A decorative background pattern of stylized pink leaves with yellow outlines, arranged in a symmetrical, branching fashion.

PROVISION FOR CARERS IN GUERNSEY: Initial Findings

CARERS GUERNSEY WORKING GROUP

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Executive Summary

It is estimated that there are between 2,000 and 4,000 persons providing un-paid voluntary care within the Bailiwick of Guernsey. There is an increasing recognition of the economic and social contribution made by such Carers. An initial estimate provided by the States of Guernsey in its report entitled “The Supported and Living Well Strategy” (Billet D’Etat III 2016) suggested that the replacement cost of such informal care would be of the order of £29 million per annum. Within that same report the States of Guernsey recognised the importance of ensuring the provision of support to carers to undertake their caring roles and the States of Guernsey committed to deliver a “Carers Strategy” during 2018.

The recognition of the contribution attaching to the role of carers, the need to identify levels of support for carers and the absence of a body representing the interests of carers led the Guernsey Community Foundation to establish a working group to investigate the merit of developing an organisation in the Bailiwick to provide information and support to carers and to give carers a voice in matters affecting them.

This report is the outcome of the investigations and research undertaken by that working group. It reflects views and opinions elicited from a broad range of voluntary organisations that have contact with members of our community with particular medical or mental conditions and those who care for them. The working group presented its initial findings to those organisations at a meeting held at the beginning of December 2016 and invited feedback. The working group also consulted with various parties within the departments of the States of Guernsey responsible for the delivery and funding of community services and drew on the experiences of organisations operating either nationally or locally within the United Kingdom in the provision of support for carers.

The working group identified a number of key services or areas of support that are essential for carers. In broad terms and without attaching any particular order of priorities they may be summarised as follows:-

- A voice for carers
- A central point of information and advice for carers
- Emotional and practical support for carers
- Training and learning
- Financial security
- Flexible respite
- Peer support for carers

Measured against that list the working group identified a number of gaps in the existing range of services and support available to the community of carers within the Bailiwick. This report does not attempt to address how such gaps might immediately be satisfied. Such matters will need to be the subject of further dialogue between the States of Guernsey, the voluntary and private sectors in the context of the development of the promised “Carers Strategy”.



The working group does however recommend the early implementation of the following actions as a precursor to the development of such further services and support:-

- The establishment of a new body (Carers Guernsey LBG) to co-ordinate services and support offered to carers of all ages and across all conditions and to represent and act as the voice of carers within the community especially in dialogue with the States of Guernsey in the formulation of its Carers Strategy.
- For that body initially to employ the services of a manager to assist in its establishment and a qualified health care professional to provide an outreach service to access carers in the community and to provide emotional and practical support to such carers. In the longer term, potentially to engage the services of an additional person to co-ordinate the contact between each carer with the relevant services and support available within the public, voluntary or private sectors.
- For that body to seek the co-operation of the voluntary sector in order to undertake a comprehensive review to establish the extent of services and support within the existing voluntary sector available to carers within the Bailiwick of Guernsey and to identify possible areas of under utilisation or duplication.
- The working group has identified that the three year funding cost for such a project would be of the order of £356k. No approach has been made for funding but possible sources of initial funding from the charitable sector have been identified.



Guernsey Community Foundation's involvement with Carers

In 2015 the Guernsey Disability Alliance (GDA) flagged up the issue of a lack of support for carers, which had become evident when changes with significant impact on carers were proposed to the Pensions, Tax and Benefits System in Guernsey in April of that year. The importance of support for carers was also being raised within the developing Supported Living and Ageing Well Strategy (SLAWS) and recognition by the States of Guernsey to develop a Carers Strategy.

The GDA approached the Foundation to discuss the issue and found that GCF was also identifying a gap in provision for carers and the fact that carers have not had a voice in the public debate about issues which affect them.

This led to GCF starting project work on carers, and eventually to the formation of a GCF facilitated working group.

Within its research, the working group was to look at the merit of developing a specific organisation in Guernsey dedicated to providing information and support to carers and to give carers a voice in matters that affect them. The proposed organisation would be to support carers of all ages and across all conditions.

Background

Carers are generally very busy with their caring responsibilities and can often fall 'under the radar'. Many would benefit from services or financial assistance to support them and/or the person they care for – but the information available about the support available from public, private and voluntary services is limited and often obscure, and many carers lack the time or energy to navigate such information. Carers would benefit from a service that interprets the information for them, helps them to apply it to their own situation, and shows them how to access the services they need.

There are some services already in place: for example, advice provided by Health Information Guernsey on a face-to-face basis, however the service is not available 24-7, and it requires carers to be aware of and seek out Health Information Guernsey and ask for help. A similar situation is true of the local Citizens Advice Bureau. There is also the local website signpost.gg hosted by the States, which has developed over the last couple of years and now offers detailed signposting services for adults and children with caring responsibilities. However, there is not currently a wide awareness about signpost.gg.

Carers do not have a service that they can access 24-7, or that they can consult discreetly and there is no dedicated emotional support service. Crises and worries don't respect office hours and currently carers have nowhere to turn out of normal office hours if they have concerns or questions, or are dealing with a crisis (if not an emergency). Not all carers will have internet access, so current online signposting would need to be supplemented by written information and a telephone helpline.

Discussed further below, most of the voluntary organisations established to support carers in Guernsey operate on a limited scale (e.g. Carers Coming Together) or focus on a particular medical or mental condition and support carers alongside the people they care for (e.g. Alzheimer's Society,



the Guernsey Disability Alliance, Ageing Well in the Bailiwick, Wigwam). There is no single organisation with an overall view of what it means to be a carer in Guernsey, and which can speak out and promote social change on behalf of carers.

It is also important to note that unlike many other jurisdictions, especially those with whom Guernsey has contact on the British Irish Council, Guernsey lacks statutory recognition and protection for the status of carers.

The background described above was considered alongside the following issues:

- Lack of overarching strategic thinking on provision for carers
- Lack of representation for carers
- Diminishing funding for support of carers services (within States and voluntary sector)
- Confusing / conflicting information on services available
- Mainly only condition-specific services
- Limited emotional support services

Formation of the Carers Working Group

In January 2015, the GCF Board agreed to provide staffing resource to a dedicated workstream to look at carers and the provision of services, with a view to providing a solution to how carers could be better supported within our community.

The decision was taken to form a working group which would firstly investigate and identify the current provision for carers and the challenges that they face, and secondly to explore the suggestion that a dedicated organisation for carers may plug gaps in some of the issues already identified.

By April 2016 a Chair had been secured, Peter Harwood. Peter is an ex Deputy, ex-Chief Minister of Guernsey and relevant here, previous Chair of the SLAWS working group. He therefore already had a very good understanding of the issues that carers face.

Further members of the working group were secured:

- Andrew Carey – Carers Representative, Guernsey Disability Alliance*
- Julie Bulpitt – volunteer and carer
- Caroline Mullins – States Disability Officer
- Alastair Bisson – Director, Guernsey Community Foundation
- Sadie Siviter de Paucar – Development Manager, Guernsey Community Foundation

*Note – Andrew Carey stepped down from his roles within the GDA and the Carers Working Group at the end of 2016



Aims of Carers Guernsey Working Group

The working group started with the following aims:

- To investigate Guernsey provision for carers
- Key challenges faced by carers in Guernsey and how these may be addressed
- To look at best practice and support for carers elsewhere

The group would achieve this by liaising with voluntary and private sector representatives and States departments responsible for developing services and strategies which impact on carers' lives.

Methodology

The working group conducted face to face interviews with major stakeholders. A full list is detailed as Appendix 1.

Desktop research was conducted on relevant social policy and best practice.

Working group members also had phone interviews and meetings with UK providers (see section on best practice below).

On the 1st December 2016 a stakeholder meeting was held to present the initial findings of the working group and to invite feedback. The feedback from this meeting is included below and is taken into consideration within the group's recommendations.



FINDINGS

Carers within the Guernsey social policy context

It is important to consider the role of carers within the recent and current social policy context. Several important policies are currently in development by the States of Guernsey which will have an impact on the way carers are supported.

The following States strategies all contain reference to the provision of support for carers:

- Supported Living & Ageing Well Strategy (SLAWS)

Taken from (Billet III 2016):

“We will recognise the value of informal carers and seek to ensure that they are supported.”

“The Working Party acknowledges that given the demographic and family challenges ahead, there has never been a more important time to focus resources on ensuring that informal carers themselves feel supported to continue their caring role.”

“To make nine strategic commitments required to bring about the significant transformational change necessary to deliver the strategy ... we will recognise the value of informal carers and seek to ensure that they are supported.”

“To direct the Policy and Resources Committee, in conjunction with the Committees for Health and Social Care and Employment and Social Security and appropriate third sector organisations to develop, as a matter of priority a Carers’ Strategy and to report to the States with its recommendations no later than June 2018.”

The SLAWS outline strategy was approved by the States in 2016 and is now in implementation phase, with the Policy and Resources Committee holding responsibility for its progress. After a period of limited staff resourcing for the project, funding was agreed for a new SLAWS Policy Coordinator who will be in place in March 2017.

