



# **basic education**

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Department:  
Basic Education  
**REPUBLIC OF SOUTH AFRICA**

**THE DRAFT POLICY FOR THE PROVISION OF QUALITY  
EDUCATION AND SUPPORT FOR CHILDREN WITH  
SEVERE TO PROFOUND INTELLECTUAL DISABILITY**

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## ACRONYMS

AAC	Alternative and Augmentative Communication
AET	Adult Education and Training
CPTD	Continued Professional Teacher Development
CSTL	Care and Support for Teaching and Learning
DBST	District-based Support Teams
DPO	Disabled Peoples' Organisation
DSD	Department of Social Development
ECD	Early Childhood Development
EMIS	Education Management Information Systems
FET	Further Education and Training
FSS	Full-Service School
GET	General Education and Training
HEI	Higher Education Institution
ISP	Individual Support Plan
ITE	Initial Teacher Education
LURITS	Learner Unit Record Information and Tracking System
NCS	National Curriculum Statement (Schools Grade R –12)
NSC	National Senior Certificate
NGO	Non-governmental organisation
NPO	Non-profit organisation
SAPS	Police Service

SASA	Schools Act (Act 79 of 1996)
SASL	Sign Language
SBST	Site/School-based Support Team
SGB	School Governing Body
SIAS	Screening, Identification, Assessment and Support
SMT	School Management Team
SNA	Support Needs Assessment
SSRC	Special School Resource Centre
SPID	Severe to profound intellectual disability
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

## DEFINITIONS

**Compounded vulnerability** - Environmental as well as personal contexts can lead to compounded vulnerability to exclusion and human rights violations for persons with disabilities. These contexts could range from gender, race, impairment, where people live, socio-economic status, age, qualification levels, cultural beliefs, health status, etc.

**Community based rehabilitation workers** – This class of personnel are community based health care workers who have specialised training of one to two years in rehabilitation and community integration of people with disabilities. They provide a link between health and education services and the community and provide basic rehabilitation services in the home.

**Caregiving staff** – these staff are employed at special care centres to provide physical care for children, including feeding toileting and washing. Caregiving staff have an important educational role to play by offering care so that it promotes independence as part of the learning programme for children with SPID.

**Child and Youth Care Centres** - A child and youth care centre is a facility for the provision of residential care to more than six children outside the child's family environment in accordance with a residential care programme suited for children in the facility (Chapter 13, Children's Act, no 38 of 2005- Department of Social Development)

**Drop in Centre** - Drop in Centre is a day centre run by the social services or a charity that persons may attend on an informal basis. It offers a supportive, safe place to meet others who are facing similar struggles, to share experiences, to find hope, support and encouragement, and to create a social network of new friends and associates (Chapter 14, Children's Act, no 38 of 2005)

**Development** - In the context of this policy , development can be understood as: a) normal child development which provides a baseline by which to identify the child's needs and b) skills development which is the goals of educational programmes.

**Duty of care** - Every teacher has a 'duty of care' towards every student under his or her supervision, by virtue of the conditions of the teacher's employment, and by virtue of the common law principles of negligence. Generally speaking a teacher owes a student a duty to

take reasonable care to protect him or her from foreseeable risk of injury. In the context of children with SPID, the duty of care encompasses an awareness and avoidance of the dangers of improper physical handling, feeding and other care practices. Caregivers in centres are also bound to this duty of care.

**Early intervention** ‘Coming between’ any negative effects that exposure to particular risk factor/s (e.g. poverty, low birth weight, family stress etc.), a developmental delay or disability might have on a child’s development. This is in an attempt to minimise, if not to prevent the impact of the disability/delay on the child’s development (Down Syndrome South Africa). Early intervention is closely associated with the ECD sector and requires the involvement of the family rather than a focus purely on the child with a disability. The impact of the environment on the child with SPID also needs to be considered and adapted to meet their needs.

**Education** - Children with SPID are able to learn and develop with the appropriate input and hence can benefit from an education that is aimed at developing their potential to the maximum. The focus of this education is on the development of communication, personal and self-care, practical and conceptual skills, within their natural daily environment rather than on academic skills.

**High support needs** –refers to the support that children with SPID need in order to function optimally. However, it must be emphasised that there are many children who may have high support needs for whom the learning programme described in this is NOT appropriate as they might not have an intellectual disability and would benefit from the general curriculum. High support is described in SIAS as follows:

“Highly specialised support resources, personnel, programmes and facilities for a group of learners with **high support needs** requiring access to the same support programme or resources on a high frequency basis, can be provided at site level such as in special schools or specialised settings attached to ordinary schools.” Thus it is very likely that children with severe and profound intellectual disability will fall into this category given their multiple and complex disability.



**Home based services** - Home based services, (also referred to as domiciliary care, social care, or in-home care), are supportive care services provided in the home. they can include a variety of activities such as nursing care, rehabilitation services (for example, physical therapy), assistance with activities of daily living (ADL's), assistance with housekeeping, chores and meal preparation, or assistance with activities to maintain health such as taking medications.

**Inclusive education** - This is defined in Education White Paper 6 (2001) as a system which acknowledges that all children can learn and that all children need support and accepts that all learners are different in some way and have different learning needs which are equally valued and an ordinary part of our human experience. It is about enabling education structures, systems and learning methodologies to meet the needs of all learners and respecting differences in learners, whether due to age, gender, ethnicity, language, class, disability or HIV status. It is broader than formal schooling and acknowledges that learning also occurs in the home and community, and within formal and informal modes and structures. Inclusive education is about changing attitudes, behaviour, teaching methodologies, curricula and the environment to meet the needs of all learners so as to maximize the participation of all learners in the culture and the curricula of educational institutions and empowering learners by developing their individual strengths and enabling them to participate critically in the process of learning.

**Intellectual disability** - (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

- i. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
- ii. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

- iii. Onset of intellectual and adaptive deficits during the developmental period.”  
(Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition)

**Severe intellectual disability** is defined by the following levels of functioning:

**Conceptual domain** Attainment of conceptual skills is limited. The individual generally has little understanding of written language or of concepts involving numbers, quantity, time, and money. Caretakers provide extensive supports for problem solving throughout life.

**Social domain** Spoken language is quite limited in terms of vocabulary and grammar. Speech may be single words or phrases and may be supplemented through augmentative means. Speech and communication are focused on the here and now within everyday events. Language is used for social communication more than for explication. Individuals understand simple speech and gestural communication. Relationships with family members and familiar others are a source of pleasure and help.

**Practical domain** The individual requires support for all activities of daily living, including meals, dressing, bathing, and elimination. The individual requires supervision at all times. The individual cannot make responsible decisions regarding well-being of self or others. In adulthood, participation in tasks at home, recreation, and work requires ongoing support and assistance. Skill acquisition in all domains involves long-term teaching and ongoing support.

**Profound intellectual disability** is defined by the following levels of functioning:

**Conceptual domain** - Conceptual skills generally involve the physical world rather than symbolic processes. The individual may use objects in goal-directed fashion for self-care, work, and recreation. Certain visuospatial skills, such as matching and sorting based on physical characteristics, may be acquired. However, co-occurring motor and sensory impairments may prevent functional use of objects.

**Social domain** - The individual has very limited understanding of symbolic communication in speech or gesture. He or she may understand some simple instructions or gestures. The individual expresses his or her own desires and emotions largely through nonverbal, non-symbolic communication. The individual enjoys relationships with well-known family members, caretakers, and familiar others, and initiates and responds to social interactions through gestural and emotional cues. Co-occurring sensory and physical impairments may prevent many social activities.

**Practical domain** - The individual is dependent on others for all aspects of daily physical care, health, and safety, although he or she may be able to participate in some of these activities as well. Individuals without severe physical impairments may assist with some daily work tasks at home, like carrying dishes to the table. Simple actions with objects may be the basis of participation in some vocational activities with high levels of ongoing support. Recreational activities may involve, for example, enjoyment in listening to music, watching movies, going out for walks, or participating in water activities, all with the support of others. Co-occurring physical and sensory impairments are frequent barriers to participation (beyond watching) in home, recreational, and vocational activities. Maladaptive behaviour is present in a significant minority. (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition)

**Lifelong learning** - recognises that learning is not confined to childhood or the classroom but takes place throughout life and in a range of situations. Lifelong learning can enhance social inclusion, active citizenship, personal development, and self-sustainability, rather than competitiveness and employability.

**Outreach services** - these provide services to persons who might not otherwise have access to services. Usually the outreach teams providing outreach are not stationary, but itinerant; in other words they are meeting those in need of outreach services at the locations where those in need are. In addition to delivering services, outreach teams have an educational role and have to raise the awareness of existing services. Outreach is often meant to fill in the gap in the services currently provided by NGOs but also government. Children with SPID may also receive services from local hospital rehabilitation teams or

specialised education outreach teams with representation from three key government departments as in the Western Cape.

