

Educação Especial: tendências e desafios contemporâneos

People with disabilities: Fighting for their rights in the United States of America and Brazil¹

Pessoas com deficiência: luta por seus direitos nos Estados Unidos da América e no Brasil

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Abstract

This study focuses on guaranteeing the right to Education for people with disabilities, from the point of view of the human rights organization and the Special Education policy in two countries: United States of America and Brazil. The goal was to understand how the right to Education has been guaranteed to people with disabilities in these two countries. Since the law in the United States of America is organized at state level, New York was chosen as example.

¹ This article is the result of the research carried out during the scholarship of the Santander Mobility Program, with scientific initiation that integrated the activities of scientific initiation on disability and gender in the publications on Special Education of the student Larissa Costa Santos, under the guidance of Teacher Doctor Carla Biancha Angelucci.

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We made a comparative study not to produce a ranking that shows what is the best or worst way of committing to implement the right to education for people with disabilities, but rather to understand, through different political, cultural and social contexts, the ways in which such rights were brought forth in the law and in public policy design. We present a brief history of disability rights in the United States of America and Brazil. Then the Special Education policy in both countries is discussed, and some comments are made on Special Education in the state of New York. There are differences related to the idea of inclusion as adopted by each country, because political and legal organization in both countries differ significantly, especially about the definition of the target audience and the definition of the educational tools to be used. Both countries emphasize the participation of disability rights social movements in the creation and monitoring of public policies.

Keywords: People with disabilities. Social rights. Special Education.

Resumo

Este estudo trata da garantia do direito à Educação por parte de pessoas com deficiência, na perspectiva da organização da luta por direitos e da política de Educação Especial nos Estados Unidos da América e no Brasil, com o objetivo de entender como o direito à Educação tem sido garantido. Como a legislação estadunidense é organizada majoritariamente no nível estadual, Nova York foi escolhida como exemplo. Foram tomadas em consideração a história de organização dos movimentos sociais de pessoas com deficiência e a legislação dos dois países. Trata-se de estudo comparativo, não para produzir hierarquia que defina qual o país com maior ou menor compromisso com o direito à Educação de pessoas com deficiência, mas para caracterizar tais lutas, a partir de diferentes contextos políticos, culturais e sociais. O trabalho apresenta uma breve história dos movimentos sociais organizados pela luta de direitos nos Estados Unidos da América e no Brasil e discute a política de Educação Especial nos dois países. Conclui-se que há diferenças relativas à concepção de inclusão adotada em cada país. Política e legislação sobre Educação Especial também diferem significativamente no que se refere à definição do público-alvo e do serviço a ser frequentado. É possível ainda afirmar que em nenhum dos dois países há ênfase na participação dos movimentos sociais de pessoas com deficiência na criação e no monitoramento das políticas públicas.

Palavras-chave: Pessoa com deficiência. Direitos sociais. Educação especial.

Introduction

This article is the result of an exchange of knowledge and experiences provided by the Santander Program for International Mobility Grants for undergraduate students enrolled in the Scientific Initiation Program (*Programa de Iniciação Científica*). The exchange was between student and faculty from the School of Education of the University of São Paulo in Brazil (*Faculdade de Educação da Universidade de São Paulo/Brasil*) and a faculty member of the Stony Brook School of Health, Technology and Management in New York, United States of America (USA).

This study focuses on guaranteeing of the right to Education for people with disabilities, from the point of view of the human rights organizations in two countries: United States of America and Brazil. The laws from both countries on Education for people with disabilities will be taken into consideration. Since the law in the United States of America is organized at state level, New York was chosen, as it is where the Stony Brook University School of Health and Technology and Management is located.

The goal of this study was to understand how the right to Education has been guaranteed to people with disabilities in these two countries.

First, we discuss the people with disabilities and their fight for their rights, then the way in which educational policy for people with disabilities is organized. We understand that, from the explanation of the points of consensus and dissension, the study can be useful for understanding the challenges present today, in guaranteeing the right to Education for people with disabilities. We also analyzing the way each country has been implementing its laws and policy guidelines, and how Brazil has been implementing the commitments undertaken in the framework of the International Convention of Rights for People with Disabilities (Brasil, 2008a).

Methodological Procedures

The purpose of this study is not to apply a *senso stricto* comparative analysis because it is understood that political decisions and the legal organization of each country refer to a historically significant social and cultural set of conditions, which complicate the analysis of phenomena that change decisions made by a country, to abstractly establish comparisons that categorize a specific organization as better or worse.

It is worth considering that value judgments are made all the time. We are not neutral subjects, and science does not guarantee neutrality. In our process of knowledge production, we are motivated by interests that operate on the definition of our objects of study, on our interpretation of phenomena and the result we desire.

In this way, we made a comparative study not to produce a ranking that shows what is the best or worst way of committing to implement the right to education for people with disabilities, but rather to understand, through different political, cultural and social contexts, the ways in which such rights were brought forth in the law and in public policy design.

