the research design, the critical review of the article and approval of the version to be published.

## References

1. Benjamin W. Experiência e pobreza. In: Benjamin W. *Magia e técnica, arte e política: ensaios sobre literatura e história da cultura*. 7ª ed. São Paulo: Brasiliense; 1994. p. 114-119.
2. Paulo SM, Freitas LBL, Pinho GS. *Documento subsidiário à política de inclusão*. Brasília, DF: Ministério da Educação, Secretaria de Educação Especial; 2005.
3. Pereira JE. A infância e a deficiência intelectual: algumas reflexões. In: *Anais do Seminário de Pesquisa em Educação da Região Sul*; 2012; jul./ago. 29-1; Caxias do Sul. p. 1-15.
4. American Association on Mental Retardation (AAMR). *Mental retardation: definition, classification, and systems of supports*. Washington: AAMR; 2002.
5. Sasaki RK. Terminologia sobre deficiência na era da inclusão. *Rev nac reabilit* 2002; 5(24):6-9.
6. Brasil. Ministério da Saúde (MS). Secretaria de Atenção à Saúde. *Política Nacional de Saúde da Pessoa Portadora de Deficiência*. Brasília: MS; 2008.
7. Bastos OM, Deslandes SF. A experiência de ter um filho com deficiência mental: narrativas de mães. *Cad Saude Publica* 2008; 24(9):2141-2150.
8. Caminha LL. *Cuidados prestados por profissionais de saúde aos pais de recém-nascidos com deficiência* [monografia]. Feira de Santana: Universidade Estadual de Feira de Santana; 2008.
9. Silva RMM, Viera CS, Toso BRGO, Neves ET, Cardoso LL. Itinerário de famílias em busca de atenção no adoecer das crianças. *Ciênc cuid saúde* 2014; 13(1):12-19.
10. Alves PCB, Souza IM. Escolha e avaliação de tratamento para problemas de saúde: considerações sobre itinerário terapêutico. In: Rabelo MCM, Alves PCB, Souza IM, organizadores. *Experiência de doença e narrativa*. Rio de Janeiro: Fiocruz; 1999. p.125-138.
11. Cabral ALL, Martinez-Hemáez A, Andrade EIG, Cherchiglia ML. Itinerários terapêuticos: o estado da arte da produção científica no Brasil. *Cien Saude Colet* 2011; 16(11):4433-4442.
12. Brasil. Ministério da Saúde (MS). Conselho Nacional de Saúde. Resolução nº 466, de 12 de dezembro de 2012. *Diário Oficial da União* 2013; 13 jun.
13. Bardin L. *Análise de conteúdo*. São Paulo: Edições 70; 2011.
14. Kubler-Ross E. *Sobre a morte e o morrer*. 7ª ed. São Paulo: Martins Fontes; 1996.
15. Ribeiro MFM, Barbosa MA, Porto CC. Paralisia cerebral e síndrome de Down: nível de conhecimento e informação dos pais. *Cien Saude Colet* 2011; 16(4):2099-2106.
16. Associação de Pais e Amigos dos Excepcionais. *Sobre a deficiência intelectual: como diagnosticar* [Internet]. 2015 [acessado 2015 dez 9]. Disponível em: <http://www.apaesp.org.br/SobreADeficienciaIntelectual/Paginas/Como-diagnosticar.aspx>.
17. Lemes LC, Barbosa MAM. Comunicando à mãe o nascimento do filho com deficiência. *Acta paul enferm* 2007; 20(4):411-415.
18. Hoher SP, Wagner ADL. A transmissão do diagnóstico e de orientações a pais de crianças com necessidades especiais: a questão da formação profissional. *Rev estudos psicol* 2006; 23(2):113-125.

19. Góes FAB. Um encontro inesperado: os pais e seu filho com deficiência mental. *Psicol ciênc e prof* 2006; 26(3):450-461.
20. Neves AP. *O aluno com necessidades educacionais especiais numa escola técnica: limitações, desafios e possibilidades* [monografia]. Brasília: Universidade de Brasília; 2011.
21. Lima MADS, Ramos DD, Rosa RB, Nauderer TM, Davis R. Acesso e acolhimento em unidades de saúde na visão dos usuários. *Acta paul enferm* 2007; 20(1):12-17.
22. Brasil. Ministério da Saúde (MS). Secretaria de Atenção à Saúde. Departamento de Ações Programáticas e Estratégicas. *Atenção à saúde da pessoa com deficiência no Sistema Único de Saúde*. Brasília (DF): MS; 2009.
23. Barbosa MAM, Pettengill MAM, Farias TL, Lemes LC. Cuidado da criança com deficiência: suporte social acessado pelas mães. *Rev gaúcha enferm* 2009; 30(3): 406-412.
24. Milbrath VM, Amestoy SC, Soares DC, Siqueira HCH. Integralidade e acessibilidade no cuidado à criança portadora de paralisia cerebral. *Acta paul enferm* 2009; 22(6):755-760.
25. Otehiro MB, Ayres JRCM. Necessidades de saúde da pessoa com deficiência: a perspectiva dos sujeitos por meio de histórias de vida. *Interface (Botucatu)* 2012; 16(40):219-233.
26. Dezoti AP, Alexandre AMC, Freire MHS, Mercês NNA, Mazza VA. Apoio social a famílias de crianças com paralisia cerebral. *Acta paul enferm* 2015; 28(2):172-176.
27. Barbosa MAM, Balieiro MMFG, Pettengill MAM. Cuidado centrado na família no contexto da criança com deficiência e sua família: uma análise reflexiva. *Texto Contexto-Enferm* 2012; 21(1):194-199.

---

Article submitted 01/02/2016

Approved 27/06/2016

Final version submitted 29/06/2016