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Early Childhood Development and Children with Disability

> *"Children with disabilities are one of the most marginalized and excluded groups in society. Facing daily discrimination in the form of negative attitudes, lack of adequate policies and legislation, they are effectively barred from realizing their rights to healthcare, education, and even survival".*
>
> UNICEF

1. Introduction

The provision of Early Childhood Development (ECD) services is an underlying theme of the Children's Act 38 of 2005. It is defined therein as "the process of emotional, cognitive, sensory, spiritual, moral, physical, social and communication development of children from birth to school-going age."[1] The early years are essential in achieving sustainable development thus "ensuring the children's rights to survival, protection, development and participation are safeguarded."[2] ECD Centres play an important role in realizing these goals. Not only are they a place of supervision and care, they are also in a position to identify problems a child may be experiencing and to make the necessary referrals.[3] They are also places where parents can receive advice regarding a variety of issues including nutrition, care of infants, and the positive discipline of children; and where they can receive guidance and support. This is particularly the case regarding children with disabilities

The rights of children with disabilities are asserted in the UN Convention on the Rights of the Child of 1990; the African Charter on the Rights and Welfare of the Child of 1999; the UN Convention on the Rights of Persons with Disabilities of 2006; the Constitution of the Republic of South Africa, 1996; the Children's Act 38 of 2005; the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000; and the South African Schools Act 84 of 1996.

2. Appropriate ECD Services and Programmes

Every child has the right to the ECD services and programmes that enable that child to realize his or her full potential. However, children with disabilities or who are chronically ill have special needs which must be addressed so that they might be differently 'abled'. This calls for an individualized child-centred approach which speaks to the fundamental importance of *appropriate* ECD interventions.[4] Otherwise, the child will struggle to learn; as has been said, "a barrier to learning is anything that stands in the way of a child being able to learn".[5]

Appropriate interventions include services and programmes, as well as assistive devices and structured environments that enable *that child* to participate as much as possible by removing barriers to participation and catering for that child's particular needs. The Children's Act is clear that this entails "providing the child with parental care, family care or special care as and when appropriate; making it possible for the child to participate in social, cultural, religious and educational activities, recognizing the special needs that the child may have and providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in

The Act differentiates between 'services' and 'programmes'.[6] An ECD service is described as a service that intends to promote the development of children from birth to school-going age,

which is provided regularly by a person who is not child's parent or caregiver. For example, an ECD service may be provided by a crèche, a pre-primary school, or a home-based intervention focused on the development of young children. An ECD programme is planned within an ECD service, which intends to provide learning and support suitable to a child's level of development. It is a planned schedule of activities designed to promote development. This means that a child's age, stage of development and abilities must be considered when developing an ECD programme.[7]

ECD Centres can play an important role in the identification of disability issues and can provide for the assessment of children who are not reaching their developmental milestones. Similarly, they are in a position to notice possible abuse and neglect, to make the relevant referrals and to provide support for parents/primary caregiver.

ECD programmes may be offered at ECD centres but occupational and physical therapies, as well as speech therapy, can take place in a child's home or in other settings. [8] Parents need to be capacitated to consciously engage in ECD programmes at home and in their daily activities. For example, horse riding for children with disability is a very effective physio-therapy. ECD activities need to be fun and to provide encouragement and nurture self-esteem, thus enhancing engagement with the world. ECD for all children should encourage respect for those children who are differently-abled and for what they have achieved in spite of the difficulties they encounter. A 'wow you can do that' approach promotes equality and does much to reduce stigma.

The role of ECD for children with disability is to allow them to access the levels of support required to achieve optimal functioning, to be as independent as possible, and to control their own environment as much as possible. The goal is to take the 'dis' out of disability. 'I can do this but I do it differently'.