These issues refer to the perspective of social history or sociological history, where history and sociology attempt to benefit from concepts and methodological instruments, which include the comparative method. However, we must distinguish between comparativism, which honors social phenomena and turns them into quantities, and the comparative methods, which are based on history and preserve local and secular specificity of those phenomena, and sees them in relations established with other phenomena, under the action of individual and collective subjects. A review of existing studies on political science and on the comparative method show a starting point that is similar to that of sociology, first in the sense that political and social facts are not produced in a laboratory, and second by the acknowledgement of the plurality and diversity of facts and solutions, emphasizing the differences and specificity of situations. General political and economic factors, such as the decolonization of several countries, have brought new political contexts to the scene, and have led to new studies, and to surpassing casual and mechanistic relations in favor of a historical interpretive sociology. This has also been criticized for the limits of a comparison that is more interpretive than explanatory (Franco, 2000, p.214, our translation)⁴.

⁴ "Estas questões remetem à perspectiva da história social ou da sociologia histórica, onde história e sociologia buscam beneficiar-se de conceitos e instrumentos metodológicos, entre os quais o método comparativo. No entanto, há que se distinguir o comparativismo que homogeneiza os fenômenos sociais, transformando-os em quantidades, e o método comparativo que tem a história como base e preserva a especificidade local e temporal dos mesmos fenômenos e visualiza-os nas relações que estabelecem com outros fenômenos, sob a ação de sujeitos individuais e coletivos. Educação & Sociedade, ano XXI, no 224 72, Agosto/00 A revisão das referências disponíveis sobre a ciência política e o método comparativo mostram um ponto de partida semelhante ao da sociologia, em primeiro lugar no sentido de que os fatos políticos e sociais não se produzem em laboratório; em segundo lugar, pelo reconhecimento da pluralidade e da diversidade dos fatos e soluções, pondo em relevo as diferenças e a especificidade dos acontecimentos. Fatores de ordem política e econômica mais geral, como a descolonização de vários países, trouxeram à cena novos contextos políticos, levaram a novos estudos e à superação das relações causais mecanicistas, em favor de uma sociologia histórica interpretativa. Esta também tem recebido críticas no sentido dos limites de uma comparação que é mais interpretativa do que explicativa".

Hence, it can be stated that this is a study that attempts to understand distinct paths produced in Brazil and in the United States of America for the implementation of a guarantee to rights for people with disabilities, especially the right to Education.

For a comprehensive study of the phenomena in question, a documental analysis was used (Lüdke & André, 1986) to question the set of documents of each country about what they reveal on the guarantee of rights to people with disabilities, and on the concept of Education for this portion of the population.

Results and Discussion

In order to fully understand the context of modern special education policy, it is important to consider the history of disability policies and disability rights advances not just for children, but across the lifespan. Disability studies focuses not on the diagnoses and treatment but rather on understanding and disability experience from the perspective of the disabled person. This is also important for special educators to consider, as sometimes this is a view at odds with the views of educators both historically and in modern times. Disability studies considers disability not originating in physiological difference, but rather in the socio-cultural and environmental structures that either support or create barriers for people who have such differences (Linton, 1998). Thus we will provide a summary of the history of disability rights in both countries, noting areas of particular relevance to modern special education.

The history of special education in both countries will be the element used for analysis of the concept of people with disabilities in different moments in history, as well as of the social solutions found to serve this part of the population.

According to Palacios (2008), the models for needlessness (by death and marginalization), rehabilitation and the social models originated in historical times and in specific societies. However, one did not prevail over the other, nor cease to exist presently. On the contrary, what can be seen is their coexistence within the same society, and often in the same policy or law. It is about ways of conceiving disability and the people who live with this condition and coexist, and consequently produce contradictions that constitute the fight for change and the implementation of laws. Therefore, this study does not intend to describe different models, which originated in diverse historical contexts, but rather consider the effect that these models have on modern productions of social participation of people with disabilities proposed in both countries studied.

A brief history of disability rights in the United States of America

Education for disabled children in the United States of America was not guaranteed until well into the 20th century. Prior to the 1975 Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and the Education for all Handicapped Children Act (EHA), disabled children did not have the right to attend public school in the United States of America. Some schools accepted them, or even provided tutors for children in their homes, but they were under no obligation to do so. This changed after 1975, when schools were mandated to accept and educate all children in their district (Wiegerink & Pelosi, 1979). EHA was renewed and its name changed to the Individuals with Disabilities Education Assistance Act (IDEA) in 1990.

Prior to 1975 the only specialized educational option for disabled children was private schools. Private schools for both blind

and DEAF students were opened in the USA and internationally starting in the 19th century. These residential settings, though sometimes oppressive (for example, some refused to teach DEAF students sign language) were sites for the development of rich cultural traditions and community formation. Generally, both deaf and blind students valued the relationships with students and teachers formed in these institutions. These close-knit communities also lead to the development of Deaf and disability activism to advocate for policy changes, fight stigma and the emphasize Deaf and disability culture (Koestler, 2004; Van Cleve, 2007).

