

Report from the Guernsey Disability Alliance

Response to Consultation on Provision of Equipment Aids and Adaptations

January 2023

The Committee for Health and Social Care (HSC) sought the GDA's help to progress a review of the provision of equipment, aids and adaptations. This is the GDA's response.



Photo Credit: ITV Channel - Paula is blind and had to privately fund her walking cane. (https://www.itv.com/news/channel/2022-06-08/guernsey-states-accused-of-not-doing-enough-for-islanders-with-disabilities)

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Recommendations

The GDA recommends:

- Universal non means tested grants are used to fund equipment, aids, and adaptations and the associated training and maintenance for people with impairments to reduce barriers to living independently; should this not be acceptable to consider:
 - a. reduction in the cost to the user of adaptations, aids and equipment as much as possible particularly where there is a benefit to maintaining independence, or where the recipient is a child
 - b. providing grants for adaptations for children as a universal benefit that is not means tested (as in the UK)
 - c. moving from full means testing to an annual income limit, as with Severe Disability allowance, which is £113,400 per household in 2023, or Family Allowance £120,000 per household, if some sort of cap is required for equipment aids and adaptations
 - d. the financial benefits, compared to the cost of administrating claims.
- 2. Amendment to the application and assessment process so that it is timely, transparent and clear and takes a whole view of the current and ongoing needs of the applicant providing:
 - a. an easier, co-ordinated one stop application process with a single point of contact
 - b. a plan for future funding
 - c. information on the application processes
 - d. assistance / advocacy if needed with applications
 - e. a comprehensive, integrated system approach with HSC, ESS, third sector and suppliers
 - f. clarity on what is or is not funded
 - g. a map of the system so that everyone in it can understand the relationships between the parts and so that complexities can be reduced, duplication removed, and gaps filled
 - h. information on what is available within all systems, not having to seek out information from different sections, Committees, or charities
 - i. information on what they can expect to obtain in value and what they might have to fund or seek funding from at the beginning of the process
 - j. information on the criteria under which their applications for funding are judged
 - k. a quick decision process
 - I. a process for quick and easy information to be provided on why any application is rejected
 - m. transparent, independent quick and easy appeals process for any rejected applications where the user does not agree with the outcome
 - n. flexibility, as in the current system to meet individual specialist specific needs on a case-by-case basis
- 3. If GST is introduced in Guernsey a similar relief should apply as in the UK for persons with impairments needing equipment, aids and adaptations.

- Quality standards need to be monitored and the roles responsible for the monitoring identified widely with robust mechanisms for addressing failures to meet standards.
- 5. Housing strategies need to contain provision for accessible accommodation and respite accommodation
- 6. Consideration needs to be given to underwriting suppliers of equipment and aids if it is otherwise uneconomic to provide such services
- 7. Training needs to be included in the budget for any system for staff as well as users of the equipment, aid or adaptation
- 8. Information should be in an accessible format for individual applicants and provided widely with advertising of the schemes with a clear communications plan
- 9. It is recommended that a review is undertaken of the current prosthetists/orthotists contract and consideration given to:
 - Whether the visiting service should be independent of supplier
 - How the quality of the service is monitored
 - What sanctions can be taken if quality standards are not met
 - Provision of assistance with the cost of travel etc if the visiting contractor cannot meet the service users needs
 - an independent prosthetists/orthotist or other qualified person undertakes
 the assessment of need and is not limited to one contracted supplier but
 can recommend the best company to undertake the work for an affordable
 cost within a suitable time frame
 - monitoring the quality of suppliers work by HSC
 - providing a complaints procedures where complaints are pursued by HSC with the external suppliers
 - changing contractors
 - not having an exclusive single contractor

Introduction

HSC asked the GDA, other stakeholders, individuals with impairments and their carers for help to progress a review of the current provision of equipment, aids and adaptations.

States Resolution

Following a successful amendment to the Reform of Health Care Funding in June 2019, proposed by Deputy H J R Soulsby and seconded by Deputy M K Le Clerc, the States agreed:

- "... that the funding of disability-related equipment, aids and adaptations, under section 10 of the Income Support (Guernsey) Law, 1971 ('section 10'), is an area requiring transformation in order to be more structured, fair and effective, consistent with the principles of the Partnership of Purpose and of the UN Convention on the Rights of Persons with Disabilities;"
- "... to direct the Committee for Employment & Social Security and the Committee for Health & Social Care, in consultation with relevant States Committees and other stakeholders, to review this area, and any associated services or schemes for the provision or funding of equipment, aids and adaptations which they may consider relevant, and to return to the States, no later than the end of July, 2022, with recommendations, which shall include a proposal to transfer the powers conferred by section 10 (or any proposed replacement scheme), and an associated general revenue budget, from the Committee for Employment & Social Security to the Committee for Health & Social Care." CHttpHandler.ashx (qov.qg).

The above is referred to as the "States resolution" throughout this report.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)



Picture: United Nations logo

In 2013 the States of Guernsey agreed:

"...4. To direct the Policy Council to seek the extension of the UN Convention on the Rights of People with Disabilities to Guernsey at the earliest appropriate opportunity. ..." (Billet d'État XXII of 2013 Disability & Inclusion Strategy - https://www.gov.gg/CHttpHandler.ashx?id=85262&p=0)

This is important as any new policy introduced should be UNCRPD compliant as, whilst the States of Guernsey has not yet sought extension to the UNCRPD, it is their agreed intention to do so.

There should be no decision made about us without us. This is the intention under article 4(3) of the UNCRPD which we believe should include persons with disabilities in decisions about them.

"4(3). In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html

We are therefore grateful to HSC for providing an opportunity to comment on the proposals for changes to section 10 at an early stage of its policy development.

The States resolution above sets out one of the reasons that there needs to be transformation of section 10, is to be consistent with the UN Convention on the Rights of Persons with Disabilities. The UNCRPD sets out worldwide standards and obligations for governments and other bodies. Article 1, below, sets out the Conventions purpose.

Article 1 Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include 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.

(https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html)

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) was reviewed for this report. Where there are relevant Articles to a section of this report, these have been quoted in that section.

Methodology

There is a general acknowledgement from HSC and the Committee for Employment and Social Security (ESS) that there are weaknesses in the current system and that work needs to be done with charities and islanders with impairments to understand their experiences and shape solutions accordingly.

HSC are currently in a fact-finding period so that they can plan further work and add to their knowledge of the current systems and provision and what gaps the third sector are already filling. It was on this basis that the Senior Strategy and Policy Officer of the States of Guernsey met with representatives of the GDA's Social Policy Group on 25th April 2022 and sought the GDAs help to progress a review of the provision of equipment, aids and adaptations.

The GDA agreed to send out survey questions. Questions were sent to individual members whose responses are in Appendix 1. A different set of questions was sent to member organisations and charities. Their responses are in Appendix 2.

In addition the GDA organised a drop in workshop on 8th June, 2022. The detailed responses from the workshop are in Appendix 3.

Internet searches were also made for some additional material.

This report provides the feedback from the survey, consultation, workshop and any other research undertaken by the GDA. It is broken down thematically by section.

Funding

Current States Provision

Whilst the States resolution refers only to Section 10 of the Income Support (Guernsey) Law, 1971 there are different schemes available under different legislation which provide for some assistance with the provision of equipment, aids and adaptations.

