chapter 8

Disability Studies in Inclusive Education

Connecting schools, families and communities, and developing an inclusive school

Brian Watermeyer & Rose-Anne Reynolds

Chapter learning outcomes

After completing this chapter, you will be able to:

- Explore experiences of childhood disability in families.
- Describe an ecosystemic model of inclusive education.
- Explore inclusion and exclusion as connected processes of a mainstream school on its journey to becoming an inclusive school.
- Identify the role of the children, teachers, parents, school leadership and the broader community in the process of creating an inclusive school.

Preparatory activities

WATCH: Everyone a changemaker: The story of Pinelands North

Creator: Ashoka
Date: 2015
Duration: 7 minutes

Watch the seven-minute video. Don't rush. Watch it more than once and look at different aspects of the video the second time around. Reflect on the roles of the children, teachers, parents and school leadership, and how each of these role-players contribute to processes of inclusion (and exclusion). Consider the kinds of decisions the school principal had to make to ensure that a child with a disability could join the school as a pupil – and subsequently many more children with disabilities and varied needs. What is the ethos of the school? What is valued? What do you notice about the relationships between the children and the staff? How are animals included in the life of the school? How is learning support best extended to include the needs of the children at the school? Record your responses.

WATCH: Disability, poverty and the family

Creator: Brian Watermeyer
Date: 2021
Duration: 20 minutes

READ: Guidelines for responding to learning diversity in the classroom through CAPS

Author: Department of Basic Education
Year: 2011
Estimated reading time: 1 hour
File size: 1.53 MB

CASE STUDY: Disability, structural disadvantage and the family

Jenna-Lee (JL) is 17 and lives with her mother (Mo) and siblings, Ursula (21) and Theo (16), in Atlantis, a low-income community an hour from Cape Town. JL has a severe physical and speech impairment, resulting from cerebral palsy following an acute neurological illness as an infant. JL was hospitalised for six months, undergoing several brain surgeries. This time was unbearable for the family, who received very little support.

JL's father, Fa's (56) unemployment led to divorcing Mo (52) and estrangement from his children. Mo believes Fa's inability to cope with JL's disability caused the divorce. JL worries that this is true. Mo supports her children by working part-time at an NGO that supports families of children with disabilities.

For years after the divorce, Mo and the children struggled with housing, first living with family and then in small rented spaces, sometimes moving to escape negative attitudes towards JL expressed by neighbours and co-habitants. During this time, Ursula feared for JL's safety "as a girl".

JL's care dependency grant stopped unexpectedly, leaving Mo struggling to feed the family. Mo repeatedly visited the offices of the South African Social Security Agency (SASSA), which administers the Social Relief of Distress Grant, only to have the issue dismissed by SASSA agents.

JL receives physiotherapy fortnightly at Groote Schuur Hospital in Cape Town. To attend, Mo takes a day's leave, spending most of the weekly budget on taxi fare. State services will not provide the specialised wheelchair JL needs which costs R30 000 and the family has no medical aid.

JL spent two years at a school for children with physical impairments but was asked to leave as the school considered her incapable of learning. After waiting two years, JL flourished at a school for children with cerebral palsy, until she could no longer physically access the school bus. Taxi transport with a wheelchair was traumatic and unsustainable. After another wait, JL enrolled at a school for children with learning disabilities, where she is bullied. Mo worries that no teaching occurs.

Ursula is overwhelmed and frustrated by the full-time responsibility of caring for JL. Theo ran away from home, works for a drug dealer and is severely depressed. The continuous challenges depress Mo.

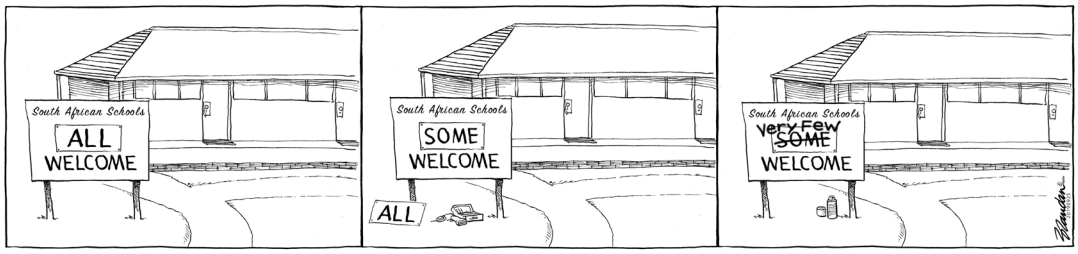
Respond to the following four questions and share your responses with one of your peers:

1. List as many of the difficulties facing this family as you can, briefly describing each.
2. Think about the possible knock-on effects of these difficulties, including how some issues exacerbate others.
3. What supports would be of value to this family – in the past, currently and into the future? Think of referral options to address these needs.
4. What role could the schooling system play in supporting and empowering families in circumstances such as these? How might you, as a teacher, offer help to this family?