Starting in the 19th century specialists in “Idiots, Imbeciles, and Morons” also worked to develop educational options for children with these diagnoses. Residential schools were formed with the goal of education, rehabilitation and then a return to their communities. Unfortunately, the communities did not want the intellectually disabled adults, and so residential institutions established in the 19th century became not places to educate children, but by the 20th century were overcrowded warehouses filled both children and adults (Trent, 1995). Eugenics era social policy of the early 20th century also viewed such populations as dangerous to both social morality and the gene pool and better kept apart (Goddard, 1912). These institutions were plagued with scandals, as the inhabitants were often experienced physical and sexual violence, or were subject to diseases of crowded conditions such as Hepatitis. Controlling the sexuality of the institutionalized adults was of central importance to institution administrators, but failing that, sterilization could at least ensure against pregnancy (Cohen, 2016).

When institutions became more crowded, and negative eugenics policies were enacted of sterilization and release of individuals capable to

supporting themselves in the community. Such people sometimes became “wards” of families of high social standing who used them as unpaid servants. Others were able to get paying jobs, marry, and carry on with life, often unaware they had been sterilized, and never knowing why they could not have children (Cohen, 2016). Due to scandals, such as Geraldo Rivera’s 1972 exposé of the deplorable conditions at the Willowbrook Institution, in Staten Island New York (Rivera, 1972), a movement to move institutionalized citizens into the community began, resulting in the closure of hundreds of facilities across the country and the establishment of the modern community-based service systems for adults with developmental disability (Carey, 2009; Levinson, 2010).

Section 504 of the 1973 Rehabilitation Act was drafted to address civil rights for disabled people (Scotch, 2001). It stated:

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service (United States of America, 1973).

Any entity receiving federal funding were barred from denying or discriminating against disabled people in contexts such as education, public services, or employment. However, the law had still not been implemented in 1977 at which time disability rights protesters lead by activist Judy Heumann occupied a federal office building in San Francisco for 25 days. This was a crucial moment in the formation of US disability rights activism (Fleischer & Zames, 2011). Also

in 1972, Ed Roberts started the independent living movement by the opening of the first Independent Living Center in Berkeley California. By 2016 there were hundreds of independent living centers in every US state and internationally, including Brazil (Scotch, 2001). The mission of Independent living centers in the United States of America, is peer support, advocacy, and information and referral. In 1962 Ed Roberts had fought resistance to insist on his right to a university education at Berkeley and to his right to live on campus like any other student (Fleisher & Zames, 2011; Schotch, 2001).

In 1975 the Atlantis Community in Denver Colorado formed by Glenn Kopp to protest the lack of accessible transportation. Beginning in 1978, they engaged in protest actions to stop public transit buses to bring attention to the lack of disability access to these public services (Scotch, 2001). In 1983 Atlantis activists formed a national organization called American Disabled for Accessible Public Transportation and the protests continued nationally for decades to come, expanding beyond transportation to include advocating for community based personal assistance services and protests against long-term institutionalization of disabled people in hospitals, residential facilities and nursing homes (Scotch, 2001).

The organization also demonstrated in favor of the Americans with Disabilities Act (ADA) which was passed in 1990. In a far stronger way than Section 504 of the 1973 Rehabilitation Act, the ADA promoted the rights of disabled Americans to accessible housing, public services, communication, transportation and employment (Fleisher & Zames, 2011). With the passage of this law, these rights were expanded not just to those places receiving federal funding but were applied to all businesses including private colleges and universities that had continued to

ban disabled students, using the fact that they did not receive federal funding as an excuse (Fleisher & Zames, 2011). Telephone services now were required to provide services for Deaf customers. Television and film had to provide captioning, and employers and businesses of all sorts could not discriminate against disabled job applicants and customers or faced stiff penalties.

With the Olmstead Decision of 1999, the USA Supreme Court upheld the right of disabled people outlined in the ADA to live in the "least restrictive environment". It confirmed that disabled people should be allowed to living in the community with proper supports funded to the same extent as funding would be provided to support them in long term care facilities such as nursing homes (Rothstein & Mcginley, 2010). As a result, transition programs were put into place across the United States of America to help individuals who wished to live in the community leave nursing homes and other long term care facilities.

Great strides have been made for disability rights, however there is still much discrimination, segregation and institutionalization that continues to exist in 2016. Sexual oppression of disabled people is a major source of concern in current disability activism (Kulick & Rydstrom, 2015). The inequalities that exist at the intersection of disability, race, gender and sexuality is a major concern of disability justice activism (Erevelles, 2014; Grace, 2013; Kafer, 2013; Mingus, 2010). Special education has made tremendous strides, but supports available to children still vary dramatically according to region and with documented disparities along lines of race, class, and gender (Erevelles, 2014). Despite the Olmstead decision, many disabled people continue to be unwillingly institutionalized in hospitals or nursing homes because there are not enough resources for the supports people

need, especially those with complex medical conditions that require complicated technologies or constant nursing assistance (Block *et al.*, 2016). Disabled people are also disproportionately represented in prisons. The USA prison system constitutes the largest psychiatric hospital facility in the United States of America (Ben-Moshe *et al.*, 2014). People experience hate crimes due to continued prejudice against disabled people – this may range from hurtful words to acts of violence and even murder (Shah & Giannasi, 2015). Violent acts against disabled children in schools are reported in the news regularly, and research has shown that half of police killings in the United States of America are against disabled people of color (Perry & Carter-Long, 2016). These are the future directions of disability rights activism and disability studies scholarship in the United States of America, especially in the era of Trump's political rise to the presidency.