**Partial care** - refers to care that is provided when a person whether for or without reward, takes care of more than six children on behalf of their parents/caregiver during specific hours of the day or night, or for a temporary period, by agreement between the parents/ caregiver and the providers of the service. (The Children's Act, no 38 of 2005, Department of Social Development)

**Partial Care facility** - is any place, building or premises maintained or used partly or exclusively, whether for profit or otherwise, for the reception, protection and temporary or partial care of more than six children apart from their parents/ caregivers. The essential feature of this care is that it is of relatively short duration and that the children are still cared for and live with their parents and /or primary caregivers. The prime responsibility for care of the children still lies with the parents and or/primary caregivers. (The Children's Act, no 38 of 2005, Department of Social Development)

**Protective Workshop** - safe, disability-friendly environments providing opportunities for persons with disabilities from the local community to develop and improve their skills and to earn an income through the products that they make to supplement their disability grants

**Respite care** - is the provision of short-term accommodation in a facility outside the home in which a loved one may be placed. This provides temporary relief to those who are caring for family members, who might otherwise require permanent placement in a facility outside the home. (The Children's Act, no 38 of 2005)

**Special Care Centre** - these centres are places where children with SPID are cared for on a daily basis. They are often run by mothers of disabled children. Some of these centres are registered with the Departments of Health or Social Development but many of them are not registered and run on minimal resources. They range from being well-equipped centres that are fully staffed, equipped and run by NGOs to single rooms in houses or shacks.

**Stimulation centres** - this term is applied to day care facilities that offer some kind of daily programme that is intended to provide not only care but also education and stimulation for children with SPID

**Severe to profound intellectual disability** – is the term used in the policy . This term refers to children who are at the lower end of functioning within the severe category and also those with a level of functioning as described in the profound category.

**Skill** - A skill is a learned ability to carry out a task with pre-determined results within a given amount of time or energy. It is the ability and capacity acquired through deliberate, systematic and sustained effort to smoothly and adaptively carry out complex activities

**Transversal service delivery model** - transversal programme planning and delivery should result in integrated services. It should reflect planning and delivery which is not segregated and means looking systemically and holistically at matters affecting the target group. In this transversal teams refer to intersectoral teams. The complex needs of children with SPID require the support of transdisciplinary teams of health and education professionals.

## CHAPTER 1

### INTRODUCTION TO THE POLICY AND IMPLEMENTATION PLAN

#### 1. PURPOSE OF THE POLICY

- (1) The purpose of this policy is to provide a framework for inclusive, quality and developmental education of children with severe to profound intellectual disability who function at the lowest levels of development and who attend special or ordinary schools, special care centres (partial care or residential, formal and informal), ECD centres and home education .
- (2) The education of children with SPID deserves closer attention in the education transformation process. In terms of the Constitution (Act no 108 of 1996) access to basic education is a fundamental right without limitations (Section 27) and no child of compulsory school-going age should be discriminated against on the basis of disability (Section 9).
- (3) However, to date the majority of these children have not had access to public funded education and support, leaving them vulnerable and outside the net of services being provided to all school-going children.
- (4) As a result of this situation, the Western Cape Forum for Intellectual Disability took the Government of South Africa and the Western Cape to court to establish the right to education. In 2010 the Western Cape High Court found that: “the respondents have failed to take reasonable measures to make provision for the educational needs of severe to profoundly intellectually disabled children in the Western Cape, in breach of the rights of those children to a basic education, protection from neglect or degradation, equality and human dignity.” The ruling laid out processes to be followed to rectify the lack of services in an order of the court with clear time frames and responsibilities for a number of Government Departments.
- (5) This policy asserts the rights and dignity of one of the most neglected and vulnerable groups in South Africa and globally - those who are in need of lifelong care. It also acknowledges that the social and economic cost of this care is currently borne by

families with minimal support from the state in the form of social grants. Families need greater support in their care responsibilities. The Department of Basic Education (DBE) recognises its role in providing this support through appropriate educational provision.

- (6) This policy recognises that the needs of children with SPID are complex and lifelong. Therefore access to appropriate education requires inter-sectoral collaboration between government departments. This policy therefore sets out the role of the Department of Basic Education in relation to the responsibilities of other relevant Government Departments.
- (7) Inter-sectoral collaboration that recognises lifelong dependency is critical. The Department of Health (DoH) and Department of Social Development (DSD) must facilitate early intervention and screening, identification, assessment and support in the 0-5 year age group before compulsory schooling. By the same token DSD needs to develop policy to support youth with SPID and their families after the end of schooling at age 18. The collaboration between these departments should be such that this group experiences a smooth transition from one life phase to the next.
- (8) This policy is based on international and national best practice taking into account historical and contextual realities. It makes provision for progression from the earliest developmental levels of children towards optimal levels of engagement and lifelong learning.
- (9) Furthermore the policy recognises that the complex needs of these children and their families require a person-centred, holistic and integrated approach that will ensure the maximum development of each child's individual potential.
- (10) Given the need for lifelong support for children with SPID, families and communities are integral to their education. The way in which person-centred exit planning is done for individual learners in terms of community integration and networks of care is outlined in this.
- (11) The policy outlines the institutional arrangements and steps to be in place for the implementation of the programmes.

- (12) The policy includes a learning programme for children with SPID that outlines early intervention for children from birth to four years within ECD programmes as well as within the compulsory educational age range from chronological age of five to 18 years. The programme also includes guidelines for early intervention, transition to supported employment and adult life.
- (13) The learning programme takes into account critical cross field skills, the Indigenous Knowledge Systems and Values of the learning environment as well as HIV and AIDS awareness. The learning programme is not tied to a designated delivery site and may be used in different settings, ranging from home care through to formal schooling.

## **2. RELATED LEGISLATION AND POLICY**

- (1) This policy is aimed at rationalising and standardising education delivery and services for children with SPID and must be read in conjunction with the following treaties, legislation and policy documents:
  - (a) The Constitution of South Africa (Act No. 108 of 1996)
  - (b) The Schools Act (Act No. 84 of 1999)
  - (c) Education White Paper 6 on Special Needs Education: Building an Inclusive and Training System (2001)
  - (d) The Convention on the Rights of Persons with Disabilities (2006), specifically Articles 7, 23 and 24.
  - (e) The Convention on the Rights of the Child (1989) specifically Article 23
  - (f) The Education White Paper 5 on Early Childhood Development (2001)
  - (g) The Children's Act (Act No. 38 of 2005)
  - (h) The National Curriculum and Assessment Policy Statement, Gr R–12 (2011)
  - (i) HIV and AIDS in Education Policy (1999)



- (j) Integrated School Health Policy (ISHP) (2012)
- (k) The Care and Support for Teaching and Learning (CSTL) Programme (2008)
- (l) School Nutrition Policy (2013)
- (m) Minimum Uniform Norms and Standards for Public School Infrastructure (2013)
- (n) Mental Health Care Act, Act 17 of 2002
- (o) Promotion of Access to Information Act, 2000 (Act No. 2 of 2000)
- (p) Promotion of Equality and Prevention of Unfair Discrimination Act, (2000) (PEPUDA or the Equality Act, Act No. 4 of 2000).
- (q) The National Curriculum for Children from Birth to Four (2015).
- (r) National Early Learning and Development Standards for Children Birth to Four Years (NELDS) (2004).
- (s) Policy on Screening, Identification and Assessment and Support (SIAS) (2014)
- (t) The High Court Judgement of November 2010 Case no: 18678/2007.
- (u) The National Disability Rights Policy: Draft (2014)

## CHAPTER 2

### RATIONALE FOR THE POLICY

#### 3. INTERNATIONAL CONVENTIONS

- (1) Human rights with regard to disability are detailed in the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** that was ratified by South Africa with its Optional Protocol without reservation in 2007. This committed the country to respect and implement the rights of persons with disabilities as laid out in the various Articles. Furthermore South Africa recognises the definition within the UNCRPD of disability as an evolving concept that arises in the interaction between a person with impairment and their environment. Thus the environment and context is critical in determining the degree of disability and does not depend on the individual impairment alone.
- (2) Article 7 of the UNCRPD requires of Government to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children and to ensure that the best interests of the child be a primary consideration in all actions concerning children with disabilities. It states that children with disabilities have the right to express their views freely on all matters affecting them.
- (3) Article 23 relates to respect for home and the family. This article promotes equal rights of children with disabilities to family life. Early and comprehensive information, services and support should be provided to children with disabilities and their families in order to prevent abandonment, neglect and segregation. Where the immediate family is unable to care for a child with disabilities, the child should not be removed from their parents without due legal process. Government should make every effort to provide alternative care within the wider family, and failing that, within the community in a family setting. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.
- (4) Article 24 of the UNCRPD requires that Government shall ensure that children with

disabilities can access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live, and no person with a disability can be excluded from the general education system on the basis of disability.

