

# **Disability Consultation Paper** TO INFORM A DISABILITY STRATEGY FOR JERSEY

Large print version

January 12<sup>th</sup> 2017

#### **Overview**

#### 1. Why are we consulting?

As part of planning for the future, in the Strategic Plan 2015-2018, the Council of Ministers committed to supporting the development of a disability strategy for Jersey.

We want to ensure that a strategy is developed and delivered in partnership with the community.

Throughout 2015 and 2016 extensive research and consultation was undertaken to understand more about the experiences of individuals living in Jersey with a disability, impairment or long-term condition.

These experiences have been brought together into a set of draft actions and priorities for a future disability strategy, as set out in this document.

The aim of this document is to consult islanders and understand which of these draft actions are the most important to people.

The responses to this consultation will be used to further refine the proposed actions and priorities, which will go on to be developed into a disability strategy for Jersey.

# Please tell us what you think by 10<sup>th</sup> March, 2017

# 2. After the consultation – next steps

I. <u>Review consultation responses</u>

Following this consultation, a report will be published, summarising what people have told us.

II. Publish the strategy

We will then develop and publish a disability strategy for Jersey. This will reflect what people have said to us. The strategy will be presented to all States members and published on www.gov.je.

# III. Set up a strategy delivery group

A group of people will be brought together to form a strategy delivery group. It will include representatives from the business, voluntary and community sectors and the Government of Jersey, including disabled representatives. They will work together to identify resources and to agree how and when strategy actions will be delivered.

# 3. Who should respond to the consultation?

We would like to hear from:

- members of the public
- voluntary & community sector organisations
- local employers, businesses and trade organisations

# 4. What we would like to know?

This consultation paper summarises suggestions for the priorities and actions that could be included in a proposed disability strategy for Jersey.

We would like to know:

- whether you agree with the proposed actions
- any additional actions that are required

# 5. How to participate in the consultation

A. You can attend a consultation event

Date	Time	Venue	Book ticket
Friday 20 <sup>th</sup> January	12.15- 13.15	St Paul's Centre	https://www.eventbrite.co.uk/e/disability- strategy-for-jersey-consultation-event-1- tickets-31065168756
Tuesday 24 <sup>th</sup> January	19.00- 20.00	St Paul's Centre	https://www.eventbrite.co.uk/e/disability- strategy-for-jersey-consultation-event-2- tickets-31065457620
Thursday 16 <sup>th</sup> February	13.00- 14.00	St Paul's Centre	https://www.eventbrite.co.uk/e/disability- strategy-for-jersey-consultation-event-3- tickets-31065598040

The total capacity of these venues is limited, please book in advance following the above links or by calling 01534 440682.

The venue is wheelchair accessible and has hearing loop facilities. If you have any additional access or communication needs, please use the contact details below and we will do our best to accommodate your needs.

In addition, we will work with local voluntary and community organisations to ensure that those who are unable to attend public meetings can engage in the process.

- B. You can submit your comments:
- by completing our online consultation survey (www.gov.je/consult)
- by email (<u>a.hamon2@gov.je</u>)
- in writing (or by filling out a printed version of this document)

Write to: Disability Strategy consultation Cyril Le Marquand House PO Box 140 St Helier Jersey JE4 8QT

C. Comment via Facebook and Twitter

Comments made on the States of Jersey Facebook page (https://www.facebook.com/StatesofJersey) and the States of Jersey Twitter feed using the hashtag #disabilitystrategyjsy will be reviewed but will not necessarily be included in the final report, unless they address the issues raised in this consultation document.

# Your submission

If you are writing or emailing please provide the following information with your response:

- your name and contact details
- whether you are responding on behalf of an organisation or as a member of the public.

Please note that consultation responses may be made public (for example; sent to other interested parties on request, provided to the Scrutiny Office, quoted in a published report, reported in the media etc.). You therefore need to tell us if you:

- a. agree that your comments may be made public and attributed to you
- **b.**agree that your comments may be made public but not attributed (i.e. anonymous)
- c. do not want your comments made public.

In the event that you do not provide this information, we will assume that you do not want your comments, or your name, made public.

#### **Offensive comments**

Offensive comments will not be included in the consultation report and, if any are posted, via Facebook or Twitter, they will be removed.

# **Disability Consultation**

TO INFORM A DISABILITY STRATEGY FOR JERSEY

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# A. Strategic Context

In the 2015-18 Strategic Plan, the Council of Ministers made a commitment to develop a new Island Vision defining the major outcomes that Jersey should aspire to over the next 20 years.

The key elements of this new approach are -

- a focus on outcomes end results that people can identify with, such as 'rewarding employment' or 'feeling safe'
- headline measures by which we can measure Jersey's progress towards these outcomes
- targets setting out the level of change we can realistically aim for

The Island Vision will bring social, economic and environmental measures and targets together in one place so everyone is clear about where Jersey is headed and what the States is working to achieve, not just during one political term of office, but in the longer term.

The Island Vision has 10 strategic goals, one of which relates to the health and wellbeing of Jersey's population. This goal has, in turn; three outcomes - one of which is people living with a long-term health condition or disability enjoy a good quality of life.



# Figure a: Health and Wellbeing in the Island Vision

A disability strategy for Jersey will be one of the first 'delivery strategies' developed to support the new Island Vision. It will set out how, by working together, we can help improve the quality of life for people living with long-term health conditions or disability.

# B. Developing a strategy together

Different individuals and organisations in our community provide support and services to Islanders with a disability, impairment or long-term condition. This includes the family and friends of people living with disability, the voluntary and community sector, local businesses and the Government of Jersey. This is why a disability strategy for Jersey must involve the whole Island. Research was carried out in 2015 and 2016 to build a picture of the lives of Islanders with a disability, impairment or long-term condition. The research has provided us with a clearer understanding of the numbers of disabled Islanders as well as a greater understanding of the challenges individuals face because of their disability or impairment. The views of disabled Islanders have now been brought together in these proposed priorities and actions from which the disability strategy will be developed.

A broad group of stakeholders has helped in this process. (See appendix 1 for details of stakeholders).

# C. In this document

**Section 2** of this paper summarises the research that has been carried out to inform the development of a strategy and help define potential priorities and actions for a strategy.

**Section 3** sets out the overall strategy outcome and the proposed indicators that will measure the impact of a strategy, to assess whether it will make a difference to improve the lives of Islanders. It also outlines how the future strategy will be delivered.

**Section 4** sets out 5 priorities for the strategy and a wide range of proposed actions to support the priorities.

All sections of our community; the public, private and voluntary sector, will need to own and deliver these actions. It will be an island-wide strategy, not simply a 'Government of Jersey strategy'.

In this section you will be asked to provide your comments on the proposed actions and to suggest any additional actions that you feel will help achieve the proposed outcome of the strategy.

**Section 5** asks for basic information, such as contact details, from people who respond to this consultation. We need this so that we can process the consultation responses and keep in touch.

# A. Research undertaken

Whilst there is a great deal of data available about the lives of people living with disability in the UK and other jurisdictions, up to now, the information gathered in Jersey has been limited and disjointed. Rather than make any assumptions about the lives of Islanders based on UK data, it was considered important by stakeholders to build a rounded picture of disability in Jersey.

The development of a strategy to date has been informed by three key pieces of research:

- I. Household survey
- II. Behaviour and perceptions research
- III. Strategy themes review of other jurisdictions (see appendix 2)

# **B.** Household survey - overview of findings

# Approach

The Government of Jersey commissioned the social research agency, Public Perspectives Ltd, to conduct an extensive disability survey in Jersey – The Health and Life Opportunities Survey. The purpose of this was to help us better understand the profile and prevalence of disability on the Island.

The research was conducted via a self-completion postal and on-line survey in September and October 2015. 1 in 4 households in Jersey were randomly selected to participate. In total, the research achieved a 42% response rate with 4,300 households responding. This response level provides us with statistically robust data.