A brief history of disability rights in Brazil

The first government initiative to create a narrative about the history of disability rights movements was in 2010, after the inclusive approach was adopted as the ethical and political guidelines for public policies that focus on this section of the population. This is when the Department of Empowerment of Persons with Disabilities (*Secretaria Nacional de Promoção dos Direitos das Pessoas com Deficiência*), which was added to the Department of Human Rights (*Secretaria de Direitos Humanos*), took the initiative to make a movie and write a book about the topic. In this way, the public was shown the many people who were directly involved with organizing the movements of people with disabilities in *Brasil*.

This study does not intend to review the entire period from 1970 until today, since there are high quality books available on the topic (Brasil, 2010; Crespo, 2012). Only a few historical aspects will be presented in order to help understand the importance of the discussion of persons with disability in the fight for social rights and the formulas that resulted in the right to inclusive Education.

Until the 1950s in Brazil, the organizations that prevailed aimed at people with disabilities, and they were fundamentally philanthropic and welfarist. Thus, the lives of this part of the population were limited to family and community environments only. In the 1960s and 1970s, the number of organizations grew, and they were created and managed by (not for) people with disabilities, increasing the importance given to people with disabilities in relation to the discussion and definition of their social rights. This period is known as "associativismo"⁵, when institutions for the blind, the deaf, and people with disabilities, as well as sports associations were consolidated.

The first "associativistas" organizations of people with disabilities did not have their own offices, statutes or any other formal elements. They were initiatives that focused on mutual help and did not have a defined political purpose, but they created areas for interaction, where people could discover and discuss problems they had in common. As a result, a political action on behalf of their human rights was initiated. In the end of the 1970s, the movement gained visibility, and from then on people with disabilities became active political agents searching to transform society. Their desire to become key political figures led

⁵ We call it "associativismo" to refer organizations created and run by disabled people themselves, based on solidarity between peers, aiming at mutual assistance and survival, without a prioritized political objective.

to national mobilization (Brasil, 2010, p.34, our translation)⁶.

In the early 1980s, during the final period of military dictatorship, people with disabilities, together with other social rights movements, improved their organizational structures, whereby associations went from being an organization that merely provided services and mutual help to important centers for debate and organization of political figures, gaining attention in the streets and the media. Undoubtedly, these transformations gained momentum because the United Nations Organization (ONU) declared 1981 as the international year for people with disabilities. During this time there was the Pro-National Federation Alliance (*Coalizão Pró-Federação Nacional*), the First National Conference of People with Disabilities in 1998 (*I Encontro Nacional de Entidades de Pessoas Deficientes*), the Second Brazilian Congress of Social Reintegration in 1980 (*II Congresso Brasileiro de Reintegração Social*), the Second National Conference of Organizations of People with Disabilities (*II Encontro Nacional de Entidades de Pessoas Deficientes*) and the First Brazilian Congress of People with Disabilities in 1981 (*I Congresso Brasileiro de Pessoas Deficientes*) and the Third National Conference of Organizations of People with Disabilities in 1982 (*III Encontro Nacional de Entidades de Pessoas Deficientes*)⁷. As a result, in the Third Meeting the movement was reorganization by types of disabilities:

The plenary decision in the Third National Conference of People with Disabilities

caused a rearrangement in the movement of the people with disabilities in Brazil and the definition of a new political strategy: national organization by type of disability. Although people with disabilities made an effort to continue discussing common issues, the proposal made by the Brazilian Counsel of Organizations of People with Disabilities did not become effective. The initial proposal to form one movement was lost due to the difficulty to meet specific needs of each area of disability manifestation at the time [...] (Brasil, 2010, 54, our translation)⁸.

The separation by area of disability reflected the diversity of aspirations that existed in the movement. Specificities of each group, the difficulties to reach a consensus, above all in leadership practice, led the movement to take another path. However, this decision did not divide the other movements; there was a change because of the informed decisions made during discussions with people with disabilities, a reflection of the movements' own internal conflicts. The strategy of separating by type of disability aimed at better addressing the specificities of each one, without excluding the joint action for addressing general issues.

The transformation involved the disassociation of the National Conferences, which led to many battles by different movements that had distinct organizational capabilities and forms of social expression. There is a system in which the same social right is not attained for all the people with disabilities, but for a par-

⁶ "As primeiras organizações associativistas de pessoas com deficiência não tinham sede própria, estatuto ou qualquer outro elemento formal. Eram iniciativas que visavam o auxílio mútuo e não possuíam objetivo político definido, mas criaram espaços de convivência entre os pares, onde as dificuldades comuns poderiam ser reconhecidas e debatidas. Essa aproximação desencadeou um processo da ação política em prol de seus direitos humanos. No final dos anos 1970, o movimento ganhou visibilidade, e, a partir daí, as pessoas com deficiência tornaram-se ativos agentes políticos na busca por transformação da sociedade. O desejo de serem protagonistas políticos motivou uma mobilização nacional".

