

Priorities for access to early childhood development services for children with disabilities in South Africa



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Background: South Africa has migrated the responsibility for early childhood development (ECD) centres from the Department of Social Services to the Department of Basic Education. This functional shift has ushered in consultations and discussions on how best to implement ECD, including opportunities the change may bring.

Aim: By anchoring the understanding of ECD services in nurturing care, this study aimed to elucidate the provision of appropriate, inclusive services in early childhood development, including early childhood intervention, for children with disabilities in South Africa against the backdrop of the migration of services from one government ministry to another.

Methods: This is an analytical article based on South African literature on ECD services, including interventions, with particular attention to children with disabilities, basing our understanding of these services in nurturing care.

Results: We elucidate how the ideals of the Nurturing Care Framework can be achieved in the context of children with disabilities in South Africa using five themes: the need to localise services, developing tools and strategies for screening and early intervention, enhancing the efficacy of caregivers, supporting and training staff and collaborations.

Conclusion: It is necessary to empower caregivers and professionals to address early childhood intervention and ECD needs of children with disabilities. Early childhood development centres are an important context for nurturing care, providing opportunities to promote and sustain health amongst a large number of children. Considering the function shift of ECD services in South Africa, these centres are well positioned to further nurturing care to children with disabilities through the provision of supportive environments that promote health and well-being.

Keywords: children with disabilities; early childhood development; early childhood intervention; impairments; nurturing care; South Africa.

Introduction

According to the World Health Organization (2018), more than four in every ten children in low- to middle-income countries face the risk of missing critical development milestones because of poverty or stunting. Investing in early childhood development (ECD) could help to mitigate this challenge. Early childhood development refers to 'children's cognitive, physical, language, motor and social and emotional development, between conception and age 8' (World Health Organization 2018:47). According to the General Household Survey (Department of Basic Education 2019), participation of 0–4-year-olds in ECD programmes in South Africa has increased from 8% in 2002 to 44% in 2018. However, inequalities in early learning opportunities in general abound, which is attributed to a lack of teaching resources, the worrying children to teacher ratio of 1:31, the poor infrastructure of ECD centres, more than one million children aged 3–5 years not attending ECD centres and the fact that formal education before the age of 7 years was not compulsory until 2020, amongst other factors (Department of Social Development 2015; Visser et al. 2021). Moreover, little is known about ECD services for children with disabilities in South Africa.

As stated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

[P]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations 2006:4)

Children often depend on ECD facilities for essential services and resources and the risks facing children with disabilities who may be excluded from these services are substantial. Access to quality ECD programmes can play a critical role in addressing inequalities by cushioning children against the effects that come with poverty, poor nutrition, inadequate healthcare and lack of education (Putcha & Van der Gaag 2015). Indeed, it has been observed that providing appropriate ECD services at an early age makes it possible for children to attain their full potential (Ashley-Cooper, Van Niekerk & Atmore 2019). In the words of Raffi Cavoukian, singer and founder of Canada's Centre for Child Honouring, 'when you pay attention to the beginning of the story, you can change the whole story' (Early Childhood Peace Consortium 2021: para. 1).

Whilst every child needs ECD, early childhood intervention (ECI), on the other hand, always relates to some risk factor, such as disability, which requires targeted interventions of different kinds. According to Guralnick (2019), ECI addresses the development of infants and young children facing a risk of delay because of environmental disadvantage or biological risk, including the population of children with disabilities. Early childhood intervention might involve providing diagnostic or evaluation medical services, assisting technology devices, nutrition services, physiotherapy, occupational therapy, psychological services and caregiver training, amongst other services. Early childhood development centres, in coordination with the Department of Health (DoH), can play an important role in ECI through the early identification of children with disabilities, for instance using assessments for disability. This potential role of ECD centres is particularly outstanding taking into consideration that caregivers might lack the resources to have their children assessed independently (Department of Social Development 2014). Indeed, South Africa's Department of Basic Education (DBE) has the Policy on Screening, Identification, Assessment and Support (SIAS) whose purpose is to standardise 'the procedure to identify, assess and provide programmes for all learners who require additional support to enhance their participation and inclusion in school' (DBE 2014:1). However, a 2014 audit of ECD centres in the country established that the number of centres where professional assessments of children for disability took place was relatively low across all disability types. This suggested that ECD centres either were not aware of the importance of conducting assessments for disability or lacked the resources to carry out such assessments. Therefore, the development of the children with disabilities in ECD centres may be profoundly impacted because their disabilities remain undiagnosed (Department of Social Development 2014).