These include:

- The Health Service (Benefit) (Guernsey) Law, 1990, as amended, Part VI of which provides medical appliances to residents of Guernsey and Alderney from a defined list (see <u>Health Service (Benefit) (Guernsey) Law, 1990 (guernseylegalresources.gg)</u> and see lists in <u>Health Service (Medical Appliances) Regulations, 1990 (guernseylegalresources.gg)</u>);
- The Social Insurance (Guernsey) Law, 1978, as amended, Section 39A of which provides for funding in relation to insured persons for work rehabilitation for tools, equipment, transport and other items (see https://www.guernseylegalresources.gg/CHttpHandler.ashx?documentid=807
- The Education (Amendment) (Guernsey) Law, 1987, Section 7(2) does not specify aids equipment or appliances but states that where the Committee has determined the special educational provision in respect of a child, it shall be the duty of the Committee to arrange that the special educational provision

specified in the determination is made for the child. (see <u>CHttpHandler.ashx</u> (<u>quernseylegalresources.gq</u>));

This is in addition to Section 10 of the Income Support (Guernsey) Law, 1971 (see https://www.guernseylegalresources.gg/CHttpHandler.ashx?documentid=80760), which the States resolution relates to. For more details on Section 10 see Appendix 4.

The ESS is also looking at bringing back to the States proposals for an access to work fund. This would go further than the Section 39A provisions above by covering for persons seeking to enter or retain employment (and not just to return to work). The Access to Work scheme would only be limited to aids and equipment.

Where a person is not covered under any of the States provisions and provision is not made by their residential accommodation, such as at a residential or nursing home, they must rely on their employer or other organisation providing reasonable adjustment or self-funding or charity funding. Where none of this is available there will be an unmet need, the level of which is not known.

UNCRPD on Funding

The UNCRPD does not have a specific requirement for funding aids, equipment and adaptations but has a requirement for the provision of information and promotion of research of such technologies at a minimum, least or affordable cost. Where it talks about mobility aids there is more onus on the States to facilitate provision and provide training. In relation to the information provided it must be accessible at no additional cost to the user.

Under Articles 4(f) and (g) of the UNCRPD a State Party (which would be the States in Guernsey) would have the following relevant general obligations:

- (f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, ..., which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
- g) To undertake or promote research and development of, and to promote the availability and use of new technologies, ..., suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html)

As well as the general provisions above cost is mentioned in the following articles.

Article 9 Accessibility, sub-paragraph 2(h)

"(h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost." Article 9 – Accessibility | United Nations Enable

In Article 20, Personal mobility, there is more onus on the States to facilitating access to personal mobility and access to mobility aids, devices, assistive technologies as well as providing training.

"States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- (b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- (c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- (d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities." Article 20 Personal mobility | United Nations Enable

The concept of reasonable accommodation (reasonable adjustment in the Guernsey legislation) is defined in Article 2 (see https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities) as:

"necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

The UNCRPD is more specific about reasonable accommodation in the workplace and stipulates in Article 27 <u>Article 27 – Work and employment | United Nations Enable</u> that states shall safeguard and promote the realization of the right to work by ensuring

"that reasonable accommodation is provided to persons with disabilities in the workplace".

For Guernsey this has now been enshrined in the Prevention of Discrimination Ordinance, 2022

https://www.guernseylegalresources.gg/CHttpHandler.ashx?documentid=83765 where there is a duty imposed to make reasonable adjustments. These adjustments might be aids, equipment or adaptations.

Where these are related to employment Section 39A of the Social Insurance (Guernsey) Law, 1978, as amended (see

https://www.guernseylegalresources.gg/CHttpHandler.ashx?documentid=80776) applies. Whilst the consultation was specifically about the powers under Section 10 of the Income Support (Guernsey) Law, 1971 representatives of the GDA have been to a recent presentation on a new access to work scheme to be brought in to complement existing benefits where a reasonable adjustment might not be

reasonable for a business to make financially. The suggested fund would help broaden employment opportunities for some persons who might otherwise find opportunities are skewed towards employers with greater resources.

All the States provisions, including the new ones, should be co-ordinated.

Article 28 - Adequate standard of living and social protection <u>Article 28 - Adequate standard of living and social protection | United Nations Enable</u>, goes wider than just employment and under sub-paragraph 2(a) the States should ensure access to appropriate and affordable services, devices and other assistance for disability-related needs.

GDA and Member Comments on Funding

Some members have questioned the rational of not funding equipment that is required for their independence and feel that all such equipment should be funded by the States.

From the 1986-87 Health and Activity Limitation Survey (HALS) (Dunn, 1990; Statistics Canada, 1988). undertaken in Canada on its older population, cost was identified as the principal reason for not obtaining needed technical aids. 56366222.pdf (core.ac.uk)

Although a more recent local survey has not been undertaken on unmet need in relation to aids, adaptations and equipment, the Primary Care Survey https://www.carewatch.org.gg/primarycaresurvey22, undertaken locally in 2022, found that some people were not seeing a doctor due to the cost. In this report 48% of people said they had delayed a trip to the doctor, physiotherapist or emergency department because of the cost. It is therefore likely that some people will not be obtaining aids, adaptations or equipment, that they need, due to cost.

The recent report from the Resolution Foundation (El Dessouky & McCurdy, January 2023, Costly-differences.pdf (resolutionfoundation.org)) provides an insight into how the cost of living crisis has highlighted the problem of households ability, where someone is living with an impairment, to deal with fast rising prices. As in Guernsey, as the population ages, the numbers of people with impairments increases. People with impairments are more vulnerable to rising costs of essentials because energy and food make up a greater share of their budgets, on average, than for other households, in part because of additional needs caused by the impairment. Some of the Key findings were:

- Disposable income is significantly lower for households where someone has an impairment.
- People with an impairment are far more likely to be poor than the rest of the population.
- In-work people with an impairment face an increased risk of being on lower incomes.

- People with an impairment are almost three times as likely to live in material deprivation than the rest of the population.
- People with an impairment have been stung by fast rising energy and food prices.
- Around two-fifths of people with a disability (41 per cent) said they couldn't
 afford to keep their homes warm, compared to under one-fifth (23 per cent) of
 the non-disabled population.
- Almost one-in-three (31 per cent) people with a disability say they have had to reduce their expenditures on food, compared to 18 per cent of the nondisabled population.

Where people are already reducing expenditure on food and unable to heat their homes, they cannot budget their way out of poverty. Other means of increasing income or reducing expenditure, such as working more hours or relying on favours, such as lifts to reduce transport costs, or using active transport may also not be as available to people with impairments as they are to the rest of the population. This means that where an extra expense such as aids, adaptations or equipment is needed, the person needing this is starting from a position of being less likely to be able to budget for this expense, if they are required to self-fund, or repay a grant.

There is some reluctancy to claim a means tested grant, not only due to the detailed information required but due to stigma around such benefits which are not universal. There is also some confusion over what should be expected to be covered as part of any server disability allowance, for day to day additional expenditure and at what level of expenditure assistance should be sought under section 10. Not everyone needing equipment, aids and adaptations is currently claiming any benefit and entry into the system can also be a psychological barrier.

Some parents questioned why they should be means tested as a family for items required for their children. The following comment was made by one respondent:

"Means testing should be looking at needs of child, not at the parents."

In the England Wales and Northern Ireland, the Disabled Facilities Grants for adaptations does not take account of parents' income for the needs of children under 18. Disabled Facilities Grants: What you'll get - GOV.UK (www.gov.uk)

In the same jurisdictions the Disability Facilities Grant also enables landlords to get a grant without their income and savings being taken into account. The council may ask for the property to be let to another disabled person if the current tenant moves within 5 years.

With the Committee for Education, Sports and Culture's (Education's) remit having changed recently to cover at 0-25 year olds, further provision should be made to determine the special educational provision and subsequent funding for this wider age group. Provision of equipment aids and adaptations for one child in the family should not adversely affect other children in the family. Work needs to be undertaken

with Education so that it is clear who is responsible for funding children's equipment etc.

Education establishments together with employers, providers of goods and services, including landlords and clubs, will be required to provide reasonable adjustment under the new Prevention of Discrimination (Guernsey) Ordinance, 2022 Prevention of Discrimination (Guernsey) Ordinance, 2022 (guernseylegalresources.gg) due to commence in October 2023. Whilst it will not have a huge impact on the requirement for provision currently applied for under section 10, it may help to mitigate cost for people who are having to self-fund equipment and aids, particularly if these are used for school or work.