# Summary of the findings

The findings from the research are summarised in the following infographics, these are grouped under the following topics:

- Profile and prevalence of disability
- Health and wellbeing
- Living with disability in Jersey
- Carers

# PROFILE & PREVALENCE



of Jersey residents living in private households are disabled as defined under the UK Equality Act



That translates to 13,900 people



Or 10,800 households

Rates of disability elsewhere:

UK 16.8% Guernsey 21%

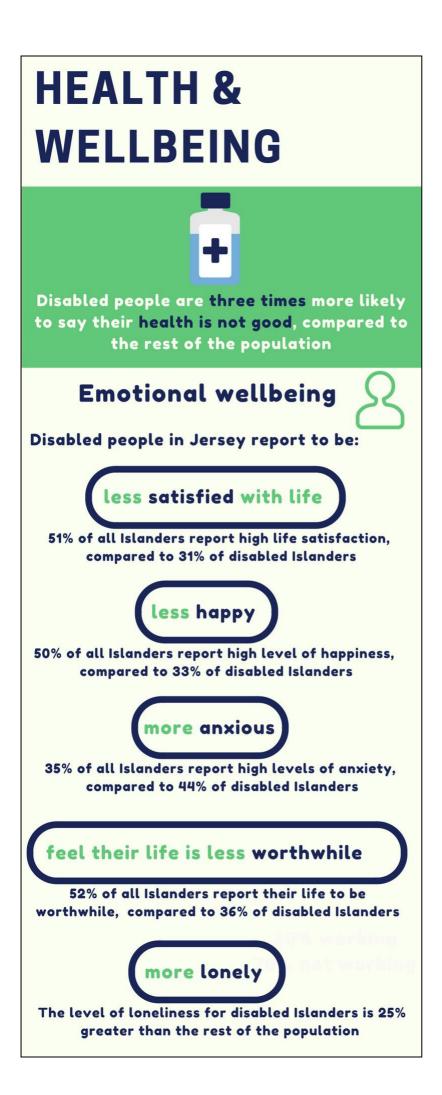


#### **Profile of disability**

People most likely to be disabled in Jersey are:

#### Older

On low incomes Living in social housing Not in employment Living alone



# LIVING WITH DISABILITY IN JERSEY





60% of disabled

Islanders experience

difficulty taking part

in community

activities

**41%** of disabled

**Islanders** experience

difficulty travelling

around Jersey

28% of disabled Islanders experience a lot of difficulty getting the work they want



**50%** of disabled Islanders experience difficulty getting the healthcare they need



26% of disabled Islanders experience difficulty getting information in an understandable format

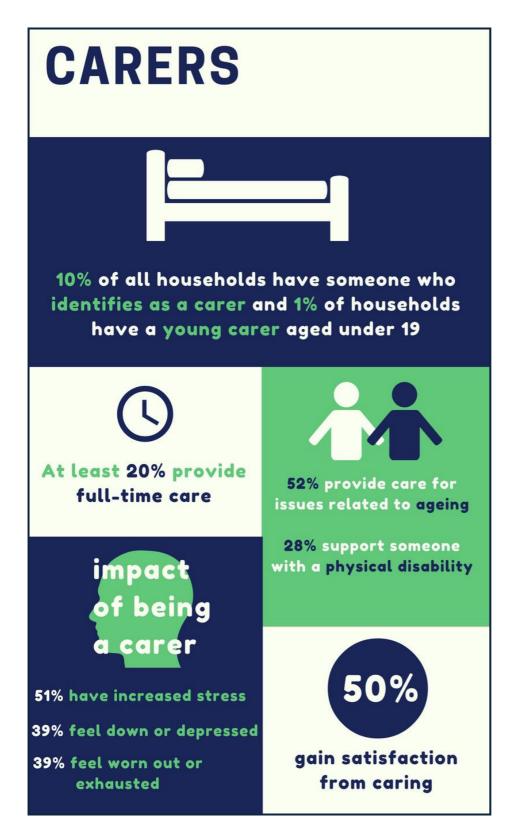
**30%** of disabled Islanders experience difficulty getting education and training support



**31%** of disabled Islanders experience difficulty moving around in their home



28% of disabled Islanders report experiencing discrimination in the past 12 months



For the full findings report on the Health & Life Opportunities survey please visit:

http://www.gov.je/government/pages/statesreports.aspx?rep ortid=1829

# C. Behaviour and perceptions research - overview of findings

**Approach:** A qualitative research study, consisting of interviews and focus groups, was undertaken by the Government of Jersey during an 8-month period between August 2015 and April 2016.

The research involved a series of one-to-one interviews and discussion (focus) groups with a wide range of Islanders who have a disability, impairment or long-term condition and with people who provide unpaid care for family members. In addition, an engagement session was organised which gave service users the opportunity to share their experiences directly with policy makers (both officers and politicians). Around 100 individuals participated in the research.

The information gathered during these sessions has been considered and analysed. Consistent 'universal' themes emerged on the issues that affect people living with disability, regardless of the nature of their disability, their age or their personal circumstances.

For more detail on who participated in the research, please see appendix 3.

**Key themes:** The experiences and circumstances of individuals with a disability, impairment or long-term condition are complex and interlinking. The key issues that emerged from the research have been grouped in the following themes:

- I. Health, wellbeing & support
- II. Access & navigation

# III. Attitudes & awareness

# I. Health, wellbeing & support

Main issues described by participants:

- There is a strong link between individual perceptions of physical and mental health and the impact of this on an individual's general wellbeing.
- The perception of support has a strong correlation with a higher sense of wellbeing.
- Often people living with disability, carers and family members report that they do not know where to go for support, or what support could be available to them – timely emotional support can be critically important.
- Voluntary and community sector organisations are felt to provide wide-ranging support, to many. However, it can feel like a 'lottery' in terms of support available:
  - For example for individuals with autism or a visual impairment, there is strong support on island. But for an individual with Cerebral Palsy, there is little targeted support available.
- Adequate housing can have a huge impact on an individual's sense of wellbeing.
- Individuals often face barriers to accessing activities that promote both physical health and emotional wellbeing - including work, socialising, sporting activities and cultural events.

I was at crisis point; I didn't know where to turn. Eventually I found this support group and haven't looked back.

Carer to son with mental health issues

My granddaughter bought me an iPad for Christmas; she's shown me how to use it and now I can use Skype, I've seen my great grandson for the first time.

Older female, mobility issues

A family I represent have a child with complex needs – essentially the ground floor of their house is a hospital – with a constant flow of equipment and care providers; this means they have no 'living space' to relax in, which impacts on their wellbeing and togetherness in the family.

Voluntary representative

# **II. Access & navigation**

Main issues described by participants - information and services:

- Access to information can provide confidence and reassurance
- However, getting information is often not straightforward – both in terms of availability and accessibility of information
- Specific communication needs of disabled Islanders are often not met by services – both those specific aimed at the individual and their needs (e.g. specific hospital department) and universal services (e.g. GP or income tax)

- Navigating services is often challenging and problematic – provision is designed around services, not the individual who requires the service.
- Some individuals report 'missing out' on services, as access and information was not readily available to them

I only found out about Home Carers Allowance when I bumped into a neighbour. She made the mistake of asking how I was. I broke down in tears, and she told me I was acting as an unpaid carer and was entitled to financial support

Carer to husband with multiple disabilities

I get so many letters saying, 'to book an appointment, ring this number' – I can't use the phone, but they don't offer any alternative way to get in touch.

Male, hearing impairment

I was in hospital giving birth, but couldn't communicate with the midwives. At one point there were complications, they had to call for my social worker in the middle of the night to act as interpreter – luckily she made it in time. There was no communication support available.

Female, British Sign Language User

Main issues described by participants - transport:

- Physical isolation can trigger feelings of loneliness and social isolation individuals who find it difficult to leave their home can experience a lower sense of wellbeing
- Access to transport supports independence.
- The Island's geography creates challenges to using transport, and can be isolating, in spite of the small size of the Island
- Transport solutions need to meet the greatly varied needs of disabled people, flexibility is key.

I live in Trinity; unless my son drives me, I just can't get out and about. Support to get to the shops would make such a difference.

Older female, stroke survivor

I can afford to pay for parking, like everyone else. What I need is to be able to park right in the centre of town, close to where I need to be.

Female, amputee & blue badge holder

#### III. Attitudes & awareness

Main issues described by participants:

- Defining disability is complex and controversial, there is no universally agreed definition
- Disability can be fluctuating and it can be invisible; an individual can feel or be considered to be 'disabled' in one situation, but not in another
- An individual may not define themselves as having a disability, but are given that label by others

- Real awareness and understanding of disability on the Island is felt to be low
- Many disabled individuals report having experienced discrimination from members of the public, health professionals and employers/ work colleagues.

I don't wake up in the morning and think 'I have a disability'. I get up and get on. I understand why labelling things sometimes is important, but it's not how I see myself

Female, registered blind

They wouldn't let me in to the restaurant with my guide dog; I was told it's 'unhygienic'

Female, registered blind

People see the wheelchair, not me. They panic. I once had: 'you're too pretty to be in a wheelchair'.

Female. wheelchair user

The eye clinic receptionist told me to take a seat. I asked her to indicate where that was. She replied, 'Oh. You don't look blind'

Male, visually impaired

# SECTION 3: DELIVERING AND MEASURING SUCCESS OF A STRATEGY

# A.Strategy outcome

In line with the Island Vision, which will define Jersey's future ambitions, the key outcome of a disability strategy will be to ensure:

People living with disability in Jersey enjoy a good quality of life

We know that currently, people living with disability in Jersey report having lower level of wellbeing than non-disabled islanders. Disabled Islanders are less likely to be happy and more likely to have greater levels of anxiety, than other Islanders. They also have a lower level of life satisfaction and feel that what they do in life is less worthwhile.

A disability strategy for Jersey should work towards 'levelling up' to reduce the inequality between the wellbeing of disabled and non-disabled Islanders. Over the longer term, we will know that the strategy is working if we can see an improvement in these four wellbeing indicators:

- Life satisfaction
- Sense that what one does in life is worthwhile
- Happiness
- Anxiety

# **B.Learning from the research**

The Jersey Health and Life Opportunities survey asked participants a series of questions using these wellbeing indicators. These questions were based on the ONS (UK Office for National Statistics) measures of wellbeing.

The results highlighted the significant difference between responses from disabled Islanders and the rest of the population. For example, the average life satisfaction rating for non-disabled Islanders is 8.4 (out of 10), compared to only 6.8 for disabled islanders.

For each of the wellbeing measures the difference between disabled and non-disabled Islanders is shown in the graph below [figure b].

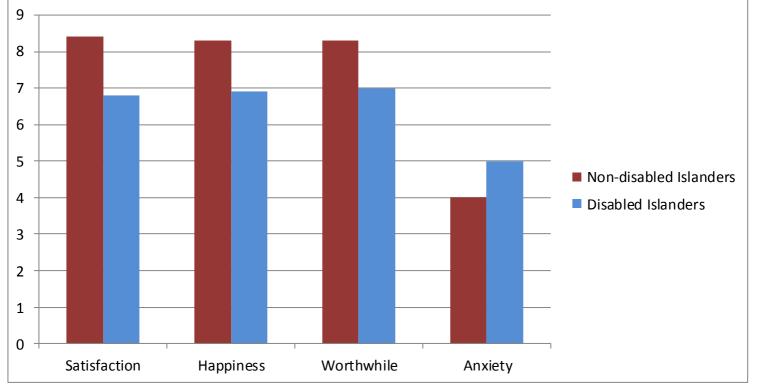


Figure b: Wellbeing of Islanders

Average ratings (out of 10) of the 4 measures of personal wellbeing: life satisfaction, happiness, anxiety and feeling what one does in life is worthwhile.

# C.Turning the curve

In order to gauge the long-term success of a disability strategy for Jersey, we need to measure changes to the wellbeing of the population over a period of time.

To demonstrate that a strategy is having a positive impact, over time, we would look to narrow the gap between the overall wellbeing of disabled people and the population as a whole (using the four indicators). In order for this change to happen, a series of desired priorities and the actions needed to bring about change are proposed in the next section (Section 4). Carrying out these actions should create change and have a positive impact on the lives of disabled Islanders – this will in turn, 'level up' or 'turn the curve'.

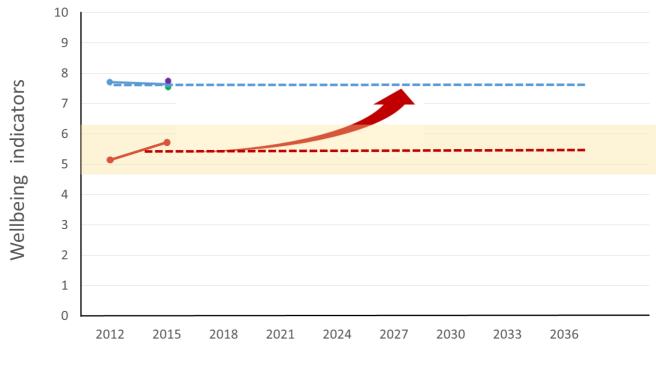




Figure c: Turning the curve

Every three years, questions on the four wellbeing indicators will be included within the Jersey Opinions and Lifestyle Survey (formerly JASS -the Jersey Annual Social Survey), which is the key data source for gauging attitudes and opinions within our community.

As these indicators are used by the ONS on a national level, as well as monitoring changes within Jersey's population, we will also be able to compare our results to UK levels.

# Measuring the impact of individual priorities

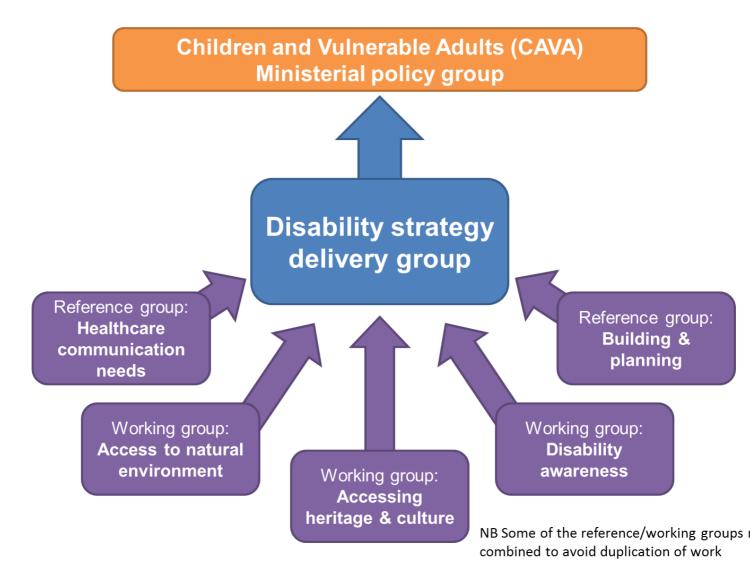
Beyond these headline indicators which provide long-term trend data at a population level, for each of the proposed priorities for the strategy, 'performance measures' will be developed within an action plan. These will measure the impact of the individual priorities on specific groups and could include measurements such as:

- '% of disabled Islanders of working age who have difficulty getting the type of paid employment they want'
- '% of disabled Islanders who feel they have been discriminated against in the past 12 months'

# D.Delivering and reviewing a disability strategy

# **Delivering a strategy**

Once a strategy has been developed, a core delivery group of representatives from the business sector, the voluntary and community sector and the Government of Jersey, including disabled representatives will be established to implement this action plan. This group will be supported by a number of reference and special interest groups as referenced in section 4 of this document.



#### Figure d: Proposed structure

Within the current Medium Term Financial Plan (MTFP) no additional funding has been allocated to a disability strategy. Part of the work carried out by the delivery group will be to identify actions within the new strategy that can be implemented using existing resources, and to create a business case for the actions that will require additional resources, so that they can be funded from within the third MTFP – from 2020 onwards.

It is proposed that a **disability officer**<sup>1</sup> is recruited in order to co-ordinate the delivery group, increase knowledge and capacity within the Government of Jersey and to act as a conduit between Government of Jersey departments, the voluntary sector and local businesses. The disability officer would have responsibility for coordinating some of the proposed actions, and for raising the profile of disability in the Island. The post will be in place as soon as funding is secured.

# **Reviewing the strategy**

It is proposed that an annual progress update on a disability strategy is produced. In addition, a full review and progress report on the strategy will be undertaken after 5 years. By reviewing the strategy we can ensure that it is delivering its outcomes. Where progress is not being made, or is not happening as quickly as it should, the strategy can look to evolve and improve. By making the review publicly available, the work of the delivery group can be scrutinised, and the strategy will be owned by the Island as a whole.

<sup>&</sup>lt;sup>1</sup> The requirement for a dedicated disability officer, with an appropriate knowledge base, has been consistently raised by key stakeholders.

# **Defining disability**

Defining disability is complex and can be conflicting; there is no universally agreed definition of disability.

Disability can be fluctuating and it can be invisible; an individual can feel or be considered to be 'disabled' in one situation, but not in another. An individual may not define themselves as having a disability, but are given that label by others.

In line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), this strategy will recognise disability in the broadest possible sense. The strategy is based on a social model of disability, and defines disability as including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

#### A.Overview

In order to achieve the outcome "People living with disability in Jersey enjoy a good quality of life", this paper sets out the five proposed priorities for the future disability strategy:

**Priority 1: Have support to communicate and access information** 

Priority 2: Have greater access to the Island

Priority 3: Have good health and wellbeing

Priority 4: Have access to education, employment & enriching activities

**Priority 5: Have equal rights and experience equality** 

Within each priority, a number of associated actions are proposed. These actions are grouped into themes, or 'action areas'.

The priorities and actions reflect back what disabled people and their representatives have said is their experience of living with disability in Jersey, what is important to them, and what they believe can or should be done to help them enjoy a good quality of life.

Within each action area we describe the change that people say they want and why (this may be because people have directly told us it is what they want or because the research suggests it is what they want).

When a disability strategy for Jersey has been developed and the actions have been agreed, an action plan will be produced. This will outline the timeframe for completing the action, the key partners involved, the resources required to deliver the action and how we will measure success.

In many cases, the actions that have been proposed by disabled people and their representatives would provide support to a wide range of vulnerable Islanders, and not just those with a disability.

#### What change is wanted?

People living with disability want to be able to communicate well. To understand, be heard and be understood. This includes having support with individual communication needs and being supported to access information.

#### Why is this change important?

We know that people living with disability can face challenges in communicating and accessing information. Communication and the flow of information goes two ways; to improve communication we must support disabled Islanders to be heard and better understood. We must also support the community as a whole to listen to these voices and better understand what people living with disability have to say.

#### We know that:

- 26% of disabled Islanders experience difficulty getting information in an understandable format
- 60% of disabled Islanders experience difficulty taking part in community activities

#### What are we doing now?

Examples of ways the Island is currently working towards improving communication and access to information:

- Jersey Online Directory is an online resource administered by the Citizens Advice Bureau, with information on services available to all Islanders, including those living with a disability and carers.
- October 2016 saw the pilot launch of the **Connect Card scheme**, to promote individual communication needs
- States of Jersey Community Policing team works to raise disability awareness within the community, including community awareness days

# How could we make further change happen?

The tables below outline the suggested actions to bring about the change required to ensure Islanders living with disability have support to communicate and access information; they are divided into 3 action areas.

#### Your view

For each of the proposed actions in the following tables, please indicate whether you feel these are a high or low priority [place a tick or cross in the appropriate box], in order to ensure disabled Islanders have support to communicate and access information:

#### The changes people say they want and why it is important

- 1. Make it easier for people to find out about services and support.
  - Some Islanders have told us they don't know where to go to find information about what may be available to them.
- 2. Help disabled Islanders better communicate with the Government and local businesses
  - Some disabled Islanders say that they have experienced difficulties in communicating with local businesses and services, including government, they find it difficult to express the support they need.
  - They feel that some staff can find it hard to know how best to support and communicate with disabled customers.
- 3. Make information about benefits and financial support more readily available and easy to understand.

- Qualitative research suggests that some people are not aware of financial support that they may be entitled to. Others who are in receipt of financial support, do not understand how much they receive and what it is intended for.
- It has been said that the recent introduction of the long-term care scheme has increased the need for greater understanding of entitlements.
- 4. Make information about the accessibility of local businesses publically available (restaurants, hotels and entertainment venues etc.)
  - Many locals and visitors to the Island have specific accessibility needs, and many say they want to be assured that these can be met before visiting an establishment
- 5. Facilitate individual appointments with Government of Jersey services.
  - 39% of Islanders with a severe impairment have difficulty in getting information in an understandable format. Many individuals struggle to access services that only provide face-to-face customer support at a desk counter.
  - Some departments already offer individual appointments in appropriate, quiet spaces. A private appointment can transform the experience for those involved by better accommodating access and mobility needs, and improving the flow of communication.
  - They feel that much of the available information is out-of-date or does not address their communication needs

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very High Priority	Don't know
а	Review Jersey Online Directory (JOD – <u>www.jod.je</u> ) to ensure it is accessible and up-to- date.					
b	<ul> <li>Review the availability of information about financial support (both from the Government of Jersey and the voluntary &amp; community sector)</li> <li>Assess whether information needs to be made available in a central resource</li> <li>Ensure the information is provided in a clear, accessible format</li> </ul>					
С	Work with Visit Jersey to enhance availability of online information regarding accessibility of tourism and hospitality facilities					
d	Progress and promote 'Connect Card' communication scheme – a credit card-sized, document that specifies individual communication					

	needs.		
е	Promote diversity training as part of ongoing training requirements for customer-facing staff and support individuals with a disability to deliver awareness training to staff		
f	Review Government of Jersey customer service policies to ensure recognition of the specific communication needs of disabled Islanders, and encourage local businesses to do the same		
g	Work with individual departments to allow customers to specify their communication preferences to the Government of Jersey – i.e. telephone, text, letter		
h	Develop plan to communicate the option for individual appointments for disabled Islanders at customer-facing Government of Jersey departments – including Social Security and Income Tax.		

# 1.2 Promote communication within health and care

- 1. Improve access to communication support for individuals using primary and secondary care
  - Islanders with specific communication needs report difficulty in accessing communication support for medical appointments. This can result in information not being communicated correctly, a lack of information to make informed decisions about treatment options, underdiagnosing or appointments being missed
  - Individuals often have to rely on the support and availability of friends and family to act as 'interpreter', including when divulging private information.
  - In addition, people with disabilities are less likely to access health prevention activities – for example the World Health Organisation (WHO) states that women with disabilities receive less screening for breast and cervical cancer than women without disabilities.
  - Efforts are being made to improve communication such as the 'health passport', to support individuals with learning disabilities, but more could be done

- 2. Improve communication between different health services so that disabled people receive co-ordinated treatment and care
  - Some individuals with multiple healthcare needs have reported difficulty and frustration in the lack of 'joined up' treatment they have received, and at the perceived lack of communication between different health services.
    - For example, respondents within the qualitative research study reported that test results and records were not always communicated between departments. This is felt most keenly by individuals who receive part of their treatment in the UK.
- 3. Adults with complex needs to be supported in navigating services available to them.
  - Many individuals and their families struggle to navigate between services provided by different Government of Jersey departments and by the voluntary and community sector.
  - They want support to synthesize and navigate information provided to them, and to understand where to go for support and services.
- 4. Make it easier for individuals being cared for and their care workers to communicate with each other
  - Stakeholders within the Government of Jersey and within the voluntary sector believe that many individuals, particularly those in residential settings with a specific communication need, struggle to communicate with those that provide care for them. This in turn impacts on their quality of life and sense of wellbeing.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very High Priority	Don't know
а	Establish a working group to examine the communication support needs of disabled Islanders when accessing healthcare, including provision for those with British Sign Language as their first language (include consideration of accessing preventative care – such as screening.)					
b	Review how different health services communicate about an individual's treatment/care					
С	Explore option of introducing Care Co-ordinators to support adults with complex needs and their families (similar to support currently available to children with complex needs)					
d	Review the need for training of workers in care settings, including residential homes, to enhance their communication support skills					

# 1.3 Harness technology and innovation

- 1. Provide support to individuals to access digital technology and the internet
  - The impact of not having access to new technology and the internet can compound feelings of social isolation. We know that disabled Islanders level of loneliness is 25% greater than non-disabled Islanders.
- 2. Supporting individuals to get online and use technology such as smart TVs and phones, can improve their sense of wellbeing and connectedness.
  - Where Islanders living with disability are provided with assistive technology, the equipment is able to 'follow the individual'
  - An individual's support should go beyond their interaction with a particular service. For example, a child benefiting from communication technology at school would also benefit from that technology at home and beyond term-time. In fact, not having access to it could be detrimental to their development and wellbeing.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very High Priority	Don't know
а	Support existing initiatives which help people to use technology and get online – for example the computer training sessions at the public library					
b	<ul> <li>Review how the Government of Jersey loans assistive technology, to maximise the benefit.</li> <li>For example if an individual is deemed to need communication support equipment that support should be able to follow them wherever and whenever they need it.</li> </ul>					

## Your view

a) Please suggest any further actions you think will help achieve the priority 'Have support to communicate and access information'.

If you are answering any of questions above, please could you also complete the questions set out at the end of this document, as this will help us to know who has responded to the consultation.

### What change is wanted?

People living with disability want to access all the Island has to offer. This includes enabling people to get around, access public spaces or even move around their own home.

### Why is this change important?

We know that many people living with disability face challenges getting around. This includes physical access to buildings, the town centre, the countryside and beaches. People often face barriers to accessing suitable transport to take them to and from the places they want to go.

#### We know that:

- 41% of disabled Islanders experience difficulty travelling around Jersey
- 31% of disabled Islanders experience difficulty moving around in their home
- 39% of disabled Islander experience difficulty moving around other places

The design of buildings, roads and services often does not take into account the specific needs of a disabled individual.

Barriers to accessing all the Island has to offer can have wide-ranging consequences, for example increasing feelings of loneliness and isolation, which can impact on an individual's wellbeing.

## What are we doing now?

Examples of ways the Island is currently working towards being more accessible:

- A concessionary bus pass will be introduced in 2017 for people who have a long-term health condition that prevents them from driving.
- Future St Helier working group is looking to make improvements to the town centre
- Restoration of Plémont headland by the National Trust, improved accessibility of the site for those with restricted mobility

# How could we make further change happen?

The table below outlines the suggested actions to bring about the change required to ensure Islanders living with disability have support to communicate and access information; they are divided into 3 action areas.

#### Your view

For each of the proposed actions in the following tables, please indicate whether you feel these are a high or low priority, in order to ensure disabled Islanders have greater access to the Island:

## The changes people say they want and why it is important

1. Improve access to the bus network

- Research shows that some individuals face barriers to accessing the bus network. These barriers can be geographical (proximity to bus stop), physical (ability to access bus) and social & emotional barriers (ability and willingness to use bus).
- 2. Improve accessibility within St Helier
  - Many Islanders face difficulties moving around the St Helier area. Particularly residents living on the outskirts of town.
- 3. Ensure Blue Badge parking scheme and disabled parking spaces meet the needs of disabled residents
  - Many disabled Islanders with access to a vehicle and in possession of a Blue badge, would benefit from more centrally located parking, or wider spaces.

• The current scheme is not felt to meet the needs of all disabled Islanders, in terms of the application process, eligibility requirements and benefits of the scheme. There is also anecdotal evidence of the scheme being misused.

4. Provide further support to isolated Islanders who have additional transport needs

- Islanders living with disability are at greater risk of isolation and loneliness. The level of loneliness amongst disabled Islanders is 25% greater than non-disabled Islanders.
- The ability to get out and about can have a significant impact on levels of loneliness and isolation.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very High Priority	Don't know
а	Implement and monitor a concessionary bus pass scheme. Use additional scheme funding to invest in other bus travel initiatives, such as travel training and travel buddy schemes.					
b	Improve accessibility standards of town centre, through Future St Helier working group.					

C	Review availability of disabled spaces (quantity, location & size) within carpark modernisation scheme	
d	Review Blue Badge scheme to assess suitability of application process and review eligibility criteria.	
e	Work with voluntary and community sector to introduce an island-wide volunteer driver scheme (disabled Islanders would be supported by a trusted volunteer driver, to attend appointments, go to social activities or shopping.)	

## 2.2 Accessible housing options

## The changes people say they want and why it is important

1. Homes that can meet accessibility needs

• Accommodation that meets an individual's needs – whether purpose built, or adapted- is critical to supporting and maintaining their independence and sense of

wellbeing. 31% of disabled Islanders report difficulty moving around inside their own home.

- Small adjustments can have a big impact on accessibility and wellbeing for example adding a hand rail, so that a toilet can be used unaided.
- 2. Disabled people are provided with fair access to a full range of housing options across a variety of housing tenures
  - Accommodation that meets an individual's needs is critical to their wellbeing, those living in private sector accommodation should not be at a disadvantage, or less likely to have their needs met.
- 3. Disabled individuals have equality of access and individual choice in the allocation of social housing, (and the needs of the housing needs of the whole household are taken into account.)
  - Confirming an offer of accommodation is a major life decision, disabled individuals often have additional consideration factors to take into account when making that decision- for example proximity of public transport or shops.
  - Some individuals may require more time to make this decision, or require additional support to do so. In addition the needs of the individual have to be balanced with the needs of the household.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Work with the Occupational Therapy, Social Security and Environmental Health teams to ensure that funding to retrofit existing accommodation is effective and meets tenants' needs.					
b	Ensure that Social Housing providers allow for adequate adaptations to homes, to meet individual tenants' needs.					
С	Investigate options for the provision of purpose built or specially adapted accommodation, as well as options to increase "Extra Care" provision for people with care support needs.					
d	Review current planning and building regulations are fit-for-purpose and encourage adequate accessibility, including the availability of "Lifetime Homes".					
е	Work with voluntary and community sector to advise on basic design adaptations (for example – don't place a fire alarm next to a light switch for visually impaired tenants)					

f	Strategic Housing Unit to review if disabled individuals have equal access to social housing, and appropriate assistance through Supported Housing where necessary.		
g	Strategic Housing Unit to work with private sector to ensure that landlords treat disabled people fairly and recognise their housing needs.		
h	Ensure that appropriate advice about housing options and related support services are in place to help disabled people live in accommodation suitable for their needs - to promote individual choice and independent living.		

2.3 Access to buildings, St Helier and the countryside

## The changes people say they want and why it is important

1. Incorporate the views and experience of service users when planning and building developments of public interest

- Whilst public spaces and buildings conform to building and planning standards, individuals and voluntary organisations have told us that the input of 'real life user experience' can improve the usability of these places whilst in the design phase to ensure that they achieve a higher level of accessibility.
- 2. Promote accessibility of the natural environment
  - Many studies, including 'Feel Better Outside, Feel Better Inside' a study undertaken by the University of Essex for Mind (UK) show that being outdoors in the natural environment can increase wellbeing.
  - Outdoor areas, however, are often inaccessible to disabled Islanders. The Countryside Access Strategy for Jersey 2016 aims to promote access to the natural environment, whilst taking into account conservation.
  - It is recognised that more could be done to increase the accessibility of open spaces and visitor attractions such as beaches, coast and countryside paths and visitor centres.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Establish an accessibility reference group to advise on the 'real life' needs of new and refurbished public buildings and spaces (including the Future hospital and St Helier.)					
b	Work with the groups set up within the Countryside Access Strategy for Jersey to maximise accessibility of the outdoors- including development of online map to promote accessibility of the natural environment.					

