National Plan for people with intellectual disabilities and their families

Annex 1: Situational Analysis

Section 3 of the Bermuda Intellectual Disability Plan sets out a brief summary of the current needs of the population and the services that are available to them. This Annex provides a more detailed account, and provides some of the historical perspectives that have shaped the current service provision as it has transitioned away from a reliance on institutional care towards a more person-centred and community-focused model of support.

Intellectual Disabilities: Prevalence and Health Inequities

While detailed population specific information for individuals with intellectual disabilities is not available in Bermuda, there are statistics of the prevalence of individuals with intellectual disabilities and research as it relates to health inequities for individuals with intellectual disabilities in other jurisdictions including the UK, US and Canada.

It is challenging to gather definitive demographic data of the number of people with intellectual disabilities in Bermuda. Data on service uptake can be obtained from the various ministries/ services that have some responsibility for providing services to people with intellectual disabilities (e.g. Ministries of Health, Aging and Disability Services, MWI, WindReach, Tomorrow's Voices, etc), however not all individuals with intellectual disabilities access services on a regular basis, and therefore this will be an underestimate of prevalence. There have been efforts to collect information on the number of individuals by combining information collected by government departments on the presence of intellectual disabilities among people using particular services, overall population predictions as well as epidemiological research. In the 1990s there was the development of a more systematic Case Register database but unfortunately this has not been maintained.

A recent systematic review of the prevalence and incidence of intellectual disabilities (McKenzie et al., 2016) highlights the paucity of international studies that provide prevalence estimates. In the 1970s when diagnostic criteria focused on standardized intelligence quotient tests (IQ), a cut-off score of 70 was used to identify people with an intellectual disability. Using this cut-off score, it was estimated at that time that 3% of the population would be expected to have an intellectual disability. However, it is recognized that IQ alone is not sufficient to diagnose intellectual disabilities. The studies with the best methodological characteristics that were identified in the meta-analysis indicate that the global prevalence of intellectual disabilities is likely to be in the region of 1% of the general population (Maulik et al., 2011).

Using this prevalence estimate of 1% it is possible to make an estimate of the number of people in Bermuda who are likely to have an intellectual disability and hence are likely to fall under the remit of this plan. Figure 1 provides estimates of the prevalence rates for different ages, based upon the 2016 Bermuda Population and Housing Census (Government of Bermuda, 2016). The estimates use the De Jure population of 63,779 for the total population. This figure represents all persons who have lived, or are expected to live in Bermuda for 6 months or more as of Census Night (20 May 2016) irrespective of where they were physically present on Census Night. As such, residents present on Census Night and temporarily overseas for vacation, business, school or other purposes are included. It excludes overseas visitors and the institutional population.

The 2016 Census identifies that Bermudians represented 79% of the total population- 50,201. Figure 1 also includes an estimate of prevalence of intellectual disabilities in the Bermudian population, by excluding the non-Bermudians from the calculation. 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 (9,513) will be resident in Bermuda on work permit. Therefore, this figure is also included for purposes of comparison.

Depending on the baseline population that is adopted, and based upon a prevalence estimate of 1%, there are likely to be between 503 (121 children and 517 adults) and 638 (99 children and 403 adults) individuals in Bermuda who have an intellectual disability

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.

With advances in medicine and access to community and social support services, individuals with intellectual disabilities are living longer, surviving beyond childhood and adulthood into older age. Increasing supports have meant that these individuals are living in the community, and participating more actively in all aspects of society. In England, 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 (Emerson and Baines 2010). However, people with intellectual disabilities face many disadvantages in relation to health (Emerson and Baines 2010, Department of Health 2001). Documented evidence of a *sample* of specific health challenges/health inequities that individuals with intellectual disabilities face are listed below. It should be noted that the majority of statistical information presented below pertains to the UK population where comprehensive information is available through their annual "People with Learning Disabilities in England" 2015 annual report (PHE, 2016):

- **Increased mortality rates:** In the UK, more than three times the number of people with intellectual disabilities die than would be expected at age/gender standardized rates. The three most common causes of death for people with intellectual disabilities are circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%).