Where conditions change frequently or where a person is still growing quick decisions are vital. Participants at the workshop also put the following comments in the **strongly disagree** column on the response:

"Funding has not progressed with need"

"Self-funding where needs change frequently"

Some of the respondents had self-funded items:

"I have now bought a wheelchair (£400+) and have my bathroom fitted with grab-handles etc – as advised by Occupational Therapists" (Response 4 Appendix 1)

If we look at an example of the NIC Guideline for Motor neurone disease: assessment and management (Recommendations | Motor neurone disease: assessment and management | Guidance | NICE) the phrase "without delay" occurs 11 times out of which 8 are relevant to the provision of equipment or aids. Where there are barriers in place to the provision of equipment, participation in activities of daily living and maintain quality of life is reduced and independence lost.

A person is not looked at holistically. One member commented:

"If someone has multiple needs e.g. wheelchair + ipad + gates, each need is looked at individually across several pots, not looked at as a whole."

Most GDA members who responded have questioned the process, transparency, and fairness of allocation of the funding. Information on funding is also difficult to obtain and there is no centralisation or co-ordination of the process around the whole of the individual's needs, in most cases.

One person at the workshop commented:

"You don't really understand until you've got a disability. But when you're born with it, you've just got to carry on.

That's how it is, but it would be nice if they did help sometimes."

One of the strengths identified of the current section 10 was its flexibility to meet individual need whether that was an adaptation to a person's residence or new technology. Any changes to the system should not reduce this ability to meet

individual specialist need on a case by case basis. One group from the workshop (Appendix 3) gave the following responses:

"Strongly agree: Certain equipment will be funded ...

Agree: Sometimes (for some) individualised, personalised equipment, aids, adaptation needs are met"

Goods and Service Tax (GST)

The cost of living crisis has disproportionately adversely affected people with impairments and their families compared to the rest of the population. The implementation of GST on all goods and services would again be likely to affect these same households adversely disproportionately if it were introduced in the Island.

In the UK there is VAT relief for people with impairments. <u>Financial help if you're</u> disabled: VAT relief for disabled people - GOV.UK (www.gov.uk)

If you qualify for the VAT relief you will not be charged VAT on products designed or adapted for your own personal or domestic use. Also, you will not be charged VAT on:

- the installation and any extra work needed as part of this
- repairs or maintenance
- spare parts or accessories

If GST is introduced in Guernsey similar relief should apply.

Assessment of Barriers to Activities of Daily Living

Separate from the funding and financial assessment is the assessment of need for equipment aids and adaptations required to overcome barriers to everyday activities. Following any initial diagnosis people with impairments rely heavily on professional knowledge to know what is available. Respondents from the workshop strongly agreed with the following provision (Appendix 3):

"Specialist assessment OT + others available !(NOT TIMELY)!"

The timeliness of any services has previously been mentioned in relation to assessment of funding above. The whole end to end process needs to be considered and made as easy to navigate as possible for the applicant.

There was also a comment on the availability of equipment to try during, or post, assessment.

"Limited assessment trial equipment"

Not all services are available on Island and the following comments were relevant to gaps in service provision.

"Gaps in specialist services and assessments" (Return 4 Appendix 3)

"Fortunately, I have previously had contact with Adult Disability so they could complete the forms. I needed to do the information and research, since there

is no social services provision for sight impairment. I used appropriate resources for this, including specialists from RNIB - but this was not sufficient for the referral. The person who submitted the referral only used the professional assessments and research that I provided." (Response 2 Appendix 1)

People who have had impairments for some time may become expert in what is available to meet their needs. It can also be difficult to find someone to undertake an assessment or support your application if you have not been seen by any service for some time as your condition is stable.

"I don't have any support from statutory services as fall outside the criteria or there aren't any services available..." (Response 2 Appendix 1)

Parents may also be expert on their child's needs. However, parents were not always listened to or are treated differently (worse) for advocating for the needs of their child. One parent noted (Appendix 3)

"Let down by services. Parents voices are not heard, or their concerns are not fully understood."

"If you raise your voice for your child you get labelled as "difficult" and not treated the same way."

It is understandable that where the cost is from the public purse that some checks and balances will be needed. This could be through:

- an occupational therapist,
- other professional locally
- charity
- other independent assessment off island.

For more common conditions a whitelist could be provided of what is available in agreement with NICE or other guidelines or local guidelines could be developed and funded.

A multidisciplinary team approach to assessment would enable all of the needs of the person to be viewed holistically. Whilst specialist services have an ongoing part to play in the assessment of needs for aids, equipment and adaptations there is also a requirement to take an holistic view of a person's needs. This is particularly important with impairments affecting development in children and young people, affecting multiple systems in the body, or where there is co-morbidity.

In the statement by the President of the Committee for Employment & Social Security on 19 October 2022 Deputy Roffey said:

"Phase 3 of the Supporting Occupational Health & Wellbeing (SOHWELL) programme has got underway. This has been identified as a health recovery action under the Government Work Plan. Although still at an early stage of development, it is envisaged that the programme will have a focus on prevention and early intervention activities, to improve access to occupational

health and the health and wellbeing of the population. The Committee looks forward to working in partnership with the Committee for Health & Social Care to progress this important work."

It is suggested that the requirement for OT input to assessments for aids equipment and adaptations is looked at within the SOHWELL programme to ensure appropriate levels of staffing for timely assessments.

Where there are gaps in services locally, assessments may need to be undertaken elsewhere or through a visiting service.

Individuals should not be prevented from applying but the onus should then be on HSC to provide the assessment if the application does not fall within guidelines.

Again using the example of the NIC Guideline for motor neurone disease (MND): assessment and management (Recommendations | Motor neurone disease: assessment and management | Guidance | NICE) when MND is diagnosed it is recommended that people are provided with a single point of contact for the specialist MND multidisciplinary team.

Regardless of the impairment, a single point of contact is what most respondents have suggested is needed to help navigate through the local system. This might be especially difficult if your impairment is rare, and the specialist treatment has been provided in the UK where the team providing treatment does not know the local system.

One member commented (Appendix 3):

"Its difficult if you are the only person on the Island with a condition"

"Only yearly visits from specialists."

Where a person is growing or their needs are changing rapidly there needs to be adequate opportunity for appropriate assessment and reassessment, with a plan put in place at the outset.

Again using the example of the NIC Guideline for motor neurone disease (MND) : assessment and management (Recommendations | Motor neurone disease: assessment and management | Guidance | NICE) the following assessments may be required:

- 1. social care needs
- 2. carer assessment,
- 3. assessment for respite care
- 4. assessment for other support
- 5. cognitive assessments
- 6. carry out regular, coordinated assessments at the multidisciplinary team clinic (usually every 2 to 3 months) to assess people's symptoms and needs
- 7. end of life care needs
- 8. information needs

In addition assessments for the use of the following equipment, aid and adaptations might also be required:

- 9. humidification and nebulisers
- 10. equipment and adaptations that meet the person's needs so that people can participate in activities of daily living and maintain their quality of life as much as possible
- 11. assistive technology such as environmental control systems
- 12. wheelchair services
- 13. ensure that equipment, adaptations, daily living aids, assistive technology and wheelchairs meet the changing needs
- 14. regularly review their ability to use equipment and to adapt equipment as necessary
- 15. integration of all equipment, for example, integrating AAC aids and devices and environmental control systems with wheelchairs
- 16. home adaptation.

It is unlikely that one person will be able to make all such assessments and so a multi-disciplinary team approach is required. This type of approach should be used for all assessments. One response from the workshop (Appendix 3) suggested:

"Adaptations team"

when considering what might be improved.

