



Western Cape
Government

POLICY FRAMEWORK- SERVICES TO PERSONS WITH INTELLECTUAL DISABILITY

**REVISED NOVEMBER 2014
Approved by Cabinet February 2015**

Table of contents

| | |
|--------------------------------------|------|
| Foreword | p 3 |
| Executive summary | p 4 |
| Abbreviations and acronyms | p 9 |
| Purpose of Policy framework | p 10 |
| Background | p 10 |
| General Principles | p 11 |
| Legislative framework | p 11 |
| Definitions | p 13 |
| Burden of Disease | p 14 |
| Categories | p 16 |
| Models of Support/ service delivery | p 20 |
| Care acuity for Residential services | p 25 |
| General principles for funding | p 26 |
| Core functions of each department | p 27 |
| Human Resources and Training | p 30 |
| Monitoring and Evaluation | p 30 |
| Implementation plan | p 30 |
| Reference Group | p 31 |
| Reference List | p 32 |

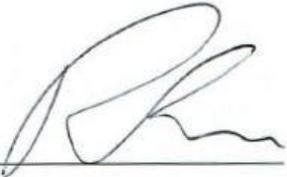
FOREWORD

The Western Cape Government is committed to support our citizens with Intellectual disability. It is through this policy that the coordination of services to Persons with Intellectual Disability are set.

This policy provides the statistics; principles and guidelines for implementation of services to PWID which have been previously overlooked. The implementation strategy will be reviewed annually in line with the policy.

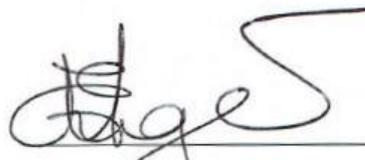
This document is the culmination of work between the various WCG departments to ensuring that delivery of services to this previously marginalised group are now coordinated, streamlined, planned for and implemented.

The task team would like to express our appreciation to all the provincial departments for their inputs as well as their commitment to ensuring that effective and efficient services are delivered to our clients.



2016 -08- 24

Dr. Robert Macdonald
Head of Department
Social Development



Dr. Beth Engelbrecht
Head of Department
Health



 Ms. Penny Vinjevold
Head of Department
Western Cape Education Department



Ms. Jacqui Gooch
Head of Department
Department of Transport and Public Works

EXECUTIVE SUMMARY

Purpose

People with Intellectual Disability have significant, variable, but lifelong needs across the health, social care and education spectrum. There is no single sector that can fully meet the needs of individuals and their families across their lifespan. For government to enact the person-centred approach to People with Intellectual Disability (PWID) and their families as promoted by the World Health Organisation, it is essential that a policy framework exists for:

- 1) **Determining the profile of needs of the PWID across sectors**
- 2) **Determining the appropriate departmental roles, responsibilities and potential funding models to meet the needs identified**

Background and General Principles

1. The majority of PWID in the Western Cape only access government services such as health-care, social-support and educational-support when needed. It is estimated that there are approximately 180,500 people with varying degrees of Intellectual Disability in the province.
2. Only 2.1% (3 828 out of 180 500) currently have access to community-based support (day-care, workshops or residential placements) which only forms a part of the service-delivery platform. This means that the majority are being cared for by their parents/relatives at **their own** cost
3. Where previously the focus was on institutional care the emphasis has now shifted towards an integrated community-based model. Only 600 people remain in hospital based residential care at Alexandra and Lentegeur Hospitals. This approach is not only in the best interests of the individual and family, but may also ultimately reduce costs for governments.
4. There is now a clear drive from service providers across governmental and non-governmental sectors to provide the PWID with every possible opportunity to live in a community-based environment [stay as long as possible in an appropriate non institutional environment
5. Furthermore, it is unacceptable that individuals with ID and their families do not play key roles in decision-making about the needs of the PWID.
6. The prevalence of behaviour that challenges is significantly **higher** in people with Intellectual Disability who have a diagnosed psychiatric illness (such as mood disorders, anxiety disorders) and therefore there will always be a certain proportion of people requiring specialised services. At any one time between 40-50% of PWID will have such behavioural challenges and up to 80% of PWID will have some of these difficulties at some point in their life.
7. Not all challenging behaviour is attributable to mental illness. Other reasons may include pain, physical illness, communication difficulties, sensory issues, environmental changes or abuse. Each of these reasons may require a different intervention or support.

Current Categories and funding model

At present the financial responsibilities of departments are determined according to the IQ level of the PWID. It is clear that this approach is over-simplistic, not person-centred and does not provide sufficient flexibility to identify needs and required services. The current funding model also does not provide adequate consideration of **core functions** of individual governmental departments which may have led to inappropriate use of resources. Current transversal financial responsibilities are outlined below:

| Category | IQ range | Departments | Services |
|--------------------------------|-----------------|-------------|---------------------------------------|
| Profound ID | IQ under 20 | DOH | Day care and residential |
| Severe ID | IQ 20- 34 | DOH | Day care and residential |
| Moderate ID | IQ 35 – 49 | DSD | Group Homes and workshops |
| Mild ID | IQ 50 – 69 | DSD | Group Homes and Workshops |
| Moderate and mild (6-18 years) | 50-70 | Education | Special schools |
| All categories | IQ 70 and below | SASSA | Disability and care dependence Grants |

There is no specific provision made for PWID with behaviour that challenges in the current system.

Determining appropriate funding arrangements

It is of key importance to develop a revised approach to funding in a manner that is more targeted and needs-based. There are a number of international human-rights and governmental imperatives that provide the framework for such a revision:

1. Person-centred approach

In order for government to provide a truly person-centred service a fundamental shift is needed in how the person with Intellectual Disabilities is perceived. The current funding model assumes that all PWID in a certain IQ category will have the same level of need and that they will remain in the same category of functionality with no potential for growth, positive outcomes or change. The service needs to focus on the individual first with abilities strengths and interests together with limitations. It includes the right to fully participate to the best of their abilities in decision, being able to make choices and where possible include the person in setting personal goals and outcomes

2. Moving from IQ to adaptive functioning (ICF)

In general a PWID should be assessed and re-evaluated to determine individual outcomes. The assessment should be primarily based on the adaptive functioning of the person together with IQ. This will form a matrix of support needs that would aid decisions regarding funding allocation. Functional assessment will include aspects such as mobility, self-care, communication, inter-personal relationships and other strengths and weaknesses.