- (5) The UNCRPD states as general principles that persons with disabilities should receive the support they need within the general system which should offer “reasonable accommodation” of the individual’s requirements.
- (6) The **UN Convention on the Rights of the Child (1989)** deals not only with legal rights but also every child’s right to development - Article 23 states:  
“..... a mentally or physically disabled child should enjoy a full and decent life in conditions which:
  1. *ensure dignity;*
  2. *promote self-reliance, and*
  3. *facilitate the child’s active participation in the community.”*

#### **4. THE CONSTITUTION**

- (1) The impetus for the current policy is to be found in the Constitution, which establishes a human rights based approach. These rights underlie all decision making with regard to legislation, policies and programmes in South Africa.
- (2) The constitutional right of children with SPID to education and support was reasserted in the High Court of South Africa (Western Cape) Case no: 18678/2007.

#### **5. EDUCATION WHITE PAPER 6 ON SPECIAL NEEDS EDUCATION: BUILDING AN INCLUSIVE EDUCATION AND TRAINING SYSTEM**

- (1) Education White Paper 6 proposes a wide vision of inclusive education which has not yet been realised for all children of school-going age. This Policy addresses the gaps in delivery as envisaged in the following definition of Inclusive Education, namely that it aims at:

- i. Acknowledging that all children and youth can learn and that all children and youth need support.
- ii. Enabling education structures, systems and learning methodologies to meet the needs of all learners.
- iii. Acknowledging and respecting differences in learners, whether due to age, gender, ethnicity, language, class, disability, HIV or other infectious diseases.
- iv. Broader than formal schooling and acknowledging that learning also occurs in the home and community, and within formal and informal settings and structures.
- v. Changing attitudes, behaviour, teaching methods, curricula and environment to meet the needs of all learners; and
- vi. Maximising the participation of all learners in the culture and the curriculum of educational institutions and uncovering and minimising barriers to learning.

## **6. THE NATIONAL WHITE PAPER ON THE RIGHTS OF PERSONS WITH DISABILITIES**

- (1) The National Disability Rights Policy: draft identifies policy directives to be followed in implementing the UNCRPD. *Policy Directive 7: Reducing compounded vulnerability* is pertinent here:
  - (a) All legislation detracting from the right to equal recognition before the law for persons with psychosocial and/or intellectual disabilities should be reviewed to bring it in line with the obligations contained in the UNCRPD;
  - (b) All public and private institutions should develop costed action plans to ensure that persons with compounded vulnerability as a result of environmental and/or personal factors, e.g. gender, race, impairment, where people live, socio-economic status, age, qualification levels, cultural beliefs, health status are affirmed, have equal access to all programmes and services, and enjoy specific protection against disease, abuse and human rights violations.
  - (c) Priority should be given to providing technical and financial support to programmes targeting women with disabilities, children with disabilities, persons with psychosocial

and intellectual disabilities living in impoverished and/or rural communities.

- (d) All public and private institutions should provide training for staff responsible for design and planning, budgeting, service delivery and monitoring and evaluation on strategies and measures to reduce vulnerability to exclusion and human rights violations.
- (2) The National Plan of Action for Children (NPAC) 2012-2017, which constitutes the cross-cutting plan for implementation of the Convention on the Rights of the Child, mainstreams the rights of children with disabilities as an integral part of the NPAC.
- (3) The National Development Plan 2030 requires the Department of Social Development to systematise guidelines, norms and standards to ensure that they “take into account the needs of children with disabilities in all communities”.
- (4) The Children’s Act, no 38 of 2005 calls for an enabling environment to respond to the special needs of children with disabilities, and prohibits the exposure of children with disabilities to “medical, social, cultural or religious practices that are detrimental to his or her health, well-being or dignity.” The Act states that “in any matter concerning a child with a disability due consideration must be given to”:
  - (a) providing the child with parental care, family care or special care as and when appropriate;
  - (b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;
  - (c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and
  - (d) providing the child and the child’s caregiver with the necessary support
- (5) The judgement of the High Court of South Africa (Western Cape) in the case of the Western Cape Forum for Intellectual Disability vs. Government of South Africa and the Western Cape (Case no: 18678/2007, November 2010) specifies steps to be taken in achieving the right to education and support services for children with SPID.

This ruling requires all the respondents to provide for children with SPID according to the guidelines of the court and outlined their respective responsibilities.

- (6) The purpose of the current policy is to outline the role of the DBE with regard to ensuring the promotion and protection of the rights of children with SPID within the policy and in compliance with the order of the Court.

## CHAPTER 3

### PRINCIPLES OF THE POLICY

#### 6. TARGET GROUPS

- (1) The primary target group of this policy is children with SPID who function at the lowest levels of development. While it may be contrary to the spirit of Education White Paper 6 to refer to a group of learners in terms of their specific disability, it is necessary for this policy to identify the group. While service delivery is person-centred and based around an individual's aspirations, strengths and needs, service planning requires collation and categorization of demographic health needs information, and it is here that the label of SPID is called for. There is a need for a detailed analysis of the numbers and needs of children with SPID so that rational planning can be carried out.
- (2) The secondary target groups of the policy are the families and caregivers of these children. The high degree of dependence of this group means that their well-being and development is intimately tied to their caregivers. The quality of care that they receive is therefore directly related to the capabilities and the degree of support that families and caregivers receive.
- (3) The third target group is the school community including the district and provincial officials. This policy offers strategies for incorporating education of children with severe to profound disabilities within the provincial and district educational planning.

#### 7. FAMILY AND COMMUNITY INTEGRATION

- (1) Families are the first to be involved with the caring, developing and learning of the child with a disability before any interventions provided by therapists and teachers. They will remain a driving force in the child's life long after all service providers have moved out. It is through collaboration between families and teachers / carers / therapists that children with disabilities receive the most meaningful development and learning experience that could lead to successful outcomes. The high burden of care can be reduced through community involvement.

- (2) Too often, children with disabilities have not been given opportunities to participate in organised community activities. Integration of persons with disabilities within a community can have two major goals:
  - (a) To create opportunities that allow each person with disability to live as fulfilling, self-reliant and whole a life as possible, in close relation with other people.
  - (b) To help other people—family, neighbours, school children, members of the community—to accept, respect, feel comfortable with, assist (only where necessary), welcome into their lives, provide equal opportunities for, and appreciate the abilities and possibilities of persons with disabilities. One of the best ways to bring about better understanding and acceptance of persons with disabilities is to involve both disabled and non-disabled persons in shared community activities.

## **8. ORGANISING PRINCIPLES**

- (1) Children with SPID are capable of learning and have a right to be provided with an appropriate education. Such education should focus on the development of life skills, communication, thinking and perceptual skills and purposeful occupation and vocational training.
- (2) The lifelong dependency of these children must be recognised, Family and community support to meet these dependency needs throughout the lifespan must be developed throughout the educational programme.
- (3) The rights of this group to maximum self-determination needs to be recognised and their ability to make choices must be developed and respected in the educational process.
- (4) The learning programme that accompanies this policy serves as a guideline to teachers/caregivers and can be delivered in a range of educational or therapeutic settings, ranging from ordinary schools through to special schools and special care centres to home based programmes.



- (5) Regardless of where the learning programme is delivered, the Department of Basic Education needs to provide support as outlined in this policy .
- (6) Inter-sectoral collaboration is fundamental to the right to education for this group due to their multiple and complex needs. The provision of community family and community support services, the provision and maintenance of assistive devices, the treatment of health conditions, the building and maintenance of facilities and transport are some of the aspects that need attention from other government departments.

## CHAPTER 4

### REALISING THE RIGHT TO EDUCATION FOR CHILDREN WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY

#### 9. THE NEED FOR AN INTERSECTORAL APPROACH

- (1) At a minimum this policy must address the requirements of the High Court as these are legally binding. The court order outlines an inter-sectoral approach that leaves no gaps in the system that can continue to constitute barriers to learning and participation for these children.
- (2) This policy therefore aligns to others that require inter-sectoral collaboration such as the **Integrated School Health policy (ISHP)** and the **Action Steps: National Model for Care and Support for Teaching and Learning (CSTL)**.

#### 10. CONDUCTING A BASELINE AUDIT

- (3) The purpose of the baseline audit is to determine the scope of the policy by :
  - (a) Identifying the number of children with SPID in special and ordinary schools;
  - (b) Identifying the children with SPID in each province in community based centres (special care centres, residential facilities, in special and regular ECD centres);
  - (c) Identifying the number of children of school going age with SPID who are **at home without services**; and
  - (d) Assessing the needs of children with SPID in all the above mentioned sites through the SIAS protocols to determine the level and nature of their impairments, assistive devices required and family support needs.
  - (e) Identifying the number of personnel in the education sector who have the requisite skills to address educational issues of learners with severe and profound intellectual disabilities

- (f) Identifying availability of resources required to intervene adequately
- (4) The audit will require collaboration between provincial Departments of Education, Social Development and Health. This audit should include information relevant to an integrated inter-sectoral support plan.
- (5) Children with SPID and the services rendered to them must be recorded on the Learner Unit Record and Information Tracking System (LURITS) so as to ultimately ensure sustainable tracking and monitoring within the education system. This should lead to placement of children with SPID on the education system databases and they should be recognised as children in the compulsory school going age and therefore recipients of all education programmes including school health and nutrition.