- **Poorer general health status:** In the UK, the risk of children being reported by their main carer (usually their mother) to have fair/poor general health is 2.5-4.5 times greater for children with intellectual disabilities when compared to their non-disabled peers (DoH, 2012).
- **Increased use of hospital services:** In the UK, in the two numerically largest specialties, medicine and surgery, people with intellectual disabilities used significantly more hospital care than others. Use of hospital services by individuals with intellectual disabilities was substantially higher than the general population in pediatrics, dentistry and psychiatry (episodes of care as well as bed days.) Use of hospital services was markedly lower in obstetrics and gynecology when compared to the larger population.
- **Greater need and use of mental health care:** People with intellectual disabilities have substantially higher rates of major mental health problems and dementia than other people and also higher rates of common mental disorders such as anxiety and depression. In the UK, the prevalence of psychiatric disorders is 36% among children with intellectual disabilities, compared to 8% among children without intellectual disabilities, with children with intellectual disabilities accounting for 14% of all British children with a diagnosable psychiatric disorder (Emerson & Hatton, 2007; Emerson, 2003).
- **Higher rates of injuries, accidents and falls:** A UK study has reported that adults with intellectual disabilities experience higher rates of injuries and falls when compared to the general population (Finlayson et al., 2010). High rates of accidents and injuries amongst people with intellectual disabilities, including injuries from falls, have also been reported in studies undertaken in Canada, Australasia, the Netherlands, and the US (Grant et al, 2001). In Denmark and Australia, accidents have been reported to be a more common cause of death among people with intellectual disabilities than in the general population.
- **Greater dependencies on social and community services**
- **Increased need for family support:** For carers where the primary support need of the person they care for was intellectual disabilities or difficulties:
    - over half (51.4%) spend 100 or more hours a week caring for that person, compared with 38.1% for all carers in England
    - 74.3% of carers of a person with intellectual disabilities had been in a caring role for more than 20 years, compared with an average of 20.1% for all carers in England
    - 30.2% were not in paid employment because of their caring responsibilities, compared with 20.5% for all carers in England
    - For 87.4% of carers the person they care for usually lives with them rather than somewhere else, compared with an average of 73.0% for all carers in England

There is no reason to believe that there is a significant difference between the UK and Bermuda in terms of these factors. Indeed, anecdotal observations support the hypothesis that similar risk factors impact on life experiences of people with intellectual disabilities in Bermuda.

Human Rights and Legislation affecting People with an intellectual disability

To truly enable social inclusion and quality of life for persons with intellectual disabilities requires their fundamental rights to be assured and protected. The UN Convention for the Rights of Persons

with Disabilities sets the standards for all persons with disabilities including intellectual disabilities. Some fundamental recognition of these rights and protections exist. For example, the Human Rights Act and more recent amendments to the Mental Health Act establish protections or rights that persons with intellectual disabilities would fall under. However significant gaps and areas for development remain. Key areas to address include:

- 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 persons with intellectual disabilities who are under 65 years of age and at risk of abuse or neglect.
- Ensuring the criminal justice system recognizes needs of persons with intellectual disabilities so they can participate equitably to obtain justice for crimes against them.

Fundamental to any movement towards ensuring the rights of persons with intellectual disabilities are recognised and respected requires community awareness and education. The introduction of any of the key areas outlined would require more sustained, coordinated and strategic education and awareness campaigns than provided within our current system.

History of Intellectual Disability Services and strategic initiatives in Bermuda

From St Brendan's to the Community

For many years, St Brendan's Hospital was the sole provider of residential care to people who had an intellectual disability. Bermuda followed a similar model of social policies to those seen in the U.S., U.K. and other countries, namely that people with an intellectual disability and could not live with their families, were frequently placed in institutional settings. Historically this was seen as a liberal proposal, intended to "protect them from the worst elements of society" (Radnor Report, 1908), with their management falling within the medical field.

By the 1970's, St Brendan's Hospital cared for adults with moderate/severe intellectual disabilities on Oleander Ward and children on the Edna Watson Ward. Patients with mild intellectual disabilities or additional mental health problems were usually cared for on the other long-stay wards (Hinson and Devon Lodge). The physical state of these wards was poor, and lacked air conditioning or ceiling fans. Most of the accommodation was dormitory style and patients lacked individual clothes or the opportunity to develop skills of independence or engage in community activities. In the early 1980s, the Hospital Board proposed the redevelopment of part of the St Brendan's site with a new 48-bed unit. This was intended to replace the 26 beds on Oleander Ward, the 16 beds on Watson Ward, and provide for some of the individuals on the long-stay mental health wards. It would also create additional space for new admissions of people who were currently living with family carers.

In the 1970s and 1980s, there was a strong move internationally away from institutional care and towards care in the community. An alternative option to the new hospital wing was proposed in 1983 by the St Brendan's Medical Staff (Advisory) Committee. This recommended that instead of increasing the number of beds on the hospital site, albeit within an improved physical environment, 27 of the patients should be discharged into 6 community group homes. The committee proposed a significantly reduced number of inpatient beds that would be provided for people with the most

complex needs, and that training and occupational places should be provided away from the St Brendan's site. It also proposed the development of a Home Support Team that would provide advice, support and practical help to families and individuals living in the community, with the aim of preventing inappropriate long-term admissions to hospital.