We note the strong link that exists between ECD and ECI for children with disabilities. Disability in childhood not only requires ECI but also might be a threat to inclusion in ECD, depending on issues of access and inclusivity on the part of those running the ECD services. Children with disabilities might thus incur superimposed risks, from disability and deprivation of important developmental experiences.

Under the National Integrated Early Childhood Development Policy of 2015, the DoH is responsible for giving a comprehensive package of ECD services for all children aged 0–2 years in South Africa, including supporting responsive caregiving, early learning and inclusive and specialised services for children with disabilities, at both health facility and household levels (Department of Social Development 2015). Before 2019, ECD centres in South Africa were the responsibility of the Department of Social Development (DSD). The focus of the DSD regarding ECD centres was towards monitoring facilities rather than assessing children, supporting high-quality programmes and directing the implementation of curricula, including play pedagogy (Vorwerk 2020). In 2019, the South African government announced a 'function shift' of ECD services, that it would migrate the responsibility for ECD centres from the DSD to the DBE. According to the DBE (2021), the migration intends to improve the development of children and the quality of ECD education in offering optimum support to learners from an early age onwards:

DBE functions include the development of early learning curriculum; continuity and synergy between early learning and Grade R; integration of key health messages in the school curriculum; and training, implementation and monitoring relating to curriculum implementation from birth to four-year-olds. The new functions include ensuring universal availability and adequate quality of, and equitable access to, inclusive learning opportunities; and the development, delivery, regulation, registration, quality monitoring, improvement and evaluation of ECD programmes. (DBE 2019: para. 4)

The functional shift aligns with the changes happening in other countries of moving from 'viewing ECD less as a child protection function and more as an early learning function that is led and coordinated by national ministries of education' (DBE 2019: para. 1). Remaining in the DSD are functions such as child protection, psychosocial services, administering the child support grant, parental support programmes, partial care facilities related to after-school services, private hostels and temporary respite care centres and access to social services to prevent and address risk factors.

The functional shift has ushered in consultations and discussions on how best to implement it, including the question of what opportunities the change may afford. Various concerns have been raised by stakeholders; for instance, what will happen to existing ECD centres and their staff, what is the training required for staff under the DBE, what are the accommodations needed to ensure the safety and development of young children in the DBE controlled ECD schools and how the funding needs for the new ECD centres can be met, amongst other issues (Vorwerk 2020). Furthermore, this study focuses on the question of providing appropriate, inclusive services in both ECI and ECD domains for children with disabilities in South Africa, against the backdrop of the massive migration of services from one government ministry to another. The situation not only presents immense challenges but also possible opportunities.

We base our article on South African literature on ECI and ECD services, with particular attention to children with disabilities. Most examples used in the article refer to hearing impairment and its sequelae; hearing impairment herein is intended to serve as an example of other impairments. We anchor our understanding of the ECI and ECD services in nurturing care.

