

Review

ECD policies in South Africa – What about children with disabilities?

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The importance of the young child in South African policy has been recognised through the inclusion of early childhood development (ECD) planning in documents relating to the National Departments of Health, Education and Social Development. However, despite the inclusion of the ECD sector in these three key departments there has been no indication of how policy will be implemented, nor how the young child with disabilities in particular will be served effectively. And although South Africa is recognised as having progressive and comprehensive policies in place to ensure the rights of people with disabilities, it is also acknowledged that not having a specific budget for children with disabilities means that the needs of these children may be neglected (Department of Social Development, 2009). Due to this gap in service provision HI HOPES (which stands for Home Intervention Hearing and language Opportunities Parent Education Services), a non-governmental, non-profit programme providing free support services to families of infants with a hearing loss, was launched. This article engages with the current South African ECD landscape and tracks HI HOPES' first steps towards the implementation of ECD policy and its attempt at improving the status of infants and young children with disabilities within governmental policies and procedures.

Key words: Infants, hearing loss, family support, early childhood policies, disability, child development.

INTRODUCTION

The first few years of an infant's life form the foundation on which all future development – including linguistic, socio-emotional and cognitive is built. The fact that specialists now agree that "learning begins at birth" (UNESCO, 1990: 5) reinforces the need for urgency in laying a solid foundation for development and growth. For this reason the field of early childhood development (ECD) has been initiated in various sectors of the community to focus on acknowledging, understanding and meeting the unique needs of the young infant. In South Africa, ECD is recognised as a crucial area for development and various government departments have begun focusing on the specific needs of this age group. However, there is no common understanding of family needs with a subsequent lack of a coordinated effort to

meet these needs within the diverse South African context. In addition, the lack of mandated policy for provision of ECD services contributes to the fact that intervention within the early childhood development sector is not yet formally recognised as a profession in South Africa. This has the effect of placing less emphasis on the need for training, which then ensures that the field remains wanting in sufficient substance (in terms of both the theoretical enhancement of the field as well as the day-to-day support of the infant and family).

The field of early childhood development as it relates to government policy within the three South African government departments (Department of Education, Department of Social Development and Department of Health), will now be discussed in order to gain a better understanding of the status quo in the South African context. Policies will be explored and discussed with the aim of identifying strengths and weaknesses in our policies, gap areas of service delivery and finally to make

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recommendations on a way forward. Let us begin by exploring the definition of ECD.

The Education Department through its White Paper 5 (2001: 9) defines ECD as “an umbrella term that applies to the processes by which children from birth to at least nine years grow and thrive, physically, mentally, emotionally, spiritually, morally and socially”. The Department of Social Development (2006) and the Department of Health (2004) on the other hand recognise the importance of the period from birth to four and birth to seven years, respectively for this intense period of development. While there is disagreement regarding the age categories to be included in the term “early childhood development” there is, particularly recently, a shared recognition of the importance of the holistic development of the young child in all areas, with the National Integrated Plan for Early Childhood Development in South Africa acknowledging 3 phases within the broad ECD definition – birth to three, three to six and six to nine (UNICEF, 2005: 3), with a central focus on the birth to 4 years of age (UNICEF, 2005: 6). This shared recognition of the importance of early childhood is evident in the fact that all three of the departments have policies and key documents relating to early childhood.

POLICIES, LEGISLATION AND DISCUSSION DOCUMENTS

With early childhood clearly recognised for its importance in establishing foundations of development, this awareness has shown an impact on the South African government. The three key government departments that play an integral role in early childhood development, care and education are the Departments of Social Development, Health, and Education, with each department acknowledging the ECD sector to various degrees in a number of their policies and position statements. The National Department of Education is seen as the “key role-player in driving ECD policy”, though ECD services are acknowledged as a provincial responsibility shared between Education, Health and Social Development (Human Sciences Research Council, 2004: 13). However, the lack of policy delivery in the ECD sector was highlighted in a study on the situation of young children in South Africa, which indicated that policy does not acknowledge the importance of the first three years of child development or the needs of working parents (Palmi, 2007). An audit into the provision of ECD services in South Africa (Department of Education, 2001c) indicated the poor funding of this sector, the lack of uniformity in implementation of policy by the different provinces and a lack of children with disabilities (under the age of 7 years) being serviced at ECD sites.