⁷ With respect to historical processes, we used expressions to designate people with disabilities as they were at the time.

⁸ "A decisão da plenária do 3º Encontro Nacional de Entidades de Pessoas Deficientes provocou um rearranjo no movimento das pessoas com deficiência no Brasil e a definição de uma nova estratégia política: organização nacional por tipo de deficiência. Embora as pessoas com deficiência tenham evidenciado esforços para continuar discutindo questões comuns, a proposta do Conselho Brasileiro de Entidades de Pessoas Deficientes não se efetivou. O propósito inicial de formar um movimento único se perdeu com a dificuldade de atender, naquele momento, às necessidades específicas de cada área de manifestação da deficiência".

ticular movement. Similarly, there are different perspectives on the way in which a right is put into practice, depending on the specific group of people with disabilities discussing them. An example of this polyphony is the implementation of the right to Education. As will be seen in the next section, there are sectors of social movements and people with disabilities that organize their pleas so that Education is offered in typical classes in typical schools, while there are sectors that demand segregated schools.

Only in 2006, with the First National Conference of Rights for People for Disabilities, it was possible to resume discussion and political organization, by claiming rights and definition of political guidelines jointly. Other conferences took place in 2008, 2012, and the 2016 conference was integrated with the set of measures from the Human Rights National Conference. Such venues for discussion and democratic dispute were implemented with participation from the disability rights movement, organizations, public policy makers and government representatives. Where education right is concerned, the following approved guideline is important:

Promote educational policies for people with disabilities, including a quota system in public universities, guaranteeing the implementation of specialized educational services in multifunctional classrooms, bilingual education for deaf students in bilingual classrooms or schools with specialized professionals who work with students according to their disability, global developmental disorder, or talent, as well as stimulate and promote literacy programs and education for the elderly with

disabilities, including issues of gender, race, sexual and generational diversity (Brasil, 2016, our translation)⁹.

It is important to note that these initiatives of communication and exchange between the different movements came from the Human Rights Department (*Secretaria de Direitos Humanos*) over the past fifteen years. Not only the process of preparing conferences, which included municipal, regional, state and national stages, but also the documents that were drawn up discuss different social agents with different interests, creating possibility for dialogue and production of common guidelines. During the Temer administration, the Special Department of Rights for People with Disabilities (*Secretaria Especial de Direitos das pessoas com Deficiência*) became part of the Ministry of Justice and Citizenship (*Ministério da Justiça e Cidadania*), which may decrease the extent to which the advancement of the rights for people with disabilities is related to the guarantee of human rights, the acknowledgement of a person's dignity. Implementing human rights depends on the acknowledgement of the prominence of people with disabilities in the discussion, proposition, and implementation of public policies that will guarantee rights. After all, as coined in the 1990s: nothing about us without us.

Special education services in United States of America

Current educational public policy for people with disabilities in the United States of America is regulated by the Individuals with Disabilities Education Improvement Act (United

⁹ "Fomentar políticas de educação para pessoas com deficiência, incluindo a reserva de vagas em universidades públicas, garantindo a implementação do atendimento educacional especializado em salas de recursos multifuncionais, educação bilíngue para pessoas surdas em classes ou escolas bilíngues, com profissionais especializados para atender a todos/as os/as alunos/as de acordo com sua deficiência, transtornos globais do desenvolvimento e altas habilidades/superdotação, bem como estimular e promover programas de alfabetização e de ingresso ao ensino da pessoa idosa com deficiência, contemplando as questões de gênero, raça, diversidade sexual e geracional".

States of America, 2004). This law ensures that more than 6.5 million eligible children, infants and youth with disabilities in the United States of America will receive services. IDEA legislates how early intervention, special education and related services are provided by states and public agencies. Special Education in the United States of America is offered to a:

[...] child with a disability who “means a child evaluated in accordance with Sec. Sec. 300.304 through 300.311 as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as “emotional disturbance”), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services” (United States of America, 2004, online).

The diagnosis and processing of a child experiencing developmental delays for the special education services, according to Idea, are “defined by the State and measured by appropriate diagnostic instruments and procedures, in 1 or more of the following areas: physical development; cognitive development; communication development; social or emotional development; or adaptive development and, who, by reason there of, needs special education and related services” (United States of America, 2004, online).

Although the document, in one of its sections, defines the disabilities included in the law and requiring the care of specialists, it does not specify the ramifications of the diagnosis for educational purposes, for example, by discussing the procedures for student referrals to the services, or the implications of evaluation and methodology in their academic curriculums.

In 2006 there was an alteration in the law regarding the special education referral process.