The significance of nurturing care

Nurturing care refers to a stable environment that is sensitive to children's health and nutritional needs, with protection from threats, opportunities for early learning and interactions that are responsive, emotionally supportive and developmentally stimulating:

[N]urturing children means keeping them safe, healthy and well nourished, paying attention and responding to their needs and interests, encouraging them to explore their environment and interact with caregivers and others. (World Health Organization 2018:12)

As an overarching concept, nurturing care is supported by a large array of social contexts – from home to parental work, child care, schooling, the wider community and policy influences. It consists of a core set of interrelated functions, including behaviours, attitudes and knowledge of caregiving (health, hygiene, care, feeding); stimulation (talking, singing); responsiveness (early bonding, secure attachment, trust, sensitive communication); and safety (routines, protection from harm).

The Nurturing Care Framework (NCF) (World Health Organization 2018) gives a roadmap to the attainment of the Sustainable Development Goals (United Nations Department of Economic and Social Affairs 2015), amongst other global policy blueprints, to leave no one behind. The NCF does this by outlining why attempts to improve health and well-being should start in the earliest years, the main threats to ECD and how nurturing care can shield children from the effects of adversity and promote physical, emotional and cognitive development. It also outlines what families and caregivers need to offer nurturing care for children.

Although its target is children aged 0–3 years, the NCF is a valuable source of inspiration for ways to ensure that older children in South Africa, including those with disabilities, develop to their full potential. The NCF proposes five essential components for children to reach their full potential: good health, adequate nutrition, responsive caregiving, security and safety and opportunities for early learning. Good health refers to the health and well-being of the child and their caregiver. An important observation made is that the physical and mental health of caregivers can affect their ability to care for the child. Adequate nutrition addresses both maternal and child nutrition. The nutritional status of the mother during pregnancy can affect her health and well-being as well as that of the unborn child. Furthermore, after birth, the nutritional status of the mother can affect her ability to provide adequate care to the young child. Safety and security is about safe and secure environments for the

children and their caregivers. This component considers physical dangers, emotional stress, environmental risks and access to food and water. Opportunities for early learning refer to opportunities for the child to interact with people, places or objects in the environment. This component appreciates that positive or negative interaction or absence of interaction, influences children's brain development and laying the groundwork for later learning. The final component, responsive caregiving, is about the ability of caregivers to notice, understand and respond to their children's signals in a timely and appropriate manner. This is a foundational component because caregivers who are responsive can ably support the other four components. Our discussion now turns to how the ideals of the NCF can be achieved in the context of the children with disabilities in South Africa.

The need to localise services

To begin with, ECI services for children with disabilities need to happen in the locality of children with disabilities. Yousuf Hussein et al. (2018) observed that meeting the early intervention needs of children with disabilities, such as screening, in their localities enhances the cost effectiveness, efficiency and access to health services in poor communities of children with disabilities. The use of technology is helpful in cutting costs when localising ECI services. According to Yousuf Hussein et al. (2018), community health workers can explore cloud-based technologies for the asynchronous management of disability screening and follow-ups.

Moreover, Grinker et al. (2012) and Van Heerden and Kritzinger (2008) suggested that localising ECI programmes for children with disabilities allows for accounting for cultural dynamics. Considering the cultural context when screening for disabilities helps in delivering appropriate and effective health services. For effectiveness, both the culture of the patient and the provider of the intervention need consideration. Engaging local knowledge of disability, such as beliefs and needs, helps in analysing the relationship between disability and culture and can in turn suggest areas of research and facilitate community engagement in contexts of limited clinical and educational resources.

Yousuf Hussein et al. (2018) equally observed the importance for ECD programmes for children with disabilities to be offered in the locality of the families. It is desired for ECD centres to be situated in the locality of the families of children with disabilities. Furthermore, home-based programmes, mobile ECD programmes and toy libraries need strengthening, with a specific focus on serving children with disabilities who may still face challenges accessing ECD centres. Offering ECD programmes in the locality improves access to them, instead of offering them elsewhere, which results in incurring extra costs for transport. According to Yousuf Hussein et al. (2018), localising ECD programmes in South Africa is especially crucial when the high poverty rate is considered, together with the financial cost of disability in families.