## **11. INTRODUCING THE LEARNING PROGRAMME**

- (1) This policy includes a learning programme (LP) that outlines the learning and support needs of these children. The LP provides content and assessment criteria to guide caregivers and teachers to create an enabling environment in which children can develop their full potential.
- (2) The DBE will develop a strategy for advocacy, training and implementation of the LP so that the programme can be implemented in a range of institutional and home environments.
- (3) In order to ensure quality education the DBE, in collaboration with the partner departments of Health, Transport, Social Development and Public Works will source adequate funds to support the implementation of the learning programme.
- (4) An important aspect of this will be collaboration with the DoH to allow for the procurement, fitting and management of assistive devices through existing transversal national tenders – provision should be based on needs that have been properly assessed.

## **12. DEVELOPING THE TRANSPORT SYSTEM**

- (1) Lack of transport to and from care centres is a major barrier to education. DBE will collaborate with the Scholar Transport Directorate in the Department of Transport to ensure that children with SPID are not prevented from attending centres due to lack of transport.
- (2) Children with SPID should have accessible and safe transport (including supervision) from their home to the education site (including ECD centres, schools and special care centres) so that the burden of transport does not revert to their families.
- (3) Transport should also be made available to providers that offer education programmes that are delivered at homes and community sites.

## **13. STAFF LEARNER RATIOS**

- (1) The high support needs of these children will necessitate a high staff learner ratio. A carer to learner ratio of 1:4 (for children with physical care needs) and 1:6 (for other children) in Special Care Centres/ Stimulation Centres.

It was noted that this ratio may vary and may need to increase. It must therefore be determined by the level of support needs in the class but should be sufficient to ensure that there is time for education and stimulation as well as care activities.

- (b) The grouping of children should also take into account the level and nature of support needs so as to maximise on the skills and number of staff that are available

## **14. INTEGRATION WITHIN THE EDUCATION SYSTEM**

- (1) The right to education can only be realised through the full integration of children with SPID into educational systems. Based on the baseline audit provincial education departments will plan for this to happen.
- (2) This policy describes a transition process which outlines how children with SPID who are currently educated in special care centres are integrated into compulsory

education provision.

- (3) The policy recognises the critical role currently played by special care centres to deliver services that otherwise do not exist, and outlines the measures that will be taken to enact the transition over a number of years.
- (4) The DBE will provide the learning programme and oversee its implementation in the education system and in special care centres through training and advocacy. They will provide norms and standards for funding as well as for staff provisioning related to service delivery at special schools and care centres.
- (5) Provincial education departments will integrate educational provision for this group of children in their budgets in line with this policy. Budgets will include funding for the baseline, the implementation of the LP and staff provisioning for special and ordinary schools and for the transversal outreach teams.
- (6) The registration and licencing of care centres will be managed in the following way:
  - (a) DSD will be the main registration authority and will register centres in accordance with the norms and standards outlined in the Chapter 5 of the Children's Act, 38 of 2005;
  - (b) DOH will licence the centres in accordance with the Mental Health Care Act, 17 of 2002; and
  - (c) DBE will register the centre in terms of its capacity to deliver a Learning Programmes that complies with criteria set in this policy at Par. XXXX.
- (7) Centres will not receive funding unless they comply with all three levels of registration/licencing.
- (8) All three Departments will be responsible for the monitoring of and support to the centres.
- (9) The Provincial Education Departments will in the short term capacitate the outreach teams to monitor the implementation of the learning programme for all children with

SPID in the province and ensure that they receive services on an equitable basis with all other learners. Provinces will include the needs of children with SPID in the planning and budgeting.

- (10) The admission and retention of children with SPID into special and ordinary schools through the provision of appropriate support will be promoted throughout the education system. The provision of home based care is a last resort that should be subject to the same requirements and processes as home schooling.
- (6) Schools, hospitals and NGOs should be encouraged to run parent outreach programmes for parents, caregivers or siblings of children with SPID on how to stimulate them from birth.
- (7) A cadre of well-trained specialised teachers and auxiliary support staff needs to be developed in accordance with the model applied in ECD. In the age group 0 to 4, caregivers with specialised skills to provide early intervention and stimulation to children with SPID, need to be provided by DSD.
- (8) Where children with SPID are identified within the compulsory school going age, services available within compulsory education should be extended to them. These would include the School Nutrition Programme and School Health services as outlined in the Integrated School Health Policy.

## CHAPTER 5

### HUMAN RESOURCE DEVELOPMENT, UTILISATION AND ACCREDITATION

#### 15. STAFF INVOLVED IN THE DELIVERY OF THE LEARNING PROGRAMME

- (1) There are several categories of staff involved in service delivery to children with SPID. Part of the implementation plan of the policy will be to delineate which posts will be funded by which departments, ensuring that staff who provide whatever form of education or educational intervention, are incrementally transferred into the ambit of the Education Department.
- (2) Personnel working with children with severe and profound intellectual disability should receive adequate and appropriate training to address the educational and other needs of this group of children.
- (3) **Caregiving staff**
  - (a) Caregiving staff are responsible for basic personal care. The nature of the LP requires that these care tasks are integrated into the educational programme. Caregivers are therefore performing an important educational role for which they also need to be trained.
  - (b) Adequate personnel to support the day to day delivery of the learning programme in a variety of sites must be provided.
  - (b) This will require the employment of caregivers to provide direct care to the children or to support parents in this task.
- (4) **Teachers**
  - (a) On-site qualified teachers specialised in delivering the LP to children with SPID in schools, centres and other learning sites.

- (b) Specialist teachers that are members of the itinerant transversal teams working in schools, special care centres and other delivery sites.

**(5) Support Staff**

- (a) Centre based staff who fulfil management and coordinating functions respectively in special care or residential care facilities to support and monitor the delivery of the learning programme.
- (b) Community based rehabilitation workers who may act as a link between the community and service providers by identifying children with SPID, providing home based care and education and maintaining links between service providers and families in the community.
- (c) Social Workers and Social Auxiliary Workers support the learning programme by ensuring that families social and economic needs receive attention and that there is continuity in the provision of care and lifelong learning after the school going years.

**(6) Rehabilitation / Education Professionals**

- (a) Therapists would include physiotherapists, occupational therapists, speech therapists, audiologists, orthotists and prosthetists, play and music therapists.
- (b) It would be critical that services are provided to sites through a transversal service delivery model in accordance with the real needs of each individual site at which services have to be delivered.
- (d) Care has to be taken that there is coordination in the delivery of services between therapists from different departments, the NPO sector and the site itself.

**16. IMPROVING EDUCATIONAL QUALIFICATIONS**

- (1) The multiple and complex needs of children with SPID have previously put care provision in the foreground while stimulation and education programmes have



received less attention. In the special care centres of the Western Cape it was found that only 15% of staff had post-school qualifications. Around 40% of caregivers were parents who had a child in the special care centre. Thus parenting is often their only qualification to care for these children.

- (2) This has resulted in the situation where the learning programmes to support teachers/caregivers in the centres were developed largely by therapists in the health sector. However, these valuable programmes are still not recognised within the Qualifications and do not contribute to career pathways.
- (3) Therefore a cornerstone of human resource development (HRD) for the implementation of this policy is the provision of accredited training for staff across the spectrum of delivery ranging from caregivers to the development of teachers with a specialisation in education of children with SPID. Training should allow for career pathing opportunities for staff. Therefore carers with accredited training can ultimately apply for posts within DBE.
- (4) In the current situation multi-disciplinary outreach teams (including but not limited to specialist teachers, therapists, social workers, psychologists and other staff such as nurses as required by the context) should continue to develop caregiver skills through task shifting and short courses.
- (5) Further education programmes should be developed in accordance with the way in which ECD Practitioners are accredited by SACE. Caregivers of special care centres must also have the opportunity to be placed on a career path within the education sector which would enhance their employment and career opportunities and avoid a situation where people with extensive experience leave centres for other work that offers greater job security.
- (6) More attention should be focused on the needs of children with SPID and their families within existing curricula for therapists, teachers and social workers. To this end there should be consultations with Higher Education Institutions (HEIs) as to how this can be achieved and incorporated into higher education curricula.
- (7) Ongoing in-service professional development needs of teachers, caregivers and

rehabilitation therapists must also be addressed through dedicated and structured programmes coordinated respectively by the Departments of Education, Health and Social Development. The content of this policy as well as the learning programme should be mediated through an incremental roll-out plan collaboratively conducted by the three departments at national and provincial levels, involving all expertise that already exists in the NGO sector.

- (8) The Education, Training and Development Practices Sector Education and Training Authority (ETDP, Services and other SETAs) must become involved in establishing learnerships and skills development initiatives which will benefit this sector.