One member noted:

"Technology changes so rapidly." (Return 2 Appendix 3)

This can have implications on stock available locally to see or try and on the time required to keep up to date with what is coming to market. Whether an assessor of need, or supplier of equipment, time needs to be taken to keep up to date with technology. Given the range of impairments this can be difficult. (Also see the section on training below.)

Part of any assessment should also consider the storage, cleaning and maintenance of any equipment, aids and adaptations and if additional support, or storage will be required.

Suppliers of Adaptations and Alternative Accommodation

UNCRPD on Housing

United Nations Enable of the UNCRPD – Adequate standard of living and social protection | United Nations Enable of the UNCRPD – Adequate standard of living and social protection the States would need to recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including ...adequate housing, and to the continuous improvement of living conditions. In addition Article 28 gives the States the following obligations:

"c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related

expenses, including adequate training, counselling, financial assistance and respite care;

d) To ensure access by persons with disabilities to public housing programmes;"

Adaptations

Home adaptations are changes to make it safer and easier to move around your home and do everyday tasks. An occupational therapist will normally be the person expected to undertake a home assessment and might suggest big or small changes to meet a person's needs. Work will then normally be undertaken by businesses in the building trades.

Quality of work, cost and timeliness of work are all important to the final adaptation meeting the need of the person with an impairment and reducing barriers. Lead in time for work by building trades in Guernsey can be long and not always meet the time scales of the person requiring the adaptation.

Adaptations might include:

- widening doors and installing ramps or grab rails
- improving access to rooms and facilities, for example with a stairlift, or level access shower
- improving access to your garden
- building an extension, for example a downstairs bedroom or downstairs toilet
- providing a heating system suitable for your needs
- adapting heating or lighting controls to make them easier to use



Photo Credit: PFM -Accessible shower room for domestic use https://www.pfmuk.org/wet-room/)

UNCRPD and Building Regulations

Article 4 (1)(f) of the UNCRPD <u>Article 4 – General obligations | United Nations Enable</u> gives the following general obligations for the States:

"To undertake or promote research and development of universally designed ... facilities, ... which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;"

The UNCRPD also provides for accessibility in Article 9 <u>Article 9 – Accessibility | United Nations Enable</u>. This is not just access to buildings, but the States need to take appropriate measures to ensure persons with disabilities have access to:

- the physical environment,
- transportation,
- information and communications, including information and communications technologies and systems, and
- other facilities and services open or provided to the public, both in urban and in rural areas.

If design takes account of accessibility at the outset, then there is no need for the majority of adaptations to be undertaken. However, this would only apply to new builds not existing housing stock. The building regulations set out access criteria for development work.

Building regulations have been changed over the years to provide more accessible buildings. Guernsey Technical Standard M CHttpHandler.ashx (gov.gg) will be met by making reasonable provision to ensure that buildings are accessible and usable.

"People, regardless of disability, age or gender, should be able to:

- a. gain access to buildings and to gain access within buildings and use their facilities, both as visitors and as people who live or work in them;
- b. use sanitary conveniences in the principal storey of a new dwelling.

The provisions are expected to enable occupants with disabilities to cope better with reducing mobility and to 'stay put' longer in their own homes. The provisions are not necessarily expected to facilitate fully independent living for all people with disabilities."

Whilst the compliant buildings under part M will provide more accessible housing stock in the long term, -the reality is, most people live in older housing stock and will require adaptations to be made.

Landlords

Where the person needing an adaptation is in rented accommodation this should not preclude them from an adaptation being made. Either the landlord or the tenant should be able to submit the application.

In the UK, Landlords can get a grant without their income and savings being taken into account. The council may ask for the property to be let to another disabled person if the current tenant moves within 5 years.

Respite Accommodation

Consideration needs to be given to alternative accommodation provision and cost whilst work is being undertaken. As an example, if you only have one bathroom, which is being adapted, you may not be able to live in the house while work is being undertaken.

Alternative Accessible Accommodation

Some people may prefer to move out to alternative accommodation rather than modify an existing dwelling. Co-ordination of looking at all options both short and long term will need to be undertaken.

Provision of accessible housing stock needs to be considered by social housing and other providers as well as short term respite accommodation whilst work if undertaken.

The 2017 KPMG report noted the following in relation to over 55 accommodation:

"Without sufficient choice of over 55s dedicated housing tenures, individuals in the 55-80 age bracket may end up living in accommodation that is unsuitable for their needs. They may continue to live in larger properties which become difficult and expensive to maintain, restricting the availability of homes for growing families. Additionally, studies in the UK such as 'The Value of Sheltered Housing' commissioned by the National Housing Federation have suggested there are benefits to individuals from the elderly living in sheltered housing accommodation including less time spent in hospital, lower housing costs (such as energy and maintenance bills), reduced loneliness and greater independence. Benefits to government can include reduced expenditure on health and social care."

https://www.gov.gg/CHttpHandler.ashx?id=109412&p=0

We acquire impairments as we age, and it is therefore important in looking at adaptations that the whole housing market and strategy for provision is considered.

Equipment and Aids Suppliers

General Suppliers

Trials of equipment were seen as a good opportunity to see what was available and whether it worked for the individual. It can, however, be frustrating, following a successful trial, if equipment is not then immediately available.

"Given a trial on equipment, it worked well, but then taken away and had to wait with no idea on how long it will take."

To enable people to trial equipment many members had suggested some sort of library or repository. Given that some Charities such, as Guernsey Blind Association (Response 1 Appendix 2), have developed their own specialist services there may be opportunities for other charities to be advisors and suppliers.

There is also a specialist wheelchair service, provided by HSC, but no comments were received specifically about this service.

St John Healthcare shop has just announced its closure <u>Healthcare Shop to close</u>: <u>St John Guernsey</u>.

John Hollis, Knight Commander and chairman of the Commandery of St John in Guernsey said about the closure:

"We are living in very difficult economic and social times, perhaps the worst for at least a generation. Like other organisations, a St John board of directors may therefore sometimes be forced to take decisions with very difficult implications. St John personnel invariably try to do their utmost to provide services to the community that can be funded, in line with their "Caring for Life" ethos. The St John entities therefore welcome all those in our community who can assist in an appropriate professional, voluntary or charitable funding basis."

The viability for charities to run a library or other premises providing specialist equipment has therefore to be considered carefully. Without sustainable funding it might not be possible for a charity or business to maintain supply of equipment and aids. The supply would then fall wholly on the States or need would be left unmet.

There is a glimmer of interest from the charity sector with the response from UnLtd saying:

"We want to create a project user group of people with an interest and some knowledge of Enabling Technology." (Appendix 2)

However, the National Autistic Society said:

"The NAS has a specialist toy library but has not recently had any volunteers to enable the library to operate." (Response 4 Appendix 2)

There is a concern that a wholly unpaid volunteer model would not be sustainable as a supplier in this area. The UNCRPD requires States to move away from charity model thinking.

HSC will need to consider its own part in the supply chain and how lead in times can be reduced through the whole system. It should also consider what its role needs to be in potentially financially underwriting suppliers, particularly if the supplier is a not for profit/ charity organisation.

Transport

Equipment enabling independent transport is valuable in maintaining contact outside residential accommodation, whether for work, shopping, leisure or socialising. The provision of cars, adaptations to cars, mobility scooters etc are important to maintaining many peoples independence.

The UNCRPD provides for accessibility in Article 9 <u>Article 9 – Accessibility | United Nations Enable for transport.</u>

Orthosis and Prosthesis

Orthosis and prosthesis are two types of devices that help people who have difficulty using a limb or limbs. An orthosis is a device used to correct or enhance the use of a part of your body, it does not replace a part of the body. The orthosis is an assisting device, while the prosthesis is a replacement device whose purpose is to restore function and/or improve appearance (cosmesis). (Orthotics and Prosthetics? - The Australian Orthotic Prosthetic Association Ltd. (AOPA))

We received a number of negative comments about the current orthotic supplier and the relationship with HSC. See Appendix 1 response 4 for one persons experience of the service. One quote from this response relates to the cost that he had to self-fund:

"I am now obtaining my calliper from the previous orthotist firm appointed by HSC ...(HSC Previous Contractor)... which is to be made of steel but which costs £1200. Furthermore I have to attend their workshop in Leeds for a fitting. Whilst there I will get my car fitted with a hoist to ease the handling of my wheelchair. My son will kindly take time off work to accompany me and act as carer/driver. Total cost of equipment and trip: c. £3,400."

The father of another orthotic user, who has an impairment which requires his son to have specialist shoes, said that he only ever had one pair at a time. He further commented:

"It's emotional. You feel ignored, I feel as if I am letting him down, his mother down. But it's hard for me as a father." Guernsey States accused of not doing enough for islanders with disabilities | ITV News Channel

The visiting service of prosthetists and orthotists is provided by the contractor rather than by an independent prosthetists/orthotist. This appears to limit the range and choice to that supplier's products regardless of who is paying for the equipment or the suitability of other products on the market. If the quality of the contracted supplier is also not being monitored and provision is only being made for cosmesis rather than functional equipment, then HSC and its contractor are failing to meet the needs of Islanders.

Training

UNCRPD on Training

Under Article 4 of the UNCRPD <u>Article 4 – General obligations | United Nations Enable</u> the States have a general obligation to promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.

More specifically under Article 20 <u>Article 20 – Personal mobility | United Nations</u> <u>Enable</u> the States should provide training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities.

Article 26 of the UNCRPD <u>Article 26 – Habilitation and rehabilitation | United Nations Enable</u> provides the States with the duty to:

"promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation."

Staff

It is not clear as to what training is provided to which staff.

The following comments are from one person using the orthotic service:

"No one has ever asked me whether I can afford these services."

"At no point throughout the past 70 years has there been any monitoring of the quality of orthotic service provided to me."

From these comments HSC staff have not been able to advise fully on the system or quality of service. Whether this is due to lack of training or for other reasons is not clear, but training must be available for staff to fulfil their roles and time must be allocated to ensure the full roles within job descriptions, which may also need amending, can be undertaken.

Ongoing wide training about the system (or whatever it changes to) for HSC and ESS staff is required. Where equipment is not provide free to the user, staff should be able to advise on cost and ESS benefits or other financial assistance available, where the cost might otherwise be unaffordable.

As well as the wide training above, training in specific areas of responsibility for specialist HSC staff (or contractors) should also be provided.

Where there are contractual obligations, staff should be aware of how that contract is to be monitored and what the process is for escalating complaints.

Staff should be trained so that they can clearly advise on what to do if equipment breaks down, needs repairing or replacing and who is responsible for payment and arranging the repair / replacement.

All training needs to be budgeted for and included in staff job descriptions, with time allocated within the working year for it to take place, so that staff are kept up to date with advances in technology and changes to the system.

HSC and ESS training should be available to third sector organisations who provide advice, sign posting, advocacy, or who provide equipment and training.

Persons with impairments

In line with NICE guidelines <u>1 Guidance | Patient experience in adult NHS services: improving the experience of care for people using adult NHS services | Guidance | NICE the States should ensure that education programmes:</u>

- are evidence-based
- have specific aims and learning objectives
- meet the needs of the person with the impairment (taking into account cultural, linguistic, cognitive and literacy considerations)

 promote the person with the impairment's ability to manage their own health if appropriate.

Training may be provided in a number of ways to the person using the equipment and/or their carer/parent. Some will be provided by Occupational Therapists, Physiotherapists, HSC contractors, equipment providers and the third sector. On some occasions the equipment might be provided with no training on its use.

Specialist charities or services can help by proving information to keep up to date with changes in technology. Guernsey Blind Association (Response 1 Appendix 2), not only keep stock of certain items for anyone with a visual impairment to try or buy, but also organise companies providing aids to visit the Island once a year for people to try different technology and speak to the company representatives. They also have links to other charities with expertise in the UK.

Information (see next section) needs to be provided whether as part of face to face, or on-line training or as printed or on-line information in an accessible format for the user at a time convenient to them. It should include what to do if the equipment or aid goes wrong or needs repairing as well as what maintenance is expected from the user as well as limitations on its use.

If the aid or equipment is used at work or school other people may require training to be included as part of the set up cost e.g. a teacher may need to know how to use a communication aid. Colleagues and the IT department, at work, may need to know how to use a specific piece of software etc. The facilities manager might need to know how a piece of equipment should be cleaned and stored etc.

Information Required

The UNCRPD on information

Whether the States provide information in training sessions, as above or online or in printed or other formats it will have the same obligations under the UNCRPD as above for training.

The States therefore has a responsibility to promote the knowledge and use of assistive devices and technologies

Under Article 4 <u>Article 4 – General obligations | United Nations Enable</u> the States has an obligation "to promote the availability and use of" and "to provide accessible information …about" mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities. Sub-paragraph(1)(g) above even goes as far as stating that priority should be given to "technologies at an affordable cost".

The UNCRPD also provides for accessibility in Article 9 <u>Article 9 – Accessibility | United Nations Enable</u>. Aids which reduce or eliminate barriers to accessibility are therefore also part of accessibility and information should be provided on them by the States. This includes access to the internet and new technologies.

Article 21 – Freedom of expression and opinion, and access to information, provides the States with an obligation to provide accessible information without additional cost to the user.

"a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;" Article_21
Freedom of expression and opinion, and access to information | United Nations Enable

The States as an information provider

It is suggested that the States should ensure that information about equipment aids and adaptations is widely and publicly promoted – for example, in GP surgeries and community spaces, as well as in specialist services and within the third sector.

Where available, the States should provide information about the circumstances in which independent local advocacy is provided.

Both written and oral communication should be used to provide information. The most effective way of communicating with each person should be established and ways to improve communication explored and should be accessible to that person. Examples include using pictures, symbols, large print, Braille, different languages, sign language or communications aids, or involving an interpreter, a patient advocate or family members.

The person with the impairment (and/or their family members and carers) should be provided with information to enable them to use any equipment correctly. This should include information on its cleaning, maintenance and storage. Ensure that the user and their family members and carers feel adequately informed, prepared and supported to use the equipment and to carry out self-care and self-management.

Charities / third sector as information providers

Charities can help with promoting the use of assistive devices and technologies and some such as the Guernsey Blind Association hold an annual road show for suppliers to visit the Island to showcase new and existing technology. UnLtd (Ron Short Centre) is also looking for ways to enable people to try different assistive technology before they purchase or are provided with it.

As above with suppliers any provision of information needs to be sustainable.

Persons with impairments, parents, and carers

Many people want to be active participants in their own healthcare and social care, and to be involved in creating and managing their health strategy and use of services. Self-care and self-management are particularly important for people with long-term conditions. Overview | Patient experience in adult NHS services: improving the experience of care for people using adult NHS services | Guidance | NICE

In line with the Care Act 2014, local authorities in England must provide information about care and support services for people and their carers, including:

- "the types of care and support available
- how to access care and support, including eligibility criteria
- how to get financial advice about care and support
- local safeguarding procedures and how to raise safeguarding concerns or make a complaint
- rights and entitlements to assessments and care and support services
- personal budgets and all the options for taking a personal budget for example, local authority managed, Individual Service Fund or direct payment."

Recommendations | People's experience in adult social care services: improving the experience of care and support for people using adult social care services | Guidance | NICE

References

Most references are linked within the text with the relevant website.

Dunn, 1990; Statistics Canada, 1988

O El Dessouky & C McCurdy , Costly differences: Living standards for working-age people with disabilities , Resolution Foundation, January 2023

Appendix 1 - Written responses to questions for individuals

Questions

The following questions were asked of individual members and a small number of written responses were provided which are reproduced in this appendix.