- Disability & Inclusion Strategy

The States resolved in November 2013: *“To approve the Disability and Inclusion Strategy and affirm the States commitment to promoting positive and inclusive attitudes towards disabled people and carers.” Disability and Inclusion Strategy (Billet XXII 2013).*

Approved in 2013, the Disability and Inclusion Strategy has faced several hold ups during the implementation phase. Now that responsibility has moved to the Committee for Employment and Social Services, there is a new project plan in place, increased resources for the project and commitment to implementing activities. Signpost.gg falls under the mandate of this strategy and has recently launched the adult services information section (see further information below).

- Mental Health & Wellbeing Strategy

Taken from Billet III 2013:

“A number of cross-cutting themes have been explored. These include:



- *Challenging stigma and discrimination.*
- *Addressing the needs of specific vulnerable groups.*
- *Addressing the needs of carers”*

“The experience of a family member having a mental health problem can have a significant impact on carers. In recent years this has been acknowledged and there is a growing expectation that carers should be involved in care planning and their needs should be assessed as part of this process. The Mental Health and Wellbeing Strategy should help to ensure that the needs of carers and relatives are included in care plans and review processes.”

“Act to meet people’s needs by ...

- *Facilitating assessment, early diagnosis and care planning.*
- *Providing integrated community team support to maintain independence.*
- *Ensuring access to support for carers and family.”*

Approved in February 2013, the implementation of the Strategy was then delayed due to a lack of staff resource to carry forward recommendations. Following an agreement to second the Executive Director of Guernsey Mind to the States for a period of 2 years to lead the implementation process (with funding from the Guernsey Community Foundation), the Strategy is now moving forwards. A recent public consultation provided a review of current systems and services in Guernsey, consideration of where more needs to be done and identified a model for working together as a community. Guernsey Mind is working closely with the Committee for Policy & Resources and the Committee for Health & Social Care to drive this forward and during 2017 will finalise an Action Plan.

- British Irish Council – Carers Workstream

Guernsey is a member of the British Irish Council, with political responsibility lying with the Policy & Resources Committee. One of the current workstreams of the Council is on ‘Carers: Supporting people who provide unpaid care in the home’.

“Carers are an integral part of Society caring for family, friends and neighbours affected by physical or mental illness, disability, frailty or substance mis-use. Whilst caring can be a positive and rewarding experience, high intensity caring can result in poor health both physically and mentally. Carer’s policy sits within a wider context of tackling economic, health and social inequalities and with regard to young carers within the holistic ‘child at the centre’ context. A decisive shift towards preventative approaches rather than crisis-led responses should be accompanied by greater integration of services at a local level.”

(British Irish Council- Social Inclusion Work Sector; Report 17/06/2016)

“Informal carers are increasingly recognised through national policies in other jurisdictions. Guernsey stands out at present for being the only member of the British Irish Council not to have a Carers Strategy.”

(States of Deliberation Billet III 2016.)



- Carers Strategy within SLAWS

The Carers Strategy is at initial development phase, due to report back to the States by June 2018. Responsibility for the Carers Strategy lies ultimately with the Policy and Resources Committee as part of the implementation of SLAWS, although our understanding is that the Committee for Health & Social Care will be leading on its development.

Definition of Carers

There are varying definitions of carers and it will be important for any future organisation to establish its definition at an early stage. It will also be important to give input to the definition used within the proposed Carers Strategy.

Some examples of definitions within other jurisdictions are set out below by way of illustration.

“A carer refers to someone who provides a substantial amount of care on a regular basis to another person.”

(Northern Ireland Human Rights Commission)

“Someone who provides unpaid help and support to a family member, friend, partner or neighbour, who has a physical illness or mental health difficulties, is frail, or who has alcohol or drug related problems.” (Jersey)

“A carer is anyone who cares unpaid, for friend or family member who due to illness, disability, mental health problem or addiction cannot cope without their support”. (Carers Trust UK)

Identification of Carers

The identification of carers can be one of the biggest challenges for identifying the provision needed for carers' services.

“Carer identification is the first step to supporting carers. However some people do not wish to be identified as carers whilst others will clearly identify later on in the caring journey when the caring role intensifies. Some young carers may fear family break-up if they are identified whilst others will wish to be identified.”

(British Irish Council)

“Carers are not a homogenous group. Carers can be all ages from children to the very elderly who are looking after family members. Each carer is an individual who has her or his own story to tell and particular needs. It is why the right to an individual carers' assessment needs to be fully recognised.” (Northern Ireland Human Rights Commission)

“A carer refers to someone who provides a substantial amount of care on a regular basis to another person.”

(Northern Ireland Human Rights Commission)



- Young Carers

There is a particular issue with the identification of young carers, who are even less likely than adults to identify themselves as carers. The Hub (and prior to this, Health Information Guernsey) has been doing some work with young carers, supporting them when they have come forward. However, even after promotion work during 2016, at school assemblies for example, young carers are still not being identified or coming forward to look for support.

Numbers of Carers in Guernsey

Carers Trust UK estimates that 3 in 5 people will become a carer at some point in time. This would represent a Guernsey equivalent of approximately 37,800 people.

Having reviewed local research papers, the working group found that:

“Current estimates suggest that there are between 2,000 and 4,000 carers in Guernsey”
(Research Report for Supported Living and Well Being Strategy).

This estimate is backed up by further research; e.g. the Disability Needs Survey (2012) estimated that 8% of households (i.e. 2085 households) contained carers in 2012.

The Guernsey Healthy Lifestyle Report (2014) estimated that 5.7% of participants had caring responsibilities (by extrapolation equivalent to 3516 in whole population).

The Housing Needs Survey (2011) estimated 15% of households contained people with caring responsibilities (i.e. 3847 households).

Financial Impact

As part of the work undertaken to develop the SLAWS report the States of Guernsey made a provisional estimate of the replacement cost of informal care based on an extrapolation from UK research. That research would suggest that the replacement cost to the States of Guernsey of informal care would be of the magnitude of £29 million (States of Deliberation Billet III 2016).

In addition to such replacement costs further research undertaken in the UK by Carers UK and Age UK suggested a further cost to the UK economy caused by the withdrawal of carers from the labour market to be of the order of £1.3 billion per annum (Carers UK/ Age UK Report – Walking the Tightrope 2016). Using the same basis of extrapolation as that used by the States of Guernsey in its calculation of the replacement costs quoted above the annual cost to the Guernsey economy caused by the withdrawal of carers from the labour market could be as much as £1.3 million.

Age profile of carers

Carers may be of any age, but it has been identified by a Carers UK/Age UK Report that “People aged 50-64 are most likely to be carers”.



These figures are backed in Guernsey by the Guernsey Healthy Lifestyle Survey 2013 which found that “the age range with the largest caring responsibility is the 55-64 age group”.

Notwithstanding the typical age profile quoted above there are a number of significant identifiable categories of carers outside that age profile. In particular:

- Young carers

Barnardo’s define young carers as children who help look after a member of the family who is sick, disabled or has mental health problems, or is misusing drugs or alcohol, and state that the average age of a young carer in the UK is 12. Carers Trust estimate that in the UK there are 700,000 carers under the age of 18, the Guernsey equivalent could be as high as 700.

- Grandparents caring for grandchildren

“Grandparents are most commonly sought after as a provider of childcare with around two in five children under the age of 16, for whom childcare is used, being cared for by their grandparents. Whilst most of those children are under the supervision of their grandparents for fewer than 5 hours a week one in ten are in their care for more than 20 hours over the course of the week..... Grandparents also contribute one of the cheapest forms of childcare provision. This all combines to demonstrate the key role played by grandparents in providing regular and crucially affordable care for children under the age of 16 in Guernsey and Alderney.”

(States of Guernsey – Childcare Needs Survey 2009/2010.)

- Ageing Carers

Matters of particular concern among many of the voluntary organisations are the problems and anxieties faced by many ageing carers. According to Carers UK, an ‘army’ of vulnerable ageing carers are looking after their spouses, who are of a similar age and may be equally as frail or older.

Carers UK also flags concern at the 35% increase in the last 10 years of retirement age people caring for ill partners or their own ageing parents.

Another typical example of an older carer is that of a widow in her late seventies or early eighties who is providing care and support to a child in his or her mid to late fifties. Many carers in this category do not consider themselves to be carers but accept their role as an incident of parenthood.

The particular concern expressed to the working party relates to the decline of the health and well being of such carers, the difficulties both practical and financial of providing future care and support both for the carer and the person presently cared for and the anxiety for the elderly carer in the absence of certain knowledge of what will be available in the future for the cared one. The working party recognises the need for future programmes to be put in place for such eventualities before crisis occurs.

- Sandwich carers

This term refer to a parent (s) who is looking after young children whilst also caring for older or disabled loved ones. This can also be referred to as ‘dual caring’ and those that fall into this bracket can be referred to as the ‘sandwich generation’. These carers are of working age and may face difficulties to stay in the labour market or experience financial hardship if they have to leave employment to focus on their dual caring responsibilities.