ACTIVITY

Estimated time: 20 minutes

Using the cartoon below to inform your choices, comment on which categories of exclusion make very few schools accessible to children in South Africa, especially children with disabilities. The COVID-19 pandemic has made schooling very different around the world and in South Africa; think about how the pandemic and COVID-19 protocols that were introduced and enforced in schools have contributed to categories of exclusion.



(Cartoon by Brandan Reynolds, used with permission)

Introduction

In this chapter, we focus on the question of how to develop schools into places of real inclusion through promoting support and cooperation among important role-players in the education of a child with a disability. Parents and families are crucially important and must be carefully thought about here, as they cope with the demands of caring for their child along with a range of other possible stressors, such as poverty. Creating trusting and sustained alliances between families, teachers, school leadership and others involved in supporting education, such as therapists, is our goal. The lived experience of a schoolchild does, however, have many layers, all of which may be a support or a barrier to full participation.

We will begin by considering the experiences of families of children with disabilities, focusing on their many challenges and finding ways to support them as key partners in promoting inclusion.

After that, we will move on to a method for systematically thinking about the environment of the child, from home to school to community and beyond, which can help us as we track aspects that either promote inclusion or present barriers. In approaching the challenge of moving schools from a traditional "mainstream" model of functioning to becoming inclusive, the point of departure must be full acceptance of the principle that all children can learn, given the supportive and attuned environment they need. Our schools can become welcoming environments which truly value diversity, and which are responsive to the needs and learning styles of learners, rather than the other way around. We will explore strategies for achieving this. So, let us begin by thinking about the challenges faced by families of children with disabilities, as we work to create partnerships around the common goal of promoting inclusive education.

Disability, poverty and the family

Caring for a child with a disability is both physically and emotionally demanding for parents and other family members, and this difficulty is compounded in many ways by poverty. While these challenges are always considerable, in socio-economically deprived families they may be but one among a host of problems. Here, basic survival may be in question, and must be prioritised. As we shall see, impairment-related challenges can also interact with other problems of living arising from poverty, making the lives of families more precarious.

Many scholars in Disability Studies have identified the mutually reinforcing relationship between disability and poverty – sometimes referred to as a "vicious cycle". This is because disability can cause or worsen situations of poverty, while living in poverty also renders people more vulnerable to becoming disabled. Let us explore some of the mechanisms at work here.

Families with a disabled child have been found to be more likely to be poor and less likely to manage to escape from lives of poverty by accumulating resources. Providing for the needs of a disabled child can involve a range of extra expenses, depleting the household budget. For example, added transport costs may arise due to the child attending a special school which may be in another neighbourhood, or as a result of the need to attend rehabilitation sessions or medical appointments. Further, the child may require costly resources, such as chronic medication, special foods or assistive devices. An important and often neglected issue is the fact that a child with high support needs may require constant care, which means that an adult carer must always be present in the home. This reduces the earning potential of the household, as the carer cannot be gainfully employed.

As we have seen, while disability can contribute to poverty, poverty also increases the prevalence of disability. Impairment in childhood is more likely in poor communities because of the increased risk of a low quality of health care, including obstetric and post-natal care.

This may lead to a higher risk of birth complications that can cause impairment, as well as the failure to diagnose and treat diseases of early childhood. Further, communities living in poverty are exposed to poorer living conditions, such as unreliable access to clean water, and a lack of safe places for children to play, which can lead to diseases or accidents that may cause impairment. Lastly, violence, criminality and abuse are likely to be more prevalent in such communities, relating to high levels of unemployment, poor security and substance abuse, presenting risks for disabling injuries.