Questions for individuals:

- 1. Have you ever applied to ESS for support under Section 10?
- 2. Did you know you could apply for a states grant or loan under Section 10?
- 3. How did you find out you could apply for a states grant or loan towards the cost of equipment, aid or adaptions?
- 4. What support or advice did you get in making that application?
- 5. Was the application for someone over or under 18yrs old?
- 6. Should there be a consolidated equipment library in the community on which people with a disability or their carers could draw on when they needed?

Comments about the system:

From a users perspective, HSC are also very interested to know.

- 1. What the current system feels like, is it meeting the need?
- 2. Were you/Are people, helped through the system by particular professionals, perhaps your GP or the community occupational therapists?

Please add any general comments you think relevant.

Response 1

- 1. Have you ever applied to ESS for support under Section 10? **No**
- 2. Did you know you could apply for a States grant or loan under Section 10? No
- 3. How did you find out you could apply for a States grant or loan towards the cost of equipment, aid or adaptions? **Unaware that the service existed and do not know it's scope or eligibility criteria.**
- 4. What support or advice did you get in making that application? **Unaware of service or where to apply.**
- 5. Was the application for someone over or under 18yrs old? N/A
- 6. Should there be a consolidated equipment library in the community on which people with a disability or their carers could draw on when they needed? Yes. It would be beneficial for people to have the opportunity to see and try items especially of assistive technology or mobility aids before either committing to purchase one or applying for assistance on what might not be the correct equipment for their use case.

I hope this helps but I regret I knew nothing of this service or what might be obtained through it. Hopefully the committee might provide some clarity so that potential beneficiaries might be able to obtain equipment to assist with home or work

Response 2

No I have never received anything from section 10 Income Support and have never been advised that I can receive help in any way. Yes I do believe that a library for equipment would be a big help in the community.

Response 3

- 1. Yes more than once, some accepted, and some declined
- 2. Yes
- 3. Yes
- 4. (a) Some years ago through Guernsey Blind and also Adult Disability, one application for a number of items including assistive technology for computer Guernsey Blind supported this, assessed what would be useful and sent the letters to Social Security; that was declined.
- (b) In 2020, Adult Disability had assessed my needs and I researched what cooking aids would work for me; I forwarded all the details to AD, which was a talking combi microwave/grill/oven and a talking induction twin hob, plus putting worktop in the space where a conventional cooker would be; I had to find out what would work, as AD didn't have the relevant experience in this field, then they used this in their application which was approved.
- (c) In 2022, I wanted to apply for funds for a refreshable braille notetaker. RNIB Technology Team had assessed what would be best for me and Guernsey Blind also wrote to support this. These were submitted, but then it needed a referral from a designated professional. I don't have any support from statutory services as fall outside the criteria or there aren't any services available, but Social Security contacted AD who had previously worked with me and they agreed to put in a referral. I sent all of the information from RNIB and Guernsey Blind to them and it was submitted and accepted again, AD doesn't have the relevant experience in this area so they relied on the information I had provided.
- 5. Over 18
- 6. For some things, a community library would be helpful. It depends what the equipment is and how much it would be used. The items which I need are specialist and are for permanent use. I can see that some items which people would use short term and that are frequently requested could be good in an equipment library.

I would like to add that the current referral process can be difficult. I am registered blind and am autistic, but I don't have a statutory key worker or be within any system.

Fortunately, I have previously had contact with AD so they could complete the forms. I needed to do the information and research, since there is no social services provision for sight impairment. I used appropriate resources for this, including specialists from RNIB - but this was not sufficient for the referral. The person who submitted the referral only used the professional assessments and research that I provided.

More recently, I spoke to AD to see if it would be possible to also get a Perkins brailler through this scheme. I can write on the braille notetaker but cannot produce hard copy and also am still learning braille (which I paid for) and using a Perkins is highly recommended. I had tried using the very old ones that Guernsey Blind had but they were not operational. My initial enquiries were that it could be submitted if I provided the quote, information, reasons etc, but was also asked if this equipment would help with getting back into employment (which is not on the cards) and if it was 'essential'. Very few things in life are actually essential and as a very literal autistic, I could not answer this. Also, by the time I had got quotes, referrals (which as I am not on anyone's case would have to be 'fitted in'), the decision made, ordering if approved - it was going to take several months and I needed it for coursework right now. I did not pursue this and ended up getting a second hand one, but still had to pay out for it.

It is very difficult to know what would be covered within the section 10. I receive Severe Disability Benefit, so this genuinely gets spent on disability-related costs and any large expenditure falls outside this. However, when asking for things like Supernova, it was declined and I still have to pay quite a lot for upgrades. Obviously, smaller things should be paid for within my benefits. It would be really helpful to know what type of things would be covered.

It would also be good to have some type of self-referral process so that I could submit things directly with appropriate documentation from qualified professionals (eg RNIB), those who are experienced with equipment for visual impairment (Guernsey Blind and RNIB) and those who know me as a person and what I need help with (Guernsey Blind, Autism Guernsey). This would provide a much more accurate application for what I need. Alternatively, someone appropriately qualified within Social Security who I could have an appointment with (taking someone to support me if needed) and take all of the information and reports with me. This would need to be someone with understanding of needs, aids and so on, not just a person receiving documents. This would enable me to say - this is what I have issues with, this is what I need to overcome these and be able to explain.

Response 4

The HSC contractors names have been removed from the following response.

Questions for Individuals:

- 1. Have you ever applied to ESS for support under Section 10?
 - 1.1. Not personally but medical staff have applied for me e.g. an air ambulance to Southampton

- 2. Did you know you could apply for a states grant or loan under Section 10?
 - 2.1. I thought my income would rule out any support of this kind so have never sought assistance.
- 3. How did you find out you could apply for a states grant or loan towards the cost of equipment, aid or adaptions?
 - 3.1. I was never really aware of this support until now. Perhaps I should test the water to see if my income and savings are low enough to warrant support from ESS.
- 4. What support or advice did you get in making that application?
 - 4.1. N/A
- 5. Was the application for someone over or under 18yrs old?
 - 5.1. N/A
- 6. Should there be a consolidated equipment library in the community on which people with a disability or their carers could draw on when they needed?
 - 6.1. This seems like an excellent idea
 - I contracted polio at the age of nine in 1950 and spent 18 months in hospital over two periods – two years absence from school altogether. My right leg is completely paralysed and requires a full length calliper and raised shoe. My left leg and lower back was affected but largely recovered. For most of my working life I have managed with the aid of the calliper, raised shoe and one walking stick.
 - At no point throughout the past 70 years has there been any monitoring of the quality of orthotic service provided to me. I ordered new aids directly from the orthotic supplier appointed by HSC and I bore the full cost.
 - In 1996 I was diagnosed with Post-Polio syndrome and gradually my left leg
 has deteriorated such that I can only walk a few yards without resting it or
 having extra support from two walking sticks. I have now bought a wheelchair
 (£400+) and have my bathroom fitted with grab-handles etc as advised by
 Occupational Therapists.
 - I have a particular complaint regarding the current orthotic firm ...(HSC Contractor)... which supplied a calliper to me last year. On the first day of use it failed to support my weight (14st) and the metal struts buckled. I requested they make the struts of steel or refund the cost (£670). They chose to refund the cost. Are HSC concerned that ...(HSC Contractor)... are using materials of inferior quality? Or is that the inevitable result of appointing the cheapest bidder?