## **17. SCOPE OF TRAINING**

- (1) The three sectors of education, health and social development must ensure that the qualifications for the various categories of professional staff are expanded to ensure specialisation in delivery of services to SPID.
- (2) Mid-level workers (e.g. Community Development Workers) should receive appropriate training and be accordingly accredited and supervised to implement the Learning Programme in community care centres and on home visits.
- (3) A professional teacher education qualification specifically focused on SPID needs to be developed in conjunction with HEIs. It must be noted that it is unlikely that existing teacher training programmes that focus on special and inclusive education would be adequate preparation for this type of work. Ideally there will be articulation of this qualification with the accredited caregiver and mid-level worker training, enabling a career path for those who wish to take advantage of this.
- (4) DSD will provide for training of staff.
- (5) DOH will provide for training of staff.
- (6) Such training for all staff would need to be part of an integrated human resource development strategy that would take into account the development of the child as a holistic being. It would include knowledge of:

- Individual strengths, needs and interests of the child
  - Health needs, including nutrition and management of medication and toileting
  - Integrated Educational programmes
  - Alternative and augmentative communication
  - Use and maintenance of assistive devices
  - The importance of the role of working with families
  - The importance of the role of, and working with, the community
- (7) Further training in governance to ensure programme implementation should be provided for the facility managers of special care centres or units as a prerequisite.
- (8) Early childhood development training forms the foundation. It must be supplemented with health and rehabilitation knowledge. The current ECD programme should combine community based rehabilitation skills with education skills to be able to equip the trainee further.

## **18. ROLES AND RESPONSIBILITIES OF STAFF**

- (1) The learning programme can be delivered in a variety of contexts with different staffing implications. It is critical that the different sectors involved in the learning programmes are clear about what their role is.
- (2) Caregivers are responsible for the care of children with SPID. Since the aim is to provide an integrated care and education programme, these caregivers need to be specifically trained in the field of SPID and supervised by the education outreach team.
- (3) The services of professional staff could be optimised by organising them in transversal outreach teams with a dedicated task of managing, guiding, mentoring, supporting and monitoring the delivery of the learning programme in the range of sites.
- (4) The categories of professional staff to be included in the transversal outreach support and their role functions will be the following:

### **(a) Special needs teacher**

- (i) To provide ongoing training and mentoring of caregivers on how to integrate the Learning Programme into the daily programme
- (ii) To supervise the development and implementation of an individual support plan for each child
- (iii) To guide caregivers on the development and use of resources to stimulate learning and development.

**(b) Therapists**

- (i) The role of therapists is critical in the provision of education to children with severe and profound intellectual disability. Their skills regarding feeding, seating and communication, amongst others, are much needed.
- (ii) The way in which these skills are shared needs to be within a collaborative model where teachers and caregivers are taught skills and provided with programmes that they can implement with the guidance of therapists.
- (iii) Individual therapy in the home environment could be included where this is justified. As the training of caregivers and teachers becomes more highly developed and less support from therapists is required, there may be more scope for individual work. They will have an ongoing role in the assessment and development of individual support plans for these children.
- (iv) The training and inter-sectoral mandate of therapists should enable them to work in an interdisciplinary team and collaborate with professionals from other sectors (e.g. transport, social development etc.).

**(c) Social Workers**

- (i) The role of social workers also needs to be spelled out. As noted previously, the support needs of this group of learners are lifelong and highly dependent on family provision. Emotional, financial and logistical support to families must therefore be carefully considered and provided through linking to service providers and government agencies.

- (ii) Services for adults with SPID must be developed by the Department of Social Development so that there is a smooth transition from schooling to adult services.
  
- (5) A recruitment process must be introduced to ensure the availability of Occupational Therapists, Speech Therapists and Physiotherapists looking at a range of options such as sessional posts, contract posts, itinerant teams and graduate therapists who have to do their community year service. The options must be negotiated between the Departments of Health, Education and Health Sciences Faculties of Universities so as to come with an integrated actions plan.
  
- (6) The national programme will prioritise deep rural areas where there are as yet no care centres. A community reintegration model must always be the priority option.
  
- (7) All the above steps will be costed so that a short, medium and long term implementation plan can be developed.
  
- (8) A monitoring and accountability system will be set in place.

## CHAPTER 6

### RESPONSIBILITIES OF GOVERNMENT DEPARTMENTS

#### 19. GOVERNMENT DEPARTMENTS INVOLVED

- (1) This draws on the Integrated School Health Policy (ISHP) as a model for interdepartmental collaboration. Like the ISHP this policy requires collaboration largely between the Departments of Health, Basic Education and Social Development.
- (2) However, as was noted in the High court judgement Public Works and Transport have important roles to play in ensuring adequate infrastructure to support education as well as the necessary transport to and from the centre of learning. Collaboration should occur at the different levels of government.

#### 20. RESPONSIBILITIES AT NATIONAL LEVEL

- (1) A national intergovernmental forum with representation from all the above named departments will support provinces in the development, monitoring and implementation of this policy. The steps that are involved include the following:
  - (a) Guide the provinces with audits of provision for children with SPID across the different departments;
  - (b) Make recommendations as to the distribution of roles and responsibilities across departments;
  - (c) Provide technical support for the implementation of this policy;
  - (d) Develop a five year implementation plan across the relevant departments;
  - (e) Develop appropriate norms and standards for the provision of service to children with SPID;
  - (f) Ensure that the resources necessary for implementing this programme are in place and ring-fenced;

- (g) Monitor and evaluate the impact of the policy;
- (h) Identify research priorities for children with SPID in conjunction with Higher Education Institutions;
- (i) DSD must develop a feasible policy for the screening, identification, assessment and support for children between the ages of 0-4. This needs to relate to the SIAS process and link with it. It should be accompanied by advocacy within communities for early intervention as parents do not always understand the importance of this process.
- (j) Furthermore DSD and DBE must work together to establish a smooth transition from education to protective workshops and adult care centres for when the child with SPID turns 18 and is no longer within the compulsory education age range.
- (k) DOH will assess, procure, fit and maintain assistive devices; provide medical interventions; address long waiting times where carers are needed in the facilities; provide outreach and ensure access to ISHP mobile services.

## **21. RESPONSIBILITIES AT PROVINCIAL LEVEL**

- (1) Provincial task teams with representatives from DOH, DBE, DSD, Public Works and Transport and other key stakeholders need to be established.
- (2) The provinces will establish multi-disciplinary teams comprising of professionals working in the field of SPID. They will be responsible for ensuring that all children with SPID have access to quality education and are treated with dignity.
- (2) Key responsibilities include:
  - (a) Develop a five year implementation plan across departments and a detailed implementation plan for the first year
  - (b) Conduct a provincial audit of provision for children with SPID across the different departments

- (c) Make recommendations as to the distribution of roles and responsibilities across departments
- (d) Secure the required financial, material and human resources across departments
- (e) Monitor and evaluate the implementation of the policy
- (f) Develop institutional arrangements to ensure the progressive inclusion of children with SPID into the education system with individual support plans that are supported by all the departments concerned
- (g) Capacitate district offices to implement and monitor projects
- (h) Integrate children with SPID in the compulsory school age into nutrition, school health and other learner support programmes

## **22. RESPONSIBILITIES AT DISTRICT LEVEL**

- (1) The responsibility at the district level is to ensure the provision of educational programmes with appropriate support to children with SPID. Each district should establish a team that is responsible for overseeing such programmes. Where a district based support team (DBST) has been established this team may play this role or a smaller more focused team may be established. The team should develop an implementation plan with clear objectives and indicators which will form part of the district education plan.
- (2) **Each district will need to:**
  - (a) Ensure that the plan for educational provision for children with SPID is developed and integrated into the district education and other relevant plans
  - (b) Allocate a person to oversee and manage the programme
  - (c) Conduct an audit of existing capacity for delivery of the programme
  - (d) Appoint support teams who are responsible for coordinating the provision of services for educational provision for children with SPID
  - (e) Strengthen existing systems for communication, transport, equipment and



referral

- (f) Monitor implementation of the programme
- (g) Conduct capacity building of both health professionals and educators
- (h) Integrate children with SPID in the compulsory school age into nutrition, school health and other learner support programme
- (i) Work interdepartmentally with other departments and stakeholders regarding the management of facilities and care of the child. These can relate to concerns or other referrals that need to be done in the best interest of the children or the facility.

### **23. RESPONSIBILITIES OF SCHOOLS AND CENTRES (ORDINARY, SPECIAL SCHOOL AND SPECIAL CARE CENTRES)**

#### **(1) Ordinary schools**

Ordinary schools can play an important role in supporting the children with SPID

- (a) Provide educational support to those who are delivering the integrated support package
- (b) Share infrastructure
- (c) accommodate children with SPID with appropriate support
- (d) Develop programmes which encourage teachers and children to integrate children with SPID into recreational, sport and arts activities

#### **(2) Special schools**

Special schools are positioned to act as a great support for the provision of an integrated support package.