Developing tools and strategies for screening and early intervention

Infant disability screening is a feasible and viable strategy for early disability detection. In South Africa, delays persist in the diagnosis of disability and the implementation of interventions, which are partly attributed to a shortage of support services for early intervention (Van der Spuy & Pottas 2008). Concerns have been raised about the efficiency of the Road to Health Booklet (RtHB), the tool available to all healthcare workers in the public healthcare context in South Africa to conduct screening for developmental delays or disorders. A study by Van der Linde et al. (2015) established that the RtHB checklist could not identify more than half of infants at risk of developmental delays or disorders within the primary healthcare context in South Africa. The RtHB 'requires adaption with subsequent validation or replacement by existing tools appropriate for the context to ensure timely identification of at-risk infants towards improved outcomes' (Van der Linde et al. 2015:194). It is essential to develop screening models that ensure infants with disabilities, for instance hearing loss, are provided an opportunity for optimal development and integration into society (Olusanya et al. 2007). One way of doing this is through offering accountable and contextually relevant Early Hearing Detection and Intervention (EHDI) strategies (Swanepoel, Louw & Hugo 2007). Furthermore, Kanji and Khoza-Shangase (2012) observed the necessity of constantly modifying the list of indicators for hearing loss and providing more detailed categorisation of severity, because risk factors are often affected by the type of resources, nature of the community and diseases present in a given context and at different time periods. Less frequent risk factors need further investigation by audiologists, as these could result in growing evidence for including additional elements on the high-risk register, which would take into consideration the specificity and relevance of the context. According to Kanji and Khoza-Shangase (2012), this could lead to appropriate referrals to relevant medical professionals, including audiologists.

Also, it is necessary to develop appropriate assessment tools for language and communication development, for instance in preschool children with visual impairment. Moreover, it is necessary to develop effective language and communication stimulation techniques for the caregivers of children with visual impairments to use during the early stages of development, at which time such difficulties often manifest (Mosca, Kritzingler & Van Der Linde 2015). Similarly, the Communication and Symbolic Behaviour Scales-Developmental Profile is deemed useful in assessing early social communication skills for English-speaking South African toddlers and particularly in identifying children below 2 years who have more pervasive social communication delays. This early assessment aims at preventing later severe and costly delays in communication (Chambers, Stronach & Wetherby 2016).

Early intervention is of extreme importance for children infected with human immunodeficiency virus (HIV) who are

on antiretroviral therapy (ART) because such children are associated with high levels of neurocognitive impairments. Early initiation of ART is necessary to improve cognitive functioning of these children. Similarly, intervention strategies that optimise early cognitive development in children on ART are necessary (Lowick, Sawry & Meyers 2012). Again, the use of childhood developmental screening tools is an important part of holistic HIV treatment as it has the likelihood of limiting potential disabilities and maximising developmental outcomes. However, it is to be observed that childhood developmental screening tools are likely to be underutilised in over-burdened and staff-constrained paediatric facilities for the treatment of HIV (Strehlau et al. 2016).

Importantly, early identification that is not coupled with early intervention should not be promoted. Early identification should be directed at providing early intervention services. In the case of ECD, it should not be assumed that young children with disability labels will not benefit from ECD programmes (Hayes, Turnbull & Moran 2018).

