

## **Lesley Harrison: Care Conference: Understanding Differences: Friday 20<sup>th</sup> October 2023**

**Script for slide pack.**

### **Slide 1: Autism Jersey Logo Holding Slide**

#### **Slide 2:**

My name is Lesley Harrison, I am Head of Charitable Services of Autism Jersey, which is the leading charity in Jersey dedicated to the assistance and support of people on the autism spectrum. This is a new role designed to support and align with the operational commissioned support service provision. Identifying and delivering charitable services initiatives and programmes to enhance quality of life of people with autism to enable them to lead a full and inclusive life and enjoy a degree of independence.

Today, our goal at Autism Jersey is the same as it always was – to create a society that works for autistic people, but society has changed a lot since that kitchen table conversation with a group of desperate parents fighting for a voice and the right to be heard, as has what we know about autism and what autistic people rightly expect from the world around them.

#### **Slide 3:**

The relationship between Autism Jersey and the Government of Jersey, is a strong and positive one, and Autism Jersey are a preferred supplier of services.

Autism Jersey is a registered provider of home care service in Jersey. As part of our registration, we are Regulated and Inspected by the Jersey Care Commission.

Autism Jersey hold advance status from the National Autistic Society.

- We believe in taking a collaborative, partnership approach to the work undertaken in our small community in relation to autism.
- We also believe that to provide the best opportunities for individuals and families, training and support should only be given by highly experienced professionals. Our partnership approach means that we can respond swiftly to design workable and lasting solutions for support provision and develop measurable improvements in practice and wellbeing of people.
- So...we know that there are a number of organisations, and departments within GoJ that have connections with this condition and for that reason we feel that it is important to continue with the mindset from early 2000 where we had our first strategy – we believe it is important to now create a strategy involving all key stakeholders – the starting point was drawing in expertise of Prof. Richard Mills
- Prof. Mills has an impressive and extensive CV and experience/expertise., Richard is a Research Fellow in the Department of Psychology of Bath, was with the National Autistic Society initially as Director of Services responsible for early years, schools, and adult services, and later as Director of Services. Richard is also Director of AT- Autism which is a

training and consultancy organisation in all aspects of autism and related neurodevelopmental conditions. For 11 years Richard advised the GoJ and was instrumental in developing the key charity which is AJ today. (This was one of the actions of the original strategy) So significant knowledge and expertise on the subject matter and also Jersey.

#### **Slide 4:**

Autistic people and family members shared powerful stories about the barriers and discrimination they face every day in all areas of life. They told us that a society that works for autistic people recognises these very basic human rights. We are on a pathway to make this vision a reality.

#### **Slide 5:**

In September 2021, we embarked on a major exercise, to Autism Jersey and the GoJ, commissioned AT- Autism to undertake an independent survey to inform the strategy for autism in Jersey, to understand what a society that works for autistic people actually looks like, by asking autistic people, their families and professionals about the challenges they face and the changes they most want to see.

#### **Reminder on the highlights of the key findings of that report.**

- This was the first such survey. As such, there was no baseline, and as it had been some years since the previous strategy, the survey questions, developed by an expert Delphi group (comprising professionals, autistic people, and family members) began from scratch. (Well established approach to answering a research question – allows for reflection amongst participants, who are able to nuance and reconsider their opinion based on the anonymised opinions of others.
- Respondents: 23% were autistic or identified as autistic.
- Respondents report multiple groupings – may feature in one or more response category – A number of survey respondents represented more than one demographic, in that they may have been autistic, with an autistic child, and also held a professional position. (Therefore, will not add up to 100%)
- Language and terminology reflect the stated preference of autistic people (Kenny et al 2016). Therefore, condition -first and not person-first terminology is used throughout this presentation.
- Using the Delphi method - a systematic and qualitative method of forecasting by collecting opinions from a group of experts through (often several) rounds of questions. Autistic people, relatives of autistic people, professionals were represented. Basically, ensuring the 'right' questions were asked in the 'right' way to increase the statistical confidence level.
- The survey was completed online via a link and respondents were asked to complete a Likert scale. (a psychometric scale commonly involved in research that employs questionnaires) Confidential comments were added, including priorities. Several respondents met multiple criteria e.g., autistic, a parent, *and* a professional.

- Results, plus a representative sample of verbatim quotes are included in the full report. Comments that identify individuals have been redacted. Full results have been shared in confidence with the commissioners, but all statistical results are unredacted.
- Given an assumed Jersey autistic population of around 1000 children and adults, when relatives and associated professionals are added, the statistical power of the survey is rated at 95% confidence level, with a margin of error of 7%.

## **Slide 6: Priorities: Move onto slide 7**

### **Slide 7:**

#### **The following summary points identify key findings and ways forward.**

**General progress of autism in Jersey.** The survey reported examples of good practice and progress in key areas, notably transport, adult support, access, short breaks, employment, and training, although this is regarded by respondents as rare, uncertain, or uneven. In some areas, such as acceptance, inclusion, autism awareness, education, and mental health there was a feeling this has regressed.