3. Individualised assessments

In order to identify needs, all PWID should be assessed individually. This should as a minimum be done on first referral to generate a baseline of needs. Further evaluations should be performed when a change in needs may have occurred. An agreed-upon inter-sectoral assessment tool should be used as a baseline for determining: 1) individual support needs 2) at what level the service should be accessed and 3) which department should take responsibility. The tool should include aspects on behaviour that challenges within Intellectual Disability.

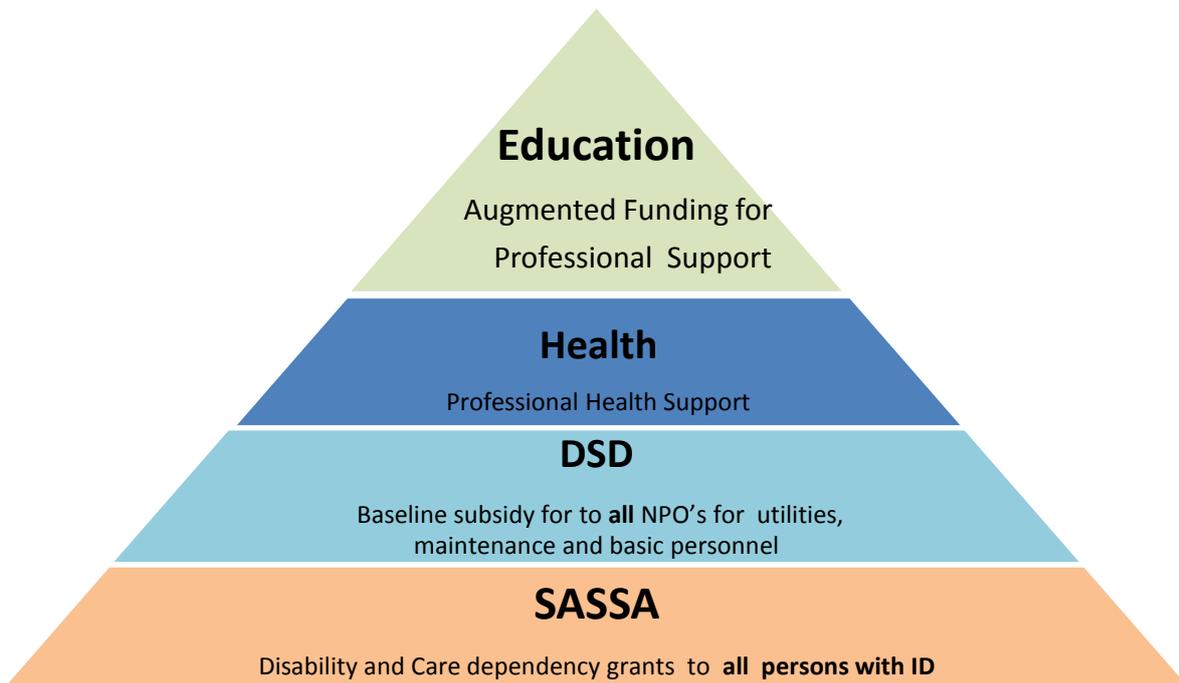
4. Core functions of departments

The lack of well-defined national strategic direction and legislation forced provinces to use their own initiatives with regard to funding of services for PWID. In some instances (such as community-based services) departmental financial responsibilities are not aligned with core functions of departments. To allocate resources appropriately this should be done as a matter of priority.

4.1 Proposed funding arrangements

- 1. A fundamental shift in policy direction is proposed where departments re-align their services to shift emphasis from a purely IQ-based to a needs-based approach to consider how PWID and their families can be supported at service delivery level.**
- 2. Departments prioritise service delivery around their core functions as spelt out in the broader document.** The biggest impact of accepting proposals 1 and 2 will be seen in the provision of community-based services as all other services such as health-care and social support are integrated into general services.
3. Currently all community-based services are largely outsourced to NPOs who are able to offer the service at a more cost-effective rate.
4. There remains a large unmet need which would require a strategic intersectoral developmental plan. This should include aspects such as
 - Developing a data base of persons on waiting lists of NPO's, persons registered with social development offices, SASSA and patients of health establishments
 - Phase in an assessment process to determine the individual and the family's needs
 - Compare current resource with unmet needs taking into consideration equity and access
 - Create a developmental approach for capacity building of NPO's and public services to support families within current structures
 - Annual budget planning process specifically looking at the extension of community based services to PWID with regards to unmet needs. This should be an inter-sectoral process based on core functions.

4.2 Implications of policy shift



4.2.1 Implications for SASSA

- a) Provision of Disability and care dependency grants remain **unchanged**

4.2.2 Implications for Department of Social Development (DSD)

- a) Centralised coordination
- b) Ensure implementation
- c) Ensure Policy alignment
- d) Facilitate joint M&E activities -Licencing, quality assurance, and compliance
- e) Coordination of all funding activities (SLAs; TPAs)
- f) Collaboration with National Departments

**For further details refer to implementation plan*

4.2.3 Implications for Department of Health (DOH)

- a) Licencing of Mental Health Community based facilities
- b) Medical care at health establishments
- c) Clinical and medical support to facilities
- d) Assistive devices and outreach clinics
- e) Integrated School health programme

** For further details refer to implementation plan*

4.2.4 Implications for Department of Labour

- a) Co- ownership of funding protective workshops with taking full responsibility in future

4.2.5 Implications for Non Profit Organisations (NPOs)

- a) Re-alignment of services according to support needs and funding available
- b) Ensure all new applicants to centres be assessed through a standardized assessment
- c) process which could implemented across the sector which will guide the intervention
- d) process

4.2.6 Department of Education

- a) Curriculum development
- b) Training and capacity building
- c) Provision on norms and standards for formalising educational setting
- d) Quality assurance of curriculum delivery
- e) Care and Support for Teaching and Learning (CSTL) framework
- f) Integration strategy to be developed
- g) Appropriate placement of learners into formal education setting