Additionally, programmes and activities aimed at improving the quality of life of children with disabilities operate within silos with little attempt for integration across departments (Department of Social Development, 2009). This together with a paucity of national focus on collation and implementation of the various ECD related documents and policies has led to an interesting dilemma: a country with wonderful legislation and policies, yet lacking the actual implementation and practice of these policies. Next is an attempt to unpack ECD from within the framework of each of the three departments in order to move beyond the silo effect and toward a comprehensive way forward in the particular field of early childhood and hearing loss.

The Department of Health

The interest of the infant and young child and their support system falls primarily within the domain of the National Departments of Health and Social Development, with collaboration from the Department of Education and the newly launched Department of Women, Children and People with Disabilities. With this core focus, the Free Health Care Policy (1994) was developed to ensure access to public health services for children less than six years of age, all children with disabilities as well as pregnant and lactating mothers. A study into the implementation of this policy (Leatt, Shung-King and Monson, 2006) indicated that in addition to being idealistic the implementation of this policy is hampered due to a shortage of staff at government institutions resulting in a long waiting period for services, and a lack of transport for children to reach facilities.

The Strategic Priorities for the National Health System, 2004-2009 states that there will be an implementation of “activities and interventions to improve key family practices that impact on child health” and though not specifically ECD focused, the acknowledgment of the family is applauded (Department of Health, 2004: 13). A document that is intended to improve the quality of health care in South Africa states that there is a need to “focus on the most vulnerable sectors of society, that is, women, children, older people and people with disabilities” (National Department of Health, 2007: 10). This indicates recognition of the need for attention to healthcare for young children with disabilities, though there is neither reference to an implementation plan nor how this will be achieved in terms of budget or resource allocation.

The Department of Education

This department has as its primary role the education of

learners within 3 broad categories namely early childhood, school and tertiary education (hence the recent establishment of 2 separate departments, namely Basic Education and Higher Education). The birth to 5-year age group is recognised as a critical stage in terms of children's growth, and White Paper 5 (on early childhood development) focuses wholly on the development and rights of the young infant, along with the implications for the South Africa education sector (Department of Education, 2001a).

Education is seen as the context in which all children are to be treated as equals, and an inclusive education environment supportive of the various barriers to learning in which all learners get equal access to education is proposed (Department of Education, 2001b). In order to ensure barriers to learning are identified with the necessary action plans in place with the move toward inclusion, the Department of Education developed the National Strategy on Screening, Identification, Assessment and Support (2008). The key focus on early identification of barriers to learning is to ensure typical early childhood development and effective inclusion into society, and the document therefore recognises the importance of public centre, community centre and home-based ECD service providers in the provision of information and recording of factors that may impact on a child's education (p. 21). There is an awareness of the importance of training parents and caregivers to be more knowledgeable in the early identification of problems that may lead to barriers to learning and an acknowledgment of the role of ECD service providers in informing and equipping schools with the information and necessary strategies on how to deal with these learners with special educational needs (p. 22). Finally, the Interim Policy on Early Childhood Development (1996) focuses on the provision of services for children from birth to 9 years, with an acknowledgment of the importance of the collaboration of different government departments as well as the importance of linking with community based ECD programmes and non government organisations.

The Department of Social Development

The Department of Social Development also acknowledges this need for collaboration, and specifically intersectoral collaboration due to the lack of facilities for the early detection, management and intervention for children with disabilities (National Department of Social Development, 2006). The Department of Social Development proposes to focus on disadvantaged children under five years of age, the age group birth to three years and disabled children for the provision of ECD services (Department of Welfare, 1997). Subsequently, the Department of Social

Development has developed a document called Guidelines for Early Childhood Development Services (National Department of Social Development, 2006). While this is not a policy document, it is a document that sets out the importance of ECD services, the roles and responsibilities of provincial departments of social development as well as minimum standards for the provision of ECD services in South Africa.