- (a) Establish learning programmes for children with SPID where possible and maximise their existing capacity for delivery of the programme
- (b) Pool resources for transport

- (c) Offer this curriculum for children with SPID and accept children from community care centres that would benefit from this curriculum or that offered for severe intellectual disability
- (d) Appoint support teams who are responsible for coordinating the provision of services for educational provision for children with SPID
- (e) Strengthen existing systems for communication, transport, equipment and referral
- (f) Monitor implementation of the programme
- (g) Conduct capacity building of both health professionals and educators

## CHAPTER 7

### **RECOGNISING FAMILIES, COMMUNITY-BASED ORGANISATIONS AND THE PRIVATE SECTOR AS PARTNERS IN SERVICE DELIVERY**

#### **24. CURRENT SITUATION IN SOUTH AFRICA**

- (1) Children with SPID are not catered for within the formal education sector. Other than their health needs, which have been accommodated by the Department of Health, the care and support that they have received comes largely from families, community based organisations and NGOs. It is imperative that this contribution be acknowledged and built upon.
- (2) In terms of the requirements of the High Court community based centres should be consulted in the programme planning and their needs in providing support for children with SPID should be supported and seen as a driving force for the implementation of programmes.

#### **25. THE ROLES OF PARENTS' AND COMMUNITY BASED ORGANISATIONS AS PARTNERS IN SERVICE DELIVERY**

- (1) NGOs concerned with vulnerable children, early childhood development and other related matters can be considered as partners in meeting the needs children with SPID.
- (2) Training of ECD caregivers and teachers should include input on dealing with disability in both inclusive and separate centres. There should be recognition of the additional costs that having a child with SPID imposes on the family and poverty alleviation initiatives must pay particular attention to these families.
- (3) The social isolation of families and of children with SPID needs to be addressed through community awareness which is best achieved by getting them out into community activities. The burden of care for families should be alleviated through community involvement that will encourage community participation and alternatives for respite care.

- (4) The lifelong dependency needs of children with SPID must be recognised. The interactions between Departments of Health and Social Development must be strengthened in the Early Intervention phase of 0-4 years so that intervention can be appropriately managed from the outset. It is acknowledged that education does not prepare them for independence alone, but it feeds into lifelong learning. Therefore there also needs to be a seamless transition of service provision and support from DBE to DSD once the child exits the education system

## **26. THE ROLE OF BUSINESS AND THE PRIVATE SECTOR AS A PARTNER**

- (1) Partnerships with business must be explored through the National Education Collaboration Trust in terms of supporting the outreach programmes and provision of expensive assistive devices, support for centres and possible bursaries for teachers as well as community engagement.
- (2) The private sector as an employer needs to be encouraged to accommodate parents in meeting the additional care needs associated with having a family member with SPID.
- (3) Businesses can create school to work opportunities for children with SPID and collaborate with sites of learning in transition to a work environment.

## CHAPTER 8

### SCHOOLS, SITES AND SERVICE DELIVERY MODELS

#### 26. RECOGNISING THE RANGE OF EXISTING SITES

- (1) Currently children with SPID are accommodated in special day care centres and some are residents at special care centres. Others are at home without any educational provision.
- (2) The learning programme of this policy can be delivered in a range of sites with appropriate support. The existing options can be developed as follows:
  - (a) Ordinary schools with a dedicated teacher's assistant and differentiated curriculum.
  - (b) Special schools in appropriate groupings of learners
  - (c) Special day care centres with experienced and appropriately trained staff
  - (d) Inclusive ECD sites with teacher's assistant and differentiated curriculum.
  - (e) Educational provision in residential facilities
  - (f) At home with ongoing support, especially where there are transport and health issues
  - (g) At clinics with ongoing support

#### 27. SERVICE DELIVERY NEEDS AT EXISTING SITES

- (1) All of the existing sites have ongoing support needs from rehabilitation and health staff.
- (2) Well co-ordinated inter-sectoral collaboration is needed in the provision of health care, therapeutic interventions and assistive devices that are fitted, managed and maintained.

- (3) The provision of residential care also comes with an additional range of support requirements and staffing needs.
- (4) Ongoing supervision of staff regarding care of the children in accordance with norms and standards set
- (5) Governance training, mentoring and support for the more informal sites is much needed for them to offer the services and to meet the compliance requirements set in the norms and standards

## **28. SERVICE DELIVERY MODELS TO ENSURE A CONTINUUM OF SUPPORT PROVISION**

- (1) The approaches to applied in accordance with provincial contexts will include the following:
  - (a) Existing special schools can, within the of their role as resource centres, provide outreach services to special care centres. A multi-disciplinary team can also be established at the district or circuit level consisting of learning support teachers, psychologists, therapists and social workers who will act as an itinerant support team to the special care centres, establishing programmes, training, mentoring and monitoring care centre staff (this model is being field tested in the Western Cape). This will require inter-sectoral collaboration to ensure that norms and standards applicable to the centres are adhered to.
  - (b) It is important that children who attend such centres are registered with the provincial education department and are eligible for existing services rendered by all government departments, e.g. infrastructure programmes of Public Works, the National School Nutrition Programme, transport, community health services, provision of assistive devices, psychological, therapeutic and social work services, provision of assistive and mobility devices, etc.
  - (c) Establishing units at existing special schools where learners with high level needs (including children with SPID, with complex and multiple disabilities and

those with autism) can be accommodated (this approach is being followed in KwaZulu Natal with some success). In this model it is imperative that all possible measures would be taken to integrate the programme into that of the rest of the school and that the learners will not be isolated and marginalised.

- (d) Children who are out of school should, as far as possible, be included at existing special schools. Enrolment of this group of learners into special schools for severe intellectual disability should be actively facilitated through a rigorous process of monitoring admissions by Provincial Directorates of Inclusive Education through the implementation of the Policy on Screening, Identification, Assessment and Support.
- (e) It must be taken into account that enrolling learners who have high level support needs will require appropriate staff provisioning and training.
- (f) A multi-sectoral approach is required and should be prioritised at provincial level.
- (g) Provinces need to be aware that whichever approaches they choose, the associated budgets must reflect the funds required to implement. This will be monitored by the DBE.

## CHAPTER 9

### PREPARING THE SYSTEM

#### 29. SYSTEMIC DEVELOPMENT

- (1) All the above approaches to extend services to care centres and incrementally start enrolling learners at special schools are dependent on some preparatory steps to capacitate the system:
  - (e) Developing and implementing a survey and implementation strategy to determine how many children of school going age are out-of-school, where they are and what would be the most appropriate service delivery model for them in their respective settings.
  - (f) Capacity building of staff at the Special Care Centres by the multi-disciplinary teams that have themselves been trained on latest best practice regarding the developmental, social and health needs of learners with intellectual disability. Special Care Centre staff should further be included in existing staff development programmes of Special Schools as part of the professional support strategy.
  - (g) Clustering of centres in relation to existing special schools and multi-disciplinary teams.
  - (h) Negotiations on job descriptions of special educators and time allocated for these outreach services which will also involve time tabling at the special schools.
  - (i) Introducing a short course within the Integrated Teacher Development Programme for existing teachers at special schools for severe and SPID on how to address the needs of children with SPID.
  - (j) Upgrading of physical infrastructure at most neglected care centres through Public Works infrastructure programmes. Since many centres are not on government owned land, the DPW may not build on this land but they may consult on upgrades. They may also allocate land/buildings which are vacant at



rentals that are lower than market related prices.

- (k) The Department of Transport should provide various options for making transport of learners accessible and grow the existing structures to include SPID. Transport resources for staff across the departments conducting the necessary outreach activities (e.g. visiting schools/ special care centres) must also be included.
- (l) Procurement, fitting and management of assistive devices through the transversal national tender processes– provision should be based on needs that have been properly assessed. Maintenance of assistive devices and client seating services and postural management processes need to be set up and implemented.
- (m) A recruitment process must be introduced to ensure the availability of occupational therapists, speech therapists, physiotherapists and social workers looking at a range of options such as sessional posts, contract posts, itinerant teams and graduate therapists who have to do their community year service. The options of placement of the community service year incumbents must be negotiated between the Departments of Health, Education, Social Development and Health Sciences Faculties of Universities so as to come with an integrated actions plan.
- (n) A critical intervention is to consider making use of community rehabilitation workers as mid-level workers who can visit centres and also maintain the link to the home of the children and their families. Models such as used in India can be explored where CBR workers are supplied with motor bikes to visit families in remote rural villages.
- (o) Special schools in collaboration with specialist NPOs should further be encouraged to run parent outreach programmes for parents, caregivers or siblings of young children with severe and SPID on how to stimulate them from birth.
- (p) The national programme should prioritise deep rural areas where there are as yet no care centres. A community reintegration model must always be the priority option.