Service Provision for Carers

Whilst we have attempted to identify services that are currently available from the States of Guernsey and voluntary sector we cannot claim this to be comprehensive review. Further work needs to be undertaken to identify the totality of services available and to consider the areas of overlap and the underutilisation of services.

It is proposed that 'Carers Guernsey' would continue with this work and ahead of undertaking any further services other than the initial emotional support. See 'Recommendations' section below.

1. STATES PROVISION

Committee for Employment & Social Security (ESS)

Of key importance is the role of ESS in providing benefits for disabled people and carers and funding for some of the services provided by private care providers, in particular through the application of the Long Term Care Insurance Fund. The limitations associated with that fund have been identified and we believe will be the subject of further political review.

ESS also has responsibility for the Equality & Rights Programme, including the development of Disability Discrimination Legislation which aims to "prevent discrimination against disabled people and carers and provide for equality of opportunity" (Billet XXII, 2013, resolution 3).

Carers Allowance

Previously known as Invalid Care Allowance, this allowance is available for carers who look after someone who claims Severe Disability Benefit, and is related to bodily functions or supervision to avoid substantial danger; if carers provide care for more than 35 hours a week; and are over 18 (including those who are in full time education in the island).

The 2017 rate is £81.77 per week and available to those with a household income lower than £94,000. 460 people are in receipt of this benefit (2016 figures). An 8 week continuing payment applies for the benefit of carers beyond the death of the cared for individual. A 4 week continuing payment is also allowed if the cared for individual moves into permanent care.

Supplementary Benefit

The scheme can provide some support to carers and cared for persons in assisting with costs for medical expenses, home adaptations, incontinence and other incidental costs. Access to any of these benefits depends on fulfilling the basic eligibility criteria for supplementary benefit. This support can be in addition to cash benefit entitlement as a top-up to other income.

Longer Working Lives Project

The Committee for Employment & Social Security is working on developing an approach to Longer Working Lives in response to the resolution from the Personal Tax, Pensions and Benefits Review:

To direct the Social Security Department, in consultation with all other relevant departments, to investigate measures aimed at supporting longer working lives and assisting



older people who wish to work to remain in the workforce, and to report to the States of Deliberation with its findings no later than December 2017.

(Billet d'État IV of 2015)

In order to increase the number of people in their 50s and 60s who are economically active it is important to examine, as part of Longer Working Lives, what could be done to ensure that work and care responsibilities become more compatible for those who wish to balance both.

[Signpost.gg](http://www.signpost.gg)

The Disability and Inclusion Strategy approved by the States of Guernsey in November 2013 included providing information for disabled people and carers.

Following consultation with Guernsey Disability Alliance members, other charities, disabled people and carers in Guernsey a new website www.signpost.gg was developed.

The first stage of the website development provided information about support, services and activities for parents and carers of children with a disability.

The next phase of the website aimed to provide information about support, services and activities for disabled adults and carers and was launched in January 2017.

The content of the website will continue to develop over time as individuals are encouraged to leave comments if they do not find the information they are looking for. Feedback is important as it assists in providing the information that individuals need.



Committee for Health & Social Care

The following services are included here because they provide either direct or indirect support to carers.

Community Services

Adults residing in Guernsey and Alderney are entitled to an assessment of their health and social care needs by a qualified professional.

Carers are entitled to an assessment in their own right. There is a carer's assessment form, which is now a requirement for carers to complete before being able to gain access to some H&SC services.

Community services consist of:

- Community Nursing Team
- Social Work
- Rapid Response Team
- Health Visitor for Older People
- Extra Care Housing
- Support Services
- Home Help Service
- Shopping Service
- Community Services Support Team
- Voluntary Car Service
- Short Break Service
- Lifeline Telephone System
- Meals on Wheels – run by Guernsey Voluntary Service.
- Social Care
- Senior Carers
- Some outreach offered e.g. Older Adult Mental Health Team
- Occupational Therapy

There is an open referral system in place for adults in Guernsey and Alderney. Health and social care professionals, potential service users, their relatives or carers and staff from other agencies can make direct contact however there are eligibility criteria for each of these services.

The Community Nursing Team is made up of Community Specialist Nurses, Staff Nurses and Nursing Assistants/Support Workers. The team delivers individualised assessment and nursing care to service users who are over the age of 18, and support to carers, in the home environment. The Community Nursing Team operates a 7 day a week, 24 hours a day service. This service is for people who, due to frailty or illness, would have difficulty accessing a practice nurse.

Social Workers

Anyone can ask for help from Social Services at any time in their lives, although it may be necessary for people with mental ill health/physical, sensory or learning disability to be referred onto a specialist team. The Social Workers also provide support to the Princess Elizabeth Hospital and



respite co-ordination for carers of service users. The social work team operate Monday to Friday from 9am to 5pm.

The Rapid Response Team is a multi-disciplinary team aiming to prevent avoidable emergency admissions to hospital, residential and nursing homes. The team aims to maintain service users in their own homes during a period of crisis, which can be resolved with additional short-term nursing/social/therapy support. This includes carer crisis which requires rapid support short-term. The service is available 7 days per week, for a maximum of 14 days. After this period, if input is still needed, service users are referred on to other services.

Health Visitor for Older People

Health Visitors work in partnership with individuals and the community by providing accurate and up to date information and support, empowering people to make informed choices. The Health Visitor works alongside other H & SC services to provide an accessible and equitable service that meets the health needs of the community. The role of the Health Visitor is about the promotion of health and the prevention of illness. The service is free and confidential and the health visitor can refer onto other professionals and carry out 'low level checks' on carers' wellbeing and situation.

The aim of the health visitor is to help people to lead as healthy a life as possible, both physically and mentally. In addition, their aim is to improve the quality of life of older people by maintaining their independence and contributing to keeping them safe and well in their own home. The Health Visitor is for older people in the community who are aged 65 years and over.

Home Help Service

The home help service helps with basic domestic and household tasks. This is for people unable to access conventional cleaning services due to financial position, frailty or because they require additional considerations that would fall outside of a private cleaner. This service is means tested by Social Security or is chargeable by the hour.

The Shopping Service

This service provides assistance to service users who are, for reasons of ill health or frailty, unable to perform this task themselves and who have no one else who could assist them. This includes providing shopping service support when the main carer is unable to carry out this activity due to ill health. Prescriptions are also collected for service users on the shopping day and personal items that service users may need from St John Healthcare store.

Community Support Services Team

This service assists people to live in their own homes by helping with maintenance, support duties and other minor adaptations. They also carry out the delivery and collection of equipment for nursing and social care requirements in the home. The service aims to help people remain in their own home, safe, secure, warm and independent.

This service may incur a nominal charge; the service user will pay for the materials used or goods fitted, on top of the nominal charge. While there is no limit to the number of requests that can be made, work will be prioritised as to the urgency of need.



The service is available to adults who, for a variety of reasons including illness and frailty, cannot access other maintenance/handyperson services and where there is no other available option or family/friend support available.

Voluntary Car Service

This service, operated in conjunction with Health Information Guernsey, provides transport for service users to hospital or necessary health related appointments.

This service caters for service users who have no available relatives or for other reasons are unable to use public transport or provide other means of transport. Referrals should be made by a Health & Social Care Professional or GP surgery.

Short breaks service ('sitting services' and 'respite care')

Short breaks can offer carers a break from the on-going responsibility of caring for:

- an ill, frail or disabled adult who is being looked after at home by providing a short stay in a Residential or Nursing Home, Extra Care facility or Hospital for the cared-for person according to need.
- This can be a planned break for a carer, or can be arranged as a result of an emergency situation.
- Short breaks ('sitting service') can be provided for a maximum of 4 hours per week within the home to enable a 24hr carer to have a break. This could be a regular or intermittent service dependant on need.
- For individuals requiring a short break of up to four weeks annually provision can be made in extra care, residential or nursing care, subject to availability and the assessment of needs.
- At times of critical illness, overnight short break provision may be available. The professional working with you will arrange this, subject to availability.
- Service users who are registered with the Learning Disability Services will receive their short break from that service.

Referrals can be from a relative, GP, Adult Community Services or self-referrals. Social Security will normally pay for up to 4 weeks short breaks care a year. In most cases there is no charge for this service. However, there may be an additional daily charge made by some of the private homes. This will be a private agreement between the customer and provider.

If a referral has been accepted, a full assessment of a person's care needs will be undertaken by a health and social care professional.

There is respite provision at the following settings, subject to availability and individual care needs:

- La Nouvelle Maritaine, Rosaire Court and Le Grand Courtil extra-care facilities
- Private nursing & residential homes
- The Duchess of Kent House



There is some outreach respite provision which is recently being offered, where a carer is provided to look after an individual within his/her home. H&SC stated that they would like to provide further respite of this nature within the Learning Disability Services.