## Your view

b) Please suggest any further actions you think will help achieve the priority 'Have greater access to the Island'.

If you are answering any of questions above, please could you also complete the questions set out at the end of this document, as this will help us to know who has responded to the consultation.

### What change is wanted?

Disabled Islanders want support access to health and care which meets their needs. They also want to promote wellbeing through access to emotional support and activities that promote self-worth and combat loneliness.

### Why is this change important?

50% of disabled Islanders say that they have at least *some* difficulty getting the healthcare they need, and 10% said they experienced a *lot* of difficulty accessing healthcare The reasons for this are diverse. For some, additional help is required in terms of communication support (as covered in Priority 1), others want more say in how their long-term health and care needs are met.

Disabled people in Jersey report being less satisfied with life, less happy and more anxious. Many people have said that they would benefit from greater access to emotional support and access to activities that promote better health, both physical and mental wellbeing.

In addition, 51% of people caring for friends or family members with a disability say that it increases their stress levels and 39% have said it has exhausted them or made them feel depressed. In order to benefit both carers and the people they care for, we need to ensure they are able to access the support they need.

## What are we doing now?

Examples of ways the Island is currently working towards supporting good health and wellbeing include:

- A **Mental Health Strategy** for Jersey was published in 2015, which focuses on prevention and early intervention and looks to improve access to services and co-ordination of care.
- Family Care Coordinators support families who have children with complex needs
- Individual appointments are provided by some Government of Jersey departments for people with special communication needs
- An **exercise referral scheme** supports individuals with certain medical conditions to undertake regular physical activity to improve health & wellbeing

# How could we make further change happen?

The table below outlines the suggested actions, to bring about the change required to support disabled Islanders to have good health and wellbeing; they are divided into 4 action areas.

#### Your view

For each of the proposed actions in the following tables, please indicate whether you feel these are a high or low priority, in order to ensure disabled Islanders have good health and wellbeing:

- 1. For people living with disability to know how to find help when they need it.
  - We know that disabled Islanders are more likely to have a lower sense of wellbeing than other Islanders. There are many occasions when an individual's wellbeing may be at particular risk, for example at the point of diagnosis.
  - We also know that 39% of carers say their role can make them feel depressed.
  - Getting help early can help prevent problems escalating, but knowing what and how to get help is often more difficult than it needs to be
- 2. Improve signposting to support services.
  - Within the qualitative research study, many individuals and carers said they were not aware of all the support that was available to them at their time of need.
  - For many, support provided by the voluntary and community sector was felt to be invaluable; however awareness of the availability does not always reach those who need it.

- 3. Ensure disabled Islanders are able to get more help when they need it.
  - There is an inequity of service provision at present which is unfair, as evidence shows that disabled people and their families can benefit from timely support.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Ensure that services and organisations which offer support, including counselling are on the Jersey Online Directory					
b	Support primary and secondary care providers to signpost their service users to further support					
С	Work with voluntary and community sector to review the availability of support provided to Islanders with different impairments and disabilities, to include the availability of support groups for individuals, carers and family members					

## 3.2 Promote practical support and independence

### The changes people say they want and why it is important

1. Improve children's transitions to adult services in health.

- Many children and their families report to experience difficulties in switching from children's to adults services; this can have a knock-on effect on an individual's wellbeing and their trust and confidence in services.
- 2. Enable individuals to have ownership and input on the way their long-term care needs are met.
  - Many individuals and professionals feel that services operate and are structured to benefit the service, rather that the individual.
  - Some people with long-term care needs feel that their needs are not best met by what has been offered to them. Giving them control of how the funds available to them are used would provide a sense of control and empowerment, and ultimately wellbeing.

	Actions that have been proposed	Low priority	Medium priority	•	Very high Priority	Don't know
а	Review and implement ways to smooth the transition to adult services, including the possibility of a transition plan and a designated professional, to support the transition.					
b	Consider the feasibility of introducing personalised budgets and review ways of increasing person- centred care					

## 3.3 Access to activities that promote wellbeing and good health

- 1. Greater access to sporting and fitness activities.
  - Maintaining a level of fitness is vitally important in contributing towards good mental and physical health. For Islanders living with disability, accessing sporting activities

can be a challenge. Barriers to access can be geographical (e.g. proximity to facilities), physical (e.g. ability to access facilities, need for specialist equipment) and social/ emotional barriers (including confidence to participate).

2. Improve access to social and cultural activities.

 Access to social and cultural activities helps promote wellbeing and contributes towards good mental and physical health. Disabled Islanders face multiple barriers to accessing social and cultural activities including physical access, ability to communicate and cost.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Work with sports development team to promote					
	accessibility of current sports facilities (for example					
	disabled access at Les Quennevais swimming pool).					
b	Work with sports clubs to offer a mentor/buddy					
	service to support those who wish to increase					
	fitness, for example support to attend a weekly					
	exercise class or to enter a marathon.					
С	Work with community groups to support and					
	increase the availability of accessible fitness groups					

	such as walking clubs.			
d	Encourage venues to facilitate special communication needs (for example, on request turning down music in a restaurant, so that a customer with a hearing impairment can communicate)			
е	Set up a working group with key organisations to maximise accessibility to cultural experiences – including Jersey Heritage, Jersey Arts Centre, Jersey Opera House and Jersey Arts Trust			
	And encourage cultural providers from the private sector (with which the Government has no direct funding link) to review and improve access for disabled people			

3.4 Support for carers and the family unit

### The changes people say they want and why it is important

1. Provide more flexible respite options for carers.

- Provision of respite is vitally important to preserve the wellbeing of individuals and carers. 45% of carers say that the caring role means that they have less time to themselves or to do the things they want to do.
- Many families with carers have complex, busy lifestyles having respite options that fit around their needs rather than having to fit around what is available, can further enhance the benefit of receiving short break services.
- 2. Support and protect carers' rights.
  - The work unpaid carers provide is invaluable in supporting disabled individuals. Consideration needs to be given to protecting the rights of individuals, to ensure that they feel fully supported and valued within our society.

	Actions that have been proposed	Low priority	Medium priority	Very high Priority	Don't know
а	Review respite and short break services available to individuals and carers, with a view to increasing the variety and flexibility of options available.				
b	Consider whether the rights of carers should be set out in law, including the right to a carer's assessment and support package.				

### Your view

c) Please suggest any further actions you think will help achieve the priority 'Have good health and wellbeing'.

If you are answering any of questions above, please could you also complete the questions set out at the end of this document, as this will help us to know who has responded to the consultation.

**Priority 4: Have access to education, employment and enriching activities** 

## What change is wanted?

People living with disability want to be able to contribute to society by having access to appropriate education, training and employment opportunities. Those who cannot work should have access to enriching activities, so that all Islanders are able to lead a fulfilling life.

### Why is this change important?

28% of disabled Islanders say that they have a lot of difficulty in getting the type or amount of paid work they want. Islanders who are able to work feel it contributes to their wellbeing and life satisfaction, however many face challenges in finding the right employment or training to meet their needs and ambitions. Over a quarter of disabled Islanders have some difficulty getting the support or equipment they need at work or school.

Islanders who are not able to work, or who have retired, feel that access to enriching activities, such as volunteering or learning new skills, is important for their wellbeing and self-esteem.

Many disabled young people enjoy and benefit from the education they receive, however some struggle to translate this into finding suitable employment once they have completed their education. Others would like to have more encouragement to have greater career ambitions, and to see older role models who can inspire them.

## What are we doing now?

Examples of ways the Island is currently working towards supporting access to education, employment and enriching activities include:

- Targeted support for children with special educational needs within the Island's primary and secondary schools.
  - Support entering and maintaining employment and career advice provided by Government of Jersey employment services and the Jersey Employment Trust.
  - JACS (Jersey Advisory and Conciliation Service) an employment relations service which supports both employers and employees, including providing advice on discrimination.