- I am now obtaining my calliper from the previous orthotist firm appointed by HSC ...(HSC Previous Contractor)... which is to be made of steel but which costs £1200. Furthermore I have to attend their workshop in Leeds for a fitting. Whilst there I will get my car fitted with a hoist to ease the handling of my wheelchair. My son will kindly take time off work to accompany me and act as carer/driver. Total cost of equipment and trip: c. £3,400.
- A marked difference in service between the two service providers is that
 ...(HSC Previous Contractor)... consultant stayed in Guernsey each month
 until all clients had been seen. ...(HSC Contractor)... consultant is permitted
 only one day per month to see local adult clients thus creating a waiting list of
 up to four months in my own case.
- Two years ago I wanted to order a new raised shoe but when I mentioned the matter to ...(HSC Contractor)... consultant (no longer employed by ...(HSC Contractor)...) I was advised "I wouldn't get your shoes from us." An alternative UK firm was recommended but HSC declined to engage them to provide footwear. I was advised by HSC to 'go private' but that entails finding a supplier in the UK and travelling there for at least one fitting. I need a carer/driver thus increasing the cost.

In all normal financial matters if I pay the full cost of a service I should be free to choose the supplier. If HSC chooses the supplier of orthotic services then they surely have an obligation to monitor the service actually delivered to ensure standards are maintained and to feed into the appraisal and re-appointment process.

No one has ever asked me whether I can afford these services. What happens to those who cannot afford them or are less able than me to look after themselves?

This survey gives me hope that things will change.

Additional comments to the above were also emailed by the same respondent which follow.

Thanks for raising this issue. I see that I may have misunderstood some aspects of past medical events. In recent years I have benefited from support when I had a stent inserted into an artery - an air ambulance no less! I think I may also have benefited from paid fares when I went to Southampton for an eye operation. (I really can't remember.) When assistance was provided for those events it was instigated by the medical staff involved – not by me. On that basis I think I should change my response and now have attached new copy *(above)*. Apologies for messing you around.

I have been fortunate to have been in a relatively well paid position for much of my life and my savings currently are sufficient to cover these costs. On that basis I have not asked for financial assistance. At the same time no one has enquired of me if I could afford these costs.

I have no problem with my name being disclosed to anyone over these points – except that I don't want to appear in the media over this. I wrote to the Director of

Operations at HSC to complain that I had received professional advice that ...(HSC Contractor)... were not recommended for making raised shoes and requested they engage another firm for shoes only. I was told to go private instead. When I complained about the quality of the calliper I received a refund from ...(HSC Contractor)... but there was no response from HSC who were copied with my emails to ...(HSC Contractor)....

Thank you for your attention to my case. Much appreciated.

Appendix 2 - Written responses to questions for organisations

Questions for charities or organisations

- 1. Does your charity or organisation hold equipment and if so please indicate what sort and how many items you hold?
- 2. How many people a year do you support?
- 3. Is this support for the under 18yr age group or adults?
- 4. Is the equipment given, loaned and do you make a charge?
- 5. Is there a cost to you in storing and maintaining equipment?
- 6. Do you share equipment with other organisations or charities?
- 7. Do you provide assistance or advice to members in making applications to access disability related equipment, aids or adaptions under Section 10, currently administered by ESS?
- 8. Should there be a consolidated equipment library in the community on which people with a disability or their carers could draw on when they are needed

Response 1 – Guernsey Blind Association

- 1. Does your charity or organisation hold equipment and if so please indicate what sort and how many items you hold? we have a fully stocked resource room of various equipment and aids to assist those with a visual impairment in their day to day life and we also order in specialist larger or more expensive equipment as and when needed to reduce redundant stock.
- 2. How many people a year do you support? hundreds, both regular clients and ad hoc assistance
- 3. Is this support for the under 18yr age group or adults? all ages are supported
- 4. Is the equipment given, loaned and do you make a charge? it very much depends on circumstance and equipment, if an item is sold it is always at cost price, if a client can afford if not it is reduced and sometimes given free of charge
- 5. Is there a cost to you in storing and maintaining equipment? no cost in storing but we try reduce redundant stock by ordering in when needed and having 'demo' items to try before buy type situation
- 6. Do you share equipment with other organisations or charities? only really with other sight related charities due to the nature of stock, for example Macular Society
- 7. Do you provide assistance or advice to members in making applications to access disability related equipment, aids or adaptions under Section 10, currently administered by ESS? yes, we have been asked for assistance in this regard such as Disability Allowance, Blue Badge applications etc

8. Should there be a consolidated equipment library in the community on which people with a disability or their carers could draw on when they are needed – I think it would be too broad to have one consolidated equipment library as most of our equipment is so specialist and such a broad range. We are for vision support and have such a wider array, I don't think it would be possible to have all equipment for all impairments together! Funding should perhaps be provided to charities to assist with equipment purchase for service users in need for us to best help our clients and make the process more accessible

Commonly stocked and most requested equipment at Vision Support Centre;

- **Bump Ons** £1 round, self adhesive dots can be used for easy and effective marking of every day items around the home
- Long Cane £30 upwards extends from the floor to the user's sternum and they are used to avoid obstacles if you have restricted or low vision. The cane is used by either rolling or tapping from side-to-side as you walk
- **Liquid Level Indicator** £9 Helps people with sight loss make hot drinks. This small water level sensor beeps and vibrates when your cup is nearly full (we also have specialist kettles, talking jugs, scales etc etc)
- Talking Watches/Clocks £25 upwards give users peace of mind knowing they can hear the time announced with the press of a button. Choose a basic model for time only, a talking watch with advanced features such as an hourly time report, talking alarms and calendar
- Wrap Around Sunglasses £15 upwards Some eye conditions, like agerelated macular degeneration (AMD), glaucoma or cataracts, can increase your sensitivity to light so these glasses can go over prescription glasses to limit light.
- Hand Held Magnifiers £40 Illuminated hand-held magnifiers provide magnification and illumination for near spotting tasks and are ideal for inhome uses such as looking up phone numbers, setting the thermostat, or reading the prescription on a medicine bottle
- **Monomouse** £180 ish device designed to magnify text and display it on a TV screen for easy reading. It features a Reverse Mode that displays white text on a black background ideal for those with macular degeneration.
- **Smartlux** £280 ish portable video magnifier with full HD camera that features a 5" reflection-free display, large field of view

- **Orcam Read** £1,500 ish handheld device with a smart camera that seamlessly reads text from any printed surface or digital screen
- Apple iPad £260 ish (not kept in stock) enables speech to text for sending messages & emails, camera enables photo to enlarge to magnify, various apps such as Be My Eyes, Seeing AI & NaviLens - enable visually impaired client gain independence discretely.
- USB player £60 for services users to listen to weekly recorded Audio News and also Audio Stories
- Lamps various With age, pupils decrease in size (less light is received by the eye) therefore older adults need more light (to see clearly) than healthy young adults. We stock an array of energy-efficient LEDs to produce different levels of brightness, which can be independently adjusted for each shade.
 With the addition of a flexible arms and the ability to position each lamp head separately
- **Games** large print puzzle books, tactile dominoes & playing cards, dice, board games etc
- High Visibility clothing such as vests, coats & sash for increased visibility for safety when out and about in lower or dull lighting areas

There is so much equipment available for visual impairments and we rigorously test to match to service users to ensure suitability in terms of dexterity and usability – it is very much a case by case basis, what works for one will not work for another – hence we like to have demo products to try before you buy to best help and assist our service users efficiently and cost effectively.

Response 2 – Autism Guernsey

Questions for charities or organisations.

- 1. Does your charity or organisation hold equipment and if so please indicate what sort and how many items you hold? Weighted resources / books
- 2. How many people a year do you support? Currently 200
- 3. Is this support for the under 18yr age group or adults? Both
- 4. Is the equipment given, loaned and do you make a charge? Loaned
- 5. Is there a cost to you in storing and maintaining equipment? ???? part of building however approx £2,000
- 6. Do you share equipment with other organisations or charities? Yes
- 7. Do you provide assistance or advice to members in making applications to access disability related equipment, aids or adaptions under Section 10, currently administered by ESS? Yes if applicable
- 8. Should there be a consolidated equipment library in the community on which people with a disability or their carers could draw on when they are needed yes however AG equipment highly specialised

In addition if you are able to ask your members for their views we would also be keen to hear their answers to the following:

Only way to enquire is via FB and not sure section 10 cover AG clients will await your reply on if you feel it is appropriate to post on FB

There are also some systems questions from a users perspective, HSC are also very interested to know the answers to.