** For further details refer to implementation plan*

13.7 Department of Public Works and transport

- a) Provide infrastructure support
- b) Provide upgrade funding
- c) Provide capital funding allocation
- d) Provide support for maintenance
- e) Assist with plan and implementation of transportation of children

** For further details refer to implementation plan*

13.8 Municipalities

- a) Capacity building of organisations
- b) Access to land
- c) Rezoning and Health clearance certification
- d) Non – compliance issues
- e) For further information refer to implementation plan

ABBREVIATIONS AND ACRONYMS

| | |
|------|--|
| CBS | Community-based services |
| CCW | Community care worker |
| DHS | District Health Service |
| DOH | Western Cape Government Department of Health |
| DSD | Department of Social Development |
| HCBC | Home and community-based care |
| ID | Intellectual disability |
| NPO | Not for profit organisation |
| PHC | Primary Health-care |
| PWID | People with intellectual disability |
| WHO | World Health Organisation |

1. Purpose of Policy framework

Persons with Intellectual Disability (PWID) have significant and lifelong needs across the health, social care and education spectrum and there is no single sector that can fully meet the needs of individuals and their families across their lifespan. A person centred approach for PWID and their families it is required and it is essential that a policy framework exists to:

- 1) Determine and define the support-needs of the PWID in terms of service delivery and then,
- 2) Determine the appropriate government departmental roles and responsibilities in such a support-needs model.

2. Background

The majority of persons with ID and their families only access government services (such as health) when necessary and may be aware of services such as day-care or residential care but prefer to provide care themselves or for various reasons, cannot access community based services. Where the focus was previously on institutional care, that focus has now shifted to family or community-based settings. So although there is a large unmet need, not all families may wish, or are able to optimally make use of services.

Some services are offered within government structures and facilities but community-based services for PWID in the Western Cape are currently delivered mainly by the NPO sector with financial support from the Departments of Basic Education, Social Development and Health. In some instances more than one department is involved in contributing towards service-provision.

Non-Profit organisations are able to offer more sustainable service at a much lower cost to government due to their ability to augment funding through fundraising, and less acuity requiring a different level of staff.

Community-based services are supported by different government departments which has caused confusion and in some cases, not taking responsibility for their roles.

Formulating a transversal policy framework will promote effective and efficient service delivery and should provide clear guidelines to services providers and departments.

3. General Principles

The following principles underpin the content of this document:

- 3.1 Consideration should be given to the basic rights of dignity, equality and access to services for persons with Intellectual Disability as set out in the Constitution of the Republic of South Africa, 1996, ((Chapter 2: Bill of Rights).
- 3.2 Social Integration with the focus on facilitating inclusion and integration into main-stream society as appropriate and possible
- 3.4 Person -centred quality of care together with a recovery-based approach.
- 3.5 A move towards an outcomes-based approach
- 3.6 Building strategic partnerships and inter-sectoral collaboration
- 3.7 All PWID should be viewed as citizens where multi-sectoral services and care are equitably accessed
- 3.8 Cost effectiveness and sustainability of services
- 3.9 Strengthening of the District based model of health service delivery.

4. Legislative framework

The following legislation pertains

- 4.1 The Constitution of the Republic of South Africa Act, 108 of 1996
- 4.2 UN Convention on the Rights of Persons with Disabilities
- 4.3 Children's Act (No 38 of 2005)
- 4.4 Non-Profit Organizations Act No 71 of 1997
- 4.5 Older Persons Act No 13 of 2006
- 4.6 Mental Health-care Act, 17 of 2002
- 4.7 National Health Act, No 61 of 2003
- 4.8 National Mental Health Policy framework
- 4.9 South African Schools Act (Act 84 of 1999)
- 4.9 White Paper 6, Special Needs Education, Building an Inclusive Education and Training System, July 2001
- 4.10 Education for All (EFA) Action Plan to 2014: Towards the realisation of schooling 2025, Department of Basic Education, 2010

- 4.11 Care and Support for Teaching and Learning, Department of Education,
- 4.12 National Strategy for the integration of services for children with disabilities,
Department of Social Development, August 2009
- 4.13 Intergovernmental Relations Framework Act, 2005
- 4.14 Western Cape Integrated Provincial strategy, 2002
- 4.15 National Policy on the provision of Social Development Services to People with
Disabilities , May 2013
- 4.16 Health-care 2030
- 4.17 White paper 6 on Special Needs Education
- 4.18 Social Assistance Act , No 13 of 2004
- 4.19 National Policy on the Provision of Social Development Services to People with
Disabilities (DSD)- May 2013

5. Definitions

5.1 Disability

Disability refers to the loss or elimination of opportunities to participate equitably such as having physical, sensory, psychological, developmental, learning, neurological or other impairments which may be permanent, temporary or episodic in nature, thereby causing limitations of activity and restrictions in participation with mainstream society. *(Adapted from National Policy on the provision of Social Development services to persons with Disabilities, May 2013)*

5.2 Intellectual Disability

This is constituted by a group of developmental conditions characterised by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills. *ICD-11: (proposed by WHO working group for Classification of ID, 2011)*

5.3 Behaviour that challenges

A range of possible behaviours seen in persons with intellectual disability that challenge the systems can cause some concern. Behaviour may pose a risk to either the PWID or another person or property. It may threaten the person's physical health, or have a marked effect on the person's quality of life or others and can have a range of possible underlying predisposing, precipitating or perpetuating factors *(Adapted from Adnams, C: 2013 and De Vries, P: 2013)*

5.4 Intermediate care

Inpatient transitional care, which facilitates optimal recovery from acute illness or complications of a long-term condition enabling patients to regain skills and abilities in daily living with the ultimate discharge destination being home or an alternate supported living environment. Intermediate care constitutes only one part of the patient's overall care pathway. *(Department of Health, Intermediate Policy Framework, 2012)*

5.5 Intermittent support

Person requires support on an as-required or episodic basis during lifespan transitions. When required, the support can be of a varying intensity from low to high.

5.6 Low support

Most persons with Intellectual Disability are able to improve their adaptive behaviour with additional training and support. Support may be required regularly and should assist with navigating everyday situations. Less input and staff are required at this level than with the moderate support category.