## How will we make further change happen?

The tables below outline the suggested actions to bring about the change required to make sure that Islanders living with disability have access to employment, education and enriching activities; they are divided into 3 action areas.

### Your view

For each of the proposed actions in the following tables, please indicate whether you feel these are a high or low priority, in order to ensure disabled Islanders have access to education, employment and enriching activities:

### 4.1 Education to meet individual needs

- 1. Ensure all children with special educational needs have their needs met throughout their pre-school, primary and secondary education.
  - Education is critical in helping children develop as individuals and support them on their journey to adulthood. Children with special educational needs may have specific learning styles or require additional support to help them achieve and receive maximum benefit from their education.

- Promotion of inclusion from an early age can benefit schools as a whole, by encouraging early disability awareness.
- 2. All school leavers with a disability are fully supported to continue their education if they wish to.
  - In the research carried out, many children and parents of children with special educational needs or a disability felt well supported during their school years. However, upon reaching school leaving age, felt that their options for further education on-island were limited.
- 3. Greater disability awareness within schools amongst pupils and staff.
  - Many young disabled people feel that there are few 'role models' successful disabled Islanders in the public eye or even working within schools. Whilst inspiration can be taken from further afield, role models closer to home could inspire young people to achieve and live fulfilling lives.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Review Special Educational Needs Code of Practice – to ensure high quality provision which promotes inclusion for children with disabilities					
b	Carry out a review of post-16 education opportunities for individuals with a disability or special educational need.					
C	Establish a 'disability champion' within all schools					
d	Voluntary and community sector to work with schools to promote disability awareness within classes and as part of additional school activities. Disabled people invited to deliver awareness training.					

4.2 Access to employment opportunities

- 1. Disabled individuals are able to have a satisfying and rewarding career.
  - The qualitative research highlighted the experience of a number of working individuals striving for a satisfying career, who felt they were held back by barriers they faced because of their disability. For example, difficulty in accessing further education or training. A number felt that they were not supported to change jobs or progress up the career ladder in order to achieve their goals.
- 2. Government of Jersey, as the Island's biggest employer, to lead the way in demonstrating positive actions towards employing disabled people.
  - Additional support measures can maximise the potential of employees, and promote their sense of satisfaction and wellbeing.

- For example in the UK in early 2017, National Institute For Health and Care Excellence (NICE) is due to publish guidelines for employers on "support for employees with disabilities and long-term conditions."
- 3. Reduce levels of discrimination in the workplace.
  - Workplace discrimination is cited as the most common source of discrimination for disabled Islanders – of those who felt discriminated against, 34% cited their employers as the source, and 27% cited work colleagues (the 1<sup>st</sup> and 3<sup>rd</sup> most common sources of discrimination).

	Actions that have been proposed	Low priority	Medium priority	Ŭ	Very high Priority	Don't know
а	Government of Jersey to promote opportunities & support disabled people to change jobs/ progress in their career.					
b	Government of Jersey to set up an action group to explore how to act as a positive employer for disabled people. • And identify 'champions' or mentors to					

	support those who have recently entered the workplace	
C	Work with JACS (Jersey Advisory and Conciliation Service) to ensure that appropriate and accessible information is provided to employers and employees	
d	Work to review and address the factors that contribute towards workplace discrimination	

4.3 Opportunity to participate in enriching activities

- 1. Adults who are unable to work, are able to participate in enriching activities
  - Many disabled adults who do not work have access to enriching activities, but not all. Regardless of disability, individuals should be entitled to access activities that enhance their wellbeing.
- 2. Disabled people are supported to participate in volunteering opportunities

- Volunteering can be enjoyable and rewarding and contribute to a sense of satisfaction and wellbeing. It can provide additional benefits, such as providing a form of physical activity, and an opportunity for socialising.
- However, some people living with disability may require additional support to participate, for example help with transport. There may be some individuals who are able to volunteer, but are not ready for paid employment; such individuals should be supported to contribute to the community in an unpaid capacity.

	Actions that have been proposed	Low priority	Medium priority	Very high Priority	Don't know
а	Carry out a holistic review of all daytime activities and employment opportunities available to adults unable to work, including those with learning disabilities and autism, as well as individuals with mental health conditions that impact on their ability to work.				
b	Work with voluntary and community sector to promote opportunities for volunteering and review interplay between volunteering and receipt of income support payments.				

#### Your view

d) Please suggest any further actions you think will help achieve the priority 'Have access to education, employment and enriching activities'.

If you are answering any of questions above, please could you also complete the questions set out at the end of this document, as this will help us to know who has responded to the consultation.

#### What change is wanted?

Disabled Islanders want to be able to participate fully and equally within our community and to challenge discrimination.

#### Why is this change important?

Islanders living with disability want to be able to contribute to our community, both in terms of raising the profile of disability-specific issues, but also being involved in wider Island matters. One barrier to participation is discrimination - over a quarter of disabled Islanders report to have directly experienced discrimination in the past 12 months. In addition to this, Islanders who are most likely to be disabled are older, on low incomes, living in social housing and not in employment – and therefore face barriers beyond those challenges associated with their disability. Challenging attitudes and discrimination through changes to legislation and policies will help support more equal participation in society.

#### What are we doing now?

Examples of ways the Island is currently working towards equal rights and equality include:

- Working towards the introduction of disability discrimination legislation in 2018.
- Ministers took up 'Ant's Challenge' of living with disability in August 2016, to promote awareness and understanding within the community.
- The inaugural Liberate CI Equality and Diversity Awards took place in September 2016

## How could we make further change happen?

The table below outlines the suggested actions, to bring about the change required to ensure that disabled Islanders have equal rights and experience greater equality; they are divided into 4 action areas.

#### Your view

For each of the proposed actions in the following tables, please indicate whether you feel these are a high or low priority, in order to ensure disabled Islanders have equal rights and experience equality.

## 5.1 Challenge discrimination

#### The changes people say they want and why it is important

1. Make it illegal to discriminate against a person because of their disability

- Eliminating discrimination should be driven by a change in social and cultural attitudes, via education and public awareness raising, legislation can be a vital tool in protecting the rights of individuals and bringing to account those who discriminate.
- 2. Promote disability awareness on an island-wide scale
  - Many disabled and non-disabled people feel that disability awareness is low on the Island. More needs to be done to help Islanders to better understand disability and the diversity of the word.
  - In the My Jersey survey, a quarter of all respondents <u>didn't know</u> how Jersey is currently doing in terms of ensuring that people living with long-term health conditions or disability enjoy a good quality of life. [This is the second highest score; the only outcome for the Island people were *less sure* about was climate change.]

- Raising the profile of disability is a major challenge, working together and supporting the voices of disabled individuals across the Island, in all sectors, will start to challenge prejudice and misconceptions.
- 3. See a truer reflection of disability in the local media.
  - Often the voice of disabled individuals is underrepresented in the media, by working in collaboration with local media outlets, a truer picture of disability can be reflected focusing on the individual and their abilities, not their impairment or disability. This can help shape people's attitudes.
- 4. Explore options for ensuring that victims of crime are well supported
  - People living with disability are more likely to be victims of crime. People with mental health issues and social or behavioural impairments, including those with autism and Asperger's syndrome, experience particularly high levels of crime.
    - The UK Equality and Human Rights Commission found that disabled children are almost twice as likely to be victims of crime as non-disabled children.
    - 50% of disabled women have experienced domestic abuse compared with 25% of non-disabled women
    - In the UK, prosecutions for disability hate crimes have risen by more than 40% since 2014/15.