3. Spectrum of Disability

There is a broad range of disabilities and illnesses which may affect the intellectual and physical well-being of children and indicate the need appropriate interventions. "In the field of child development intervention means 'coming between' any negative, disabling effects that a developmental delay or disability might have on the developmental process in general. This is in an attempt at least to minimise, if not to prevent, the impact of the disability/delay on the child's development."[9] One child might have multiple disabilities and may have intellectual as well as physical disabilities and intellectual disabilities. However, this should not be assumed without diagnosis. The kind of ECD programmes provided, and the level of support required, depend on an accurate diagnosis. Notwithstanding the foregoing, children with special needs are often difficult to diagnose and it may require sometime to 'discover' what is needed. One child's progress should not be compared to that of others. The child must set the pace.

The extent of the disability is the determining factor in the choice of educational settings. There are special schools which cater respectively for children who are deaf or blind. Deaf children learn sign language while blind children learn braille.[10] Some children with disabilities can attend mainstream schools with the right degree of assistance.[11] Teacher assistants can play an important role in mainstreaming disability in schools. Some children remain in ECD centres once they are of school-going age because there is no educational facility that can accommodate their needs. However, as Inclusive Educative points out, the Department of Basic Education has a duty to accommodate children with disability.[12]

4. Intellectual Disabilities

The Diagnostic and Statistical Manual defines intellectual disabilities as "neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living."[13] Such a diagnosis requires difficulties in "reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience;" as well difficulties "in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility."[14]

The majority of children with severe to profound intellectual disability have secondary disabilities such as cerebral palsy, visual and hearing impairment, and epilepsy. A child with severe disability is one whose every aspect of development is distinctly delayed. Their optimal level of functioning capacity will seldom exceed

that of a child between the ages of three to five, while their optimal intellectual capacity is that of a child of three. According to the Western Cape Forum for Intellectual Disability, children with profound disabilities may gain basic self-help skills but are unable to take care of themselves. These children may have seizures, as well as severe physical disabilities, and need a high level of care.[15]

5. Down Syndrome

Down syndrome is a lifelong condition which is a consequence a genetic chromosome-21 disorder causing developmental and intellectual delays. The child is born with distinct physical features and some degree of cognitive disability. "It is one of the most frequently occurring chromosomal disorders. Down syndrome is characterised by a variety of unique features and a wide range of abilities in physical and cognitive areas of development" and while "it cannot be cured, people with Down syndrome benefit from loving homes, appropriate medical care, early intervention, and educational and vocational services."[16] The incidence of Down syndrome in South Africa as a developing country is estimated to be one in every 650 births.

The Down Syndrome Association of the Western Cape emphasizes that early diagnosis, early intervention, and referral services are critical to positive outcomes. Parental counselling and ECD training should begin as soon as the child is diagnosed.[17] Parents who benefit from the experiences and support of other parents feel more empowered and able to deal with the needs of their child.

6. Foetal Alcohol Syndrome

Foetal Alcohol Syndrome (FAS) is caused by exposure to alcohol while in the womb and is a consequence of alcohol abuse. Typically, the features of an affected child include small eyes, flattened cheeks, a short nose and a smooth philtrum above a thin upper lip.[18] "They have an IQ of between 60 and 70, as opposed to the average 100, are born underweight and stay small and short throughout their lives because of growth retardation."[19] They may have bone and joint deformities as well as heart defects. Such children demonstrate learning disabilities; exhibit hyperactivity and have difficulty in concentrating; and demonstrate behavioural problems and difficulties in bonding. It is a "devastating condition which is 100% preventable, but equally 100% incurable."[20] Focused ECD interventions can reduce some symptoms.

7. Cerebral Palsy

Cerebral palsy affects body movement, muscle control, muscle co-ordination, muscle tone, reflex, posture and balance. It can also impact fine motor skills, gross motor skills and oral motor functioning.[21] The condition is a consequence of some damage to the brain during pregnancy or at the time of birth. The degree of disability varies considerably, and the kind of interventions required vary accordingly. Some children are high functioning while others require a great deal of assistance as their capacity to move and/or speak is severely compromised. Not all children with cerebral palsy experience intellectual disability. Some children with severe mobility challenges may develop respiratory problems which are difficult to treat and may result in frequent hospitalization.