Policies developed within the different departments of government show an acknowledgment of the role of all sectors within the field of early childhood including the family, community and NGOs. However, it is apparent that there is a lack of the integration of knowledge as well as the formal implementation of policies within the governmental departments, leading to a lack of integrated ECD service planning and delivery that will allow for the holistic development of the child (this will be especially evident in a child with a disability). The realisation of the need for an integrated plan for ECD and the importance of the inter-sectoral collaboration led to the development of the National Integrated Plan for Early Childhood Development in South Africa 2005-2010 (UNICEF, 2005) with specific emphasis on the birth to four cohort. This national plan recognises the importance of collaboration between different departments, the necessity of partnerships between government, NGOs and private enterprises, and the importance of the involvement of families and communities (UNICEF, 2005: 2). However, there is a lack of provision for early identification of disability (birth to three) and strategies that should be put in place to ensure early identification and intervention so that there is minimal disruption to holistic development of the child. Despite these gaps South Africa is indeed making inroads into ECD services with all three national departments and the recent establishment of the Ministry of Women, Children and People with Disabilities recognising the need for effective service delivery to the most vulnerable in our society. Of these most vulnerable, we will now focus on the needs of disabled infants, specifically those with hearing loss.

EARLY CHILDHOOD AND DISABILITY

Each policy developed by the different departments highlights certain aspects that are important for consideration in national planning, yet have not been directly considered in the National Integrated ECD policy 2005-2010 (UNICEF, 2005). Additionally, there is lack of an indication of how the different policies will be implemented to ensure a cohesive plan on provision of and access to services for children with disabilities. The Service Delivery Model for Social Services as developed by the Department of Social Development (2006) advocates approaching provision of services from a

social development perspective and recognises the need for prevention of disabilities. However, this document does not give a clear indication of screening programmes for early identification of disorders (birth to 3 years), or early intervention programmes that could be put in place once a disability is identified in the first three years of life. While there is some reference to early identification of and prevention of transmission of genetic disorders, it must be recognised that genetic disorders are not the only cause of disabilities. Early screening for disability should form an important part of the child wellness regimen for all infants. The National Integrated ECD plan does not make overt reference to early identification programmes, nor of implementation plans and budgetary implications; however, the focus on early screening through the Road to Health card (the national card that tracks an infant's inoculation journey) and the education documents focusing on screening (though it applies it to the first grade) can be used as points of departure for beginning integrated implementation.

Integration and prevention of discrimination is an important part of the South African democracy. The South African Constitution (Republic of South Africa, 1996) entrenches the equal rights of all its citizens (8.1) and states further that "no person shall be unfairly discriminated against, directly or indirectly, and, without derogating from the generality of this provision, on one or more of the following grounds in particular: race, gender, sex, ethnic or social origin, colour, sexual orientation, *age, disability*, religion, conscience, belief, culture or language" (8.2. Italics added). The recognition of the need for the acknowledgment of people with disabilities as contributory members of society is also apparent in the Gauteng Provincial Government Disability Policy (Gauteng Provincial Government, 2003). This policy states that there is a focus on a developmental approach toward disability that necessitates a shift away from a dependency model (p. 2-3) and a move towards an analysis of the types and needs of people with disabilities and the promotion of self-reliance. This proactive approach includes prevention, early identification of the problem, incorporation of people with disabilities into mainstream economy and awareness of the rights of people with disabilities and rehabilitation programmes whenever possible (p. 3). The focus on incorporating people with disabilities into mainstream economy before a focus on rehabilitation services indicates a lack of understanding of both the impact of disabilities and the importance of early detection and intervention.

The Department of Social Development (in its White Paper on Social Welfare in 1997) recognises the importance of the family as "the basic unit of society" and indicates the importance of family-oriented policies and programmes to strengthen family life. There is also

an acknowledgment of lack of services for children 0-3 and for children with disabilities. Inherent in this statement then is the lack of appropriate services for disabled children that are in the 0-3 age range. There will thus be a necessity for the provision of services to this particular subgroup of children since they are the least serviced and in need of intervention. This White Paper further acknowledges the role of specialist organisations in advocacy, policy formulation, the integrated planning of services, primary prevention programmes through public education, and in providing assistance with the development of appropriate community-based interventions in particular fields. All aspects of this have been incorporated into the National Integrated ECD plan, together with a particular focus on the 0-4 year old, with the main focus of intervention being on the household and community with minimal emphasis on formal service provision. However, there is still a lack of a focus on dealing with children with disabilities and the importance of early identification and intervention for these children. The Integrated National Disability Strategy White Paper (Office of the Deputy President, 1997) and the new National policy and strategy acknowledges that existing prevention policies are not effectively linked to identification and early intervention policies (p. 18), and there is a move towards the provision of ECD services that are intersectoral, community-based and integrated. However, as with most of the policy documents in South Africa there is a need for an indication of how this will be implemented and where the funds will come from.

The lack of a focus on children with disabilities could be due to the lack of consensus regarding disability from the different sectors, a lack of statistical data on disability in children and disagreement regarding the perspective and philosophy from which disability is viewed. Disability tends to be viewed from a medical and welfare framework where there is a focus on correcting or handling the disability medically and therapeutically, with seeming ignorance regarding the social needs of people with disabilities (Office of the Deputy President, 1997: 4). This may offer an explanation for the fact that although the Integrated National ECD plan recognises the importance of immunization and prevention of illnesses, and the importance of family and community involvement in early childhood development, it does not acknowledge early identification and intervention for children with disabilities. The lack of a provision for children with disabilities and an indication of a lack of communication between government departments to implement the National Integrated ECD Plan is indicated by a lack of focus on ECD in the policy statement on Strategic Priorities for the National Health System (2004-2009). The focus is on the health care of school-aged children, youth and adolescents and the reduction of childhood

infectious diseases, as opposed to discussing the identification and management of disabilities and the subsequent provision of ECD services. This is not consistent with the Department of Welfare's (1997) commitment to the provision of ECD services that focuses on prevention and advocates social investment towards ensuring maintenance of health.

Another possibility for the lack of ECD services in South Africa could be a shortage of funds. The Education White Paper 5 states that independently funded ECD institutions are better funded to serve this group rather than relying on state intervention. However, families may not be able to afford to pay the fees involved. This then will result in a similar status quo as reported by Colletta and Reinhold (1998), where in the apartheid era, there was minimal acceptance of the development of the 0-6 year old age group. The development of a South African Congress for ECD by NGOs to assist the State with policy formation was meant to increase and improve ECD services through the establishment of accreditation norms and standards. However, there was a lack of manifestation of outcomes due to a lack of follow through on the implementation of policies (Palmi, 2007). This lack of implementation plans and subsequently the lack of budgeting for the ECD sector, are indicators not of a lack of resources, but of a lack of prioritising for this sector.

However, it is not just in South Africa that there is a lack of focus on children with disabilities. Statistics regarding children with disabilities are lacking in many policy documents in Africa and this was made evident by Olusanya, Renner and Okolo (2008) when they documented with gratification the fact that the latest UNICEF report had included data on 2-9 year old children with seizure, cognitive, motor, visual or hearing disabilities. However, it is also acknowledged that these data are sparse and based on parental accounts rather than actual medical recordings/ formal data on the disabilities. This lack of awareness of the needs and services for infants with disabilities is especially true for infants with hearing loss.

CHILDREN WITH HEARING LOSS

It has been estimated that approximately 180,000 children with permanent bilateral hearing loss are born in Sub Saharan Africa annually (Swanepoel, Storbeck and Friedland, 2009; Swanepoel, 2008). When it is considered that undetected hearing loss affects children's linguistic, social, communicative and cognitive development (Moeller, 2000; Yoshinaga-Itano et al., 1998; Morton and Nance, 2006), it becomes clear that this will have a deleterious effect on a child's holistic development, where delays in the ECD phase impact greatly on future development in terms of education and literacy, employment and ultimately quality of life. The

importance of including early hearing detection and intervention into ECD programmes thus becomes pertinent. However, it is only recently that a position statement on paediatric hearing screening (HPCSA, 2007) has been put into place in South Africa. When it is considered that a number of countries have already started implementing universal newborn hearing screening programmes (e.g. USA, UK, Poland), it becomes evident that South African policies and procedure for early hearing detection and intervention are lagging. Pilot programmes on hearing screening have been conducted at immunisation clinics (Swanepoel, Hugo and Louw, 2006) and at a private health care hospital (Swanepoel, Ebrahim, Joseph and Friedland, 2007), and data from both these screening sites indicate the lack of parental awareness regarding the early identification of and intervention for hearing loss. Added to this lack of policy on hearing testing/screening and intervention, hearing loss will certainly result in profound negative effects on children directly impacted by this "silent epidemic" (Swanepoel, 2008). However, it does need to be noted that the identification of a disability without the provision of intervention services is seen as unethical (Olusanya, Luxon and Wirz, 2006).