Many parents of children with disabilities have endured years of stress due to a range of factors. These include economic stress, which can interact with the physical and emotional demands of caring for a child with a disability. In addition, living in a society full of disability-related exclusion means that parents must fight for access for their children to essential services such as health care, and especially education. Such struggles may drag on for years, as a child is turned away from one school after another – this is what is often going on behind the crisis in education for children with disabilities in South Africa which we read about in **Chapter 2**. The South African situation is not at all uncommon, especially in countries of the Global South. Parents may also experience prejudice from their communities on the basis of disability, worsening feelings of isolation. All of these factors can present risks to the mental health of parents and other family members, who need both professional and community support.

Creating partnerships between schools and families

As key role-players in promoting the inclusion of learners with disabilities in education, it is essential that secure, trusting and cooperative relationships be maintained between teachers, other school-based workers and parents. Parents are central in shaping the life-worlds of children with disabilities and must be viewed by educationists as a crucial resource.

The family centred services (FCS) model emphasises partnerships between parents and all service providers, such as teachers, doctors and community workers, creating a situation in which families are involved in all aspects of service provision for their child (**Rosenbaum et al., 1998**). In order to develop truly collaborative relationships with parents, it is essential that educationists cultivate the skill of listening, creating a compassionate space in which parents' experiences of struggle may be heard and validated. Parents and other family members are the people who know the disabled child best – their strengths, needs, preferences and personality – and this knowledge should have a central role in creating an attuned, supportive environment for the child at school.

Conversely, parents may also learn techniques from teachers, such as how to support learning at home through creating and using accessible learning materials. Providing services using the FCS model has been shown to improve outcomes for children, as well as leading to greater levels of satisfaction with services among parents. Importantly, the approach is also associated with lower levels of stress in parents, as collaborative relationships provide support rather than the conflict which so many parents of disabled children often experience in their engagements with institutions such as schools and hospitals.

If we are to be successful in promoting the inclusion of children with disabilities in the school as well as the community, it is essential that we fully understand all aspects of the environments they occupy. In order to help us think systematically about the life-world of the developing child, the psychologist Urie Bronfenbrenner has developed the eco-systemic model, which we will now explore.

Bronfenbrenner's eco-systemic model

To help us understand the context of child development, Bronfenbrenner's model divides the environment into five subsystems. These are called the microsystem, the mesosystem, the exosystem, the macrosystem and the chronosystem. Below is an explanation of each one, paying particular attention to issues in education which may arise at the various levels.

The microsystem

The microsystem refers to a child's immediate context, involving direct relationships with family members and close friends who the child interacts with on a daily basis. In thinking about creating an optimal supportive and inclusive environment for education, we might explore the ways in which the home environment may or may not support learning. For example, there may be barriers to learning caused by familial conflict or extreme stress, or parents may be unequipped to support the learning of their child due to other factors. In purely physical terms, the home may be a difficult place to learn. Inadequate space for all members of the household may mean that there is constant noise, while a lack of electricity could mean that after-dark lighting in which to read or do homework is insufficient.

The mesosystem

The mesosystem refers to the interrelation between two or more settings in which the child actively participates. For example, it encompasses relations between such settings as the home, the school, the neighbourhood community, and the child's peer group. It is understood that these microsystems are continually interacting with one another in ways which may be supportive to education or present barriers. At this level, we may be interested in whether parents and other household members are interacting with the teacher and the school in a mutually supportive, collaborative manner.

The exosystem

The exosystem of the developmental environment includes one or more settings that do not involve the child as an active participant, but in which events take place which have an effect on the child. An example of such settings is a school's governing body, where policies affecting the child, such as those concerning disability inclusion, may be formulated. Here, we may also investigate whether key stakeholders in inclusion, such as school-based staff, mobile educational support teams and school governing bodies, are cooperating effectively and whether each has the necessary capacity to promote inclusion.

The macrosystem

The macrosystem level of analysis refers to the broader cultural world which surrounds the developing child. Relevant here are the positions on disability and inclusion reflected in government policies, cultural customs and beliefs, influential historical events, dominant political ideologies, and the prevailing economic system in a society. Here, we may ask whether appropriate provisions for inclusive education are made in a country's constitution and legislation, and whether such provisions are both broadly understood and effectively implemented.