8. Autism Spectrum Disorders (ASD)

"Autism is a lifelong developmental disability which first displays itself in infancy and early childhood, causing delays in many basic areas of development, such as learning to talk, play, and interact with others."[22] Children with autism experience difficulties in social interaction and verbal and non-verbal communication; display repetitive behaviours; and experience differences in sensory perception.[23] They tend to be very solitary and may not easily adapt to mainstream schooling.

Parental education and counselling are crucially important in helping parents to understand this condition. The early introduction of ECD programmes can play an important role in connecting with the child. Children with autism have difficulty in adjusting to noisy play situations, which may be an impediment to engagement. While Autism and Down syndrome are not the same there are instances of these conditions co-existing and this must be taken into account in the process of diagnosis and programme planning.[24] The right ECD setting plays a significant role in encouraging the child to achieve his/her potential.

9. Impact of Poverty on ECD

Poverty plays a determining role in childhood well-being, and the life of a child may be compromised while the child is very young. South Africa has a very high incidence of stunting which, if left untreated in the first two years of life, is irreversible. Dr Lisanne du Plessis, of the Division of Human Nutrition at Stellenbosch University warns that the damage is severe: "Stunting is a nutritional disorder that comes about due to a number of factors, including inadequate diet, disease, suboptimal caring practices, poor food security, inadequate healthcare, poverty and poor governance of health, food and other resources. It manifests in poor growth, particularly in height. It also impacts on brain growth. The child cannot reach his or her full cognitive potential, which impacts on schooling achievement, and later on educational and employment opportunities."[25]

In an effort to address such nutritional deficits, the Department of Social Development has introduced the 'First Thousand Days' policy, which targets the period from the time of conception to the age of two. The first steps in this policy are for the nutritional needs of pregnant mothers to be assessed, and for household food security needs to be addressed.[26]

10. The Catholic Welfare and Development Model

Catholic Welfare and Development (CWD) "is the leading partner of the Department of Social Development in providing for training, upgrading and registration services for crèches and early learning centres in the Western Cape."[27] Adherence to the norms and standards set out in the Children's Act for ECD centres is challenging, particularly in rural areas and areas of extreme poverty. CWD runs ECD programmes in six Western Cape communities affected by high levels of poverty.[28] A nutrition monitoring tool and a child development database have been established which alert ECD practitioners to problems with cognitive and/or physical development, so that appropriate referrals can be made. This means that ECD practitioners need some training in the field of disability to enable them to identify such problem areas. At present these centres focus on the use of drawing and writing materials; story telling; problem solving; developing a feelings vocabulary; and encouraging independence. The emphasis is on active learning and co-operation and, very importantly, health screening. "ECD is foundational and crucial for all children who are vulnerable at this age to development challenges."[29]

The Early Learning Services Organisation (ELSO) is a service operating within the CWD which "provides training and support to informal crèche personnel in order to capacitate teachers, and assists with infrastructure development of early childhood development centres to enable them to qualify for registration with the Department of Social Development. ELSO is ability neutral and therefore does not discriminate between abled and disabled children."[30]

11. Assistive Devices and Modified Environments

Appropriate assistive devices and modified physical environments play an important role in addressing the challenges of disabilities. It can be as simple as a pair of spectacles; a hearing aid for a hard of hearing child; a wheelchair ramp; hand rails along school corridors; accessible toilets; or computers that are easy to use. Wheelchairs for children are not 'one size fits all': the wheelchair must accommodate the disability and extent of mobility of the child concerned. Children outgrow their wheelchairs, which require replacement accordingly. Wheelchairs for children in rural areas need to accommodate the terrain as well. Transport for children in wheelchairs to ECD centres and health services is particularly lacking.[31] Places of residence may need to be modified to facilitate ease of movement. The lack of appropriate assistive devices further marginalizes children with disability and compromises their access to educational and health care services.