[This law] has been changed to require the eligibility group for children suspected of having Specific Learning Disability (SLD) to include the child’s parents and a team of qualified professionals, which must include the child’s regular teacher (or if the child does not have a regular teacher, a regular classroom teacher qualified to teach a child of his or her age) or for a child of less than school age, an individual qualified by the State Education Agency (SEA) to teach a child of his or her age; and at least one person qualified to conduct individual diagnostic examinations of children, such as a school psychologist, speech language pathologist, or remedial reading teacher (United States of America, 2006, p.2).

The right to education for people with disabilities was legally established in 1975 through the Education for All Handicapped Children Act (Public Law nº 94142). Before this law, education for people with disabilities was not guaranteed in the public education system. Thus, families and students with disabilities who were not accepted in the public system were forced to seek private or philanthropic education services. Aside rare cases where school districts or teachers chose to take on the extra responsibilities, the few students with disabilities who were matriculated in the public system did not receive specialized care according to their needs, for that did not exist as a systemic provision at the time (United States of America, 2004).

Discrimination against people with disabilities profoundly influenced the history of education in the United States of America. The first three principles of Idea - zero rejection, appropriate education, restrictive environment - are connected to this history of discrimination in public schools (Skrtic, 2014). The principle of a ‘non-discriminatory evaluation’ is based on ethno-

racial problems and social class. When comparing the diagnoses of poor black students with white middle class students, many authors show that the former were more frequently diagnosed with stigmatizing disabilities, such as mental retardation and emotional problems (Skrtic, 2014; United States of America, 2004).

Even though legislation points out the problems and states its sociohistorical determination, little has advanced in producing referral solutions. Skrtic (2014, p.178) classifies such legal aspect as "in the best-case scenario, indeterminate, institutionally mediated, and ineffective, especially for children and families that are economically disadvantaged and culturally diverse. The problems that have been pointed out continue to occur as long as there is no proposal for change to prevent the repetition of this mindset".

Among other rights, access to Education and specialized educational service for students with disabilities, as previously mentioned, was the result of a political battle in the country, where civil rights and disabilities rights activists and scholars demanded democratic solutions for access to the public educational system in the country (Skrtic, 2014). In a 2004 law, public authorities stated that around thirty years of research and educational experience expresses "Strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home" (United States of America, 2004, online).

The federal document does not effectively point in the direction of creating policies that promote equality and rights. It is up to the state policies whether they will reinforce and increase actions by the state that fight for equal access to Education or not. Hence, it is possible to affirm that there is no Special Education policy outlined

establishing guidelines and modes of action for all states in the United States of America.

According to Skrtic (2014), national laws makes the family responsible for guaranteeing the right to Education. However, it does not outline this policy with referral procedures and instructions for educational service.

New York state laws

Some aspects of public educational policy in New York will be mentioned in order to comprehend how the state is organized in terms of federal law in the United States of America. As already mentioned, the states are responsible for implementing public policy, with autonomy to remove or propose changes and additions.

Educational Department specially designed individualized or group instruction or special services or programs, as defined in subdivision 2 of section 4401 of the Education Law, and special transportation, provided at no cost to the parent, to meet the unique needs of students with disabilities. (1) Such instruction includes but is not limited to that conducted in classrooms, homes, hospitals, institutions and in other settings. (2) Such instruction includes specially designed instruction in physical education, including adapted physical education (New York, 2016, online).

The state of New York uses Committees on Special Education (CSE) and Committee on preschool special Education (CPSE) to implement federal special education policy. These committees are multidisciplinary teams that include family members or guardians, regular and special education teachers, an educational psychologist, a knowledgeable representative of the school district, someone to interpret any evaluations that were administered, a school physician, (on request), and people who might

have insight or special knowledge of the student (New York, 2015, online). There are additional personnel added for Preschools, as it is necessary “for a child in transition to have, from early intervention, programs and services, at the request of the parent, the appropriate professional designated by the agency that has been charged with the responsibility for the preschool child; and a representative of the municipality of the preschool child’s residence”. These committees can represent progress, for they remove the responsibility placed solely on family members, including a team of professionals to manage the referral process up to the implementation of an individualized educational plan. This measure shifts the issue of making decisions about education for people with disabilities away from the private sphere, and elevates it to a collaborative plane involving school staff.

The student suspected of having a disability shall be referred in writing to the chairperson of the district’s committee on special education. After the referral has been accepted, the student is evaluated by the Committees on Special Education (CSE), which shall include the student’s regular education teacher and at least one person qualified to conduct individual diagnostic examinations of students (such as a school psychologist, teacher of speech and language disabilities, speech/language pathologist or reading teacher). This evaluation or reevaluation is made according to a physical examination, an individual psychological evaluation, a social history, an observation of the student in the student’s learning environment and other “appropriate assessments or evaluations” (New York, 2016, online).

If it has been determined that the student is eligible for special education services, the committee shall develop an Individualized Education Program (IEP) which “must consider the

results of the initial or most recent evaluation; the student’s strengths; the concerns of the parents for enhancing the education of their child; the academic, developmental and functional needs of the student, including, as appropriate, the results of the student’s performance on any general State or district-wide assessment programs” (New York, 2016, online).