Short breaks are funded through the Long-term Care Insurance Fund. To be eligible the person requiring care from the short breaks service must:

- Have been assessed as being in need of care which could be provided in a private residential care or private nursing home.
- Be in possession of a valid Needs Assessment Panel Certificate, issued by HSC, and have a bed in a home (a certificate from the Needs Assessment Panel is not a guarantee of a bed).

Some day care centre provision is also accessible through H&SC such as at the Willows.

The Lifeline telephone system enables help to be summoned in an emergency 24 hours a day by simply pressing a button on a telephone or on a pendant which is worn by the user. Pressing the button alerts the control station at the PEH who will assess what the issue is and contact a named family member or friend if help is required. If no named supports can be contacted the emergency services can be summoned. This is arranged via Sure Ltd. to whom a line rental payment is paid for the service. The application for the service can be made via a health or social care professional or directly via Sure.

Meals on Wheels – provided in coordination with Guernsey Voluntary Service, this service delivers cooked meals to those who need and request it. The service is provided for a nominal charge and is available 6 days a week Monday to Saturday.

Senior Carers

Senior Carers provide support with personal care such as washing, dressing, going to the toilet, catheter care, assistance at meal times or help prompting medication. They provide assistance as necessary but also encourage independence.

By the provision of social care support in the community, home care provision helps service users who need assistance with the activities of living, to live as independent a life as possible, whilst remaining in their own home.

The amount of help required will depend on the needs of the service user, who is encouraged to remain as active as possible.

An assessment of care needs will be completed by the most relevant professional and the service user or carer. A care plan will then be provided.

Adult Disability Services

The following services are managed with a coordinated referral system around St Martins Community Centre (Adult Community Care Services):



- Positive Behaviour Support
- Learning Disability Accommodation Service
- Community Disability Team (physical and sensory)
- Community Learning Disability Team
- St Martins Community Centre Day Service for people with a learning disability
- Short break and respite services for people with a learning disability
- Off island placements

Referrals are open and accepted from anyone although there are eligibility criteria for services. Those individuals that meet the criteria for learning disability seem to gain access to a wider range of services than those for other disabilities, a point which came up in many of our conversations.

H&SC is aware that more day care services are needed.

Other services

The following services also provide support to service users in the community:

Older Adult Community Mental Health Team, which includes dementia services, social workers and some outreach, and also a support group for carers.

Community Mental Health Team, which includes community mental health nurses. The team works with medium term conditions and aims to prevent deterioration in well-being and development of longer term conditions.

Decider Skills mental health courses – plans to roll out these successful courses to carers as well as those living with mental health conditions.

Psychological Therapy and Intervention Service:

Support Time and Recovery team – promotes independent living, provides support with daily living

Community Drug and Alcohol Team, a multidisciplinary team specialising in assisting people with severe alcohol or opiate dependence.

The Croft - respite provision for children and young people with learning disabilities, although provision may be extended to a wider disability range in future.



2. VOLUNTARY SECTOR PROVISION

In carrying out its initial research the working group was able to interview representatives of approximately 20 voluntary organisations operating in Guernsey. The summary of services listed in this section is only a snapshot of some of the services provided by those organisations. It should not be regarded in any way as comprehensive. It should also be noted that unfortunately we were not able to interview similar organisations in Alderney.

Discussions with voluntary sector representatives have often raised concerns over the sustainability of these services.

From our discussions it is apparent that for specific conditions there can be organisations which are able to offer support and a wide range of services to carers. However, this means there are gaps for other carers whose 'go to' condition specific organisations do not offer these services.

Many of the organisations offer activities to the looked after person which can provide a break for the carer for a few hours.

Several organisations say their services are either underutilised or could be extended if further funding were to be made available, for example Les Bourgs Hospice (day care) or Guernsey Voluntary Service (bathing facilities) and Samaritans (telephone support). Some of these organisations have sufficient funding in place to offer more services but these are not taken up due to a lack of awareness or lack of referrals/signposting to the services. In this respect, a body which would assist with information provision and coordinating services for carers would be greatly beneficial to making the most of what the voluntary sector can offer to carers.

The majority of those organisations we met with were supportive of the proposal that a representative body for carers is needed. This was also demonstrated in feedback from the carers stakeholder meeting on 1st December (see below).

Other than the information given for Carers Coming Together, the summary of services below is categorised by the type of support available to carers.

Carers Coming Together

The only voluntary service dedicated to supporting carers in general is Carers Coming Together. This small volunteer-led organisation offers monthly Away Days for carers, providing a break and relaxation for carers, along with peer support. They also offer social events, including a men's support group. Referrals come from health professionals, social workers, other charitable organisations or self-referrals. There are usually between 40-50 people who frequently attend the Away Days. A barrier to carers attending is finding someone to look after their cared for person during the day.

Carers Coming Together asserted that many carers in the community are not being supported and are only picked up by health or social care services when a crisis situation occurs. Carers Coming Together believes there is a need for an overarching body to represent and work with carers.



Information provision / signposting

Health Information Guernsey provides some information and signposting services for carers. These services are not advertised extensively and are not explained on their website, so many people are not aware of them and therefore the service is underutilised. HIG organized a Caring Conference a few years ago which was well attended by health sector professionals, and holds an affiliation with Carers UK. HIG has HSC funding for various projects and gets good referrals from some health staff but the lack of awareness of their information services for carers is currently perceived as a barrier to development. HIG has a new staff and board structure and is understood to be working on strategic development.

Citizen's Advice Bureau is able to offer some signposting services to carers and can provide advice on legal matters such as power of attorney and guardianship.

Condition specific charities are able to provide literature or information on those conditions. Guernsey Alzheimer's Association has a library and loans out publications, the Alzheimer's Society Guernsey provides information to clients and the newly formed Dementia Friendly Guernsey aims to provide a central information service for a local understanding of dementia.

Umbrella /overarching groups such as the GDA and Guernsey Mind are able to provide information to their followers which are often specific to the needs of carers.

Training

In 2016 Guernsey Mind started running a 'Carers in Mind' training courses aimed at carers, family and friends of people living with mental health conditions. The course covers mental health issues, relationships, caring for the carer – coping skills, emotional resilience, stress; and to develop action plans, working with mental health services and understanding carers and patients' rights. Mind has run 3 courses with around 15 participants on each course, with courses being oversubscribed and receiving very good feedback. Evaluation of the course showed that many participants felt that this had been the first time they had been really listened to and 'heard' and that they were only now beginning to understand the impact of being a carer on their own mental health. Mind now facilitates peer support groups for people who have attended these courses. Mind asserts that support for the mental health of carers is key. The course will continue to run in 2017 but is dependent on attracting funding to run it. Although its focus is on carers of those with mental health conditions, it could be extended to cover other carers as well.

The Guernsey Alzheimer's Association runs basic training sessions for carers, with health care professionals from HSC and other agencies covering various topics such as incontinence, aggression. Importantly the Association is able to offer an activity for the person the carer looks after so that carers are able to attend sessions without having to find alternative care. Around 15 carers usually attend these training sessions.

St John has previously run training courses for carers, which covered general topics such as manual handling, benefits, incontinence, difficult behavior etc . One of the most useful aspects of the course was for carers to come together to discuss their shared experiences. Although feedback on the courses was very good, attendance was patchy because carers struggled to find people to look after



their cared for person whilst they attended the training. St John could re-run the training course in future if funding is gained. At the moment the course is not commercially viable so St John is not able to offer it.

Training for dealing with specific conditions can be provided, e.g. the Guernsey National Autistic Society, which has run seminars and working groups, or Dementia Friendly Guernsey which has online training for dementia.

Sitting services

Guernsey Alzheimer's Association is able to provide a private carer or sitter that can go into a private home to provide care and give carers a break. This is usually for an hour or two and there is no charge for this service. This service is currently underutilized and the Association could offer this to more clients. Guernsey Alzheimer's Association believes that not many people are aware of this service.

Emotional /peer support for carers

Guernsey Alzheimer's Association offers support to carers, through social events and activities for those diagnosed with Alzheimer's or dementia.

The Alzheimer's Society Guernsey provides information, education and support for people with dementia and their carers locally. It has a paid support worker who is able to offer direct support to people all forms of dementia, and their carers. This support can be via phone, email or outreach at private homes. The support can be advocacy or accompanying people to specialist appointments. Although the worker has a steady case load of around 30 individuals plus carers, he could take on more referrals, but there seems to be a lack of awareness of his services. Activities provided for those with dementia include the Alzheimer's' Café and singing group, to which carers usually come and can thereby receive peer support and discuss issues affecting them in a secure environment. The singing group is oversubscribed but the charity does not have the resources (funding or volunteers) to take on new referrals.

Wigwam is a support group which offers friendship, support and advice to local parents, families and friends who have, or are involved with, children and young people with a special need. Peer support is provided through family events and the charity now employs a dedicated family support worker. This role involves supporting families directly and can involve accompanying parents to specialist meetings and advocacy work. The charity provides support at the transition stage from child to adult services, which has been described as services / provision 'falling off the edge of a cliff'. Wigwam's committee members have great experience within the field, with many of them being parents of disabled children, and committee members often provide support alongside the worker.