Enhancing the efficacy of caregivers

What is required is a holistic, multidisciplinary approach to supporting families and their children with disabilities, with the goal of informing and equipping parents and caregivers to make their own decisions on the basis of specific needs of their children. Enhancing the efficacy of caregivers to take care of the early intervention needs of their children with disabilities is crucial because a link exists between parental self-efficacy and early childhood outcomes. It has, for example, been shown that caregivers' self-efficacy is linked to child outcomes in communication (Harty, Alant & Uys 2007; Popich, Louw & Eloff 2007). Capacitating mothers to overcome maternal depression can also lead them to better care for their children (World Health Organization 2018). More efficacious parents tend to participate more actively with their children, stimulating them and giving input, consequently impacting positively on development. Swanepoel and Almec (2008) have, likewise, linked poor compliance with early interventions programmes to problematic cultural dispositions of parents, such as superstitions regarding the causes of disabilities. In such cases, enhancing the knowledge of parents through providing them with sufficient and sensitive information, which highlights the proven causes of disabilities could be helpful. In the same way, it is helpful to provide families with open, unbiased information that assists them in recognising, as well as responding to, their children's disabilities, as with communication and language needs (Störbeck & Pittman 2008). It is crucial that support of the efficacy of caregivers be ongoing to ensure the support is stimulating, sensitive and responsive to the cues of children with disabilities (van der Spuy & Pottas 2008). It then follows that the support and informed decisions of parents could result in the success of early intervention programmes that, by extension, could lead to access to ECD programmes. Also, it is important to build the capacity of staff.

Supporting and training staff

Promoting support programmes for professionals who implement ECI and ECD services for children with disabilities is essential. Similar to that of parents, the support of professionals, such as educators, needs to be a continuous, lifelong process founded on connecting research with practice (Wium, Louw & Eloff 2010). The support programmes would enhance ECD service provision through improving the practices of foundation phase teachers, including pedagogy, confidence and creativity to overcome contextual challenges. Training of teachers in impairment-specific skills is particularly urgent, as South Africa currently faces an acute shortage of such skills (McKenzie et al. 2020). Initial teacher education programmes do not train teachers on impairment-specific support to children with disabilities, despite the position of the SIAS policy (DBE 2014) calling for the same (Kelly & McKenzie 2018). Teachers have been observed to 'face the challenge of reconceptualising difference, not as a source of difficulty and exclusion that may require technical procedures but rather as the centre of their planning and practice' (McKenzie et al. 2020:13). The adoption of the Universal Design for Learning approach can guide practice by facilitating thinking about diversity and planning for it from the start (McKenzie et al. 2020).

In terms of ECI, training of health professionals, such as community nurses, is necessary for them to embrace family-centred care, referral and collaboration. Moreover, staff support programmes are needed to improve healthcare management, to shift attitudes towards disability and to enhance provision of better services with less resources (Kanji & Krabbenhof 2018). The use of technology is significant in this regard. As an example, a computer database to continuously store and retrieve data on clients could assist in overcoming the challenge of relying on the perceptions of parents regarding outcomes of an intervention (Jessop, Kritzing & Venter 2007).

Encouraging staff to own their professional development is also crucial (Leech, Van Wyk & Uys 2007). This means that ways of making staff self-motivated in pursuing professional development should be pursued. Nevertheless, effective and quality healthcare provision to children with disabilities not only depends on the initiative of individual professionals but also on the targeted involvement of other main stakeholders, such as the government and civil organisations (Kanji & Krabbenhof 2018). The buy-in of these ECI and ECD stakeholders would create favourable conditions for staff to pursue further professional development, for instance, by providing study leave and other motivational benefits. Involving key stakeholders also links to the need to create collaborations.

Collaborations

Promoting collaborations between the various stakeholders involved in ECI and ECD services for children with disabilities is crucial. Professionals and caregivers need to

develop synergistic relationships to the benefit of children with disabilities (Popich et al. 2007; Storbeck & Calvert-Evans 2008; Van Heerden & Kritzing 2008). The DoH is the anchor department for nurturing care and, commendably, leads the 'Side-by-Side' campaign, aimed at ensuring that all children in South Africa get the nurturing care they need to develop optimally. This is achieved through enhancing coordination amongst all the stakeholders who provide components of care to children, including national, provincial and local departments, non-governmental organisations, community-based organisations and all other partners who work and care for children (Side-by-Side, 19 February 2022).