The educational plan considers the existence of a special class according to similarities, and respecting rules inserted in the law that refer to number of students and staff (class size) and another aspect, namely severe deficiency. It is worth noting that in the state legislation the student evaluation may result in referral to special classes. In this way, Special Education continues to offer possibilities for education, from isolated actions made by schools in relation to one student, without causing any changes in the way the educational system is considered. Thus, we can hypothesize that the proposal is organized according to the very inclusive integrationist ideology, finding impediment in the disability of a student, and not in the social barriers imposing on a dignified life, as proposed by the International Convention on Rights for People with Disabilities (Brasil, 2008a).

Special education policy in Brazil

The Special Education policy in Brazil is currently regulated by the National Policy and Special Education Aimed at Inclusive Education document, 2008, and by decrees and resolutions that complement it, specifying aspects of specialized educational service and specific education sectors of the target group. It is worth noting that such federal policy governs all the educational systems and types of education, public or private, at municipal, state or federal level. This study will present some of the principles that rule the actual policy.

The document, which is advanced in relation to previous documents, including the Federal Constitution, expresses the adoption of the inclusive approach in Special Education, using typical classrooms in typical schools as the location for all types of students, indistinctly, to exercise of the right Education. Attendance at segregated educational locations that substitute typical classrooms is an exception, and it must occur by means of evaluation by educational teams and systematic attempts at educating in a typical classroom. It is also worth mentioning the adaptations that were made, which simplify the school curriculum and deplete the educational coverage. To substitute the common proposal for the curricular adaptation in the 1990s and beginning of 2000s, the document aims to produce educational resources that support learning, guaranteeing full access to the curriculum. These aspects prove the concept that possible difficulties that students have throughout the educational process do not occur according to organic, mental or functional conditions of the subjects, but according to barriers that were built, historically, by the school in order to enjoy the heritage that has accumulated throughout civilization.

In Brazil, students with disabilities or global development disorders, and gifted and talented students are considered target groups of Special Education (Brasil, 2008b). In this respect, it is necessary to consider that the federal law from 2010 establishing that people diagnosed with autistic spectrum disorders must be considered people with disabilities, to guarantee their rights (Brasil, 2014a).

Also in 2014, the Ministry of Education edited Technical Note nº 4 (Brasil, 2014b), to explain that there must not be any overlap between the rights to Health and Education, thus deconstructing the idea that an individual should first be submitted to a diagnostic process, and only then have access to Special Education. Despite retaining the nosological characteristics of Special Education target groups, the above-mentioned Technical Note emphasizes the pedagogical function of the school, without conforming to clinical aspects:

To carry out the AEE, the teacher working in this field must elaborate a Specialized Education Service Plan - AEE Plan, a supporting document stating that the school, institutionally, acknowledges the enrollment of students of the special education target group in a public school, and secures the service of their educational specificities. In this legal bond, a medical certificate (clinical diagnosis) cannot be indispensable for a student with disabilities, global development disorders, and gifted and talented students, since the AEE is characterized as a pedagogical rather than clinical service. During the case study, the first step in elaborating the AEE Plan, the AEE teacher may, if necessary, work together with professionals of the health area, making the medical certificate, in this case, an attachment of the AEE Plan. Therefore, it is not a mandatory document, but rather a complementary one, when the school deems it necessary. It is important that the right of education for people with disabilities is not hampered by the demand of a medical certificate (Brasil, 2014b, online, our translation)¹⁰.

¹⁰ "Para realizar o AEE, cabe ao professor que atua nesta área, elaborar o Plano de Atendimento Educacional Especializado - Plano de AEE, documento comprobatório de que a escola, institucionalmente, reconhece a matrícula do estudante público alvo da educação especial e assegura o atendimento de suas especificidades educacionais. Neste liame não se pode considerar imprescindível a apresentação de laudo médico (diagnóstico clínico) por parte do aluno com deficiência, transtornos globais do desenvolvimento ou altas habilidades/superdotação, uma vez que o AEE caracteriza-se por atendimento pedagógico e não clínico. Durante o estudo de caso, primeira etapa da elaboração do Plano de AEE, se for necessário, o professor do AEE, poderá articular-se com profissionais da área da saúde, tornando-se o laudo médico, neste caso, um documento anexo ao Plano de AEE. Por isso, não se trata de documento obrigatório, mas, complementar, quando a escola julgar necessário. O importante é que o direito das pessoas com deficiência à educação não poderá ser cerceado pela exigência de laudo médico".

The organization of specialized educational services is based on two documents (Brasil, 2009; 2011) that establish three conditions that guarantee the right to Education: availability of classrooms with multifunctional resources, which are complementary spaces rather than classroom substitutes; the continual training of general and specialized teachers; collaborative work between the normal classroom teacher and the multifunctional classroom teacher to create individualized educational plans that serve the educational needs of the students.

Hence, each educational system is organized in a way that allows for the implementation of these guidelines, organizing the availability of the resources classrooms in the reference schools or pedagogical service centers. Similarly, it is up to each system to provide support strategies for faculty members to elaborate political-educational projects with an inclusive approach, as well as systemize the continual training for general and specialized faculty members.

Undoubtedly, it is a significant challenge to undertake a transformation of a group of educational systems that serve over 53 million primary school students and a radical change in the educational project for over 5 million people with disabilities, global development disorders, and gifted and talented people that go to school. There is an exclusionary tradition in our schools, based mainly on innate concepts of education and development, we just have to notice the innumerable times we have been told that such and such a student has talent (or not) for a school. Therefore, the current Special Education policy must be considered an important strategy of resistance to the persistent and intense culture of stigmatization that forms the thoughts and actions of our communities, educators and public policy makers.

Final Considerations

As we said, this is a study that attempts to understand distinct paths produced in Brazil and in the United States of America for the implementation of a guarantee to rights for people with disabilities, especially the right to Education.

In these concluding remarks, some aspects of the fight to guarantee rights for people with disabilities can be highlighted, with emphasis on the right to Education.

In relation to the organization of the movement for people with disabilities for their rights, not only Brazil but also the (United State of America) has a history of recent social mobilization which took place after long periods in which a vision of welfarism prevailed, often aimed at rehabilitation processes. Similarly, it can be stated that in both countries the guarantee of social rights has advanced by pressure of the social movements that were organized, which propelled the transformation in different levels, including (a) epistemological, as the concept of disability suffered significant changes; (b) legal, in that changes in the way guidelines establishing the guarantee of rights were altered; (c) political, given the reorganizations made by the governments of both countries, so that services could be implemented with new concepts and guidelines and social participation of people with disabilities.

In the USA, new movements made by people with disabilities continue to influence public policies and laws, mainly through social mobilization. In Brazil, the fragmentation of different movements due to divisions along lines of different disabilities led to a scenario with less social mobilization, becoming dependent on actions of the state that bring these groups together to form a scenario of discussion and

collaborative deliberation, like the Convention on Rights for People with Disabilities.

Another aspect that important to highlight refers to the reorganization of the Education policy. In both countries, it is possible to observe significant changes in the beginning of the 19th century, aiming to make advances in adopting an inclusive perspective. The right to universal education is recognized, including the population with disabilities. As far as the way in which Special Education availability is made, it is worth noting the different decisions made in Brazil and the USA. There are differences related to the idea of inclusion that were adopted by each country, where political and legal organization in both countries differ significantly. In Brazil, federal law serves as guidelines for the federal, state and municipal systems, public and private, while in the USA federal guidelines are characterized as more general, allowing each entity of the federation to organize itself independently. In Brazil, the inclusive approach in Special Education results in education availability, preferably in typical classrooms and schools, with specialized educational service support, while in the USA emphasis is on the family deciding which is the most adequate approach to be used by the student with disability. In the USA, according to federal law the responsibility of deciding which educational project will be tested and which treatment will be used by the student lies with the family. In Brazil, according to national policy, this decision is made by teachers, based on the contact they have with the student in educational situations.

The state of New York, which was used in this study as an example of policy implementation based on federal guidelines, comprehends that the choice of the educational project and the equipment must be a result of collaborative work between the family and education professionals (teachers, educational psychologists and

administrators) and health professionals who are responsible for student services.

The understanding in both countries of the Special Education target group is based on nosological categories, revealing the persistent inheritance of the biomedical model in education. Yet, in the USA, the target group, as described previously, is characterized as a person with differences in physical development; cognitive development; communication development; social or emotional development; or adaptive development and, who, by reason thereof, needs special education and related services. These conditions must be confirmed through diagnosis made with specific evaluation instruments. In other words, a student must go through a biomedical diagnostic procedure as prerequisite to enter the Special Education system. However, in Brazil, as previously mentioned, the target group is made up of people with disabilities or global development disorder and people with special gifts or talents, a profile that is a result of a study made by a group teachers based on their contact with the student in an educational environment. To complement this study, is it recommended that health teams be involved with the student and the student's family's care.

Finally, it is worth noting that when decision-making procedures about an educational project and type of service are mentioned, both countries did not consider the movements of people with disabilities as prominent representatives to be included in the decision-making process. Family members and professionals are consulted, but not representatives of the people with disabilities movement, which validates the production of policies for the people and not with the people with disability. In this way, people with disabilities are pushed away from the commitment of acknowledging their intrinsic dignity - that any human being must have - and from the respect

for the autonomy of social movements, which have repeated for a few decades now: “nothing about us without us”. With these thoughts, we hope to contribute to the elaboration of public policies and academic research based on this ethical and political principle.

Contributors

C.B. Angelucci idealized the project, coordinated the actions and was responsible for writing on the history of the social movement of people with disabilities in Brazil, as well as the characterization of Special Education in Brazil. P. Block was responsible for organizing the writing about the social movement of people with disabilities in the United States of America, as well as subsidizing graduation student L.C. Santos in the production on the characterization of Special Education in the United States of America. The three authors were responsible for the elaboration of the final considerations.

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