The National Autistic Society Guernsey is able to offer peer support to parents of children and some limited advocacy support. Autism Guernsey has an outreach worker who is able to offer emotional support to the carers of their clients. They offer a carer drop-in to discuss any issues and provide advice. Other Autism Guernsey staff can also support with advocacy.



Drug Concern runs 'Reach' peer support programmes for carers of people affected by substance misuse. The first course was run in 2015 and prior to this there was little support for these carers. Around 12 carers have now been through the course. Participants report that they feel less isolated, more supported and give the course a high score.

The Parent Carer Council, Alanon, Guernsey Cancer Support, the Mental Health Service User Group, Headway, Mencap, GSF Mental Health Fellowship, Stroke Association are all able to offer some form of peer support for their respective conditions. Philippi Guernsey is able to offer counselling services to carers and Samaritans Guernsey receives calls from carers seeking emotional support.

Representation of carers

Guernsey Disability Alliance (GDA) is able to represent the views of disabled groups, charities and individuals. The GDA has a 'carers representative' who works to highlight issues for carers of people with disabilities. The GDA is involved in the development and implementation of several States strategies and uses their voice to give constructive and specialist input.

The Parent Carer Council works to represent all those families and individuals who are on the learning disability register (currently around 200 adults and 150 children). Meetings of this council are every quarter and minutes are shared to all families to keep them informed of developments and issues arising. The Council becomes involved in consultations on services or issues that would affect their members. Council members are also able to offer limited advocacy to members and also peer support.

The newly launched Dementia Friendly Guernsey also aims to become a representative voice for people with dementia in Guernsey.

Ageing Well in the Bailiwick represents older people and has representatives on the SLAWS working group.

Mencap, Wigwam and Guernsey Mind also work to represent their carers.

Day care / respite

Guernsey Voluntary Service runs day care services for older people, generally 65 years plus. Services are run from the new Russells Centre at Longue Rue, which can take 24 clients per day, and from Jubilee House at Delancey which can take up to 25 a day. Hair styling is offered at the centres. Previously bathing facilities were available but now are not. Volunteer drivers can often provide transportation for clients to attend these services. There is a charge of £6.50 for attending the day centre which includes lunch.

Age Concern offers afternoon day care sessions, three times a week, at three different locations (Vale, St Martins and St Peter Port). Transportation is provided for clients to attend sessions.

Les Bourgs Hospice offers day care provision, for people with life limiting conditions. Day care is offered twice a week and can support 10 patients. More days could be added with further funding. Les Bourgs is also able to offer some respite care provision for longer stays.



The Ron Short Centre offers a range of activities and support services for local people with physical disabilities. These include an on-site workshop, social evening club and afternoons. The Centre has its own minibuses and can provide transportation for clients.

Charitable residential and nursing homes, such as St John's Residential Home, are able to offer day care services but these usually have a charge.

The Cheshire Home has a bed for respite care for people with physical disabilities, and is also able to offer some day care services.

Mencap provides vital funding of two respite care beds at Le Grand Courtil, which are specifically for learning disability respite.

Jumbulance offers respite holidays for physically disabled people – there is usually one trip with around 10 people attending.

Parkinson's UK (Guernsey Branch) offers a drop-in service which has developed more into an informal day service (well morning), with care support for users being provided. They provide taxi services to and from sessions. The charity has also provided assistance / care through professional nursing/care providers but is very dependent upon funding being available as this carries a high cost. Due to a lack of funding the charity may not be able to offer this service in 2017.

Funding

Condition specific charities are able to assist with financial assistance e.g. for home adaptations, equipment, and some respite costs.

For example, Guernsey Alzheimer's Association is able to assist with small grants to individuals to assist with equipment, transportation, home adaptations. Wigwam can assist with some private transportation (taxis) for their members, but have very limited funds.

Meals on Wheels

Guernsey Voluntary Service runs this service which provides hot meals to people in their own homes. 150 clients receive meals over 6 days a week. Referrals come from health or medical professionals. There is no age limits for clients (i.e. the service is not just for older people) and can benefit people who are living with a range of conditions, some of which have carers, or people returning home from hospital. 120 meals can be served a day (limit that the hospital can supply).

Transportation

There is a Voluntary Car Service for health appointments run by Health Information Guernsey, administered on behalf of HSC, with referrals coming from HSC staff.

Individual charities can assist with providing transportation to events or with transportation costs.



Young Carers

Health Information Guernsey used to offer support to a group of young carers but responsibility for young carers has now passed to the Hub which is able to offer more specialized support services.

The Hub is able to offer one to one support for young carers or group work if appropriate. The Hub raises awareness about young carers and has organized local campaigns. Identification of young carers remains a challenge within the Guernsey context with many not wishing to come forward to access services. Sometimes it is only when young carers reach crisis point that they then come forward. The Hub is then able to provide support, advocacy and signposting services. The Hub is in regular contact with schools and has presented to all head teachers about young carers and the signs to look out for which may identify a young carer.

The Hub has offered a 'sibling caring course' for young people who have a sibling with a disability. The course was very successful and valuable to participants.

Befriending schemes

Guernsey Welfare Service has recently started the Guernsey Linking Lives Scheme, which is a befriending scheme targeting older people who are isolated. So far 12 volunteers have been through the training process and are linked with an isolated, older person. 2 more volunteers are about to be linked up and there are 5 more volunteers in the last stage of the process. Most of the referrals have come from GPs or Social Workers within HSC. It is hoped to extend the scheme.

Supported employment services

Supporting people with disabilities or mental health conditions into work can relieve significant caring responsibilities and financial burdens for carers.

Guernsey Employment Trust's objective is to create employment opportunities for disabled people and to assist them to prepare for, find, and maintain work in Guernsey. Services are for people with any form of disability, including mental health conditions.

Grow provides training and a sheltered work environment in horticulture for people with a learning disability.

GO (Giving Opportunities to Guernsey's Young People) provides employment opportunities and training to people with social, language, or communication difficulties. Funds raised through their shops are used to train young people, build their confidence and increase social skills.



3. PRIVATE SECTOR PROVISION

The working group has only conducted preliminary research into this sector. A meeting was held with Connie's Carers, which we understand to be the largest provider of private care in the island although there are a few other providers.

Connie's Carers provides bespoke caring services directly into the homes of individuals or families with care needs. They provide care to any age, any condition, and react to demand.

They source staff appropriately although there can be a shortage on island, especially for the specialist skills needed for caring for certain conditions or disabilities. There is also the pressure of the private sector competing against HSC in the recruitment and retention of health care professionals.

Feedback from families using private care suggests that when carers buy in care they are in control of the situation, rather than when community services are involved. Using private carers at home enables people to stay at home for longer. The longer an individual remains at home, the less expenditure the States will have on providing more expensive residential or nursing accommodation.

Funding of private care is an issue for most carers and the lack of personal care budgets is a barrier to more buying in care. A few condition-specific voluntary organisations indicated that they can fund private carers to provide some care within the home or outreach care, thereby giving a few hours respite to the carer.

We are aware that some families also buy in UK carers to care for loved ones at home, where the limited private provision available on island may not be appropriate to their circumstances. In some cases, buying in carers from the UK is a cheaper option.

Private care provision could expand. Connie's Carers would encourage more public-private partnerships or tendering contracts for care, which are commonplace in the UK. However, it is difficult for the private sector to develop without personal care budgets.

We understand that there is no regulation of private care providers, although there are regulations in place for residential and nursing homes. Jersey has just introduced a Care Quality Commissioner which works across all caring sectors.



Services for Carers - Best Practice in UK

We have carried out research into the services provided by two UK wide umbrella organisations, Carers Trust and Carers UK, and three regional Carers groups: Carers Trust Northern Ireland, Carers United Sutton Coldfield and Carers Isle of Wight. Please see Appendix 2 for a comparison of services provided by these organisations.

The information has been obtained by either personal contact i.e. telephone conversations, face to face meetings/visits and information obtained from charity websites and annual reviews.

It is obvious that there is no “one size fits all” and the models adopted very much reflect local needs and circumstances.

Following these meetings, Carers Trust and Carers Isle of Wight were then invited to attend the stakeholder session held in December (see below) to discuss their services and how these experiences could support the development of a dedicated carers support service in Guernsey.

Carers Trust offered for Carers Guernsey to tap into their network of support and expertise and there is the potential for Carers Guernsey to become a network partner of Carers Trust.

Carers Isle of Wight

Having considered the various off-island options and models, we recommend that the Carers Isle of Wight model is most suited to Guernsey and therefore list their services here. Carers in the Bailiwick have similar challenges to those in the Isle of Wight and would benefit from the similar infrastructure and services offered e.g. full and part time workers, support/outreach workers and volunteers, carer drop-in sessions and collaborative working with other charities and medical professionals. Help with assessment forms and respite services, such as day/afternoon sessions for carers and peer support groups.