In 1987 Oleander and Watson wards were closed and everyone who had an intellectual disability transferred to Fairview Court with the 3 areas serving different functions. Bayview provided a rehabilitation function, Coral House cared for people who had additional physical disabilities and Sandpiper was the specialist challenging behaviour area.

At about the same time, Hope Homes was established and demonstrated a model of support that enabled people to live with increased independence in the community within a domestic setting.

A further report to the St Brendan's Management Committee by the Mental Handicap Steering Group Committee in 1986 added to the proposed development of community group homes and the Home Support Team, with recommendations for:

- An inter-agency planning forum to coordinate assistance for families who are experiencing difficulties
- Updating the Case Register to provide information about the needs of the community
- Inter-agency planning group to take forward recommendations for schemes such as adult special fostering to reduce unnecessary admissions to St Brendan's Hospital
- Create adequate facilities for emergency short term care and for planned holiday relief
- Increased participation in community activities
- Increased involvement of parents in the planning of care
- Improved legislation to promote the rights and protection of people with intellectual disabilities
- Further public awareness concerning the needs of the group

In 1991 a pilot group home was set up at Keepers Cottage (the old overseer's residence). When this was deemed a success, these 4 residents moved into a group home in the community. The then Minister of Health, Quentin Edness, gave a commitment to transfer more people into group homes in the community, and between 1991 and 2004 the majority of people moved to community group homes from Fairview Court. In 2010, Fairview Court was completely closed with the last 4 patients transferring into Keepers Cottage which became the specialist challenging behaviour home.

2010 Development Disabled Continuum of Care

The 2010 Developmental Disabled Continuum of Care Report produced by the Developmentally Disabled Task Force provides a brief overview of services in Bermuda. Excerpts from the report that detail the history of services is provided below:

In 2007 there were four programmes within the Ministry of Health and two in the Ministry of Education that provide services to people with developmental disabilities. The programmes provide assessment, treatment and support service designed to permit each person to live to their functional capability. In 2007 at the request of the Minister of Health, a position paper was prepared regarding the alignment of the administration of the Ministry's special needs programmes. That paper outlined the rationale for the transfer of Opportunity Workshop (OW) and the Orange Valley Centre (OVC) from the Ministry of Health as well as the Learning Disability Programme at Mid-Atlantic Wellness Institute (MWI) and placing them under one administration within the Ministry of Culture and Social Rehabilitation.

The recommendation to move the programs was prompted by several key findings including:

1. The absence of a single assessment centre or agency that follows the progress of clients through their various developmental phases
2. Agreement amongst administrators for a need for an integrated approach to service provision as there are gaps in the continuum of care
3. An increasing need for community participation, job training, increased socialization and friendship development
4. Need to address the programmes offered to the senior adults as these clients are no longer trainable and existing programmes are not suitable to their requirements
5. Need to create a process to address the care of persons whose care giver dies or is no longer able to provide care except for the client to be admitted to MWI.

The recommendation to transfer programs from the Ministry of Health was not accepted by the Ministry of Culture and Social Rehabilitation. The resultant discussion saw the Bermuda Hospitals Board (BHB) offering to provide the administration of the programmes. The proposal under the BHB guidance would have four objectives:

- Integrate the philosophy that Learning Disability Services (LDS) be managed under a Social Model rather than a Medical Model.
- Establish a single point of assessment, referral, admission and discharge for the three services
- Establish a coordinated seamless continuum of LDS services delivery.
- Ensure that the manpower, financing and resources are appropriate, based on census and cost effectiveness.

The proposed implementation was placed on hold while matters associated with staffing conditions of employment were resolved. In October 2009, the government established the Developmentally Disabled Taskforce with the following objectives:

- To identify lack of resources including human resources
- Identify the gaps in service
- Identify a common criterion for admission to be used by all facilities
- Skill sets needed
- Recommendations for solutions to the above

Recommendations from the **2010 Task Force** were as follows:

1. Coordination: Establish one administrative entity to be responsible for the national strategic direction and policy development for the developmental disabled.
2. Data collection: Develop a database that can be used by all agencies providing the appropriate security features for each agency.
3. Storage space for equipment: Assess on and off-site storage at all facilities with appropriate air quality control and determine need. Research the feasibility of KEMH servicing equipment. Research the need to establish an adaptive devices programme as per the Ontario/English model.
4. Programme expansion: Determine by departments and services/gaps in services and produce the justification for filling the gaps. Include human as well as financial assistance

5. Certification for Para-professionals in allied health: Review and restructure the entry level for teachers and Para-educators. There should be a training programme for the teachers and Para-educators and a time frame for them to complete it in. We must specify which type of special needs we are talking about because special needs are a big category.
6. Awareness and advocacy: Special Olympics' and other sports, recreational activities would bolster the confidence of young people and provide an opportunity for advocacy. Develop/ liaise with specific charities to enhance their advocacy roles.
7. Legislation for vulnerable persons: Establish a small group to research the topic and make recommendations to the Minister of Health.

KMCC Review 2019

In 2019 a Review of KMCC was undertaken by the Management Consulting Section of the Cabinet Office. The review identified key areas of program improvement and development including but not limited to:

- Establishing a charitable arm
- Expanding key allied health staff
- Expand client job placement support and coordination with other services
- Collaborate with existing services in the charitable sector for program development
- Determine short and long term options for required upgrades to building including a purpose built option.

BHB Clinical Services Plan 2017

In 2017, Bermuda Hospitals Board undertook a review of many of the services being provided by the hospitals. This included the Intellectual Disability Service as one of the ten 'Communities of Practice' (CoP). The Clinical Services Plan (CSP) was a project that was undertaken as part of Bermuda Hospitals Board's Strategic Plan (2016-2021). The strategy aims to improve the patient experience, improve the health of populations, and reduce the per capita cost of care and work towards a vision: *Exceptional Care. Strong Partnerships. Healthy Community.*

The Bermuda Hospitals Board (BHB) Clinical Services Plan (CSP):

> "Identifies population needs, and defines the scope and scale of clinical services offered at BHB (including which should grow, stay the same, or be divested), along with the associated organizational requirements, meeting high standards of quality, patient experience and value to best serve the people of Bermuda."

When completed, the CSP would describe the types of services and the projected volume of services that BHB should be prepared to deliver to meet the needs of Bermudians in 2020 and 2025.

The review involved a wide range of stakeholders and made the following recommendations with respect to the intellectual disabilities services:

Expand the service that is provided by BHB:

- The proposal is that **Multi-Disciplinary Community Support teams** be expanded to support the needs of the entire adult ID population regardless of living location. The scope of service will expand to include early intervention and caregiver support/education, with the goal of

supporting individuals as effectively as possible from an early date. To encourage efficiency and quality, consideration should be given to moving towards an integrated case management approach, so that all service provider supports are around the table (page 107).

- Should BHB become a provider of complex long-term care, there will be an opportunity to offer **respite to the ID population**, as well as other specialized populations. This would most likely be appropriate for only a certain segment of the ID population, and it may be advisable to "segment" the respite population by type of need. Individuals with more complex medical or challenging behavioural needs would receive respite in BHB's long-term care beds; those who do not require such intense respite, should continue to be accommodated in group home respite care when these beds are available.

BHB to continue to provide this service:

- The CoP agreed that **the Group Homes** did not need to be managed and operated by BHB. However, no alternate service provider was identified; the service is an essential element in the continuum of care for people with ID in Bermuda and must be maintained and potentially expanded. The BHB Clinical Services Plan will assume that BHB will continue to provide this service (within the planning horizon [i.e. 2025] of the plan), and that there will be a funding model established to ensure that BHB is fully compensated for the provision of the service. The 3 – 5 year Long Term Care Strategy that is being led by the Ministry of Health is considering the need to increase long term care homes and home care capacity; it is expected that the needs of people with intellectual disabilities will be included in this planning.
- There are a small number of individuals with ID who are "permanent" or "long term residents" at MWI because there are no other placement options for these individuals (unable to be cared for in Group Homes due to capacity and higher needs than can be supported by unqualified care staff). A portion of these individuals have complex medical needs that are too challenging for the current group homes to manage. Proposal is to develop the capacity to accommodate medically complex and behaviourally challenged ID individuals in a more appropriate setting. A minority of these individuals may be required to be accommodated in specialized long-term care beds at BHB. Bermuda is proposing to develop improved capacity in long-term care in the community to better align capacity with the anticipated long-term care needs of the population. **Beds for Individuals with ID with more complex care needs should be included in the LTC capacity plan**. BHB would no longer be the "setting of only resort". BHB may be the provider of some of these specialized long-term care beds, but some may be administered more appropriately by others in the community. It will be important that wherever the care setting, these individuals and caregivers have access to the MDT for input/support and consultation in managing the ID care needs of these individuals over time. The CoP agreed that as BHB develops LTC capacity, a component of this capacity should be designed to support individuals with ID (and other high-needs sub-populations) who are currently in rehab beds (Devon Lodge) and older adult beds (Reid), and who are too complex to be supported in group homes.

BHB to provide support to a partner organisation to provide the service:

- There is a lack of data on the changing needs and demand for services to support Bermudians with Intellectual Disabilities. There is a need to better assess the current and changing demands to better understand service requirements and to develop improved funding models. The CoP strongly supported the establishment of a **National Register of Bermudians with ID** as a component of the Chronic Disease Management register currently being established by the Ministry of Health.

Recommended that BHB should not continue to provide this service in its present form:

- It is proposed that the New Dimensions Day Programme and the K. Margaret Carter Adult day centre programme be merged. This will help to provide a better continuum of provision across all levels of need as well as support greater independence, choice and vocational training. Discussions have already started to promote more integration and better collaboration between the two services. The CoP agreed that enhanced coordination and allocation of client placement based on program resources is required; initial collaboration is underway to determine ways to achieve this. The CoP agreed that to achieve this, **the two existing adult day programmes should amalgamate**. Amalgamation would ensure that the existing two programmes would be administered as a single programme. This would help avoid the situation where individuals are 'lost' between the two programs; no exclusion criteria can be applied when there is a single programme.

Long term care service gaps identified to date

Services requires of persons with intellectual disabilities fall under the general classification of long term care (LTC). Therefore gaps identified in the LTC system in general can apply to this sector as well. Below is a summary of some of the key gaps in relation to persons with intellectual disabilities:

- Data on the number of persons with intellectual disabilities, needs and their ageing carers.
- Limited access to intensive/comprehensive client case management and care coordination services.
- Limited access to preventative and rehabilitative care and supports within existing services.
- Availability and diversity of day care programs- existing services are at capacity, limited options for seniors with intellectual disabilities, and vocational training.
- Access to group homes for persons with intellectual disabilities, especially those under 65 years, and 24/7 skilled nursing facilities.
- Specialized residential and clinical services for persons with high risk challenging behaviours, especially young adults.
- Access to transportation and technology to help people remain in their homes and the community.
- Insufficient legislation and resources for adult protection and support.
- Financial sustainability for Government, service operators and families/individuals.
    - High costs of facility based service provision especially as needs increase.
    - Expectations of individual vs government financing of LTC
    - Uneven access to home care benefits for families (i.e. they are not currently part of SHB) and sustainability of current personal home care benefit financing.

-END-

Annex 2: Reports and References

Reports Reviewed:

Report of the sub-committee of the St Brendan's Medical Staff (Advisory) Committee to look at the development of services for severely handicapped people in Bermuda (February 1983)

Report of services for mentally handicapped people at St Brendan's Hospital (November 1986)

Social Welfare Act (bermudalaws.bm)

Recommendations for a National Policy on ID (2006). This policy document was commissioned by the Ministry of Human Affairs and a task force was created by the Ministry of Human Affairs that focused on various areas noted within the policy document.

Developmental Disabled Continuum of Care (June 2010). A Developmental Disabled Task Force was created to work on various components of this document.

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Public Health England (2016) People with Learning Disabilities in England 2015: Main Report https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

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Annex 3: Glossary of Terms

Intellectual Disability

Individuals with an intellectual disability (ID) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning), and;
- which is apparent before adulthood is reached and has a lasting effect on development.

Each of these three criteria must be met before someone can be said to have an intellectual disability; Intelligence Quotient (IQ) alone should not be used to determine presence of an intellectual disability. In terms of intellectual functioning, intellectual disability is conventionally defined as an IQ score in the region of 70 or below. However, it is not appropriate to use a 'cut off' figure of 70, as the results of a recognised IQ test require skilled interpretation. There should also be significant difficulties in adaptive and/or social functioning, for example in relation to conceptual, social and practical skills (such as language, interpersonal skills and activities of daily living).

The level of support someone needs depends on individual factors, including the severity of their intellectual disability, which can range from someone with a mild or moderate intellectual disability to someone with a severe or profound intellectual disability. The extent and nature of a person's intellectual disability may be determined by the presence or not of a single major genetic or environmental cause or by multiple factors interacting with educational and social opportunities that facilitate intellectual and the development of functional and social skills.

There is a growing consensus internationally to adopt the term *intellectual disability* to identify the group of people whose needs are being addressed within the Bermuda National Plan. DSM-5 and ICD-11 classification systems are both adopting this terminology. This is particularly important in Bermuda where the North American and UK definitions of the term *learning disability* have significantly different meanings; in the US, it refers to a weakness in a certain academic skill (e.g. dyslexia), but in the UK, it is synonymous with intellectual disability.

Autism

Also referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC).

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them.

The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with:

- Social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice);
- Social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own);
- Social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with.

Autism is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives, while others (including those who also have an intellectual disability) may need more support. It is estimated that around 50% of people with autism also have an intellectual disability.

Challenging Behaviour

> "Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion." (R. C. Psych, 2015)

Some people with an intellectual disability and/or autism display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and does not in itself imply any understanding as to the causes of the behaviour. The behaviour may be a way for someone to let people know what they want or how they feel, or to try and control what is going on around them, or be a response to physical or mental distress.

A variety of factors are likely to contribute towards the development and escalation of behaviour that challenges, these include (but are not limited to): biological and genetic factors, physical ill-health, impaired communication difficulties, mental ill-health, the impact of poverty and social disadvantage, quality of support and exposure to adversities. Some care and support environments may increase the likelihood of behaviour that challenges, including those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise, as well as environments where physical health needs and pain go unrecognised or are not managed.

Behaviour that challenges can often result from the interaction between personal and environmental factors, and can include self-injury or physical aggression, severe agitation and extreme withdrawal, as well as behaviours that can result in contact with the criminal justice system – in some cases leading to someone being arrested, charged and convicted of an offence.

Some people may have a long and persistent history of behaviour that challenges, perhaps starting in childhood. In others, it may be highly episodic – arising only under specific circumstances of stress or when the individual has a physical or mental health condition. In others still, it can be traced to a specific life event, such as a bereavement. This means that even if someone does not display behaviour that challenges today, they may do so in the future.

Active Support

Active Support (AS) is defined as:

> *Providing enough help to enable people to participate successfully in meaningful activities and relationships, so that they gain more control over their lives, gain more independence and become more included as a valued member of the community, irrespective of degree of intellectual disability or the presence of additional difficulties (www.unitedresponse.org.uk)*

Active support has been shown to be important in determining the quality of life of people with intellectual disabilities, and in particular in increasing peoples' participation in daily life, social and community activities as well as increasing people's skills, adaptive behaviour and choice.

There are four elements or principles of active support that can be applied to anyone in any activity to help staff work out what they should do:

- *Every moment has potential:* Viewing everything that happens (however mundane) as an opportunity for people to be actively involved.
- *Little and often:* Providing slow, frequent and obvious support to enable people to actively participate in the small parts of each opportunity.
- *Graded assistance to ensure success:* Ensuring the type and level of support provided gives just enough help for the person to take part successfully.
- *Maximising choice and control:* Seeking opportunities for people to make more choices in, and take more control of, when and how they will be engaged.

Profound and multiple intellectual disabilities

There is a wide range of definitions of the term 'profound and multiple learning (intellectual) disabilities' (PMID). A review of the literature and series of focus groups recommended that:

> *People with profound and multiple intellectual (learning) disability (PMID):*
>
> - *Have extremely delayed intellectual and social functioning*
> - *May have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch, gestures)*
> - *Often require those who are familiar with them to interpret their communication intent*
> - *Frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments.*
>
> *They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualized relationship with a carer.* Bellamy et al. (2010).

Capable environments

The term *Capable Environments* is used to describe supported environments that help to provide vulnerable people with the best possible outcomes including quality of life improvements for individuals, better work environments for staff and a reduction in incidents of challenging behaviour that can lead to placement breakdown and the additional costs that are frequently associated with this (McGill et al. 2020). Services should be striving to meet the characteristics of a *capable environment* as set out in the following table.

Capable environments promote the following:

Characteristics	What does this involve?
1. Positive social interactions	• Carers like the person and interact (speak, sign, physically etc) frequently with them in ways that the person enjoys and understands.
2. Support for communication	• Carers communicate in ways the person understands and are able to notice • They interpret and respond to the person's own communications whether indicated by speech, sign, gesture, or behaviour
3. Support for participation in meaningful activities	• Carers provide tailored assistance for the individual to engage meaningfully in preferred domestic, leisure, work activities and social interactions.

	• Assistance is the least required and employs speech, manual signs, symbols or objects of reference as appropriate. • The person receives positive feedback about their achievements
4. Provision of consistent and predictable environments which take full account of personalised routines and activities	• Carers support the person consistently so that the person's experience is similar no matter who is providing the support. • Carers use a range of communication and other approaches tailored to the individual (e.g. visual timetables, regular routines) to ensure that the person understands as much as possible about what is happening and what is about to happen.
5. Support to establish and/or maintain relationships with family and friends	• Carers understand the lifelong importance to most people of their family, and the significance of relationships with others (partners, friends, acquaintances etc). • Carers actively support all such relationships while being aware of the risks that sometimes arise in close or intimate relationships.
6. Provision of opportunities and choice	• Carers ensure that the individual is involved as much as possible in deciding how to spend their time and the nature of the support they receive from the relatively mundane (e.g. choice of breakfast cereal) to the rather more serious (e.g. who supports them).
7. Encouragement of more independent functioning	• Carers support the individual to learn new skills, to try new experiences and to take more responsibility for their own occupation, care and safety.
8. Personal care and health support	• Carers are attentive to the individual's personal and healthcare needs, identifying pain/discomfort, enabling access to professional healthcare support where necessary and tactfully supporting compliance with healthcare treatments.
9. Provision of acceptable physical environment	• Carers support the individual to access and maintain environments that meet the individual's needs/preferences in respect of space, aesthetics (including sensory preferences), noise, lighting, state of repair and safety.
10. Mindful, skilled carers	• Carers understand both the general causes of challenging behaviour/ distress and the specific influences on the individual's behaviour. • They draw on the expert knowledge of the individual's family and friends to improve their understanding. • They reflect on, and adjust, their support to prevent and/or quickly identify circumstances that may provoke challenging behaviour or distress.
11. Effective management and support	• The frontline team is managed and/or supported by individuals with administrative competence and the skills to lead all aspects of capable practice.
12. Effective organisational context	• The support provided by frontline staff is delivered and arranged within a broader understanding of mental health and challenging behaviour that recognises (among other things) the need to ensure safety and quality of care for both individuals and carers.

When providing support to people who have intellectual disabilities, the aim is to design services that meet the characteristics of the *capable environment*. This applies to residential settings, day services, supported employment and even family homes.

McGill, P., Bradshaw, J., Smyth, G., Hurman, M. & Roy, A. (2020), Tizard Learning Disability Review, 25, 3, pp 109 – 116.

Compassionate Care

Locally, the Inter Agency Committee for Children and Families, is promoting the approach of *Compassionate Care.* This uses best practice standards to build positive, nurturing, healing and resilience-building relationships with the people being served. It builds on the principles of adults in caring positions having the knowledge, skills and emotional competencies to create and sustain Compassionate Care. Institutions that care for children and their families require policies, practices and culture that enable and empower Compassionate Care.

www.iacbermuda.org

Carers

In this document we use the term ‘carer‘, to mean those people who provide unpaid support to someone. This is often a family member, but not always. We refer to people who provide paid support as ‘paid support and care staff’.

Annex 4: Services and Supports for adolescents and adults with intellectual disabilities

Bermuda Hospitals Board – Intellectual Disabilities Service

The Intellectual Disability (previously termed Learning Disability) Programme has its administrative base at the Mid-Atlantic Wellness Institute, although many of the services are provided in the community. The programme provides a range of different types of support to adults who have learning disabilities (intellectual and developmental). Services include 24-hour support in 14 group homes across the island, the New Dimensions Day Programme, respite care and multi-disciplinary support.

The philosophy of the Intellectual Disability Programme is that every service user should be supported in ways that increases their engagement in meaningful activities and relationships (Active Support). This requires the service user to be at the forefront of everything that is done to support them (Capable Environments).

Each service user in the group homes and New Dimensions will have an up-to-date Person Centred Passport that sets out what is important to them, and what staff need to know in order to support them to have a good day every day. To this end, all support staff have undergone the City and Guilds certificate programme in Supporting Individuals with Learning Disabilities (4200), or are commencing on a new programme that is being run in collaboration with Bermuda College. They have also attended training workshops in active support and person-centred approaches.

A number of clients present behaviours that are considered to be challenging to those who are supporting them. The Intellectual Disability service has adopted the principles of Positive Behaviour Support as the approach used to understand and respond to challenging behaviour.

This approach includes viewing the behaviour as being the person's way of communicating that something is upsetting them. By changing the situations and events they experience, we can increase the person's quality of life and reduce the likelihood that challenging behaviours will occur. Each service user whose behaviour is considered challenging will have a Positive Behaviour Support plan in place. The plan emphasises ways to avoid trigger situations and how to de-escalate any situations that we have been unable to avoid.

Group Homes

There are 14 group homes across the length of Bermuda. Each home supports between three and nine people, with a total of 65 residents across all the group homes. The homes are staffed by community support workers, who are supported by three clinical managers, a clinical supervisor, and the members of the multidisciplinary team.

Two of the group homes have been adapted to enable people who use wheelchairs to be supported with dignity while maximising their independence. One of the 14 properties belongs to BHB, but the other homes are rented on the open market or from Project 100, a charitable organisation established to purchase and adapt suitable houses.

A small number of clients in group homes are supported into sheltered employment. Up to 25 service users attend the New Dimensions Programme each day, while others are engaged in different community-based activities from the homes. Homes have access to the service's cars/minibuses to enable the clients who cannot easily use public transport, to access the community.

New Dimensions Day Programme

The New Dimensions Day Programme provides an array of services for up to 25 clients who attend from our group homes. The programme aims to empower and support all clients in their quest to reach their full potential in an inclusive, diverse and creative environment. Clients are encouraged to excel in many different areas, such as arts and crafts, bowling, cricket, fishing, spirituality, exercise, work skills and visiting places of interest in the community.

Respite Care

Respite care can be provided in six of the group homes. Adults who live in their family home can apply for respite of up to six weeks per year. The aim of respite care is to provide regular breaks for families to enable them to support their family member throughout the rest of the year. Access to respite care is through the team's social worker.