- 1. What the current system feels like, is it meeting the need? NO
- 2. Were you/Are people, helped through the system by particular professionals, perhaps your GP or the community occupational therapists? NO

Response 3 - UnLtd at the Ron Short Centre

We will be launching the Enabling Technology project prior to building work starting.

We want to create a project user group of people with an interest and some knowledge of Enabling Technology.

Response 4 - (Verbal) National Autistic Society(NAS) - Guernsey Branch The NAS has a specialist toy library but has not recently had any volunteers to enable the library to operate.

Appendix 3 - Responses from Workshop

Return 1

How well do the current arrangements work?

Response: Strongly disagree

Other questions not answered on this form

(Note: Members did not all continue to respond individually but put collective responses together.)

Return 2

How well do the current arrangements work?

Response: Not answered

What works well regarding the provision of aids, adaptations and equipment?

Response: Technology is working better than manual/paperwork versions.

NovaChat works well.

What could work better in the provision of aids, adaptations and equipment?

Response:

- Means testing
- No help from States for adaptive shoes
- NovaChat, process of paperwork took 3 months frustrating. Means testing dealt with ESS – Income Support, MEIS, ACE and Fiona Black identified equipment
- Equipment is for a fixed time
- PECs
- Its difficult if you are the only person on the Island with a condition
- Communication, a point of contact lacking
- Let down by services. Parents voices are not heard, or their concerns are not fully understood.
- No sharing of notes between GP and MSG.

We need:

- An equipment library, with a central list, or signposting to services with equipment
- A dedicated staff member to oversee aids /adjustments / equipment or Ace charity sponsors a Guernsey representative for communication devices for example
- Include a panel of people who know about that equipment

It is who you know, need coordinated approach.

Have needed crowd funding.

Means testing should be looking at needs of child, not at the parents.

It says you can "appeal funding", but you can't! You can appeal process but not funding decision.

Anything else

If you raise your voice for your child you get labelled as "difficult" and not treated the same way.

Lack of consistency in decision making.

Child is not considered.

Wants an outline / flow chart of process, with decisions/ meetings ahead to know what lies ahead.

Not enough literature.

Only yearly visits from specialists.

Given a trial on equipment, it worked well, but then taken away and had to wait with no idea on how long it will take.

Technology changes so rapidly.

When parents borrow equipment, it needs to be the right thing.

Lots of equipment that was given out, that's no longer needed. That doesn't get recycled.

Severe Disability Allowance is designed to pay for equipment but there is a disconnect with what recipients need to use the money for.

If someone has multiple needs e.g. wheelchair + ipad + gates, each need is looked at individually across several pots, not looked at as a whole.

Return 3

How well do the current arrangements work?

Response:

Disagree – Not advertised

Lack of awareness

Strongly Disagree - Lack of transparency of process

What works well regarding the provision of aids, adaptations and equipment?

Response: Don't think from our feedback that it helps or works well!

What could work better in the provision of aids, adaptations and equipment?

Response:

- 1. Easier process
- 2. Defined criteria to apply for assistance

- 3. Communication!
- 4. Transparency

Anything else

Response: High dependency on charity assistance

Lack of funding

Return 4

How well do the current arrangements work?

Response:

Strongly Agree Certain equipment will be funded

Specialist assessment OT + others available !(NOT TIMELY)!

Agree Sometimes (for some) individualised, personalised equipment,

aids, adaptation needs are met

Some service users of all aids want electric wheelchairs and

chair buggy scooters (despite some risks)

Undecided Victoria Hospital Funding

Social Investment Fund

Funding

Gaps in specialist services and assessments

Charity funding available – not commissioned by HSC – (relying

on these – not states funded)

No contract with allocated companies for equipment aids

Needs a trial showroom

Public perception for self-funding aids where they have savings

and are not in receipt of benefit.

Disagree – SSD lack of fair process

Replacement and repairs

Maintenance / servicing - process and availability on island

Different funding schemes

SSD funded equipment no longer needed not re-used (lack of

process)

Strongly Disagree - Funding has not progressed with need

No criteria

Self-funding where needs change frequently

Limited assessment trial equipment

More money needed for all equipment for users and life improving operations especially for young people

What works well regarding the provision of aids, adaptations and equipment?

No response

What could work better in the provision of aids, adaptations and equipment?

Response:

- > Equipment database
- > Equipment service for all
- > Above with long-term loan for main equipment needs
- Adaptations team
- > Free sponsorship of equipment

Anything else

No response

Appendix 4 - What is Section 10?

Current System

Section 10 of the Income Support (Guernsey) Law, 1971 (see https://www.guernseylegalresources.gg/CHttpHandler.ashx?documentid=80760) (referred to throughout as 'Section 10') enables ESS "to make such arrangements as it may deem necessary or expedient for promoting the welfare of disabled persons".

It is a very wide provision which, among other things, allows ESS to make funding available to individuals or families who need to access disability-related equipment or aids, or to adapt their homes. You do not otherwise need to be claiming income support to obtain assistance under Section 10.

Section 10 can cover small items as well as complete refurbishments or extensions to accommodate the needs of a person with impairments. Under Section 10 (2)(c) specific provision is made for "providing disabled persons with equipment aids and appliances as required".

Under section 10, ESS can decide whether to provide financial support for the full cost, or part of the cost and which might be provided as a grant, or a loan, or a mixture of both.

Unlike Section 39A of the Social Insurance (Guernsey) Law, 1978, as amended (see https://www.guernseylegalresources.gg/CHttpHandler.ashx?documentid=80776)
Section 10 is not limited to employment or occupation but covers a wide number of daily activities whether domestic, social employment etc.

What are the Problems with the Current System?

HSC were looking for feedback on what people have found to be the problems of the current system.

Section 10 is a completely discretionary power. This means that ESS can make whatever decision it sees fit, within reason, as to whether or not to fund the equipment or adaptations someone is requesting.

In practice, this can allow the Committee to make sensitive, individualised decisions on complicated applications. But it also means that people don't know what help they can expect when they are facing significant costs; that two people in similar circumstances could be treated quite differently by the same Committee; and that different Committees, over time, could interpret this provision quite differently.

This is not in accordance with the States' commitment to fairness and transparency in the way that health and care services are provided, which is summed up in the guiding principles of the Partnership of Purpose, especially those relating to fair access to care, a universal offering, and user-centred care. Eligibility for services, including financial support from the States, should be based on clear and fair criteria, and those who are refused services should have a right of appeal.

Section 10 needs to be put into the context of the overall provision and funding of equipment, aids and adaptations in Guernsey, as follows:

Children and adults who need disability-related equipment, aids and adaptations will usually be assessed by an Occupational Therapist or other relevant professional working for HSC. There is a specific Wheelchair Service for people who need wheelchairs. These services may assist people (and/or their families or carers) to order the equipment they need, and to navigate the various funding options available – but ultimately responsibility for this sits with the individual.

Those who can't afford the costs of necessary equipment or adaptations can either apply to ESS for assistance through section 10, or can seek assistance from local charities. The voluntary sector in Guernsey plays an important role in making equipment and adaptations affordable to individuals and families who can't cover the costs themselves. Some charities provide grants towards the cost of aids and adaptations, while others sell on (at low cost) or redistribute donated equipment.

There is no form of regular, predictable public subsidy for disability-related equipment, aids and adaptations. The costs of specialised items can run into hundreds or thousands of pounds.

The current system is challenging for families and individuals to navigate, and is especially hard on families of children with complex needs (who grow quickly and therefore regularly need new equipment that suits their size and stage of development) and for adults with rapid degenerative conditions, such as motor neurone disease, who may need several increasingly-specialised wheelchairs, for example, in a space of a few years or even months.