This would include working closely with the management, trustees, staff and volunteers of the many voluntary organisations within the Bailiwick and observing their sessions, activities and other events in situ.

Carers Isle of Wight offers the following services:

- **Information and Advice** from home visits to help with completion of assessment forms and carers register etc. Advice to employers on employing, supporting and retaining carers.
- **Newsletter** 1000 members receive quarterly newsletter, produced by volunteers
- **Support Groups** differing venues and times, refreshments and one drop in session, facilitated by a regular support worker and volunteers, for both past and present carers.
- **Peer support** from both past and present carers.
- **IPad lending library** attend the drop in session, training on iPads, e.g. emails etc., provides peer support outside sessions.
- **Male Carers Support Group** Once a month choosing venue/activity with facilitator and ring around and ‘buddy’ system.
- **1:1 support and crisis situations**



- **Community Project - Monthly meal/activities** run with local church group for carers and cared for people and others in the community.
- **Joint activities with Carers and Former Carers** Therapist who meets regularly with former carers.
- **Two residential weekend experiences per year (breaks for carers)**
- **Mini respite experiences around the island and also for dementia** includes therapy and pamper sessions, art/craft, low cost with bring and share lunch. Separate activities for carers and cared for.
- **Attend Alzheimer's Café** to meet carers
- **Consultations and Training** e.g. Carer Awareness Training for Health & Social Care staff, moving and handling training 2 one hour sessions every month
- **Drop in mental health hospital** weekly to meet carers and work with staff members
- **Ring around service and take a break** possibly weekly, fortnightly, and monthly depending on situation.

Carers Isle of Wight works in partnership with other voluntary bodies, statutory service leads as well as Government departments, both Health and Social Care and trusted assessors to encourage independent living and adult care processes. They assist with hospital discharge planning for effective discharges and work with doctors' surgeries.

Carers Isle of Wight has worked with Government departments to simplify carer assessment forms as well as influencing development and implementation of the Carers Act.

For a more detailed description of their services and other UK charities see Appendix 2.

Carers Isle of Wight has offered support with the development of Carers Guernsey; a good working relationship has been formed with its management.



Gaps in Provision

A key element in the work undertaken by the working group was to try and ascertain 'gaps in provision', i.e. to identify services that were not available to carers within the Bailiwick. This exercise required an initial understanding of the range of services that would be expected within a Community such as the Bailiwick of Guernsey.

The working group was able to draw on work undertaken by Melinda Phillips for the States of Guernsey in the development of the SLAWS project. Melinda Phillips identified a need for third sector organisations to provide support for carers. She acknowledged the work of Carers Coming Together but recognised that it was relatively small and had limited capacity.

In her report to the SLAWS working group Melinda Phillips suggested that the Bailiwick should develop a Carers' Strategy along the lines of the Southwestern Sydney Local Health District "Carers Compass". That Compass identifies seven key components; Full Information, Recognition of the health and well being of the Carer, A life of their own for the Carer, Time off from employment for the Carer, Emotional Support, Training and Support to Care, Financial Security and a Voice.

The Carers Strategy adopted by the States of Jersey similarly recognised certain key themes:- Information and Advice, Emotional and Practical Support, Flexible respite, Training and Learning, Effective Partnership working with other independent providers and health and social care services and Personalised financial and social support.

The Social Inclusion Work Sector of the British Irish Council in its report "Carers: supporting the people who provide unpaid care in the home" identified similar areas of support for Carers.

"Support targeted specifically at carers is important. This includes short breaks, training, emotional and practical support, advocacy, emerging and future planning and income maximisation, including income support."

The working group was also able to obtain information from other external sources, in particular, Carers Trust (a UK national charity) and Carers Isle of Wight. Representatives from both organisations attended and presented to the stakeholders meeting held at Les Cotils. The range of services provided by Carers Isle of Wight was of particular interest to our stakeholder group.

Members of the working group held a number of one to one interviews with a range of voluntary organisations, primarily those concerned with the provision of support for those with specific medical, mental or physical conditions. Most of those organisations, at least provide some level of indirect support for the carer, e.g. by providing weekly drop in sessions or activities for the cared one, which gives some respite for the carer. At least one such organisation is able to offer a subsidised limited hours sitting service. The level of support for the carer varies enormously and at least one of the organisations that we interviewed expressed concern over the financial sustainability even of the limited support that it is able to provide.

All the organisations interviewed recognised the need for one organisation to act as the "voice" and representative of the community of carers in the Bailiwick. Civil servants also indicated that a



preferred option for them would be to communicate with one representative organisation, rather than several, with HSC staff recognising that a representative organisation may help carers to 'keep being carers'.

Those interviewed also recognised a number of existing gaps in the support currently available for carers, in particular:- insufficient respite facility (public and voluntary sectors), lack of personal care budget and other financial support for those cared for at home, lack of information on support for carers and pathways for carers, lack of 24/7 emotional support, advocacy and advice for carers, lack of carer peer support, lack of training for carers, lack of awareness raising about the important role carers have and their needs, transportation for carers, lack of knowledge and support offered by GPs to the carer (as opposed to the one cared for) and lack of referrals to the voluntary sector, the need for better identification and targeted support for young carers.

In relation to services available within the public sector the working group was made aware of concerns over the limitation of staff and financial resources, particularly within the key community services team and for specialist roles such as geriatricians, the apparent lack of coordination between the various services, the lack of signposting to appropriate services by health professionals, and the difficulty for carers to navigate and access the different services. It was recognised that acute services need to develop a more holistic approach to include carers in care management plans.

Most of the voluntary organisations interviewed by the working party drew attention to the lack of financial support available for carers outside the strict eligibility criteria for the Carers Allowance, which is only available for those carers who look after someone entitled to Severe Disability Benefit and the further eligibility criteria for supplementary benefit. The absence of such targeted financial support limits the ability of carers to access services within the private sector for the provision of care at home rather than care provided in a residential or nursing home. The absence of such financial resource in turn inhibits the development of services within the private sector.

The working party was also made aware of particular difficulties for parents of children with special needs once they move from the educational system into adult services. As a result of that transition, the parent often has no alternative but to assume a greater proportion of care commitment with consequential financial and emotional consequences.

It was highlighted that carers should be referred for support/targeted services immediately on diagnosis of the individual they care for. This could be done by a GP and would mean that carers are picked up from the outset. Carers also need to be better informed and involved in treatment plans for the person they are caring for. Several organisations said that proper carers assessments are not done although we understand that HSC is trying to address this. These gaps underline the need for a person centred care approach, with the carer at the centre.

The initial findings were presented to a meeting of stakeholders held at Les Cotils on 1st December 2016. A summary of the feedback from that meeting is attached to this report at Appendix 3. Of particular significance, however, was the unanimous support for the need and creation of a new body such as a "Carers Guernsey" to act as the voice for the community of carers, to act as a point of co-ordination and as a key stakeholder in the development of the proposed Carers' Strategy within



the “SLAWS” programme. There was a general recognition that such a body could also serve to provide the general level of emotional and practical support for carers that was seen to be lacking within the Bailiwick. At that meeting the view was also expressed that a more detailed audit of services currently available across the voluntary sector was required before deciding on what, if any, additional services should be offered by that new body.



RECOMMENDATIONS

As can be seen from the detail above, there is a strong indication that a substantial gap exists between what might be considered standard or good practice and Guernsey's support for its caring community.

The Carers Working Group believe this gap to be sufficiently damaging to those in caring positions as to merit the creation of a new entity under the banner of 'Carers Guernsey', to support carers of all ages and across all conditions.

We recognise that any such action will require a substantial investment of both volunteer time and funds from a variety of sources, but we also recognise that a sustainable model may not be achievable relying solely on voluntary funding.

