

Deaf Services – Jersey Findings and recommendations report

The purpose of this report is to assess current support and services for deaf people on the island of Jersey, identify gaps in provision and make recommendations to the island's Government so that deaf people living on Jersey are able to live independently and achieve their full potential.

About RAD

Founded in 1841, the Royal Association for Deaf people (RAD) is one of the oldest charities working with deaf people in England. We ensure that deaf people have access to services in British Sign Language (BSL). From supporting children and families; to helping deaf people find work; to befriending older people; we are here to make sure the people who use our services get the support they want, when they need it and that it is accessible to them

A note on terminology

Throughout this report we refer to:

- deaf: is an all encompassing term that includes people who are profoundly
 Deaf and use sign language as their first language, those who are deafened
 and people who have hearing loss.
- **Deaf:** is used when describing those with profound deafness and who use sign language as their first or preferred language.
- Hard of hearing (HoH): people who have hearing loss, but rely on some hearing and/or lipreading.

Summary - key findings and recommendations

We recognise that there is a distinct lack of specialist support for the local deaf community in Jersey reflecting both d/Deaf communities. BSL services on the island are lacking, whilst face-to-face interpreting is rare and only provided, in the main, at official Government-hosted meetings or in some medical settings. It is therefore a welcome step forward that the Government has recognised there is an issue and is actively seeking to address it.

The Government has taken the initiative to assess the broader situation having recognised that communication presented as a challenge following the onset of Covid -19, <u>and</u> other influencing factors such as the impact of changes to social work practice that effected the support network of this community, specifically the definition of/ what constitutes social work practice.

The Government considers that contribution from voluntary sector organisations is necessary to provide wider specialist support for the deaf community, as is common practice on the island for other charities and specialist groups. The deaf partnership board at times, appears ineffective and whilst there is communication between stakeholders, this seems somewhat fractured.

Urgent investment is needed for the development of robust services that will achieve meaningful outcomes for people living on the island; enabling them to be empowered and live independent and fulfilling lives.

A collaborative effort is only just beginning to take shape. Despite well intentioned support from members of the community, professionals and the Government, a collaboration of any meaning has been slow. Understanding and agreeing the true needs of the community and working together to address how to support people effectively has resulted in ongoing delays.

The Government have taken proactive steps in commissioning the Royal Association for Deaf People to support this collaboration and to ensure actions can be agreed, committed to and monitored in the longer term.

Introductions

According to latest estimates, 107,800 people live on the island of Jersey. Around 16% have a reported hearing loss, whilst there are thought to be 24 deaf BSL users. There are also approximately 13,000 adults who have reported a hearing loss. The Government must ensure people are properly supported, whilst effectively preparing for the future.

Having successfully campaigned for better services, deaf issues are now on the Government's agenda – it is acutely aware that services for deaf and hard of hearing people are lacking, in part. Relationships have broken down between the community, Government and professionals, Hearing and Deaf support teams and audiologists, and the challenge is to bring about change and a meaningful, long-term culture of collaboration. We appreciate that Jersey is a small island and that there are difficulties associated with providing a full service; however, there is no doubt that the Government needs to play a much bigger role in supporting local infrastructure organisations.

¹ Government of Jersey, 2019:

https://www.gov.je/Government/JerseyInFigures/Population/pages/population.aspx#anchor-0

²Number of people with hearing loss (FOI), 29 June 2018:

https://www9.gov.je/government/freedomofinformation/pages/foi.aspx?ReportID=2181

³ Number of people with hearing loss (FOI), 29 June 2018

Jersey's core value principles are:

"We are respectful"

We care about people as individual and show respect for their rights, views and feelings.

"We are better together"

We share knowledge and expertise, valuing the benefits of working together.

"We are always improving"

We're continuously developing ourselves and our services to be the best they can be for Jersey.

"We are customer focused"

We're passionate about making Jersey a better place to live and work for everyone.

"We deliver"

We're proud of Jersey as a place and are passionate about shaping and delivering great public service.

"I want to show what I can do as a deaf person but I can't achieve my dream here in Jersey"

Methodology

After initial discussions with senior representatives from RAD and the Government of Jersey, two RAD representatives visited the island (5 to 8 July) to consult with the community, Government officials and health professionals (see Appendix). Consultation, in groups and individually, was focused on:

- Experiences from a deaf customer perspective
- The Government's perspective
- Other stakeholders what is/is not working
- Challenges past and present
- What the future should look like

More than 25 people participated in our consultation, as follows:

Government ministers and officials

Richard Renouf, Minister for Health and Social Care
Judy Martin, Minister for Social Security
Jo Poynter, Associate Managing Director, The Government of Jersey
Anna Hamon, Senior Policy Officer, The Government of Jersey
Paul Rendell, Principle Social Worker
Professor Claire de Than

Community Groups

Jersey Deaf Society
Deaf partnership board
Jersey Deaf club
Jersey Employment Trust (JET) (Charity)

Health, education and social care professionals

Six professionals including health/audiology and social care Esther Tremeer, Team Lead, Hearing and Deaf Support Team – Education

"Constantly challenging people and proving myself regularly"

Initial findings

The community

Consultation clearly demonstrated the frustrations of the community; people feel let down and unsupported.

Specialist services are lacking and mainstream support is often inaccessible.

There is limited/ no in-work support, therefore deaf people are isolated in their workplace, not following what is going on or understanding training, policies and procedures.

Whilst there is an Access to Work Grant available to islanders to support with aids and equipment, this is limited to £5,000 and does not cover support worker assistance (which presumably would include BSL interpreters).

BSL interpreting provision is scant, at best, whilst face-to-face interpreting is rare and only provided, in the main, at official Government-hosted meetings or in some medical settings. General video relay support relies on quality connection but at times, this can be poor – although the Government does make clear that this was not a longstanding solution and was offered as an interim solution with a view to testing the response.

The twelve parishes on the island are inaccessible to the community, providing little or no support to deaf people.

The deaf partnership board appears fractured and ineffective.

There is a lack of take up in respect of people learning BSL.

Deaf people, both BSL users and Hard of Hearing experience the same challenges on the island; feeling isolated, socially marginalized, without support or access to information – some of this has been improved over the last six months with the Governments implementation of RAD support on the island.

There is a reluctance within the deaf community to understand and accept the changes to social work practice and understandably, people are slow to trust. Some recognise how valid their contributions are and are pleased to see the Government are taking steps to improve support, but others still display dependency and reliance needs, and are frustrated at the time it is taking to establish accessible support.

People are feeling disempowered and without access to what they feel are critical support networks.

Government (including actions and assumptions)

The Government's vision of what constitutes a social work service appears to conflict with the specific needs of deaf people. For instance, because deaf people's needs are primarily around access to advice, this does not fit neatly within the Government's own support model (the Jersey Government mentions services for 'people with physical or sensory disabilities' on its website, explaining that this 'care group includes people aged 18 to 64 who need help because of a physical disability or illness, or because of sensory disabilities'. It goes on to say that 'the levels of needs of people with physical and / or sensory disabilities are defined in terms of the frequency with which they need help from others and in terms of their ability to live safely and independently').

One outcome of the 2017 Independent Jersey Care Inquiry was the creation of a Children's Commissioner, whose duty is to promote and protect children and young people's rights – including those of disabled children and young people under the age of 25. It is clear from our conversations with education and social care professionals that not all of the specific needs of deaf young people are currently being met. We understand that there are presently no deaf children and young people on the island for whom BSL is their first language/communication preference - it is possible that this is due to trends in some areas where we are seeing attitudes and choices to communication changing, due to advances in digital technology and cochlear implant surgery.

There is currently no deaf Children and Adolescent Mental Health Services (CAMHS) and young deaf people appear to be falling through the cracks (between mainstream and complex service provision), with a lack of clear pathway/s, especially in early years settings. In respect of adult social services, we learned of a handful of deaf young adults who were still awaiting contact after one year of being referred. Historically, the transition from child to adult had been smooth with the support of the Government social work team as service users were supported with advice and advocacy to live independently. Following the change to their support provision and given they do not meet the threshold for mainstream social work services, young people have been on a record of need throughout their education and are still without support.

Social work teams sit within Health, which encourages a medical model approach rather than a social model approach to disability. We also learned that deaf adults

The Government acknowledge that it was previously employing a senior social worker who was using the Care Act as guidance towards achieving best practice. It also acknowledges that the activities being undertaken at that time were more aligned to community support and reablement. When a decision was made, by the Government to stop this arrangement, a support gap was created and plans to recruit internally (for a more suitable support role) fell through, leaving the deaf community without a service that they had become reliant on.

The Government understand that a culture of dependency exists, more so after changes were made internally and when support stopped for the deaf community, however this problem could have been addressed more sensitively and effectively which the Government have acknowledged and are actively engaged in working to resolve.

The community's need for communication support appears to have been significantly underestimated by the Government, as family and friends have been bridging the gap. This is something the Government has recognised, stating they 'believe this issue is a real problem for the community'. There is a lack of community link workers with various specialisms who could provide support to deaf children, young people and their families, and to adults more widely within the community, to live independently, access society - with social prescribing efforts and communication support.

It is positive that the Government has acknowledged there are significant issues that need addressing and is taking action, including by commissioning this review. It is also a welcome step that the Government appears willing to build partnerships going forward. However, if the Government is to provide or coordinate important services, it will need the necessary resources and support in order to do so.

Relevant legislation is woefully lacking, which provides limited means of holding the Government to account.

The Discrimination (Jersey) Law 2013 first came into force in September 2014, and initially applied to race. Protection against disability discrimination was not added until 2018, four years later, under the Discrimination (Disability) (Jersey) Regulations 2018. This now means that businesses must make reasonable adjustments so that individuals are not treated unfavorably because of their disability. It applies to discrimination at work, as a consumer, in education and when using public services. Whilst this is a welcome step forward, it is clear that much more needs to be done to ensure that businesses and employers are aware of their duties under the legislation and that it is being effectively implemented on the ground.

The Government operates a single point of referral system (SPOR) that is viewed by the community and professionals (e.g. health/education) as inaccessible and more suited to those who have mental health and cognitive challenges.

There also appears to be a lot of confusion amongst officials and professionals about what constitutes 'social care' and where responsibility lies for the provision of social care services. More should be done to support people in the community to understand what constitutes social work. Similarly, we would recommend greater deaf awareness training for Government officials to help them better understand the needs of deaf people, which will not necessarily be categorised as social work which has been recognised within Government.

Since the reduction in support, the Deaf Partnership Board reports that people are suffering from increased isolation, deteriorating wellbeing and ill health.

The Government traditionally expects local charities to provide services to their local communities and this appears to apply in the context of deaf services. However, there is currently no such provider that has the capability to do so effectively.

There is only now, a push from the Government to make services accessible to deaf people on the island having reviewed the current situation and they are actively exploring what their role should look like, however, the Government expects a collaboration between stakeholders and are actively supporting engagement and encouraging partnership working.

Health

It seems that an agreement was made between the Government and the island's 13 GP practices which saw health professionals come together to tackle the coronavirus pandemic. This was a short term agreement, but longer term collaboration is needed in order to better support people under health and care.

As referenced previously, social care sits within health which tends to result in a medical model approach.

Communication services are woefully lacking on the island and residents are reliant upon SignVideo interpreting services, where connection is often poor - this exacerbates people's frustrations. Feedback suggests this is not the ideal scenario for everyday support and could be limited to specialist appointments or where there is no alternative.

"The system is wrong and is failing deaf people"

Recommendations

The Government must immediately review the way in which it determines 'need' for all deaf people. The approach should be one of **independence**, **progression** and **fulfilment**.

It is recommended that the Government focus on the following actions and outcomes:

- 1. Local infrastructure, including charities and support groups, are adequately funded and supported so that they can deliver services to deaf people
- 2. Effective statutory services are in place to protect and support communities
- 3. To enhance existing services and make them more accessible
- 4. To work with others to provide a network of information including deaf awareness for businesses and organisations to be more accessible and approachable
- 5. Monitoring and reporting systems, and processes, are established; providing the evidence of need that is required to ensure services are working well
- 6. Jersey's Disability Discrimination Regulations (2018) and any related guidance should be strengthened to promote the rights of deaf people
- 7. The dependency culture is eradicated, and people are living as independently as possible working with deaf people and not acting for them
- 8. The Government must accept that some dependency will exist by nature of a person's disability and after meaningful assessment has been undertaken,

- ensure support processes are in place such as those as provided by the social work team's Community Link Workers (to be recruited).
- 9. Review and refresh the language used on the Jersey Government's website, ensuring it is more deaf-friendly and in line with the social model of disability
- 10. The Jersey Government should use the development of its new Disability Strategy as an opportunity to enhance the needs and rights of all deaf people on the island. Whilst we are looking at issues more relating to equality than disability, feedback from professionals is that they believe in this Disability Strategy and a collaboration between agencies is the best opportunity to implement meaningful change the Government to decide RAD's role

Next steps

- 1. A full internal review of statutory services, in order that they can meet the needs of deaf people living on the island (currently underway)
- 2. The Jersey Government should use its new Disability Strategy to strengthen rights and recognition for deaf residents this could include the development of an NHS Accessible Information Standard (AIS) equivalent for the island
- 3. The Government, supported by RAD, to provide a position statement to make clear to the islanders the timeline and ambitions
- 4. The Government to recruit and employ a Community Link Worker (CLW), on a fixed-term contract, to support these changes (mentoring and support can be provided by RAD). The CLW, Jersey Government and RAD can work together to prepare the Jersey Deaf Society to fulfill the longer-term ambition of providing high quality services that really work with other community professionals
- 5. Explore the pooling of health and care funding to support the achievement of positive outcomes e.g. improved health and wellbeing
- 6. Look at social prescribing to support positive wellbeing and reduce the burden on more expensive health and care services
- 7. Provide support for local deaf charities to enable them to collaborate, build capacity and capability to meet local need, for example by:

- Defining a service model, in collaboration with RAD, which includes independent statutory services for the deaf community e.g. community support and Information, Advice and Guidance (IAG) services - RAD has shown what good practice looks like
- Defining the relationship between and the roles of Government and Parishes, and communicating this to the community
- To support the implementation of volunteers as 'Inclusion Champions'
- Developing a sensory pathway, in collaboration with VI partners
- Reviewing the role, responsibilities and membership of the partnership board
- Implementing a programme of deaf awareness training for professionals, authorities and service providers
- To expand deaf awareness to into local communities and businesses
- 8. Review in-work support schemes to provide deaf and disabled people with equal access to the workplace

Challenges will be felt by people with all levels of hearing loss. Many people will find it difficult to feel like they have a voice in respect of their care, support needs and when making choices in their everyday lives. It is important to take a person centred approach. In the UK, we have introduced support such as social prescribing, jargon busting, equipment support, introducing captions, hearing loop systems, translations, and when it is impossible to use telephone based systems, introducing non telephone based services ie; Textphone, SMS, Email, Video Relay which has helped improve community access, access to professional appointments and other experiences including social media access. Improving general communication access to widen choices is critical. To explore device needs for islanders and propose Jersey Deaf Society make contributions is something to be considered.

There is a lack of adult support workers, community link workers and/ or ambassadors who could support deaf children, young people and adults. These are key colleagues, in active community roles that could better understand how to undertake assessment, communicate, improve accessibility and put in place systems of support for BSL users, Hard of Hearing people, non-signers, spoken language users – and support the wider network of professionals who recognise this as an issue. Often where BSL needs are met for profoundly deaf people, this would widely meet the needs for people with all manner of hearing loss.

Additional interpretation may be needed for general appointments, access to community facilities, education and for employment related meetings. A CSW model could support this as part of a Community Link Worker role, to facilitate communication and to emphasise deaf awareness and how to make reasonable adjustments to mainstream providers.

When information is shared, the Government and associated groups should avoid using long descriptions and jargon. To use short bullet points in narrative and where possible, provide online content ensuring that information is easy to understand, that subtitles are used and to ensure BSL is considered.

The Interim

It is proposed that a three-year interim plan is put in place to support the Government through this period of change and to build capability amongst the island's charities/service providers to support reablement and community activity.

Greater awareness of deaf diversity is needed to meet the needs of a wide range of people with varying levels of hearing loss. The current group of deaf adults is qualitatively and quantitatively different to the generations coming through and their needs are different.

There is no one solution where one size fits all i.e. interpreter versus community link workers. RAD have listened to a case study where the needs of a patient in hospital were largely outside the skill set of an interpreter, but equally understand the concerns around community link workers having the right skill set at this point in time. Time must be taken to train and develop the right people to undertake the role of Community Link Worker, utilising the expertise of experienced organisations such as RAD to carry this for forward in the recommended timeline.

The continuation of the disability strategy meetings to ensure informed discussion of deaf needs past, present and future, based on evidence and experience, collaboratively.

RAD will provide meaningful outcome reporting as a result of island engagement with the community and a summary of ongoing case need to help shape services and support that may be needed. To create journeys of

change for individuals who can and will become independent when an accessible support structure is in place.

RAD can tell people face to face about our ongoing work on the island and provide positive feedback to the Government about how deaf residents are feeling.

RAD proposed a period of consultation with members of the community, including for deaf children, young people and their families – this will be taken forward with the Hearing and Deaf support team. This is important in terms of informing and designing services for this generation.

The Government needs to decide if it wishes to continue utilising RAD support both in respect of community support for island residents and for consultancy.

Appendix

Consultation questions

To ministers we asked:

- What do you understand about the issues that deaf people face?
- What would you like to see in place for deaf people?
- Do you feel it is clear who is responsible for providing support to deaf people?

To social workers we asked:

- What do you see as the main challenges of providing support?
- What do you feel are the main challenges for deaf people living in the community?
- What support do you think deaf people need?

Of the *community* we asked:

- What is the 'problem' and what do you see as solutions?
- What services do you think are needed for the island?
- What does good look like for Jersey deaf and hard of hearing residents?

"I'm very worried about the future, not for myself but for the Jersey deaf community"