5.7 Moderate support

Persons with Intellectual Disability requiring moderate support are able to attend to their basic self-care but require on-going home living assistance and supervision.

5.8 High support

Requires high- intensity support, constantly, across all life environments and which is potentially life-sustaining in nature. This support involves more staff and intrusiveness than other levels of support. (*Mental Retardation: Definition, Classification and Systems of Supports,* 10th edition, Washington ,DC, American Association on Mental Retardation, 2002, p.152)

5.9 Day Care Centres (referred to herein Special Care Centres)

A day care centre provides individual support, care and stimulation to both adults and children with Intellectual disability on a daily basis. (*National Policy on the provision of Social Development services to persons with Disabilities, May 2013*)

5.10 Residential Facilities (referred to herein 24 hour facilities)

It is a facility for the temporary or permanent care, protection, support, stimulation, skills development and rehabilitation of people with disabilities, who due to their disability and social situation need care, (when the need cannot be met at home and in the community) within a safe, secure and stimulating environment of a home for people with disabilities or in a residential facility. (*National Policy on the provision of Social Development services to persons with Disabilities, May 2013*)

5.11 Protective Workshops

Protective workshops refer to an institution or organisation that provides rehabilitation services and occupational opportunities for people with disabilities, who due to the environmental and / or social situation experience barriers in accessing the open labour market. (*Adapted from National Policy on the provision of Social Development services to persons with Disabilities, May 2013*)

5.12 Community-based care

Care that is provided outside of institutional and hospital settings, as near as possible to the places where people live, work and study. (Department of Health: National Mental Health Policy framework and strategic Plan 2013-2020)

6. Burden of Disease

There is a general lack of research with regards to burden of disease and prevalence of Intellectual disability in the Western Cape. Global figures were used to extrapolate the estimated burden for our province. There is however, no reason to believe that rates are likely to be lower than elsewhere. Disability is strongly influenced by environmental opportunities, which are highly limited in South Africa and in the Western Cape. If anything, rates of disability are therefore likely to be higher than reported elsewhere.

6.1 Prevalence

The estimated prevalence for Intellectual Disability (Adnams: 2010)

| Per Category | % | |
|--|--------|-----------------|
| Mild ID (Intermittent support) | 2.5 % | } Of population |
| Moderate ID (Low support) | 0.4 % | |
| Severe and Profound ID (moderate and high support) | 0.1% | |
| ID with behaviour that challenge (life time prevalence) | 80 % | } Of PWID |
| ID with behaviour that challenge (Point prevalence) | 40-50% | |
| Total ID | | 3.0% |

6.2 Estimated number of PWID in the Western Cape Province by region and severity based on the census 2011 statistics and the prevalence percentage is as follows:

| | Population | Total ID | Mild ID (intermittent support) | Moderate ID (low support) | Severe /Profound ID(moderate to high support) |
|---------------------|------------|----------|--------------------------------|---------------------------|---|
| Western Cape | 5,822,734 | 174,682 | 145,568 | 23,291 | 5,823 |

6.3 Number of clients currently receiving community-based services

Data on the accessibility of community-based services are more readily available than data on persons accessing district health services or Social Development services. However, the estimation of services being offered in the community by NPOs is set out as:

| Categories of placements | Nr |
|--|-------------|
| Workshop placements for adults with intermittent and low support | 764 |
| Residential placements for adults with intermittent and low support | 1134 |
| Special care centre placement for children with moderate and high support (some adults) | 2396 |
| 24 Hour residential facility for children with moderate and high support (some adults) | 298 |
| LSEN Learners currently in the special school system | 4978 |
| LSEN Learners currently in mainstream schools or others | 743 |

Individuals remaining in residential hospital care at Alexandra and Lentegeur Hospitals (600) are not included in the table above.

7. Categories

International diagnostic systems (DSM-5 and ICD-10) categorise persons with Intellectual Disability based on their level of intellectual function as well as their adaptive functioning in order to determine the level of support required for optimal development of independent living skills. Given the wide range of skills and adaptive behavioural needs in people with ID, international guidelines clearly advocate a 'person-centred' approach in order to identify the individual's needs to determine services provision, rather than to fit a person into a service framework. The following principles with regard to individualising, is therefore important to recognise:

- a) A personalised approach should always take priority above any categorisation
- b) A continuous process of assessment and re-evaluation should be followed as part of a developmental approach
- c) Assessments require evaluation of multiple levels of skills, functions and need, and may therefore usefully be done in the form of a matrix model with outcomes attached.
- d) An individual can move from one support category to another during their life course depending on their circumstances and transitional events
- e) An individual may also fall between two support categories depending on their potential and development in different life areas.
- f) The individual and his/her family should always form part of any planning and decision making process and all efforts should be made to make individuals with ID and their families partners in these processes.

7.1 Current categories

Historically, the financial responsibilities of departments were determined by the IQ level of PWID and this continues to be the case. **Adaptive functioning** and **Core functions** of departments have not been taken into consideration and therefore the inappropriate use of resources continues. At the same time IQ alone makes it impossible to assess the support needs.

Current financial responsibilities are outlined below:

| Category | IQ range | Target group | Departments | Services |
|------------------------------|-----------------|---------------------|-------------|--|
| Profound ID | IQ under 20 | Children and Adults | DOH | <ul style="list-style-type: none"> • Special care facilities • 24 hour facilities for children |
| Severe ID | IQ 20- 34 | Children and Adults | DOH | <ul style="list-style-type: none"> • Special care facilities • 24 hour facilities for children |
| Moderate ID | IQ 35 – 49 | Adults Children | DSD | <ul style="list-style-type: none"> • 24 hour faciities, • Protective workshops • Special Care centres |
| Mild ID | IQ 50 – 69 | Adults Children | DSD | <ul style="list-style-type: none"> • 24 hour facilities • Protective workshops • Special Care centres |
| Severe to Mild (6-18 years) | IQ 20-69 | Children | Education | <ul style="list-style-type: none"> • Inclusive and Special schools |
| All categories | IQ 69 and below | Children and Adults | SASSA | <ul style="list-style-type: none"> • Disability and care dependence Grants |

* There are very limited resources for PWID with behaviour that challenges within the current system

7.2 Proposed categories

As mentioned above, the shift towards adaptive functioning will support an outcomes based approach aimed at the support needs of the individual. Although not ideal, for the purposes of government understanding the link between the current and proposed categories, (IQ and adaptive functioning) is indicated in the table below.

| | |
|------------------------------------|---|
| High Support (Profound IQ) | <p>The PWID requires high level of support, supervision and total care due to the constancy and high intensity of their needs, in all life areas</p> <ul style="list-style-type: none"> • Specialist services are required • Requires stimulation programme adapted to suit the support needs with maximum assistance • Requires specific support regarding ADL tasks; constant supervision; constant care |
|------------------------------------|---|

| | |
|---|--|
| | <ul style="list-style-type: none"> Requires all carers and role players in the PWID's life to be trained to support him/her in life areas |
| Moderate Support (Severe IQ) | <p>The PWID requires a moderate level of support, supervision and partial care in some of their life areas</p> <ul style="list-style-type: none"> Specialist services may be required Requires stimulation//educational/vocational programme adapted to suit the support needs with moderate assistance Requires specific support regarding ADL tasks; supervision; partial care Requires all carers and role players in the PWID's life to be trained to support him/her in life areas |
| Low Support (Moderate and Mild IQ) | <p>The PWID requires a lower level of support, supervision and reminding of task completion in some of their life areas</p> <ul style="list-style-type: none"> Specialist services may be required Requires educational/vocational programme adapted to suit the support needs Requires specific support regarding some ADL tasks; lower level of supervision; partial care Requires all carers and roleplayers in the PWID's life to be trained to support him/her in life areas |
| Intermittent support (any range) | <p>The PWID requires intermittent support, supervision and/or partial care in some of their life areas at a specific time in their life. Intermittent support can be required at any time for any person in the above categories depending on their circumstances at that point and time.</p> <ul style="list-style-type: none"> Specialist services are required Requires an adapted programme according to the support needs at that time Requires specific support regarding ADL tasks; constant supervision; constant care Requires all carers and roleplayers in the PWID's life to be trained to support him/her in life areas <p>Able to manage without regular support or assistance during the day but may require only additional supports during times of transition, uncertainty, or stress.</p> |

***All interventions need to be underpinned by a multi-disciplinary team approach**

7.3. Behaviour that challenges

Inclusion of persons with Intellectual Disability and challenging behaviour in current community-based services has been severely neglected due to the previous model of custodial, institutional care as well as a lack of trained staff to render appropriate services to PWID. Whilst hospital based care and rehabilitation may still be required intermittently, less restrictive models of supported living should be extended to include them. The fundamentals of challenging behaviour are set out below

7.3.1 Presenting behaviours that are challenging generally include

- Verbal or physical aggression towards self or others
- Damage to property and destructiveness
- Disruptive behaviour and verbal abuse
- Inappropriate sexual behaviour

7.3.2 The prevalence of behaviour that challenges is significantly **higher** in people with Intellectual Disability who have a diagnosed psychiatric illness such as a mood, anxiety or psychotic disorder but **not all** challenging behaviour is due to a mental illness.

7.3.3 Persons with Intellectual Disability displaying behaviour that challenges can be due to developmental limitations i.e. poor adaptive functioning, problems with communication or social skills sensory sensitivities or physical pain. Stressors in the environment play a critical role

7.3.4 Generally the higher the prevalence of this behaviour the more the individual's adaptive functioning is impacted.

7.3.5 Medication is usually required for persons with a comorbid diagnosis.

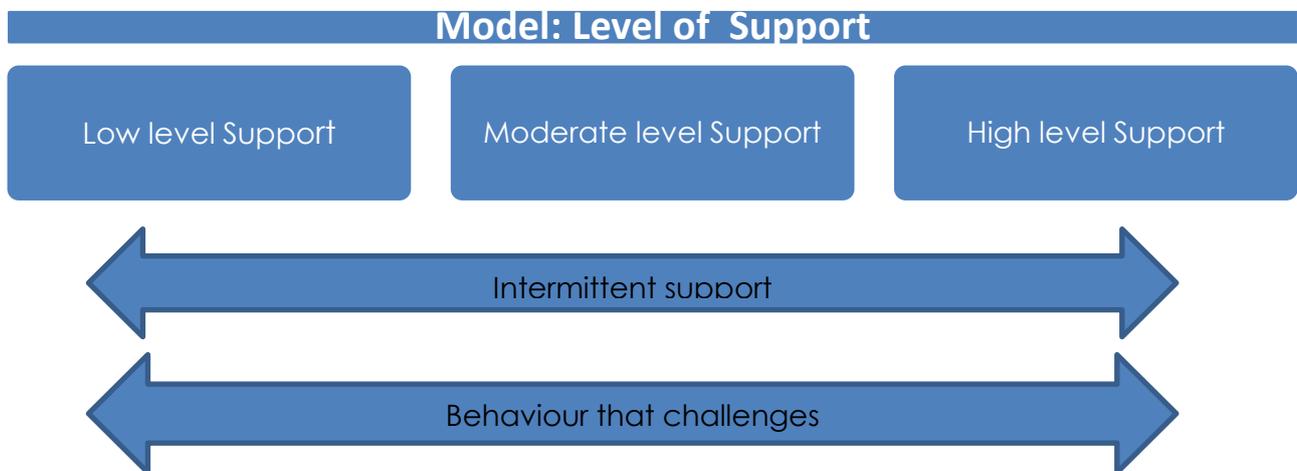
All persons, but especially the person with challenging behaviour, may at any time during their life-course require intermittent and **additional** support to cope with transitions in their life.

8. Models of Support/ service delivery

When determining appropriate models of support it is important to look at the areas in which support is required. The main life-areas as referred to in the International Classification of Functioning, Disability and Health (ICF) and other documentation are

- a) Learning
- b) General tasks
- c) Communication
- d) Mobility
- e) Self-care
- f) Domestic life
- g) Inter personal relationships
- h) Community life
- i) Cognitive behaviour

It is proposed that the following model of support be adopted and that each life-area be unpacked to evaluate the level of support the client requires to appropriately plan and implement intervention. Behaviours in Intellectual Disability that challenges mostly resorts under high support but can span across any of the support levels. The grid following unpacks each of the support categories using the ICF Framework and linking it to the responsibility of the relevant departments.



| Service Model according to levels of support required | | | | | |
|---|---|--|---|--|---|
| Levels of Support | High Support | Medium Support | Low Support | Intermittent support | Lead Department/ Other government Departments/ NPO- service provider/ Partner |
| Personal Support | | | | | |
| | Accommodation | | | | |
| | Accommodation is provided in family home/ group home/ residential care facility | Accommodation is provided in family home/ group home/ residential care facility | Accommodation is provided in family home/ group home | Accommodation is provided in family home/ group home | Family/ Social Development/ Health/ NPO |
| | Level of care provided | | | | |
| | Carer provides 24 hour care and assistance to the PWID | Carer provides 24 hour supervision to the PWID | Carer assists the client regularly | Individual cares for him/herself with intermittent support | NPO/Family/ Health/DSD |
| | Carer skills | | | | |
| | 1. Follow an individual support plan to improve self care and domestic skills | 1. Follow an individual support plan to improve self care and domestic skills | 1. Maintain and improve self care and domestic skills | 1. Improve self care and domestic skills | NPO/Family/ Social Development/ Health/Education |
| | 2. Following a communication tool/plan to understand the needs | 2. Communication plan available for client to make needs known | 2. Maintain and improve communication to allow client to make needs known | 2. Improve communication skills | NPO/Family/ Social Development/ Health/Education |
| 3. Ensure daily seating and positioning compliance of assistive device(s) to enhance seating; posture and/ or mobility (buggy; sidelyer; splints) | 3. Ensure daily seating and positioning compliance of assistive device(s) to enhance seating; posture and/ or mobility (buggy; sidelyer; splints) | 3. Assisting to maximise independent mobility with the use of assistive devices where indicated ie. May need to be assisted with transfers | 3. The client is independent in mobility | Health/Family/ NPO | |

| | | | | | |
|------------------------------|--|---|---|---|---|
| | Hospitals for challenging behaviour | Hospitals for challenging behaviour | Hospitals for challenging behaviour | Hospitals for challenging behaviour | |
| | 6. Referral to specialist services as required | 6. Referral to specialist services as required | 6. Referral to specialist services as required | 6. Referral to specialist services as required | Health |
| | 7. Hospitalization for acute physical illness | 7. Hospitalization for acute physical illness | 7. Hospitalization for acute physical illness | 7. Hospitalization for acute physical illness | Health |
| | 8. Access to Dietician and Special feeds | 8. Access to Dietician on referral | 8. Access to Dietician on referral | 8. Access to Dietician on referral | Health |
| Specialised Support | | | | | |
| | 1. Neurology | 1. Neurology | 1. Neurology | 1. Neurology | Health |
| | 2. Admission for Mental illness or challenging behaviour | 2. Admission for Mental illness or challenging behaviour | 2. Admission for Mental illness or challenging behaviour | 2. Admission for Mental illness or challenging behaviour | Health |
| | 3. Access to Therapies: Speech; Occupational Therapy; Physiotherapy | 3. Access to Therapies: Speech; Occupational Therapy; Physiotherapy | 3. Access to Therapies: Speech; Occupational Therapy; Physiotherapy | 3. Access to Therapies: Speech; Occupational Therapy; Physiotherapy | Health/Education/NPO |
| | 4. Access to Seating clinic services | 4. Access to Seating clinic services | 4. Access to Seating clinic services | 4. Access to Seating clinic services | Health |
| | 5. Statutory Services (Children's Act; Child Justice Act; Mental Health Care Act) | 5. Statutory Services (Children's Act; Child Justice Act; Mental Health Care Act) | 5. Statutory Services (Children's Act; Child Justice Act; Mental Health Care Act) | 5. Statutory Services (Children's Act; Child Justice Act; Mental Health Care Act) | Social Development/ Health |
| Learning Support | | | | | |
| | 1. Access to day programme for all ages | 1. Access to day care/ special school/ vocational rehabilitation programme and protective workshops | 1. Access to day care/ special school/ vocational rehabilitation programme and protective workshops | 1. Access to day care/ special school/ vocational rehabilitation programme and protective workshops | NPO/Education/ Social Development |
| Environmental Support | | | | | |
| | 1. Universal Access to buildings and community | 1. Universal Access to buildings and community | 1. Universal Access to buildings and community | 1. Universal Access to buildings and community | Municipalities/ Public Works/ Family/ Communities/NPO |

| | | | | | |
|--------------------------|---|---|---|---|---|
| | 2. Safe environment | 2. Safe environment | 2. Safe environment | 2. Safe environment | |
| Transport | | | | | |
| | 1. Access to transport | Department of Transport/ Municipalities/ Family/NPO |
| Financial Support | | | | | |
| | 1. Care Dependency Grant/ Disability Grant | 1. Care Dependency Grant/ Disability Grant | 1. Care Dependency Grant/ Disability Grant | 1. Care Dependency Grant/ Disability Grant | SASSA/ Social Development/NPO |

9. Care acuity for Residential services

Planning for community-based services requires careful consideration as PWID tend to require additional support and assistance therefore increasing the cost of living. For the purpose of this framework the higher the support needs the more human resources are required.

| | | |
|------------------------------------|---|--|
| <p>High Support needs</p> | <p>Due to Care/Assistance Facility manager Professional Nurse / Nursing staff Sessional Physiotherapist/OT Care Workers (ratio 1:6) Due to behaviour that challenges Sessional Occupational therapist Higher Care Worker to resident ratio Sessional Psychologist</p> | <p>Infra-structure Domestic residential units geared for disabled person with enough space for moving of assistive devices or larger more formal buildings. Infra-structure should be re-aligned to meet the need of persons with high medical needs who are potentially at greater risk (e.g tube feeding, tracheostomies; stoma bags; post-operative supervision etc), For persons with behaviour that challenges units should be safe and secure to reduce harm to property and equipment</p> |
| <p>Medium Support</p> | <p>Manager House parents Programme implementer Care workers (Ratio 1:8) Due to behaviour that challenges Sessional Occupational therapist Higher Care Worker to resident ratio Sessional Psychologist</p> | <p>The physical infra-structure would largely consist of normal domestic residential units that are clustered in such a way to accommodate economies of scale</p> |
| <p>Low Support</p> | <p>Manager(part time or for several homes) House parents Programme implementer Care workers (Ratio 1:10)</p> | <p>Normal domestic residential units clustered to accommodate economies of scale</p> |
| <p>Intermittent Support</p> | <p>Increase in care worker support and additional MDT support (possibly from other departments)</p> | <p>May require low secure area or single safe observation room at times</p> |

10 General principles for funding

- 10.1 Financial responsibilities should be determined by the core function of each department.
- 10.2 It is acknowledged that government funding resources would currently be unable to meet the full cost of care of all PWID. It is proposed that government will subsidise 80% of actual costs which include care and support functions as well as the basic operations of the organisation. NPO'S are still responsible for their own fundraising to cover their total budget requirements.
- 10.3 Consequently the most efficient approach for service delivery for PWID would be organised collaboration between government, non-governmental organisations and the private sector. One of the approaches may be to outsource non-acute and community based services.
- 10.4 Focus and prioritization should be geared towards the need for services of the specific district/region which could include but are not limited to
- Community based services for these mental health care users as close to home as possible to retain community participation
 - services for persons with Intellectual Disability whose behaviour is a serious challenge
 - PWID with high support needs
 - Children with severe and profound intellectual disability
 - Persons with intellectual disability with co-morbidity
- There is a large unmet need that should be addressed systematically and progressively.
- 10.5 Persons within in any support level may require intermittent support from time to time over their lifespan. This requires additional support from professionals and staff
- 10.6 Government should consider accessing available under-utilised buildings on government property which could reduce the cost of Service provisions

11. Determining appropriate funding arrangements

It is now important to determine how to rectify historical practices and policies and the following elements could contribute in determining future funding frameworks.

11.1 Person-centred approach

In order for government to provide a truly person-centred service a fundamental shift is required in how a person with Intellectual Disabilities is perceived. The current funding model assumes that the PWID will remain in one category of functionality with no potential for growth or positive outcomes. A person-centred approach should correct this perception.

11.2 Moving from IQ to adaptive functioning (ICF)

In general a PWID should be assessed and re-evaluated over a life span to determine changing support needs. The assessment should be based on the adaptive functioning, IQ and health

status (will include aspects such as mobility, self-care, communication, inter-personal relationships etc) This will indicate a matrix of support needs that in turn would indicate the funding that should be allocated.

11.3 Individualised assessments

Consideration should be given to such assessments for all new applicants for community-based facilities in future. An agreed upon standardised inter-sectoral assessment tool should be used as a baseline for 1) determining individual support needs 2) what level of the service should be accessed and 3) which departments should take primary responsibility. The tool should include aspects on behaviour that challenges within Intellectual Disability and a central point for coordinating assessments should be considered. All relevant staff to receive training in the application of the tool

11.4 Alignment of Core functions

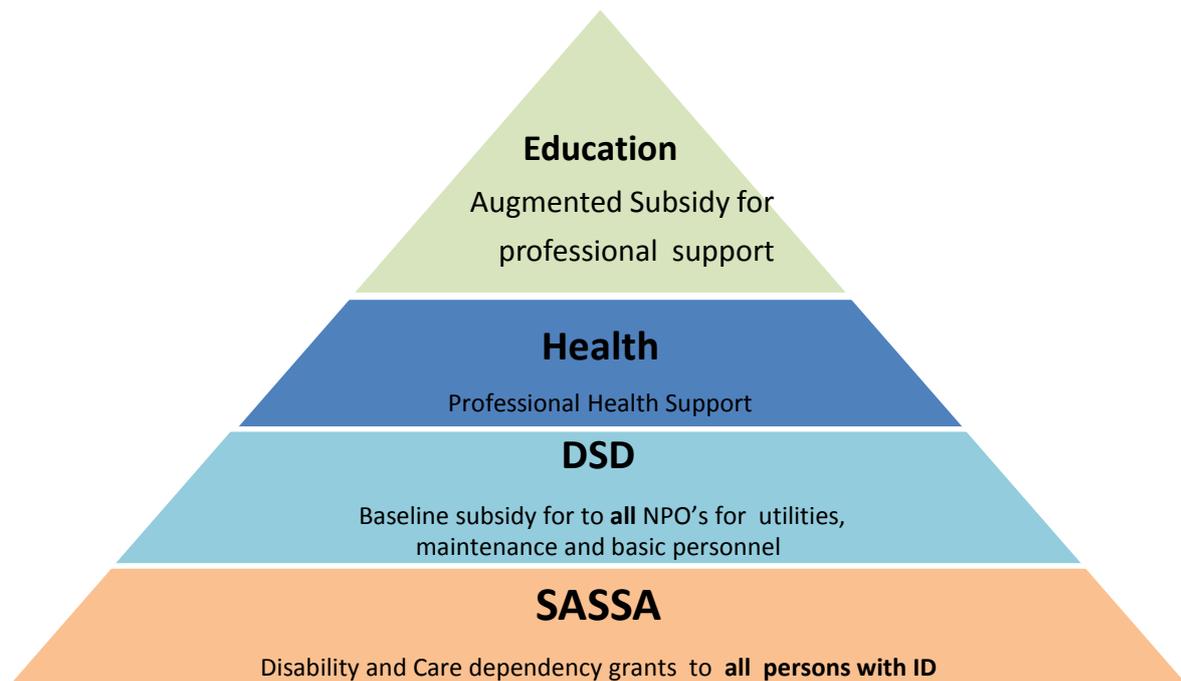
The lack of well-defined national strategic direction and legislation forced provinces to use their own initiatives w.r.t funding of services for PWID. In some instances (such as community-based services) departmental financial responsibilities are not aligned with core functions of departments. To appropriately allocate resources this should be done as a matter of priority.

12 Core functions of each department

12.1 A fundamental shift in policy direction is proposed where departments re-align their services to placing emphasis on adaptive functioning and support needs rather than IQ and how PWID and their families can be supported at service delivery level instead of families trying to fit into a fixed governmental approach.