The chronosystem

The chronosystem adds the dimension of time, drawing our attention to ongoing shifts that occur in all of the other systems. For example, we might want to gather knowledge on how, over time, educators and schools have undergone processes to make them more prepared for disability inclusion. It takes time to create more accessible school environments, to capacitate teachers, promote availability of assistive technologies, and to perform public advocacy for inclusive education. Progress in such areas must be continually monitored over time.

Bronfenbrenner's framework brings several advantages to the analysis of a child's environment, including with respect to the creation of inclusive education. We are able to explore inclusive education at the level of systems and their interaction, as well as the individuals within those systems. An emphasis on the interconnectedness of systems means that each aspect of the environment, such as the home, the school and the peer group, is not examined in isolation, but as part of a complex interaction. Within each system, inclusive education may be either supported or undermined by various components, inviting an examination of the ways in which practices are shaped by an interaction of individuals with their environments.

Developing an inclusive school

Inclusion is about extending meaningful inclusive practices and structures that would enable all learners to access education. Inclusion is a philosophy which reimagines child, teacher, knowledge and schooling. All children can learn. One of the first documents which helps provide an anchor for how to think about inclusion and inclusive education, the UNESCO *Salamanca Statement and Framework for Action on Special Needs Education* (**1994**) was adopted by the World Conference on Special Needs Education: Access and Quality in Salamanca, Spain, in June 1994. It is still used widely and is the basis for the South African Department of Education's EWP6 (**2001**). The Salamanca Statement helps us to think about why schools should be inclusive. Inclusion is difficult and inclusive education is complicated, but that does not mean we should not try. The Statement reads:

> *The guiding principle that informs this framework is that schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistics or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalized areas or groups. These conditions create a range of different challenges to school systems.* (**UNESCO, 1994, p. 5**)

Education White Paper 6

EWP6 was published by the South African Department of Education in 2001 and offers a way to think about systematically moving away from using segregation as a way of categorising disabilities and as an organising principle for institutions. During apartheid, we discriminated against children based on race and perceived ability. During apartheid, children who needed special-needs schools were also discriminated against in terms of race and disability. The fact that South Africa is one of the most unequal countries in the world has a massive effect on our schooling system and some schools continue to be far "worse" resourced than other schools post-apartheid. EWP6 offers some of the history of inclusive education in South Africa and outlines how education and training systems can transform and contribute to establishing a caring and humane society. In order to do so, our education system needed to change post-1994 to accommodate the full range of learning needs of all children in the schooling system, especially those who are disabled and need varying levels of support.

The Salamanca Statement helps us to think about a wide range of children and the different difficulties they could be facing. For example, what about migrant children who are disabled or children who do not have any status politically, who may be disabled? This framework provides some ways of thinking about how to support these children in schools and with their learning. We are not suggesting that the best place for every child is a school because there are many other places where children can learn and be supported, but our focus in this chapter is on how we can think about making our schools more inclusive. It is also important to remember that we need to trouble the notion of inclusive education in schools, as inclusivity does not only need to be addressed in schools, but should instead include different types of educational settings.

Inclusive education

When we think about inclusion in schools there are a couple of things that inclusion is not.

Inclusion is not **assimilation**. It is not about asking a child with a specific need to ignore that need and be made to feel they need to be just the same as everyone else and do whatever everyone else at school is doing. Inclusion is also not only about **accommodation**. For example, if a child is in a wheelchair, it is important to think carefully and creatively about how to include the child in the wheelchair. It is about making the changes necessary so that the person in the wheelchair is included in the activities and functioning of the whole school. It involves re-thinking how particular activities can take place so that the child in the wheelchair is valued for every part of themselves and the wheelchair is not seen as an inconvenience, but as part of the child's life and way of being in the world.

Inclusion is also not just about **tolerance**. Often, there is pressure to minimise our differences from each other simply to conform to social conventions and dominant norms. This is problematic and these norms need to be contested. For example, that all children learn to read or write in the same way. It is very important to remember that there is no recipe for inclusion and inclusive education. It is about taking the time to get to know specific children and what their needs are. It is possible to do this for all children if we make inclusion a priority. Inclusion and exclusion are related concepts because we include until we exclude and this happens in small and big ways – in families, schools and more broadly in society.

Figure 1 visually illustrates the difference between separation, integration, assimilation and inclusion.