In line with the new screening position statement, South Africa recently launched an organisation called EHDI (Early Hearing Detection and Intervention)¹, the umbrella body for all practices concerning early hearing screening, diagnosis and intervention programmes. This organisation was developed after the first Africa EHDI conference was held in South Africa in 2007. Proceedings from the conference indicated the need for a joint effort from all stakeholders to promote and support initiatives that will improve the early identification and enrolment into intervention programmes for children with hearing loss (Swanepoel and Storbeck, 2008). EHDI has a membership which includes teachers of the deaf, interventionists, audiologists, speech therapists and ENT specialists with a focus on improving early identification and diagnosis of children with hearing loss. This will be achieved through the promotion of newborn screening programmes and referral into early intervention programmes to inform, support and empower families of the hearing impaired infant.

In order to ensure that screening and diagnosis are not in vain (Olusanya et al., 2006), that the ethical dilemma of screening without the hope of intervention is prevented, and that families and their infant with the hearing loss get the correct intervention in order to ensure typical development and equal opportunities and

¹ Led in partnership by two Universities, the University of Pretoria and the University of the Witwatersrand

support, the HI HOPES early intervention programme was developed. The programme will be discussed with reference to the aim and implementation of such an initiative in a South African situation.

HI HOPES: EARLY INTERVENTION FOR FAMILIES OF INFANTS WITH HEARING LOSS

HI HOPES (an acronym which stands for Home Intervention Hearing and language Opportunities Parent Education Services) is the first home-based early intervention and support programme for families of deaf and hard of hearing infants (ages 0-3 years) in South Africa and is available to all families (both within public and private healthcare sectors) at no cost. HI HOPES was developed on the model of SKI-HI, an internationally renowned early intervention programme which has been implemented for over 35 years in the USA (Bodner-Johnson and Sass-Lehrer, 2003; SKI HI Institute, 2004; Strong et al., 1994; Strong, Clark and Walden, 1994). The aim of HI HOPES is to partner with parents, informing and empowering them in order to understand all aspects of the child with a hearing loss (Storbeck and Pittman, 2008; Storbeck and Calvert-Evers, 2008). There is no indication of bias or preference of amplification or communicative modality, and parents are empowered to make decisions that will be to the benefit of their child. Due to the unbiased nature of the support, as well as the fact that there is no financial gain (either in terms of amplification choices or choices in mode of communication) HI HOPES is able to provide parents with true access to 'informed choice' (Young et al., 2006). This programme recognises the importance of multidisciplinary collaboration with health care workers as well as paramedical professionals such as therapists and audiologists (Storbeck and Pittman, 2008) and sees the intervention as a partnership between the interventionist and the parents. Interventionists (named Parent Advisors, PAs) are usually drawn from fields of education, audiology and speech therapy, social work and early childhood, and are trained in local communities, thus ensuring that local communities become sustainable in terms of equipping and providing support locally. PAs are trained in early child development, the needs of the deaf child and home-based intervention and assist the family in understanding their hearing-impaired child's journey.

Home visits occur weekly and usually last approximately an hour. During this time the PA provides parent-directed information (using adult education principles) in the language of the parents, in a culturally appropriate manner where necessary. Topics covered range from child development, language and communication options, amplification, play, literacy and issues in behaviour. At all times, topics are presented within the

context of natural routines for the infant and combine information and skills. In addition to the PA home visits HI HOPES also introduces hearing families to deaf adults (called Deaf Mentors, DMs), who act as language and cultural role models and can be communicators in any of the communication options (e.g. oral, signing, total communication, etc).