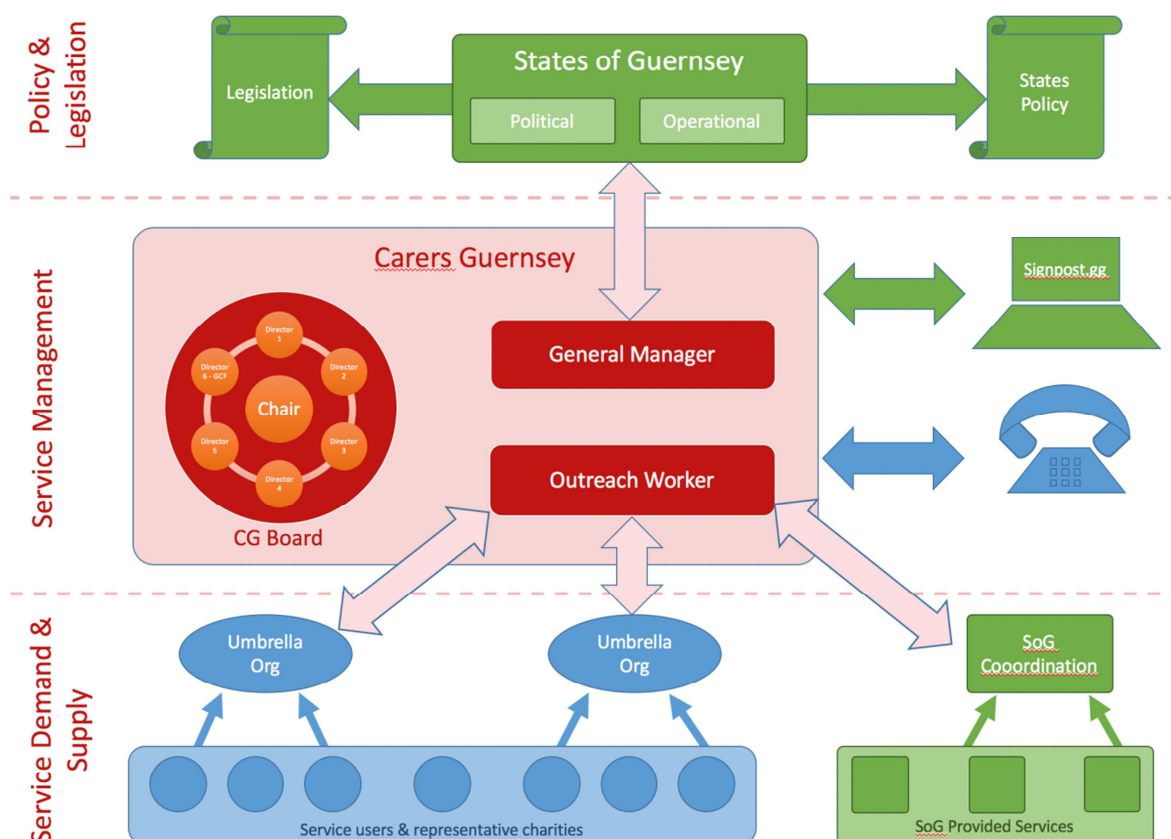
Specifically, our recommendations are;

1. To form an umbrella organisation, 'Carers Guernsey' with the following objectives;
 - To give carers a voice in matters that affect them
 - To provide emotional and practical support to carers of all ages and across all conditions
 - To provide a central service for information and advice to carers
 - To assist in the identification of and sourcing of services from various providers to all carers
2. To source sufficient funds to allow for the setup and operation of Carers Guernsey for a three year period.
3. To recruit an initial team of two staff;
 - One General Manager
 - One Outreach Worker / Case Manager
4. For the GCF to support Carers Guernsey in;
 - the creation of a Board to run Carers Guernsey, including a GCF representative for an initial two years
 - the sourcing of the IT systems required to operate
 - the sourcing of leased premises, potentially from the proposed community centre hub being proposed by H&SC
5. To use Carers Guernsey as a vehicle to provide input into the development of the States Carers Strategy within SLAWS.



The Shape of Carers Guernsey

The diagram below aims to illustrate, at a high level, how Carers Guernsey might operate.



The organisation aims to focus its attentions in two different, but complementary, directions.

Firstly, Carers Guernsey will seek to work with the States to improve the operational and legislative aspects impacting carers. This may be anything from the manner in which the States manages case work for those being cared for, to lobbying for specific changes in legislation that are significantly lagging international best practice. Given its connection to the broader carer community it will be the best source of independently verified carer qualitative and quantitative data on the island. As such, it will be of huge benefit for the States to work hand-in-hand with Carers Guernsey to ensure that States resources are used efficiently and effectively.

Secondly, Carers Guernsey will provide a wide range of services to the carers community, both directly and via other service providers on the island. It will coordinate the use of untapped capacity in the huge range of services provided by the island's voluntary organisations, and work directly with the States to ensure the third sector and public sector services work together where possible.

It is worth highlighting that, while other charitable service providers may provide the majority of services, it is anticipated that Carers Guernsey may also provide its own set of direct services such as:



Initial services:

- Emotional support sessions
- Carer peer support and former carer peer support
- Ring round service
- Support in the completion of forms
- Carer training
- Use of technology as a means of facilitating contact e.g. iPad library (containing carer info + Facetime for Ring Rounds)
- Assistance with sourcing respite breaks and other care

Potential further services:

- Carers assessments, or support of a States process
- A carers register

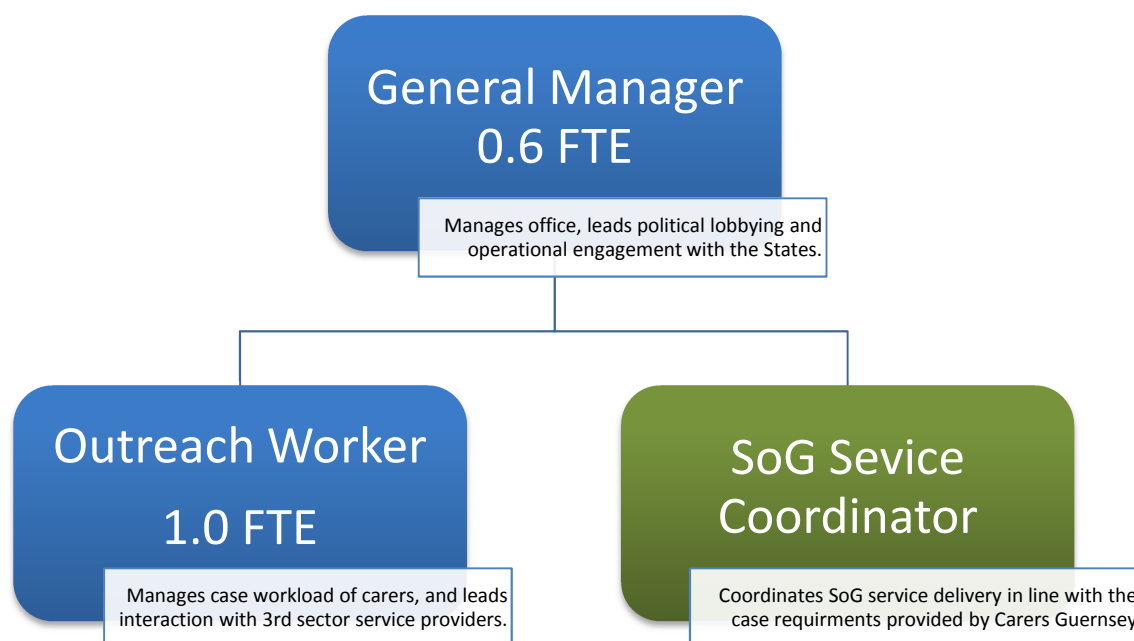
Board of Directors

As a company limited by guarantee (“LBG”) Carers Guernsey will require a board of directors to provide the necessary levels of governance both fiscal and corporate. Ideally such a board should have a minimum of 3 and a maximum of 7. The skills criteria for such members should however not only reflect the typical governance roles but most importantly also include an element of professional care qualification to ensure an appropriate level of professional oversight of the staff of Carers Guernsey. The directors will also be expected to have sufficient knowledge of the voluntary sector and the carers community to be able to make an active contribution to the role of Carers Guernsey as the “Voice” of Carers.

Staffing

As mentioned above, the working Group recommends that the minimum staffing required to operate Carers Guernsey at the outset would be two employees, with a combined utilisation of approximately 1.6FTE.





Volunteers can be used for support services as Carers Guernsey develops – full training would need to be given. Volunteers could be used for services such as a telephone support service, some outreach work, and peer support.

General Manager

The General Manager role will have two specific phases, and may require two different individuals as a result.

In the first instance, the role will be required to establish Carers Guernsey from an operational perspective. This will include everything from getting to know the intricacies of the political and civil service landscape, to setting up the office, as well as prioritizing and managing the introduction of the various services CG will provide. The General Manager will also be required to work with the Directors to act as the voice of carers regarding input into the Carers Strategy.

To address concerns raised by stakeholders (voice first then conduct gap analysis before service provision), the manager would, as one of his/her first actions, map out the existing services in detail – using this report as a basis.

Once established, the role will move to steady-state management, with the focus being upstream towards the States political and operational influencers. It will retain overall responsibility for the day-to-day running of Carers Guernsey and will obviously work closely with the outreach worker to ensure that services are being delivered effectively and the voice of the carer community is being heard.

The General Manager role is considered to be part time, approximately 3 days per week, and need not in the first implementation phase require specific healthcare professional qualifications, but it will require someone that is genuinely passionate about carers and caring if the organisation is to be successful. Gross salary has been set at a full time equivalent of £55,000 per annum.



Outreach Worker

The role of the Outreach Worker will be to both provide direct services, such as those listed in the section above, and to act as the representative of Carers Guernsey within the carer community. It is critical that Carers Guernsey develops a strong dialogue with both the various voluntary organisations and the carers themselves.

The Outreach Worker will use a case management platform to manage an ongoing case workload of carers, while at the same time coordinating the use of services provide by 3rd sector and the States.

The role is considered to be full time and, as at least some of the duties are clinical in nature, applicants will require carer-specific qualifications. Gross salary has been set at a full time equivalent of £40,000 per annum.