Many aspects of ECI touch on the health of the children; for instance, developmental delays in the child may need identification by a health professional before ECI services are offered. Working closely with the DoH would enhance such identification and intervention. In the example of hearing impairments, services between audiologists and caregivers should be strengthened; audiologists need caregivers' input to develop standard care and service delivery interventions in order to provide operative information and continued support (Van der Spuy & Pottas 2008). In addition, 'systematic planning and implementation of international level gold standards at various levels of service delivery, in both the Department of Health and the Department of Basic Education' is necessary (Kanji & Khoza-Shangase 2012:6). Thus, collaborations should involve caregivers, different professionals and also the institutions in charge of ECI and ECD. Such a combined effort could allay the fear reported by experienced educators in the early intervention programmes of being left out in the rollout of the function shift (Vorwerk 2020). The importance of child-centred and family-directed early intervention should be emphasised, including taking into consideration the South African context in order to encourage collaborative practice and unbiased (in terms of technological or communication preferences) and empowering decision-making, which best benefits the family and child (Storbeck & Calvert-Evans 2008).

Way forward

The most powerful contexts for nurturing care are not only the immediate home and the care settings of young children often provided by mothers but also fathers and other family members, as well as child care services (Britto et al. 2017). The NCF recognises the importance of empowering caregivers to address ECI and ECD needs of children. 'Caregivers are most able to provide their children with nurturing care when they are secure – emotionally, financially and socially' (World Health Organization 2018:12). The importance of strengthening the engagement of families and communities of children with disabilities in the function shift needs to be taken into consideration. To this end, there is the need for the DBE, the DSD and DoH to hold consultative meetings with families and communities of children with disabilities on how best to implement ECI and ECD. When communities are engaged, it leads to their

empowerment, which consequently leads to more successful implementation of ECI and ECD as the communities' contextual needs and concerns are addressed. This aligns with NCF's strategic need to focus on families and their communities. It is necessary to empower families and communities whilst respecting their local context, including 'building on the positive social norms and practices (e.g. ECI and ECD services) that already prevail in the community' (World Health Organization 2018:28). It means that the concerns that have hitherto been raised by communities on how the function shift is to be implemented (e.g. Vorwerk 2020) could be addressed if more effort is made to give a voice to parents and communities. The need to involve families is especially crucial when it comes to children with disabilities because it must be recognised that parents are experts of their children (De Geeter, Poppes & Vlaskamp 2002). In addition, the poverty challenge in South Africa needs attention. For example, it remains difficult for many families to access ECI services because of the cost of transport. Thus, it is crucial for ECI services to be 'included' in communities, rather than being provided in separate spaces elsewhere. Technology can play an important role in this pursuit; for instance, screening could be carried out remotely, with data shared via the internet. Mobile phone technology is also a feasible strategy in this regard, given the general continued growth in coverage of mobile cellular networks (World Health Organization 2011). For instance, a project in Kenya has documented caregivers' successful use of a mobile phone application to monitor their children's developmental milestones (Kitsao-Wekulo et al. 2021). A similar approach could be applied in South Africa.

When it comes to ECD centres, these institutions are an important context for nurturing care. As observed by Vorwerk (2020), they not only provide an excellent opportunity to promote health, as interventions can reach a large number of infants, children and families at one time, but also over an extended timeframe that is essential for sustainable changes to occur. Concerning education, ECD teachers need to be equipped with specialised skills to enable addressing the needs of children with disabilities and, in this regard, adopting the Universal Design for Learning approach can guide planning and practice. Given the challenges that children with disabilities might face in accessing ECD centres in South Africa, it is suggestive that home-based ECD programmes, mobile ECD programmes and toy libraries are well positioned to further nurturing care to children with disabilities within their communities in South Africa through the provision of supportive environments that promote health and well-being.

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Authors' contributions

A.K. and C.S. analysed the data and wrote the original draft. B.W. contributed to the structuring of the article. J.M. and R.V. contributed to the conceptualisation of the article, review and the data analysis.

Ethical considerations

This article followed all ethical standards for research without direct contact with human or animal subjects.

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Data availability

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