**The autistic experience and voice: Neurodiversity.** An important and positive development is the greater involvement of autistic people in the life of the island, and it is central to the new strategy that this voice is heard, and autistic involvement is built upon. Strategic priorities will reflect this and is an opportunity to embed full autistic participation and inclusion as a central principle in all future development. It is also of note that since the previous strategy, the concept of *neurodiversity* has emerged and requires greater recognition by the community. There a growing awareness of the presence and needs of neurominorities across all sections of the community.

- **Priorities.** Let's look at the priorities, 27% of the respondents referred to the challenges with diagnosis, both for children and adults, and issues related to pre diagnosis, getting an assessment and post diagnosis. Also, issues highlighted relevant to women and girls. Some people felt really strongly about getting a diagnosis as it was seen as a 'ticket' to other entitlements. Also, we know that children and adults can present with behaviours of concern, this is also a reason for prompt diagnosis.
- **Education:** within the survey respondents did make some positive comments about education and felt that in some areas there was a really good understanding of autism. There was a request to have specialised provision on island, including more inclusivity within our current school system. Points were raised about students who get excluded and the need for taking that action. Respondents requested more support towards further education and vocational capacity for adults.
- **Employment:** Looking to ensure correct reasonable adjustments are made in relation to people in employment. Also scope for wider support in employment opportunities as well as mentoring.

- **Mental health:** 10% of the respondents felt that there needed to more consistent skills with employees in this field. There is also a need to develop more on-island services which challenge us most. This highlights a training need also,
- **Awareness and training.** We have comments and indeed evidence that SPELL is well received across various sectors, however, there is a need for a more intensive rollout of this programme geared to different sectors. We also want to now look at the involvement of autistic individuals.
- **Housing:** We know from speaking with autistic individuals that they require space, natural light, and low arousal environments to mention a few. Whilst we have some compliments about the support the housing association provides, we need to consider further accessible housing for this population. This will need to be bespoke in design, taking into account sensory sensitivities.
- **General Support:** 14% of respondents want us to consider more family support, some examples of that were transition, respite, and short break. Some respondents mentioned to have personalised packages of support.
- **Other services:** Respondents mentioned the need for bespoke advocacy services, additional therapies, Criminal Justice, and Social Security got a mention – complemented but clearly need to do more work in those areas.

#### Slide 8:

So, to remind us of these are the 8 priorities.

#### Slide 9:

At every stage, a strategy for autism must be guided by what we heard from autistic people, families, staff and external experts.

The Autistic Experience and Voice – delivering a neurodiverse strategy for Jersey – was an interactive workshop which took place in this very room in November 2022 and included autistic individuals, parents and carers, staff and professionals who all engaged and help prioritise those priorities, to help inform and develop an action plan which will form the basis of a strategy with key primary and stakeholders identified with delivery milestones for Years 1-3.

It can't be done in isolation, collectively we are bolder and louder and in a position of strength to influence and implement change. A society that works for autistic people is a society worth fighting for – and we won't stop until that vision is a reality.

So, let's keep pushing for a kinder, fairer, more compassionate society, where every autistic person has the opportunities, they deserve.

#### Slide 10:

- **Pivotal actions and 'quick wins'** It is timely to think of how *pivotal actions*, that could address multiple needs, could be developed. These would simultaneously address different priorities, e.g., diagnosis, education, and mental health. These might include for example,

accelerating the development and capacity related to training; information, advocacy, buildings design (including Universal Design (UD)), and how these policies would extend to and affect all groups within the community; intersectionality.

- Today's presentation is designed with a view to inform and engage, and we do need to ensure buy in across GoJ departments and all relevant stakeholders if we are to have a truly collaborative approach and design and deliver cost-efficient, cost-effective solutions and positive outcomes for individuals in our small community. We need to have those relevant key influencers and decision makers sitting round the table as part of our steering group to contribute to the design and delivery of a strategy for autism in Jersey.
- Collectively we need to influence and collaborate with others to improve standards and adjustments – that includes the public and private sector and third sector organisations. Our campaigning and advocacy must be targeted, persistent and based on autistic voices.
- As you can see a lot of investment in time and money to lay solid foundations has already taken place. Work so far undertaken is not lost, and consideration will be given to how that aligns and compliments the Government of Jersey Neurodiversity Plans for 2024
- It feels like we are moving forward with a vision that is truly authentic and that vision is full of hope, aspirations and expectations that really will help us to create a society that works for autistic people.

**Slide 11:**

At Autism Jersey, we are fully committed and truly look forward to working with you and each of those respective stakeholders in order to develop and deliver a truly inclusive strategy for autism in Jersey, that will provide positive outcomes for a diverse and inclusive society in our small community, which align with public sector values, and underpin overarching Government strategies for the island.

**ENDS:**

**Note: Panel Q&A**