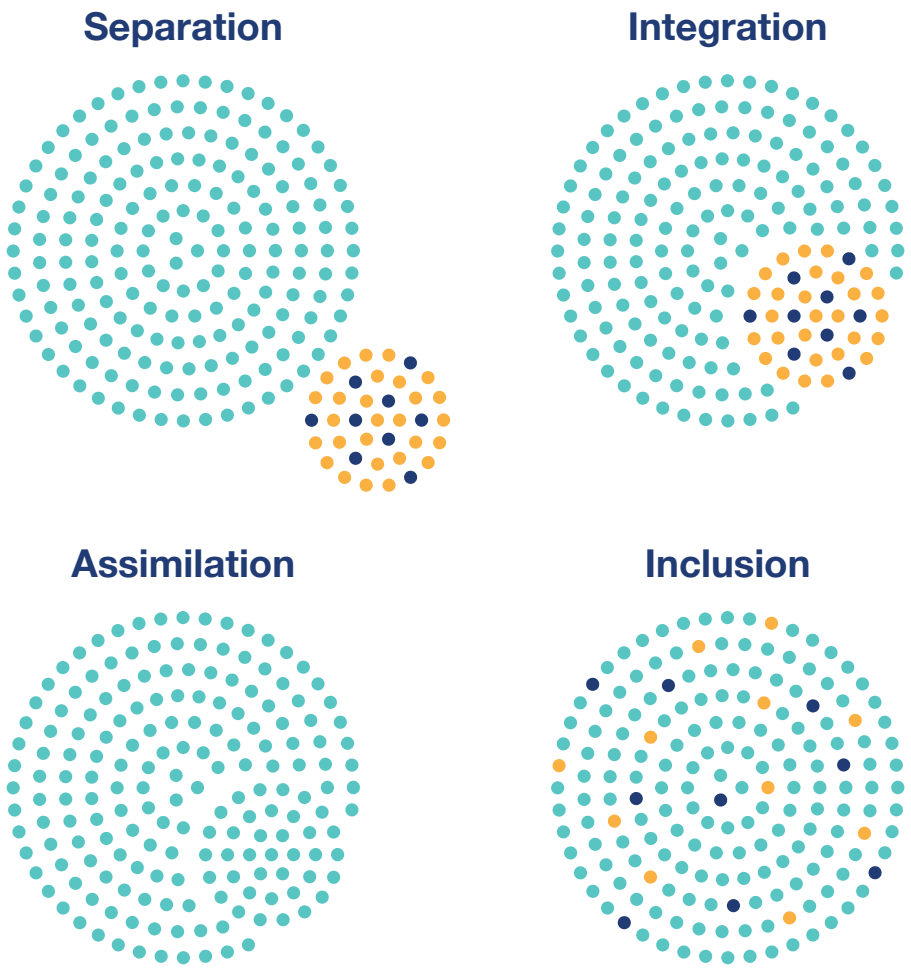


Figure 1: Illustration of the difference between separation, integration, assimilation and inclusion

In the circle in the top left-hand corner is **separation**. While this is obvious it is still problematic as it is the preferred and sometimes standard response to why schools are not embracing the philosophy of inclusion or being inclusive. The idea that it remains okay for us to be separated in this world is exclusion in its most basic form. In the circle to the right labelled **integration**, there is very little influence on those integrating within the dominant group. This is not really integration, it can be identified as simply being invited in to participate, to show quite superficially that a door has been opened.

The circle in the bottom left quadrant labelled **assimilation** is a very clear illustration that those who have been included are now assimilating to the dominant values and ways of the community. Features that differentiate them (such as a unique hairstyle) are hidden or changed so that they become like everyone else in the community. The value of difference is diminished and similarity and sameness is valued. As if this is even possible.

Again, this is a very superficial and inauthentic community. In the circle on the bottom right quadrant, labelled inclusion, the colourful dots have maintained their colour and are spread throughout the community. This is not to suggest inclusion is without difficulty – but it does show what is possible!

Please note that this is simply an illustration and it is important to remember that the light blue dots in each circle are not homogenous either. Simply being at a school does not necessarily mean that a child is included.

We now look at the role of teachers and parents in making inclusion a reality.