- (q) All the above steps need to be costed so that a short, medium and long term implementation plan can be developed.
- (r) A monitoring and accountability system should be set in place.
- (s) Teacher and caregiver training based on identified competencies within SAQAs should be developed and offered by HEIs and TVETCs.
- (t) Service delivery implications require that provincial budgets and processes be put in place across the concerned departments. The respective responsibilities of the different departments need to be spelled out and budgeted for.
- (u) Assessment that focuses on the appropriate placement of learners and the level of support they require must be in place. A holistic intervention plan including the individual support plan should be compiled guided by the SIAS.
- (v) Orientation and training on guidelines for education of children with SPID will need to be carried out at the relevant levels of the DBE and provincial education departments.
- (w) The provincial education departments need to ensure that children with SPID receive funding on a par with other children in a service package that may include caregivers, professional staff, provincial district or schools based, transport to clinics, consumables, LTSM, play equipment and other resources.
- (x) Implementation of the policy will necessitate transitional arrangements and the streamlining of systems and legislation, specifically stipulations of the Children's Act, School's Act and Mental Health Care Act.

## **ANNEXURE A:**

### **CHILDREN WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY AND THEIR CONTEXT IN SOUTH AFRICA**

#### **1. DESCRIPTION OF CHILDREN WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITY**

- 1) Children with SPID function at the lowest levels of development. They exhibit significant developmental delay and although they are able to learn daily routines and aspects of self-care, they will always need a great deal of care and supervision (Department of Paediatrics, 2013).
  - a) Such children frequently experience multiple impairments including profound or severe motor disabilities, sensory disabilities, seizure disorders, chronic pulmonary infections and skeletal deformations. The DBE will work with the definition of intellectual disability as defined in the Diagnostic and Statistical Manual of mental disorders, the DSM-5 (2013) (see definitions in the glossary).
  - b) The specification of an IQ score is not definitive for the diagnosis of SPID as: "IQ test scores are approximations of conceptual functioning but may be insufficient to assess reasoning in real-life situations and mastery of practical tasks." (DSM-5, 2013) Therefore, within this definition levels of severity are not determined by IQ scores but by levels of functioning.
  - c) For children with SPID, their impairment is a chronic, lifelong condition, requiring high levels of support if they are to engage meaningfully socially or educationally. They will continue to require high levels of personal care through their lives. Thus the role that parents play is a very important one. They are often spokespersons for their children, as their children cannot speak for themselves and are therefore essential in communicating the needs and wishes of their children and should be considered as experts in their care.

- d) While family caregivers are committed to the care of their children with SPID, caring is a heavy responsibility. Caring tasks include physical management - lifting, handling and positioning - and care activities including dressing, bathing and toileting, as well total assistance at mealtimes. The management of epilepsy and tube feeding as well as meeting other healthcare needs will also require close attention. Hogg (1999) cites a study where parents report that on average they spend 7.5 hours per day in these activities. It is not surprising that parents therefore feel the need for respite care where their child can be well cared for and the rest of the family can have a break from caring duties. Currently there is almost no provision for this kind of service in South Africa.
  - e) People with profound intellectual disabilities are more vulnerable than their peers of the same gender and age to abuse. Of particular concern is the prevalence of epilepsy with 64% of children and 59% of adults reported as having seizures “occasionally” or “frequently” (Hogg 1999). Training in the management of epilepsy for professional and family caregivers is therefore very important.
  - f) Many children with SPID have significant difficulties with feeding due to a variety of causes. Both dehydration and undernourishment can result from such difficulties. Many people with severe to profound intellectual and multiple disabilities exhibit significant challenging behaviours inter alia, particularly making disruptive sound or noises, self-injurious behaviour and eating inappropriate objects or substances (Hogg, 1999).
- 2) In the Western Cape where an audit was carried out by the DBE and other relevant role players, the number of children in the 44 special care centres in the Western Cape is estimated to be approximately 1500. However, there are many other children that are not in such centres. Kleintjes, Flisher, & Fick (2006) estimate an incidence of profound intellectual disability (SPID) in the Western Cape of 0.15% of the population, amounting to around 8700 individuals according to the Western Cape population of in the region of 6 million in the 2011 census (Statistics South Africa, 2012). Approximately one third of the population in the Western Cape is under 18

(Statistics South Africa, 2012) and when extrapolated to children with SPID, this suggests that there are approximately 3000 such children in the Province. This is a very rough estimate that may or may not apply to other provinces, but it does indicate that the numbers of children with SPID are relatively small but often neglected by services.

- 3) Currently children with SPID are cared for by their families, who in cases where they have low incomes, receive social support in the form of a care dependency grant. Such children are generally not accepted into regular schools on the basis that their levels of support exceed those which the school is able to provide.
- 4) In addition, they are not admitted to special schools, often because special schools tend to focus on a specific impairment whereas this group of children is likely to have multiple disabilities (e.g. sensory and physical and intellectual). A further barrier to schooling exists where such children are not toilet trained. The work and the cost involved in dealing with a child in nappies is not currently accommodated within special schools.
- 5) The consequence of this lack of provision is that many parents, with the support of non-governmental agencies, have established day care centres to provide for their children. The important role that these centres play is widely acknowledged as is the need to support the centres with resources and skills development.

## **2. CURRENT PROVISION FOR CHILDREN WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY**

- (1) Partial care centres: Many children with SPID are accommodated in Partial Care facilities that are registered with the Department of Social Development in terms of the level of development of the centre, which is conditional registration for the centres that are still in the process of meeting the required standard. Full registration is given to a fully established and developed facility that meets all the required norms and standards. These centres provide temporary respite care for disabled children between the ages of 0 – 18yrs.

- (2) Formal care centres/schools: These are privately run centres that provide high support needs services that are paid for by parents through school fees and which are supplemented by fund raising. For example, Pathways in Pretoria runs a comprehensive programme for children as well as a small business facility for young adults. They offer outreach services on a consultancy basis.
- (3) Outreach programmes: In urban centres various NGOs offer services ranging from stimulation centres and protective workshops to outreach services training of caregivers. For example, the Sunshine Centre Association in Gauteng offers specialised stimulation and early intervention programmes catering specifically to the needs of children with developmental delays and intellectual / physical disabilities. They do this by supporting early intervention centres and offering training programmes for parents and teachers. Their START manual and programme is well-established and can be applied in a variety of contexts.
- (4) Umbrella organisations: The Western Cape Forum on Intellectual Disability acts as an umbrella training and advocacy organisation for many of the special care centres in the province. Alternatively a multi-disciplinary team could be established at the district or circuit level consisting of special needs teachers, psychologists, therapists and social workers who will become an itinerant support team to the care centres, establishing programmes, training, mentoring and monitoring care centre staff (this model is being field tested in the Western Cape). Capacity building of staff at the Special Care Centres by the multi-disciplinary teams that have themselves been trained on latest best practice regarding the developmental, social and health needs of learners with intellectual disability. Special Care Centre staff should further be included in existing staff development programmes of Special Schools as part of the professional support strategy. Upgrading of physical infrastructure at most neglected care centres through Public Works infrastructure programmes. Making transport arrangements for learners to be brought to the schools / centres as well as for the multi-disciplinary teams to visit the schools.
- (5) In deep rural areas there is little provision. In rural Manguzi for example, therapists report that children with SPID are not visible in the community. They are not at any facility, and it is assumed that they must be at home. They are rarely seen at the

clinic, usually only when parents would come and ask for nappies. Rehabilitation therapists support them by issuing wheelchairs and sometimes trying to control self-injurious behaviour and getting medication.

- (6) Community based centres: Many parents, with the support of non-governmental agencies, have established day care centres to provide for their children. These centres vary in the degree to which they are formalised and make use of community resources. For example, the Amass centre in Acornhoek Limpopo gets funding from Lotto, the Department of Social Development, private funders from overseas as well as donations in kind from the community. The children are transported to the centre by a bus that was donated to them and they are cared for by carers with matric level education.
- (7) The important role that these centres play is widely acknowledged as is the need to support the centres with resources and skills development. Many of these centres have very poor facilities due to lack of funding. Experience within special care centres in deep rural areas indicates that many children in community based special care centres require a more formal educational programme and should be accommodated in existing special schools. Similarly children with multiple impairments might be incorrectly viewed as having an intellectual disability and therefore be excluded from programmes that are better suited to their intellectual level.
- (8) In many rural areas, outreach to community centres is undertaken by the rehabilitation therapists of the local hospital. This is the case for Amass centre where therapists (some of whom are on community service) and students visit and support the centres. While they are often willing to do so, these therapists may have difficulties getting allocated transport and in gaining official sanction for this role in the community.
- (9) Special schools: Some existing special schools have established units at which learners with high level needs (including children with severe and profound intellectual disability, with complex and multiple disabilities and those with autism)

can be accommodated (this approach is being followed in KwaZulu Natal with some success).

- (10) Home based programmes: Currently such programmes would largely be run by therapists in health facilities. The format would be a parent support group where parents meet and receive education on how to carry out a home programme with their child. In some instances such a home programme might be supported by visits from a community health or rehabilitation worker (such as in Acornhoek in Limpopo).



