DRAFT National Plan for People with Intellectual Disabilities and their Families 2022-2027

FOR CONSULTATION

Bermuda National Plan for People with Intellectual Disabilities and their Families

Draft for consultation

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1. Executive summary:

Bermuda has approximately 100 – 125 children and 400 – 500 adults with an intellectual disability. Although many of these individuals live at home with their families, most require a range of support services from one aspect of their daily lives to full-time residential care. People with intellectual disabilities have a higher incidence of health and other challenges compared to the general population. They have poorer general health, higher rates of injuries, accidents and falls, and increased mortality rates. This results in increased use of hospital services, greater need and use of mental health care, dependency on social and community services, over-representation in the corrections system, and an increased need for family support.

The Bermuda National Plan for People with Intellectual Disabilities and their Families ("the Plan"), has been written by a small group of stakeholders following discussion with the Minister of Social Development and Seniors. No single agency or sector has overall responsibility for providing the support they require; the Plan requires an integrated response across health, social care, education and the voluntary sector. The Plan's purpose is to set out a shared vision, goals (priority areas) and objectives across our services and community that will result in a realistic set of annual actions that work towards these objectives and can begin to improve people's lives. .

The Plan focuses upon the needs of adults (aged 18 years+) with intellectual disabilities, and their families. The Plan recognises that the transition into adulthood is extremely important, therefore it also considers the needs of children aged 14 years and older as they transition into adulthood. Aspects of this plan will require future coordination to merge with the wider set of needs of children with intellectual disabilities.

The Plan is based upon the principles of rights, independence, promoting person-centred support, improving quality of life, increasing choice and control, increasing opportunities to be included in community-based activities, and supporting families to enable people to live at home for as long as possible. It sets out a five-year vision for the future and provides a detailed one-year action plan that will start to achieve the longer-term aims.

The Plan has five priority areas (goals) with three to five objectives that must be addressed to reach the goal. Action plans, developed and reviewed annually by key stakeholders, will be established to achieve these objectives, many of which will take more than one year to complete.

The five priority areas for action:

Quality: Ensuring that people have access to required level of high-quality, person-centred supports, and they can participate in work, recreation and other community activities.

Education and workforce: Providing informal carers and staff with required support, advice and training.

Policy regulation and accountability: Ensuring the necessary legislative framework, policies and governance frameworks are in place to protect people and provide oversight to services.

Financing: Ensuring that services are well managed and that finances are used effectively.

Advocacy and communication: Empowering individuals and their families to influence the development of services.

It is recognised that wider stakeholder involvement is essential to ensure the success of this integrated plan, and that in particular, people with intellectual disabilities need to be involved at the heart of a plan that concerns their quality of life. The National Plan Steering Committee will consult with advocacy and self-advocacy groups about the content of this Plan and representation by persons with intellectual disabilities and their families will be part of the annual objective and action plan review and development.

2. Introduction

This *National Plan for People with Intellectual Disabilities and their Families* ("the Plan") has been written by a range of stakeholders who are concerned about the needs of this group. The Plan integrates a set of responses across the key ministries, departments, social services and the voluntary sector. The stakeholder group that developed the Plan reflects the shared responsibility for delivering the actions within it. The Plan was developed by reviewing existing reports and previous work, including the 2018 visioning workshop for people with intellectual disabilities, in addition to updated information from stakeholders.

The purpose of the Plan is to establish a shared vision, priority areas (goals) and objectives across our services and community to ensure the wellbeing of persons with intellectual disabilities through coordinated action. As a result, a realistic set of annual action plans that work towards these objectives will be established to facilitate more coordinated and inclusive initiatives. The Plan is based upon the principles of: rights, independence, promoting person-centred support, increasing people's quality of life, increasing their choice and control, increased opportunities to be included in community-based activities, and supporting families in ways that enable people to continue to live at home with their families for as long as possible.

Whose needs are considered in the Plan?

The Plan focuses on the needs of adults with intellectual disabilities and their families. The Plan does not have an upper age limit and includes people's long-term care needs and end-of-life care. Although the focus of the Plan is on adults (aged 18 years+), it recognises the transition to adulthood is extremely important. The Plan therefore also considers the needs of children aged 14 years and older. The Plan does not attempt to address the wider set of needs of children who have an intellectual disability. A second phase of a National Plan may be commissioned for children from birth to when they transition into adulthood. This second phase plan would require a wider group of advocates and service provider stakeholders for its development.

The term "intellectual disabilities" (ID) will be used throughout this document to describe the people who are being considered within the Plan. See Annex 4 (Glossary of Terms) that further defines this term.

There is a wide range of intellectual disability that is in part determined by the person's level of cognitive impairment, any additional physical disabilities and any co-morbid conditions (e.g. autism, mental illness, etc). Each person is unique and it is important that a National Plan addresses not only their commonalties of need, but also the individual factors that affect people's needs and their quality of life. The Plan includes the needs of people with autism, but only when this is in addition to an intellectual disability. People with an intellectual disability are at increased risk of showing challenging behaviours. Another significant group of people whose needs are addressed within the Plan are those with profound and multiple intellectual disabilities. The Plan

Whose needs are addressed by the plan?

Intellectual disability is gradually being adopted internationally as the term that describes people who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); this often taken to be an IQ of less than 70, with
- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning)

These reduced abilities are apparent before adulthood is reached and have a lasting effect on development.

focuses on those with the greatest degree of need but recognises need is impacted by family supports, financial and other personal circumstances.

3. Bermuda situational analysis

This section sets out an overview of the local demographics and the current service provision and supports for adults with intellectual disabilities, and adolescents in transition. A more detailed description can be found in Annex 2.

a. Intellectual disabilities: prevalence

There is estimated to be between 502 (99 children and 403 adults) and 638 (121 children and 517 adults) individuals in Bermuda with an intellectual disability. Approximately 80 of these adults are currently receiving full-time residential support under the care of Mid-Atlantic Wellness Institute (MWI). The majority reside in group homes in the community, while a very small number who have additional nursing care needs (e.g. for end-of-life care) reside in a hospital ward. The remaining adults live at home and most are supported by their families.

Figure 1: Estimated prevalence rates of people in Bermuda with an intellectual disability

Age band	Total Bermuda population		Bermudian population (excludes the 21% of the total population who are non-Bermudian) **	
	General population	Estimated ID population based on 1% prevalence*	General population	Estimated ID population based on 1% prevalence
0 – 18 years	12,063	121	9,949	99
19 – 85+ years	51,716	517	40,252	403
Total	63,779	638	50,201	502

* Based on international prevalence estimates that 1% of the general population is likely to have an intellectual disability (Maulik et al., 2011).

**There is an assumption that the prevalence of intellectual disability is likely to be significantly lower in the non-Bermudian population, as the majority of this group (13,578) will be resident in Bermuda on work permits, and less likely to have dependents with an intellectual disability on the island.

b. Health inequities

With advances in medicine and access to community and social support services, individuals with developmental disabilities are living longer, surviving beyond childhood and adulthood into older age. The life expectancy of people with intellectual disabilities has increased over the course of the last 70 years. This is despite the fact that people with intellectual disabilities are 58 times more likely to die before the age of 50 than the rest of the population. However, people with intellectual disabilities face many disadvantages in relation to health. This includes increased mortality rates, poorer general health status, increased use of hospital services, greater need and use of mental

health care, higher rates of injuries, falls and accidents, greater dependencies on social and community services, and increased need for family support. Bermuda is assumed to follow these international trends. However local data on people with intellectual disabilities is limited in general and in relation to health inequities. This is due to a variety of factors including: absence of a unique patient identifier, provider coding practices, coding classifications and current data collection and consolidation systems.

c. Human rights and legislation affecting people with an intellectual disability

To truly enable social inclusion and improve the quality of life for people with intellectual disabilities, their fundamental rights need to be assured and protected. The UN Convention for the Rights of Persons with Disabilities sets the standards for all individuals with disabilities, including those with intellectual disabilities. Fundamental recognition of these rights and protections exist currently on island in the Human Rights Act, The Charter for the Rights of Seniors and Persons with Long Term Care Needs, and more recent amendments to the Mental Health Act. However there are key areas to address such as:

- Ratification of the UN Convention of Rights for Persons with Disabilities.
- Establishing best practices within law, policy and daily practice for substitute and supportive decision-making.
- Establishing an Office of the Public Guardian to ensure support and accountability for substitute and supportive decision-making.
- Ensuring appropriate protection interventions for people with intellectual disabilities who are under 65 years of age and at risk of abuse or neglect.
- Ensuring the criminal justice system recognises needs of people with intellectual disabilities so they can participate equitably to obtain justice for crimes against them.

Ensuring the rights of people with intellectual disabilities are recognised and respected requires community and service awareness and education. The introduction of any of the key areas outlined will require increased, sustained, coordinated and strategic education and awareness campaigns.

d. Supporting people to live in the community

Bermuda has transitioned from institutional to community based care for people with intellectual disabilities over the last 30 years. The move towards community-based care requires a full complement of resources to support people with intellectual disabilities and their families. Bermuda has developed a strong foundation in some key areas; however there remains significant service gaps.

In terms of residential living, there are currently 14 group homes, operated by MWI, supporting a total of 64 adults. The smallest home provides support to two individuals, while the largest supports seven people. Each home provides for people with differing support needs, and seven respite beds are available across the service. However, most people with an intellectual disability do not live in a residential group home setting, making in-home support a vital component of our system. Home care support became more accessible through the introduction of insurance-based home care benefits, starting in 2015 with the government subsidized health plans, followed by similar benefits being adopted by some of the private health insurance providers.

In addition to residential living, a range of clinical, therapeutic and recreational support is required. Day services provide important support to families of adults with intellectual disabilities. Two day programmes exist in the community serving up to 75 adults. These are MWI's New Dimensions programme that serves clients from their group homes, and K Margaret Carter Centre (KMCC).

KMCC is a government operated day programme serving people from the general community and provides functional skills training, employment training, production work as well as treatment and support services.

In the charitable sector, WindReach provides a range of recreational, therapeutic, educational and social activities to up to 200 individuals per week who have special needs. Participants range in age from pre-schoolers through to our older adult community. Tomorrow's Voices - Bermuda Autism Early Intervention Centre has provided therapeutic services based on applied behaviour analysis/verbal behaviour to clients with autism and other developmental disabilities for the past 14 years.

Dame Marjorie Bean Hope Academy (DMBHA) is a government school that provides services to students ages 4 through 18 who have severe/profound multiple learning disabilities and complex care needs, including intellectual and developmental disabilities. The school has an adapted curriculum, with an emphasis on language and communication development, pro-social skills, activities of daily living, gross and fine motor development, health and wellness, functional mathematics, pre-vocational training, recreational and leisure skills.

The school can support a maximum enrolment of 24 students. Currently, 20 students are enrolled; nine of the students are 14+ years of age, and five of those are over the age of 18. Upon reaching age 18, students should be transitioning to adult services, specifically KMCC. However, due to a lack of resources, KMCC has not been able to accommodate those ready to transition for a number of years. The Minister of Education has granted an extension of school years for parents who submit a letter of request, but this is not a given. It is determined by student need, space at the school and available resources.

In 2021, the MWI Community Intellectual Disability Team was established, providing multi-disciplinary support and practical advice to adults with intellectual disabilities and their families, living at home in the community.

However, overall there remains much work and resources required for service development and improvement that align with the international best practice standards. Some of the key areas to address include:

- Data on the number of people with intellectual disabilities, their support needs, and their ageing carers.
- Sustained intensive/comprehensive client case management and care coordination in particular for people transitioning between services (e.g. overseas to on-island; child to adult services).
- Improved access to preventative and rehabilitative care and supports within existing services.
- Increased availability and diversity of day care programmes- existing services are at capacity, limited options for seniors with intellectual disabilities and vocational training.
- Increased access to group homes, especially those under 65 years, or who require 24-hour nursing support due to current resources being at capacity.
- Development of specialised residential and clinical services for people with high risk challenging behaviours, especially young adults.
- Increased access to transportation and technology to help people remain in their homes and the community.
- Ensuring financial sustainability for Government, service providers and families/individuals due to costs of long-term care, especially for people with more complex needs.

4. Vision, guiding principles and outcomes

Vision

People with an intellectual disability have the right to the same opportunities as anyone else to live satisfying and valued lives and, and be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships and receive the support they need to live a healthy, safe and fulfilling life.

Principles

The principles which underpin this plan are ***rights***, ***independence***, ***choice*** and ***inclusion***.

Ultimately these principles are to ensure a good quality of life for people with intellectual disabilities. These principles require working in partnership with individuals, families/carers and support services, and rely on a foundation of person-centred care and support.

Below are key concepts that underpin the principles of this Plan.

- Quality of life – people should be treated with dignity and respect. Care and support should be personalised, enabling the person to achieve their hopes, goals and aspirations; it should be about maximising the person's quality of life regardless of the nature of their disabilities. There should be a focus on supporting people to live in their own homes within the community, supported by local services. When this is not possible, and the person lives in residential accommodation, the aim should be to achieve the same outcomes as if it was the person's own home.
- Human rights – to truly enable social inclusion, people's fundamental rights must be assured and protected.
- Keeping people safe – people should be supported to take positive risks, whilst ensuring that they are protected from harmful consequences.
- Choice and control – people should have choice and control over their own health and care services; they should make decisions about every aspect of their life. There is a need to 'shift the balance of power' away from more paternalistic services which are 'doing to' rather than 'working with' people, to services that recognise that individuals, their families and carers are experts in their own lives, and are able to make informed decisions about the support they receive. People should be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interests, involving them as much as possible and those who know them well.
- Least restrictive practice - support and interventions should always be provided in the least restrictive manner. Where people require care and support, this should be provided in ways that enable the people to have as much independence as possible, in as many aspects of their lives as possible. Carers and paid support staff should work in ways that aim to maximise independence and choice-making within community settings.
- Equitable outcomes - these outcomes should be comparable with the general population, by addressing the determinants of health inequalities. The starting point should be for mainstream

services, which are expected to be available to all individuals, to support people with an intellectual disability and/or autism, making reasonable adjustments where necessary, with access to specialist, multi-disciplinary, community-based health and social care expertise as appropriate.

- Community participation - irrespective of a person's level of disability or behaviour, they should have the opportunity and support for community involvement. People should be seen by the wider community as citizens of Bermuda who can and do participate in the same activities as everyone else. It may be necessary for adaptations to be made to facilities in order for this to happen, but the emphasis should be upon people actively participating in their communities.

Expected outcomes

In order to achieve these outcomes, specific environmental conditions need to be put in place that will promote optimal support that is based upon individual need and delivered in ways that aim to improve the person's quality of life. This requires that carers and paid staff have the skills and support to create and sustain approaches that use the principles of compassionate care, capable environments and active support (See Annex 3). These approaches are needed in order to create the setting for positive relationships within a human rights framework that can support individuals to become more independent, lead a valued life in society, and achieve the following outcomes:

Figure 2: Expected outcomes for people with intellectual disabilities

1. *"I have a good and meaningful everyday life"*
   - People with an intellectual disability should be able to access training, employment, social and recreational activities that are fulfilling and stimulating.

2. *"My care and support is person-centred, planned, proactive and coordinated"*
   - Planners should have access to current and accurate information about the needs of the local population in order to anticipate and meet the needs of people who require support.
   - Everyone should have a person-centred plan that sets out their life goals and aspirations. If they have specific risks or health needs, they should have support plans that are communicated as necessary.

3. *"I have choice and control over how my health and care needs are met"*
   - Individuals and, where appropriate, family members should be integral partners in care and support planning discussions. Even where people lack capacity to make specific decisions, they should be involved to whatever extent is possible, and any decisions should be made in their best interests, focusing on what is important to the individual.

4. *"My family and paid support and care staff receive the help that they require to support me to live in the community"*
   - Families or carers who are providing support should be able to access practical support easily. In situations where the level of need is increased due to the person's behaviour, physical health needs or other additional support needs, the service responses should be speedy and well-coordinated.
   - Families should have access to respite support at times of crisis or as a practical support to enable them to continue their caring role.

5. *"I have access to suitable residential support if I am no longer able to live at home"*
   - Families and individuals should be able to access residential support if families are no longer able to care for individuals at home.
   - Residential accommodation should be safe, high quality and provide a level of skilled support that will meet the person's needs
   - Services should have systems to ensure that anticipated needs are planned for and that families have reassurance that the person will receive the level of personalised support that they will require.

6. *"I receive good care and support from mainstream health services"*
   - Everyone who has an intellectual disability should have access to all the usual mainstream health services (e.g. GP, dentistry, chiropody etc).

7. *I can access specialist health and social care support in the community"*
   - Everyone who requires it, should have easy access to responsive, integrated, community-based multi-disciplinary support.
   - This specialist support should enable people to access mainstream health services, work with mainstream services to develop their ability to make reasonable adjustments, and deliver direct assessment and therapeutic support.

5. Priority areas for action and objectives

There are 5 main priority areas with specific objectives under each to work towards the vision of this Plan. Work to achieve these goals and objectives will be done through annual action plans. Many of the objectives will require longer than 12 months to fully achieve. The intention is for each objective to be reviewed annually with stakeholders, and a new set of actions developed building upon the achievements in the previous year.

Priority Area 1: Quality High quality, person-centred supports for individuals and their families are readily available and ensure that: • People have access to high quality assessment, rehabilitation and ongoing support. • They can easily access the health care that they need in order to lead healthy lives. • They are able to participate in work, recreation, education and other community activities. • They can access the required level of support that they need to promote independence in community settings.	
1.1	Increased and improved access to daytime support that is appropriate to people's needs and helps to promote independence, quality of life and a valued position in society.
1.2	All families that require support have easy access to assessment, advice and effective interventions.
1.3	Individuals who have the most complex support needs receive appropriate care that is close to home and is well coordinated.
1.4	Families and individuals experience a smooth transition as they age through the available systems and services.
1.5	A range of accessible housing options exist for people with ID (at home with family, own home, group home, respite), especially for those with family members who are no longer able to provide the support required (see also 4.3).

Priority Area 2: Education and workforce Informal carers and staff who support individuals and their families are well trained and can access specialist advice easily	
2.1	There is an accredited continuum of training for support staff that provides the necessary skills to be able to deliver modern, evidence-based care.
2.2	Training opportunities are available for informal caregivers.
2.3	Providers, carers and clients are aware of and uphold capacity and decision-making rights, principles and practices
2.4	Mainstream services (e.g. financial services, human resources departments of large employers, Bermuda Police Service, EMTs etc) are aware of the needs of people with intellectual disabilities.

Priority Area 3: Policy, regulation and accountability A legislative framework, policies, and governance arrangements are in place to: • Provide protection to vulnerable adults. • Monitor the effectiveness and delivery of this plan. • Provide oversight of matters that impact upon people's lives.	
3.1	There is appropriate Ministerial oversight and accountability for supporting and improving the quality of life of people with intellectual disabilities.
3.2	Planning and service developments are informed by data.
3.3	The Bermuda legislative framework provides the protection that is required by vulnerable people and their families.
3.4	Adults with intellectual disabilities who receive long term care services, receive care that is safe, caring, responsive, effective and well-led.
3.5	Service gaps are monitored, prioritised and addressed.

Priority Area 4: Financing • Services are well managed and public finances are effectively used to support people. • Families have access to the financial help to which they are entitled and they can access the services that they require. • Health insurance benefits are used effectively to fund care. • Appropriate financial incentives are in place to support families to care for their loved ones at home for as long as possible.	
4.1	Day time activities are appropriately resourced to meet demand and good practice standards.
4.2	Financing support is available for more specialised support services and devices (e.g. dieticians, speech and language, physiotherapy, tube feeding etc).
4.3	Resources are allocated to clients and their families on the basis of need to ensure that people with high support needs can access sufficient skilled support that enables them to age in place.
4.4	People with intellectual disabilities and their families are able to benefit fully from the health insurance schemes.
4.5	Local specialist care is available to decrease reliance on overseas placement (see also 1.3).

Priority Area 5: Advocacy and communication • Family carers and people with intellectual disabilities are empowered to influence how services are developed and managed. • There is accountability of services to the people who the services are for.	
5.1	The public are well informed about the rights and needs of people with intellectual disabilities and are aware of the available resources that they can access.
5.2	Family carers are involved in the planning and delivery of services.
5.3	People with intellectual disabilities are involved in the planning and delivery of services.

6. From policy to action - stakeholder accountability

This draft Plan was written by a small group of stakeholders following discussion with the Minister of Social Development and Seniors. It is recognised that wider stakeholder involvement is essential and that, in particular, people with intellectual disabilities need to be involved at the heart of a plan that concerns them and their quality of life. The National Plan Steering Committee is consulting on the Plan with a broad range of stakeholders to ensure this occurs.

A key purpose of the Plan is to ensure coordinated actions are set each year to reach the objectives that will help improve the lives people with intellectual disabilities and their families. It is recognised that many of the objectives are longer-term aspirations, therefore the actions will be updated annually under the guidance of a *Stakeholder Oversight Group*. The *Stakeholder Oversight Group* will have representation from lead agencies and other appropriate stakeholders including people with intellectual disabilities and carers. This group will also be responsible for reporting to the Minister and to the public to ensure there is ongoing accountability for the actions under the Plan.

7. National Plan Steering Committee

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