Multi-Disciplinary Support

Multi-disciplinary support is available to family carers, support staff and people with intellectual disabilities within both the group homes and the wider community. The members of the MDT include nursing, clinical psychology, occupational therapy, physiotherapy, social work, dietetics, speech pathology, and rehabilitation therapy. The team has access to a consultant psychiatrist as needed.

Community Intellectual Disabilities Team (CIDT)

The Community Intellectual Disabilities Team was established in April 2021 as a specialist, multi-disciplinary team to assist in meeting the needs of those persons in Bermuda with an intellectual disability who do not live in the MWI group homes. The aim of the service is to bridge the gap in access to health services for this group and support clients to live as healthy a life as possible. This service is delivered through a process of assessment of needs, and support plans that are designed and implemented by members of the team. The team's purpose is to provide safe and effective person-centred support using a multidisciplinary approach to enhance the client's well-being within the community.

https://bermudahospitals.bm/services-listing/mental-health/learning-disability-programme/

K. Margaret Carter Centre

Day services provide an important support to families of adults who have intellectual disabilities. The K. Margaret Carter Centre (KMCC) provides support and training for adults with intellectual and physical disabilities through a range of programme areas including an adult day centre, employment training, functional skills training and production work. The clients range in age from 18 to over 50. Prior to Covid-19, the K Margaret Carter Centre (KMCC) provided day service support to 50 individuals who attended on a daily basis. At present KMCC services 40 clients on a weekly basis. The facility currently operates at half capacity, with two client groups attending on select days due to the recommendations of the Department of Health (DOH). However, it is anticipated that all 50 clients will attend the facility on a daily basis when it is safe to so under the guidance of DOH. In 2018, a Management Services Review of KMCC was undertaken by the Management Consulting Section of the Cabinet Office. The recommendations included a proposal that KMCC be amalgamated with New Dimensions and managed by MWI. The full report is expected to be available soon. https://www.gov.bm/k-margaret-carter-centre

Dame Marjorie Bean Hope Academy

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 can support a maximum enrolment of 24 students with a 2:1 ratio in each of our four classrooms. Additional accommodations are made for students who require 1:1 support. Applicants for admission to Hope Academy must meet the following requirements: 1) Have a diagnosis of severe/ profound multiple learning disabilities 2) Require more than three hours of special education support during the school day. 3) Require significant therapeutic interventions. 4) May experience significant medical challenges.

Promoting the shaping of student independence is a critical focus of our programming. Each student is exposed to 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. Our strong community partnerships and community involvement aid in the rounded development of our students. However, the COVID 19 pandemic is currently impacting our volunteer programme and interaction with peers from other schools.

Bermuda Special Olympics (Reg. Charity #972)

Bermuda Special Olympics provides year round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities. Those activities give them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship. Currently Bermuda Special Olympics offers opportunities for athletes in athletics, swimming, bocce, bowling, equestrian, and tennis.

https://www.specialolympics.org/programs/north-america/bermuda

WindReach (Reg. Charity #92)

WindReach exists to enrich the quality of life for people with special needs. It is registered as a Health Service Provider (Advanced Level) with the Bermuda health Council.

WindReach is a fully-accessible 4-acre facility located in Warwick Parish, Bermuda, featuring a multi-purpose Activity Centre, Animal Zone, Therapeutic Riding Centre, a fully-accessible playground and a purpose-built Adult Day Care Centre. Our unique setting offers a variety of therapeutic and educational experiences for people with varying physical and intellectual abilities. Today, we have on average 200 participants benefitting from our programmes on a weekly basis. Participants range in age from pre-schoolers through to our older adult community.

www.windreachbermuda.org

Tomorrow's Voices (Reg. Charity #816)

Tomorrow's Voices is a clinical Centre registered as a healthcare provider with the Bermuda Health Council. Our Centre meets the needs of individuals with Autism and other Developmental Disabilities through the use of Applied Behaviour Analysis (ABA)/Verbal Behaviour (VB) therapy. Our year-round Centre offers a variety of programmes including 1:1 Clinical In-House Programme, Summer Programme, Saturday Social Skills Programme, In House/In School Consultation Services, Bi-Monthly Community Workshops, University Student Internship Opportunities and our newest programme Thriving Beyond 21 (Adult Day Programme). Our programmes service clients ranging from 2yrs of age through to adulthood and our year-round day programmes (In-House 1:1/Thriving Beyond 21) are recognized by insurance providers. Yearly our Centre supports up to 40 clients in our various programmes and through these programmes we help to improve socially significant behaviours for our clients and their families by relying on evidence-based research and data collection.

www.tomorrowsvoices.bm

Benefits available for persons with intellectual disabilities-

See: **A guide to benefits available to persons with disabilities in Bermuda by the Disability Advisory Council** (2019) https://www.gov.bm/long-term-care-resources

For more general LTC supports and services visit: www.helpingservices.bm