	Actions that have been proposed	Low priority	Medium priority	Very high Priority	Don't know
а	Develop and implement disability discrimination legislation				
b	Establish a working group to explore a co- ordinated approach to promoting disability awareness amongst the general public.				
С	Work with Island's media outlets to reflect a 'true' picture of disability in Jersey				
d	Explore options for ensuring that victims of crime are well supported				
е	Undertake research to better understand the links between disability and domestic violence				

### 5.2 Promote participation and engagement

- 1. Have the opportunity to engage with services, in order to help shape future service development.
  - Listening to the voice of service users is vital to improving services and working towards developing a service that works around the needs of the individual, not the service itself. In addition, engaging with services can promote an individual's selfconfidence and wellbeing.
- 2. Disabled Islanders have the opportunity to share their experiences with States Members and policy makers.
  - Participating in engagement events can be rewarding and can build confidence. Dedicated engagement sessions provide the space and time for politicians and policymakers to listen to the experiences of Islanders first hand, to consider what is going well, and the better understand areas where change is required.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Develop engagement opportunities for people with disabilities with all relevant Government of Jersey services – including adults & children's social services, hospital users and the Social Security department.					
b	Establish an annual event where Islanders living with disability and carers can share their views and experiences with their elected members, and those responsible for developing policies that will have a direct impact on them.					

- 1. Identify the extra costs faced by disabled Islanders and explore ways to reduce those additional costs.
  - Many disabled Islanders report facing 'extra costs' in day to day life as a result of their disability. This can include direct expenditure such as home adaptations and communication technology, as well as additional costs brought about by societal barriers, such as having to use the corner shop, and not being able to access cheaper stores, due to lack of transport options. First we must understand what these cost are, before measures can be developed to mitigate them.

	Actions that have been proposed	Low priority	Medium priority	Ŭ	 Don't know
а	Review 'extra' costs faced by disabled people- as per the UK extra costs commission				

## **5.4 Civic Participation**

#### The changes people say they want and why it is important

1. Improve disabled Islanders' access to the political system.

- Many disabled Islanders report difficulty in engaging in the political environment. Barriers to access include lack of support to vote and difficulty in accessing political candidates - for example in attending hustings.
- 2. Ensure people living with disability have opportunities to be active citizens.
  - Barriers currently exist for some disabled Islanders with regard to becoming more active citizens - these barriers can be both physical and attitudinal. Additional support could help overcome these barriers and increase the influence and voice of disabled Islanders.
- 3. Young Islanders living with disability are supported to be active citizens.
  - Encouraging young people to become active citizens and engaged in the Island's political debate can be a challenge, young disabled Islanders can face additional

barriers to engagement. However, it is vital that their voice is heard. Their views, votes and actions can make a difference to the future of their Island.

	Actions that have been proposed	Low priority	Medium priority	High Priority	Very high Priority	Don't know
а	Establish a project team to work on removing barriers to engaging in the political environment – including voting, access to political candidates, manifestos etc.					
b	Work with Jersey Community Relations Trust to ensure disabled people have opportunities to be active citizens –for example as jurors, board members and elected representatives					
С	Youth Inclusion project to continue to promote citizen engagement for young people					
d	Work with schools to encourage young people with disabilities to participate in the annual Youth Assembly.					

#### Your view

e) Please suggest any further actions you think will help achieve the priority 'Have equal rights and experience equality'.

If you are answering any of questions above, please could you also complete the questions set out at the end of this document, as this will help us to know who has responded to the consultation.

## **RESPONDING TO THE CONSULTATION**

If you are responding to any of the consultation questions above, please complete the following questions. This information will help us to process the consultation responses and to keep in touch.

#### <u>About you</u>

- a) Your name:
- b) Email address:
- c) Postal address (a postal address is only required if no email address is provided).
- d) Are you a Jersey resident? Please tick:

Yes	
No	

- e) <u>If no, where are you resident?</u>
- f) Are you responding in your personal capacity? Please tick:
   Yes
   No

If you are responding to any of the consultation questions above, please complete the following questions. This information will help us to process the consultation responses and to keep in touch.

a) Are you responding as an official representative of an <u>organisation or group?</u> Please tick:

Yes	
No	

b) If yes, is that organisation or group:

-		
i.	A group that supports Islanders with a	
	disability, impairment or long-term	
	condition	
ii.	a faith group or religious organisation	
iii.	other (please state):	

## Publication of responses

Consultation responses may be made public (for example sent to interested parties on request, quoted in a published report, reported in the media etc.). Please indicate which one of the following three options applies to you.

Option 1	
You agree that your comments may be made	
public and attributed to you	
Option 2	
You agree that your comments may be made	
public but not attributed to you (i.e. anonymous)	
Option 3	
You do not want your comments made public.	

## **APPENDIX 1: STAKEHOLDER GROUP**

## The stakeholder group consisted of representatives from:

## **Voluntary & Community Sector**

- Autism Jersey
- Citizens Advice Bureau
- dDeaf Partnership Board
- EYECAN
- Family Nursing & Homecare
- Headway
- JACI (Jersey Association for Carers Incorporated)
- Jersey Alzheimer's Association
- Jersey Community Relations Trust
- Jersey Disability Partnership
- Jersey Employment Trust
- Jersey Mencap
- Les Amis
- Mind Jersey
- MS Society Jersey
- Shopmobility
- SNAP (Special Needs Advisory Panel)
- Stroke Association
- Visually Impaired Partnership Board

## **Government of Jersey**

- Chief Minister's Department
- Department for Community & Constitutional Affairs [previously Home Affairs]

- Department for Economic Development, Tourism, Sport and Culture
- Department for Education
- Department for Infrastructure
- Department for Social Security
- States of Jersey Police
- Strategic Housing Unit
- Department for Health & Social Services including:
  - Adult's Social Services
  - Children's Complex Needs Team
  - Jersey General Hospital
  - Occupational Therapy
  - SALT (Speech & Language Therapy)

## APPENDIX 2: SUMMARY OF KEY THEMES FROM INTERNATIONAL DISABILITY STRATEGIES

A short review was carried out of disability strategies in seven other jurisdictions:

- Guernsey
- United Kingdom
- Northern Ireland
- Republic of Ireland
- Australia
- New Zealand
- European Commission (Priority Area objectives)

Whilst these strategies vary greatly in terms of format, scope, timeframe and level of detail, a number of themes emerge. These are outlined below:

- Accessibility
- Inclusion including minority groups
- Participation and active citizenship
- Equality
- Choice and independence
- Support
- Employment and economic security
- Education and training
- Health and wellbeing
- Rights and Social Protection Justice, Standards of living; community safety; poverty reduction
- European Commission: External action

# APPENDIX 3: QUALITATIVE BEHAVIOUR & PERCEPTIONS RESEARCH METHODOLGY

Around 100 individuals participated in the research by taking part in either one-to-one interviews, group discussions (focus groups) or an engagement event. Interview and groups took place either in the respondent's own home, Government of Jersey premises or in a public area, depending on the individual's needs and preferences. The interviews varied in length from 45 minutes to two hours. The engagement session was a 3-hour event.

## **Interview Type**

#### **One-to-one depth interviews**

- Allowed for greater depth of discussion of singular issues and individual experiences.
- Included the views of those unable to participate in a group environment

## **Group discussions**

- Facilitated the sharing of ideas
- 'Group dynamic' allowed for a more in-depth, nuanced response to questions

## **Engagement Event**

- Engagement event at St Paul's Centre
- Attended by circa 50 individuals, a mix of service users, Ministers and Government of Jersey officers
- Aim of the event was for service users (disabled Islanders & carers) to share their views and experiences of living in Jersey with a disability

## Research respondents – who we spoke to

## Recruitment

Those interviewed were recruited via a range of agencies including charities & voluntary organisations and various Government of Jersey services including Occupational Therapy, the General Hospital and the Children's Complex needs team.

## **Demographic spread**

An overview of the demographic make-up of the sample is provided in the graphic below [figure f]

## WHO WE SPOKE TO



96 individuals (including carers)



69% female 31% male



36% living in town28% in town outskirts36% in rural parishes



individuals with a wide range of disabilities, impairments and long-term health conditions



a spread of ages:

6% aged 0-16 20% aged 16-30 30% aged 31-50 23% aged 51-65 21% aged 65+



#### 30% working 70% not working



56% Jersey-born 44% other



42% co-habiting 58% single