## **ANNEXURE B:**

### **PRINCIPLES OF EDUCATION FOR CHILDREN WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY**

- (1) Children with SPID have previously been classed as ineducable and therefore not the concern of the Department of Education. The current evidence suggests otherwise as these children do learn albeit in a different way to other children (Downing & MacFarland, 2010). They can acquire self care skills, communication skills, social skills and safety skills. Some have developed basic academic skills in literacy and numeracy. The judgment of the High Court of South Africa reinforces this view and states children with SPID are entitled to an appropriate education as their constitutional right within South Africa. The DBE is therefore challenged to incorporate this group of learners within educational provision and this is the concern of this policy and .
- (2) Children with SPID require lifelong care and therefore education needs to engage the families if it is to contribute to a meaningful life of good quality for these individuals and their families. Their needs over the lifespan are multiple and complex. Foremost amongst these is a good quality of care that is respectful and competent. As family members are most likely to provide this care there must be a partnership between parents and service providers in providing the care. Education and skills development focuses on increasing the individual's capacity for self-care and communication skills. There will also be a need to develop motor control which may include finding the most effective posture or position for the child and sufficient swallowing and oral coordination as well as skills of social interaction with adults and peers according to her abilities. Furthermore such children will frequently require assistive devices such as wheelchairs, standing frames, specialised seating etc. that needs to be fitted and maintained for maximum benefit to the child. These devices must be available to the child at school and at home.
- (3) Ongoing care is required outside of the compulsory schooling ages, both before in early childhood development and after in transition to work. Educational provision must take this into account and focus on building links with other sectors so that there can

be a smooth transition between these phases and a continuity of care. Care consumables such as nappies and special foods must also be factored in to provision of care and educational services.

- (4) Current best practice in education for children with SPID (adapted from Downing & MacFarland, 2010) confirms the following principles:
  - (a) Highly Trained Teachers - To ensure that learners with severe disabilities reach their full potential highly qualified teachers need to be skilled in positive behaviour support, communication skills development, systematic instruction, meaningful, age-appropriate programming, active family involvement, and collaborative teaming.
  - (b) A New Way of Thinking - The deficit mode of thinking about learners with disabilities needs to shift from a perspective of caretaking and protecting to an expectation of learning and growth. The expectation is that children can learn given the right types of instruction and support. While early intervention is a recommended practice, learning can occur at any age.
  - (c) High Expectations - Providing the necessary types and amount of support can greatly enhance the child's ability to learn and achieve. Therefore, emphasis is placed, not on what the child cannot do, but rather on the supports that they need to achieve to their maximum potential. In terms of this policy this requires that an individual support programme for each child be developed. Furthermore, there is a growing trend toward teaching self-determination skills. Self-determination skills can include simple choice-making, as well as more advanced skills, such as decision-making, problem-solving, goal setting, self-monitoring, and self-evaluation. When students learners can learn to advocate for themselves, the dependence on others is reduced.
  - (d) Inclusive Education - Another change in thinking involves the issue of where children with SPID should receive their education. They have been shown to benefit from learning with their peers in general education classrooms. Bringing students learners together rather than keeping them apart has shown considerable merit.
  - (e) Greater Community Involvement - Children with SPID can leave the school system

and assume meaningful roles in their communities provided that they are given needed support and encouraged to partially participate in activities. Educating students learners with severe disabilities in the natural environments of their neighbourhood and community supports their ability to assume more typical adult roles upon completing their basic education. Through supervised employment, volunteer work and/or service learning, children with SPID can develop valuable skills for adult life while giving back to their community.

- (5) Recommended Practice for Teaching children with SPID/SPID (adapted from Dowling and MacFarland, 2010)
- (a) Supporting the changes mentioned above are recommended practices in the teaching of students with severe disabilities. These recommended practices include: systematic and direct instruction within natural learning environments; individualised, meaningful and culturally responsive learning; active family involvement; collaborative teaming; and positive behaviour support.
- (b) Systematic Instruction - When teaching children with SPID, the use of systematic and direct instruction is highly recommended. This consists of a well laid out compiled plan of teaching that involves targeting and evaluating what students can learn given meaningful opportunities to practice their skills. Such instruction involves specific procedures for identifying, prompting and reinforcing targeted behaviours, within typical age-appropriate environments. Assessment data is used both to measure student progress and to provide teachers with important information used to modify and change instructional programs. Systematic instruction is used to teach both academic skills and non-academic skills (e.g., communication, self-care, self-determination), and can occur in typical classrooms at schools as well as in the community.
- (c) Individualised, Age Appropriate and Culturally Responsive Learning - Recognising the needs and strengths of children leads to individualised instruction that is chronologically-age appropriate, culturally responsive and meaningful for the student. learner Researchers have stressed the importance of considering the child's interests as well as cultural implications when teaching various concepts.

- (d) Active Family Involvement - Given the importance of meeting individual needs that reflect cultural differences, religion, experiences, and language, active family involvement to assist with assessments and determining instructional programs for a particular child is a recommended practice. When children are unable to speak for themselves, which is often the case for students persons with severe disabilities, information from family members regarding expectations at home, skills and interests of the child, concerns, and future goals serves to guide educational programs. The home-school relationship is vital. Approaches to obtaining information from families are designed to keep the individual student as the focal point, with those closest to the student using their in-depth knowledge and caring for the person to guide their comments and hopes for the future.
- (e) Collaborative Teaming - This teaming approach prioritises the collaboration between the families of individuals with SPID and teachers to develop and implement intervention and support strategies. Collaboration among team members includes shared assessments and development of instructional programs, co-teaching in age-appropriate classrooms by special and general educators, use of natural peer supports, and use of related service providers, such as speech-language therapists, who provide support within natural learning environments. Members of the team pool their resources and knowledge to support the overall learning goals of the student, rather than isolated skills representative of one discipline.
- (f) Post-secondary Options - Person-centred exit planning should be done for individual learners. Perceptions regarding future options for children with SPID also have changed. In the later school years, all children are preparing to transition to their adult life, whether they plan to go to further education or directly go into the work force. Since generalisation of skills is often difficult for those with SPID to acquire, learning in the actual community, or community-based instruction is usually preferred.

## **ANNEXURE C:**

### **INTERNATIONAL AND NATIONAL CONTEXT**

#### **1. International context**

- a) In Finland, 75% of teachers working with children with SPID have a diploma in special education. Teachers use a developmental curriculum based on normal development. They find that choosing inclusive methods for teaching and providing a curriculum model for students diagnosed as having intellectual disabilities is a challenge in Finland (Kontu & Pirttimaa, 2010).
- b) In the Netherlands there are high levels custodial care and less developmental work for learners with profound intellectual and multiple disability (PMID). There may be non-performance of therapy due to health concerns and hence inactivity. In the Netherlands, a national curriculum for these children is not (yet) available and as a result the number, type and frequency of activities and therapies that are being offered can be very diverse. Teachers are special education trained and therapists were specialists in their field. Up to a third of planned therapies and activities for individuals with severe to profound intellectual and multiple disabilities simply do not take place not only because of the absence of the child but also because of the absence of the professional or planning difficulties (Zijlstra & Vlaskamp, 2005).
- c) Also in the Netherlands, only a small number of studies that describe inclusion of children with PIMD in general schools are available. When inclusive education was introduced, the focus was on students with relatively mild disabilities: This focus shifted more and more toward the inclusion of students with PIMD only in recent years. Now a growing number of initiatives are being under-taken, which focus explicitly on the inclusion of children of this target group. No teacher training program is available to prepare teachers for the inclusion of children with PIMD and hence there is some uncertainty as to how they may best be included (de Boer & Munde, 2014).
- d) In The United Kingdom the provision of education for children with severe to profound and multiple disability is largely offered within special schools. However, Simmons and Bayliss (2007) critique the notion that inclusion in mainstream schools is not an option for

this group of children. They base this critique on research that shows that teachers in special schools struggle to meet the needs of this groups of children as they do not have specific training. In addition the centrality of social interaction in enhancing learning for children with SPID indicates that they might benefit from more inclusive mainstream environments (Simmons & Bayliss, 2007).

- e) In India it was found that the role and impact of parents as co-trainers in a joint multidisciplinary team effort directed at children with severe learning disability and complex needs is very significant. They recommend that involving parents as co-trainers in all early childhood education/training programmes will yield better and effective progress in the child and will develop a healthy teacher–parent relation-ship. In India there was a strong emphasis on building a healthy relationship between parents and professionals, based on mutual trust, understanding and sharing to solve their emotional and social issues related to their children. Furthermore they recommend regular meetings with parents where mutual accountability between parents and teachers/ caregivers is encouraged and developed. (Kurani, Nerurka, Miranda, Jawadwala, & Prabhulkar, 2009).
- f) The overall impression of the international context is that the inclusion of children with SPID within the education system is in its early days. While South Africa has much to learn from these experiences, the implementation of this policy will also contribute to the international engagement with this issue.

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