The role of teachers in inclusive education

The Department of Basic Education's *Guidelines for responding to learner diversity in the classroom through CAPS* (**2011**) is a useful resource which focuses on understanding diversity in the classroom and responding to diversity in very practical ways. Curriculum is sometimes seen as the biggest barrier to inclusion, so this document specifically addresses aspects of curriculum differentiation, which is particularly helpful for teachers. If a teacher wants to know how to differentiate a standardised national curriculum for children in their classroom, this is a good place to start. It also provides some ideas for differentiating the learning environment. These are some specific strategies for teachers from the *Guidelines*:

- Recognise any biases or stereotypes we as teachers may have.
- Treat each learner as an individual and respect each learner for who they are (knowing that this changes from day to day).
- Avoid using language that is biased and undermines certain groups of learners.
- Refrain from making remarks that make assumptions about learners' experiences.
- Consider the unique needs of learners when designing learning programmes and lessons.
- Utilise constant re-evaluating methods for teaching and assessing learners in a diverse setting.
- Consider different approaches, methodologies and strategies when teaching.
- Create opportunities for all learners to participate in activities.

All these strategies contribute towards making the curriculum, classroom and school more supportive of the specific and diverse needs of children in the classroom. The child does not need to be changed, but the way they access their learning needs to be adapted to suit their specific needs. Differentiation is a way to think about how children are learning and meeting their specific needs.

Teachers can try to identify the specific needs of the children in their class. It is not possible to know or understand every disability, but to better understand the needs of the children in the class is important. Connecting with colleagues like doctors, occupational therapists, speech therapists, physiotherapists and learning support specialists who are willing to share ideas and particular strategies about how to make each classroom more inclusive is important. Teachers also need to include themselves in their classroom so that they can be supportive of the various needs presented in the class, including their own! If a teacher is able to identify their needs, strengths and challenges, this will lead to empathy and a different way of viewing the diverse needs of the children in their classroom.

The role of parents in inclusive education

The question this section deals with is how parents can be supported by schools and specifically how teachers can support families. Parents need empathy and understanding about how their child will be included in the classroom and school. It is necessary to create a comfortable space in the classroom and at the school for the child where they can feel at ease; parents can assist with this by bringing particular insights about their child. There need to be regular meetings between parents and all staff who interact with the child, especially as needs and curriculum change. Parents must be included in all decisions which will affect the child. These decisions often affect the family and the resources they have available outside the school.

Teachers also need to manage the necessarily high expectations and deep concerns of the parents as well as their hopes and desires for their child. At different times there will be a need to prioritise different areas of support that need to be accessed. The teachers and learning support team need to facilitate the Screening, Identification, Assessment and Support (SIAS) process (see **Chapter 6**) and the referral to the District Based Support Team (DBST). Parents need to be included in the development of the Individual Support Plan (ISP) and guided through the implementation of the required areas of support. Parents can also be supported through the development of a parent support group, which could be in person or through a virtual platform such as Zoom or WhatsApp.

Conclusion

The process of creating education which is inclusive requires the support and cooperation of everyone involved in the life-world of the child. It is impossible to overemphasise the importance of the deliberate effort which teachers must make to build relationships and open communication with parents, as well as with one another, for mutual support and guidance.

Trusting relationships are created through good listening and the development of empathy – when parents feel that there is time and care available for their experiences to be heard and understood, they become more able to trust teachers as allies and recognise the importance of their own role in their child's education. As should be clear by now, inclusion is not an "end point" which can be reached and celebrated on a particular day, after which the work will be over. Inclusion is an ongoing process based on communication and observation, which leads to ever-growing awareness of barriers and the creative process of implementing solutions. There is always more to do, as we learn more about our differences and how to create environments which are caring and welcoming to all.

References

Department of Basic Education. (2011). *Guidelines for responding to learner diversity in the classroom through CAPS.* Government Printer. **https://wcedeportal.co.za/eresource/214261**

Department of Education. (2001). *Education White Paper 6: Special needs education: Building an inclusive education and training system.* Government Printer. **https://www.gov.za/sites/default/files/gcis_document/201409/educ61.pdf**

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. *Physical & Occupational Therapy in Paediatrics, 18*, 1–20. **https://doi.org/10.1080/J006v18n01_01**

United Nations Educational, Scientific and Cultural Organization. (1994). *The Salamanca Statement and framework for action on special needs education*. United Nations Educational, Scientific and Cultural Organization. **https://unesdoc.unesco.org/ark:/48223/pf0000098427**