12. And What Now?

While there may be a paucity of services available to children with disability, once they reach adulthood there are even fewer resources available. There are some work centres which provide opportunities for social interaction and stimulation. However, those who have multiple disabilities, and who may not be suited to any kind of work, have very few opportunities for social interaction and their isolation may result in depression, which further compromises well-being. The investment made in ECD needs to be sustained by services and programmes which extend into adulthood. Those with disability

cannot live in limbo: the importance of mainstreaming disability in all its manifestations is central to the realization of equality. In this regard there is a need for greater accountability; data collection and evaluation;[32] funding and governance; and support for parents.[33]

13. Conclusion

It must always be remembered that a child with special needs is first and foremost a child who also has the same needs as any other child. They have a right to equality, and all decisions made regarding the child must be 'in the best interest of the child' – this particular child.[34]

Reflecting on her daughter with a chromosome 'abnormality' and the need for prayer, Heather Lanier writes that she knows that "the tip of my daughter's chromosome will never appear in every one of her cells. But I do not want anyone to "fix" my kid. That is not the miracle I seek. Instead, I want someone to lay hands on the people who presume she is less than. I want someone to eradicate the idea that bodies are either productive or burdensome, that they either contribute to the gross domestic product or drain it. I want some mystical saviour to eradicate the assumption that disability is a curse, a calamity. Wouldn't that be the bigger miracle?"[35]

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[1] Section 91 (1) of the Children's Act No 38 of 2005
[2] 'Power of Play', Mail and Guardian, November 11 -17 2016
[3] An ECD Centre is in a position to refer any suspected abuse or neglect to the appropriate authorities.
[4] On the 19th April the SACBC Parliamentary Liaison Office hosted a Roundtable Discussion focusing on 'Early Children Development and Children with Disability'. The Roundtable was addressed by Ms Tineke Ganz-Malan and Ms Marise Wattel of the Down Syndrome Association, Mr Kevin Roussel of Catholic Welfare and Development and Ms Vanessa Japtha of Inclusive Education
[5] Inclusive Education Fact Sheet
[6] http://www.ndacampaigns.co.za/home/63/files/Documents/Childrens-Act-Guide-for-ECD-Practioners.pdf
[7] See 6 above
[8] https://www.ncbi.nlm.nih.gov/books/NBK332877
[9] http://www.downsyndrome.org.za/main.aspx?artid=66&print=1
[10] There is some discussion that sign language should be included as an official language
[11] Vanessa Jafta from Inclusive education points out that the transition from an ECD to a mainstream school can be a difficult transition.
[12] Presentation by Inclusive Education on the CPLO Roundtable on 'ECD and Children with Disability'
[13] The 5th edition to Diagnostic and Statistical Manual
[14] As 7 above
[15] Western Cape Forum for Intellectual Disability Leaflet
[16] http://www.downsyndrome.org.za/main.aspx?artid=16
[17] Presentation at Roundtable Discussion.
[18] News 24 28th May 2016
[19] http://www.fasfacts.org.za/
[20] http://www.fasfacts.org.za/
[21] http://www.cerebralpalsy.org/about-cerebral-palsy/definition
[22] https://www.westerncape.gov.za/general-publication/autism
[23] https://www.down-syndrome.org/updates/341/

[24] See 13 above
[25] https://www.dailymaverick.co.za/article/2017-05-02-analysis-nutritional-stunting-and-why-sa-is-coming-up-short/?utm_me
[26] Eating the right kind of food is important. A diet that is rich in starch is inadequate
[27] Presentation by Kevin Roussel Director of the CWD at the Roundtable Discussion.
[28] Samora Machel; Tafelsig; Khayelitha; Masiphumelele; Gugulethu and Elsies River.
[29] See 21 above
[30] See 21 above
[31] There are buses that are especially made to accommodate children in wheelchairs but the writer is unaware of the use of such a transport in South Africa.
[32] The lack of reliable and disaggregated statistical research on the prevalence of childhood disability seriously hampers programme planning. This is particularly the case in the rural areas
[33] Presentation at the Roundtable Discussion on 'ECD and Children with Disability'
[34] The defining principle of the Children's Act No 38 of 2005
[35] "My daughter has a disability, I don't want Jesus to 'fix'her", Heather Kirn Lanier 'America' May 2017