In establishing the HI HOPES early intervention programme for families and their deaf or hard of hearing infant we want to achieve the four goals as set out by the National Integrated Plan for Early Childhood Development in South Africa 2005-2010 (UNICEF, 2005: 8):

- 1) Create environments in which children, particularly vulnerable children, can learn, grow and thrive socially, emotionally, physically and cognitively.
- 2) Increase opportunities for young children to enter formal schooling in a state of better preparedness.
- 3) Provide support to adults who care for young children and the communities in which they live in order to enhance their abilities to care for and educate these children.
- 4) Reduce the adverse developmental effects of poverty and other forms of deprivation to children from birth to four.

This is planned to be achieved by focusing on the five approaches to working in ECD identified by the World Bank (Young, 1996):

- 1) Addressing the immediate basic development needs of the child: Topics addressed in the SKI-HI intervention programme include all areas of development, from early communication, to literacy, play and cognitive development. In order to address the immediate needs of the young infant all the learning is situated within the child's authentic home environment and daily routines.
- 2) Training caregivers and educating parents: Parents are educated (informed in an unbiased manner) on all aspects of their child's hearing loss and are empowered to make informed decisions regarding communication, schooling, etc. The intervention, being home-based, focuses on all significant care-givers including extended family, siblings, grandparents, nannies, etc (though it is parent directed in terms of who is trained).
- 3) Promoting community development: The ECD interventionist (PA) is a member of the community in which the family lives in order to ensure cultural congruency as well as to promote development of the community in terms of resources and access to information. Support is given to the community as a whole, allowing parents to share with and include the community as they choose. It also raises awareness within the community of the needs of this unique infant from the community and advocates within the

community for supporting infants with hearing loss.

4) Strengthening institutional resources and capacity: Parents are empowered and encouraged to advocate for services such as therapy, hearing aids, etc so that these services become part of the standard capacity offered and will improve access for other children in the community. Through training of local community based interventionists, local communities grow capacity internally and thus become a resource both to their members and those needing support and intervention.

5) Building public awareness: A key feature of the programme is to improve public awareness of hearing loss and the importance of early diagnosis and intervention. This is done through the provision of information brochures, talks at government and private hospitals as well as appearances on national radio and television. Additionally, once parents are empowered and skilled, they too become spokespeople for support and the rights of families with hearing loss.

The HI HOPES programme has partnered with government and private institutions to ensure access to families requiring services. The importance of community based ECD services as well as partnering with medical and paramedical professionals and the family is recognised. These are points that form a part of all key ECD policy documents (Department of Health, 2007; Department of Social Development, 2006). The National Screening, Identification, Assessment and Support document (Department of Education, 2008) indicates that NGO organisations can either operate on a voluntary or contract basis. In accordance with the Department of Health's (1994) policy on free provision of services for children under the age of 6 years, the HI HOPES programme has been operating free to families through the provision of funds from donor organisations. The focus of the HI HOPES programme on community development and the provision of services within the home indicates a recognition of the importance of the Department of Social Development's (2006) recommendation of including communities and parents as complements to the provision of ECD services (p. 14).

The HI HOPES programme has thus been operating as a non-governmental, non-profit organisation with the aim of improving ECD service provision for families that have a child with a hearing loss. There has been adherence to departmental policies relating to the provision of services and a commitment to improving the status of ECD service provision in South Africa. This programme has been operating in the pilot phase in Gauteng, with recent progression into the provinces of Kwazulu Natal and Western Cape.

In order to ensure the sustainability of early intervention programmes that meet the agreed-upon needs within the ECD sector to support and educate

families of infants with special needs, government will need to commit to more than just documenting policy and discussion documents. There is an urgent need for focusing on implementation plans, including budgets and role and responsibility allocations.

Due to the fact that equality is entrenched in the South African Constitution's Bill of Rights (Chapter 2: 9 p. 3) along with the rights of the child and the acknowledgment that all have a right to education, it is imperative that the South African government ensure that the ECD sector be equally represented in both policy planning and implementation thereof, thus ensuring that infants and young children are not discriminated against on the grounds of age, disability, language or birth (South African Government, 1996: 3). Government will thus need to develop more integrated policies and procedures for effective implementation of policies; while ensuring that children with disabilities are accounted for in planning as well as budget allocations. The silo mode of service delivery needs to be replaced by integration of working within departments as well as between organizations, and a recognition of the role that non-profit organisations play in provision of services.

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