12.2 Furthermore, departments need to revert to their core functions namely

- Department of Social development services and poverty alleviation provides the baseline subsidy to all NPO's for care needs, utilities, maintenance and basic personnel
- South African Social Security Agency (SASSA) provides social assistance and social grants.
- Department of Education in this context provides inclusive education and educational support services to learners from 6 to 18 years.
- Department of Labour creates conditions to broaden the range of employment options
- Department of Public Works and Transport provides accessible transport and government infrastructure.
- Department of Health provides health services and professional support
- Departments of Trade and Industry and Economic Affairs and Tourism to create opportunities to broaden the range of employment to all persons with Disabilities



13.1 Implications for SASSA

13.1.1 Provision of Disability and care dependency grants remain **unchanged**

13.2 Implications for Department of Social Development (DSD)

13.2.1 Centralised coordination

13.2.2 Ensure implementation

13.2.3 Ensure Policy alignment

13.2.4 Facilitate joint M&E activities -Licencing, quality assurance, compliance

13.2.5 Coordination of all funding activities (SLAs; TPAs)

13.2.6 Collaboration with National Departments

**For further details refer to implementation plan*

13.3 Implications for Department of Health (DOH)

13.3.1 Licencing of Mental Health Community based facilities

13.3.2 Medical care at health establishments

13.3.3 Clinical and medical support to facilities

13.3.4 Assistive devices and outreach clinics

13.3.5 Integrated School health programme

**For further details refer to implementation plan*

13.4 Implications for Department of Labour

13.4.1 Co- ownership of funding protective workshops with taking full responsibility in future

13.5 Implications for Non Profit Organisations (NPOs)

13.5.1 Re-alignment of services according to support needs and funding available

13.5.2 Ensure all new applicants to centres be assessed through a standardized assessment process which could implemented across the sector which will guide the intervention process

13.6 Department of Education

13.6.1 Curriculum development

13.6.2 Training and capacity building

13.6.3 Provision on norms and standards for formalising educational setting

13.6.4 Quality assurance of curriculum delivery

13.6.5 Care and Support for Teaching and Learning (CSTL) framework integration strategy to be developed

13.6.6 Appropriate placement of learners into formal education setting

**For further details refer to implementation plan*

13.7 Department of Public Works and transport

13.7.1 Provide infrastructure support

13.7.2 Provide upgrade funding

13.7.3 Provide capital funding allocation

13.7.4 Provide support for maintenance

13.7.5 Assist with plan and implementation of transportation of children

**For further details refer to implementation plan*

13.8 Municipalities

13.8.1 Capacity building of organisations

13.8.2 Access to land

13.8.3 Rezoning and Health clearance certification

13.8.4 Non – compliance issues

**For further details refer to implementation plan*

14. Human Resources and Training

This will become part of an implementation plan once an inter-departmental policy framework has been accepted.

15. Monitoring and Evaluation

Monitoring and evaluation systems would be put in place to ensure that implementation is taking place as per the time frame recommended in the implementation submission to cabinet

16. Implementation plan

A full inter-departmental implementation plan is being developed that will accompany the inter-departmental policy framework for acceptance by Cabinet.

Reference Group

The following persons were consulted as part of the reference group

Prof. C.K Househam (Head of Health)

Dr L. Hering (Senior Medical Manager: General Specialist hospitals +Project leader)

Mr A. Van Niekerk (CFO, Department of Health)

Prof Colleen Adnams (Vera Grover; Professor of Intellectual Disability, UCT)

Prof Petrus De Vries (Sue Struengmann Professor of Child & Adolescent Psychiatry, UCT)

Ms Patiswa Momoza : Deputy Director Disability, Department of Social Development

Ms Nina Klein: Project Manager, Special Programmes, Department of Social Development

Dr Thereza Bothma: Senior Psychologist, Department of Education

Dr Rob Allen (Clinical Head: Lentegeur Hospital)

Ms Lynette van der Berg (CEO: Alexandra Hospital)

Dr Keith Ganasen (Consultant Psychiatrist: Alexandra Hospital)

Dr Granville Marinus (CEO: Lentegeur Hospital)

Ms Marinda Roelofse (Provincial Mental Health Coordinator)

Reference List

1. Technical Report Part II: A review of intellectual disability services and development of a framework to inform intellectual disability health policy and service provision, Western Cape Government Department of Health, Adnams C, 2013
2. National policy on the provision of social development services to people with disabilities , National Department of Social Development, May 2013
3. Strategy for the Integration of Services for Children with Disabilities, Revised Draft August 2009
4. Models of Service Provision to Adults with an Intellectual Disability with Co-existing Mental Illness University of Queensland, August 2002
5. Valuing people Now: A new Three Year strategy for people with learning disabilities, HM Government , March 2001
6. National Mental Health Policy Framework and strategic plan, National Department of Health,2013-2020
7. International Classification of Functioning, Disability and Health, WHO, 2001
8. Raising our sights: Services for adults with profound Intellectual Disabilities, Mansell, J: 2010
9. Mental Retardation; Definition, Classification and Systems of support 10th Edition, Washington DC, American Association on Mental Retardation, 2002
10. Putting people first: Transforming adult social care. Working together for change: using person-centred information for commissioning; Bennett, S and Sanderson, H, 2007
11. Department of Health, Intermediate Care Policy Framework, Sept 2012
12. Psychosocial Interventions for People with Intellectual Disabilities and Mental Ill –Health , Dave Dagnan, 2007
13. Enabling Community Integration, Towell, D, Beardshaw, V: The King' s Fund Colleague,1991
14. Perspective: Public Policy and Intellectual Disability: Intellectual Disabilities, Volume 47, number 4, 2009
15. *The World Health Organisation Report: Mental Health: New Understanding New Hope* (WHO, 2001)
16. Draft status report on challenges relating to the rollout of special needs housing in the Western Cape, Project Preparation Trust of KZN, January 2012
17. Mental Health and Intellectual Disabilities: Addressing the Mental Health needs of people with Intellectual Disabilities, WHO, 2011
18. WHO resolution on the health of children and young people with intellectual disability and their families (Resolution RC61/R5)
19. People with Intellectual Disabilities and Mental Health Problems, Bouras, N