Recruitment

After careful consideration the Working Group agreed that the launch of Carers Guernsey would require both of the above mentioned posts to be filled before services can be delivered. As mentioned above, consideration has been given to the idea that the General Manager role may require different post-holders for the setup and operational phases.

Operating Budget

The table below captures the majority of setup and day-to-day running costs for Carers Guernsey.

Capital expenditure		Forecast spend		
Item	Notes	Item value	Units	Budget
Car for Outreach Worker	Ex-demo	£8,000	1	£8,000
LBG setup	Pro bono	£0	1	£0
IT equipment	2 x laptop + phones, printer/copier	£2,000	1	£2,000
Travel & training	IoW visits for both staff x 2	£1,600	1	£1,600
Marketing & comms launch	Various materials + campaign +website	£3,500	1	£3,500
				£15,100

Revenue expenditure - annual		Forecast spend		
Item	Notes	Item value	Units	Budget
General Manager	Indicative salary from SdSP + 18% on-costs	£64,900	0.6	£38,940
Outreach Worker	Indicative salary from SdSP + 18% on-costs	£47,200	1	£47,200
Rent + utilities	Out of town location @ £1k/mth	£1,400	12	£16,800
Bank & insurance		£30	12	£360
Transport costs for Outreach Worker	45p/mile including servicing + insurance	£0	7500	£3,375
Sundry office expenses	Stationary, tea/coffee, publications, socials	£300	12	£3,600
Software subscriptions	CasePro by The Diary, Office suite	£185	12	£2,220
Training		£50	12	£600
Telephony	2 x mobile + landline / broadband	£110	12	£1,320
Annual operating expenditure				£114,415

Total Year 1 costs	£129,515
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Setup funding

The Working Group is confident that setup and operation costs could be secured for the first 1-2 years from known sources. This may include applications to the GCF itself, Pargiter Trust, Lloyds Bank Foundation and/or other discrete trusts.

There is also an expectation that the States may wish to be actively involved in the development of Carers Guernsey as it stands to benefit substantially from the service coordination aspects. Whether any funding or other contribution could be garnered from the States in support of ongoing staffing requirements will need to be further explored.

Ongoing operation

One of the key working assumptions of the team is that, in order for Carers Guernsey to deliver its services effectively, it will need to dovetail its service provision with that of the States. The integration of services is expected to be tight enough as to make it a viable option for the States to second one or more HSC staff to Carers Guernsey for extended periods.



Appendix 1: Stakeholders Consulted

Voluntary Sector

- Carers Coming Together
- Alzheimer's Society
- Alzheimer's Association
- Wigwam
- Autism Guernsey
- National Autistic Society
- Age Concern
- Young People Guernsey / the Hub
- Health Information Guernsey
- Guernsey Disability Alliance
- Ageing Well in the Bailiwick (represented by Sue Fleming)
- Parent Carer Council (for parents of adults with learning disabilities)
- Guernsey Mind
- St John
- Care Managers' Association (represented by Sue Fleming)
- Guernsey Voluntary Service
- St John's Residential Home (represented by Sue Fleming)
- Jenny Hooper (founded Wigwam, carer)
- Drug Concern
- Citizens Advice Bureau

Private sector

- Connie's Carers

States

- Committee *for* Employment & Social Security:
 - Ed Ashton, Deputy Chief Officer
 - Michelle Dumont, Policy Officer
- Committee *for* Health & Social Care:
 - Dermot Mullin – Assistant Director, Adult Community Services
 - Karen Leach – Service Manager, Adult Community Services
 - Ruby Parry
- Policy Council
 - Deputy Jane Stephens, Policy & Resources Minister
 - Helga Carre, Policy Officer



Appendix 2 - Services provided by UK Carers charities

	Carers Trust – national charity	Carers UK – national charity	Carers Trust Northern Ireland	Carers United – based Sutton Coldfield Birmingham	Carers IOW – based Isle of Wight
Charity set up	1991, name change 2012	1965, name change 2001	1965, name change 2001	2016	2014
Number of Carers as at census 2011	Over 6,500,000	Over 6,500,000	214,000	107,000	16,000
Percentage of population (2011)	10%	10%	11.8%	10%	12.25%
Number of Carers (service users)	471,000	Unknown (In excess of 150,000 access information each month)	unknown	600	1,200
Number of Young Carers	21,800		unknown	Service not yet provided	Service provided by YMCA
Funding	Fund raising - £5,000,000 per annum. Consolidated income £7,880,000	Donations and legacies £1.014m Fundraising Events £118k; Corporate income £195k. Incoming resources from charitable activities, received primarily from local authorities and Government£1.9m.	Fund raising Lottery funding	Fund raising and legacy for carer events Individuals pay for outings	Fund raising Government Grant (2 years expire 2017) Joint lottery funding with other services Legacy for carer outings Individuals pay for outings
Staffing	Unknown as network	Unknown as affiliate	unknown	2 part time , plus 2 part	3 full time, 5 part time

	of other providers	membership by other charities		time outreach workers	and 35/40 volunteers
Services provided: Support Groups	Network of service providers - 116 independent carers centres, 55 Crossroads Care schemes and 99 young carers services Service provision, including respite care Information CarerSmart Club – discount offers Groups Networking Emotional and peer support interest based such as health and wellbeing, yoga, massage	Free membership for individuals Affiliate membership for organisations (annual subscription) Supportive network and movement for change Expert advice/information & support Telephone helpline Research, campaigning, media case studies Consultancy for local authorities Technology for carers Employers for Carers forum	See main Carers Trust details	Carers Café – monthly Advice Café – twice monthly	Weekly at different venues Male groups Ring Around service 1:1 support in crisis
Social Events	See above	n/a	n/a	Theatre Trips Knit/natter groups	Walks Afternoon Teas Art/craft Meditation/massages/Quiet days Bring share lunches Cooked lunches - church group Events for carers/former carers Events for carers/cared for



Carer Outings	See above	n/a	n/a	Day outings – 3 per year and Christmas Party	Respite weekends – twice yearly Respite days Drop in respite days
Outreach	See above	See above	See above	Attend other charity events	Attend other charity events Drop in - GP surgery and mental health hospital
Training provided	Training i.e. specific to carers, understanding dementia, first aid, moving and handling, back care, back to work – job seeking skills,	Training for healthcare professionals	See main Carers details	In due course	Moving/handling iPad loan and training Dementia Awareness Reaching Communities (DARC) for Carers
Befrienders Scheme	See above	See above	See main Carers details	In due course	Not known
Newsletter	No	No	No	In due course	Quarterly
Social media/webs ite	Information website www.carers.org Online forums (incl young carers)	Information website www.carersuk.org Online forum for mutual support	Information website www.carers.org/count ry/carers-trust-northern-ireland	In due course	www.carersiw.org.uk
Government Lobbying	Various campaigns	Various campaigns	Various campaigns	In due course	Aging Better Steering Group for Caring4carers Drop in Consultation Day for Carers Carers Assessment Form simplification



Appendix 3 - Key points from Stakeholder Meeting 1st December 2016

We were delighted to be joined by representatives of the Carers Trust and Carers Isle of Wight, who talked about the work and experiences of their respective organisations.

Key feedback from the stakeholder meeting confirmed:

- Unanimous support for the need and creation of ‘Carers Guernsey’.
- Model for Carers Guernsey - three models were presented at the meeting:
 - 1) To act as a voice for carers;
 - 2) To provide services such as emotional support for carers; and
 - 3) A combination of acting as a voice and offering provision of services such as support.

Most participants favoured the combination of voice plus service provision. Some favoured a phased approach with the voice first and a gap analysis of current service provision before offering services - to better define the need for which services to offer and to avoid any duplication of services with other stakeholders.

- That Carers Guernsey should act as a key stakeholder in the development of the proposed carer’s strategy within the Supported Living and Ageing Well Strategy (SLAWS).
- Evidence from research so far shows that most stakeholders believe there is an immediate gap or need for emotional support for carers as well as a voice/representation side which would feed into the development of the carers strategy.
- Recognition that from day one of operations, Carers Guernsey should raise awareness about the vital work of carers.
- Emotional support to start with should be via a telephone and outreach service.
- The voluntary sector can do more to support carers e.g. Guernsey Voluntary Service indicated that they could offer bathing facilities to other clients; Les Bourgs Hospice could offer their premises to other clients for day care provision.
- Stakeholders appreciated the offer of support and expertise that Carers Trust could provide.



- Stakeholders were very impressed by the services that Carers Isle of Wight provides and would like Carers Guernsey to be developed along similar lines and to learn from their experiences.
- Key issues that Carers Guernsey will need to focus on: identifying carers (including young carers); respite; access to accurate information and signposting; carers assessments; improving communications between GPs and carers; financing of care.

NOTE: Subsequent to the stakeholder meeting, HSC approached the Working Group to request that it works in partnership on the development of the Carers Strategy.

The Working Group has accepted this request with the proviso that if and when Carers Guernsey is set up that Carers Guernsey becomes the partner organisation.

Proposed model for Carers Guernsey:

